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Roma health mediation in Romania

ROMA HEALTH – CASE STUDY SERIES **NO. 1**

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The Series
The Roma Health Case Study Series provides a forum for sharing knowledge on how to improve the health and well-being of the Roma population in the WHO European Region. The aim of the papers is to review the evidence and country experiences with an eye to understanding practice and innovative initiatives, and encouraging debate on the connections between Roma health, its social determinants and the broader policy environment. The papers are all peer reviewed.

Background
This paper was commissioned by the WHO Regional Office for Europe. The case study was produced to inform a resource package for health professionals to be used in multicountry capacity-building events to promote the reorientation of strategies, programmes and activities related to Millennium Development Goals 4 and 5 (child and maternal health) for greater health equity, with an explicit but not exclusive focus on the Roma population.

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Executive summary

The case study relies on secondary data (research reports, evaluation reports, legislation, and data in the Roma Center for Social Intervention and Studies (Romani CRISS) archives) to provide a critical overview of the Roma health mediation programme in Romania. It discusses the social and political context in which the programme was developed, the general characteristics of the mediation, as well as the lessons learnt after 10 years of implementation.

Health mediation was designed to improve the health status of Roma and their access to health care services. According to official statistics, Roma are the third largest ethnic group in the country (3.2% of the total population). Compared to the general population, Roma ethnics have higher infant mortality rates, lower life expectancy at birth and lower rates of childhood immunization. At the same time, Roma fare worse than other ethnic groups with respect to the use of health care facilities and are more likely to experience discrimination in the medical system.

The objectives of the programme are to facilitate communication among medical personnel and Roma communities, and to increase the efficacy of public health interventions. Mediators are usually Roma women with an average level of education, who have been recommended by local communities, approved by medical practitioners and who have successfully completed a brief training. Their main responsibilities are:

- to serve as a liaison between communities and health care practitioners;
- to collect data on the health situation in the community;
- to facilitate Roma access to health care;
- to provide health education; and
- to support public health interventions in Roma communities.

The programme was institutionalized in 2002, in the context of the National Strategy for Improving the Situation of Roma. It builds upon the experience of a Roma health mediation project developed six years earlier by Romani CRISS. By 2008, there were approximately 600 health mediators working in Roma communities throughout the country. The decentralization of the health system in 2009, as a result of which mediators were transferred from county health authorities to local public administrations, initiated a period of insecurity with regard to the prospects of health mediation. The programme's successes include:

- collaboration between governmental and nongovernmental structures in the planning and implementation of health mediation;

- a high number of women trained and hired as health mediators;
- a high number of beneficiaries;
- broad geographical coverage; and
- transferability of the model to other European countries that have significant Roma populations, such as Bulgaria and the former Yugoslav Republic of Macedonia.

Other strong points of the programme are its focus on preventive, instead of curative care, its contribution to knowledge pertaining to health among Roma, and the assistance provided to some of the most vulnerable categories of Roma, particularly persons lacking identity documents.

Among the challenges encountered during programme implementation have been insufficient initial training, modest remuneration of the mediators, difficult working conditions and changes brought about by the decentralization.

The programme has often been criticized for shortcomings in the supervision of health mediators (use of formal and quantitative templates for activity reporting, no empirical verification of the reports and lack of feedback) and the insufficient use of data collected by mediators in the communities. Lack of transparency in programme funding and limited opportunities for continuous training of mediators have also attracted criticism.

Social and policy context 1

Demographic characteristics

According to the preliminary results of the 2011 Population and Housing Census, the stable population of Roma in Romania is 619 000 (accounting for 3.2% of the country's total population). Roma represent the third largest ethnic group in Romania, after Romanians (88.6%) and Hungarians (6.5%). In 2002, 50.7% of the Roma were males, whereas women represented 49.3% of the population. While the basic ethnic structure of the population remained constant in all three state censuses, the Roma community experienced a steady increase in both absolute size and share of the total population. Thus, the number of people self-identified as Roma increased from 401 087 (1.8%) in 1992 to 535 140 (2.5%) in 2002. Although the 2011 data indicate the highest number and proportion of Roma ever recorded in a Romanian census, these figures are significantly lower than estimations made by independent researchers and Roma civil society activists *(1–3)*. In 2003, the European Commission acknowledged that the Roma population in Romania is likely to be in the range of 1 800 000–2 500 000[1] *(4)*.

Two important characteristics of the Roma community in Romania are cultural heterogeneity and territorial dispersion. According to the 2011 census, the number of people whose mother tongue is Romani (defined as the primary language spoken in the household when the respondent was a child) is 247 058, representing 1.3% of the total population of the country and 39.9% of the total Roma population *(5)*. This represents a minor increase from the previous census, in which 237 578 persons (1.1% of the total) declared speaking Romani as their primary language. There is no official collection of data on affiliation to subethnic groups, but the findings of a survey conducted in 2007 indicate that 45% of Roma consider themselves to be "Romanianized" (i.e. assimilated), 23% have no affiliation to subethnic groups, 15% come from former traditional groups having lost their cultural specificity (Rudari and Lovari) and another 15% belong to traditional communities (Kalderash, Ursari, Caramidari) *(6)*. From a religious standpoint, Roma communities are more homogenous: the overwhelming majority of the members (81.9% at the 2002 census) belong to Christian Orthodoxy.

In terms of geographical distribution, Roma tend to be dispersed in relative uniformity across the territory of the country, representing more than 1% and less than 9% of the population in every county *(județ)*. The highest proportion of Roma is encountered in the counties of Mureș (8.8% at the 2011 census and 7% at the 2002 census), Călărași (8.1% and 5.7%, respectively), Sălaj (6.9% and 5.1%, respectively) and Bihor (6.1% and 5%, respectively) *(7, 8)*. Similarly, at the level of locality, Roma tend to represent less than 10% of the total population *(8)*.

Social and economic conditions

Official data released by the Romanian Government in 2008 indicate the precarious economic

1 Several factors contribute to the undercount of Roma in official statistics, including procedural limitations (exclusionary definitions of ethnicity; impossibility of declaring more than one ethnic affiliation, or mixed ethnicity; use of non-Roma enumerators in compact Roma communities); reluctance of Roma to disclose ethnicity (for fear of discrimination; distrust in local authorities; limited awareness of the importance of census as a data-gathering mechanism; lack of awareness of the handling of ethno-cultural data); and enumerators' departures from data-collection rules (abusive filling of questionnaires; leading respondents to a particular answer; exclusion of some households from the enumeration). *(5)*

situation of Roma and the disproportionate exposure of the community to unemployment and poverty.

- The share of Roma without an income was double that of non-Roma (41.9% versus 20.2%).
- The main sources of income for Roma were social benefits, such as maternal allowance, children's allowance, additional family allowance (received by 26.1% of the Roma population), and guaranteed minimum income (received by 14.4% of Roma versus only 2.0% of non-Roma).
- Revenue was derived primarily from inactive sources (43%) and involvement in informal lucrative activities (22.7%) *(9)*.

The Joint Memorandum on Social Inclusion, drawn by the Romanian Government and the European Commission, Directorate General for Employment and Social Affairs in 2005, acknowledges the economic vulnerability of Roma, delineated in terms of low employment rate (47% versus the national average of 61.7%), prevalence of unsalaried employment (72.5%) and concentration of the employed persons in agricultural activities *(10)*. The Memorandum also indicates that in 2003 Roma were three times poorer than the average *(10)*. The barriers to securing and maintaining employment in the formal economy are diverse, including lack of identity documents *(11)*, limited formal educational background, widespread discriminatory practices in the labour market, living areas with limited economic opportunities, decreased demand for traditional occupations and, in the case of women, a traditional gender division of labour that assigns women to the household to perform domestic chores *(12)*. Early marriages, a practice still encountered in some traditional communities, affect disproportionately Roma girls, limiting their period of school enrolment and reducing the likelihood that they will obtain employment later on *(13)*. In this general context of economic hardship and limited opportunities, migration to western countries, such as France, Italy, Portugal and Spain, has been seen as a solution by many Roma.

With respect to education, the situation of Roma is characterized by lower enrolment, higher rate of early dropout and increased likelihood of abusive placement in special education than for non-Roma. Segregation represented a major issue in the past decade, but there is not enough data to assess the situation at the moment. Official data released by the Ministry of Education in 2005 reveal that the overwhelming majority of unschooled youth (80%) are members of the Roma ethnic group, and over one third of them (38%) are functionally illiterate. At the same time, only 64% of Roma are enrolled in primary education, compared to the national average of 98.9% *(14)*. Independent quantitative research confirms the gap in school attendance between Roma and non-Roma *(12, 15–17)*, and identifies a significant negative correlation between early childhood education and leaving school before the completion of the 10 years of mandatory education *(17)*. In other words, children who were not enrolled in early childhood education are more likely to withdraw from school before completing 10 years of education. The factors contributing to school dropout are economic (indirect costs of education, involvement of children in lucrative activities outside of school),

institutional (discrimination of Roma children by teachers and classmates, teachers' low expectations, absence of a curricula reflecting and valuing cultural diversity, fluctuation in the teaching staff) and cultural (early marriages) *(17)*. A serious discriminatory practice encountered in the Romanian educational system is the placement of Roma in special education schools for disciplinary reasons or lack of competitiveness *(3)*.

In terms of political representation, several Roma parties have competed in elections. The Roma Party has been the most successful of them, securing one seat in the Chamber of Deputies, the lower chamber of the Romanian parliament, in each legislature since 1990 *(3)*.

Inequalities in health status and access

Despite persistent optimistic self-assessment of health status *(18)*, Roma have higher mortality rates and lower life expectancy at birth than the majority population *(8)*. In 2002, the median age of Roma was 24.2 years, compared to 37.4 years for the general population *(8)*. Given the absence of official medical data disaggregated by ethnicity and the different methods of assessing ethnicity (hetero-identification or self-identification), the knowledge of the health status in Roma communities is only approximate. A recent survey conducted on a representative sample found that more than half of Roma adults aged 45 and over suffer from disabilities or chronic illnesses; more than 60% of adult men and women have cavities; and about half of the adults are either overweight or obese *(18)*. The same research discovered that 45.7% of Roma children have not completed the compulsory immunization scheme, and half of these have not received any vaccine. About half of Roma women either have never seen a gynaecologist (12.2%) or have only seen a gynaecologist during pregnancy (34.1%). The situation of Roma women aged over 45, despite their higher risk of cervical and breast cancers, is even worse: 10.1% have never seen a gynaecologist and 47.6% have done so only during pregnancy *(18)*.

Qualitative research *(19)* revealed a series of obstacles to accessing health care services, including absence of identity documents (which prevents people from formally enrolling with a general practitioner), lack of medical insurance, high costs of medical procedures, informal payments, family doctors' leeway to accept or deny patient enrolment and the existence of discriminatory practices in the medical system, such as segregation in maternity wards; redirection of patients to other medical practitioners; separate time slots to receive Roma patients, usually towards the end of the work schedule; and use of derogatory language. Apart from access per se, Roma mentioned discontent with the quality of visits to family doctors due to limited physical contact during medical examination, no involvement of patients in deciding treatment; use of aggressive medical procedures; and insufficient provision of information regarding the prescribed treatment *(19)*. The perceived low quality of the interaction with medical practitioners represents a major deterrent from seeking medical help, particularly for minor health issues.

Cross-sectoral policies to improve socioeconomic conditions

Governmental commitment to address the structural ethnic inequalities and improve the situation of Roma can be traced back to the European Union (EU) accession process *(20, 21)*. Some milestones in the recent involvement of national authorities in Roma issues have been:

- joining the Decade of Roma Inclusion (2005–2015);
- elaborating the Strategy of the Romanian Government to Improve the Situation of Roma (2001–2010), including various provisions pertaining to Roma in the National Plan for Combating Poverty and Promoting Social Inclusion (2002–2012); and
- elaborating the Strategy of the Government of Romania for the Inclusion of the Romanian Citizens Belonging to Roma Minority (2012–2020).

As part of the Decade of Roma Inclusion, the Romanian Government (through the National Agency for Roma) elaborated in 2007 specific national action plans for the four domains of priority intervention – education, employment, health and housing. Despite the careful planning of the measures and efforts to synchronize them with other policies targeting Roma, an intermediary evaluation performed in 2010 by the Civic Alliance of Roma in Romania *(22)* revealed serious shortcomings in the implementation:

- lack of collaboration among institutions in charge of carrying out the measures;
- limited political support;
- sectoral approaches to the issues in the national action plans;
- insufficient monitoring of the implementation; and
- absence of constant dialogue among public authorities and Roma civil society.

The Strategy of the Romanian Government for Improving the Situation of Roma, drafted after consultation with experts and Roma civil society activists *(21)*, established 10 areas of priority intervention – community development and public administration, housing, social security, health, economy, justice and public order, child protection, education, culture and cults, and communication and civic participation (chapter VI). An assessment of the implementation made in 2009 *(21)* identified among the positive effects: the emergence of institutions charged with handling Roma issues (the county offices for Roma), the creation of jobs focused on social inclusion of Roma within the public administration system and the development of a Roma elite. At the same time it criticized the inadequate funding for implementing some measures, the inefficient monitoring procedures and the lack of specialists on Roma inclusion in the institutions in charge of implementation. In 2011, a new strategy was adopted for the period 2012–2020 without a rigorous evaluation of the former ten-year plan.

Policies to increase health system access

The Strategy included eight directions for action pertaining to health *(21)*:

- improving Roma access to preventive and curative public health care services by institutionalizing the health mediation system, and drafting and implementing specific programmes of prophylaxis and treatment;
- training health mediators, nurses and doctors from Roma communities;
- identifying solutions for including Roma in medical insurance systems, enrolment with family doctors and securing compensated medication;
- developing and implementing programmes for dissemination of health information,

health care counselling and family planning for Roma women, with an emphasis on child and maternal care;
- conducting vaccination campaigns in Roma communities;
- conducting campaigns for diagnosing tuberculosis (TB), HIV/AIDS, dermatological problems and sexually transmitted diseases;
- conducting epidemiological studies regarding the health status in Roma communities; and
- increasing the number of health care practitioners of Roma ethnicity through affirmative action measures in the public medical education system.

The national action plan in the field of health developed in 2007 as part of the commitment to the Decade of Roma Inclusion focused on:

- drafting and implementing health programmes adapted to the specific needs of Roma;
- promoting intercultural education within the national health system; and
- increasing access to health services, particularly for some extremely vulnerable categories of Roma, such as people living in poverty and people lacking identity documents.

Among the specific measures designed in the national action plan were:

- expanding the network of health mediators;
- providing trainings for health mediators;
- establishing partnerships among public health institutions and nongovernmental organizations (NGOs); and
- increasing awareness of medical practitioners on discrimination.

One of the most important policies with respect to increasing Roma access to health was the institutionalization of health mediation. Initiated as a pilot project by Romani CRISS, health mediation was adopted in 2002 by the Ministry of Health as a formal policy *(19)*. The decentralization of the health system that took place between 2008 and 2009 effected major changes in the organization of health mediation by transferring responsibility for this activity to local authorities *(19, 22)*.

2 The Roma health mediator programme

To understand the current dynamics of Roma health mediation in Romania, it is necessary to look at the origins of the programme and its subsequent transformations. After examining health mediation in historical perspective, this chapter will provide a general overview of the programme, based on legislative regulations as well as on evidence from secondary data. The final section will discuss the determinants of health addressed by the programme, with an emphasis on service coverage.

Historical overview

Five stages can be distinguished in the evolution of health mediation in Romania:

- early development (1996–2002), a period of project pilot-testing initiated by Romani CRISS, a Roma NGO;
- institutionalization (2000–2002), during which the Ministry of Health adopted mediation as a programme, and the health mediator job was officially recognized and included in the Classification of Occupations in Romania;
- consolidation (2002–2008), when the number of persons trained and appointed as mediators increased considerably;
- decentralization (2009), which transferred health mediators from county health authorities to municipalities; and
- incertitude in the aftermath of decentralization.

The origins of mediation as a form of social action can be traced back to 1991, in the context of inter-ethnic conflicts *(19)*. Mediators were trained to become liaisons among Roma communities, non-Roma and local authorities and to facilitate the identification of peaceful solutions to local problems. Building upon the early experiences and shifting focus from conflict resolution to improvement of social conditions for Roma, Romani CRISS initiated in 1996 a pilot project on health mediation with technical and financial support from the Catholic Center against Famine and for Development (CCFD) *(19, 23)*. The responsibilities of the appointed mediators, most of them Roma women living in the communities where they worked, included raising the health literacy of Roma, with a focus on preventive health care, raising awareness among the health care providers of the situation of Roma and addressing the social determinants of access to health, such as absence of identity documents *(23)*.

To increase the efficacy, expand the coverage and ensure the sustainability of health mediation services, Romani CRISS advocated the institutionalization of the programme and recognition of health mediator as an occupation. As a member of the Working Group of Roma Associations, a consultative structure involved in the elaboration of the 2001 National Strategy for Improving the Situation of Roma, the organization managed to introduce on the

agenda the issue of health mediation. As a consequence, the adopted Strategy included among the directions of action in the field of health the institutionalization of the health mediation programme and the training of health mediators coming from Roma communities. The Ministry of Health was requested to draft, in cooperation with NGOs and county public health authorities, a national plan for the training and coordination of health mediators, with responsibilities in the prophylaxis and treatment of Roma. The deadline for this activity was set for 10 April 2002.

Following a series of consultations, the Ministry of Health, the Organization for Security and Cooperation in Europe–Office for Democratic Institutions and Human Rights and Romani CRISS signed in September 2001 an Agreement of Cooperation for carrying out the activities pertaining to health in the Strategy. The Agreement was subsequently renewed in 2005 and 2008 *(19)*. At the same time, the Ministry of Labour introduced "health mediator" in the Classification of Occupations in Romania (base group 5139, code 513902). In the context of the Agreement, Romani CRISS provided health mediation training to 84 Roma women with an average level of education, and the Ministry of Health created the legal framework for their appointment (Order 619/2002). The institutionalization of the health mediation system in Romania was the result of a particular configuration of factors, including international pressure to improve the situation of Roma, governmental commitment to achieve this goal, proactive involvement of civil society and support from international organizations.

The following years (2002–2008) were a period of programme consolidation, characterized by a significant increase in the number of persons trained in health mediation and contracted to work in Roma communities, growth of budgetary allocation to the programme, elaboration of training materials and performance of independent programme evaluations. By 2005, there were 395 appointed health mediators *(24)*. Three years later, in the heyday of the programme, their number reached 600 *(19)*. The budget for Roma health mediation consequently increased from €30 000 in 2002 to €438 000 in 2005, according to information provided by the Ministry of Health *(25)*. In addition to the initial training, mediators benefitted from a series of continuous training sessions on issues pertaining to prevention of TB, human rights, communication and administrative procedures for obtaining identity documents *(19)*. At the same time, several publications were developed by NGOs, including:

- *A guide for health mediators (19);*
- *Training of Roma health mediators in reproductive health (26); and*
- *Introduction to Roma culture: exploring cultural diversity for Roma doctors (27).*

Independent evaluations of the programme conducted by John Snow Inc. (JSI) Romania and the Center for Health Policies and Services *(24)*, and COTA Brussels (a Belgian NGO) *(25)* in this period considered the programme a success and a model of cooperation among government, NGOs and international donors, but also revealed some major shortcomings in implementation. Similar conclusions were reached by an assessment of health mediation in Bulgaria, Finland and Romania performed by the Open Society Institute (OSI) *(28)*. A brief examination of the criticisms is provided in the next section of the report.

An abrupt change in the organization of the health mediation programme occurred in 2008–2009, with the decentralization of the health system. The Government regarded decentralization as a means to improve the quality of health care services, by adapting them to the needs of local communities, while at the same time relieving the Ministry of Health of the duty to coordinate and monitor the activity of institutions and personnel at local level (Government Decision 562/2009). As part of the process, the organization of health mediation was transferred from county health authorities to local public administration. Mediators were integrated into social work services or the mayor's office.

However, the process has not gone smoothly. While the legislative framework granted mediators security of employment (Government Emergency Ordinance 162/2008, Art. 20) and income according to the same pay scale when hired by the local health directions (Government Emergency Ordinance 162/2008, Art. 10(1)), the legal provisions have been applied unevenly by local authorities and numerous claims of abuses have been reported. Monitoring during the transition by Romani CRISS indicated that at least 100 mediators faced difficulties, such as a hiring refusal and discriminatory treatment at the workplace *(19)*. The departures from the legal provisions in the transfer of health mediators were rendered possible by the hasty implementation of the decentralization strategy, inadequate informing of local administration about the mission and objectives of Roma health mediators and the limited involvement of the Ministry of Health and its territorial structures in the transfer process.

The decentralization, which coincided with an economic crisis and a period of political turmoil, led to a climate of insecurity with regard to the future of health mediation. Recent studies and evaluations of the programme have revealed that a considerable number of mediators still face difficulties in adjusting to their new workplace, are required to perform tasks unrelated to their job description, and were hired for a fixed term. The latter condition entails the risk that these positions will be discontinued if funding for the programme ceases to come from the national budget *(19, 29, 30)*.

These circumstances led health mediators to create the professional association "Zurale Romnia" in 2011. The objectives of the organization include defending the rights and interests of the mediators and improving their working conditions, developing partnerships with similar professional bodies for the transfer of good practices, ensuring professional and personal development for its members, and pursuing activities to improve the health situation of Roma in Romania.

General overview of the health mediation programme

Mission, objectives and activities

Romani CRISS initiated the health mediation programme as a model of social intervention for improving the situation of Roma in Romania. The objectives included:

- civic and social mobilization, by involving local communities in the programme's implementation;
- facilitation of communication between Roma communities and local medical providers;

- facilitation of access of Roma to health care services;
- increased stock of knowledge pertaining to health among Roma communities; and
- empowerment of Roma women *(23, 25)*.

After the Ministry of Health adopted the programme, it redefined its objectives by focusing only on the facilitation of communication among medical personnel and Roma communities, and increasing the efficacy of public health interventions (Order 619/2002, Annex 1, Art. 5).

The responsibilities of the health mediators, as delineated in the legal framework regulating their activity, can be grouped into five clusters:

- serving as a liaison between communities and health care practitioners;
- collecting data on the health situation in the community;
- increasing Roma access to health care;
- providing health education; and
- participating in public health interventions (Order 619/2002, Annex 1, Art. 11).

As liaisons, mediators are responsible for increasing mutual trust and improving communication between members of the community and medical personnel. Mediators also collect data on pregnant and recently confined women, the infant population of the community and immunization and check-ups of children aged 0 to 7. To increase access to health care services, they help enrol newborns with family doctors and explain the advantages of being medically insured and the procedures for obtaining insurance coverage. Mediators are charged with raising awareness on family planning, child health care, nutrition, breastfeeding and hygiene. They also contribute to public health interventions, by mobilizing community members to take part in health campaigns (on vaccination or chronic diseases for example), identifying cases of TB and transmittable diseases and informing medical practitioners about the occurrence of particular problems within the community, such as transmittable disease foci and intoxications.

The extensive list of responsibilities does not establish an order of priorities. In practice, however, some activities appear to be given more weight than others. A comprehensive survey conducted December 2009 to April 2010 indicated that in the three months prior to the interviews:

- 91% of the health mediators conducted awareness-raising activities in the Roma communities they served;
- 87% were involved in childhood immunization;
- 85% mediated encounters between Roma and medical practitioners;
- 71% monitored the health status of community members;
- 44% collected data; and
- 42% performed activities related to social work *(19)*.

Mediators tend to perceive their work not only as an occupation but also as a vocation; and this translates into providing services outside working hours, at home *(25)* and involving issues that fall beyond their responsibility, e.g. informing parents about the importance of education, raising awareness on domestic violence, identifying cases of discrimination and taking part on a voluntary basis in local activities *(19)*.

Duration

Health mediation was institutionalized in 2002 and has functioned without interruption ever since. Although there is no time limit for the programme, mediators have been appointed right from the beginning for a fixed period (Order 619/2002, Annex 1, Art. 2), usually a year, with the possibility of contract renewal at the end of the period. Recent data indicate that over two thirds of health mediators have fixed-term contracts *(19)*, and this leads to a feeling of insecurity with regard to future prospects *(29)*.

Number of beneficiaries and geographical area

Data collected in 2009 by Romani CRISS indicate that the number of active mediators at that time was about 500, and each county had at least 2 persons appointed to provide health mediation services. The counties with the highest number of mediators were Sibiu (29), Mureș (23), Brașov (23), Galați (22) and Vaslui (22), whereas the lowest number of mediators were encountered in Bucharest (4), Neamț (4), Suceava (4), Hunedoara (2) and Vâlcea (2). The existence of mediators in each county is consistent with the relatively even territorial distribution of the Roma population, which accounts for at least 1% of the total population in each of the counties *(7)*. Although Romania fares better than other countries in the region in terms of its number of active health mediators, the ratio of 2.05 mediators per 10 000 Roma suggests a shortage of staff employed as liaisons between community and medical practitioners *(31)*.

According to legal provisions, a mediator serves a community of 500–750 persons, with the possibility of working in smaller communities that have peculiar problems related to health status and access to health (Order 619/2002, Annex 1, Art. 9). In practice, however, the situation is different. Early evaluations of the project emphasized that the number of persons served by a health mediator often exceeded the maximum foreseen in the law *(24, 28)*, and this situation remains largely unchanged *(19, 29)*. An independent evaluation commissioned by the Ministry of Health in 2012 indicated that the average number of clients for each health mediator in the areas under scrutiny was as high as 1108 *(32)*. The large number of clients raises legitimate concerns about the ability of the mediator to successfully carry out the activities.

Organizing partners

The history of health mediation is characterized by institutional cooperation. The pilot project was made possible by collaboration between an international donor CCFD, Romani CRISS and the formal and informal Roma groups at local level *(23)*. After institutionalization, the Ministry of Health and its territorial structures became involved in the organization of health mediation. The collaborative approach consisted of the following distribution of tasks: leaders of local communities select a person meeting the eligibility requirements for being trained as

a health mediator; the Ministry of Health in partnership with Roma civil society organizations provides the initial training; county health authorities appoint the trainees who passed the examinations; county health authorities and Roma organizations ensure monitoring and evaluation of the mediators. Since decentralization, local public administrations have been responsible for coordination of health mediators, but the mediators' activity reports are directed to both the local public administration and the county health authority *(29)*.

Monitoring and evaluation

Monitoring and evaluation of the activities performed by health mediators are delegated to county health authorities, whereas the Roma organizations are responsible for monitoring the mediators' efficiency and working conditions (Order 619/2002, Annex 1, Art. 13). The monitoring consists primarily of analysing the activity reports drafted by mediators and countersigned by the doctors with whom they collaborate. However, it is uncommon for doctors and county health authority representatives to empirically verify the data provided by the mediators *(24, 25)*. Moreover, activity reports tend to be formal and quantitative in nature, using templates that do not allow for accurate recording of all the activities actually carried out within the community. The assessment of activities is not comparative, and feedback is not usually provided to the health mediators *(24)*. Thus, the monitoring strategy does not contribute to standardization of mediation practices; instead, it offers mediators plenty of leeway in carrying out their duties.

Evaluations of the programme have been commissioned by CCFD and Romani CRISS *(25, 30)*, JSI Romania and the Center for Health Policies and Services *(24)*, the Roma Center for Health Policies – Sastipen *(29)*, and the OSI *(28, 31)*. Although realized at various stages of programme implementation and using different research strategies, these assessment reports were consistent in describing as strengths the institutionalization of the mediation, the partnership between public authorities and NGOs, mediators' commitment to improve Roma health status and access to health, and the success achieved so far in raising awareness on health-related issues among members of Roma communities. Among the shortcomings mentioned were the insufficient and inadequate monitoring of mediators, the difficult working conditions (lack of an office, low wages, insecure employment), the limited period of training, and the limited use of data collected by the mediators. To address the issue of monitoring raised by the evaluation conducted by COTA *(25)*, Romani CRISS initiated in 2006 six regional centres for monitoring and support for mediators, in the counties of Giurgiu, Cluj, Gorj, Vaslui and Covasna, and the city of Bucharest *(24)*. The centres were active until 2011 *(19)*.

Funding

Prior to decentralization, the budget allocated by the Ministry of Health to each county for health mediation was administered by the county hospital; and evaluations indicate that the administration of funds was not transparent. Even representatives of county health authorities, in charge of planning, monitoring and evaluating mediators' activities, were not aware of the budget for implementing health mediation at county level *(25)*. Information provided by the Ministry of Health for the period 2002–2005 indicates a constant increase in the budget for

sanitary mediation, from €30 000 in 2002; to €160 000 in 2003; €300 000 in 2004; and €438 000 in 2005 *(25)*.

Since decentralization, health mediation has continued to be financially supported by the national budget. The funds are transferred by the Ministry of Health to the local budget (Government Emergency Ordinance 162/2008, Art. 3(1)). The average net monthly income of a health mediator is only €133, the lowest among the six countries in the region assessed by the Open Society Foundation's evaluation in 2011 *(31)*. According to Ministry of Health Order 619/2002, mediators are entitled to receive compensation for work-related expenses, such as transportation and acquisition of office supplies. In practice, however, these costs are rarely reimbursed *(19, 25, 31)*.

Health mediation and politics

The health mediation programme originated in the Roma social inclusion efforts made by Romania in the period of pre-accession to the EU. As this political objective was shared by all the parliamentary political parties, there was no opposition to the Strategy for Improving the Situation of Roma and the measures devised for its implementation, health mediation included. The programme survived several changes in the country's government, and its transformation (particularly as a result of the decentralization) was related to the overall reformation of the health care system. The only political party that was actively involved in the programme was the Roma Party, which included many community leaders among its members. The Roma Party was the main source of recommendation for the position of health mediator (identified as such by 42% of the respondents to a questionnaire sent to all active mediators) (*19*). The mediators themselves are apolitical.

Determinants of health addressed by the Roma health mediation programme

Development of the health mediation programme was one of the measures taken by the Ministry of Health to accomplish the objective of promoting the health of women and children at community level (Order 619/2002, Art. 1). While not explicitly related to Millennium Development Goals 4 and 5 (to reduce child mortality and improve maternal health, respectively) the mediator's responsibilities are consistent with these objectives. The programme's target groups – Roma women and children – are among the most vulnerable categories of the Romanian population. Despite the absence of official health statistics disaggregated by ethnicity, survey-based evidence indicates that, at the inception of the programme, Roma infant mortality in Romania was three times higher than the national average *(33)*. As some of the structural factors accounting for the health disparities between Roma and non-Roma (poverty, living conditions and level of education) were difficult to tackle, the programme focused on increasing health care service coverage among the members of the target population.

The Tanahashi model of service coverage *(34)* can be used to explain the areas of mediators' intervention. According to the model, service coverage has five dimensions: availability, accessibility, acceptability, contact and effectiveness. Availability refers to the existence of resources necessary for the provision of the service (such as staff and medicines). Accessibility

refers to "the number of people who can reach and use it". Acceptability comprises both affordability of the service and people's willingness to use it. Contact refers to the actual use of the service, whereas effectiveness refers to users' satisfaction with the services they received *(34)*. Health mediators are involved in four of the five dimensions of health coverage; availability falls beyond their reach.

Availability tends to be very good in Romania as health care units with adequate personnel and material resources exist throughout the country. There are some notable exceptions, however. For example, during the summer of 2010 there was a shortage of some of the vaccines included in the national immunization scheme *(19)*. These vaccines, provided free of charge according to Romanian legislation, were not available in family doctors' offices at that time; and parents were requested to buy them in order to have children vaccinated according to the schedule. Many Roma parents in poor economic situations lacked the means to acquire the vaccines.

Accessibility can be assessed based on the distance between medical units and communities and the entitlement of persons to use medical services. According to a survey conducted in 2009, the medical infrastructure serving Roma communities is generally good, and the average time it takes a person to go to the closest medical facility is about 30 minutes *(18)*. In terms of entitlement to health care, all persons, regardless of insurance status, are allowed to register with a family doctor, and persons aged below 18 are insured. However, persons lacking identity documents are formally excluded from registering with a family doctor. Health mediators' work to ensure eligibility for health care services consists of assisting with the enrolment of newborns with family doctors; informing parents about the benefits of having medical insurance; and explaining the procedures for obtaining medical insurance (Order 619/2002). In addition, they help people who do not have birth certificates or identification cards complete the process of obtaining them *(19, 24)*. This is regarded by many mediators as their most important task *(25)*.

With respect to acceptability, mediators are primarily concerned with increasing individuals' willingness to use medical services. Survey data suggest that Roma in Romania are preoccupied with health, but many are reluctant to look for qualified medical support when dealing with health difficulties *(18)*. Several factors account for this tendency, including costs of health care services (both formal and informal), perceived discrimination during the interaction with medical staff, doctors' lack of familiarity with Roma culture and the lack of information *(18, 19)*. Mediation addresses particularly the last factor. A significant part of mediators' work is related to providing members of the Roma community with reliable information about health issues, and raising awareness on the importance of prevention.

The topics discussed in communities include family planning and use of contraception, personal and household hygiene, vaccination, seasonal influenza, TB, sexually transmitted diseases, the importance of breastfeeding, healthy nutrition and the correct administration of antibiotics *(19)*. It is worth mentioning here that mediators themselves have constantly expressed the need to acquire more information about health determinants and methods

of prevention, and have complained about the lack of support materials for use during the information campaigns in the community *(19, 24, 29)*. Through awareness-raising activities, mediators strive to convince members of the community to look for specialized medical help whenever necessary.

With respect to use of medical facilities, data show that most Roma see a doctor at least once a year *(18)*. It is not the use in itself that represents a challenge, but rather the reasons for seeing a doctor. As Roma are more inclined to see a medical practitioner for diagnosis and treatment than for prevention, mediators are particularly involved in convincing them to have their children vaccinated according to the immunization scheme; to have general medical examinations on an annual basis; and, in the case of vulnerable groups, to undergo screening for the diseases they have a higher risk of developing.

Increasing the effectiveness of health care services seems to be the programme's main raison d'être. Interaction between Roma and health practitioners is often unpleasant. Patients complain of doctors' lack of interest, reflected in "avoidance of physical contact, lack of involvement of patients in the selection of the treatment, inadequate informing of the patient with respect to side-effects and risks of the treatment and the use of aggressive procedures" *(19)*. About one fourth of doctors working with Roma patients mention difficult encounters because of alleged aggressive behaviour, verbal violence, inappropriate behaviour, failure to respect the appointment and low education level *(19)*. In this context, mediators act as liaisons between doctors and Roma patients, trying to reach common ground for the effective delivery of health care.

Lessons learnt 3

Successes of the programme

Implementation of the health mediation programme represents acknowledgment of the gap between Roma and non-Roma with respect to health and an indication of the Government's commitment to address some of the salient factors contributing to this situation.

Institutionalization of a programme piloted by Roma civil society is in itself a success story, showing that collaboration between governmental and nongovernmental structures is both necessary and possible. Subsequent involvement of local communities and international organizations in the planning, implementation or evaluation of the programme provided legitimacy and added expertise to the initiative. Institutionalization allowed for continuation of the programme, higher geographical coverage, a significant increase in the number of persons receiving health mediation training and being appointed to work in the communities, and a significant increase in the number of persons benefitting from mediation services. At the same time, the mediators' responsibilities were standardized and mediators benefitted from their formal recognition as part of the medical apparatus.

In 2008, there were 600 active health mediators, and the service was provided in each county. Given that one mediator works on average with about 1100 members of the Roma community *(19, 32)*, it can be inferred that approximately 660 000 Roma have been served at some point by health mediators. This represents between one third and one fourth of the total number of Roma in Romania according to independent estimates, and more than the official number of Roma living in the country according to the most recent census *(4, 7)*.

Other positive aspects of the programme include the focus on preventive health care, the contribution towards increasing the stock of knowledge pertaining to health among Roma and the support provided to the most vulnerable categories of the Roma population. While surveys on Roma health are consistent in emphasizing the Roma's predilection for curative health care, their tendency to consult a doctor in the advanced stages of a disease, and the existence of unhealthy lifestyle traits, health mediation emphasizes the importance of being proactive with respect to health care, undergoing regular medical examinations, immunizing children and adopting adequate nutrition. The effectiveness of mediators' intervention in the community is a matter of debate, yet the mere fact that their work advocates for a different approach towards health among Roma is remarkable.

Change, however, is not possible in the absence of information. The trustworthiness of mediators, as members of the community, and their ability to adapt the message to the ideological peculiarities and the mindsets of the interlocutors represent important assets that the programme takes advantage of. Raising awareness on issues such as family planning and

contraception, vaccination, hygiene and a healthy lifestyle is likely to have contributed at least to a reconsideration of behaviour related to health. Another positive aspect is the mediators' work to increase access to health care services, by helping Roma obtain identity documents, acquire health insurance and enrol with family doctors.

In addition to these expected contributions, the following unintended consequences can also be considered as successes of the programme: challenging patriarchal ideologies of gender power relationships; providing employment and opportunities for personal and professional development to Roma women; and addressing issues that are not related to the responsibilities of health mediators, such as school mediation and lobbying for the improvement of living conditions in the Roma communities.

Challenges in programme implementation

The most important challenges in achieving the programme's objectives have been the insufficient training, wages and working conditions of the mediators and the decentralization of the medical assistance services.

Health mediation is a demanding job, requiring skills in communication, and conflict prevention and resolution, among other areas, knowledge of the relevant legislation and extensive knowledge related to health. The initial three-day training could not cover all these aspects in depth *(24, 25)*. Continuous training sessions have been provided, but only occasionally and often with a limited focus. In a recent survey, mediators emphasized the need for training in three areas – health knowledge, personal and professional development, and legislation *(19)*. More specifically, they were interested in sessions about cancer, TB, reproduction health, first aid, using computers and discrimination.

The limited material incentives for pursuing a career as a health mediator represent an important challenge in recruiting and maintaining staff for the programme. Mediators in Romania earn only €133 per month, less than persons appointed in a similar position in other countries in the region, such as Bulgaria, Serbia, Slovakia, the former Yugoslav Republic of Macedonia and Ukraine *(31)*. In addition, they have to personally pay for their own work-related expenses, such as transportation, communication with beneficiaries and supplies. Although the legal framework mentions the possibility of having these expenses reimbursed provided there are funds for this in the programme budget, the latter is rarely the case. In addition to low wages, many mediators face difficult working conditions, such as a lack of desks and computers. Continuity of contracts is another problem: over 70% of mediators are appointed for a determined period and many are unsure that their contracts will be renewed *(19)*.

Decentralization represents a major challenge for the health mediation programme. While the new institutional arrangement was supposed to maintain the mediators' rights and responsibilities, the deficient preparation for its implementation seriously affected a large number of mediators. Over 100 complained about various problems, including local authorities refusing to hire them; change of responsibilities; periods of unemployment; a

change in contract status from undetermined to determined period; and discriminatory treatment at the new workplace *(19, 29)*. However, no impact evaluation has been performed yet to assess the impact of the decentralization on the mediators' activities. An unintended consequence of decentralization has been the decreased involvement of the Ministry of Health in the coordination and monitoring of the programme. This translated into limited assistance to mediators during the transition process to local public administration, lack of activity of the Ministerial Commission for Roma and decreased cooperation with Roma civil society.

Criticisms of the programme

While the programme's existence has not been questioned so far, several aspects of its implementation have been constantly contested. Insufficient monitoring of the mediators and insufficient use of data collected in Roma communities are two of the most salient reproaches that have been brought forth. According to the legal framework regulating the activity of mediators, they have to complete weekly activity reports, which need to be countersigned by the doctors with whom they collaborate and then presented to the county health authorities. Since decentralization, they have also been required to justify their work to the institutions they work with. However, the template of the reports favours the collection of quantitative data that are not, in many cases, relevant for the work actually performed by the mediators *(24)*. Moreover, doctors and representatives of county health authorities in charge of the mediation programme do not go into the Roma communities to verify the accuracy of the reports. This leaves large leeway to mediators in performing their work. Another problem pertaining to monitoring is that mediators rarely receive feedback on their activity reports. The loose supervision strategy prevents sanctioning of mediators who fail to accomplish their duties and represents a deterrent for those who do well and do not receive any formal recognition for their merits.

Insufficient use of data collected by mediators *(31)* has been a second criticism. Given the absence of official health data disaggregated by ethnicity, the only available information about the health status of Roma communities comes from surveys. Supplementing survey data with information from health mediators would help create a more accurate representation of the situation and would support the development of policies and other forms of intervention tailored to the needs of Roma.

Funding

One of the most urgent issues at present is to clarify how long the Ministry of Health will provide financial support for the implementation of the programme. If responsibility for funding the programme is transferred to local public administrations, this could put the entire programme into jeopardy. The difficulties encountered during decentralization suggest that many local administrations are reluctant to accept health mediators.

An overview of the programme funding during the 10 years of implementation shows a lack of transparency with regard to the budget allocated to the programme as a whole and the amounts allocated to various activities. At the same time, it reveals that mediators are

underpaid, the salary scheme is not unified and work expenses are not usually reimbursed. Additional funds are also necessary for the continuous training of active mediators.

Recommendations for establishing similar programmes elsewhere

The Romanian experience suggests that a bottom-up approach is more likely to succeed in the implementation of mediation programmes catering to the needs of marginalized groups for at least two reasons: first, the authorities tend to be less aware of how to approach the target group; and second, the members of the group have better knowledge of their actual needs. Therefore, one recommendation is to involve members of the target group in each stage of programme development (designing, piloting, institutionalization, training, recruitment, monitoring and evolution).

Another recommendation is to contract international NGOs with expertise in the field to help design the programme, train the mediators and monitor and evaluate the programme. International organizations are more objective in their assessment and also have superior bargaining power in relations with authorities.

The success of health mediation programmes for marginalized groups seems to be contingent upon the quality of the training. While communication skills are an important issue, the training should cover other areas as well, such as basic medical knowledge, working in a multicultural environment, handling cases of perceived discrimination, use of computers, etc. It is also important to offer continuous training sessions, because the needs of the mediators are largely to be shaped by their work experience.

To increase the success of the mediation, training on cultural diversity should also be offered to health care providers. This would increase their cultural sensitivity and would make them aware of cultural differences that might otherwise be mistakenly interpreted as signs of disrespect for their authority and professional competence.

Providing adequate funding for the programme and ensuring decent salaries and working conditions for health mediators are also necessary.

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Regional Office for Europe
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