Issue No.- 15, September 2016

COPASAH Communiqué

Shared Practice. Grounded Knowledge.

Special Edition

Dedicated to the Struggle of the Roma People in East Europe

COMMUNITY OF PRACTITIONERS ON ACCOUNTABILITY AND SOCIAL ACTION IN HEALTH

Organised Session

November 18, 2016 (Friday)

11:00-12:30

COPASAH as a global collaborative partnership of public health accountability practitioners for engaging with and strengthening health systems for increasing access to health services

Abhijit Das COPASAH Global Convener (Centre or Health and Social Justice)
Jonathan Fox (School of International Service, American University, Washington)
Renu Khanna, (SAHAJ, India)
Borjan Pavlovski, (Association for emancipation, solidarity and equality of women – ESE Macedonia)
Geoffrey Opio, (Uganda)

COMMUNITY OF PRACTITIONERS ON ACCOUNTABILITY AND SOCIAL ACTION IN HEALTH

Satellite Session

November 15, 2016

(Tuesday,12 PM)

Understanding how citizen-led accountability initiatives contribute to health system responsiveness: engaging practitioners and researchers in the development of a common research agenda

COPASAH
Walter G Flores (Center for the Study of Equity and Governance in Health Systems, (CEGSS) Guatemala)
Miguel San Sebastian, (Umea University, Division of Epidemiology and Global Health, Sweden)

hsg The Fourth Global Symposium on Health Systems Research, Vancouver, 14-18 November 2016

COMMUNITY OF PRACTITIONERS ON ACCOUNTABILITY AND SOCIAL ACTION IN HEALTH

Film Screening

November 17, 2016 (Thursday)

11:00-12:30

Equity, rights, gender and ethics: maintaining responsiveness through values-based health systems

FILMS
Standiwe (Short film Caroline Masquillier, Belgium)
A Coming Together of Health Systems (First Nations Traditional Practitioners in Acute Care Settings, Short film Kaitlin Atkinson, Canada)
X and Y (Vulnerability to Resilience, Photo essay Musaed Abrahams, South Africa)
Shattered - Stories of Death (Denial and Discrimination (TB Death), Short film Vijayakumar S. Karnataka, India)

hsg The Fourth Global Symposium on Health Systems Research, Vancouver, 14-18 November 2016

Editorial

In Solidarity with the Roma People

E. PREMDAS PINTO

CONTENT

Social discrimination and structural inequities are seen in all societies – across both the high income and low income countries. The axes of discrimination and social exclusion - race, gender, caste, ethnicity and religion – have functioned as the pivotal determinants of poverty and indignity. The story of Roma People illustrates that such discrimination continues to operate in almost all societies and unless such discrimination is eliminated, human dignity cannot be fully upheld.

The refugee issue related to the Syrian crisis became an important political flash point in Europe in the recent past. How, little do we realize that the Roma People have been living like virtual homeless refugees in the European continent for several decades, displaced and excluded from the civilizational developments! The Human Rights declarations and treatise and the European Convention on Human Rights have not made significant impact on the life and dignity of Roma People. This reinforces the need for instituting effective mechanisms for accountability of the State and it's instrumentality- to uphold the dignity of the vulnerable citizens.

The story of Roma People spread across Europe and the discrimination that they face from the privileged and the governments is the story of a South *within the Global North*, story of penury amidst plenty. Article 14 of the European Convention on Human Rights unequivocally calls for prohibition of discrimination: 'The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status'. Article 2 promises 'right to life' for all and Article 4 affirms 'prohibition of slavery and forced labour'. However, the stories from the ground on the human rights violations of Roma People speak volumes on the contrary and a brazen attitude of the State machineries in not being accountable to the commitments they have made as far as the Roma People are concerned.

This special issue of COPASAH COMMUNIQUE is a tribute of

solidarity to the herculean efforts done by civil society to bring to the public consciousness the human rights violations that the Roma People face. This edition highlights the civil society efforts at demanding accountability from the European nations to enforce inclusive policies, institute mechanisms and draw up programmes to realize the Human Rights to health care, education, employment and above all human dignity to the Roma People.

Accountability is a continuous journey till we put in place such social structures and systems which would respect, protect and promote human dignity of the last person on this planet. COPASAH commends the efforts, determination and resilience of community leaders, civil society organisations and others who stand in solidarity with the Roma People's struggle for dignity. ■

About the Author

Edward Premdas Pinto is the Global Secretariat Coordinator for COPASAH. As an Advocacy and Research Director at the Centre for Health and Social Justice (CHSJ), India, he facilitates the thematic area of social accountability with a special focus on processes of community and accountability in health. He also coordinates the South Asia region for COPASAH. He is a Human Rights Advocate and Public Health practitioner, scholar actively engaged in processes of social justice issues of the communities of Dalit women, rural unorganized labourers and other disadvantaged communities for the last 22 years. To know more about the work of CHSJ and COPASAH please visit, www.chsj.org and www.copasah.net

COPASAH Organised Session in the 4th Global Symposium On Health System Research, Vancouver 14-18 November, 2016

Selected abstract for the organised session:

COPASAH as a global collaborative partnership of public health accountability practitioners for engaging with and health system for increasing access to health services

Abhijit Das [1], Jonathan Fox [2], Geoffrey Opio [3], Renu Khanna [4], Borjan Pavlovski [5]
Centre or Health and Social Justice/COPASAH [1], School of International Service, American University, Washington [2], GOAL Uganda [3], SAHAJ, India [4], Association for emancipation, solidarity and equality of women – ESE Macedonia [5]

Overview: Social Accountability (SA) practices have often emerged from field innovations. Critical challenge faced, however,is knowledge translation and capacity building of practitioners for sustained change. COPASAH, a global collaborative platform of SA , describes *strategies of building -stakeholder platform* and *'how-to' of influencing health system* for sustaining positive changes.

The Roma People in Europe : A Story of Marginalization and Exclusion

COPASAH GLOBAL SECRETARIAT

Roma People: History and Background

The Roma People and related minority communities constitute Europe's largest and most vulnerable minority and are present in nearly all member states. There are an estimated 10-12 million Roma in Europe, particularly in Bulgaria (10.33% of total population), Republic of Macedonia (9.59%), Slovakia (9.17 %), Romania (8.32%), Serbia (excluding Kosovo) (8.18%) and Hungary (7.05%). Turkey, Albania, Greece and Spain are other countries where they constitute close to 3 % population of the total. Well over a million Roma live in North and South America today, with the Kalderash clan forming the majority. Of the Romani populations across the world, there is no official, reliable count. Part of the reason for this is their own refusal to register their ethnic identity in official censuses for fear of discrimination, complexity of determining who is a Roma and reluctance on the part of some governments to count Roma People for fear that it will lead to political movements to remediate discrimination against them.

Tracing the early history of the Romas is like unravelling a conundrum of information lying scattered. The Roma are known to have made an appearance in Europe speaking an Indian language, but there is no sure trace of their passage across the Middle East. Their language proves to be the key to the route of their travels as they may have borrowed words from the various peoples they met during their sojourn westward. In fact genetic studies in recent years substantiate this by demonstrating that, despite inter marriages; the ancestral line of most of Europe's Roma groups can be traced to the Subcontinent.

There have been arguments among scholars about the period and manner in which they left India, but it is generally accepted that they did emigrate from northern India sometime between the 6th and 11th centuries, then crossed the Middle East and came into Europe. Some groups stayed in the Middle East. The first Roma groups reached Europe from the East in the fourteenth and fifteenth centuries.

Early Romas were horse traders and trainers, basket makers, metal-smiths, woodworkers, singers and musicians. Whatever they did, they mostly traversed land to do it. To understand the Roma problem, it is important to look at this itinerancy, which is characterised by continuous adjustment and adaptation to a changing environment.

By most measures, the Roma are a people or a nation in the strict sense of the term. They have a dominant language, a culture and, above all, a sense of being a people, although they have sought neither a country nor any form of political sovereignty or government structure for their group/ community. Roma identity is inherently linked with rootlessness.

The Roma People in Europe are a very diverse group in terms of religion, language, occupation, economic situation and way of living; and although traditionally nomadic, today, a great majority of Roma and related groups are sedentary. Dozens of Romani language dialects are spoken throughout Europe, and a number of

groups frequently affiliated or associated with Roma also speak other European minority languages, such as Shelta and Yenish.

Roma, Sinti and Kale are the three main branches. Sinti are found mainly in German-speaking regions, Benelux and certain Scandinavian countries, northern Italy and the south of France (Provence), where they are known as Manush. The Kale (commonly known as "Gypsies") inhabits the Iberian Peninsula and North Wales. The term "Travellers", used in France, Switzerland and Belgium, also includes non-Roma groups having an itinerant lifestyle. There may be different communities in the same country: so for example, in Germany and Italy, the communities are referred to as "Roma and Sinti".During the Byzantine Empire, Roma groups migrated from India to Europe via Persia, Armenia and Asia Minor. The eastern branches of the Roma are still found in the Caucasus, Turkey and the Middle East, where they are referred to as "Lom" or "Dom".

The variation in Roma reality is also enormous. The historical experience of various groups, their encounters, stopping-places, routes travelled and intersected, and the diversity of their contacts with constantly changing surroundings, have given rise to a great range of cultural and social characteristics within various groups – and this continues to evolve. Even so, there seems to exist a feeling of closeness and community; for example, in some groups the saying 'sem Roma sam' ('we are Roma, after all') is frequently cited to emphasize Roma identity and in praise of cherished group values (hospitality, generosity, friendship), to soothe interfamily tensions or as an expression of a desire to unite in the face of adversity brought about by non-Roma.

Issues of vulnerability and marginalisation

The Roma are at the bottom of the European ethnic heap, under-housed, undereducated, underemployed, underserved, underrepresented and actively discriminated against by landlords, employers, school administrators and governments. Their socio-economic condition differs across different countries but nowhere is their situation good.

The history of European repression against the Roma goes back several hundred years – following the Roma migration from the Indian subcontinent between the 11th and 14th centuries. There are records of enslavement, enforced assimilation, expulsion, internment and mass killings.

One of the first instances of discrimination faced by the Roma People settled in Europe was during the 15th-17th centuries, under the Ottoman Empire in Central Europe. In Western Europe too they were marginalised and persecuted. In the 18th century, which was incidentally the period of the "Enlightenment" in European history, the Roma faced new forms of discrimination: in Spain they were interned, in the Austro-Hungarian Empire, various laws ordered their forced assimilation. In Russia, however, they were considered as equal subjects of the Tsar and were accordingly granted all civil rights. A second wave of migration took place in the 19th century, with Roma groups in central and Eastern Europe leaving for other parts of Europe. Some even crossed the sea. In 1860, Roma slavery was abolished in the Romanian principalities. Nevertheless, at the end of the 19th and beginning of the 20th century, discrimination became more intense, largely in those regions which had been part of the former Austro-Hungarian Empire.

Discrimination reached its peak during the Second World War, with a genocide orchestrated by the Nazis; nearly 500,000 Roma and Sinti were massacred by the Third Reich. During the Nuremberg Trials, no mention was made of this genocide and no assistance or compensation was given to the Roma who had survived the concentration camps. Migration of Roma from Eastern Europe to Western Europe and then to the United States, Canada and Australia, was initially part of the movement of migrant workers. With the collapse of the Soviet Union and its satellites, and the disintegration of Yugoslavia, this took on much larger proportions. The wars in the Balkans in the 1990s affected the Roma in myriad ways: they were war victims; they were expelled (in particular from the province of Kosovo in 1999) and were granted only "economic refugee" status in the countries of destination. These events must have had spiritual and cultural repercussions on their social fabric.

Human rights violations

The Roma community is the largest ethnic minority in Europe and is a definitely situation of social exclusion and wide-ranging poverty experienced by a significant proportion of them. Over several decades, the analyses presented in reports compiled for numerous international institutions, as well as studies undertaken by various nongovernmental organizations, have all converged and condemned one aspect: the difficult conditions in which

Roma families live, or are forced to live.

Examples of direct or indirect discrimination in children are abundant: exclusion from formal schooling is reported in a number of European states and ranges from complete exclusion from mainstream schools to school truancy and abandonment. Roma children are often over-represented among the children placed in out-of-family care, including in institutional, foster care and for residential schools for children with mental challenges. Roma children are in some cases removed from their families on the sole ground that homes are not suitable and stable or that economic and social conditions are unsatisfactory and in some countries, this was a result of communist- era policies where in the state was promoted as superior to parents in raising children. Roma are reportedly trafficked for various purposes including sexual exploitation, labour exploitation, domestic servitude, illegal adoption and begging. Roma women and children are seriously over-represented as victims in all forms of trafficking.

Discrimination in access to housing often takes forms such as denial of access to public and private rental housing on an equal footing with others, and as refusals to sell housing to the Roma. Many Roma People continue to live in sub-standard conditions in most European countries, without heat, running water or sewerage. Due to lack of adequate recognition of tenure there is always the risk and threat of forced eviction. In some countries, the number of evictions has seen an increase in recent years, often targeting the same migrant Roma families, including children, on several occasions over a short period of time.

Challenges affecting the inclusion of Roma in the labour market are numerous and result in the near complete exclusion of Roma and Travellers from decent work in Europe. Despite positive efforts in some countries towards inclusiveness, levels of unemployment among Roma and Travellers in Europe are invariably higher than among non-Roma. They face discrimination in access to hotels, discotheques, restaurants, bars, public swimming pools and other recreational facilities, as well as in access to services crucial for small business activity, such as bank loans.

One would seldom find a Roma in elected bodies at local, regional, national and supra-national level. Their participation is limited in the European parliaments, with the exception of certain countries in central and south-east Europe. In some countries, the numbers of local representatives – including mayors and local councillors – appear to have been rising over the past decade but even then the proportion is extremely low by comparison with their representation among the population-at-large.

In the absence of a formal administrative existence, social exclusion only worsens.

Many factors contribute to hindering Roma access to documents and effective citizenship, including armed conflicts and forced migration, breaking down of the former countries (like Yugoslavia), extreme poverty and marginalisation and, above all, the lack of genuine interest on the part of authorities to address and resolve the issues. Restrictive citizenship laws have created additional obstacles with many Romas not being considered as nationals by any state and are frequently denied basic social rights and freedom of movement with the problem particularly acute in the western Balkans.

There is a range of avoidable injustices suffered by the Roma community, particularly with regard to health, and this sprouts from a range of issues - inadequate access to housing, education, employment and other needs, barriers to Roma access to health services. Even in instances where services are available, there is discrimination and a lack of adaptation to efficiently use these services. The precarious health situation among the Romas is not reflected in reliable and up-to-date statistics or data, a fact which further hinders the planning of targeted interventions designed to reduce and ultimately eliminate inequality.

The Roma community is particularly vulnerable to the effects of social conditions on health. Roma populations living in rundown neighbourhoods, sub-standard housing or shanty towns and those with less access to health-care and social services have deficient health habits, high morbidity rate and lower life expectancy vis-a-vis other Romas in the state or Europeans at large. Roma women suffer discrimination at three levels: for being women in a patriarchal society, for belonging to an ethnic minority affected by negative social perception and for belonging to a culture whose gender values have been associated almost exclusively to the function of mother and spouse.

The health inequities faced by the Roma People must be tackled with an understanding that Roma health is not merely to be resolved by national health systems and health professionals but addressed concurrently in all social fields and by all stakeholders. Inter-sectoral policies in education, training, labour market inclusion, housing and health must be implemented; the Roma population must actively participate in all processes of intervention; health programmes targeting the Roma population must be normalised and strengthened along with adopting a gender perspective and youth empowerment.

More remains to be done in order to achieve respect for the rights of the Roma minority. In many ways Roma demonstrate better adaptation to, both present and to future ones, than other sections of the population: due to their economic flexibility, geographic mobility, in-family education, and communal lifestyle linking the individual into a network of reciprocal security, giving him or a sense of identity. There are possibilities for concerted action. After six centuries in Western Europe, the Roma Population is still waiting for a coherent, respectful policy concerning them to be drawn up and applied.

Roma Organisations and Response of the World Community

The history of Roma organizations goes back a long way, and has passed through a number of stages. In the aftermath of the Second World War, there is hardly a state in Europe in which Roma organizations have not emerged. In conjunction with the profound transformations taking place in the states of Central and Eastern Europe since 1989, there has been a mushrooming of Roma associations there, and these are taking their place in the political arena; the number of associations is on the rise in Western Europe too.

At an international level, the Comité International Tsigane (International Gypsy Committee) was founded in 1967; which organized the first World Gypsy Congress (London, 1971) with delegates from 14 countries and observers from world over. A new international organization, Romano Ekhipe (Romani Union) emerged from the second Congress held in Geneva in 1978 which got full Consultative Status in the UN in 1993. The organization has also set up a cultural foundation, Romani Baxt, with its headquarters in Warsaw, and is gradually establishing branches further afield.

Since the early 19902, the International Romani Union has played an increasingly important role as a pressure group. The Roma political movement is taking shape on other continents as well. The International Roma Federation was founded in 1993 in the United States, with the aim of intensifying cooperation between Roma in the US with those in Europe. There are also organizations in Latin America and Australia.

In May 1989, the member states of the European Union passed a significant resolution that "acknowledges and recognizes that Roma culture has formed part of the European heritage, and this places a duty on the international authorities and governments of the member states to provide this culture and language with the means, not merely to survive, but to develop".

Public misunderstanding of Roma tends to have a direct impact on policies affecting them. Policies towards Roma often always constitute a negation of the people, their culture and their language, and this can be broadly grouped into three categories: exclusion, containment, and assimilation.

2005-15 was declared as the Decade of Roma Inclusion and the aim was to end discrimination and ensure Roma equal access to education, housing, employment, and health care. An overview of the activities of the past few years shows that European institutions have responded positively and member states are taking an active stance with respect to the Romas. An encouraging sign is that more and more states are endorsing international conventions, particularly those which open up possibilities for combating discrimination on ethnic and racial grounds. Despite the steps takenby governments during the course of the Decade, they were far from sufficient to have any substantial impact, resulting with the lack of progress on the ground. If the Decade is to be judged on its own terms – i.e. its pledge "to close the gap" between Roma and non-Roma within ten years – then clearly it has not been a success. However, all the available information suggests that education is the priority area in which the most progress has been made. Despite a slow start in designing health-related policies, available data suggests there was more progress (albeit slow and uneven progress) made in health than employment or housing.

In 2011 the European Commission adopted in 2011 an EU Framework for National Roma Integration Strategies focussing on four key areas: education, employment, healthcare and housing.

Resulting in development of an EU framework for national Roma integration strategies up to 2020. The EU Framework for National Roma Integration strategies up to 2020 brought about a change in the approach to Roma inclusion: for the first time a comprehensive and evidence-based framework clearly linked to the Europe 2020 strategy was developed. The EU Framework is for all Member States but needs to be tailored to each national situation. To reduce the health gap between the Roma and the rest of the population, the EU Framework calls on Member States to provide access to quality healthcare especially for children and women, and to preventive care and social services at a similar level and under the same conditions as the rest of the population. Following the analysis of health measures by 2014, it can be concluded that healthcare and basic social security coverage is not yet extended to all. Promising initiatives should be extended and multiplied to make a real impact on the ground.

Roma organisations

The decade for Roma inclusion contributed to the increased movement of Roma civil society. This led contributed towards formation of new Roma CSOs and building their capacities. In the course of the decade many organizations strengthened their capacities, and through their efforts in practically implementing many decade projects, raised their international profiles and won wider recognition for their achievements. But overall, Roma participation was judged to be more form than substance in terms of outcome and impact. Beyond the Roma elites and organizations, the ambition to involve Roma communities actively in the decade went unrealized, and the reports from all participating countries indicated low levels of awareness and only sporadic community participation. Nevertheless this process enabled Roma civil society to grow and build capacities and currently there are numerous profiled Roma CSO which work on local, national and international level.

About the Author

This article has been developed by the COPASAH Secretariat which is currently hosted by Centre for Health and Social Justice (CHSJ) New-Delhi (India) with inputs from Jojo John (India), an expert in social development, environmental governance, right to information, sustainable agriculture and ecological restoration. We acknowledge the inputs from Borjan Pavlovski, ESE, Macedonia.
To know more about COPASAH visit: www.copasah.net

VIDEO STORY

Vaccines are Still Unavailable for Roma people, ESE Macedonia

This visual reflects the low immunization coverage amongst Roma through examples such as that of Roma people residing in temporary Roma settlements. They do not receive any social or other welfare measures for the children. They do not receive any invitations for vaccination. They live in extreme poverty and have no means to educate their children. The visual also outlines that the immunization coverage among the Roma children remains under the national average. Roma women are visited by outreach nurses only in 2.5 times relative to 9 time visits for the other population.

Roma Minority and Social Accountability in Macedonia

BORJAN PAVLOVSKI

Roma minority in the countries of the South Eastern European region represents the most marginalized minority of people who live in unfavorable social and economic conditions compared to the general population. Roma people are deprived in many spheres of their lives, including housing, education, employment and health, access to health care and discrimination in health care settings. Social determinants of health have especially negative influence on Roma health, including but not limited to poverty, social exclusion, low level of education, to name a few, thus resulting in poorer health outcomes among Roma in comparison to the rest of the population in the region. For example, estimates are that the life expectancy among Roma in average is 10 years shorter in the region, with infant and maternal mortality rates higher among Roma.

There is a an absolute lack of health statistics segregated by ethnicity, as well as absence of relevant research studies conducted and/or developed by competent state institutions. This leads to the fact that the data on the many public health conditions among Roma people are solely based on the research reports conducted by Civil Society and international institutions. Additionally, the lack of data aggravates the health condition since the states do not have comprehensive data as guidance for policy planning and implementation.

In order to improve the conditions of Roma minority the countries from the region in 2004 signed the Declaration for the Decade for Roma Inclusion for the period 2005 – 2015 and made a commitment to undertake measures to improve the conditions of the Roma minority. Yet although a decade has ended, there is no significant improvement in the status of Roma minority in the countries of the Region. This is due to the lack of political commitment and funding for the adopted policies aimed to improve the status of the Roma people.

Roma Integration 2020 is a new initiative for improvement of the condition of Roma people, initiated by the European Union.

In Republic of Macedonia, the official census data, which is 14 years old shows that the Roma represents 2.6% 2 to 6% of the population, yet the findings of the civil society organizations shows that this number is much higher and probably reaching 5% to 6% of the population. The situation about Roma minority in South Eastern Europe described previously is also valid for the Roma minority in Macedonia.

Social accountability

Social accountability for the improvement of Roma health was initiated in Macedonia in 2009, by the Association for Emancipation, Solidarity and Equality of Women (ESE). ESE is funded by the Open Society Institute and Foundation Open Society Macedonia,that aims to improve the health status and immunization of Roma children. In

2011, the Government for the first time allocated funds specifically aimed for Roma in one of the preventive Programs under the Ministry of health. This was the result of the work initiated with the process of applied budget work, advocacy and civil society participation.

The activities included: health education of Roma people, increased number of visits of community (patronage) nurses to Roma women during the period of pregnancy and one year after the delivery of the child, along with measures for active identification and immunization of non-immunized Roma children.
In order to strengthen the demand for health rights and entitlements, civil society organizations (ESE, KHAM, CDRIM, LIL and Roma SOS) started to implement community monitoring work.

Through this work Roma communities where strengthened such that they received the rightful entitlements through the Programs for preventive health care of mothers and children. Later on, community monitoring work was expanded to include examining the policies for improvement on reproductive health of women, specifically for the Program for cervical cancer screening. Furthermore, the Civil Society Organisations (CSOs) added the social audit methodology into their work. Parallel budget monitoring work was conducted in order to track the budget allocation and execution for the foreseen measures aimed for Roma. The entire work was followed with advocacy efforts at the national and local level. The community took an important role especially in the local level advocacy process.

Many challenges were detected that related to the national level implementation of the activities aimed for Roma, including insufficient budget allocation, frequent amendments of the Program(annual budgeted program under the Ministry of Health) during the fiscal year, lack of capacities of the public health institutions to deliver the services, lack of oversight mechanisms as well as lack of transparency and accountability especially within the Ministry of Health. Community monitoring on local level showed how the problems detected on national level influence on poor service delivery at the local level. The findings from the Roma communities showed that the foreseen activities, like additional visits by patronage nurses in Roma families or educational activities for chilld's health and immunization are not implemented and does not reach the Roma people. Yet this process empowered Roma people to take ownership of their rights and entitlements and for the first time it enabled them to proactively demand fulfillment of their rights from the health care providers. The majorimpact is seen in the increased immunization coverage rates of Roma children that is a result of the proactive demand from the Roma communities and not a result of the measures foreseen by the Ministry of Health. Today they are empowered to take a rights based approach to securing their health needs. It is heartening to see that Roma people have started to voice out their dissatisfaction from the services provided, in comparison to the previous time where they felt disenfranchised. Today they demand higher quality of services. Coordinated advocacy at the national and local level has resulted in better functioning of health centers, building infrastructure and equipment, refurbishment and vehicles.

Today, ESE has initiated its work to improve transparency and accountability with the Ministry of health, continuing its work for the demand of the fulfillment of the needed services.
The groups of CSO (ESE, KHAM, CDRIM and RRC) are continuing their social accountability work in order improvement of the health and access to health services for Roma minority in Macedonia.

About the Author

Borjan Pavlovski is the coordinator of the program for public health and women's health in Association for Emancipation, Solidarity and Equality of women in Macedonia (ESE). ESE develops and assists the women's and civic leadership (especially that of Roma community) for development and implementation of human rights and social justice in Macedonia using approaches of monitoring and budget analysis, monitoring of human rights and providing assistance and information.

ESE primarily focuses on meeting the urgent needs of citizens, in particular the vulnerable groups of citizens, and on influencing the creation of long-term changes. ESE also provides legal and paralegal protection, as well as information to different categories of citizens and introduces them with the possibilities for protection of their rights. For more details on ESE please see: www.esem.org.mk/en

The Power of Community Initiative to Increase Access to Health Care: The Roma People Set the Way

TEODORA KRUMOVA

Background

The Roma Community in Bulgaria faces one of the most severe exclusions in access to health. The health status of Roma is significantly lower than that of the majority of the population of Bulgaria. Bridging the health gap requires intervention from both the Roma community and health system institutions. Since 2011, the Center Amalipe, a national Roma organization in Bulgaria has been introducing Community monitoring for Roma women and children on healthcare services. This initiative is supported by Accountability and Monitoring in Health Initiative Program of Open Society Foundation. It is used as an approach for strengthening community-informed and community driven advocacy to improve health service delivery and health outcomes.
The two rounds of monitoring are conducted every year, to examine women and children's health indicators and the emergency medical services. The monitoring uses standardized tools, to follow-through the changes that are observed in the health system with respect to the quality of services provided. It is due to the monitoring, community involvement and advocacy activities that there has been much progress made.

Preparing for Community Monitoring Exercise

The result of the monitoring is shared with the com-munity and health institution staff to take further actions to better improve the different aspects of health care services provided to women and children. Based on the results from each survey, an action plan is designed to address the harshest problem where the action items of recommendations made are implemented the next half year.

Preparing for Community Monitoring

The approach of community development and involvement in monitoring health care services and follow-up advocacy actions have led to significant changes in the health status of the Roma com-munity. Besides, it has proved helpful in raising awareness among the Roma community about healthcare rights and health services. For instance between the first two rounds of community interventions, Roma women who could identify their local primary care physician increased from 83% to 94%. However, all the rounds of community survey reflected significant concerns that communities encounter in their access to healthcare. For example, over 50% of women over 18 years did not have health insurance and so on.

The actual monitoring is preceded by various community mobilization activities in the field of health-care. Following this approach a campaign was organized by Center Amalipe and the Community Development Center in Pavlikeni to raise awareness and encourage people to restore their health insurance status. This was further necessitated by a change in the Bulgarian health insurance law that introduced a change in the period of insurance for a person, after which insurance status would have to be restored. The order came into force on

December 28, 2015, where the period of insurance was increased from three to five years. If this change was not implemented, then it would be practically impossible to secure the health needs of the socially disadvantaged people of Roma to get back again into the health system.

The campaign was based on the approach of shared responsibility. Center Amalipe with the support of the Fundamental rights agency (as part of the project LERI, implemented by the European Union Fundamental Rights Agency (FRA)) has offered ten of its most active community volunteers to cover half of their health insurance tax. In turn, they need to cover the other half and start paying their monthly health taxes regularly in order to continue to be active, and to further engage intensively with community health issues. On December 21, Center Amalipe supported 10 active volunteers at the Community Development Center of Pavlikeni to restore their health rights. The approach for supporting persons without health insurance ensures their participation and engagement: they have to pay half of the amounts for the previous 3 years as well as the entire amount since January 2016. It also stresses the community engagement: every grantee is a volunteer of the Community Development Center - Pavlikeni or the local clubs in Byala cherkva, Batak and Stambolovo. They will continue their community volunteer work.

Conclusion

Changes in policies often reflect on the most vulnerable groups and sometimes this impact does not bring a positive development. In this sense, the increase of the years to be covered in order to get back into the health care system would result in a harsher exclusion of the most vulnerable groups such as Roma. At the same time a strong community development and monitoring approach towards the healthcare services and the changes in health policies might help these groups react timely and decrease the gap through improving the access and quality of healthcare services.

**The article has been re-produced from the 13th issue of the COPASAH Communiqué*

About the Author

Teodora Krumova is a Roma activist from Bulgaria. She holds Masters in History and Archaeology from Veliko Turnovo University, Bulgaria, and in medieval studies from Central European University, Budapest, Hungary. She is the Program Director of Center Amalipe in Bulgaria and one of the co-authors of the Roma Culture Classes Program, which is being implemented in more than 250 Bulgarian schools. She has also written a number of publications on Roma history and culture, textbooks on Roma culture, monitoring and evaluation reports on Roma-oriented policies and impact of national and European policies on the Roma community, and other scholarly publications. She is an evaluation expert for applying the model of community monitoring of healthcare services in the Roma community implemented by Center Amalipe in Bulgaria since 2011. To know more about Amalipe visit http://amalipe.com/index.php?nav=home&lang=2

Write back to us with your feedback and inputs at copasahnet@gmail.com

Budget Monitoring and Dealing with Institutional Barriers in Macedonia

VANJA DIMITRIEVSKI

Budget monitoring can be a beneficial tool not only to access public information, but also to prompt public institutions to greater accountability and transparency. However given constraints this is not so feasible in country like Macedonia, despite the separate Law on Free Access to Public Information. The positive aspect in these circumstances is that the process of monitoring itself reveals institutional weakness, which on the other hand creates an opportunity for developing new communication and cooperation strategies with health institutions.

Healthy Options Project (HOPS), Skopje in 2014 decided to carry out budget monitoring in order to examine the possibility for financing the harm reduction programs in Macedonia from the state budget of the country. Now, halfway through 2016, these programs continue to get funded by the Global Fund to Fight against AIDS, Tuberculosis and Malaria. The Global Fund stops in December 2016. As late at 2014 there were no announcements made that with the Global Fund tapering off funding, the obligation for financing these programs would come from the Budget of the Republic of Macedonia. In fact, the financing of these programs in Macedonia remains uncertain, that, however, is not the topic of this discussion.

Subject of this monitoring were the budgets of: 1. Program for health protection of people with dependence disorders in the Republic of Macedonia, 2. Program for protection of the population against HIV/AIDS and 3. Program for social care –day centres and shelters for extra-institutional social protection.

HOPS made repeated requests to have free access to public information, pursuant the Law and past experiences, to all institutions in charge of planning and implementation of the three programs. Every enquiry was sent as a separate letter in the form of business reply mail. A total of 500 letters were dispatched. The questions consisted of requests for insight into financial documents of public nature: bank statements, accounting cards and invoices. We aimed towards short and clear requests, written in a language comprehensible for the institutional employees.

We were engaged in lengthy and painstaking correspondence. We received replies that revealed the institutional weaknesses. Initially, the institutions attempted to avoid the obligation of having to respond, claiming they did not have the data we asked for at their disposal. After we pressed on to their obligation to maintain necessary data and make it available to the public, they offered the excuse that this process required much effort when they were already overwhelmed with ongoing responsibilities. In order to receive the required data we had to gain the support of the Commission for Protection of the Right to Free Access to Public Information. The telephone conversations and direct meetings were most intriguing; they in fact revealed the institutional weaknesses. Like the official correspondence with

the institutions disclosed the way publically funded organizations conducted their activities in reality. For instance, in response to the written questions sent individually, we received a single response that seldom contained a reply to the questions it claimed to answer. This action disregards the rules for official correspondence and testifies of the professional negligence on the institutions' part, particularly since they insisted on this type of correspondence. The content itself revealed the incompetence of some of the officials and it further confirmed the dysfunctional human resource policy within the institutions.

We engaged in direct communication with the health institutes. The officials in many institutions were unable to comprehend the requests even though all of them were in the context of their job description. Most of them expressed reluctance to respond, while certain individuals did not hesitate to express their aversion towards civic society organizations and their obligations pursuant the Law on Free Access to Public Information. In a broader context, this rich experience testifies the damage caused by nepotism and cronyism that have been undermining the efficiency of Macedonian institutions for years.

Finally, after an extensive and laboured process, we managed to gather sufficient data, although incomplete, in order to gain clear insight in the budgets of the monitored programs. The monitoring findings aided the current efforts for representation, made by HOPS and other organizations, and in 2016, the Ministry of Health of Macedonia designated additional € 30.000 for the Program for Protection of the Population against HIV/AIDS. Unfortunately, this amount, even if portioned exclusively for HARM REDUCTION PROGRAMS amounts to less than 5% from the required finances. The budget monitoring illustrated the difficulty to fund harm reduction programs from the budgets of these three programs. Hence, we initiated a process for broader representation. However, despite our enthusiasm and dedication, the current social-political circumstances leaves little hope for timely solution of the financial sustainability of the harm reduction programs, at least not from the Budget of the Republic of Macedonia. Nevertheless, a siliver lining through this was that the budget monitoring improved the communication with state institutions and led to recognizing the advantages of the right to access public information and other activities.

About the Author

Vanja Dimitrievski is a Program Assistant at Centre for Education, Documentation and Research (CEDR) at Healthy Options Project Skopje (HOPS). He has a Master's degree in Ethnology and Anthropology and long research experience with different socially marginalized groups/communities, particularly people who use drugs.

Access to Health Can't be a Privilege!

ZORAN VIKOVSKI

To be or to have? When I started with citizen activism, this was the first question that surfaced in front of me. It is not sufficient to merely have laws, we needed good governance to go hand in hand. It is not sufficient to have two legs, two hands and head to be a Human. Laws exist to regulate relations between the people, to ensure equal rights for its people where, I believe that society is a product of civilization, a process that leads to building quality of life, knowledge and solidarity. Entitlements must be reality for every person.

It is over 15 years now that I have been working in the NGO sector where working with Roma community has been one of sharing of personal stories of success and disappointments through the narratives of life's journey. During my work with my Colleagues from NGO KHAM, we made the Roma community aware about the importance of Education. After 10 years of engagement we see positive change with more than 90% of Roma children have passed out of secondary school and a large number are studying in Universities.

KHAM is a grassroot organization that works directly with communities. When working directly with the communities, we understand that they faced with lot of barriers in implementation of their Health rights.

One of the challenges was access to immunization and Implementation rights of Immunization. With our Technical support NGO, ESE who provided us expertise and capacity building for using methodology of social accountability we decided to work in three localities of Delcev, Vinica and Crnik and implemented more than 80 project in these three localities give us legitimacy to work on Health rights. For this reason we bring Roma leaders together and decided that it is lack of implementation of Immunization of Roma children and the percentage of Immunization in Bregalnica region is not the similar to the majority population.

We began mobilizing the community on the legal empowerment on the people's right for immunization. We lead the program of 'Active protection of mother and children' and observed that this activity lacked adequate implementation in the Roma community. Through the tried research we created score card for the satisfaction of Immunization and we found many barriers that influenced the immunization process. With evidence gathered from the score card, the Community was prepared to address the problems and hold dialogues with To be or to have? When I started with citizen activism, this was the first question that surfaced in front of me. It is not sufficient to merely have laws, we needed good

governance to go hand in hand. It is not sufficient to have two legs, two hands and head to be a Human. Laws exist to regulate relations between the people, to ensure equal rights for its people where, I believe that society is a product of civilization, a process that leads to building quality of life, knowledge and solidarity. Entitlements must be reality for every person.

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succeed we needed to work towards the Legal empowerment of the community on one side, and to build the trust for people to accept their rights that belongs to them and not merely on paper. Now after five years of regular advocacy activities we have seen the evolving of different condition: Open Center for Immunization in Crnik, Specialization for Pediatric in each locality, Car for Patronage services in each locality. For sure we can say that the voice of the Community was strong and demonstrated visible changes. Now the percent of immunization coverage is larger in Roma community than in the Macedonian community.

decision makers at the local and national level to advocate for changes. For all of this to succeed we needed to work towards the Legal empowerment of the community on one side, and to build the trust for people to accept their rights that belongs to them and not merely on paper. Now after five years of regular advocacy activities we have seen the evolving of different condition: Open Center for Immunization in Crnik, Specialization for Pediatric in each locality, Car for Patronage services in each locality. For sure we can say that the voice of the Community was strong and demonstrated visible changes. Now the percent of immunization coverage is larger in Roma community than in the Macedonian community.

The same experience has been incorporated in the monitoring of program, screening of early detection of cancer and maternal health ". Again we have made progress, seeing visible results year on year. This is because the community has garnered the self confidence in claiming their rights, regaining the power balance to becoming change agents for the self and the community.

To conclude, through my own experience, I can confidently say that one can mobilize communities on issue that is most important for them. It is imperative that leaders need to be involved in the process from the very beginning. , Sustainable change is possible only if the Community augments the change for themselves as it does not come through any external agencies like an NGO. Without community mobilization and engagement, the work of NGOs will be a fight for political power, and the entitlements and rights of the ordinary people is often compromised. Behind us we have tell-a-tale of the work done, the successes, commitment, and

visibility of work.

Today, I have the courage to say that the condition of the Roma community in the Bregalnica region is one of the best in Macedonia, despite the challenges. We are living in unsustainable political condition, with constant flux of changes in the Health sector, made complex with poor governance. People living in deep poverty are mostly the forgotten as they live on the margins of society. Legal empowerment of the community is the only weapon to unite people around common issues, to help them galvanize through the processes of self-advocacy process that gives them the chance to fight for their rights.

About the Author

Zoran Bikovski, is an accountability practitioner, human rights warrior, with over 15 years of experience of working with Roma communities in Macedonia. Since 2011, he is working as Program Health Coordinator in KHAM. He is responsible for the implementation of program of Legal empowerment and Social Accountability in Health area for three localities. He is engaged with UNDP as a Coach for Roma for using active measures from Ministry of Labour since 2015.

About KHAM

NGO KHAM was established in 1999 in the Macedonian city Delcevo. The mission of KHAM is to work towards improving the socioeconomic and health condition of Roma community and other marginalized group. For more details on KHAM please see: www.khamdelcevo.org.mk

VIDEO STORY

Community Based Monitoring in Bulgaria, Amalipe

A short film on Community Monitoring practice in Bulgaria showcases the results of community monitoring through 'community inquiry', including periodical consultation (twice in the year) with the local communities about the health services they receive and their quality. The movie presents the process of Community monitoring on healthcare services implemented by Center Amalipe in Bulgaria with the financial support of Open Society Foundations. It is supplemented with two more elements. The first one is the community mobilization and building groups of activists in the community which precedes the 'community injury'. During the recent years, the program has achieved its goal to create, test, and evaluate a mechanism for mobilizing the local community in seven different towns and villages on the territory of Veliko Tarnovo, Gorna Oriahovica and Pavlikeni. The results show that the method works successfully for the mobilization of the local communities for solving issues in the field of healthcare. The second element is the advocacy activities before the local and regional health institutions as well as community campaigns for improving the health awareness. All activities are accompanied by the work of juvenile and female groups which is an important part both of the community mobilization and the advocacy.

Budget Monitoring and Legal Empowerment in Macedonia

BORJAN PAVLOVSKI, JASMINKA FRISHCHIKJ, DARKO ANTIKJ

In 2009, the Association for Emancipation, Solidarity and equality of women (ESE) in Macedonia –initiated its budget work to focus on improving the health of Roma children. Since then ESE has expanded its scope of work on the entire health budget, simultaneously ensuring that transparency and accountability of the Government is reckoned.

The health budget of the Republic of Macedonia is not progressive. The analysis of the health budget of the Republic of Macedonia shows that in the past 10 years only a meager 16% of the total national budget was spent on health. This shows that when funds are allocated to different sectors, budgeting principle based on critical priorities is clearly not applied; instead, budget allocation is made based on the application of a pre-developed mathematical formula for allocation. Thence, such a budget fails to include funds and activities that realistically meet the needs of citizens when it comes to health services and protection, leaving the health of citizens dependent on the overall budget policy of the Government of the Republic of Macedonia. Between the years 2012 to 2015, funds from the Central Budget of Republic of Macedonia increased on average by 3%. The Budget of the Ministry of Health accounts on average for 3% of the central budget, increasing annually by 1% on average during this time. The increase in the budget of the Ministry of Health is primarily due to the increased funds allocated for salaries of public administration in the health care sector, procurement of equipment, reconstruction and construction of facilities to name a few. The Ministry of Health in the period 2012 to 2014 on average executed 90% of the approved budget. The unspent portion of the budget is accounted for by preventive health care, i.e. 20%, compared to the unspent funds in curative care which on average stand at 2% annually. This practice of non-progressive allocation of funds for preventive health care programmes by the state is also exercised in case of the funds allocated for the implementation of the National Action Plan for Health of Roma .

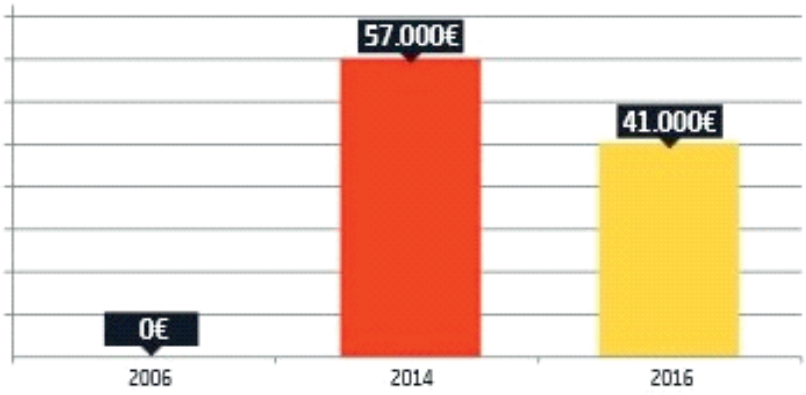
The public health budget of the Republic of Macedonia is not developmentally appropriate. The structure of the public health budget clearly indicates that most of the funds are spent on procurement of goods and services year in and year out. Over the past ten years, the funds earmarked for this purpose has reduced by 11 percentage points (89% of the 2006 health budget were set aside for goods and services, while the same portion in 2016 declined to merely 78%). Over the same period, the health institutions rendered services for which they never received funds, this led to continuous negative financial results of their operation and continuous increase of debt; this, in turn, resulted in a decrease in the quality of the health services. At the same time, the amount spent on goods and services, subsidies and transfers expenses (transfers to public enterprises, private companies, and civil society organizations) kept

rising to reach increase of 590% in 2016 in comparison to 2006. This trend was noted in the capital expenses (construction facilities, equipment, vehicles, and others.) The increase of this item amounted to 352% more than costs for goods and services.

The public health budget of the Republic of Macedonia fails to meet the principles of non-discrimination and equitable access for all in the provision of health services to different groups of citizens. The 2016 budget via support for and implementation of the Roma decade and strategy includes 29% less funds than in 2014.

The recommendation made by the Special Rapporteur on the right to health on the balanced and equitable approach of budgeting on curative and preventive health care, the Ministry of Health attached priority to curative health care. This accounts for an average of 46%, while it sets aside 7% of its budget for preventive health care. This prioritizing is evident in the continuous growth of the budget earmarked for curative health care (30% annually on average), while the budget for preventive health care increases on average by 13%. Notwithstanding the increase in the budget for preventive health care, the funds are reduced by an average of 21% with every amendment and supplement to the approved budget in the course of the year. Hence one can

conclude that the state, contrary to Article 2.1 of the Treaty fails to provide the highest possible extent of financial and human resources in order to ensure progressive and full realization of the right to preventive health care of vulnerable categories of population, such as Roma people, women and children.



State budget funds for improvement of Roma health shows the allocated funds from the state budget aimed for the strategy to improve the health of the people of Roma.

The budget for the program for health care of mothers and children is declining year-in and year out, with no funds from the budget allocated for additional patronage visits in marginalized communities with a special focus on the Roma people. As a result, Roma families receive 1.5 visits by the patronage nurses instead of 9 visits. The health education activities aimed for Roma which were part of the Program for active health care of mothers and children in the period 2011 - 2015, were removed from the Program and the budget with the amendments of the program in 2015. The program for active health care of mothers and children for 2016 also does not have foreseen activities aimed for Roma communities in its budget.

Also, the activities from the Program for Active Health Care for Mothers and Children in 2014 that pertains to antenatal checks and microbiological smear tests of pregnant Roma women who are recipients of social assistance, unemployed or from family receiving minimum income were not realized because of absence of implementation mechanisms, and were thus removed from the program in 2015. At the end of 2015 the Ministry of Health adopted measures where the co-payment for all the health services related to pregnancy is covered from the State budget, thus these services are free of charge for the pregnant women.

The program for cervical cancer screening envisages coverage of only 20% of women who are defined as a target adult group, but with the implementation of this program only 10 – 15% of women from the target group are covered annually. The Breast Cancer Screening Program was not implemented for four years (2011-2014) despite being approved and budgeted every year.

The public health fund is not aligned with the entire economic policy and the economic development goals of the Republic of Macedonia. In 2016, the Government of the Republic of Macedonia pledged to set aside 15% of

additional funds towards the health insurance of the unemployed than it did in 2014, which indicates that the planning of funds envisaged an increase in unemployment.

The public health budget is becoming increasingly dependent on funds provided in the form of loans and donations. The share of the funds provided from national sources for the purpose of financing health services is replaced each year by funds obtained as loans and donations that significantly disturbs the financial stability of the health care system in the country and impacts the continuity in the provision of health services for citizens. In 2016, the amount that the Government of the Republic of Macedonia will provide for health protection and services from the central national budget in the form of loans will be 210% higher than in 2006. The funds provided through donations in 2016 will exceed by 40% (since 2006). Most of the funds obtained through loans are spent on construction and reconstruction of facilities, while those received as donation are used for prevention programs. This leads to the conclusion that the modernization of the health infrastructure depends on loans, with a portion of the preventive health protection measures depends on donations.

Despite the continuous increase in capital expenditures, the expenditures for subsidies, transfers and foreign funds in the health sector, the health system in Republic of Macedonia still remains undeveloped and citizens continue to face obstacles in receiving proper health services and health care.

The Ministry of Health of the RM in the period 2012 – 2016 realized activities and spent funds in amount of EUR 18.760.000 from the ORIO project of the Government of Republic of Macedonia, from these funds7.428.800 Euros were financed through the Dutch grant – The Facility for Infrastructure Development ORIO , and 11.331.200 Euros were financed from the loan from the Council of Europe Development Bank and the central budget of the Republic of Macedonia (as Macedonian government contribution to the ORIO project). The project is intended for expansion and modernization of the Maternal and Child Health (MCH) system in Macedonia. The government of Macedonia through the Program for Active Health Protection of Mothers and Children contributed to the ORIO project with MKD 1.100.000 in 2011 and MKD 2.590.000 in 2012. Most of the funds were allocated towards empowerment programs and training to improve the capacities of patronage nurses, educating citizens on child health, early child development, etc. In the following four years, after signing the agreement for the ORIO project, the government cut all the measures and funds allocation used as contribution to the project. The project is delayed by four years in implementation of the activities prescribed in the application. All the funds, according to the activities planned for the development phase in the application, were used for foreign consultancy services for conducting researches which are already available on the national level, instead of providing adequate health services. Thus, it is not clear why in 2014 the Ministry of Health requested increasing of the budget by EUR 136.246.867 (from EUR 18.760.000 to EUR 155.006.867), where the ORIO grant participation was increase by EUR 182.744 (from EUR 7.428.800 to EUR 7.611.544).

The Macedonian Government, trough the document developed during the development phase of the ORIO (2012 – 2016), recognized the failure to achieve the European Commission notes for lack of effective decentralization in the health sector that negatively affect mothers and children indicators and deepening the health inequalities among the population. According to the Macedonian Government, Macedonia faces high perinatal/infant mortality rates, lack of quality of outreach capacities, poverty, and social exclusion. More precisely, trough the ORIO project documents, the Macedonian health system has identified challenges related to capacity building, financial and systematic problems.

Challenges seen in the capacities of the health system

The inefficiency in the community (patronage) nursing system in targeting mothers and children from socially vulnerable groups and the imbalance in the service delivery of the patronage nurses in vulnerable communities' especially rural population and Roma is a critical challenge. The home visits during the pregnancy period and post-delivery of children the child are grossly inadequate. The challenge is magnified with the lack of adequate transportation facilities.

•Lack of personal specialized in care for Mother and Child, poor capacities among the care providers.

•Suboptimal level of effectiveness and efficiency in the operation of the health care system.

Financial problems

•High level of social assistance and health care expenditures.

•Significantly lower health care expenditures. The percentage of expenditure on Health Care is far below the GDP of most of the countries in the region and EU.

Systematic problems

The isolation of marginalized groups of people (especially the rural population and Roma) to access mother and child health care services (7.5% of households with children are not covered with health insurance. A majority of Roma mothers and children are excluded from the health insurance system and cannot afford to co-fund or pay the costs for antenatal examinations and transport.)

•Low and insufficient level of investments in the health sector.

•Poor utilization of primary and secondary care and overutilization of tertiary care.

•Poor management in the health system.

•Minorities and poor people are underserved because they do not know their way in the system of free health care and lack of appropriate help seeking behavior.

•High perinatal and infant mortality rate in rural and Roma communities (9.8 per 1.000 live births and 25% higher than average and 23% unattended births outside hospitals among Roma).

•Poor management practices and efficiency of the MCH programs.

•Inadequate planning, budgeting and implementation of MCH programs.

•Lack of health information and statistics for planning, budgeting, monitoring and reporting on MCH programs and service delivery in the area of immunization and home visits.

•Low level of immunization coverage in the marginalized communities (especially rural population and Roma) between 63 and 89% for different vaccines that is below the general population coverage and WHO standards.

The implementation of the ORIO grant started since 2011 and funds were spent for its implementation with the main goal to "Set up of an integrated system for maternal and child health care for improved health outcomes in R. Macedonia". Yet until present there is no improvement with regards to the main goals that were supposed to be achieved with this grant.. Moreover we are witnessing worsening of the situation regarding the health outcomes of mothers and child health and coverage of these groups with health services. This situation is described in "Shadow Report on the implementation of the International Covenant on Economic, Social and Cultural Rights, 2016" , submitted by ESE and group of Civil society organizations.

The health data and health statistic managed by the health institutions is of poor quality. The health system needs to be updated with real time data, in order to serve as a base for further development of health policies. This will help in the restructuring of strategies in the health sector.

Data is not segregated by ethnicity. The allocation of funds in the health budget is based on outdated health statistic. According to the research carried out by Association for Emancipation, Solidarity and equality of women (ESE), it observed that the Ministry of health and majority of public health care institutions were non-transparent and lacked accountability in their programmatic and financial operations. For example, in 2015 the Ministry of Health reached the bottom in terms of its pro-activity level. In 2015, the Ministry of Health did not release any information about its current work on its official website. The Health Insurance Fund publishes 44% of the monitored information/documents on its program and budget operation that included it in the category of partly proactively transparent public institutions.

The analysis shows that the health care intuitions at the local level have higher reactive transparency in comparison to institutions at the national level. The level of proactive and reactive transparency is especially low regarding the data on foreign aid. For example, the Ministry of Health of the Republic of Macedonia does not provide publicly available data and

documents on the budgeted and realized activities and costs financed through the Dutch grant The Facility for Infrastructure Development ORIO, stating that it does not have the data available to publish. According to the official documentation, the Ministry of Health is the institution in charge of the ORIO project in Republic of Macedonia and hence it is unclear about the ministry inability to provide information on the funds received and utilized from foreign aid over the past 18 years .The Ministry of finance does not provide any information related to specific budget expenditures made trough the treasury system in the health sector. According to the Ministry of Finance, the data is classified and the Treasury does not publish the details to the Treasury System.

There is an unmet need of financial assistance for care of adult persons who are not able to take care of themselves provided by the State and the amount provided is insufficient to cover the costs for time allocated for care.

There is no data available of the unpaid care work done in households – the care of the chronically ill, disabled and/or elderly. Yet the data shows that the need for financial assistance from the State is increasing through the years, with the number of beneficiaries of financial assistance for care provided by the Ministry of labor and social policies has increased from 19.640 beneficiaries in 2008 to 25.444 beneficiaries in 2012. The responsibility of care giving raises the issue of gender equality, where the burden on being care givers falls on women, since women are primary care givers. The plight of care givers' ability to work outside the home, to financially contribute to the household, and other spheres of his/hers life including social life, community engagements and use of media are many. The unpaid care provided by a single care giver is worth an estimated 262.947,00 MK Denars per year, or approximately 21.912,00 MK Denars per month. Also the unpaid care work in the households is crucial because this work substitutes for the lack of availability of long-term care capacities in the health system. The State provides financial assistance for care of person in two extents: higher extent in amount of 4.348,00 MK Denars per month; and lower extent in amount of 3.846,00 MK Denars per month. This amount is merely sufficient to cover basic expenses for purchasing essential medicines and medical materials but does not cover the costs for the time allocated for care; neither provides funds for the households to hire external person/s or to accommodate the person that needs care in public or private institution towards long term care. Furthermore, the other members in the household who take care for the adult person does not receive the financial assistance from the State indicate that there are unmet needs.

Legal empowerment work in Macedonia

Two legal empowerment delivery models were developed in the country i.e. the community paralegal programs and lawyering for marginalized (socially excluded groups). Both these models are aimed at supporting marginalized groups of people, such as Roma minority, people with HIV/AIDS, drug users and sex workers. Both delivery models are addressing health and human rights violations.

The community based paralegal model was introduced in 2010 when FOSM Public Health Program that was started to support two Roma civil society organizations in provision of paralegal services in the area of health protection, health insurance and patient's rights protections, offering technical support for the Association for Emancipation, Solidarity and equality of women (ESE). This type of support is unique from two perspectives,in the first place it specifically addresses the health rights violations that specialize and profile the type of services offered in the communities and secondly it builds its own sustainability around paralegals that originate from communities where they offer these services and are familiar with their needs and mentality. It is worth noting that the community paralegal programs operate in the largest Roma community (majority of Roma lives) in the country, Shuto Orizari and Roma communities in the Bregalnica region (municipalities of Vinica, Delcevo, and Pehcevo situated in eastern part of Macedonia). So far, 1.800 Roma were served predominantly on gaining health insurance, assistance to obtain the social payments/benefits, cases on dealing with issues of healthcare access and malpractice cases.

Modest progress made over the last five years is:

•One additional Roma organization was included as community paralegal program provider.

•New paralegals were recruited and trained (three apart of the four already engaged paralegals).

•The number of geographical settings was increased i.e. in parts of the largest Roma community, Shuto Orizari and in village Crnik in city Pehcevo.

•Three community paralegal programs i.e. the provision of paralegal support is coordinated and supervised by CSO ESE- technical assistance provider that complements the paralegals work; and

•The community paralegal programs advises the local Roma communities on a much broader range of legal issues such as social protection, labor rights, education, domestic violence etc.

In the previous year civil society organization HOPS started with provision of paralegal assistance and support to sex workers in the capital of the country as a pilot initiative.

There is an obvious need and demonstrated satisfaction in the community paralegal programs operation among the local Roma communities, since more and more community members are turning up for help. What is most important is that community paralegal programs have strengthen the status of the Roma civil society members as advocates for resolving the community health problems and satisfying their health related needs. Apart of the individual cases, certain community prevailing problems are addressed, such as: immunization; emergency medical service; early screening and detection of cancer services etc. Additionally, two strategic litigation cases were identified (medical negligence concerning replacement shoulder and one related to refused coverage of costs of a health procedure that could not be obtain in Macedonia). The public institutions and especially the public health institutions became more aware and responsive to Roma health rights violation and needs. Their cooperativeness has increased over the years.

The media in its awareness of to the health rights of the people of Roma and other marginalized groups showcases the health rights violations. Academia and especially public health specialists are already involved in different initiatives related to promotion of patients' rights in health care and recognize the need of changing narratives in health care settings when speaking about marginalized groups' health status and needs.

What is most important is that there is a political support for the legal empowerment of Roma (community paralegal services and lawyering for marginalized were foreseen as measures under the National Strategy for Roma protection although financial means are not allocated for their implementation), but having on mind the turbulent political and socio-economic situation, we believe that there is much to be done in order to move further.

The community paralegals programs are being operated by Roma civil society and some of the organizations involved are CDRIM, KHAM and RRC with technical assistance and support from ESE. For the last five years these organizations have been supported by Open Society Foundations (donor) in the provision of paralegal assistance. . The role of the Roma civil society organizations is to provide access to one on one legal advice; impart information on the health rights and entitlements; to refer clients to other civil society organizations; to advocate for resolution of community health prevailing problems; to identify strategic litigation cases etc. Role of Association ESE as a technical assistance provider is to coordinate and supervise the Roma CSO providers trough different capacity building activities (knowledge and skills); taking care for the continuous and on time information about the health legal reforms; develops and upgrades the case management and filing system if needed; monitors and assesses paralegals work and provides legal consultancy in the cases referred by the paralegals. HOPS as an OSF grantee is to offer paralegal services to sex workers also.

About Authors

Borjan Pavlovski, is the Coordinator of the Program for public health and women's health in Association for Emancipation, Solidarity and Equality of women in Macedonia (ESE). ESE develops and assists the women's and civic leadership (especially that of Roma community) for development and implementation of human rights and social justice in Macedonia using approaches of monitoring and budget analysis, monitoring of human rights and providing assistance and information.

Jasminka Frishchikj, holds the position of Executive Director of ESE since 1998. Being the Executive Director of ESE, Jasminka works in several areas, such as: promotion of women's human rights and concept of gender equality; promotion of the concept of monitoring and analysis of budgets on national and local level; analysis and monitoring the extent of implementation of international documents on human rights; promotion of human rights in health care; promotion and development of legal, paralegal and other types of services for protection of the right to health, in particular the right to health of Roma, etc.

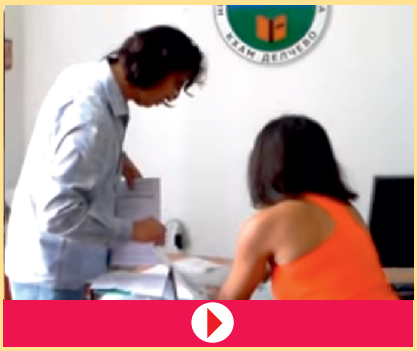
Darko Antikj is the Coordinator for Monitoring and analysis of budgets and works on promotion and advocacy for: necessity for creation of public budgets that ensure meeting the needs of all citizens equally; planning and use of budget funds by respecting the principles of efficiency, effectiveness, cost-effectiveness and transparency; financially transparent and accountable state administration; participatory and open budget processes; consistent implementation of health policies and programs etc.

About ESE: ESE primarily focuses on meeting the urgent needs of citizens, in particular the vulnerable groups of citizens, and on influencing the creation of long-term changes. ESE also provides legal and paralegal protection, as well as information to different categories of citizens and introduces them with the possibilities for protection of their rights. For more details on ESE please see: www.esem.org.mk/en/

VIDEO STORY

Barriers that Rome people face regarding access to health care- ESE, Macedonia

This short visual document reflects the barriers that Rome people face in accessing to health care. It highlights the instances of discrimination faced by Roma community in accessing health care, with example of Roma community family unable to access emergency care and further medical care in health institution. Statistics suggest that 31.8% of Roma people are not treated with respect while on a visit to doctor as compared to 6.9% of the other population. It highlights efforts of Health rights organizations, NGO KHAM and ESE Skopje working towards advancement of health rights of the marginalized Roma community.



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