

# Roma Health

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Perspective of the actors involved in the health system – doctors, health mediators and patients

ROMANI CRISS – ROMA CENTER FOR SOCIAL INTERVENTION AND STUDIES

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## INTRODUCTION

The „*Roma Health – Perspectives of the actors involved in the health system – doctors, health mediators and patients*” research is part of the project „*Promotion of anti-discriminatory measures for Roma access to health services in Romania*”, financed by the Open Society Foundation through the “Roma Health Project”.

The present study is a continuation of the process of assessing Roma access to health services, the progress made during the past years, and the shortcomings of the health system, started by Romani CRISS with the research “Health and the Roma community: Analysis of the situation in Romania” (2009). Where at that time, we insisted on the perception of Roma regarding health problems and access to services, by conducting a national survey, for the present study we chose to extend the area of investigation and diversify the research methods in order to achieve a more complex representation of the phenomenon. In this regard, we surveyed the opinion and personal experiences of the major social actors involved in the system. Firstly, the beneficiaries of the health services (Roma patients); secondly, the suppliers of these services (family doctors who serve Roma communities or who frequently work with Roma patients); and last but not least the institutional agents involved in facilitating intercultural communication in the medical field (the health mediators). From a methodological standpoint, the research used both quantitative instruments (the survey) and qualitative instruments (the semi-structured interview, the focus group, the observation).

The introduction of a health mediation programme for the Roma represents an act of the state, by which it recognises and in consequence strives to eliminate the difficulties of accessing the health system. The institutionalization of health mediation is very important but not well-enough explored in the research conducted so far. The present report brings an emphasis on the health mediators in the discussions related to the health conditions of the Roma, in three chapters. The first chapter uses a diachronic perspective on the institutionalization of the mediation system, from the moment of the emergence of local mediators in the context of interethnic conflicts during the first years after the 1989 revolution, up to the point when the local authorities decided to take it over. The second chapter was conceived following the answers received from a survey, filled-in by all the mediators that were active at the time of the research. It registers the perception of the former on their relationship with the local authorities that they subordinate to, on their relationship with the doctors that they collaborate with, and on their relationship with the communities for which they work. A sub-chapter explores the needs of the mediators. The third chapter, conceived following semi-structured interviews, offers a panoramic view on the determinants of access to health services for the Roma, as perceived by the mediators and by taking into account the professional experience of the latter. At the same time, we presented the ideology of the mediators in relation with the performed work.

The chapter referring to Roma patients raises a series of issues that the prior research did not develop enough. Among these issues, we find the following: difficulties encountered in subscribing to a family doctor, discriminatory practices to which the Roma assisted to, or the victims of whom they were, when interacting with medical staff, formal and informal costs and their consequent impact on the access to health, strategies developed in order to manage health issues. The qualitative research conducted using the focus-group method allowed a careful observation of the opinions and attitudes negotiated in the community (e.g. attitude toward informal costs).

A research concerning access to health services would be incomplete without the perspective of the health system professionals. Consequently, the research project systematically researched for the first time the following interaction with the Roma community members, the determining factors of health among Roma, the difficulties that Roma face when accessing primary medical assistance and the causes of unequal access. We also enquired on the relationship of the Roma with the health mediators and its impact on the improvement of the access to health services.

The perceptions of the actors involved in the health system together with their experiences have been enhanced by an observation-based research in the emergency wards of the county hospitals. The research follows the moral evaluation (e.g.: on other criteria than the clinical ones) of the patients in need of emergency medical assistance and shows at the same time the importance of performing the role of patient in order to be treated with priority.

The last chapter presents the legal frame that separates the access to health, starting from the Romanian experience and ending with the international jurisprudence. The right to health is conceptualised and operated starting from the four directions established by the Committee for economic, social and cultural rights of the United Nations: availability, accessibility, acceptance, and quantity. We thoroughly explored each of these directions, focusing on the controversial aspects and on the way in which the controversies have been solved within the European Union. The chapter describes at the same time the obligation of the state to implement the right to health and to achieve equal access to health services for all citizens, regardless of their ethnicity.

### **Thanks**

We would like to thank all those who contributed to the present research and to underline that drafting this research became possible with the help of a research team and of that of students. In addition, we would like to thank the company “Totem Communication” and especially the head of its Research Department, Mr Bogdan Păunescu, for conducting the survey on the doctors who serve the Roma communities or who have Roma patients. We would like to extend our gratifications to our colleagues who realised the transcripts of the interviews and of the focus-groups (Carmen Brici and Ionuț Cioartă, active members of Romani CRISS and students of the University of Bucharest; Noemi Magyari and Jobb Borbola-Boroka, students of the University Babeș-Bolyai of Cluj-Napoca). Our gratifications also go to Mr Puiu Lățea, who read the manuscript and provided various comments and suggestions for the improvement of the text, and towards Mrs Alina Covaci Tabă from the Open Society Foundation, who offered constant support throughout the implementation of the project. Finally yet importantly, the health mediators, the family doctors, brought an extraordinary contribution and patients whose information helped us understand the way in which the health system works and which are the difficulties encountered by the Roma when accessing medical services.

### CONTEXT OF THE INITIATION OF THE MEDIATION PROGRAMME

The concept of “*mediator*” was borrowed from French organisations conducting social work activities. The concept was introduced in Romania, in the communities affected by inter-ethnic conflicts, in order to mediate the conflicts between the members of the community. The persons trained to be mediators have been hired later on by Romani CRISS as *local mediators*, in the communities where inter-ethnic conflicts appeared, starting with the year 1991. Their employment was part of the project “*Local comprehensive development in localities affected by inter-ethnic conflict: Vălenii Lăpuşului and Mihail Kogălniceanu*<sup>1</sup>”. The years that followed, there has been a constant concern regarding the training of mediators, more seminars were organised upon the completion of which diplomas were issued for *conflict mediators* and *school mediators*.

Taking into account these experiences and the needs of the Roma communities, in 1996 Romani CRISS piloted the idea of *health mediator*, by conducting a programme<sup>2</sup> dedicated to the formation of Roma women in order to improve their status in the community and to involve them in public affairs. The health mediator’s definition is *a person who enhances/mediates the relationship between the Roma community and the local health authorities*. A health mediator must have very good communication abilities and must be accepted and respected by the members of the community as well as by the representatives of the local authorities.

The health mediator works for a Roma community and has the following role:

- ✓ Enhances communication between the Roma community and the medical staff
- ✓ Facilitates the access of the Roma to medical services
- ✓ Supplies information to community members on the rights and responsibilities of the state towards the citizen and the other way around.
- ✓ Informs the members of the community concerning the way in which the health system and the health insurance system function.

The programme was conducted in partnership with the French “Catholic Committee for Development and against Starvation”, starting with the year 1996 and it included a number of 30 Roma women, out of which 25 graduated from the health mediator course.

### DEVELOPMENT STAGES OF THE HEALTH MEDIATION PROGRAMME

In 1999,<sup>3</sup> Romani CRISS launched the formation courses for health mediators, having as main purpose *the improvement of the health situation of Roma communities through the active involvement of health mediators connecting the local authorities and the Roma community*. The first localities where formation courses for health mediators were organised were Ştefăneşti of Botoşani county, Temelia of

<sup>1</sup>The project “*Local Comprehensive Development in localities affected by inter-ethnic conflicts: Vălenii Lăpuşului and Mihail Kogălniceanu*”<sup>1</sup> financed by the prize of Human Rights granted by the French Government in 1991.

<sup>2</sup> The project “*Sanitary support through professional re-insertion*” implemented by Romani CRISS in 1996 and financed by the French “Catholic Committee for Development and against Hunger”.

<sup>3</sup>*Formation of health mediators in Roma compact communities*”, project implemented by Romani CRISS in 1999 and financed by the Catholic Committee against Starvation and for Development, France.



Bacău County, Panciu of Vrancea County, Slobozia of Ialomita county and Sfântu Gheorghe of Covasna County.

Beginning with the year 2000, after the elaboration of the methodology of work and of the job description, this occupation started to be institutionalised. The meetings and debates organised by CRISS in this regard led to the involvement of various actors of our society in supporting the institutionalisation of the health mediator.

In September 2001, at the headquarters of the Commission for health and family<sup>4</sup>, CRISS organised a meeting to which representatives of local authorities and of Roma and non-Roma NGOs participated and analysed the possibility of financing a Commission of the Ministry that would contribute to the implementation of the strategy for the improvement of the situation of the Roma. The participants also discussed the role of the health mediator. During the OSCE<sup>5</sup> Conference of the same year, the Cooperation AGREEMENT<sup>6</sup> between Romani CRISS, the Ministry of Health and Family and OSCE/ODIHR was signed. This AGREEMENT was renewed and signed by all parties in 2005 and in 2008.

The partnership with the Ministry of Health promoted by CRISS facilitated the implementation of the health mediation programme as well as the cooperation between Roma communities and local institutions belonging to the Ministry of Health (County Public Health Department - DPH).

During the same period, letters have been sent to the Ministry of Labour and Social Solidarity and debates have been organized in order to include the occupation of "health mediator" in the "Classification of the Occupations in Romania" (COR). Following these actions, the Ministry of Labour and Social Solidarity answered back then with a favourable decision concerning this request and in consequence, the occupation of "health mediator" was included in the COR<sup>7</sup> under the **Basic Group 5139 „Civil service clerks” code 513902**.

Taking into account the progress made on formalising the occupation of "health mediator" and the fact that the County Public Health Department initiated the employment of health mediators (6 mediators were employed in 2000-2001 in Slobozia, Botoşani, Ştefăneşti, Bacău, Panciu and Sfântu Gheorghe), action was taken in training a greater number of health mediators in order to be introduced in the health system. Consequently, from March to October 2002, Romani CRISS, with the financial support of the Catholic Committee against Famine and for Development (CCFD)<sup>8</sup>, formed 84 health mediators (Roma women of middle level education) who have been employed by the Ministry of Labour and Family, via the County Public Health Department, according to the Order no. 619/2002, article 1<sup>9</sup>. The initiative of creating a health mediator launched by a non-governmental organisation was

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<sup>4</sup>The activity was conducted between 10-11 of September 2001 at the Commission for health and family of the Romanian Parliament under the name of "Challenge to dialogue; Invitation to innovation concerning the health of the Roma" having as theme of debate the access of the Roma to public health services, conducted with the support of the OSCE/ODIHR – Contact point for Roma and Sinti.

<sup>5</sup>Conference organised with the title "Turning words into facts" on the 12th of September 2001 by the OSCE/ODIHR – Contact point for Roma and Sinti.

<sup>6</sup>The AGREEMENT document regulates the collaboration between the signatures, regarding the implementation of the activities foreseen in the strategy for the improvement of the situation of the Roma (Government Order No. 430 Of the 25th of April 2001, concerning the approval of the Romanian Government Strategy chapter D- Health).

<sup>7</sup>The Ministry of Health and Family approved in 2002 the introduction in the *Classification of the Occupations in Romania* of the Ministry of Labor and Social Solidarity of the occupation of "crishealth mediator" (basic Group 5139 "Civil service clerks"; code 513902).

<sup>8</sup>The project "National training for health mediators" conducted by Romani CRISS in 2002 with the financial help of the Catholic Committee against Starvation and Development, France.

<sup>9</sup>The Ministry of Health and Family issued the Order MSF No. 619/14.08.2002, for the approval of the occupation of "health mediator" and of the Technical Procedures regarding the organisation, functioning and financing of the activity of health mediators for the year 2002

taken over by the Ministry of Health and approved in the health units of Romania, which led to its transformation into an **institutionally** recognised **public policy**.

Additionally, from January to December 2003, the Romani CRISS team of the programme had as main objective to train health mediators who would become employees of the County Public Health Department, according to the Order no. 619 issued by the Ministry of Health. In this regard, following the requests of the County Public Health Departments, the Romani CRISS trainers travelled to each county and trained people who were employed later on as health mediators for Roma communities. It is important to mention that the Ministry of Health allocated a budget for each Public Health Department in order to cover the travelling expenses of the trainers and that of the training courses. At the same time, the Romani CRISS trainers offered juridical assistance to the County Public Health Departments who encountered difficulties in the implementation of the Order no. 619/2002.

In 2003, a series of consolidation actions for the health mediation programme were conducted in parallel with the professional training of the mediators, among which the elaboration of work instruments for the actors of the system: “**The guide of the health mediator**” part of the project “**Public health policies for the Roma - European context**”<sup>10</sup> financed by OSCE/ODIHR – Contact point for Roma and Sinti.

At the same time, by analysing the activity reports of health mediators and by communicating with the former, the need for training in specific domains was uncovered: the need for a methodology that would regulate the issuing of identification documents, notions related to human rights, health of reproduction, tuberculosis (TBC). In reply to those needs, Romani CRISS organised from February to October 2004<sup>11</sup> three courses of continuous formation throughout which a number of 96 health mediators were trained on *human rights, improvement of work conditions in the Roma community* and an apprehension of notions regarding the issuing of *identification documents*.

The Ministry of Health also supported the training of the health mediator concerning the prevention of and against tuberculosis, as part of extra-budgetary subvention projects („Doctors of the World”, „The Global Fund to fight AIDS”, „Tuberculosis and Malaria”). Throughout the development of these projects, the drafted health education materials specifically addressed the needs of the Roma community and played the role of national model.

Training courses have been organised on healthy reproduction, as part of the project “Educating Roma women on healthy reproduction”<sup>12</sup> implemented by John Snow Inc. An outcome of the same project was the “Manual of the health mediator for the health of the family and of the community”<sup>13</sup>.

The process of theoretical training of health mediators was a continuous one, and in 2004, a monitoring and evaluation methodology for the health mediators who were at that time active in the County Public Health Departments was created. This process was conducted by studying activity reports and by field operations of the coordinating team of Romani CRISS. For a more thorough evaluation of the health mediation programme, Romani CRISS requested the support of the CCFD, and the evaluation was drafted in 2006, by the anthropologist Maria Maillat.

The report was based on discussions with the members of the Romani CRISS team of that period, on the data obtained following the field activities and meetings with the health mediators and the coordinators of the health mediators of the County Public Health Departments, family doctors and other partners of the mediators.

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<sup>10</sup>“The guide of the health mediator” published by Romani CRISS as part of the project “Public health policies for Roma – European context” financed by OSCE/ODIHR – Contact point for Roma and Sinti, 2004, Publishing House Gama Expert, Bucharest

<sup>11</sup>The project “Continuous formation of health mediators” implemented by Romani CRISS in 2004 and financed by the Catholic Committee against Famine and for Development, France

<sup>12</sup> The project “Educating Roma women on healthy reproduction” 2004-2006, implemented by John Snow Inc

<sup>13</sup> “Manual of the health mediator for the health of the family and of the community”, drafted by Romani CRISS and John Snow Training & Research Institute in 2004

In 2006, as a result of the recommendations and conclusions of the evaluation report drafted by Maria Mailat, a new phase in the development of the mediation programme was achieved, by setting-up *regional monitoring centres of the activity of health mediators* (local Roma organisations). Courses of continuous formation were organised on a regular basis, stressing the basic notions of human rights, obtaining identification documents as well as a more profound study of health mediation working techniques<sup>14</sup>. The 5 regional centres initially set-up (at the end of the project 8 active such regional centres were created) have supported the health mediators at local level as well as the coordinating team of Romani CRISS, by organising local meetings and by frequent field-visits. At a county level, 41 meetings have been organised with the health mediators and with their coordinators of the County Public Health Departments, in order to identify the issues of the health mediation system.

In 2007, as part of the same project, the National Council for the Professional Formation of the Adult Population adopted the Occupational Standard<sup>15</sup> of the health mediator, which described the professional competencies to be obtained by the health mediators throughout their professional activity. By 2008, the Ministry of Health had employed a number of 600 health mediators.

On the 25<sup>th</sup> of September 2008, the National Professional Formation Centre for the Adult population granted Romani CRISS with the statute of *evaluation centre*<sup>16</sup> and the *certification for professional competences for the occupation of health mediator*, following the analysis of the setting-up file of the organisation. Following the accreditation process as an evaluation centre, 100 health mediators have been evaluated and certified based on the occupational standard, and 13 competency-evaluators were trained, evaluated and certified. At the end of 2010, a number of **192 health mediators** had been evaluated and professionally certified by the evaluation centre.

In 2010, at the completion of the implementation of the project „*Improvement of the health mediation programme in Romania*”<sup>17</sup> Marcel Dediu and Stanislas Hubert evaluated the health mediation programme and the regional centres that monitor the activity of the health mediators. Throughout the project various activities were organised: meetings with the health mediators and other actors involved in the process (e.g. interview with Nicolae Gheorghe, with representatives of the National Agency for the Roma, with NGO representatives, and with representatives of the Public Health Department), and a series of discussions with the coordinators of the regional centres for support and monitoring of the activity of the mediators. Following the evaluation, the two authors addressed their recommendations to Romani CRISS, regarding the functionality of the health mediation programme during the following years, and other aspects that had to be taken into account.

## THE HEALTH MEDIATION PROGRAMME IN THE CONTEXT OF THE DECENTRALIZATION OF THE PUBLIC HEALTH SERVICES

The year 2008 was marked by the beginning of the decentralization process, which led to a round-table meeting at a local level with the authorities and the health mediators. The main objectives of the round-table meetings were the following: to clarify some aspects of the subvention of the health mediation programme during the following years, to redefine cooperation relationships of the mediators

<sup>14</sup>The project “Improving the sanitary mediation programme for the Roma in Romania” implemented by Romani CRISS from 2006 to 2010 with the financial support of the Catholic Committee against Famine and for Development, France.

<sup>15</sup> Occupational standard for the occupation of Health mediator, Domain: Health, Hygiene, Social Services, COR Code: 513902, approved in December 2007 by the National Council for Professional Formation of the adult population.

<sup>16</sup>Throughout the project „*Acknowledgement of the learning- results*” implemented by Romani CRISS in collaboration with the Association Pro Vocation in 2008, Romani CRISS was authorised as Centre of Evaluation and Certification for the Professional Competence of the occupation of Health mediator in September 2008 and is presently functioning under the authorisation of the CNFPA – The National Council for the Professional formation of the adult population

<sup>17</sup>The project „*Improvement of the sanitary mediation programme for the Roma in Romania*” implemented by Romani CRISS from 2006 to 2010 with the financial support of the Catholic Committee against Famine and for Development, France.

with their work partners, and to conduct lobby and advocacy actions for the employment of the mediators by the City-Halls since sometimes, the Mayors of some localities where the mediators work, refused to employ the latter thus creating difficult situations.

Following the Government Emergency Ordinance no. 162/2008,<sup>18</sup> the health mediators were to be employed by the City Halls, and taken over by the Public Health Departments following a delivery and receipt protocol, that specified that there should be no changes regarding the job description or the salary of the mediators. In reality, there were cases where the Mayors refused taking over the mediators or cases where additional not connected to their competences tasks, or they imposed to the mediators to carry out additional tasks out of their area of competence, or even salary reductions.

The decentralization of the health mediation programme took 6 months to complete, from January 2009 until July 2009, only by administrative transfer, by signing protocols between the local authorities and local County Public Health Departments. The local authorities or the members of civil society have not been consulted in order to prepare the decentralization of the system. The local authorities were not prepared to take over this responsibility. Although the subvention of health mediators has been assured until present times, there was no involvement from the part of the Ministry of Health in monitoring the decentralisation process.

Nobody took on the responsibility of the continuation of the programme and what is more, there was no reaction concerning the local-level employment issues of the mediators signalled by Romani CRISS.

Because of this non-involvement evidence, the situation of the health mediators for the Roma community started to worsen. Romani CRISS actively monitored the decentralisation process through its regional support centres for the health mediators. The situation is not a positive one taking into account the fact that we registered **appreciatively 100 cases of non-conformity**, with the mention that some migration and resignation cases of the health mediators that could not be registered.

The typology of the cases begins with discrimination, continues with abusive dismissals, non-compliance to the job description by the employers, racist language towards the employees and ends with the unemployment of the health mediators.

Romani CRISS signalled these aspects to the Ministry of Health, to the local authorities and to international organisations such as the European Commission, underlining the need to react towards the situation of the health mediation programme, following the decentralisation process. Although the health mediation programme is mentioned in national and international reports as a programme of good-practice, that during 15 years, created work-places for approximately 600 Roma women, there is no action plan concerning the continuity of the programme nor any clear decision of the authorities concerned.

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<sup>18</sup>Government Emergency Ordinance no. 162/2008 *concerning the transfer of the attributions and competences exerted by the Ministry of Public Health towards the local public authorities and concerning the adjournment of some legal provisions.*

Two years ago, Romani CRISS finalised a quantitative research concerning the health conditions of the Roma communities (Romani CRISS 2009). The questionnaire drafted for that research included a set of questions regarding the access to and use of health services, but it did not cover the degree of satisfaction of the respondents with the quality of the medical services nor did it allow the understanding of the obstacles that the Roma patients face in this regard. The main purpose of the present research is to identify discriminatory practices from hospitals and medical care units, based on personal experiences of the subjects. At the same time, we take into account the interaction of Roma patients with the suppliers of medical services, with the management of difficult situations, the impact of informal payments towards the medical staff on the access to health services, and the attitude of Roma patients towards the medical personnel.

The qualitative research conducted from February to May 2010 in Cluj-Napoca, Timișoara, Craiova, Constanța, Piatra-Neamț and Bucharest consisted in six focus groups. The subjects were Roma who experienced health problems for which they requested medical assistance within the last two years. The selection of the participants took into account their gender, area of residence and type of community (traditional/modern). The interview guide focused on three hypothetical situations related to important issues uncovered by previous researches, on Roma health and access to health: absence of identification documents and of insurance; difficulties in using the ambulance service; and the recommendation of the family doctors towards the use of injection contraceptives without having informed the patients on the secondary effects of this action. We designed the situations in such a way as to stimulate the exchange of ideas between participants and to point the discussion towards other relevant aspects in order to better-understand the phenomenon in question.

The analysis of the focus-groups indicates the existence of serious obstacles faced by Roma when registering to a family doctor (lack of identification documents, limited options from which to choose a family doctor due to the refusal of some doctors to accept Roma patients), the existence of discriminatory practices in medical units (segregation in maternity, lack of involvement of the patient or of the patients' family in choosing the treatment to be followed, lack of information of the patient on the possible consequences of the prescribed treatment, sending the patient to another doctor or medical care unit, placing the patient at the end of the waiting-list, the use of offensive language, examination of the patient from a distance, superficial treatment), and the existence of increased costs associated to medical services (legal costs that affect those who are not insured, together with informal costs). Under these circumstances, the Roma have developed four approaches concerning health issues: avoidance of medical examination until the last phase of the disease, the use of traditional healing methods especially for minor issues, choosing doctors that show sympathy towards the Roma, openly trying to combat abuse situations and consequently the ones responsible for their creation.

## **ENROLING WITH A FAMILY DOCTOR**

The absence of identification documents was an essential factor for the exclusion of Roma from health services (ERRC 2006; Rechel et al. 2009; Kingston, Cohen and Morley 2010). The persons without birth certificate cannot enrol with a family doctor, cannot be medically insured, and do not have access to different social assistance programmes for the less fortunate. The quantitative researches conducted during the past year show that the percentage of persons without any identification document out of the total Roma population of Romania is below 3,5%, and that there is a decreasing tendency (Zamfir and Preda 2002:288; Cace and Vlădescu 2004:20; Sastipen 2010:32).

An important contribution to the decrease in the number of Roma without identification documents is undoubtedly a consequence of the health mediators. They inform the patients that they service regarding the administrative process to follow in order to issue their identification documents, offer assistance to them throughout the whole process and sometimes identify new financing sources of the expenses incurred:

*Are there many cases of persons without identification documents in the community for which you work?*

*Yes, yes. A lot. Recently a legalisation process was conducted, and I accompanied them to the IML (medical legal institute) in order to find out their current age. After the IML, the files have been sent to the Court House at Cornetu... eventually, decisions of the Court were issued but they are incomplete.*

*What does incomplete mean?*

*A rectification of the decisions must be made because it's missing from there... it does not meet the legal requirements. The name of the mother is not stated. In addition, out of twenty-two decisions, only two are correct. The rest of the decisions have been sent to the Court of Cornetu; I kept on calling and asking what was going on because they needed the documents. I understood that at the Court House, another tax was required; the lawyer insisted and said that it was not a mistake... not of the lawyer, not... but the decision exists. The decision has been passed on, therefore why is another tax needed and I am thinking that since October... it is already March and we still have not received any rectification. The only motivation of the court: there are many on-going trials and there is a delay with the rectification. In conclusion, it is a simple mistake... It would have been better to keep the wrong ones and to insist at the City Hall, but the woman in charge is at the national register and she said she could not issue the papers because the decision does not have the required format. Moreover, the people come from far to ask and ask and nobody cares.*

*Could you tell me what the cost is for issuing identification documents for one person, all this juridical process?*

*If the mother has an identification document and she drafts an affidavit statement even if she gave birth at home, not at the hospital, she goes to the IML (medical legal institute), and she pays there tax of one million. Apart from this tax, there is also the judiciary tax for the file. In conclusion, what can I say...? I do not know how much it costs, but these are the formalities now, only by following the juridical procedure. It cannot be done without it.*

For the persons who already have identification documents, enrolling with a family doctor is in many cases limited by the liberty of the doctor to refuse certain persons. The doctors who refused the subscription of Roma persons motivated their option with the lack of insurance or identification documents, inadequate behaviour of possible subscribers or the fact that they already had too many patients. From the point of view of the patients, the doctors' refusal represents a discretionary act, which is part of many more discriminatory practices, while the invoked motives represent simple attempts of rendering legitimate certain undesirable actions:

*In my case, for instance, two [children] are with my sister... at the doctor's. Two are in Zorilor. Moreover, there is a difference because the younger ones, when I went to register them where the older ones are registered, I have been told that there were no more places. (...) When I went the second time, when the third one was born, and I went to register him, I received the answer that there were no more places. At the fourth one, when I went to register him now, they said that there were no more places. Coming out of the doctors' office, (...) I see another pregnant woman coming with the file. She goes inside and I just sat to observe- will the doctor receive her file or not? I just sat there outside and I kept looking. Her file had been accepted by the doctor and mine not. Moreover, I sat there, file in my hand, thinking "outrageous! The file of that woman was accepted by the doctor and mine not. I went inside and she said no...so I went inside the second time asking the doctor why she accepted the file of that*

woman and mine not. I asked her what the reason was and the reply I received was that the other woman had already reserved a place. (...) I left the room and went outside.

The refusal of some experienced and well-known family doctors to register a Roma patient severely limits their liberty of choice, moreover in the rural areas, and it is perceived as an obstacle in accessing quality medical services. Most of the times, the persons they reject, end up registering with a doctor who, from various reasons, does not have many patients. The doctors in the early stage of their career are more willing to accept Roma patients, but some of them radically change their behaviour after gaining the reputation of good doctor. The Roma involved in this type of experiences concluded that the family doctors do not care about the health condition of the former, and that they care only about obtaining benefits (material or professional). The experience of repeated exclusion generates frustration and lack of trust in the medical system:

*Did it happen with that particular doctor that patients wanted to register to her and she refused?*

*Oh no. She did not refuse, she did not refuse this. The situation is the following: there are two doctors, her and another one, to whom many patients moved. The Mrs. Doctor is full, she has many patients and now... good thing she is doing....*

*In the beginning, she did not have patients, she received the patient with open arms (...) because she needed this capital so to say, but in time, she started to select them and in a way, dismiss them with her attitude (...).*

*It was there... that thing, what is it called? Medical centre for... free of charge, for less fortunate people... Exactly, community, yes. Luckily, I say that I had, this child was not registered and nobody would receive him, he does not exist. Practically this child did not exist until I sent him to Bucharest for about two years, this child suffered a lot. Without identification papers, without anything, we were lucky with that doctor who either way could not do much. I needed a suspension, when he had a cold, a pill or something else but not more than this, I would not get more than this because he did not have what to give to me. He was only registered with the community. Then, to keep the story short, this centre closed and he went to a health care centre. There, knowing that he had taken care of this child until he reached the age of two, and knowing that he would recognise us, we followed him to the Nursery no. 6 and I asked him: Doctor, would please register us as your patients? That was the moment when one could have gone to any doctor so I went to this doctor. Why? Because he was acquainted with the medical situation of my child. He nicely said (...) "you must find another doctor".*

*Is this everything he said? Did he not mention the cause?*

*As I told you, he had already had enough of the gypsies in the block of flats. He grew among us. He completed his traineeship, just like a test, so to say, on us... that is all I can say since it must have been a test in order for him to proceed. He achieved what he wanted, and afterwards he forgot all about us. Moreover, he started receiving only people of his kind, Romanians and only very few gypsies. Then again, he should not have any gypsy patients anymore, because he stopped receiving the, I am telling you!*

*In what we are concerned, since we moved here, this lady-doctor came to our community, knowing us... she became well off now. I told you, in the beginning all doctors during the traineeship period in order to progress, must have patients, behave nicely even if they starve or give some money from their pocket or their financial situation is not that good... I don't have any other opinion since the doctor we previously had does not receive us any more now, the same goes for the lady-doctor who later on might react the same once she has a better position, better remuneration she might not receive us either even if now she does and she gives us medicine...*

## DISCRIMINATORY PRACTICES

Discrimination towards the Roma starts sometimes right from the moment of their birth. The participants to the focus group mentioned that **there are certain maternities in which Roma and non-Roma women are accommodated in different wards.**<sup>19</sup> This segregation concerning the accommodation of the patients favours the discriminatory behaviour of the medical staff:

*As I stepped outside to wait for my husband, a tall, thin man aged around 40 came to me. "Excuse me, excuse me", he said. I wonder if he observed my dark skin colour and that I am a black-haired woman in order to think that I am a gypsy. Excuse me; did you deliver a baby here? Yes. Please, could you tell my wife to come out? Sure, of course! I noticed he was a gypsy, and whatever he was, he was still human. Of course! Nevertheless, where is she? I do not remember but it is with A or 16A... something with A and B. When I went there, I did not see anything, where could this annex be. I ask a nurse: excuse me, do you know where this annex is? What are you looking for there, who are you looking for? Well, a man asked me to call his wife. All right but there are only gypsies there. All right, I had gotten angry but I did not say anything, I went inside. It was cold, it was winter. January. Winter, not summer. Our children and this is true exactly as I say it, my baby girl and the children in the annex had their head wrapped in a scarf, as they did it there, some sort of bonnet. I entered in that annex, it was bigger than this one, divided in two by a folding screen, like in the gynaecology room, there was only Iris there [neighbourhood populated with Roma persons]. None of the children there, (...), did not have that type of wrapped bonnet, nor any regular bonnet, maybe the mothers could not bring any bonnets from home, the children weren't even wrapped, nothing... and the nurse was inside. I went to the woman I was looking for, I told her that her husband was waiting for her outside and she left. I ask the nurse: "aren't the children cold?" (...) Do not worry Madame, it is not cold she said, these are gypsy people. I felt so bad then, that honestly I tell you, I went out crying... now really, what did that child do wrong because he was born a gypsy and not a Romanian? This is a real and true case...*

Other practices that lead to discriminatory behaviour within the health public system are **redirecting the patients towards suppliers of medical services from the proximity; examining Roma patients after the examination of all non-Roma patients, regardless of the time of arrival of the former, and the use of derogatory language.** Apart from symbolic violence, the refuse to receive Roma patients or making them wait for an extended period before examining them may lead to an aggravation of their illness.

*I waited in line... civilised, together with Romanian people, and when he came out and saw me, he invited for examination the one who had arrived after me.*

*Here is the thing: one can wait. Alternatively, one comes with the child, for instance, he had a family doctor, and you wait outside on the hallway, in the waiting room with a seven or eight year old child suffering from a 38-39 degrees fever. Then, another one comes with a package, saying that it is like a gift, "I'm delivering lunch to the doctor." She enters and when she gets out, she has an armful of prescriptions. And this is how one gets angry and consumes his strength because one cannot make a scene, one must withhold...*

*Yes, exactly, it was him again. He told me "not with me, go to the other side! Dragon, come to the other side!" In the end I went, and when I got there guess what... he did not want to see me!" [I went] back to the ER room. That is when I got angry...*

The lack of interest of some of the medical staff towards the Roma patients can be described during the medical examination by: **avoiding physical contact with the patients; non-involvement of the patients and of their family in choosing the treatment; omission of the explanations**

<sup>19</sup> Segregation cases were registered in maternities in Romania (Romani CRISS 2007), but in Hungary as well (ERRC 2004), Slovakia (World Bank 2002:120) and in Bulgaria (ERRC 2006:54).



**concerning the risks of administering a certain type of treatment; using aggressive procedures.** The examination from a distance, without performing any medical investigation, increases the risk of a wrong diagnosis, and the experience of the participants to the focus groups abound in potential malpractice situations:

*I, if I were sick, and I am sick, he would not come, unless I said so. Just that. Only if I suggested to... or to examine me, or to get up from his chair, no, he would not do this.*

*If I tell you, lady-doctor, my spine hurts, it hurts here... she hands me the written piece of paper that sends me elsewhere... so I take an x-ray test. I had my lungs checked, everything, she says: you have problems with your spine, and you have a lumbar spondylitis. Good. With that note, I went back to the doctor, in the emergency section, in neurology... I give the note to the nurse, as the doctor said she will go on holiday, but I leave this to the nurse. Good. I came back, gave the note to the nurse. When I came back the second, the third day... she was nowhere to be found. The doctor said: I give him the treatment. Wait Madame, I gave the result... how will you give me this treatment? I know better she said and she prescribed the treatment. Oh well, those pills attacked me, they were meant for people suffering from epilepsy or psychological diseases.*

*As it was getting dark, around nine-ten o'clock, I had another stroke, my pressure dropped and the ambulance came for the second time... [Ambulance doctor:] Rest this week, take this pill, really! Take this pill, swallow it! She gave me a bit of water...and told me to go home! On my word, she let me go home alone, and I was barely walking leaning on to the walls. It was not long since the ambulance had taken me to the hospital last time, because of my heart, they kept me connected to the medical devices, and they let me go just like that, so that I managed to get as far as the hospital gate.*

In general, **Roma patients are not correctly informed concerning the risks associated with some intervention forms.** It is remarkable how many women are interested in birth-control methods. As already remarked (Mailat 2006:17), injection contraceptives are recommended on a large scale by the doctors who service in Roma communities for their increased efficiency. However, the Roma women to whom this type of treatment is recommended do not receive, most of the times, counselling regarding the effect that the injection contraceptives have on one's body, nor regarding its side effects or the risks of incorrect administration of the medicine:

*There were many cases in the Roma communities, related to the misuse of injection contraceptives. In fact, this was one of the few free contraceptive methods, and that is why everybody resorted to it. No, they weren't examined, not only Roma women, it was unconceivable... do you wish to take it? Yes. Here you go! Regardless of it was good or bad for the health of the person in question. I cannot tell you if it is correct or not, but clearly, it was being used...on a large scale. Indeed the majority of the population started to give up quickly this injection medicine and only the Roma were using it. They were using it because it was free, and it came in handy. They could see that at some point, secondary effects would appear, but they still kept on using it. Therefore, in a way, it was their choice. They were not informed correctly and nobody bothered to inform them: this injection may determine this and this. Nevertheless, even if they noticed that something was not all right, they would continue. They said that they could not have any other children, that they had no possibility of raising them. So what do you do then? It is better for me to get hurt than to torment the children in this world we live in.*

*Normally, as the medical books state, this injection is prescribed following a series of very detailed examinations regarding the hormone dosage. In Romania this is not happening, not at all, this procedure does not exist. Only on request and one has to pay for this. It is a rather expensive procedure. Indeed, with hormone dosage, it is clear who can use the treatment and who cannot, because this injection is a bomb with hormones that suddenly rush into one's body.*

## „DON'T MOVE THE TABLE, AND THEY DON'T DO ANYTHING”: INFORMAL COSTS

In a corrupted health system, the material situation of the patients represents an important drive concerning the access to health services. Beyond the legal costs of different medical services and beyond the cost of medicine, that exceed by far the material possibilities of many Roma families, there are also the informal costs, which bring about an extra pressure for the patients, and determine some of the suffering to seek for remedies outside of the medical system. The discourse on informal contributions is not unitary. There are two main approaches: moralising and pragmatic. The first one underlines the illegitimate character of the practice as well as the exclusion effect that it generates for the poor members of the community, and the second one looks more at the advantages that informal payment brings about, including the possibility of overcoming ethnic discrimination:

*Is it that difficult to find another family doctor?*

*It is very hard because it is not accepted...you know what they say. I do not compromise myself, for when they come to wait outside of my office, it may happen that there are one Romanian and two gypsies. In addition, if a Romanian comes and he sees the other two outside, he would not enter my office any more. And maybe that one brings something...anyway. And the other ones come with their hands in their pockets, only to take the prescription...*

*If one goes to the family doctor with a suffering child, or one needs to solve some medical issues, one must bring three pots with flowers. (...) Three pots, exactly! For the doctor, for the nurse, for the student who will become a nurse a few years after. And if not, some coffee, a big jar, more expensive...a box of chocolates... I know from my own experience that this is how one should go about in order to receive a prescription or to request further investigations for the children or me.*

Beyond this general consideration, the attitude towards informal payments depends on the context, the expected benefits and on the behaviour of the medical staff. In general, all informal payments are accepted when it comes to minor affections, when the amount spent in this regard is insignificant (“small attentions”), when a preferential treatment is expected, or when the doctor is not explicitly or implicitly asking for something. On the other hand, the attitude becomes quite negative when it comes to serious situations (emergencies, major surgical interventions), when the expenses exceed the possibilities of the patient and when performing the medical act is conditioned by the payment of an informal contribution (in other words, when an ethos of the gift is regarded as economic exchange). The case of a Roma, who could not have surgery due to the lack of the amount of money requested by a surgeon, was mentioned in the focus groups.

*The asthma does not let one breathe, I was waving my hands asking for help from my sister and my husband, but they could not do anything to me... eventually, the second night I went and luckily I found a young doctor, he saw me, as pain is visible...he could see that when I started to cough I had no more air, and he examined me, he sent me upstairs to have an x-ray analysis but I had nothing to offer... he told me relax, he asked where I worked and I told him that I don't work. He also asked me how old I was, and how many children I had, I answered that I had three children and that I was thirty-six years old. He said the following: “this money that you want to give to me, you take it and go buy yourself medicine. Because... he also asked where my husband worked and even if he did not work, he added, “there are still doctors who believe, there are still doctors... please take back your money”. I had not given him much, just twenty lei. He repeated that I had to go buy medicine with that money and he said that he was going to make me an aerosol; he did not accept the money, he gave it back to me, he gave me the aerosol (...) and ever since, I did not have any problems and I did not know how to thank him. I could not believe that he spoke so nicely to me and that he said that there are people who believe that maybe sometimes one does not have any money to give.*

*He asked you for seven million in order to....*

*Yes, he asked for six million lei so that the child would not suffer...*

*Eh, look at the bright side, now the doctors ask for whatever they want; they do it straight forward and ask one for money. They tell you straight to your face: "It costs this much"*

*Starting with the nurse and ending with the doctor...*

*Yes, starting with the nurse and ending with the doctor. You must give something to each of them; otherwise, they do not touch you.*

## STRATEGIES OF APPROACH CONCERNING HEALTH PROBLEMS

From the confessions of the participants to the focus groups, **the hospital and the medical care unit represent public spaces where discrimination happens very often but it is only rarely sanctioned.** The personal experiences of our close ones generate an attitude of mistrust in the medical system and in the professionalism of the medical staff. The fear of being discriminated against determines many members of the Roma community to postpone their medical appointments until the health problem reaches a very advanced stage and they are left with no other choice:

*Regarding how often I go to the doctor's I already answered. From the point of view of the disease, I only go when I find myself in a very serious emergency. Last year, after three days of terrible pain, I went.*

*If it hurts a little, it goes away. Then, another day, maybe the pain goes away... and the third day, if it still does not go away, maybe then we go. However, if the pain goes away in two days...*

*Exactly. We do not go any more.*

Resorting to traditional cures or self-medication represent another approach of the health issues, but it is exclusively reserved to minor affections (colds, coughs, headaches, and backaches). This convenient situation does not affect the budget of the family and is supposed to offer similar results as the treatment recommended by the doctor. Moreover, using medicinal plants is preferred because it does not create secondary effects:

*It is difficult to go see a doctor ... as I have said before, one does not really feel like going when one does not have any money, not even to pay the bus ticket in order to get there. In case you reach the doctors' office, at least this is how we see things; we do not really have the money to buy the prescribed treatment. That is why, we use our own resources in order to get better, some tea or some traditional treatment, or the cheapest treatment like aspirin, two or three pills, bought from a pharmacy, not the full box since one does not use it all anyway. Two –three pills are just enough for one or two days. In case we are feeling better today, we do not go the following day. We feel better today...then the health problem... affects us.*

*In conclusion, these types of natural cures exist and we have always resorted to them. Even the pharmacy, the biotherapy, it is based on the same principle and it is made out of plants...but one also needs a doses. It is better to take these pills rather than many other pills and antibiotics, because eventually it all comes down to your child's health, and in time the use of so many pills endangers it, and it is bad for the immunity. To conclude with, if you give a fruit or some onion to a child when they are not feeling well, this will surely not affect his health.*

When the Roma address the specialists, they face difficult situations, they choose another doctor, who is willing to help his patients regardless of their ethnicity, or they take action against the discriminatory practices with which they are confronted. The latter solution is applied by the Roma who

are aware of the way in which the health system is organised, they are aware of the rights and obligations of the actors involved, and they have excellent communication abilities:

*To conclude with Madame, by the obligation inflicted by your position as local family doctor, we ask you to stop by our house when performing field activities. It is also written in the booklet that the hospital offers after childbirth, in which it is clearly stated when the doctor must visit us, at what interval of time...*

*You should know that the doctors react to anything... to any type of authority, when you go, if you do not know how to make yourself heard, and to reach a constraining situation for them, you will not get anything solved. If they see a persons who is asking or begging, they notice that you don't really have a lot of self-confidence and power of persuasion... so you have to change the register to try to tell to the doctor... "I will file a complaint against you!" one must resort to other things as well...*

*Focus B: Of course, yes...*

*Focus: ... that is the moment when you make yourself noticed. "Wait a second; I'm not dealing with a stupid person... I must do this; otherwise, they can play me off. So it's a must...*

*What I want to say is that the Roma are nice people and unless you provoke them, they do not speak badly, even if they are pettish people, once you respect them, they will respect you in their turn. On the contrary, if we are provoked, then we know how to fight back.*

**INTRODUCTION**

During the summer of 2010, the research team of the project completed 17 interviews with the health mediators in the following localities: [1] Caraula commune, Dolj County, [2] Cracaoani commune, Neamț County, [3] Târgu Jiu, [4] Craiova, [5] Homorod commune, Harghita County, [6] Vaslui, [7.1] and [7.2] Sărățel commune, Iași County, [8] Râmnicu-Sărat, [9] Târgu Jiu, [10] Homorod commune, Harghita County, [11] Miercurea-Ciuc, [12] Huedin, Cluj County, [13] Câmpina city, Alba County, [14] Cozmeni commune, Harghita County, [15] Târgu-Mureș, [16] Timișoara, [17] Dumitrița commune, Bistrița-Năsăud County. In ten of the cases, the interviews with the mediators were completed by interviews of oral history. The qualitative methodology used in the research conducted on the access of Roma to health services completes the quantitative research (sociological investigation), generating a rich and detailed image of the experiences of these important actors of the public medical system and of the Roma civil society. In order to ensure their confidentiality in this report we refer to the persons by the numbers found in the above list.

The interviews aim to identify aspects related to the access of Roma to health services from the point of view of the health mediators, through the questions contained in the interview guide as well as following face-to-face discussions. On one hand, their experiences reveal the difficulties faced by Roma communities in which they activate but also the malfunctions of the public medical service. On the other hand, the stories revealed during the interviews, provide a better understanding of the problems faced by Roma women employed as health mediators.

Living in the communities for which they work, the health mediators are able to describe not only the health problems of the community and the difficulties faced in accessing medical services but also the way in which the former interfere with other aspects of everyday life and with social exclusion, such as access to decent housing and employment. Their awareness on the aforementioned aspects undoubtedly reveals the fact that looking after one's health is one of the causes as well as consequences of living a life confronted with financial difficulties but also negative prejudice and discriminatory attitudes towards Roma. The experiences of the health mediators help us understand the problem of the Roma access to medical services in the general context of the primary medical system.

Because of the fact that the interviewed health mediators have been working in this field for many years, their experiences are the mirror of the institutional process and changes from the medical field. This way, their narrated experiences could be and should be interpreted as one of the elements of the problem of Roma access to health services. The stories told by the health mediators help us acknowledge the inherent tension of the position of mediator: on the one hand, their health mediator status makes them part of the public medical system; on the other hand, they are part of the Roma communities facing difficulties in accessing health services. As mediators, they try to rise up to the expectations of both parties.

Using several excerpts of the semi-structured interviews, this report presents the following three main themes:

- 1) Living conditions in Roma communities;
- 2) Health problems and access to health services;
- 3) Micro-history of the experience of being a health mediator.

In this report, adding value to the stories of the health mediators has both analytical considerations as well as moral implications. In this regard, we follow the acknowledgement of the emic perspective (of the participants involved) on the analysed theme, but also bringing a tribute to their person and activity, which is dedicated not only to their profession but also to a feminine activist way of understanding and exercising their affiliation to Roma communities.

## **LIVING CONDITIONS IN ROMA COMMUNITIES**

Most of the health mediators live among Roma communities, which is why they have a solid knowledge of the current problems that the latter face, since at certain moments of their lives they experience themselves the same financial problems, the same lack or uncertainty related to a workplace and the discriminatory attitudes towards Roma. On the other hand, by their health mediator status and attributions, they must identify (through census-like records) the status of these communities, which is why the experiences that they share with us during the interviews are not only true and relevant but also up-to-date. These two reasons make us assert that by their narratives we can present an image of the life in Roma communities.

Hereinafter, we describe the living conditions of the Roma communities that they work for, by presenting excerpts of the conducted interviews concerning (1.1.) residential areas and lodging conditions, access to (1.2.) primary education and (1.3.) employment, and (1.4.) economic migration to foreign countries. Last but not least, this chapter aims to reveal (1.5.) the traditions observed by the health mediators in the communities and also (1.6.) the way in which they conduct their activity and the perception in the community of a job performed by women.

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### **RESIDENTIAL AREAS AND LODGING CONDITIONS**

The interviewed health mediators serve a multitude of Roma communities from both urban and rural areas, compact or dispersed, traditional or “Romanian-like/Magyar-like”, but most of the times, concentrated in colonies/communities faced with severe poverty.

According to their role, they meet the most disadvantaged groups who indeed are in need of mediation services because on their own, due to structural causes, they cannot face the medical or non-medical authorities to which they should and could resort by exerting their rights as citizens. The mediators have a better socio-economic position as compared to other members of the communities in which they live and/or work. Most of the times, they were in contact with the latter even before they started performing this job. Nevertheless, in most cases they recognise that they were shocked when better understanding the precarious conditions in which they live. When approaching a problem they always look at it from the wider context of day-to-day life but they are aware that solving most of the challenges (isolation of Roma colonies and lodging conditions) surpass their attributions and their personal abilities. Beside the fact that their lodgings do not ensure decent living conditions, and what is more, endanger peoples’ health (in some cases the houses are placed near landfills or treatment plants, or even in localities polluted by mining procedures), the housing issue involves several times, the lack of property documents attesting their ownership right on the residential spaces. In its turn, this implies uncertainty and the risk of evacuation. The latter situations may be avoided on a short-term in case the local authorities distribute rentable social lodgings to needy people, not to mention the fact that their solutions aggravate the phenomenon of residential segregation.

*In Caraulea commune, out of 3000 inhabitants 800 are Roma. Their poverty is bringing them down. Poverty comes first followed by illiteracy. We are bear handlers gypsies but our main occupation is agriculture. [1]*

*I worked in Oglinzi, in Cracaoani, in Humulești, in Vânători. Humulești is a suburb of Târgu Neamț city. The richer people live at the entrance in Humulești: the gypsy baron and his family. [2]*

*To us from Târgu Jiu, the community where I conduct my activity is the largest. It has around 2500 Roma and it is a compact community of traditional Roma. [3]*

*The Roma communities of Craiova, almost 12, are peoples of pot crafters, bear leaders, woodcrafters. These are traditional communities, especially the community in front of Luncii and the one in Popoveni. Here, we have over 2000 people. Compact communities are the ones from Luncii, Popoveni, Românești and Drumul Apelor, the rest being more dispersed. [4]*

*I used to work for the Racoș community, where 1200 Roma live. At present, I work in Ticușu Vechi and Cobor, where about 850 Roma live. In Ticușu Vechi, it is much better than in Racoș. They still have animals. In Racoș there are very many Hungarians who were reluctant in employing Roma, and the Roma where whining "Take me as an employee, take me to work". They were not employed because some of them had stolen, many were in jail and the potential employers were afraid to employ them even if the Roma in question was a nice man and had 5,6,10 children at home. Poor Roma live in houses without windows, without doors...we even discussed with a German agency who wanted to help them and brought them windows, doors, construction materials in other words. [5]*

*Reghin is a suburb of Vaslui city, located five kilometres away from the city, where a compact community of 1600 Romanian-like Roma live, who do not speak the Romani language. The place has been declared a neighbourhood. People live in houses found in a very bad condition; this is the poorest community of the city. [6]*

*In Pașcani, following the census, we found only 830 Roma, although the census registered 1200... We have traditional Roma costumes; bear handlers and "lăieși" (nomads). Most of them survive on social welfare, they do not have shoes, and for instance, the ones in Broșteni or Domeni do not have shoes and clothes for their children. Many of them eat at the soup kitchen. Others just starve. There are some who are a bit better-off, those live in the city. But the ones in the suburbs... [7/1]*

*I have bear handlers gypsies from Sărățel commune, and my colleague has the wooden -spoon crafters, about eight hundred and something. The bear handlers are better off; they are about five hundred and fifty. Most of the young people go abroad. The others, aged 35-45 live from the social welfare they receive. They are not employed, they do not own any land, and the road is very bad without asphalt, without anything. The community is compact. Many of them did not declare themselves as Roma. Especially the old ones who are afraid not be taken from their homes as it happened before. They lived the story and the fear has been passed on. [7/2]*

*The major issue of the Roma community in Râmnicu Sărat is that they do not have any water. The families that do not have water are very poor; they have a welfare meal, and no other income source. [8]*

*I work in the community of Piteștii din Deal. It is not exactly a compact community. They are brick crafters... I mean, long ago, they were concerned with making earth bricks. Others were selling second hand clothes, the women, and the men were selling bricks and used iron. About 40% of the population receives social welfare. On the other hand, in Microcolonia Meteor the situation is more decent. Only 10% of the community is needier. They have great gold thesaurus. Some of them go to Constanța harbour and buy the iron from there and they sell it. They have a gypsy baron, he is a Pentecostal, and most of them are Adventists. They collect welfare once a month and they give it to the ones at the periphery. [9]*

*The Roma community in Homorod is of about 1147 persons out of which only 900 are declared. The ones who are not declared do not understand the term "Roma", somebody could issue gypsy identification papers for them. They mistake citizenship by ethnicity. [10]*

*At present there are about 660-680 Roma in town, maybe more. They can be found in three places: in Primăverii colony, Somlyo colony and in Miercurea-Ciuc colony. There are about 200 inside the colony; on the other side about 200, up the hill there are about 60 families. There are a few who live in town also. In 2000 or 2002 many Roma families have been evacuated from the city centre and taken to the wastewater treatment plant. They live in barracks. Harsh conditions there both for adults and children. From a medical point of view living there is noxious because of the wastewater treatment plant. But they have nowhere to go... The main problem in most of the places is poverty. [11]*

*Here the tenters feel prouder, the ones who left to the other place and returned. They are wealthier, richer. They own the palaces. They own a palace but they live in one room, they have their small house in the courtyard and they live in it. This is their pride, to own the palace. But they face problems, with the small towers, with everything. Most of the Roma from Huedin still live in poverty... The Hungarian gypsies of the town are not rich, their houses are pawned. And there are the other Roma, the Romanised, who worked all their life in a factory. We have other Roma who used to be singer-entertainers. But this is not working out for them either. Then, we have the Roma who live by the landfill, by the old citadel. It is very dangerous there. During the summer, they cannot even stay there. There are rats, snakes... not to mention the smell. And they go to collect, they select the garbage. [12]*

*The living conditions of the Roma living at the outskirts of the city of Câmpina, by the woods are really bad. Their houses are made out of beams. There are some who live in brick houses with tiles, but others have roofs made out of carton. They have electricity. The City Hall helped them, granting them subventions for electricity and they took electricity from one another. Water was also provided for by the City Hall as for a long period of time they did not have running water. They did not even have garbage bins until I went to see them. There was an outbreak of infection there. Now they have containers... Only one or two families of the community have property documents. But they do have addresses on their IDs. They do not own the land. The land belongs to the City Halls, they built houses, they go, they don't have bathrooms, they build out of wood, however they can... I also had the community of Albac, it's much better there, everybody had papers. [13]*

*Cozmeni has about 900 inhabitants out of which 670 are Roma. At a commune level, the Roma minority is larger than the Hungarian minority. And precisely for this, they would have needed the mediator, the expert. But the City Hall does not want them and they cannot be forced to accept anything. The place inhabited by Roma in Cozmeni is called the Hole. In the hole, they have water; there is this common tap, from the City Hall, but no electricity. They have garbage bins. They started to clean up, they became cleaner. The land belongs to physical persons. The people live in cottages. There are six, seven, eight persons squeezed in a tiny room, which makes it difficult. They built the cottages themselves. They do not speak the Romani language any more, only Hungarian. [14]*

*I have about 700 Roma. We are six mediators in Târgu Mureş. As many as everybody has. We used to live in the Rovinal neighbourhood. Afterwards, Băneasa neighbourhood was erected and the majority went there. They received social lodgings. Before, they were illegal lodgers of abandoned buildings and now these buildings are being renovated. The social lodgings belong to the City Hall. The people pay rent to the state. [15]*

*In Timișoara, the Roma live in various neighbourhoods. Following the census, about 3500 persons were registered. The neighbourhoods to which I was assigned are not really poor, they are integrated people. The ones who live in Blascovici neighbourhood have problems, they live in barracks and the City Hall keeps evacuating them. [16]*



*Here in Dumitrița the population is of 2985 persons, out of which 900-1000 are Roma. In three villages Dumitrița, Ragla and Budacul de Sus. The bad part is that the Roma here, in Budacul de Sus do not declare themselves as Roma, they are ashamed to declare their ethnicity. Therefore, they are very few, 370 and something declared as being Roma but in my database I have about 873 persons. Usually the Roma live at the periphery of the villages, here in Dumitrița it is called "Cătunul Dumitriței", when the asphalt ends... But there are some Roma who live among Romanians. Some of their houses are made out of wood, but there are less fortunate families, with houses made out of clay, but not a great number of them. Most of the Roma have travelled abroad and earned some money, informally and they built a house. They do not have any documents attesting ownership over the land. Maybe 1-2% of the entire population of the commune have papers. Be it as it may, there are houses inherited from grandmas, aunts, great grandmas but without any papers, and this is a problem here since not all have papers. Even the majority, the majority and the Roma. Everybody. This used to be a Transylvanian Saxon village. From my mother in law I understood that the Roma were getting along very well with the Saxons long ago, when the old were younger, they spoke German. Everybody spoke Saxon, German, the Roma spoke perfect German because they collaborated, they worked together, and they were in the same village so there was no difference between Germans, Saxons or gypsies. She said that they learned many things from the Saxon women concerning agriculture, pickles, and the larder. They took over many habits and traditions from the Saxons. Now only the houses are left, I do not know, I do not know. The outside, or the inside, big rooms, high windows, high ceilings, this is specific. On the outside, nothing was left from the Saxon tradition. They have turrets. This is the pride of the Roma, the more turrets one has, the wealthier you are. One sees that his neighbour has some and he would like to have the same, this does not come from the Saxons. [17]*

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## ACCESS TO PRIMARY EDUCATION

Out of the interviewed health mediators, two have superior studies, some graduated from high school and others the gymnasium, and one of the required conditions for employment is to have completed the eighth grade. In consequence, they are role models for the other persons of the community. The mediators noticed that in most of the cases, school dropout after the 5<sup>th</sup> or 6<sup>th</sup> grade is due to economic reasons, but in other cases it is connected to the migration practice of the parents abroad, and, even if in a small percentage, it is due to the communitarian traditions that prescribe clauses regarding the protection of women/girls but also to their domestic role in the community. Last but not least, they emphasise the situations in which the children face humiliation at school from the part of their colleagues, parents and teachers belonging to the majority, but also the cases in which the local authorities refuse to take any action in order to improve the access to education for the less fortunate Roma, or in which, local authorities segregate the Roma from Romanians or Hungarians. Even if it exceeds their attributions, especially if the community does not have school mediators, the health mediators make an effort to enrol and keep the Roma children in schools. They notice a slow change in this regard: the ones who go abroad with their parents go to school there (and they speak many foreign languages); the tradition is adapted to the current educational needs; the parents recognise the value of education and they make efforts in order to ensure their children with the chance to be educated; the teachers (by themselves or under pressure) acknowledge the need for integrated education, and recognise the differences that are not in the advantage of the children, yet as a matter of expectations, they do not treat them differently, they do not discriminate.

*The children are enrolled there, abroad. We have persons who even in Greece have been enrolled for almost 5 years, the children, and when they came now and I talked to them, I could not believe that they spoke Greek. They said that they were smarter than I was, that they spoke Greek and I only spoke a bit of Spanish and Italian, and that they spoke many languages. In conclusion, the Roma children started the educational process as well but at home, they stop at the 5<sup>th</sup>, 5<sup>th</sup>, 7<sup>th</sup> grade only. [1]*

*My community was always more informed and more integrated, more emancipated in comparison with other communities that I visited. Education is indeed a value for us. [2]*

*Lately, the women of our community enrolled their children in school. And they stay at home with their children. But there are many cases of non-attendance to classes or even school abandon, generally for girls. Their parents do not allow them to go to school after the fourth, fifth grade. The reason is always the same. She does not go to school anymore because the boys are picking on her, she is in danger. In this case, we allow some time to pass and we try again, with the second chance. The solution is not very satisfying but this way we managed to enrol some more children. [3]*

*There are only a few cases in which children graduate from the eighth grade and continue, most of them drop out of school from the fifth, sixth grade when they start to go the so called work with their parents. Until then, they look after their other siblings. In the community, we have the school with grades from I-IV. Afterwards, one needs to go to the school in the other village, 5 kilometres away, which is an impediment and afterwards they should go to town after the eighth grade. Very few children graduate from high school or professional schools, not to mention universities. I think we only have five cases. [6]*

*They do not go to school. As much as I tried to persuade them, "you have an eight year old boy, you buy women for him but why don't you send him to school? So that he may have a future" And they tell me: "ah, what is he going to do with his studies today, can't you see that they are not hiring anywhere? What will he do with his studies, stay at home and starve" This is the principle that guides them, they drop out of school, go abroad, make money and come home and build a house. [7]*

*What hurts me mostly, we collaborate with the school nearby, primary school with grades 1 to 8, where I go 4 hours per day at the nursery and the girls from the 5<sup>th</sup> to the 8<sup>th</sup> grade drop out of school. School abandon has a high rate due to their religion and traditions and due to the fact that they marry at an early age. [9]*

*I also had problems with this nephew of mine in school. A difference has been made. I went with him, we were lined up, clean, elegant... Among the children, there was not any problem but the parents knew I was a gypsy. No matter how luxurious and arranged you are, you are still a gypsy. The children wanted to sit near him at the desk. And I saw their parents telling them not to. I felt very embarrassed. You can imagine that he was left all alone in the second desk. And he was the cleanest. There was no other as beautiful as he was. Now you can see in that photo he is not even black or... to say that he is black or... "Mom, I don't like to share the desk with him"... In our school, there were separate classrooms too. But they had a good teacher and that is how the children learned. Eventually somebody else came so he was thrown out. The children were left on the outside. [13]*

*They went with the request that the child is not healthy and they arranged for many children to receive a certificate for handicapped. As a result, representatives from the safety of work arrived to see how things were going, what the truth was because they knew all the children by name and they asked me to go with them because I knew them in order to find out what was going on. It was unpleasant that I had to go... In the end I found the children at home, the parents were not at home, and they were cut off some of the subventions, a bit of everything. I felt very bad, because it was my fault and I had caused all that trouble... It is very hard. But many of them were from here. Almost all the children were registered as handicapped. And indeed, the children do not have anything, they were educated by the ones at home, when they went to the psychologist, to fake, and indeed, they fooled her. They did not really go to school... Now that they started attending classes and it is much easier for them to integrate. There are no differences now; they go to school altogether, the Hungarians too. They also started going to kindergarten, about two years ago. Only that now, the Hungarians say again that there are too many gypsies and that they do not want their children to be together with gypsy children... We have very many other endeavours since my brother in law is the president of the Roma of Harghita County. He is trying*

on different levels and with funds for the program called “the second chance”, so that starting with autumn to begin the training for the adults. .

*Let us just see if things turn out the way we want. The City Hall should understand that the village wins if they go to school because they will integrate better. But they do not think this way... Four five years ago there was a class for the Roma as well. The class was in the school building, in the upper school so we went in the afternoon. After the day classes were over, we went because it was the only way. The children would come. Around ten, twelve. This lasted for one year, afterwards they stopped coming and the class was abolished. But now it is starting to get better. There still are some of them who do not come. They do not like to come because the others mock them. They call him gipsy, or they do not sit next to him, what do I know? And there is something else, the teacher tells them to sit separately. And the child feels all this therefore he does not want to go any more. They cannot study at home due to the lack of conditions, we discussed about this with the teacher. Even if some children are very talented they need more attention and patience because if at first sight they do not understand something, we must also understand that nobody can help them at home... Now the children are in normal classes, mixed. In kindergarten, the situation is different, there are four groups. Because they were so many, many of them have sent the children, so four groups had to be made. Out of them, only six are Hungarians and the rest are Roma. The Hungarian parents said that if in kindergarten so many Roma children were enrolled, they would not allow their children to go. But in my opinion, they will eventually allow them to go because otherwise they cannot solve the matter, where to take them. They must get used to this, there is no other choice. [14]*

*In our school children from the two villages of Ragla and Dumitrița attend, but also some children from Budacul de Sus. In Dumitrița the teachers are better, more severe and always on time. In Budacu, there is also a professional school for arts and crafts. The Roma children either go or not, we are fighting school abandon, they are not very constrained by the teachers... The parents whine that they do not have any money that they are being asked to pay the class fund, the school fund. They do not have money to dress their children, for cloths, for books and stationery and many other things. Or, if they have an animal or two, something to work in their gardens, they keep their children at home. If they have younger siblings, they keep the elder home to look after the younger. After the 7<sup>th</sup> or 8<sup>th</sup> grade, they drop out of school. When the school year started, we had a segregation attempt in school. It did not happen but they were prepared to set up classes made up only of Roma children. The principle of the school said that the Roma should stay where they went to kindergarten, at the outskirts of the village that they will benefit from a program, with mentorship and a hot meal. But I spoke to the school principal and the mayor and it has not happened anymore.[17]*

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## ACCESS TO EMPLOYMENT

Except for a few cases, the Roma communities serviced by the interviewed health mediators live in less fortunate areas from the point of view of economic development and of the availability of work places. For them, the changes that came after 1990 meant bankruptcy of local industries, but also the privatisation of agricultural fields and forests, and automation of many agricultural works that do not need unqualified work anymore. Under these circumstances, the Roma who do not own any property only have the chance to work by the day for the other people of the community, for the majority or for some enterprises that prefer not to hire them, or to perform seasonal jobs like picking up fruits specific to the areas that they live in. On the other hand, the market economy makes the products resulted from traditional works (for instance bricks or rod brooms) or the services through which the musicians had a place in the life of the community, not to sell any more, so that traditional occupations are not a source of income anymore. The uncertainty of their work place means living from day to day, which

determines some of them to resort to social subventions, stealing products from the fields or illegally cutting off trees, practices that are severely punished in the private property-based economy.

*I believe that the lack of work places is a general problem for both Romanians and Roma, but for the Roma it is more severe indeed... Beside the fact they work on the black market, building houses, constructions, for several owners, there are some who do employ them. [3]*

*They do work by the day, each of them does what he can, and they do not have a stable occupation. They are beneficiaries of the social subventions... A great number of them... [4]*

*In Ticușu Vechi, it is much better than in Racoș. They still have the animals, the ones in the community, they do go to work during the day, there are people in the village who employ them and they get thirty forty lei per day for food, whereas in Racoș there are many Hungarians and the Hungarians do not employ them anymore because some of them stole, many of them are incarcerated and they are afraid to employ them even if the man was good and he had 5, 6, 10 children at home. The people in Racoș actually live from the social subventions and from the allocations of their children, so the situation there is more difficult. They used to go by train to Brasov, of course without ticket, then they had problems because they did not have a ticket, they would be caught, anyway, various such problems. They would go to Brasov to beg. [5]*

*People, most of them, benefited from the law no. 416/2001, the others perform agricultural and non-agricultural labours, a few kilometres away there is the platform of the city, the Roma go there to collect used iron in order to sell it, and this is the main income source of the family. Many of them beg. They sit on the stairs and beg, give me a penny to have what to eat. [7]*

*In Căldărari there are three more special cases, the rest are better off. Even if they do not have salaries, their income is not that great, but the living conditions are better, they are better off. They sell merchandise, they go to the bazaar in Suceava or Bucharest to buy cheaper merchandise and then they sell it in the villages. They are better off, depending on how smart each of them is. [7/2]*

*Here, nobody offers work places, it is very hard. In the past, there was the cloth factory but now it is down too. Employment is down in Râmnicu-Sărat. They are left with no other choice, but to leave. From the ones who staid and the ones who are very poor have welfare meals. Or, to be able to leave you must have some money, conditions, where to live. Precisely the families that are the poorest did not have a chance to leave. They work by the day, without any other income source. It used to be better for them when they were making bricks and they were able to support themselves [8]*

*There are 225 social help files out of which 95% are for Roma. Many of them work by the day from time to time. In the commune there are many companies, I am talking about physical persons, they work for them by the day, but if they are caught, the social welfare is suspended and they are not medically insured either. By conducting social investigations, it is discovered. The rest, who do not receive social welfare, are employed with one another, but they're rather few. There is a factory in Hoghiz commune. They work at the factory and they are employed there. Some are permanently employed and some work by the day. You know what the problem is, many of them go for a while and then they leave. They probably get bored. And this is what I'm saying to them, that if we get bored we cannot solve anything. Therefore, we must try our best every day in order to make it through. [10]*

*In the past, they used to work in factories but ever since they closed down it's harder. Many of them are unemployed. It's not good for them. They live from social welfare, and from their children's allowances. They work by the day wherever they can, but are not employed. The women stay at home with the children. From time to time, they go to pick up mushrooms, depending on the season, they live from this. [11]*

*It's not better for the musicians either. People prefer to play music on the computer at weddings... and the Hungarian Gypsies were doing a very nice show, but this does not sell any more, they might be in the textile industry They buy cheaper and then resell but they don't really earn a lot of money. This is all they have to provide for their food. We don't have any companies in our town. We only have ecology. Seasonal work. About the ecology you know what they say, I have to take from every family... and I can't hire many. In a small town, how many places can there be. They also hire to clean the city. But they don't work all the time, just for a while and then they become unemployed. And while one receives unemployment benefits, they hire some others instead of him. This way, everybody gets something. A while ago there used to be a furniture factory in Vlădeasa. A division of the factory from Cluj. They used to work with all kinds. I was there too. All kinds of iron castings. And there was the auto-base, there were people working there too. But they all shut down. The ones who own land outside of Huedin, they don't have many possibilities to work it. They only work for themselves to have winter supplies. But the Roma don't even have. They work by the day. Digging, picking up fruits or vegetables, but not all summer long, it's temporary. And you know how in exchange the people don't get money. They get, potatoes, beans, bread, anyway, it's still food. But it is not a decent living Nowadays no work is guaranteed. Neither is ours. We are employed for a certain period of time. I am good at tailoring but who hires me when I'm over 40 and it's not possible for me to open my own company. There was a time when I had authorisation and I used to sell at the market. And I also had in Cluj for the textiles. When we moved here to Huedin we closed down, the authorisation. This is a small market and it's not profitable. In Cluj I had a stand and I staid there every day. I would buy the merchandise from Bucharest and Suceava. But it's not worth it to commute to Cluj for this, plus the market here is not good, the people here are poor, I know that. [12]*

*All the mines closed down and no other companies opened. Social welfare for us and nothing else. There is still wood for furniture but only one or two young people are employed there. At the City Hall there are some scavengers, only three persons. They work by the day, this is how they survive. They load or unload the wood, at the choppers... this is what they help me with. The forest is nearby, you understand, The Roma live close to the forest, and they do cut from it, not to sell the wood, to keep them warm. We also grow animals here, bulls. We have an association of bull raisers. But the Roma don't have any horses or carriages. Only two have horses and maybe they have a hen or two depending on their possibilities. [13]*

*Now they go to pick up fruits: Blueberries, raspberries, or mushrooms. It's more difficult during the winter because the social welfare is not enough. They are actually brick crafters. It's still working today, they make bricks and...they come during the winter, in spring to sell them but they still don't really make enough money so...We slowly come to a point where we have no market for this type of bricks, it's old fashioned. In the end everything stops. They also bind brooms, or wipe shoes, but these type of jobs... When the co-operative society was still working there were many of them there, and some also used to work on the fields but now they are not needed anymore. We reached a point when they are not even called to pick up potatoes, they automated this job too. The farmers say that it's cheaper this way than to feed daily I don't know how many persons, and pay them by the day. It happens for them to be called when the potatoes must be selected or put into sacks but... there's nothing left. The only option is picking up fruits during the summer, or mushrooms but only for a short period of time. And for all this period they do not receive social welfare. But this only happens here, because in other localities they receive during the summer as well. Here, the Mayor said no... And from Sânmartin and Sâncrăieni, they found refuge here for a while, afterwards, they kept on going back. Now they're all gone, they went to their homes, they're calm now and it's quiet but we don't know for how long. The Roma had to sell their horse, the ones who had horses. Horses, carriages are banned because they use them to go stealing. They don't know how to provide for their living any more.[14]*

*There are no working places, and if there are, they do not employ gipsies. In sanitation, there are poor people. They beg for employment and they pay 2 millions, Now the girls started, they are*



*entitled to social welfare, they understood how important the medical insurance is. But if they stay at home with their mother and the mother has a pension, than they don't qualify any more. [15]*

*"Caștalăii" or "caștaliii" (half-gypsies born from the marriage of a gypsy and of a non gypsy) from Budacu de sus, they don't really speak Romani language, they are also called "wood crafters", because they do cribwork of wood, baskets, brooms. They still do this now but not as much, because they don't have where to sell all these, so they go to nearby villages and try to sell their products. Most of them receive social welfare. When I used to work in Budacul de Jos there were about 10-15 files, whereas here in Dumitrița we have 180 and only from Roma. Overall, on the commune we have 220 social welfare files. The bad part is that they can't find a job because they don't have any qualifications. We accompany them to the AJOFM, if they don't have the necessary training. We go once or twice a month, depending on the meeting of the mixed work-group at the Prefecture, where all institutions participate.*

*There, we find out when the job fair for Roma opens, and not only, we guide them and we inform them. Through posters, we inform the community that there is the possibility of employment. The people go but they don't find a work place, because they don't have the required qualifications. It sometime happens that the employers don't hire them because they are Roma, and they said that out loud... There are many thefts here and the criminality rate is very high. In Budacul de Sus the main occupation is that of carpenter. They go to the woods, cut wood for the fire; they sell it to choppers, for constructions. We have more than 39 defendants locked up in Bistrița prison. The silviculture criminality. There are families where the husband is imprisoned because of several fines, criminal records, his wife stays at home with the children, she hasn't got any workplace, she does not benefit from absolutely nothing and she goes to the forest too, and if she gets caught, she is imprisoned too or if they don't get caught, best case scenario is that run away abroad... In Bistrița there are a few who work for a cable company, I don't know exactly how many persons, around 50. In the beginning they were 100. After 3-4 months they had access to bank loans. Each of them applied for a loan, two, three, but there are who applied for 7 or 9 and now they are not employed any more and they cannot pay their instalments. There are many to whom the bank comes and they put a distraint on their goods. Here in Budacu de Sus we have many cranberries, raspberries, blueberries. People work illegally if they can. The season lasts for two months and they sell the forest fruits in the village or on the street. The producers lift it up, they pay for the merchandise, lift it up and that's it. There are some at the market place but they rarely go there because they must have a producer's certificate in order to sell there and many other papers... We want to write a project concerning a collection centre on this organisation. Communitarian development, only it's a bit harder in the beginning. [17]*

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## **ECONOMIC MIGRATION ABROAD**

The temporary economic migration to foreign countries is a very widely spread phenomenon in these communities, even if, as alternative, it is not accessible to poorest. It seems to be the most efficient adaptation method to the unemployment crisis, even if beside the most accessible jobs, there are the seasonal, unqualified or by the day types of labour, without any employment forms, that ensure a long-term certainty. Even if temporary migration has undesired effects on the family and children, it generates an income that helps people build houses and improve their standard of living at home. In some cases, all the family migrates; in other cases, the children are left behind with their grandparents or relatives, there are situations in which many men leave, and the women remain. Even if the fathers send money at home, the women must take care of the children and the household, and provide for the day-to-day expenses.

Now, with this financial crisis, nobody knows where to go, what to do, how to make money... There are a lot of them abroad, about 40-50% both men and women. In Spain, Italy, France, Greece.

*Since 2006, the Roma started to leave when they realised that the agriculture was not going too well. The ones who remained are the elders, from 40 years old on. The younger ones left, most of them together with their children. But they come home for 2-3 months, and they are employed in agriculture there too... olives, onions, strawberries, potatoes [1]*

*The majority of the women receive social welfare, and the man travel abroad. The women sell second-hand clothes. From Pitești, they go by car, more women, with vans and carry the merchandise that they sell in markets here in the county or they have a place especially set-up for them. About 100 Roma women sell their merchandise. This commerce is not formal most of it, but it varies from person to person. The majority of men are in Portugal. It is the same community so they call one another to go there. It is a long-term migration. Lately, they do not come back very often. Honestly, the majority of the women stay at home with the children. They rarely go abroad too. [3]*

*In general, people have gone abroad... they work there, they come back once in a while. They beg there. The ones who have gone to school are employed in some cases. There a few who are unemployed in Italy, but only a few. They usually travel to Italy, Spain, England, Ireland. First, one of them leaves and then their relatives and their friends follow. They see that it's going well somewhere and they all go there to earn money. They leave together, men and women. Generally speaking, it's the young families that go. The old people are left behind. They stay for a few months and then they return. [4]*

*They've been away, they've returned. From Racoș we had many people who left to Poland. We had many children without birth certificates because they were born there, then they came and the children were left without birth certificates. They stood there for one, two, three years depending if they found work or not. Some of them returned. Not all of them. And since they returned they started to build their own house, which they did not have before, somewhere by the river, because up the hill there wasn't any water in the community. [5]*

*I found 830 persons following the census and there were 1200 declared after the census, the explanation would be migration. There are many marriages abroad. They go to Italy, to Spain. Many of them have gone abroad to work, they don't have any income here, they have many children and the social welfare is not enough... At least the young ones, the majority they leave, and most of them are better off than the Romanians. They built houses There are some who come and go, they leave together with their children, wife, everything, they send the money here to build their houses. I don't know exactly what they do there, they work in constructions as I've heard, that is what I heard about men especially, and the women work in restaurants, old people, wherever as long as the money keeps flowing, they make a living, each of them minds his own business, they don't steal, they don't kill and they are building their life. [7]*

*Some of them though left abroad, and they have improved their standard of living... Until 2000 they were making bricks, this was their main occupation, but it is not needed any more. And most of them have gone to France, Italy, Spain. Many of them took their families along. The ones who left together with their families have enrolled their children in schools there. [8]*

*The Hungarian gypsies go to Hungaria. Their social welfare is cut off. They stay for 2-3 months during the summer and then they return. During the wintertime, they stay at home and they benefit of social welfare. Many of them build houses with the money they bring. They struggle to live. Some of them who take their wives with them and there are many problems with those who went abroad and left their children at home. They have as many as 8 or 10 children.[10]*

*I have women from the community who left 2-3 children here and went to Spain. They have a criminal record and they run away because of this. But if they come home before 7 years, they are still followed. No company would them employ legally. They have some assets, wood, once a week they have legal access to go to the woods. But they go day and night and earn their living and many times they*

say: "what should I do, Go steal or kill?!? No, I'd rather go and cut woods and sell them and earn honest money I can't tell my children that I don't have any money or that I cannot give them food tomorrow" They have no other choice but to do this. The majority of the Roma who travelled abroad managed to save some money and they returned and built houses. The Roma from here went to Spain, Italy, Germany. They managed to survive or to build something around their houses but not more.. [17]

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## THE COMMUNITY TRADITIONS

The health mediators are affected by the traditions of the communities that they service from various points of view. They belong to groups that have strict rules regarding the role and the presence of the women in the community, but they also have corporal daily practices, to which they adapt even if personally they do not respect them any more, in order to facilitate communication with those for whom these rules are still important. Knowing the Romani language and the specific local patois is crucial in the communities of copper potters or Hungarian Gypsies. Because it might happen that health mediators belong to other Roma peoples, the former face negative labelling, which makes them, be unaccepted persons, and in those cases, they must find personalised solutions in order to be able to collaborate. On the other hand, when they want try to change the practices concerning education in schools of the girls or the family, they face the traditional way of thinking which naturalizes the domestic role of the woman and overrules the tendency of changing it, labelling the latter as foreign, unacceptable and dangerous.

*I used to speak Romani, my mother tongue, not their dialect. I understood a lot of what they were saying but I did not tell them that I knew the language. Towards the end of the day when the sun was setting, you can imagine, it was on the 19<sup>th</sup> of July, when we wanted to go to a family, suddenly, at the entrance in Humulești I realised that there lived the wealthiest, the richest. The daughter of the gypsy baron, Claudia, told her father in Romanes that she did not want to go to her godmother. He asked why and she answered in Romanes: "Look at her, she's wearing pants". From the context I understood what she said and I told to myself, Oh my God, I made a mistake on my first day. I was wearing Capri pants. And then I said I was sorry that I was sweaty and that maybe we should go the following day. The following day I wore a long dress, as my grandfather had taught me and I presented my apologies to Claudia... I was wearing my hair very very short back then. My grandmother suffered a lot when she noticed my short hair. She was very angry with me then. She said that the hair was the jewel of a woman and that she may understand that I was not covering my head with a bandana but to cut my hair that short was too much. She suffered a lot when she saw me in some photos with such a short hair. [2]*

*They are traditional Roma. There is a model indeed for marriage, unfortunately. This model still exists 15-16 year but it's not generalised, not the majority. They have grown older too, at least the past few years but half of the young people marry at 15-16 years old. Both boys and girls. [3]*

*They marry very early, at 11- 12 years old. After the marriage ceremony the girl moves in with the boy. You can imagine that she cannot go to school any more or do anything else. I have a group of 5 or 6 girls who keep asking me to speak to their parents because they want to go to school, to learn. It is not possible, out of the question, we don't even open the subject and they tell me: "she stays at home, she will not go to school not for one hour" " She must look after her man, the house, what will she do with education?" They say that this is the history of the Roma, their tradition for hundreds of years, and this is the way it must be and they will respect it [9]*

*Between the Hungarian gypsies, it happens often that the girls give birth at a very early age. But now, I know from a family, the family that I ran around for in order to issue papers, and they said that it doesn't really happen for them any more but not all of them. They wait until the children turn 16*



*which is not that early as it used to be when they were marrying at 12, 13 years old. They do change a little. Now they wait until they are 15, 16 years old, not like before. [16]*

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## THE WORK OF THE WOMEN IN THE COMMUNITY

The health mediators are women and they offer a different perspective upon the communities, a perspective that is invisible most of the time, but it is an important part of their life. They help us understand the role of women in the community and particularly the feminine condition, which gives a certain status and significance to the role that they assume. In this regard, we find the traditional feminine role, that of taking care of the others. The role of mother has a new shape in their case, a shape that offers new significance to this classical position in the family and in the community. First, it is important to observe that this is a consciously assumed position, a learned part and a political gesture. This way, we are proven that motherhood is not a natural continuation of femininity. Even if health mediators sometimes resort to their feminine instinct in order to understand the issues of the other women, they are not aware that the type of regime of the communities and socialisation are factors that turn women into women, and because of these factors, the women play the roles that they play in their interpersonal relationships (care towards the others, responsibility of creating and maintaining the spirit of a home, the duty to maintain the contacts of the family with the outer world). Secondly, we must admit that health mediation is in itself a practice of the capabilities of a woman. By this practice, credit is given to the competences that they have and their contribution to the personal/family life transforms in a public presence and in a form of civic activism that changes them and the ones around them.

*It helped a lot that I am a woman. It helped because I in my turn helped somebody else. Others helped me and I helped others and that is why [1]*

*This job brought colour into my life. After 11 years of marriage I considered myself to be “the hen around the house” I dedicated myself to my child’s health condition and I thank God that she was blessed with health. I looked after the children a lot, up to a point, when the children got hurt, during those classes, when I was away. All my formation as human, as mediator was in a little in the detriment of my children. It was a sacrifice, the fact that I was not always next to them. [2]*

*I say that it’s out of the question to have a man as health mediator, in my opinion. He would not be able to communicate with a woman; that is what I personally think. And in the end, the problems in the community are those of the women and not of men Even concerning health issue, it s the women who have them. The fact that the woman makes children, that she works more, is indeed the difference. [3]*

*Being a woman really helped me with this job. There are certain problems that women have and it is easier for them to share those with me, as a woman. There are things that she is ashamed to discuss with a man. And I don’t believe that they husband or family would allow them to speak to a man. The mediator must be a woman. [4]*

*A woman mediator is more welcomed. Because I work a lot with mother and child, maybe a man could do it, but I don’t know what to say... a woman is more..., she perceives things differently especially if she is a mother, right? You place yourself in the situation immediately in the woman’s shoes who is a mother of two, three, five children, because you perceive the situation differently not just as work. [5]*

## HEALTH ISSUES AND ACCESS TO HEALTHCARE

Following the same procedure of description as in the above emic discourse, using fragments of interviews conducted with health mediators, with the purpose of presenting the theme of the research, in this chapter we want to present the problems connected to health issues and the access to public medical services of the people in the communities that they service. From their experiences we can understand (2.1.) the impact of the environment and standard of living upon peoples' health, (2.2.) the causes and consequences of the lack of a social insurance, as well as (2.3) the practice of going to a doctor and of using traditional curing methods. The stories of the mediators show at the same time that among the most demanding challenges raised by their work are (2.3.) vaccination and (2.4.) family planning.

### IMPACT OF THE ENVIRONMENT AND OF THE STANDARD OF LIVING UPON HEALTH

The diseases faced by the communities serviced by health mediators are not diseases specific to the Roma. The below descriptions prove once again that they are not registered in the presumed biological or cultural registers, but are consequences of the reactions of the human body to the conditions of living a poor life in polluted environments. These diseases remind us that if the communities in question are placed close to landfills or treatment plants, the discrimination against Roma is fuelled by an environmental racism. The financial issues imply the not being able to eat healthy food and a minimum level of hygiene, which, even if accepted cannot be respected. The affiliation to less fortunate groups often generates negligent treatment from the part of doctors towards the people belonging to these groups, which may have dramatic consequences. Under these circumstances, the idea is that the Roma are 'used to it' and immune to precarious conditions, proves out to be only a myth sustained only by the lack of means and neglect towards them, being a sort of evasion from the responsibilities of the institutions and of the medical staff, but not only.

*TBC is on the first place here and the second is the hepatic cancer. About 5 persons have AIDS. Boys and girls, husband and wife otherwise said. It was not transmitted from mother to the child. There are two boys and we cannot believe that they are not HIV-AIDS positive. They had this infection starting with '96 or '97. Many died of this disease because we had a nurse in Plenița, at the hospital that we belong to found 7 kilometres away, and she was making injections with the same non sterile syringe. You can imagine. And many persons were infected then. That was when somebody whose boy had died, the father, found out that she was not using sterile syringes and he went there, he beat her up, they put him in prison. That is when 6-7, or even 10 people died.. The others are still alive. But the community is not marginalising those persons because of the fact that I read to them what I was supposed to. [1]*

*We have many diabetes suffering persons in our community as well as hypertensive. These are the major ones. The TBC and other diseases of the kind we did not have yet. We had an epidemic of Hepatitis A among children and it was rather difficult to get rid of the infection. But we collaborated very well with the "SANEPID"<sup>20</sup> we disinfested, we vaccinated, we wrote a few reports to Bucharest and some minutes of the meeting in order to receive this vaccine, because the vaccine is not free of charge. [3]*

*I did not come across serious diseases, only TBC at some but they were under medical surveillance... We discovered some other 2,3 cases, but no other diseases, like AIDS. I heard that*

<sup>20</sup> SANEPID- Sanitary institution dealing with different domains of public hygiene as well as the prevention of contagious diseases

*my colleague had some cases, but I don't know exactly, from what I understood it was only the parents, not the children too... I really don't know what to tell you.[5]*

*Every year we had some TBC cases, then cases for we which we were administering the treatment at the each patients' house, in order to make sure that they are taking the treatment. I also had a failure, for now I have 8 cases. The failure was the death of a mother while delivering her child, and she left behind her 7 other children and I felt very bad when I found out about this. I told myself that I should've done something, and I did not do it right, I kept saying to myself that it was my fault. The most frequently occurring cases are the ones of TBC. There was not one year not to have 5, 7 cases of TBC. The rest, are regular diseases, not specific to the Roma. The TBC cases are a consequence of the environment, because they work at landfill. [6]*

*I had many cases of TBC and hepatitis; the hepatitis of dirty hands. Most of them were children, not older than 16 years old... But I collaborated well with the Sanepid-u' and in two three weeks time the virus was removed. Then there's diabetes, tension, many women suffer from heart diseases.[8]*

*I start with the old ones who have the diseases brought about by their age, rheumatism, and epileptics in Meteor, teenagers too. Maybe it's genetic, maybe from the family; there is no scientific cause of the appearance of this disease. Many think that have a family curse. [9]*

*I only have one person in the community; she is HIV positive, aged 21, woman. From a blood transfusion since she was young. She followed the treatment since then. Now, I kept on visiting her. She got married. She is succeeding but now the problem is that we don't know what is going on, if she is still taking the treatment, this is the problem. Otherwise, she seems to be doing fine, she is being looked after by her father too, he works for the Roma party. Diabetes is very frequently occurring. I have persons who suffering from cancer, paralysed, blind, have heart affections, these are the frequently occurring diseases or blood diseases... I visit them because they need moral support. They need that a lot, and I visit them, I talk to them, the doctor takes care of them. At least the ones suffering from diabetes receive their medication on time in case they forget to take the medication themselves. Now we have a schedule. When it's time to go purchase the treatment, I visit them and remind them that they have to go to the doctor's on a specific day to get their treatment. That's about it. I have a person suffering from schizophrenia. It reached the stage of dementia. I visit them less because I cannot get in. I talk to her mother and father but only a little because I don't want to bother. There were hepatitis cases, due to the lack of hygiene and it is a battle regarding this because they don't really accept it. When I go, I can go for any reason but not with health hygiene... I was called at school by the teachers because the children have lice. I went, I discussed about hygiene with the children; they were quickly sent home from school. I went to their houses... it's very difficult because they do not accept, so there is still a lot of work to be done regarding this, because they do not accept me if I go and explain to them. [10]*

*Almost all of them have social welfare the old ones, some retired, there are also some TBC problems in the community...Many got it from the site, where they worked, in the mines, at the Roşia Montana, and from mining. But the ones I am talking about did not work in a mine. Hunger, poverty, misery, very bad conditions, they are not well fed. [13]*

*There were many persons with tuberculosis. But I really did not get sick. You go among them; you never know how you get infected. I received the medicine, I was bringing it from the hospital then I went to their homes to deliver the medicine and they took the pills in front of me. [14]*

*There are many cases of respiratory infections, there is something in the air, I don't know. There is something in this area... over 90 handicapped persons. Only 26 have files at the city hall*

*with assistant, but the others are handicapped without the need to be assisted, same disease, and same diagnostic. Physically and mentally disabled, all handicapped persons have almost the same diagnostic. This is what the doctor said, that there is something. They took various samples of water, now we have running water as we benefited from a project in this regard. We still don't have sewage but at least we have running water and it's treated and tested. The Roma have been affected by non drinkable water and it was because of the water from the wells. In Cătunul lui Dumitriței we had 37 cases of hepatitis. The water was polluted. There used to be a factory for detergents a few years ago in Rar, but not in Budac or in Cătunul Budacului, Dero. I don't know if that was the cause... [17]*

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## CAUSES AND CONSEQUENCES OF THE LACK OF A HEALTH SOCIAL INSURANCE

The Romanian social health insurance system underwent various changes. Because the Roma in the communities serviced by health mediators do not have a work place to ensure their rights of employee, they are insured by receiving social welfare. The social welfare may be cut off as a result of changes in the granting criteria (or as a result of the people choosing welfare meals and then being ineligible for social welfare), but also due to the temporary migration abroad; their status as insured is not permanent, and even the children who are born there are not registered and this is one of the reasons why they lack insurance. One of the priorities of the health mediators, successfully conducted, is to assist the less fortunate in obtaining social welfare and implicitly a health insurance, as well as their enrolment with a family doctor. Recently, the family doctors have the possibility to register on their lists persons without insurance, but this practice is more one that targets their being taken into consideration, and one that offers them free medical examination (if the doctors are willing to perform voluntary work). The gratuity of primary public health services is not at all ensured not even for the insured, be they Roma or Romanians. The overall poverty of the Romanian public system of health makes the family doctors become overloaded, to impose examination taxes for the ones requesting examination, others than the scheduled patients but also not to be able to add value to the free of charge medical prescriptions, not to mention the poorness of the special medical services in hospitals. The ones who have money, insurance and a family doctor often recur to emergency services but those are limited and of low quality.

*There are some cases without medical insurance. But only a few cases because they went abroad about one ago and their social welfare has been cut off. There are a few persons, who own houses, villas, cars, tractors and so on who don't benefit. I explain to those persons that they must subscribe a health insurance and for a while now, the majority are ensured. [1]*

*The main problem here is the lack of the quality of insured, it is known. I believe that this is a general problem. It is understandable since the majority of the women work where I told you they do, they sell old cloths and don't have the benefits of a work contract. The money that they make out of these jobs is not enough to pay for insurance. About 50% of the people in my community do not have insurance. But because of this office they come here. Many get emergency hospitalization for three days. [3]*

*For the uninsured, we are trying to mediate with the family doctor the relationship and convince them to grant them a free medical examination. They receive them in the emergency rooms... They go there when they feel much worse and the family doctor is overwhelmed by the situation; there were cases when I accompanied them, but they also go by themselves. Even if you go there with him and you say he does not have insurance, but he sees that you are a mediator and you take care of them and you are working on their getting insurance. [4]*

*The majority of the persons are not insured; now, they don't even pay the minimum wage. They don't work, they don't have any jobs, only few of them 10%, and 10% is a lot Nevertheless, most of them are enrolled at a family doctor. As soon as they're born I take their file and take it to the family doctor.... We have a good office in the community, well supplied and during that day, on their free time they come here. He gives discount prescriptions even if they do not have insurance but the pharmacies do not have the medicine... Sometimes the city hall gives us money, we make a request, say what we need, a certain sum of money, we go to the pharmacy, we buy and bring the receipt to them. [6]*

*The ones who benefit from social welfare, yes, they have insurance, but many of them have welfare meals and not medical insurance. They prefer welfare meals to the social welfare because they know that this secures their daily meal. Because the social welfare is per family about two millions, if there are many members. But on the other hand, welfare meals, offers them food on a daily basis...The majority are enrolled with a family doctor even if they don't have social insurance. [8]*

*Many of them are unemployed and do not have the means to pay for their insurance. The moment I visit them I explain to them that they have the option to pay for their insurance. What would they pay it with? The moment they go to the family doctor here in the commune, she is very nice and she sees them and she examines them but she cannot give them discounted prescriptions. The problem now is that even the ones who are insured pay. We have a very serious situation in Rupea hospital. There is no medicine in the hospital. Pregnant women faced a problem too because the maternity recently closed down, but until it closed down they had to pay for their medical exams. They did not benefit from gratuities, even if they were insured. There are no funds. Everybody's telling us that there are no funds. [10]*

*Every family has an average of 2-3 children maximum 4, there are only 10 families who have more than 6-7 members. And one has 11 children and another one has 10 and in Budac one with 12. In Budacu de Jos there were problems with the papers, certificates, children born abroad, unregistered, without birth certificates, more problems. But not here, because in 2003 by splitting the village population they had to change their IDs on the Dumitrița commune since the Cetate commune did not exist any more. That was when most of them issued their IDs. The problem here is that they do not become insured. If they are not beneficiaries of 416 they do not comply because it the decision of the Local Council, those who own a car, a horse and usually they do because the work with wood, do not benefit of social welfare. And if they don't have a stable place of work, they are incapable of paying to National House of Health Insurance, and cannot be insured. They can not benefit from medical insurance, it is very hard. If they get sick they cannot go to a doctor to be examined, only if it's an emergency they may stay 3 days in hospital. The children are insured, 0-18 years they are insured. If they continue with their studies they are students until 26; the children do not have a problem. The ones who do not receive social welfare are about 6-700. This is the main problem. There is only one doctor per commune who goes to Budacul de Sus, because there are more Roma there. He goes there every day and once a week he comes here in Dumitrița, therefore this is the health unit. Improvised; it does not have the necessary utilities to function. There is no money at the city hall for rehabilitation, and reorganisation of the space and that is why it cannot be accredited to work as health unit. [17]*

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## **PRACTICE OF SEEING A DOCTOR AND INFORMAL TREATMENT**

The culture of health in Romania is marked by the habit to go to a doctor only when facing extreme and emergency situations, the medical services being perceived as interventions in case of disease and not acts of prevention of diseases and of permanent healthcare. These practices are predominant among the less fortunate categories who do not afford to financially invest in health on the long term. In this type of situations, they use traditional healing methods that are still found in the communities serviced by health mediators who state that they do not believe in them and that

they cannot do anything in this regard, and admit that they may have a symbolic psychological role in maintaining the illusion of having successfully intervened in the treatment of some diseases. They say that as a result of permanently informing the community, they managed in some cases to encourage the people to go to the family doctor at least as soon as they notice the first symptoms of the disease, a more visible result concerning the effort of the women to take their children to the doctor. The mediators admit this thing is happening especially because if the former is nice to Roma women and he can communicate with them and build a relationship based on trust.

*People don't go to the doctor when they notice the first symptoms. Any human is like this. The first week they will take a pill, the second, the third. If it doesn't go away they go to the family doctor. They try to heal themselves by using traditional methods. But if you have a pain in the chest, if you have gastric ulcer and the old women advise you to drink some water with sugar or "ranza căzută". This is the family doctor he does not know what it means, for it means, "let me massage you" And she comes with a sieve, with pollenta and a scarf as the gipsy wear on their head. And she comes and she massages him with oil on the belly and she says that she lifts them up with that sieve. I don't know too many either... [1]*

*Here, they go to the doctor in the early stage of their disease. This has started to happen recently. But I believe that it's because they are collaborating, they get along well with the family doctor who takes care of them. That is why many of them come more often than before, the mothers with their children come more than they should lately... and by this I mean that are trying to prevent and do not wait for the disease to evolve. I evaluated or monitor their treatment but this for certain persons who don't know how to read or who are lazier. In general I do this, I remind them to come for a medical check after the treatment. [3]*

*Fist of all I know that they don't really go these periodical controls. I told you that some of them are abroad and when they come here they don't stay too long and they don't find the time to go to the doctor. There are persons suffering from heart diseases, especially the older ones, over 50 years old, and we also have persons suffering from diabetes, or cancer. They go to the doctor much later, when the disease becomes chronic. They say it happens due to lack of time. They frequently use the informal treatment, but I cannot tell you more about these, since I don't really consider those helpful. Even a fracture, jumping over a pregnant woman, over a broken leg, I don't know how to explain it to you. Or the old lady who took a button instead of a pill and she said she was feeling very well. There is the subconscious playing a role here too; I did this thing that also worked for my neighbour and I already feel better. [4]*

*Until the health mediator arrived they were not informed, they could not even communicate with the doctor. It happens to wait in line to be examined by the doctor, the Roma wait but they are not always invited in therefore they don't go any more. There is discrimination not only at the doctor's but also at the City Hall, where if they go to take some paper they are told to come later or that they don't have time to come back another day. [5]*

*They never hide their diseases. Because they hope something will happen. They go to the family doctor, from where they receive a dispatch to go somewhere else. "Look, I have a dispatch; I don't have any money, give me!" And they also receive emergency medical assistance, and probably that is why they don't hide from the doctor... There are very rare cases, depending on the family. A more respected family might hide something but the others... not to my knowledge. Anyhow, when the child is not well, the people go to the hospital. Immediately, if it's a more special case. They don't come to us on schedule in order to get a dispatch from the family doctor. It rarely happens. After the child got sick they call the ambulance and they go straight to the hospital. [6]*



*When they feel that they're in too much pain, they don't go from the beginning. They don't have very serious diseases either. Some suffer from epilepsy, heart affections, liver affections or back pains. If they have a pain in the kidneys they use a cream, they don't really go directly to the hospital. The hospital is quite far away so they prefer to get a prescription from the family doctor in order to make the pain go away. They move on but when it becomes serious, they go to the hospital.[7]*

*The children go with their parents when they have a cold, and the doctor is an exceptional women, she does not require them to make an appointment. She say that the families of Roma come with their children and she knows that they are not yet used to this appointment program. The moment they see that their child is sick they take him and bring him to the doctor.[8]*

*I was on the train with the family doctor; I was accompanying him to every insured person enrolled with him. During the vaccination campaigns the same. This way the infections and contagious diseases disappeared too. Until I came, they were using informal treatment methods. If they had a pain in their leg, they would bandage it, make brandy cataplasms or what do I know, massages. But the problem was with the children, small and fragile, you could not tell them to do anything. Then they continued but they have started to take the medicine that the doctor would prescribe... The epileptics visit the doctor at least twice a month in order to be examined and to get their medicine. [9]*

*You know what the problem is? Many of them don't have any money. They get emergency hospitalisation. Here you have to pay for everything, medicine, everything. And they don't have any money. The insured don't get anything either. Maybe an algocalmin or a quick injection in the emergency room or....They told me that they go to the doctor; get the prescription but that they don't have any money to buy the medicine. Everything is for sale here, I don't know why [13]*

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## VACCINATION

Concerning the improvement of the access to healthcare, one of the priorities of the mediators is to ensure the vaccination of the children, but several factors make this process a difficult one. Some of the factors have to do with the degree of acknowledgement of the importance of vaccines in Roma communities but also with the fear of negative consequences of vaccination, or the poverty of the Romanian public health system. While the mediators managed to control the first factors (by informing and convincing the mothers of their vital necessity), the second set of problems surpasses their ability. When the interviews were conducted, the family doctors and their patients (Roma or Romanians) faced the lack of compulsory vaccines for the children, a phenomenon observed at national level. The wealthier afforded to buy these vaccines from the pharmacy, but many ordinary Roma could not. The doctors were dazzled to see the type of explanations that they received regarding the consequences of the fact that the vaccines were not administrated in due time, and that they could be recovered at later date. The happy cases when they could obtain public or private funds, the mediators participated to the vaccination campaigns in order to eliminate focal spots of infection determined by a life lived in poverty.

*I accompany them to the doctor for vaccination. But now there is a crisis with this vaccine too, BCG...The newly born, six months old, the BCG vaccine was not administered to them when it should be administered during the first days since it protects against hepatitis B, A, more contagious diseases. But they did not have any in the hospital. [1]*

*I tell them that they have to come with their children for vaccination, and they ask why, they don't know what the vaccine means to their children. I tell them that it gives more strength to the child; it helps with calcium, to keep away contagious diseases like TBC or parotids. I explain to them the role of the vaccine and afterwards, they understand and they take their children for vaccination. Before, only few of them went for vaccination. They did not know what it was; they thought that their children would have fever after the injection and that the family doctor was not responsible for their child, they wanted to grow their children however they thought best, but now they go. And recently, when we had the vaccine crisis, they were taunting me about where the vaccine would arrive, where they could buy it from. When I ran across them on the street, they ask me, they see news on TV about this vaccine but they don't understand. [2]*

*There are cases when the young children are left with their grandmothers at home and when I go to take them for vaccination they tell me that their parents were not vaccinated either and that their parents are healthy and they work...The ones who have nothing against vaccines are aware of the nowadays diseases and consider that it's better to keep their children safe so they usually do them. Even if they're away they take them when they return. I explain that if a little fever appears it is only a secondary effect of the vaccine, and that it goes away with a suppository with paracetamol or a cold compress. It is not a situation that one should be afraid of.[4]*

*In the beginning, they were not going at all, only if the child was sick and he was not that sick they would administer the vaccine. I also had bar there in the courtyard and the vaccine was administered in the bar. They would not go downtown; they did not have clothes to dress their children, no money for the bus. I gave money to them for bus tickets but they would not reach the family doctor. Nobody would come. They were not aware of the importance of their children's' health; there were persons who understood but then I understood. What was going on was unfair but for the health of the community we make some compromises such as calling them to come to the doctor at the bar. We confronted an epidemic of hepatitis A and I vaccinated with two family doctors, wherever it was possible, on the road, tables were laid down and they took the vaccine there, in the open air. This happened because they were not coming. I informed them in due time but only about showed up so than we conducted this campaign. [6]*

*We did not have vaccines for the children for a long period of time. For nine months we had no vaccines. [8]*

*We don't mobilise for vaccination for four months now. There are no vaccines. The ones who want to administer the vaccine to their children must buy one and nobody buys because they don't have the possibility to buy it. I cannot go and tell them to buy it when I know that they don't have any money. I know them all and I know their situation. [10]*

*I worked as health mediator in Sânmartin as well for a period of time... The children were not vaccinated, nor did they want to. People are different than the ones over here. They said that their children were healthy and that they don't want to have them vaccinated because if they do it, sometimes the child becomes feverish as a secondary effect of the vaccine. They lived in great poverty. Their houses were built out of nylon; one winter when I went it I found a baby blue from cold... There are 170 Roma there, less but different than the ones over here, more aggressive. Some of the ones over there knew me and so there weren't any problems. Here in Cozmeni there weren't any problems, In the beginning there were but after a while no, because I explained to everybody that the vaccine was necessary. But over there, it took me a lot of time, many times I went around six o'clock, sat on the grass and discussed until seven eight. They told me that they did not want to, that I go there because they have fleas or I don't know what. What shall I do know I said? If I took on this job I must complete it. It's very hard. [14]*



*I would take them to get a vaccine. I went with them and their parents because the vaccine was a problem, a major one from the beginning. They did not want to go because they were scared that their children would die, that it was not good. They were so scared... and then we would go, and I explained to them that I too had two boys and vaccinated both of them, that it was against diseases, and also good for kindergarten or school, that it was required and I would manage to persuade them and they would come with me “ I will get him dressed and we go” I sat there until she would dress the child and go with them, telling them that I will be there with them, I said “ If he’s sick or he’s got a cold, I will stay there until the doctor sees him, and if he has anything the doctor will not administer the vaccine but if he’s healthy yes. And that is how I persuaded them, by letting them see for themselves. Afterwards, the mothers would give me their children to take them for a vaccine in case they could not go, I was asking the mothers to come along, but they said that I should take their children to the doctor just like I took mine. [16]*

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## FAMILY PLANNING

The most delicate aspect of the intervention of the health mediators in the Roma communities that they services is the family planning, which requires not only efforts to inform but also sensitivity towards the private and intimate character of the decisions regarding the number of children and the time of birth. There are some aspects though, on which they fund their involvement and they feel legitimate about their work: the personal decision of the women regarding the number of children, when to have them or is not entirely autonomous but it has to do with the inherent constraints of the traditional norms or of the religious beliefs; in many cases, in order to be accepted by the community or fearing not to commit a sin, the women do not use contraceptive methods and give birth more children than they wish to have; the financial problems also determine them not to resort to modern contraception methods; the excessive occurrence of abortions as a most accessible mean for the women; personal experiences of their private lives, following which the health mediators acknowledged that they have the right to decide about their own body and use modern contraceptive methods, even if sometimes they might have undesired effects, gives them the possibility to express themselves as women beyond the role of mother. In great measure, family planning is a matter discussed between women, but it happens for man to resort to these services too. The frustration related to this activity is that after they managed to capacitate the women in this regard, the Romanian medical system is stuck form their point of view too. The birth control methods offered free of charge by the family doctors are not accessible any more (public funds and private funds that supported this action have exhausted) and in general, the administrative activities connected to this service surpass the limit of tolerance in their overcrowded schedule. After the women have managed to convince themselves that family planning is not a sin committed against the tradition of the community or against religious beliefs, and that they are not egoist persons who by this practice pursuit their individual interests; after the women have managed to overcome the fear of resorting to doctors in order to have access to birth control methods, and their shame of exposing their intimacy to strangers, they are now faced with an obstruction of the health system to which they have just become used to. Therefore, the material conditions of the system and of their lives negatively affect the effective practice of their reproductive rights and their right to health. For reproductive health is not limited to guaranteeing the access to modern birth control methods adequate to their state but includes the possibility to regularly go to medical examinations and to prevent cancer of the reproductive system.

*When they must travel abroad, men come but do not speak openly. They tell me: “I would like to ask you for something” and I ask them for how long they will be away, they answer that a month or two,*

three. Then, we recalculate at the family doctor and they take them along, because they are ashamed. They tell me “can you get some for us please, we cannot go there because the family doctor will ask us in order to write the files and we are ashamed and we cannot talk, we cannot even talk about these things with you but we have nobody else to talk to” They are ashamed so I get some for them, I write their file there at the family doctor. If instead of me, there was a man in my position, he would not have the patience to speak with a woman and tell her that her period is on that date and that she must take the pill on that date. No, a man could not face the women and speak to them about such things, not in a Roma community. [1]

I distribute leaflets to the people from the Health Direction here in Craiova. I read them out to those who do not know how to read. Especially the man, you can imagine that going abroad without their wives, you can imagine that they think that while they are away they do not mind their own business. I read to them the leaflets regarding sexual life, the sexually transmissible diseases, to both men and women. They gather up more of them and I stay in the middle and I read out to them and that is when they get scared and I explain to them how to protect themselves, to be careful what they do. Of course, I distributed free condoms for 5-6 years in a row, birth control methods for the women in order not to go to the gynaecologist so often and they were happy with that. Now since the crisis, they come to me and ask me to give to them but I don't have any. They are asking me for advice. I am not reluctant to these discussions.[2]

For instance, before, as an example on family planning, it was impossible, there weren't any women going to the family planning office of the hospital. But now, many of them do. I believe they were not going because they did not know. Honestly, I have some friends both Roma and Romanian who are not aware that this office exists. The ones to which their husband forbid them to go, don't go at all. The husband should go himself several times with her, but it's important that we managed to at least take the women there. They have this idea, they are ashamed to go. Some of them have 7-8 children in my community, few families have only one child, very few, in general they have about 3-4 children per family.[3]

The fact that I have around 30 women who attend family planning once a month is satisfactory for me. The fact that I have conducted campaigns, I collaborated with the cytology division of the hospital and I managed to get some funds, resources, and less legal ways in order to have the women tested with the “Babes Papanicolau” test that they did not do before. Now over 100 women of the Roma community do this test is also a major satisfaction for me. Because of the fact that this test is not free of charge many Roma women don't take it; many don't even take it when it's for free. But the fact that I have succeeded with a part of them and even found some cases that required medical assistance... I had a case a few days ago, it is a dysphasia close to cancer, but now that we discovered it something still can be done for a young women of 23 years old...it is a great satisfaction for me.[3]

I had some girls that I accompanied to family planning in order to take birth control methods as they were young and had three – four children...Of course it required a lot of persuasion in order to get them to do this; they even thanked me! Yes...because if they have an idea it's hard to change their mind. First of all, they said that the birth control methods will make them gain weight, and provoke other diseases and it was hard to convince them that it's not harmful at all, but on the contrary, it helps with their metabolism. Moreover, with women in general, they are ashamed to talk in front of men but I tried to speak openly to the young ones. I am quite straightforward. [8]

I also conducted campaigns in order to promote reproductive health for women mostly, we gathered there into groups on Saturdays or Sundays, at church and I explained to them the disadvantages of pregnancy at the age of 12-13 years old. They barely start having menstruation and they make a child. There are risks and diseases that might appear. But it's hard to change their mentality. Sometimes I think that we don't service them well enough and I feel sorry about that. On the other hand I cannot intervene and conduct a campaign on how to use birth control methods due to their Pentecostal religion. They are not allowed to make any abortions or loose pregnancies and so on...

*They don't really use contraceptive methods. They responded in a negative way... Together with representatives of the child protection we organised a very big press conference when the law about getting married at 16 appeared... They seem to be a bit more frightened by the law in a way. [9]*

*I am very interested in a family planning course because unfortunately I did not manage to do it and I would really wish to do it. I come across various problems in the community. I tell the Roma women exactly what I learned from my older colleagues. I come across issues like health hygiene and reproductive health. When I speak about family planning I gather some women at my home and we discuss and I tell them in a subtle what they should do. I often go to the doctor in Rupea, he is a family planning doctor and he advises me on what to tell them and how to tell it. Some consider that the intrauterine devise is not for them and that they cannot use such a thin, they think it produces cancer... So I try to explain to them that it is not true. Many of them weren't really open for discussions; they are ashamed to speak openly about such things. Many times when we were only women we started to discuss more openly and they were starting to feel ashamed and they told me: "come on you, what we are talking about here?" I explained to them that it is something that we must discuss, that it is normal to discuss these things and that we can learn from one another and in time they started to accept this. [10]*

*Family planning is a more delicate thing. There are persons who, especially Roma women, are very jealous and that it when I avoid discussing with their husbands, especially on such subjects. I discuss about social problems or about the problems that can be discussed, with their husbands too but family planning is a delicate matter and I do not want to upset the Roma women, in order for them not to say that I am hitting on their husbands. In the beginning, of course, when I started to work with them, I gathered all the women at my house and explained to them what family planning was as they had no idea what it meant, and that was when I discussed with them. I don't refer to it as family planning, when I call them I say to them: "let's meet and talk about us, women"; Intrauterine devise, pills and things these kinds of things. This approach makes them understand me better rather than talking about family planning as such and their next question to be " what does it mean" Usually they don't want so many children but they make them, this is how it goes. Of course, it isn't always a success. There many persons that I talk to and they seem to understand but they still don't take any action. I have a lot persuasion work to do with them. Some of them don't feel like using a intrauterine devise, some of them wonder why they should this. In the community there are women who have children but no husband. I have to explain to them when they say "I am not married, I have no reason to do this" and that is when I point out to them that maybe they meet a boy and they enjoy it and that is why but their usual answer is "Until I meet him never mind this..." The Triregol and Rigevidon pills are the most used since until now they were free of charge but now they're not for free any more. I have discussed with the social worker and the doctor and they promised to help me, if the women come, and so I promised to accompany them. The City Hall also helps us, they pay for the intrauterine devises so that they don't give birth to other children since they already have a lot. [10]*

*It was hard at first with family planning with birth control methods, they did not agree, they were saying it was about their traditions. No birth control methods no nothing.. But after a while they started to accept this. We may say that the community is protected, about 80-90% of them, either with intrauterine devise or injections. They realised that this is beneficial. We asked them many times why they had so many children, three four...we were asking them if they wanted more children and we would tell them that we can help them. It was harder until we got things started, the first 3-4-5 women. We should not be aggressive to them. We just explain and then they realise by themselves what should be done. If you are aggressive it doesn't help at all. You must speak to them so that they understand. This is their private life; I tell them what it is about, what are the advantages and the disadvantages. "If you want our help we can help you". It's their decision to take. Men also know. At first they were against this but afterwards they realised that this is a good thing. [11]*

*In Albac it went very well with the family planning. We discussed a lot about birth control methods and it went very well. Many of them had surgery and some use the injection that lasts 3 months. It is very good. They don't start making children and then not have what to feed them. They are organised, they understood, this is the toughest part. Less women understood birth control pills. I explained to them and some of them starting taking birth control pills. They are for free I told them I also spoke to the youngest about all kinds of things, but they are not always open to discuss. [13]*

*Up to this point we managed to do something, there is an improvement regarding birth control and most of the women accept the injection. They are not so keen on pills, the injection is preferred. The pills are for free but they are illiterate and they consider the injection to be more handy, you do it once and then three months time you don't have any worries whereas the pill there is the risk of not taking it every night. There are persons whose husbands forbid this. So they take the injection without the approval of their husband. This is their tradition, the child represents a blessing. I organised various training sessions. I went to the "Landfill" to them, and we discussed there, I tried to persuade them. I talked separately to the men. In the end, everybody was free to attend, both men and women in order for them to understand that their way was not the best choice either since there were many women who had 12 -13 abortions in one year so... There were persons with whom I reached an agreement in the end. There are some who still lead this kind of life now, but the majority, 805 of them go and take their shot. [14]*

*They don't even know what birth control pills are. If one does not have a personal identification number, one cannot benefit and the poor one is the one who makes a lot of children. If one wants to go get sterilised, which is for free, one needs a medical certificate from the CAS and so on. There are many papers required and of course the needy ones give birth to 8-9 children one after the other. There are many who do not have insurance, not even birth certificates, there are new-borns without birth certificates. There are no more free birth control pills. Moreover, the only medical care unit, the only doctor who would receive them was Mrs. Sándor. But I take them to family planning up there. They must take a pregnancy test at first, to buy it and to have themselves checked, they can do this there. They run some tests and they give you the pills afterwards, and then it happens on a monthly basis. It used to be for free but now they ran out of funds and we don't have any news regarding this. 15*

*We had women who had some gynaecological affection, and they did not see a gynaecologist since they gave birth. They have around 6-7 children, they are not aware about what is going on with them. I accompanied them to the doctor, the ones I knew, and the doctor did not ask them for any money. She was a very nice doctor who helped me out however she could. There were others who did not want any other children and I would help those too. They would take birth control pills, as they were for free then. Family planning is tough; I heard that some mediators are men, now you tell me, what can a man do in these circumstances? If I come to you as a woman, and I know that you are a mediator and I tell you that I have a pregnancy problem, or some other type of problem, how can I tell all this to a man? It will not happen because Roma women feel very ashamed to speak to men, they don't even speak to their own man about all her problems because they are very ashamed. That is why, for them, it is easier to speak to a woman. I visited them in the community to check which of them were pregnant, the ones who wanted to, they would come with me, I had to enrol them because many of them did not even have a family doctor. They were also a bit afraid because they did not have any insurance either. They did not know that by being pregnant they were insured. I had cases of parents who had children of 10-15 years, or even younger, about 3-4 years old and they would say that they needed insurance for the children. They did not know. After I found out about all this, I went to them and I explained to them that the children were insured until the age of 18. You cannot make an insurance for the children? ... I take the women to the hospital in Bega, they knew me better in that hospital and I would take them for examination or an ecography, to see how the pregnancy was going. After the babies were born I would visit them to check on the babies, to administer the vaccine to them. 16*

*In Budacul de Jos, when I got to the community, the only birth control method was the abortion, which was not even a birth control method but a last resort for them. They were not aware of birth control methods. I had girls in the community who were about 30-35 years old had already performed about 20 abortions. I was terrified. I had 175 women of reproductive age on the list of the family planning doctor until the family doctor made that appeal following which one could benefit from free birth control pills. I started distributing condoms in 2003. Until then it was a planning office in Bistrița, yes. I would enrol them there, most of them took the injections, combined pills, the Marvelon, injection pills and condoms were all for free for all women belonging to the rural areas. For the urban area residents a percent of those had to be paid, I cannot tell you exactly how much because I did not work there. There was also the National Program no. 3, concerning the distribution of intrauterine devices, intrauterine devices, and a specialist doctor would make the implants for those who wanted to benefit from this type of implants. They were using mostly injections, because some of them did not want others to learn about this, their neighbour, their husband, their mother-in-law, or in case they forgot to take their pill, these were the reasons why it was easier for them to take the injection every three months and not worry about this. Some of them had problems with the injections, they were not menstruating, they were suffering from headaches or they were not feeling well. I cannot tell for sure if we can blame the injections for all their problems but some of them really didn't feel well because of this. The intrauterine device was used only if they had a child or two so that they would not become sterile. I informed them about the variety of birth control methods, that they were for free, where they were supposed to go and what to do. They were delighted to have the possibility to prevent unwanted pregnancies. For some of them I would bring to their homes the necessary, I would take them to the doctor to counselling, they would say what they wanted and in three months' time I would take to their homes what they needed because they did not have the possibility to go to town. They did not have any money for the bus, but they were happy that these things existed for free and that they could use these methods in order to prevent pregnancy. Such a program was conducted by the Child Protection representatives too but they did not want to benefit from it. They said that they already had their own lady who took care of them, with whom they collaborated, and they did not want to benefit from the program. But here in Budac there are families who are sects, and don't want to use any. They don't even make abortions. And then, the children have health issues, and the mothers too because a pregnancy every year is not good for them; neither for the mother nor for the baby. There should be at least two years distance in-between. I explain to them, I tell them but they want to have as many children as the Lord offers to them, and they do not want to benefit from anything. There are a few families, not that many, but there are some. [17]*

## **A MICRO-HISTORY OF HEALTH MEDIATION AS EXPERIENCED**

In this chapter we try to understand the institution of health mediation from the point of view of the experience of the persons who perform this type of job, or better said, who practice a certain type of involvement in solving the problems of the Roma communities to which they belong and their participation to the medical system that should effectively provide them with the right to health. The mediation role is marked by moments of tension but also satisfaction, arising from the fact that they belong to both worlds, have different loyalties, sometimes conflicting towards themselves. This role is also structured by their position in the community, built at the crossroad between their social status and their type, which offers to them the ability to empathise with the less fortunate categories, and at the same time the capacity to criticise the way in which the latter live their lives given the circumstances. Fragments of interviews have been processed here concerning the following subjects: (3.1.) beginnings of their career, (3.2.) the work of the health mediator, (3.3.) the relationship with public and political institutions, (3.4.) the relationship with the Roma community and (3.5.) the relationship with the medical staff.

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## THE BEGINNING OF THEIR CAREER

Their beginning as a health mediator in most of the cases was marked by the interpersonal formal or informal relationships that the women had in the community and outside. They have been identified as adequate persons for this job or by organizations or by Public Health Departments. Even more important is the fact that their involvement in the community by performing this job, in order to improve the condition of the Roma has been followed by their active presence (personal or through their fathers or husbands) in the community. In its turn, this presence was motivated by the willingness to help and generate change, this being the reason for which they carried on. In this regard, their job as health mediator has institutionalised what they were doing in somewhat an informal way. They were volunteers for a while, and after finishing, the compulsory courses and successfully passed the exams, during the period that they had to wait for the position of health mediator to become official. Afterwards they faced another challenge: they had to teach the authorities what a health mediator was, by proving by their contributions that they are needed. The stories related to that very moment reveal how important their role as women is for the community. We observe that they have been informed of the possibility of becoming health mediators and eventually accepted as such through their male relatives, be they fathers or husbands. Without their consent, they would not have had the necessary strength or recognition for accessing this role. The way in which they afterwards enriched this role with significant content, even if it was influenced by the conceptions of the role of the women in the community, it was marked by their personality and competences. Moreover, fragments of the interviews below prove that once they started practicing this job without precedent and without model in Romania, they have changed themselves, and by doing this, they started to change the traditional ideas concerning the role and abilities of women. Personal change is not limited to the achievement of merely formal knowledge from the field of communication, legislation, human rights or reproductive health, but it is first of all a matter of using their capacity as women, in increasing self esteem, their power to do something for the others. This is due to the spirit in which they were trained by Romani CRISS to become health mediators, in other words, by the organisation that keeps being quoted in all their stories concerning the beginning of their career. The trainings that they have participated to, were first of all occasions to know one another, and to better know themselves, to develop new friendships and collaborations, to feel the force that may emerge from women solidarity, which is the actual reason why today some health mediators are capable of self-organising and of defending their own rights.

*Our leaders went to a meeting of the Roma Party in Craiova and they receive a note from Bucharest that they had to hire a health mediator in the communes with more than 500 Roma persons. Eventually the boys came to my brother; the leader was the godfather of my nephew. They asked my brother: "who shall we name health mediator in our commune?" "Who has finished high school" and then he said "For you see, us gypsies don't really trust in and are jealous of Roma wives. Two years before I was taking care of a handicapped. I had unemployment benefits, I became unemployed having finished 10 classes, and afterwards, I issued a work permit with that person. My sister in law came to my door and she called me laughing "do you want to be employed?" and I replied back "To whom, as what?" and she said: "to our medical care unit, to inform people". She knew not what details to give to me so I laughed. "You're making fun of me, what is this, I do not believe it". I entered the house and I told to myself that I'd better get this job, that I would like to be employed but I don't know what this is, if my husband would allow it, and I agree to this. In the end, I called my husband and I asked him. My brother came too and he said "Don't laugh because the leader of the Party will come to you and ask you about this" My brother noticed that my husband became uneasy about this, he did not really agree. In tow hours time my oldest brother came, and his uncles, he does not have any parents, neither do I or my husband, we are all orphans my husband and I. We had a family meeting and that is when we agreed for me to become employee of the gypsies, Roma, what they call them... I could not believe that out of the whole commune of Roma, out of 850 persons, the first employed women in Caraula was going to be me... Afterwards I attended a training organised by Romani CRISS. I enjoyed that training very much, it was very useful, it opened up our minds. [1]*

*I work as a health mediator from 2004. From July until September I was not trained but before this, in 2002, for 20 days I kept the place of another lady mediator, the first lady mediator in Neamt County in Piatra-Neamt County... In 1998 I gave up a possible employment opportunity in a paint factory because of my child's health problems. This time I received a notification from the Prefect's Office and from the Department of Public Health to come and substitute my colleague. When she heard that I accepted the position, she requested to become active again... In 2004 a doctor called me from the City Hall; I didn't have any phone back then. This is how I found out that "the doctors of the world" had arrived conducting an anti tuberculosis programme. I did not think that it was going to be a very successful programme with such a great continuity. I came and I told my husband that we must go and attend the training with the Romani CRISS trainers in Sfântu Gheorghe, that is if I want to work as a health mediator I must be trained, and the training lasts for one week at least. He said "What, you will be away from home for one week? You will leave your children?" This was his first motivation but God knows how many other motives he was hiding behind his true gypsy thinking of Cracaoani. Eventually I left and then I had many trainings, we had trainers on legislation and communication, on health reproduction, on tuberculosis, advocacy and lobby, sexually transmitted diseases, digestion problems such as hepatitis, hygiene, basically all the elementary notions. [2]*

*I work as a health mediator for almost 8 years. I was recommended by somebody of the Roma party back then who had his wife here in the community and she had gone to the medical nurses' school. I was getting along very well with them and they recommended me. We then attended the Romani CRISS trainings. I learned about this health mediation as at first when I went, I did not know anything about it, and to be true to you, I thought I had no idea even when I left from there... I understood perfectly. We learned many things about communication, exchange of experience, each of us would talk about her community, and we became familiar with this kind of things... After classes the DPH took us over, they called us to sign the contracts, they didn't really know exactly what this was all about and we were trying to explain to them as much as we could, they just knew that they had to sign these papers... Afterwards we went to the community, which was not easy at all at that time. [3]*

*In 2007 I started to work as health mediator. From the President of the Party I found out about this position. He said that Romani CRISS is training and that it would be good for me to participate in that training, actually, before doing that, I had to take an exam at the Public Health Unit. A job of health mediator was open with the Public Health Unit for the Roma communities in Craiova. I participated, I won, I became employed, I continued with the job that I already knew. Then, In February 2007 I was trained as a real health mediator by Romani CRISS. I participated to the training and I obtained the diploma... This training teaches us how to communicate with people, how to approach them... You don't just go to a person's house and you say "I am health mediator and I have to enrol you to the family doctor" You must know how to make an introduction, to win the man's trust, to maintain confidentiality, not to go from one house to the other and to start talking about somebody else's problems. They taught us how to perform a census, they gave us some files to fill in for the census, how to count the Roma persons in the communities... The data has been centralised the census performed was given to the County Public Health Department. There followed other trainings too. On the juridical part, on how to enrol persons with the family doctor, how to obtain a birth certificate everything, late subscription, all the procedure. We would need some training on medical assistance, birth control methods, to tell us more. I also collaborate with the doctors from the family planning offices and that is how I keep myself informed. They give me leaflets that I take to the community and discuss with them with the beneficiaries... I am working as mediator, informally- without being employed, from 2000 with the organisation of the brick crafter Roma. Since then, I helped them with identification papers, enrolling to family doctors. Later on, on the juridical part with the late registration of birth certificates... I knew the President of the Party and being preoccupied with Roma issues and seeing that indeed they need somebody to help them, I preferred to volunteer. Only later on did I find out about health mediation. Basically, I was doing the same thing without knowing that it was called health mediation. [4]*



*I've been working as a health mediator for six years, and this job was very important to me as it transformed me, as a woman, as a mother, by learning certain things at the trainings I followed. I changed a lot. I hope the trainings continue because we must very well informed when we visit the community in order to be able to correctly transmit the information we receive to the other women as well, because through us they can become aware of certain health problems that they are faced with. My sister used to work with the Child's Protection. I would go with her so that she did not go alone, to help her. And I went with her for fieldwork, today, and tomorrow and then I heard of some positions of health mediator, for Roma, generally having to do with the mother and child and that is how I found out about this training. I took my first class in Buftea and then some others followed. We've been told about the pregnant women in class, how to communicate with the local public authorities, with the health staff. This helped a lot. Before, I didn't even know what to tell to the mothers. Now I am older and I am over this phase with small children, and of course it was very interesting for me to be able to deliver this information to them as well.. [5]*

*I live in the community; there was no other person there before. So we were formed as health mediators from Vaslui in May 2005. We needed the health mediator first of all because this is one of the most difficult communities from all points of view, social, health, educational and it really needed a trustworthy person on which they could rely on. I found out about the job of health mediator from the local leader. Initially I had no idea what it was about, so everybody, the police, the City Hall had a problem, they were looking for somebody, they would come to us. We have a bar at our home. At first I went to an interview to ASP. I took an exam that I passed on the basis of my study fields. After that followed a training course here in Vaslui, and then we were hired by the County hospitals. That is when we conducted the census. The ASP organised the trainings because we were the before last county without a health mediator. Afterwards we had the privilege of being trained by Romani CRISS. We would gather and we had subjects on different themes and we would discuss about those. I believe that some legislation classes, or child protection classes would've been necessary on top of what has been done, these are issues that we meet day by day in the community. [6]*

*Until now, we were four mediators and now only me and a colleague of mine are left. I work from 2007. The professor from Târgul Frumos, President of the Roma Party, first came to me and asked how many classes I had completed, I answered 12, then he asked if I passed the baccalaureate exam and I said yes. He said that the position of health mediator was open. I was not able to do it then, I had a very young baby girl, but after that I asked them to employ me and they agreed. In the beginning it was easy, it was only with high school then, it spread and they hired with 8 or 10 classes too. [7]*

*I was in from the start, I attended two trainings in order to obtain the diploma of health mediator and another one at the rehabilitation hospital of Nicolina. I am health mediator since 2002. I have been informed by the President of the Roma Party. My father knew him. I got in touch with him and I attended the trainings in Iași. Afterwards I took an exam. After the course I was a volunteer for one month. In the beginning I was not well received, I cannot say that it was the fault of the doctor, because there was the nurse of the village and she created more problems. But she called me one day to go to the health care unit. I went there, and five minutes after that the police arrived. They asked me on what occasion I was wondering around in the community, saying that I had no papers, how could I be employed? And I replied that a few days after my diploma would arrive and that I was going to be an employee of the health direction. [7/2]*

*I started in 2005... I went to training in Brăila with the Romani CRISS trainers. It simply took me by surprise...I was aware of these trainings for a long time but... I worked in a different domain until then, I worked as a warehousewoman for a construction company, I had a child and I did not get another job because I was taking care of my baby girl and during that time the health mediator trainings were conducted. I always dreamed about helping people. The President of the Roma Party insisted a lot for these health mediator trainings in Râmnicu-Sărat. Before, there were other women mediators but they left the country and the positions remained vacant and that is when we participated.*



*During the training we focused on planning and birth control. After the training, the representative of the Roma Party accompanied us to Buzău and he introduced us to the DPH. I was taken over by a family doctor. The doctor knew me from before because my baby girl was enrolled on her lists. They already had problems in the neighbourhood and she was very happy to find out that somebody was going to help her. [8]*

*I have been a mediator since 2002 until now. It all started with the training for mediators in Iași conducted by Romani CRISS. I found out about these trainings from my father, from a meeting that he had attended to. It was a project sustained by the Roma Party at that time if I remember well... they wanted to send three mediators, from Gorj for the mediator training. The Public Direction of Health opened another 10 places for training of health mediators and at that time, about 20 persons had enrolled. The themes were first aid, the rights of the insured, communication which was the basis. Interesting, I really felt well among them because I liked working in the health field, I was very interested about all the diseases, to find out about them on how to use medicine, treatments, so I really felt at ease when attending those trainings. I would now like to attend training on human anatomy but this is not up to us, the mediators. I have finished the professional school of pharmacy and many people ask me what medicine they should take for a sore throat or for a stomach ache, what to administer to the children. I am not allowed to make injections, I am very sorry. I also attended a human rights training. In 2007 they have not called me; in 2008 I went back to work after having given birth, I was a volunteer for 7 months before they hired me. [9]*

*We have a leader in our community, they had to hire a mediator for the Homorod commune and they came to my sister, not to me, they employed her and that is how I found out about this programme. My sister was responsible not only for Homorodul but also for Cuciulata, Hoghizu. And then, by performing field work with her I considered taking up the health mediator job. I used to accompany her all the time and I liked it very much. It really made me happy. It changed my life in a positive way. How she got selected? We were family friends and he noticed that she was a bright girl, for she is. She worked as a mediator until last year and she gave up the job in my favour. She left me with the position in Homorod. I've been working as a mediator for three years. First I worked in Bunești; it was very hard to go to the community. It is 28 kilometres away. I participated to various trainings. [10]*

*Back then, in 2000-2001, I cannot tell for sure, it was long ago, there was a lady, and she was in charge of this. And then of course, Jóni Géza managed the Roma community. I got in touch with him and he came here and organised a training to which I also attended. But we had already started working. We were not aware of the health mediator position yet, it was a sort of volunteer work. In case we were start, we would be ready. In 2000-2001 this training started and I started in 2003-2004. It took one year until I became employed and during this year I worked as a volunteer. Then, they hired us. And others followed. We have health mediators all around here. We started to work in 2004 in Gheorgheni, but it was hard to commute. We did commute for a few months and afterwards they found somebody from the locality and I came to Miercurea Ciuc. In the beginning it was hard because nobody knew what it was all about. It took them a while to understand. It took them one year, one year and a half in order to understand that this is to their own benefit. [11]*

*We used to work with mushrooms, sorting them, cleaning them. In Huedin it's hard to find a job. My husband worked at the city hall, the ecology department, with workers. He was with the Roma Party as well, but enlisted, only helped by them. He was some sort of secretary. He was already trained. We were informed by the City Hall of Huedin, that Romani CRISS was going to come. We did not know for what reason; there was going to be training for mothers and children here. Indeed, I was outside of the City Hall and I had just gotten back from work, I was working three- six hours. I had my hands dirty of cranberries, and somebody was asking me what I was doing. That there was some meeting of I don't know who from Cluj. I was not aware of anything. And then he said: "Why don't you come along?" Two girls were going to be chosen. I talked to the girls, to the Mayor. The girls were really scared saying that they did not want to attend this school, to be trained so they refused. And my husband tells*

me: I want you to go, I know you like this. I replied that I too wanted to go, that I liked the new things, I start learning quickly. The he added that they were looking for Roma women, who have many children. At the first meeting after my husband said that he was going to elect his wife, because he knew that she was worth it and that she is going to school. Another woman was chosen in order to be voted. The following day we had to go. Yes, today they came and the following day at school. The other women did not come any more. She thought that no training was going to be conducted and that she was not going to be hired. I liked that a lot, of course I knew what it meant. My husband accompanied me to the entrance and I entered and I attended to the course. For some training classes that we have performed, we had a very strict teacher. And I liked that, I loved it. It was very good. WE had to take and exams and some tests. I loved it! I felt very good ... And after we've finished, they called us to the DPH, the Department of Public Health. I went there too, they spoke to us, explained to us what that was. Some of us knew some of us didn't. There were eight of us. During those days there were no health mediator positions. On the 4<sup>th</sup> of October I filed a request, and that happened we received the grades for the exam. It was good since almost all of us were employed On the 9<sup>th</sup> of October the Principal called us to Cluj. She told me to go to the Huedin hospital the following day and to wait for them and to wait there for I will send you your employment forms by fax. The Principal was laughing, he had no idea what a health mediator was, he said that until he sees the job description he has no idea. I felt bad, I kept my head down. I was thinking to myself that he could talk however much he wanted; around 2 o'clock the fax was sent. When I got hired, the first day I spent it all in the hospital and I started to work by the books, I started the census. My husband helped because it was very difficult for me to do this by myself. We recorded about 900 and something then. There are more Roma here but they are abroad and that is why we were not able to register them. We made a table with the ones who didn't have birth certificates. There were many of them back then, who didn't even have IDs in 2006. You can ask at the DPH. Huedin had a bad name concerning identification papers. I did everything by the book, and my husband helped me, I could not do it on my own, as I would've been left crying at the doors. [12]

I work as health mediator for three years now, following some classes that I took in Alba Iulia. It's been very hard for me. I went to high school for evening classes, then I finished high school and I continued with the protection of the environment. In the past, during that period when I was in school I was thinking what to do. It was very hard for me, divorced with 3 children. I left Zlatna, with the cloths that I had on and with my children... I went to my parents, I was very disappointed, discouraged, I did not know what to do, where to get hired. My youngest child was 5 years old. It was very hard and I must thank the lady at the prefecture for the initiative. She was the one who called my father who was the leader of the Roma from the Apuseni mountains area. She told him the following: I know that you have a daughter wouldn't she like to be a mediator? I know that she's been studying, that she's more serious" He told me date, I prepared and I was very happy to go there. And I really enjoyed the classes, some representatives of CRISS came there. 14 women attended the training. It took them one year until they got employed. They did not have any funds. In 2007 they employed me. My heart was filled with joy. They told me that they did not know what to do and what to say. "I'll employ you, I think that you know better what needs to be done!" Over there, they had no idea, nor did they ask. Only one doctor asked me what a health mediator was. I explained to him, I brought my high school diploma as I had just finished and when I left, I left to face the world as they say [13]

I worked as a health mediator for seven years. I stopped working a year and a half ago, starting last year in August because that is when I started working in education. Since 2002 I've been a mediator, among the first. At first there were only a few of us. Here in the county it was only me and another lady. Now, there are many of them. I participated to several trainings, to classes on the health of reproduction and in the end, we became trainers of health mediators. We took many exams. In 2002 they didn't even know what it was, which were going to be our responsibilities, there were many problems related to our employment because they did not know in what category to insert us. It was very hard for us until they became used to us in the hospitals, everywhere. In the end, our help is beneficial for them too, for the Mayor for everybody. Little by little they became used to us but we experienced very many problems. We were hired here as community assistants, our salary was very

*small, the minimum 4-5 millions. Last time when I finished I had a salary of six million five hundred lei. That is why I stopped doing this, the money is not enough and that is why I went to the educational field. [14]*

*I became a mediator 5 years ago. That is when this programme started - education regarding the health of the Roma, support, behaviour and collaboration with the doctor so that the illiterate Roma may have a choice. We've been hired and trained to be the connection between the sick, person and doctor, institutions. We don't handle only health issues but also the institutions. I don't remember how I found out about this training; there are the responsible of the community, the presidents, yes? The Presidents, they must've informed me. And we've been selected, the ones who have education, this was the first condition. The other condition was...how should I put this, that the people in your residence area to be used to you. We were not the first to be trained, we were the second. We attended the training performed by Romani CRISS. We volunteered for one year because the diplomas had not arrived and other reasons. For one year we've been working on our own. We had no choice. Afterwards, for two years we were with the DPH, two three, not more, and now we only came to the City Hall. [15]*

*I started in 2006. I was a volunteer for two years. A gynaecologist helped me a lot. These two years when I was a volunteer, I did not attend trainings. In 2006, in Cluj we attended this mediator training and a week afterwards if I remember well, I started working with the Department of Public Health. We were two mediators in Timișoara. In Lugoj there are two other mediators... [16]*

*In 2000-2001 I benefited from a project of the Department of Public Health. It was a pilot project of this health mediation project I was taken in by the medical nurse in Pietriș-Cetate, since at the time being, the Cetate commune had 7 satellite villages in its subordination. He took me to this training, a PHARE project called "Positive versus ignorant discrimination", but it was the health mediation programme that received health mediators from throughout the County. The doctors of the DPH, more precisely the Department for the Promotion of Health, said that it was possible to become employed but I cannot say when or how, and we were supposed to wait to be contacted. There was a "bejerist" as we called it at the Prefecture, he knew about the positions of health mediators or everything else destined to the Roma. My colleague participated in Iasi in 2002 to the training of those of Romani CRISS and in October she became employed. I was employed 15 days later together with a colleague who services Budacu de Sus, but through the connection of the lady from the Prefecture. Our files were sent to Bucharest, to Romani CRISS, we were accepted and employed. I was employed at the Emergency County Hospital in Bistrița. On our work permit we're not called health mediators but "instructors of health education". The bad part is that we are employed on a determined period of time, since 2002 and it is already 2010. [17]*

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## THE WORK OF A HEALTH MEDIATOR

The position of health mediator differs from the majority of the occupations in Romania and from the well-paid jobs that women performed before, in the sense that it requires permanent presence in the community. Even if there is a job description, because the serviced groups of Roma have a multitude of interconnected problems, and due to the need to earn and maintain the trust of people, the daily schedule of a health mediator is adapted to the current requirements, and not resumed to the compulsory eight hours of work. Among the attributions strictly connected to this position, there is the permanent census performed on the community, informing people on the necessary actions to be taken in order to become insured, enrolling them on the lists of the family doctors, ensuring the contact of the community and the family doctor, the education regarding hygiene, informing the community on the compulsory vaccines and other vaccination campaigns but also the access to the services of family planning. Beyond these attributions, by accompanying people to the institutions in order to solve their

problems, the health mediators also facilitate the access to identification documents, birth certificates, and late registration and are involved in campaigns for the development of the infrastructure in the areas where the communities are located (paving, electricity, current drinkable water). In order for their work to be fruitful, they also collaborate with the family doctors, with public persons and institutions on a local and county area, City halls, child protection, and departments of public health, Sanepid, hospitals, family planning offices, and police. The health mediator does not only solve problems, she identifies them and involves others in order to solve them. She does not only mediate but she generates changes in the actors to which they are connected and to the relationship between them. She is an agent of change, a pole of Roma activism right from the bottom. It is a job that requires a lot of voluntary work in the most generous sense of the word. It is a work that, as the interviewed mediators say, is not performed for the income that it generates which is not that generous anyway, but because it is loved. Its satisfactions, shadowed by disappointments connected to the feeling of not being able to do stand against the reality and institutional ignorance are the ones connected to the relationship with people, the joy felt for their joy, to see their lives change in a better way in comparison to how it would be without the health mediator.

*I've been working as health mediator for 8 years. I like what I do. The work of the health mediator is a bit difficult due to the fact that we perform fieldwork all day long. It's either hot or rainy, we're always on the field and we have 850 persons in our commune...I performed the census for every domicile: The evidence of women of reproductive age ranges from 14 to 44. We perform the census every year. I explained to the people that I am not a nurse, that my role is to explain how a disease is transmitted, how one should protect himself, how to eat properly, how to take care of one's personal hygiene... I don't have time; I'm not used to sitting, to being relaxed... In the morning, I go to the office at ten to eight; I stay there for two hours. We have two family doctors. Afterwards, I take the nurse and start my fieldwork with her we check for the TBC persons if they took their medication on time, for the hypertensive the nurse checks their tension, of course I stay with her, and take here where we have to go...My most beautiful memory is when we went to Mamaia for the training. I had never been there and I was very happy when I received that phone call and I said to myself that I was not going to do anything that day. That was my most beautiful memory. Apart from this, everyday is stressful, the community, the work at home, cooking, washing and everything else. [1]*

*During the 20 days of volunteering, before I became employed, I was always trying to be informed and inform the others. I only had common notions as a mother and young woman. In the beginning I identified the women at reproductive age who wished for a birth control method, I considered that to be my problem at that particular age. And I was trying to share my experience, I was activating without any training. I contacted the family planning office in Piatra Neamț at the County hospital and programmed the women for planning and then, together with the doctor they decided on what method to use. I informed the City Hall in Piatra Neamț that some blocks of flats needed deratization. I checked the vaccines of the children, and it was such an amazement for the family doctors, in Piatra Neamț, and what is more in Dărmănești to see that a young Roma is interested in the vaccines of Roma children. That was the period when the vaccines were reported to the health departments, but were not really administered to all children. The reports were untrue. Only one lady doctor openly received my initiative, since I was not trained and I did not want to cause any conflicts. I always tried to keep my activity and beneficiaries in accordance with the provisions of the law. I always wanted to overcome my condition, I always wanted more both for my family life and professionally. I performed the census, information, and deployment of the community and of the medical staff. Some were open towards this, some doctors would tell me "You are never going to change those" Lately they ask me about houses as we also work with the habitat. If initially I was saying that health comes first we then learned to follow the factors that determine health and six years ago we prioritised education. Now I really believe that we need to find work places and to conduct professional trainings in order to succeed. I did not only resume to health related activities because I realised that I could not ask of that women who does not even have a house or water to wash the cloths of her children, or a pot to boil their food, to take care of their health and to prevent diseases. I had to adapt to their possibilities, to*

*their capacity of performing the advice received. I had to be careful not to hurt their feelings, to attract them on my side, to offer them models to be followed. I consider that the health mediator is one of the most important activists of change. [2]*

*Where I worked there was not medical unit. The closest was 8 kilometres away and it was very hard but we collaborated just fine with that doctor. One day per week he would accompany me on the field to vaccinate children, attend to the sick, because of the fact that especially during wintertime it was very hard for the people to go to his office. Meanwhile, after three years of activity, the Roma Party organised some projects in collaboration with the City Hall and two medical units were set up, the one here for this community that I service and another one for the community of Tetila. In this office a family doctor is working and he enrolled both Roma and Romanians. We used to conduct many campaigns there in Tetila, since I came along as health mediator and the doctors would come more often to the community. When the doctor's office was set up, I was able to do more for the community; children would go there all the time, family planning doctors used to come and offer information regarding birth control methods to the women who requested it. The people were happy. When I came to town, it was a bit harder although there had been another mediator before me but the people there seemed a bit more arrogant, more secure even if they were less informed and lazier than the others. I cannot say that I've changed them because people don't change that easily, in my opinion they never change...not in a good way... No, I was just joking. I did not change them, the information and the things along the way changed them. I collaborate with very many people, starting with teachers, nurses, who accompany me when performing my fieldwork. I believe that this is made not to change, but to change their attitude regarding their health, their openness to other options...We sort of solved these issues here in our community, the documents. There are people working on the Roma issues at the City Hall. And we conducted other activities and we involved various institutions such as Child protection, SANEPID, planning offices, the cytology office of the hospital, to perform the Babeş Papanicolau test for free... I was very involved in enrolling children in schools and kindergartens... If it was not a satisfying job I would not be a mediator. I cannot say that it is a job that I don't love very much I am talking about the idea of health mediator itself, the work itself and its activities that is what I love. I like best that I am in contact with people, I found out so many things from everybody and I still think that I have something to offer in my turn. [3]*

*First, I start with the census because I don't know the persons and I must know where they live, their names how many children they have. Afterwards, you have to discover their income source, how they live, their health issues, the children, there are many children with various problems. Then it's the family doctor. Why don't the children come for vaccination, and the pregnant women who don't enlist to the family doctor, you just run into them and see that they are with child. They must be advised to go to the family doctor because you never know what might happen, to give birth at home or other such problems. There are many emergencies on field. We help many of them with their documents; they don't know how to write the papers in order to apply for social welfare, for certain files, for the wood welfare. We used to accompany them to the Finance division in Rupea, they needed an certificate that they didn't come. At first it seemed harder to perform this job, now it's just like any other job. I feel good as a health mediator. I like to work with people, with women, children. I have two nephews of my own and I am crazy about them. Of course, that the lack of money makes you go to work, but I do it for pleasure... I commute to Ticuș. I don't receive any reimbursement for the transportation costs and I don't have a personal car, I ride whatever I can and pay for it out of my own salary. Nobody gives us anything anymore, they used to but not any more. Basically I loose 1 ½ only to commute, there's no bus there, no train, no nothing. There are satisfactions after a day of work because at the end of the day you realise that you bring an improvement to the community. [5]*

*I came from the community and did not have a good collaboration with community assistants. They were already trained for half a year but when we came along we supported them to penetrate to the communities but at the same time they supported us. The community medical assistant has the same attributions as the health mediator only he can also draft medical papers, and we may not. A medical*

training would also be helpful for us, but I don't think it is such a good idea because some health mediators only finished 8 classes and it would be more complicated. The first problems were the ones with birth certificates and identification papers. I did not manage to issue ids for them because they live in houses without any papers that attest their ownership, only temporary ids. The next problem was to enrol them with a family doctor and the papers needed in order to benefit from law no. 416. And then there were a multitude of problems. I was trying to tell the girls not to marry fast, but this can change in many, many years. They looked up to me in a way... The health mediator does not work until four o'clock, if anything happens I must be there when it happens, it is very hard to work with the Roma communities... I managed to make the parents aware so that their children are not taken away from them. I managed to raise money for a child to have heart surgery in Târgu Mureş. It was a success. Apart from acknowledging I also disinfected the houses, I helped some get welfare houses... And what is the beauty of it? Working with people and the satisfaction that you get when you get something done, when you help somebody, you earn the respect of the community, you become a respected person. There are difficulties, when you see that you cannot solve an issue, or reach to a point where you say "What have I done, nothing changed..." I never wanted to quit but there were many problems and the time was short. You had to go there and there and everywhere. [6]

I performed late registrations for a person with six children and no identification papers. But this is a problem beyond my competence, because she also mentally disabled and she was suspected to suffer from TBC. I performed the late registration she went to trial, and it was hard to get her registered because she doesn't have any money, no social welfare, she receives allowance from three of her children and her husband takes that money and he doesn't give her anything... The exchange of experience with my colleagues on various problems, that is what I like best and the fact that I have a job. One learns from fieldwork as well. [7]

In my case many were very happy that I issued birth certificates for them and IDs. This way they were able to benefit at least from welfare. I enrolled others to family doctors... The mediator as the name states it, is a persons who mediates. A copper potter woman came to me in order to get money from the Mayor for her prescriptions as her pension had been cut off. The Mayor said that he had no money to give to her and then he left. That is when I told her that the following day I was going to send a commission... About a month ago I had a situation, when the special intervention teams performed a descent in Broşteni and in Vatră. Ten cars of the Special Forces and they took them all to the police station. They were actually looking for two persons... They beat up everybody until they found out... I mediate problems but it all starts from the lack of money. The mediator talks a lot to the people. You guide him, you explain to him... inform him where to go in order to solve a problem. It depends on the person if they are capable of going or solving their problem by their selves, if not you go with him... this type of work changes you because you have a responsibility first of all, you can help somebody. I enjoy this work very much. You know where to go, you are informed. [7/2]

Helpless children that's what's killing me... their problems and their physical or mental disability. I have one case... they need 25 thousand euros for a surgery. The good thing is that I managed to take care of him, to bandage him, to treat him so to say. I collaborated a lot with the child protection. I used to visit them every day to see if there is any change in the conditions inside their house. It was winter then. They did not have any heating and the representatives of the child protection made a stove there... I'm thinking how to change our situation, the problems we face when applying for a job, and all the problems of the community. Shall we start the Mediators' Party in order to solve the problems faster? We meet, some of us, discuss over the phone... We are now waiting to conduct a meeting at a country level, these meetings help us mostly. [9]

I perform the census, health hygiene and family planning and guidance towards the doctor. When they have a problem, I speak of the mother and child here, when they see that their child is not feeling well, they should not wait, they should just go to the doctor, and not to wait until it becomes critical because it's too late then. I came across various cases when many people neglect themselves. If

*the child has the flu, they give him half of a pill at home and that's it. That is why I emphasise this problem too. [10]*

*Around 700 persons are needed in order to have a mediator. It's a lot. We walk a lot and they also look for us if something goes wrong. It rained a lot. The river flooded their courtyards and their barracks. I called them, I was not able to go see them, the water had a high level, and there was mud too, it's very hard. They live in very harsh conditions especially the ones in Primăverii. It's very hard, especially for the children when school starts. When it rains they go to school through mud. Poverty and they need many things. They're cute. There aren't any problems if somebody from an institution goes a mediator, they're not aggressive. They listen to us, they accept our advice... My life changed a lot since I started working. I've become a better person, I met a lot of people, I know them better, their problems, and their health condition. It meant a lot. I changed a lot. I've witnessed the conditions in which people live and how hard it is for them in comparison with us. There's a poor Roma and a bit wealthier Roma. Just like with the Hungarians and the Romanians. Some are poorer some are wealthier. I've seen Hungarian families who lived in poverty, it was all a disaster. But the Hungarian is a Hungarian, and a gypsy is a gypsy. I knew that there were difficulties in general, I was aware of them but when I went to see them, how they live, I could not even imagine that something like this exists. And yet, they do their best to send their children to school and to change. When we visit them, we see that they do their laundry, their cloths are clean. It was hard for me until I started to like this job. At my other work place, I knew exactly where I was going, I had to stay there 8 hours go home and that was all. It's not the same here. They call me in the afternoon from the hospital or from somewhere else. There is no fixed schedule. [11]*

*We had to go with the child protection to the commission in Cluj, to the hospital; they did not know where to go. I was busy all of the time. The first time I had problems with my husband and I told him that he had chosen me. My husband was the only one in Huedin who knew what a health mediator was. But he got used to it and the children have grown up now. I never had for myself but always had time for the others. They come to my house to look for me. Wherever I accompanied them they were not refused so I went along and I solved the problem. [12]*

*It's a beautiful job that one must love and which requires a lot of patience. Anyway, I had enough problems in the beginning regarding paperwork, IDs, birth certificates. In the end we managed to solve it all. There are no more persons who are not enrolled with a family doctor except for one or two families. They have insurance because they receive social welfare. In Cozmeni all gypsies get social welfare. Except one or two families in the village who have better conditions, they all receive ... It would be great for the mediators employed with the city hall to only do their job because it's very hard this way, I have to do things that are not in my attributions. A person to have as a raw model is needed of course. They accepted me, no matter what, they accepted me and we managed to prevent conflicts. I told them clearly, you have rights and obligations too. You cannot always be right. As in this case, many conflicts may be prevented, that is what the mediator position is all about. The salary is very small, five six million at most and you work all day. At some point we were told that those who had finished 12 grades and had a university diploma would receive some extra money, but nothing. It's like working with eight grades, you cannot promote. The thing is that we frequently attended trainings but nobody took that into consideration. A diploma as trainer in the health of reproduction should be recognised or any other qualification. In my opinion, in the communities there should be at least two persons. [14]*

*Everything in my enumeration happened. The lack of identification papers, no simple people would trust the authorities, they were afraid that they weren't going to handle it. I've been accepted by the community. They came to tell me their problems before too, before I became a mediator, and I would help them with their requests according to the available time I had. How could I not help the one near me...? To have a mediator it's good for them too. Because I did not have that many information either; I progressed a lott. The mothers are tidier, and cleaner. They are aware of the risks,*



*of what is good for their children and for themselves, that they must go to the doctor, not to be ashamed... I enrolled many people to the family doctor. I made a commitment because there are people who come and do not create problems. I tell the following to the people: Please go, be patient, wait. Or I tell them that the doctor said to take your file and go see her. That is what scares them and then they go. Or the doctor calls me and tells me to go call them. I am the connection between the doctor and the patient I believe I am a happy case. [15]*

*I never told them “you must go there, there’s the hospital or the medical care unit where you have to take your child’. No, I would accompany them there, even for vaccination; I never let them go on their own. And they were very happy, for any problem they had, and they were very happy. Concerning the documents, there were many children without documents, even 20 years old. I went with them to court, I helped some of them get pensions for disabled, I took their files and I did everything. I still work now even if I don’t have the job. I have made 7 files for late registration. The issue is about the children, their identification papers as some of them are born abroad. I don’t know why my contract was interrupted. I work for them with all my heart. There are many mediators who get paid and don’t do as many things as I do for free the community is my witness. I still help them because they have many problems and I pity them; they are refused if they go alone. Now for example I enrolled many children at school. Whatever I did, I did it for them not for the 4-5 million lei that I would get from them. Even in hospitals, when I heard they were there I went to see how they were doing, how they communicate with the doctors with the nurses. [16]*

*I performed many activities out of the job description. At some point I participated in an exchange of experience in France. The health mediators there, one deals with the social part and one with the medical part, one only for the Court of Law for trials on divorce cases, or domestic violence and we would laugh there saying that we are like the Power Puff girls, there is three of us, we do anything, we re not afraid. When we were asked about the salary that we get and I told them that it is 150 euro, the equivalent in lei, they said it was impossible, that they get 1500 euro. They were not paid by the Ministry of Health they were paid by the NGOs that they worked for. One thing was for sure, they were responsible for only one activity and they only performed that one. We made a lot more, we reimbursed the subscriptions for children through Child Protection for two entire years, we gave children for placement by the Child Protection, I don’t know if there’s anything we did not do; healthcare actions, educational activities, all sorts of activities not contained in the job description; No, I was never afraid to work. [17]*

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## THE RELATIONSHIP WITH PUBLIC AND POLITICAL INSTITUTIONS

As I was saying in the introduction of this research, practicing the job of health mediator is also a mirror of the institutional change that took place in Romania from its introduction into the occupation code until today. The measures that affected their position and employment were not under their control, even if the organisation Romani CRISS, who played a central part in creating the institution of health mediator, represented their interests more or less successfully throughout their career. As shown by the fragments of the above sub-chapter, from the beginning the mediators hired by the Departments of Public Health were allocated to hospitals, thus belonging to the system that is ran by the Ministry of Health. Even if they had a job description and even if their employment has been done following the official methodology, the hospitals and family doctors were not aware of these dispositions. Their initial attitude of rejection came from the lack of information concerning health mediation, but also in some cases, those women were victims of an unfriendly treatment which might have also been a consequence of their ethnicity. According to the statements, the collaboration with the Departments of Public Health was good from all points of view and in time, once the relationship with the family doctors has improved the other relationships followed the same positive pattern. The latter realised that this way they eliminate a gap in their contact with the Roma communities and in a way, their job as a doctor



servicing Roma patients with various problems arising from their poor conditions, is simplified. Concerning the first stage of collaboration with the Roma Party, it has also been beneficial. Throughout the process, many health mediators distanced themselves from the Party people when they realised that they wanted to involve them in their political campaigns through an involvement that made promises without coverage and without any dedication. Nevertheless, based on their stories, we notice that where the relatives of other nature of relationship with the party leaders remained intact along time, the fact that the health mediators were taken under the authority of the city halls, especially where the local councils had Roma councillors, has occurred without any incidents. However, taking them under the authority of the city halls was maybe the greatest institutional challenge of the health mediators. It happened in the larger context of decentralisation of the public administration. As the interview fragments below show, some of them lost their quality of temporary employee (for one or two months), or have lost it for good (at least until the time when the interview was conducted). Almost all the city halls reacted negatively to the obligation of hiring them. Some Mayors did not know why the institution they were running would need a health mediator, some others did not know or did not want to know that the salaries of the mediators will continue to be ensured by the Ministry of Health, while a few were afraid of the consequences of their employment when the employment in budgetary institutions had been blocked and some of them just placed the mediators in the social assistance department, the child protection department or even the patrimonial department. The accountants, the colleagues from other departments as well as the Mayors had more explicit attempts to intimidate and to remove them. The ones who eventually have been hired at the City Hall faced new challenges: attempts to change their job description, allocation of attributions not related to their job description, transferring responsibilities of older employees (social assistants) to the newly arrived health mediator, their obligation to perform office work in the detriment of field work which was the core of their occupation, humiliation and hateful treatment. Nevertheless, there were happier cases. The ones in which, even if they were asked to start their work programme at the City Hall (without having any desk and without benefiting from stationary), they were allowed to continue their activity in their usual way. Some of them even managed to collaborate pretty well with the social assistants and receive gratitude and earn their respect. By positioning them in this institution, there was a reiteration of what was going on in their daily work, meaning their involvement not only in problems relating strictly to health but in all social problems of the Roma communities. This has been institutionalised without changing their job descriptions or their salaries. They are now allowed to conduct social investigations but this obligation is informally imposed, meaning that if they want to conduct the job for which they were hired they have to work more for the same small salary. Due to these major changes, the health mediators unwillingly woke up with the need to mediate other actors than the ones they were used to, meaning the local public administration and the public health institutions. If until now they found themselves between two worlds, that of the family doctors and of the Roma communities, they now find themselves between the City Halls (their employers) and the Ministry of Health (from which they get their salaries). Nobody knows the solution to this paradox position. What is clear for now is that the tensions of these uncertainties affect the work of the mediators. The local and central public institutions do not want to take the responsibility of the risk of making health mediation impossible, a very positive position in the perception of the Romanian state by the European Commission concerning the methods of improvement of the Roma situation.

*I did not get along with the Roma Party leader, he is now deceased and I don't have any problems with him. He wanted to hire another health mediator ... To replace me but I do not know the reason... It seems to me that when he heard that the City Halls had to take us over. You see, with the crisis, the city halls heard about hiring a health mediator, they were thinking where to get the money for this, and when the Ministry of Health heard that we were making a big deal about this, they accepted to pay the salaries for this year too. When the city halls heard that we were going to be paid by the Ministry of Health, they gave us a chance. We will see what will happen next year. We do more things at the city hall than we used to do at the Departments of Public Health. I do what I am told to...Social investigations, or with the birth certificates of the children and child abandon. We go with the community assistant. He should be in charge of child abandon but because she does not know the*

*gypsies she takes me with her. The city hall did not stop us to go to the community; they only give us more work to do. I don't have a desk, not even in the medical office, not in the city hall. I have a cabinet in the office of the family doctor and that is where I keep my files. [1]*

*In 1998, together with my husband, for a period of three four months I activated at the level of the local representation of the Roma Party until I realised that I had no purpose in that....not necessarily ideology, because theoretically I wanted to improve our situation just like everybody else, but the inter-human relationships, the directives, the dictatorship made me withdraw... When I went to see the Mayor of Humulești, he told me "Look now dear girl, I give you one year and I don't want to see on the streets of Târgu Neamț those naked, filthy poor children from Vânători, this is the only task that I give to you"... Now, they intend to fire the mediators in the City Halls. I was speaking to my colleagues the other day about my problems, but I am not the only one with these problems, my colleagues in Pașcani, do too, where out of four there is only one mediator left or in Petrosani, where those mediators are always on the field... The social investigations are what I resent since we were taken over by the city halls. I assist the social assistants of the City Halls, but I don't have to conduct social investigations. Now if I am not required to, at least I was curious to see how, if people are happy on how social investigations are conducted in the community. Personally, I collaborate just fine with the assistants. [3]*

*I personally believe that this decentralisation did not have to take place, they should've left us where we were because now we are overloaded with work on top of our duties contained in the job description. My job description that we should follow on our own or by request if the plan of individual rehabilitation of the disabled is followed. The problem is that they don't only send us to Roma people but also to the majority. A social investigation is not performed by just by clapping your hands because this town is quite large, you cannot know everybody, one must participate to a discussion and ask exactly how the social investigation is performed. Certain aspects need to be followed and I say it's a waste of time. In the morning I have to go and sign in to the office where I have to be until 11 o'clock in order to write the social investigations performed the day before. These are the conditions so I cannot say anything about this, all workers do the same, there is no discrimination or different treatment...I work just as much with the family doctor now but I don't have so much time to deal with the Roma and the health mediation. But I think that the relationships are the same. I periodically go to the family doctor, ask him about the cases of unvaccinated children. Sometimes I identify a pregnant woman and I take her to the doctor in order to enlist her. Mainly I do the same things, but I spend less time in the community. Before, I was able to make my program however I wanted, I knew when to go to find people at home, after 2 o'clock I knew they were available, that I was able to talk to them... The city hall didn't want to hire me from the beginning. I staid two months without a salary and my work permit was closed at hospital no. 2, I had to knock on the door of the City Hall every day, to show them the law and to go on with my activity, which I did even if I didn't get paid. Eventually they paid my salary for that interval too. Our contact person at the regional centre discussed with the people of the City Hall too, he made a couple of phone calls and in the end they understood that they had to take me over [4]*

*From the 1<sup>st</sup> of July 2009, when the decentralisation was done, the situation changed. Since I passed to the City Hall, the Mayor did not accept me; the community did accept me, I worked well in the community but because of the Mayor I had to transfer from there. Although the Mayor in Racoș wanted to hire somebody not from the community, somebody from the City hall or one of his acquaintances and I had problems there; because of the Mayor I had to leave from there and now I work in Ticușu Vechi, since the 1<sup>st</sup> of February. There, I get along pretty well with the Mayor, the social assistant I collaborate quite well with them but in the community I don't know everybody like I did in Racoș... You know it really is a problem with this decentralisation, since it has been done I ended all relation with the hospital. I had a coordinating doctor in Rupea hospital, but he does not do it any more because we belong to the City halls and now it depends on the Mayor on how understanding he is. But he doesn't care, he has nothing to do with health. You go to the community but in vain you come to the*

*Mayor to tell him that that or that child is sick or where he should be taken, so no, it's not the same thing any more. We collaborated very well when we were employees of the Hospital. [5]*

*A community centre has been set up since the decentralisation, a centre for community assistance. We set up a sort of medical unit there, we have a bed, a medical kit, of course the community assistants have that...In the beginning there were problems after the decentralisation, before Christmas the Mayor gave us the resolution and we became unemployed. They didn't take us over because it was not clear whether the Ministry of Health would finance us for 2010; we were unemployed for one month but we did perform our duties. I think it was also because of the Mayor, he could have understood as others did. This matter settled when they wrote that we worked and that the Ministry of Health was going to finance the programme for 2010 as well. We did pressure the DPHs to sort it out. Then the medical nurse and the health mediator staid in a closet outside of town, in a large room, in the cold, waiting for the beneficiaries of the oil and sugar programme. Afterwards, we had to perform some sort of investigations as rumour had it that the heating welfare was going to be cut off. Now you understand how much the city hall is interested in the social part and that we have to be more involved in this, but this is good... from 8 to 10 we have office activity, write investigations, reports, what we have and then we perform the fieldwork and at three thirty four we come back... Now we have a hundred supervisors, the DPH requests the same thing, reports, because there are some indicators that need to be sent to the Ministry of Health every month. On the other hand, it's better now because they take us more into consideration. The bad part is that the actual job of health mediator is not performed as such and we have no idea of what is going to happen in 2011. It depends on the Mayor. [6]*

*There were obstacles with the City Hall at first. The community assistant was accepted but I wasn't. They kept talking to me as if I had been doing this for two years; let me ask the accountant if she has any money or not; so I went to the accountant and I told her "Madame, you are not the paying me" She was very upset; who was I to tell her about money...; "If you don't know it means that somebody must inform you"; and then the Mayor said that there was no need for a mediator, what to do with a mediator... They did all sorts of things... [7]*

*They did not agree to take us over. They took us over after two months and for two months we were without salary. We called Romani CRISS "What is going on? What shall we do?" Keep working like this they said, your money will be sent to you and they will pay you because they don't have any other choice. They did pay us eventually but they did not register those two months in our work permits. And the Mayor kept on joking that he would hire the one with blue eyes but none of us had blue eyes. [7/2]*

*Our being taken over by the City Hall from the Direction of social assistance was a good thing because we face many social problems and the Principle is an exceptional lady who is trying to solve all problems especially when the Roma families request emergency help. [8]*

*The decentralisation process started last in year December for us, we were taken over by the City Hall of Târgu Jiu, and from the 1<sup>st</sup> of February 2010 we were taken over by the Patrimonial Public Department. Now we report to them but we do not face problems like other colleagues of ours do. We perform our duties the same way we did until now, nobody gave us extra tasks. In other counties they do have this sort of problems...Nevertheless I believe that it was better before when we reported to the hospital. The Director tells us "I want to take you back but I don't know how" The advantage were the meetings that we had there together, the fact that there was an evidence of our work. We write reports here too but who knows if anybody reads those and this is how months go by. It's like we don't do anything, you understand? It's like we don't exist, we're not anybody's now... And we used to report to the DPH and we still do but because they're not our employers any more I don't think that they take into account our work as they used to... It is different when you have an impulse... The City Hall trough the Patrimonial Direction does make a difference now. When we were at the hospital we would use some stationery from there but here, nothing, they don't have any funds...We perform fieldwork just as much as before, we communicate with the family doctors, reports once a month and that's it. [9]*

*When we go to see the social assistant at the City Hall or the city Hall or the family doctor we must carefully choose our words in order not to be arrogant. We must be very subtle speak nicely because otherwise we won't have any success. In the beginning everyone here at the City Hall was very scared that we went to work there. The Mayor came to the office in the beginning with the social assistant and they feared me for some reason; because I was a Roma and who knew what I was going to do. I kept my head down for a while, spoke to them nicely about anything and that is how I succeeded. I was very scared at first too, especially when I started in Homorod, because at first I had not been accepted. The Mayor did not agree to the mediation programme, that he doesn't understand its purpose. I day after day I came to him telling him that he will need the mediator. Eventually he accepted. Of course the regional centre and the DPH insisted upon this. One month after that he accepted. I was very shy at first, I believed that they were giving me weird looks, but in time I started talking to everybody here even the Mayor. It turned out just fine. I have a lot of activity now. I stay here at the office until 11 o'clock because this is what the Mayor asked me to do, and I do it. I go home first, in the community, to have lunch and then I go to Homorod very often. Many of the days I go to Merchiaşa. When I go to Merchiaşa or Jimbor it takes longer because it's hard to get there and the time is not enough. I don't go there at 8 in the morning because even if I did, I cannot enter the houses of those people at 8 in the morning to discuss about their problems. I have to wait for them to wake up, to do their jobs. This is my work style. [10]*

*Indeed I collaborated well with the family doctor he was very involved in the problems of the Roma community. But the cooperation of the local authorities was very important too in order to solve certain cases as a team. I could not do it all by myself. I did not have any connection with the City Council back then we were not part of the employees of the City Hall... Now that we reached the City Hall we were well received. I didn't know the Mayor well... I knew Zita, I collaborated with her, but without any problems. They were aware of the situation, the work of the mediator. For my colleagues in the villages it was harder to be accepted by the Mayors, because they did not have any money, until they understood that there were money allocated in this regard; the doctor had to explain to the Mayors what it was all about and afterwards I heard that the matter had been solved. But there were no problems here in Miercurea. We meet weekly at the council; we discuss our problems if any. We collaborate very well, we get along well, and there were no oppositions, Roma or non-Roma. We must each adapt to our profession, to our job and for sure everything goes well then. If somebody respects me, I respect them. There is no difference here if you are a Roma or not. I did not feel this, never once in the 30 years I spent working here. One must adapt, like the case of the Hungarians, Romanians or any other ethnicity. One after the other, in order for everything to be ok, harmony, you must adapt... Here at the Local Council they accept my programme up to now. I don't have to stay at the office, they understand that this is fieldwork; it's specified even in my employment contract that I perform fieldwork. [11]*

*It's not good since we moved at the City Hall. I don't like it. Many believe that I came there to take their job, their chair. Or because you're a gypsy and you have a salary it seems like you are taking their salary. They know that it is the Ministry of Health who pays us but they don't like it. Not all of them like it but some of them are nice... Since I came to the City Hall I don't only work for the Roma, I work for everybody, wherever they send me. They said that we live in Romania. This is not a problem because I am not a bad woman, I understand everybody, but she finds a reason to piss me off every day. She should be a different type of woman, like a mother, but she seems to be made of ice, an ice chunk. She doesn't like people. Now the Roma Party got an office there at the City Hall but nobody interferes; but the ones from the Party are different. They like to have a function and they go around, they dance on what others sing so that it turns out all right for them. But you know what? They did threaten us! And unfortunately I heard that we will be subordinated to them, to the Roma Party. If they take us over I think that I will lay down my weapons. I was threatened over the phone... And it's even worse now at the City Hall. Nobody defends me. At the hospital the Principal would protect "If you say something bad about her it's like saying something bad about me, get out of here" [12]*

*What to say now, since I was taken over by the City Hall I performed mostly social activities. But what I dislike is that the Mayor wants me stay at the City Hall, you understand? I don't want to fight with him either because if I do maybe he will not receive me any more, what if we will be subordinated to them and he will not receive me. I cannot perform my fieldwork as I used to. To stay there in the building of the City Hall for 8 hours...But I am afraid to say anything for I don't want to be thrown out. I did what I was told to do. I went when people came looking for me, I asked for his permission to go and I went but I cannot go whenever I want, you understand? There are two women at the city hall, social assistants. I worked in the same office with them; I sort of do their job too, they keep running after me, to come faster, to help them out as they have a lot of work to do... I liked performing fieldwork. And the weird thing is that we are paid by the Health Department but we are at the City Hall.*

[13]

*The truth is that the ones from the City Hall did not like the fact that I finished university, the Mayor did not like this either, because if I knew that something was not true, I would tell it straight to his face. How did it happen that I knew more things than they did? But I don't know more things than they do, but the truth is the truth. I had many issues regarding the salary. I knew in what category I had to be enrolled and I would tell him that this is the law and according to this law you have to take me in. He would tell me that I was wrong. Afterwards I went to the hospital, I took the paper from there, I showed it to him and he said that I was right. So than if I am right why don't you do it this way? In the end, they did it their way, and it's useless to fight them because in the end they defeat you. There are more of them and only one of you, and eventually they win. People would not get their social welfare for two months. They made them sign but did not give them the money any more. It was crazy. I went to ask for the payroll and I noticed that it was signed. The people considered it outrageous. In the end I went to them, I kept looking so a meeting was convoked. The Mayor said to come up with an idea for otherwise they would beat us up. I replied that they should do that. I called my brother in law to come and see what happened. What can we do? He said that in this situation it is us against them, that there was nothing to be done. I said that if the gypsies find out what happened there is going to be a lot of trouble. God protect us from such hysteria that would be followed by fights and fire. We had to somehow avoid this trap, to settle it down peacefully. We made things up in the end, that they had signed for something else and in the end we solved the matter...The city Hall find another use for those money and they made us solve the problem in the community, and we did... There are other things too... For instance, if somebody receives a fine, the policeman stands in front of the cashier when he picks up the social welfare and he does not give him the social welfare until the fine is paid for. This is also illegal, they cannot do that... Moving to the City Hall was a bad idea. And when we got here from the hospital they told us that he is allowed to give us other things to do too, since we are now employees of the Council, it's their right to give you other things to do too. We had to be there at seven, and had to stay until 11.00 and only after that I was able to perform my fieldwork. I had to do somebody else's job and in the end I told the Mayor and the accountant and they did not like it. It was not part of my duties to do this and that, I am a health mediator and it is not my duty to the job of the social assistant. To help out is something different, but to stay there with her 4 hours everyday until 11, why is she employed then? Or if somebody came, I had to go the reception and stay there, if clients from abroad would come I would have to go and translate. They did not speak Romanian nor English and they called me. This is what made me sick and tired I was exposed to everybody's will. When I was at the hospital it was different, I knew that I had to go, to write the report every month, to do my job in the morning and that was it. But here, from 7in the morning until late evening without stopping...They're not worth fighting with, they will certainly banish you because you can't hang on for long, not even if you want to, when you have to run every day and do somebody else's work...here in the commune we don't even have a school mediator, nobody. Eventually I gave up because it has no point. Maybe I was weak back then maybe I should have acted when the meeting took place and try to sort it out but I thought it was useless. In the end there are more of them and I don't want any trouble here because this is where I live. They also did that thing with the Roma expert of the Roma National Agency. First they signed that they agreed to hire me and then, during a Council meeting they decided differently. This is how I ended up*

*quitting the health mediator job and the kindergarten job and I didn't get the position of local expert either.[14]*

*I go there every morning. We report to the City Hall. I sign and then leave. To social assistance yes, we have an office there. Until now it was easy to sign in with the doctor's stamp, but now we have to go there every day and after we sign we are registered. They don't help us with anything. I came back to the medical unit. If there is fieldwork I go, if not, I'm at home. It sometimes happens to perform fieldwork at 7 or 8 o'clock... I have a pass with which I can travel within the city on any bus. It's valid for now but this is everything we get; not even paper and a pen. I have a lot of paper at home, our profession is recognised but we are still unqualified. We are not really acknowledged at the City Hall for if we need something we must wait. At first, I was sent to the Social Assistance Department and then I got a call from the Child Protection that I have been moved. I did not agree, I told them that I had nothing to do there, and afterwards I did not say anything any more. I was wondering what I was going to do there, to go and take the gypsy children and fight with the gypsies for their children, you cannot just go to a gypsy and take away his child stating that he is not taking good care of him. In April I got a call that I was late with my report because I had so many things to do, and I was a couple of day late with the report and they called me to bring the report and the presence. It was Friday then and I took it to them on Monday and after one week they call me at the Social Assistance Department and they tell me that my contract ended, that they don't have any more money to pay us and that the DPH would not pay me, but they were paying me. I went there and I signed the papers, what was I going to do, fight with them? She made me sign and then she said that I was able to file in my request for social welfare. After that I called everywhere, I spoke to Romani CRISS and they said that they would support me as much as possible, they asked here why I was fired and nobody said anything. The Director of the Social Assistance office said that they needed me, that I worked, and that it was easy to see my work with the Roma with everything. [16]*

*We didn't really have problems with the decentralisation, but other counties did as the mediators would call me and tell me that they are not received, that they have problems. It was ok here. I heard that it is possible to extend this programme that the Ministry of Health would finance it but nothing is for sure. I am now between two jobs, I would apply for the one of expert too because we don't know what's going to happen. This RNA programme is not very sure either. It's between two chairs, you know. The DPH helped a lot the coordinating doctor of the health mediation programme, he sustained us a lot. When we got hired in 2002 he told us "your relations will be your relations" and indeed he supported us, and they resorted to persons from the institution to solve our problems, those of the community not our own problems,, We would've wanted contracts on an undetermined period this was our problem, low salaries and the employment for a determined period, because we are not allowed to move more than three times from a programme to another and we are not allowed to stay on a programme for more than two years. And we already exhausted that. We cleaned many times, we were in the National Programme III, VI, XII, II so we went from a programme to another in order not to fire us, because at a county level it showed that they were not efficient concerning pregnant women, vaccination, etc. At the health mediators' conference we spoke to the secretary of state and told him that this is what we want. We don't know what is going to happen and we are scared about tomorrow. Others encourage us, the Department of Public Health, always. They tell us not to be afraid and that the programme will continue, that we were efficient and that they find themselves in the same situation; or they tell us not to worry, to do our job, not to give up hope, but it is difficult not to think about tomorrow... Here, we have Roma councillors, two of them, from other parties from the social democrats and the democrat-liberals. They vote during the meetings, they come but we never had any support from them, we were never able to relate to them in such a way as to go tell them "Come on, let's go to the community and see what we can do for our Roma" The ones from the Roma Party, the same. From 2002-2003 they looked for us as health mediators, so that they would win more votes for their campaigns. No, we don't get involved; we know that the health mediator cannot be involved in politics because there would be a conflict of interests. The people from the community would not know what you are, a councillor for the Roma or a health mediator, or what? No, we never got involved in*

politics. We learned not to promise what we cannot do. The ones from the Roma Party promise a lot don't do anything and all the community hates them. I never did this. That's why they respect me and the people always trusted me. [17]

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## THE RELATIONSHIP WITH THE ROMA COMMUNITY

The interview excerpts below repeat what has already been discussed about the living conditions of the Roma communities serviced by the health mediators. This sub-chapter emphasises the relationship of the mediators with the community, as they perceive it, as a process marked by various changes, which in the end managed to build a relationship based on acceptance, respect, and mutual trust. Of course, this relationship has been influenced by the existence or by the lack of existence of previous contacts or different ways of thinking or life-styles. It bears the mark of the mediators' personal competences concerning communication and relation in general, but also the ability of the persons from the community to accept a "stranger" (even if familiar from certain points of view) and of their expectations from people occupying official positions. Due to their job but also to their perception on what "the outside help" means, the health mediators have an ambiguous status in the community: they dedicate themselves to helping the latter, but would like to avoid their becoming addicted to them; they must facilitate the access of people to doctors, and to induce changes to the community. The equilibrium between these needs and new challenges occurs in personalised ways, according to the ability of each mediator to generate change from inside the community and to help the needy persons. Whichever the case, the community is not the object of their work but the context in which the solution to the problem is found, and in which they share human satisfactions and discontent.

*This commune has around 850 people and none of them ever told me "I don't want to give you my ID, I don't want to enrol with you." They believed that they were enrolling to me, the census. I get along very well with them... The first time when the census was performed they would tell me "what will you give us?" or "what will you do to us?" or things like this that they had no idea about, they didn't even know what a health mediator was. In time, I explained to each of them what that was about and what a health mediator was, what I was hired for, and what were my duties in that commune. That is when they realised and they welcomed me with open arms, all the commune. [1]*

*I tell them: Be respectful when you go to the family doctor, talk nicely so that you will be accepted by the doctor as a normal person. They were not used to this, they would say hello and go in, not wait in line but now they are more civilised. I advise them you know, and they take it further. They always come to me and ask me what to do in certain situations. Many times they asked me why I was not wearing any jewels, for not all of them were Adventists, but what they really meant was „are you poor, you don't even wear earrings?" or "Are you repented?... I adapted to their costume, learned from their words and felt loved by them and appreciated in Humulești. It is an honour to take you to the good room of their house and offer to you a dress from the girls' dowry, and they took me too and I accepted. They used to kiss me when they saw me. But I also had one conflict with an old lady of the community, she was overreacting. She used to call me bear leader gypsy, which is how the tinterers call the other Roma, regardless of their people. And I defended myself and I told her using the same language that I was not a bear-leader gypsy and then we became closer. I talked to them in Romanes but at first I spoke Romanian. Little by little I was practising with the grandmother so that I may speak to them on their own language... In a word, there is a relation of dependency of the community towards the health mediator. [2]*

*I wasn't really from that community, I come from this community where I work now, and then I went to a community where I didn't know 70% of them I knew 50% of the at most but the people there did not understand what I was doing there. It was more difficult in the beginning. But they accepted me in time and we started to collaborate and perform all kinds of actions and activities, in general with*



women, which is the same now too... They were more reluctant to my presence in the city than at the country-side. The people don't know, the Roma from the country-side followed the example of the Romanians from the country-side. This community is placed between two communities of Romanians, and honestly they were not reticent. In the city, the people were tougher, not so open, they act like they know everything, they don't need... But not at the country-side, they were very welcoming. I earned their trust by being serious... This is my first work experience, I was at the beginning, I had finished university and it was my first job, and many times when I faced difficult situations I was about to quit. The discontent of the people was the only problem that I had. But I did not guide myself by the few unhappy ones and I realised that there were more of them who were happy and who would benefit from the information and that is how I managed to overcome the hard times even if I was disappointed a few times. To say more, their commodity used to upset me many times... they are not willing to receive information, to look for something or go by their selves in certain places. They're still not. They are still depending on the health mediator, or at least the women in my community. I 'm not saying that they depend on me; No! I tried as hard as I could not to make them depend on me. I used to accompany them to family planning office but now they go on their own. [3]

I was quite well received in the community, for I knew most of them. They already knew what I could do for them and how I could help them. In the other communities it was a bit more difficult, because I had to introduce myself to certain persons, to tell them who I was, what I can do for them what was the information that I could supply, to earn their trust trough work and perseverance... When the people see that you help them that you are serious, confident they let you come closer to them. [4]

Until the 1<sup>st</sup> February I used to work in Racoş. In the Roma community in Racoş, where there are about 1200 Roma. The community was good for me, I worked very well with them, but I also had enough problems that I tried to solve, and I did solve many of them. I belonged to second series of mediators, you know? And I was assigned to Racoş where there were nine of us. I succeeded in the end, it all went well, I had a lot of patients, I visited them a lot because at first they didn't really trust me, but when they realised that I wanted what was best for them they accepted me. I used to call them every month for vaccination, and by going one time and then again and again, they started to trust me. [5]

People reacted well to me, because until then, the assistant belonged to the majority and had no access to the community. And he had a concept that the gypsies were bad people, there in Reghin... I went to inform the people that there was a health mediator and that if they had any problems they should come to me to discuss it. They reacted very well; I didn't even expect such a good reaction. They had all sorts of questions related to their problems, not to me. They were asking about everything. They started with their problems and they asked me what I was going to do to them. They told me that they did not have any property documents for their houses and all sorts of things that I explained to them and they understood. The problem is not that they don't have access to the local authorities. From a political point of view we had the social democrats and they were well received at the City Hall and everywhere, because they had their votes. If you ask them, they will not tell you the same thing. But I know towns in which the Roma are not even allowed in front of the City Hall, and this never occurred here. They went there, they screamed, they did whatever they wanted, they were given what they asked for. At least in Reghin, last year they received a lot of construction materials, a person would receive materials three four times, and they built houses and some of them sold those houses, I cannot tell you really everything. When I was visiting them I had to sit on the bed, not to give the impression that I was different and I had to take them step by step. Now, during the past year, they were tougher with one another. I tell them that they should clean more, that the child protection might come in inspection and that they might take their children because the conditions are not good, or I would tell them that I wouldn't help them out any more and let the child protection take away their children, and then they get scared and they react. [6]

I was assigned to Boşteni, Lunca and Vatra and I went to perform the census. They lived with the impression that the Roma President had taken money and supplies and that he did not give anything



to them. They were afraid that I was going to do the same thing. Or in Lunca I had some who were saying: „No, maybe she will take us to the Bug this one”. Others said: „What, did you become a doctor? I am not changing my doctor.” They had all kinds of ideas but afterwards they understood and this is not a problem any more. I told them that I would accompany them where they cannot go on their own. You have to take it step by step, but you must also show them that you have authority. You must earn their respect and they should respect you too. You have to do things their way, for when you find their weakness and you help them, they respect you. And once they see that you help them and that he used your guidance, he respects you. You must not have an attitude of superiority with them, for they are people who don't have any possibilities. They must be helped, not allow them to do things by their own way of thinking. If somebody doesn't speak nicely you don't have to do the same. You wait until they calm down and then they understand that you are listening to them and afterwards you know what to tell to them. It's very important to keep the confidentiality, if you enter in somebody's house you don't go to another house and tell them what you found out about the other one” [7]

I am “lăiașă”(nomad), from a village 7 kilometres away. My father was a musician and that is how I became acquainted with older people and younger people too, and when I entered the community, it was enough in order to know a few people. You must know the people, see their problems. My first day of fieldwork seemed to have the length of one year. I went alone and it was enough to meet one person who turned me upside down. If one leaves from you with a negative feedback the word gets on the street immediately. It might happen to run into a drunk one, he shouts and speaks silly things, but I mind my own way and don't answer to him. Or if the man doesn't want you in his house, you don't go in. You speak outside with whoever steps outside. You must find the right time when to talk to the people. They are not always in the mood to invite you in, or if their house is untidy, they will not let in. [7/2]

I perform three four hours of fieldwork daily. When you meet two three persons who talk a lot, especially the older women, Oh God! They tell you all their problems that they are sick, that they have no income, that they only have social welfare, or that they're retired... We come across many problems, and we gather up in a group and discuss all of us... First of all we try to help people, to create better conditions for them, a relationship with the local authorities or with the family doctor, we try to explain to them what they should do in this regard. For instance the tinsmiths, I told them how to behave with the doctor, not to shout, to behave nicely. They understood this. [8]

They reacted very well in the community. They started to tell me their problems, that they have an ache here or there, and I would tell them to go and enrol with the family doctor and benefit from free prescriptions and medicine or examinations. And most of them understood and they enrolled. At that time, there were 2000 persons all in all and 550 were not enrolled. But I managed to enrol almost all of them. [9]

My first employment was in Bunești. I was not used to it in the beginning, I started performing the census. I took my sister with me, she was still a mediator and I took her along. I was nervous, but in time I saw that it was possible to work and the people there accepted me. On the first day when I got there I had no idea where the Roma community was. I just didn't know. I had never been to Bunești. I asked somebody and I found out where it was situated. At first, when they saw me there... when they see a stranger holding a pen and paper they all gather to see what is going on. Of course, at first they used to call me “Madame” I explained to them that I was of Roma descent that I want to perform a census on them, to have them in my evidence, to help them and to guide them. We developed a friendship but I had serious problems there with the vaccination because there are no means of transportation. That was my work in Bunești. Afterwards I transferred to Homorod. And you know why? Because when something political goes on, a lot of them go, probably from the Roma Party too, this my impression, that they promise things to them, you understand? And when I went there, they rejected me before I even had a chance to explain to them what my role was and what I wanted from them, to tell them that I wanted to help them as much as I could. Many of them rejected me saying “You all come and you

*promise us things and then you forget all about us.” But I started to explain to them what my role was, because they believed that I would lie to them and ask for something from them. Of course I explained to them that I was not going to ask for anything of them, and that the only thing that I could give them was a piece of advice. First of all, in the community where I am now, I am with them all day long, in Homorod, this is where I live. You must be very subtle to them, know how to speak to them not to impose to them to do things. The moment you tell them “you must do” they don’t like it. Very subtly you must tell them “what about doing this, this way, what do you think, would you like that?” and then immediately they do it...When they have a conflict, they come to the City Hall and I try to talk to both sides, concerning social problems, there are many social problems. I try to abstain a lot, even here at the City Hall or at the doctor’s, because the doctor is busy most of the time, it’s difficult, of course, he’s a doctor, and then if I see that he is not in the mood I go out, I go home and come back when she’s calm and we talk and that’s it. Sometimes I am angry with the ones in the community, I do shout at them, of course here in Homorod, not in Jimboș and Merchiaș. I withhold a lot, I do shout in Homorod. We’re on the same street and I shout at them to keep quiet and not to yell, not to go to the City Hall and shout I dare to because I know them very well. With the rest, I just shut up. [10]*

*At first it was hard for the community to accept us. They did not know what this was all about but little by little they started to understand. They weren’t necessarily scared they just didn’t know what it was about. We informed them that the children should be vaccinated; we had campaigns during that period, in 2004, 2005. They were scared about what was going to happen, that the children would get hurt, but they realised that this was a good thing, and I explained to them importance of this thing, that the vaccine was necessary for the children. That it protected them. It is very hard for them because they are very poor they live in harsh condition, not to mention their hygiene. There are no conditions there for children or parents. Towards the end we started to get along better, they started to understand me. In the beginning it was more difficult, the census was difficult but in the end they understood that it was good for them. From the point of view of health we evolved fine too, there were cases of TBC, and they received help from the hospitals and from the doctors. They realised that we were helping them and that it was good for them. My husband used to work in a restaurant. He started all this, he became preoccupied with the Roma. Since he was there, I knew what and how... I am also of Roma descent but... I had been working among Hungarians for a long time and it did not seem obvious to me. Nobody judged me because I was a Roma. I have never felt this, nor did my children but when I saw this community, and how they live I was shocked. I would like to help them more but this is all I can do for them and they are very thankful for this too. [11]*

*The Roma would ask me first “why are you around?” and I explained that I was a mediator, on the side of the Roma I told them what the situation was. I asked them if they had a family doctor or not, that we want to guide them, to help them, what they should do if their children are sick and so on. “You can come to me if you bring me a bagful of money” that is what they told me until they realised. A few of them were nice too, I talked to them and understood that they needed my guidance, and that is how more and more started to look for me. I was a mediator but they did not know they were asking where the “Madame” was or the “doctor” until I explained to them that I was not a doctor, but they could not say mediator; many of them still can’t. I am health mediator. Somebody came and asked for a health mediator, “I don’t know who is a health mediator but we have a lady of our own who helps us” ... In the beginning I used to buy biscuits for the children, I felt pity for them, and I even had some problems afterwards. They started to come to my house and ask for food. I started to tell them that I was not able to offer them any food, because that was the truth. When I can, I give you. They were upset but then they realised that it was hard for me too, with a small salary. [12]*

*I was completely down when I saw in what conditions they used to live. I had contacts with them before too but I was not a proud person or anything. I used to discuss to talk. But when I visited their homes for the first time, to tell you the truth, I was afraid. I know that they are dangerous too. But I knew how to talk to them, they knew my father for he was the Roma leader and many of them were happy to have met me. Ours don’t have any traditions, they have all kinds of names, but they don’t call*

ours in any way. They are people, they dress normally like everybody else, only a few of them speak Romani... I went to the community and I started from the beginning, from house to house. They were happy, I told them what I did, how I could help them and they were really happy. I asked them if they had family doctors, about their health, about their children their vaccines. We also talked about documents, IDs, houses, birth certificates. There are about 500 here. Half of them did not have any documents. There were some who didn't even have a family doctor and they were very happy when I explained that I was there to help them, to enrol them. I must've talked about everything with them. I would then visit them everyday and teach them about hygiene, and they would tell me that nobody would look at them at the hospital and I told them that the change has to start from them, to wear clean cloths when they go to the hospital or for the children, the same for if they went to the hospital dirty the doctors would not take them into consideration, they were disgusted by them... and I kept explaining what they had to do. When they saw that I visit them every day and talk to them about hygiene and children how to dress them, they liked it and they changed and I had only good words for them then. [13]

In the beginning it was more difficult with the community because there were many problems until they accepted that it was to their own advantage to be enrolled with family doctors, to have their documents in order, and to have everything in order. There were many problems with the doctors too. Some doctors did not want to enrol them, saying that they already had enough patients. They just didn't want to accept them because they were gypsies, they simply didn't want to enrol them. We faced many problems at the hospital too but in the end they got used to it. There still are problems, especially in Miercurea Ciuc, many, I don't know if you heard that they've been deported near the treatment water plant. It is a contagious terrain, infectious, I don't know how they moved them there, but they are to be found there for now. The good thing is that they gave them barracks, but what goes on there is terrible....[14]

For me it was easier to do my job because I live here and the community knows me. They trusted me more. I am the president of the youth with the Roma Party here in Harghita County. This is why they know me, it was a bit easier, but there are places where they don't even let the health mediator come in. Nor does the mediator know how to speak to the so the community must accept the mediator entirely. There must be trust, they must be understood too because you don't solve anything by being aggressive. They have their own leaders, and the leaders have their point of view in their community. When we had problems I tried to get to them in order to solve them, we discussed together in order to reach an agreement concerning their hygiene, the school. We tried to come up with an example and we went to a family where it was clean and we tried to explain to them indirectly that it's one thing to wash and be clean, because in this way the community accepts you, even the Hungarians. This is how they live, they're dirty, they go to school dirty. But what can one do, there's a lot of poverty. [14]

I work continuously. All day long, with anything. If by any chance they find me at home, they call me out at the window "are you at home?" they don't have any program, but they don't bother me. They understand when they come and they ask for something and I tell them that I don't have any time at that moment. Sometimes they run across me on the street and if I have pen and paper I write their request there on the spot. I don't have any problems with the people. My children and my husband help me too. [15]

Trust is very important, because when you work with the Roma, in order to be accepted you must be a Roma mediator, because you speak their language. There are many who do not understand even if you speak Romanian, they don't understand because at home they only speak their language... rarely they speak correct Romanian, and I help them out with this, I go with them... If they were to call me back and employ me again I would do it for them, because I keep on working even if I got fired. The only difference is that before, I was the one looking for them, but now they are the ones looking for me. They come to my house they call me, because I always gave them my number. I cannot tell them that I

*am not a health mediator any more. I tell them that I will go with them, to help them to solve what we have to solve. [16]*

*I am from Năsăud, and I've been married for 15 years, in Bistrița and I worked in Budacu de Jos. It seemed better than to work in a community that I did not know, and I thought that it would be easier like this, to earn their trust, and be more respected than in my village. You know, at the village everybody talks. I was wrong as I've been working here for one year now and I cannot complain about anything but in Budacu de Jos I got used faster to the people, they were warmer, more open, right from the start. Even if they didn't accept me, they did not know what I was doing until I went back to the house and made that database. I earned their trust quite hard; they did not know what I was doing there. I was talking about the health mediator they had no idea what it was until I conducted certain activities in the community and then they would ask for my help and support. In the beginning they thought I was a repentant, who they hated, they offended me too. "Will I find my place here?" I used to ask myself. At some point I felt like giving up, the work there was very hard. I'd better work with machines, animals, but not there, it was that hard. But every time I said that I was going to quit, the following day I would do my job more thoroughly. And this way, step by step I earned their trust, I was respected, I did many good things in the community and they started to appreciate my work. They would come to me and ask for my advice and support all the time. Even if sometimes they already knew what they had to do they would still ask: "What do you think, would it be ok, or can I do this, or not do that... I learned the Romani language after I married. When you go to the Roma community and you work for them, they see things differently, they think that you receive a lot of money for doing this, and something might happen, you have the power to change things or do something so that things will be bad for them. They are very suspicious. They are Roma, and they think that if a doctor is brought and he only examines the Roma, or in schools, what if they put only Roma children in schools. [17]*

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#### THE RELATIONSHIP WITH THE INSTITUTIONS AND WITH THE MEDICAL STAFF

Besides building and maintaining a relationship based on mutual trust with the Roma communities, the human part of the health mediator job is to create a climate of efficient collaboration with the family doctors, maybe the most important actors of the health system from the point of view of the patients. And this is not only because of the medical services that they offer but also because of their closeness to people, which should induce a quality in servicing those who come to them with a health problem they do have a certain vulnerability. The interview fragments below do not just reflect the experiences of the health mediators with the family doctors or the rest of the medical staff of the public health system, but they reflect the way in which the latter report to the Roma patients. We notice that some of them show a certain sensitivity towards disadvantaged categories, others want to correctly practice their job regardless of the social status or ethnicity of their patients, but there are some who treat the Roma differently, in a negative way. Concerning the discrimination of the Roma in the health system it seems to be more serious in hospitals. Personal discrimination is based on anti-gypsy prejudice and is less likely to occur in the case of family doctors. Some of them make an effort to neutralise the institutional discrimination that they are faced with due to their socio-economic situation and due to negative generalised perceptions of the Roma. The practice of the latter shows us that in order to eliminate this unequal behaviour we must overcome the barriers that limit institutional access to quality medical services for everyone and prevent the exertion of the right to health. At the same time, it convinces us that in order to eradicate institutional discrimination, personal efforts of the doctors do not suffice, and in this regard, a reform of all the medical system is needed in order to be able to ensure adequate budgetary resources and the implementation of affirmative measures that would ensure equality of chances in this domain. The problems of health and of access to medical services of the Roma are transmitted to us through the interviewed health mediator, and constitute a warning signal on the Romanian health system, which is now overwhelmed by its own systemic diseases and by the problems of a rather sick than healthy population.

*I was received by the doctor, who is a very, very good doctor and he explained what we should and what we should not do. He gave me my job description himself. [1]*

*We communicate well enough with the family doctors I say. Today a doctor called me and she asked me to help her find a girl... She must administer a BCG vaccine to her and she changed address. They took her out of the hospital without the vaccine, it happens for them to just leave. Many of them are afraid of hospitals they just don't want to stay in the hospital. She signalled this case to me, and I have to find her the following days, to identify her. [4]*

*In Vaslui they have a very good doctor, I have nothing to say. I could go see him for any problem... Now I found a gynaecologist who accepts to examine Roma women for free in the hospital. There were cases but I don't think that only in the case of Roma women, when the doctors to no grant enough attention when they should. [6]*

*The woman went it is true she would go many times for her child would catch a cold very often. Her little girl was one month old and she also caught colds quite often. They took her to the hospital and gave her just some powder and she cried all night long. They hospitalised all the Roma in the same annex. It did not matter what this child had or what that child had. This girl had a lung problem and bleeding diarrhoea. The woman was desperate that her child was continuously crying and all the night she mocked at that the other children were not able to sleep because of her child. At four in the morning the woman called the nurse: „Mrs. Nurse give me something for this child is screaming, she woke everybody up, and the women here are upset with me.” The nurse replied: “You gypsy, get back in the annex” and then this woman with her child in her arms hits her with her fists and then cuts her hand. That was when I got a phone call from the hospital and they told me: “I called the police, your gypsies are destroying the hospital” My gypsies were to blame. I go to the hospital to find out what it was all about. First, the director started: “Your gypsies are uneducated, they don't know how to behave, they are filthy and thieves” The head of the department was with the director downstairs as soon as I entered. She came with us but the director didn't. I start questioning the woman and the head of the department kept offending her: “Shut up you drowned, shut up if not I come to you and God knows what will happen to you. Stop talking, stop telling lies” Madame, I said, stop shouting at her, let her say what she has to say. The woman was crying and she was telling me what happened and the nurse was saying that she was preparing the forms in order for her to go home. And I told the assistant that if she wanted to prepare her forms to get her out of the hospital she had to take full responsibility for this. I said “I know what I have to do, to call the child protection and see how Roma children are treated here. If his skin is darker that doesn't make him human?” This happened here in the county hospital of Pașcani. She immediately took the baby girl from there and took her to the annex and brought another doctor and examined her again and administered medicine to her. I went there every day to see how they were treating the baby girl and they treated her. [7]*

*The doctor does not know what goes on in the community, I have to go and check. It's in their interest now to have as many patients as possible. The ones wearing traditional costumes are the loudest, when they wait there on the hall way of the hospital. They go altogether not one by one. They talk in a loud voice. When one of them is sick, many of them accompany him. This is their style; this is how they do it. You will never see a copper potter by himself; they feel more secure when there are more of them. They don't know how to express themselves because they are illiterate... and you know how things happen in our hospitals; if you don't have any money to give you keep your mouth shut. The people from the hospital do not understand, the family doctor seems to understand the difficult situation. [7/2]*

*As long as this hepatitis epidemic lasted, I had to accompany them for the tests, there were no funds, and it was hard to have all the sick ones examined. I faced difficulties, they would send me from one office to the other, because they didn't have any funds and I was surprised, I even specified this to the DPH of Buzău. It was very difficult with all this, the examination of the sick people, they would send me when here to the contagious diseases department, to the doctor who was not able to help me and*

*then back to the hospital. The hospital said that they did not have any, they would send me to the private laboratories in the city. They did not have any money, no money to perform a simple test. [8]*

*The doctors received me very well. You can imagine that as soon I showed up this burst of enrolments on the lists of the family doctor started. I did not have any problems with the family doctor. [9]*

*The doctors from the hospital refuse to receive them sometimes. When we had that case with the baby bitten by a rat... They were dirty, filthy smelly...the baby also dirty with blood and they refused to treat him. But I interfered and I gave them money from my own pocket and they attended to him then. This is it. The same goes for me when I go with my children I have to pay money from my pocket, but I tried, what shall I do, have them followed? A doctor from the Commission of medical experts for disabled people because this is what I do mostly. And the fact that I witnessed all this with my own eyes; and when somebody comes to get this degree, nothing. Maybe they give the fourth degree. You don't benefit of anything with this. I had him followed and last year he was arrested but without knowing how it all started. 9*

*The doctor behaves like this with everybody. When she is angry she is angry on everyone. She doesn't make any difference. Last week she came to the community with us, she took the baby to the hospital because one of the children that I previously mentioned is at the emergency care unit of the hospital. She even gave money to the girl who is not under aged, in order to have money for transportation to come back from Braşov. No, she does not discriminate; the community does not feel any discrimination either. There are many of them, from the community who have their own way of being. If they go somewhere, they are very daring, no audiences. The doctor does not appreciate this. I told her that I was trying to teach them as much as possible. I tell them not to have this daring attitude, here at the city hall too, when they come they ask "the Mayor, is he busy or not?" they go in and that is when I go and tell them to wait that the Mayor is busy. And then they wait, what can they do? [10]*

*We went to all the doctors. Of course, the family doctors were for the children, to be vaccinated, to have a family doctor and so on. Only a few Roma had a family doctor because before they had the lady-doctor. All Roma were enrolled on her list but she retired, she informed the clinic that she was going to retire but at that time there was no health mediator. Do you understand what I'm saying? She informed that she was going to retire in order for them to enrol to other doctors. Nobody cared about this. They did not know. Many of them are illiterate; they don't know how to read. They used to go to the office to see the doctor, but they did not have a family doctor any more. This is the rapture. The ones benefiting from social welfare, only a few of them have family doctors. After the lady doctor retired nobody else would accept them. That is when I filed a complaint to the DPH. I wrote in every report that we lack a family doctor and I also submitted it to the City Hall. Eventually God helped us and we got a family doctor and I started to enrol the Roma with her, but she was from Aghireş, and it wasn't long until she moved back there. And again the people here were left without a family doctor. I worked for three years in order to start all over again. You know what it's like; all the reports to the DPH, to the Prefect's Office...Not even the children benefit from vaccines because of this. This year, it's the fourth doctor who came and I had to do it all over again, enrolling them and everything. But at least we have her now... I've taken the women to the gynaecologist, maybe you don't believe me, and they put on an intrauterine device. They said that they didn't need medicine because they forget or their mother in law does not allow them to since this is their pride and glory, to have as many children as possible. [12]*

*I got along better with the family doctor honestly I tell you that she took all the Roma. And she said that that all the other doctors throw the shit on me. I would go to enrol them to other doctors as well but they would refuse, saying that they were not paid to have more than a certain number of patients. They would tell me to go to a certain doctor who accepted Roma patients. There are only a few men that I cannot enrol anywhere. I have called upon the Department of Public Health and they told me that if they are not enrolled by now, nobody has the obligation to enrol them. The obligation to*

*enrol is for children and pregnant women, mother and child, just that. It does not matter if they are ensured, they find reasons, they don't want to. And the hospital principal says the same, "why are they such arses, why." She says that she cannot interfere. There are four family doctors and around 8000 inhabitants in the city. [13]*

*It's the same with the family doctors. The same is happening now for I don't work as a health mediator but I do help them. The doctor is from Casinu, twice a week and the majority go to her because the other doctor only has about thirty or forty people. The one from Casinu, she has the majority, about six hundred persons. She comes here on Tuesdays and Wednesdays and I help them. They still call me to help them. I don't refuse them; I bring them what is needed against fleas and scabies, birth control pills and all sorts of other thing. I bring them to the doctor. There are another two community mediators in the village, they had to work too since I am not one any more, so they had to work and go to the sick people in the village, especially one of them is very proud, he does not want to go to the landfill. I said that he had to go towards the landfill, as there are people there too. No matter where they are you're supposed to look after them, I told him. He said that he's afraid not to get infected. I replied that it's easy to put this way. That's the kind of people that they are. They are under the authority of the local council just like we were, and when we came here the "communitaries" came too. They do the injections, bandages, measure the blood pressure anything. We were not allowed to do that since we did not graduate from the health high school, we would only mediate the relationship between the doctor and the patient. It is their duty but they don't want to do it. And if they do they should get paid. They don't really go among Roma and the thing is that the community assistant should take care of the sick, go to see them their houses, but they just stay there with the doctors and write prescriptions. [14]*

*The family doctors helped a lot. They never refused anybody since I am around, except if they did not have insurance. What can the doctor do if one has no insurance, no ID? But the child is received if he has a birth certificate. If he hasn't got a personal code number he cannot be examined, unless one pays for the examination. This is a new rule, she used to close an eye before, the doctor, and a mother with her child came. Of course she did not refuse her, she offered the first aid and sent her to the emergency unit. We only had one doctor who worked at the medical care unit in Valea Rece, there are many Roma there. The doctor's office was in Ogra but she took over the ones from Valea Rece too. She did not have any profit from this, it was a volunteer's work performed regardless of the existence of a personal identification number she wrote one two prescriptions, she somehow managed. Everybody went to see her. Here with the territorial medical care units the place remained rather empty because everybody went to see her. [15]*

*The doctors would refuse them as they had no insurance, they said that they could not hospitalise them. There was a woman whose heart had stopped and they did not want to receive her. They kept her in the hospital for two days and then they sent her home. It is very important to have somebody, even if it's not going to be me from now on, but at least to have a mediator to help them, one who works from her heart here in Timișoara. [16]*

## INTRODUCTION

The quantitative research of the perception of health mediators on the health system in Romania was achieved by applying a questionnaire to all active mediators when the project was conducted (December 2009 - April 2010). The questionnaires were distributed to health mediators in meetings of regional centres and were self-applied. The total number of valid questionnaires was 399.

The design of the questionnaires focused on seven dimensions: profile of the health mediators; the relationship with the Mayor; the relationship with the City Hall coordinator; the relationship with the members of the community; the relationship with the medical staff; the needs of the health mediators; access of the members of the community that they service to healthcare.

## PROFILE OF THE HEALTH MEDIATORS

The profile of the health mediators was built on the variables of the area of residence, year of employment as a mediator, level of education, source of recommendation for the health mediator position, number of beneficiaries served and type of employment.

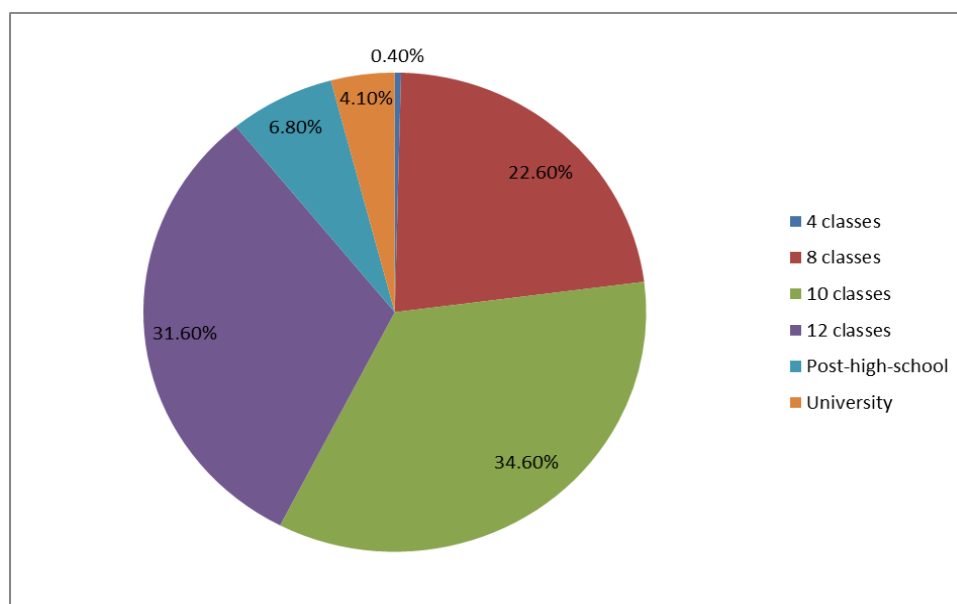
**The occupation of health mediator is completely feminised**, as there is not a single male respondent. More than half (56, 1%) of the health mediators in the sample activate in urban areas. Concerning the time of employment, two main streams may be observed: the first in 2002, when 15.7% of the mediators were hired and the second one from 2005 to 2007, when 69.7% of the mediators were hired<sup>21</sup>.

266 answers were registered to the question regarding education. Less of a quarter of the respondents mentioned that the last level of education is 8 grades or less. Most of the mediators completed 10 grades (34, 6%), or 12 grades (31, 6%). A mediator out of 10, (more precise, 10.9%) continued their education after finishing high school or a vocational school (Graph no. 1). The mediators with college or university education account for 13.5% of the mediators servicing in urban areas, and for 7.6% of the total mediators in rural areas.

The Roma party is the main source of recommendation for the position of health mediator (identified as such by 42, 1% of the respondents), and is followed by local leaders (17, 3%) and non-governmental organisations (12, 9%).

<sup>21</sup>It is about the year when the employed health mediators were still active at the time of conducting the survey.

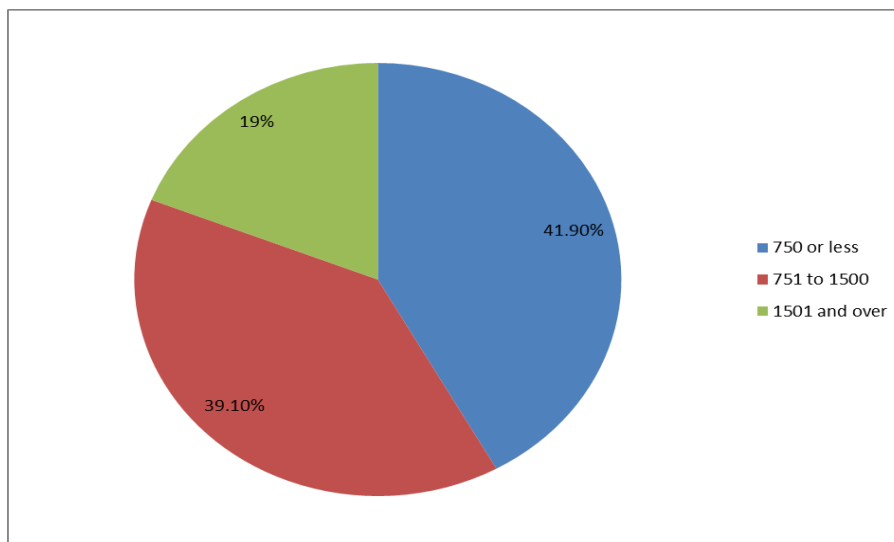




Graph no. 1. Distribution of health mediators according to their last level of studies

The sample mediators service around 110 and 5500 Roma, with an average of 1112 beneficiaries for each mediator (Graph no. 2). Although the Order of the Ministry of Health no. 619/2002 stipulates that the health mediator services Roma populations of 500 to 750 persons (children and women at reproductive age), 10.2 % of the respondents declared that they work with less than 500 Roma persons, and **19% mentioned that they work with more than 1500 beneficiaries**. It is true that the answers in the questionnaire represent a spontaneous estimation and do not make the distinction between the currently assisted persons and the ones who benefit indirectly from the activity of the mediator. In any case, the fact that a mediator out of five services a Roma population which is twice the size of the maximum foreseen in the Order of the Ministry of Health, is a matter of concern because it implies an overload of the mediator, and at the same time, inevitably reduces the time allocated to each member of the community. The communities where more than 1500 persons are served by health mediators are more often encountered in urban areas (22.4%, in comparison to 14.5% in rural areas), while for the communities of less than 750 persons the situation is exactly the opposite (45.5% rural, as compared to 39.2% urban).

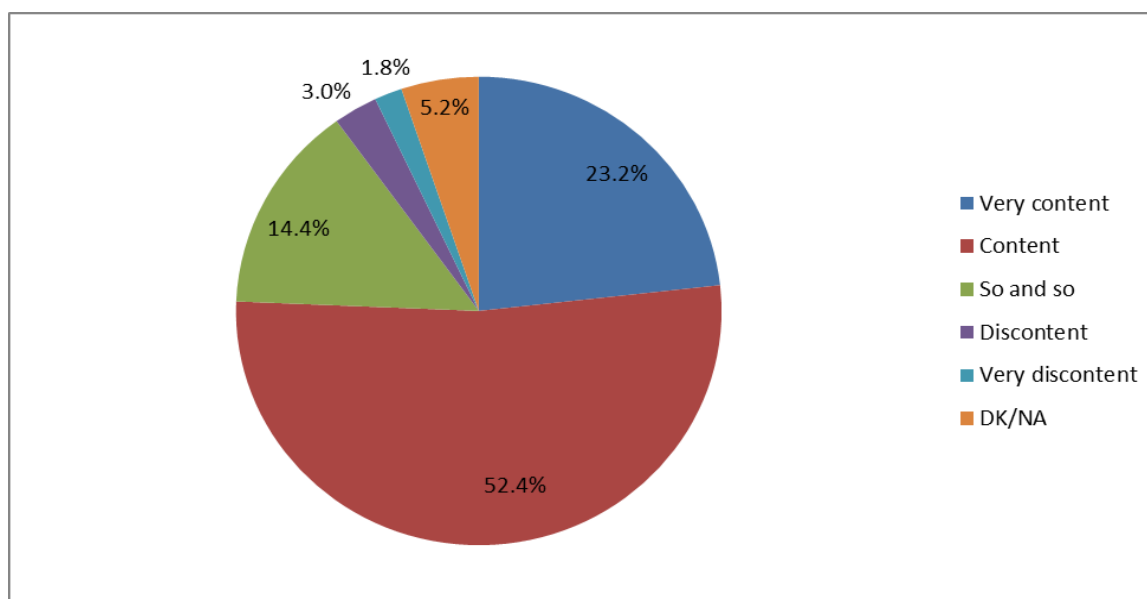
The insecurity regarding the work place is reflected by the reduced proportion of answers to the question concerning the type of contract with the city hall and the reduced proportion of the mediators with work contracts signed on undetermined period. Out of 399 mediators who filled-in the questionnaire, only 146 valid answers were registered; 70.9% of those indicated a work contract for a determined period of time.



Graph no. 2. Distribution of the health mediators according to the number of serviced persons

## THE RELATIONSHIP OF HEALTH MEDIATORS WITH THE LOCAL AUTHORITIES

Concerning their relationship with the Mayor, three quarters of mediators are satisfied or very satisfied:



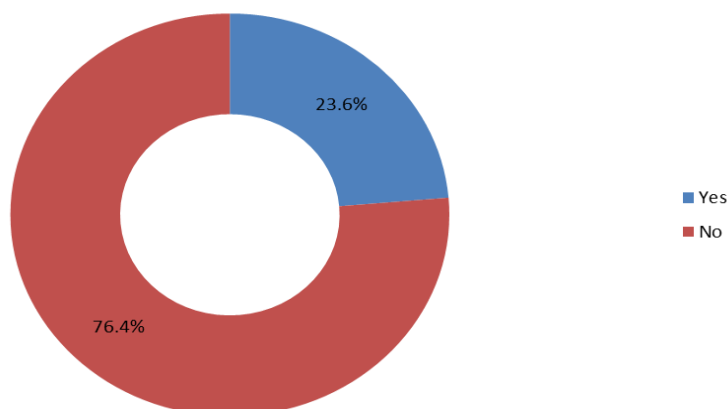
Graph no. Level of satisfaction of the mediators concerning their relationship with the Mayor

This question was followed by another question in which they were asked to justify the previous answer. The very happy or happy mediators of their relationship with the Mayor state that he is showing an interest in the problems of the Roma community; he is trying to solve the signalled problems; communicates easily with them; were receptive towards taking the mediators under the subordination of the City Hall. On the other hand, the unhappy or very unhappy mediators of their relationship with the Mayor believe that the latter does not understand the role of health mediation for the Roma, he does not show an interest towards the problems that the Roma community faces or even mention that the Mayor refused to take them in his subordination following the decentralisation process.

Regardless of the level of satisfaction of their relationship with the Mayor, the mediators were invited to mention the problems that they have come across when interacting with the former. Most mentioned **employment related issues (not paying the salaries on time, being hired on a part-time basis, not returning the money spent of transport between the serviced community and the city hall, excess of tasks, reduced time allocated to field work, the instability of their workplace). Faulty communication, repeatedly non-honoured promises and disproof of the professional legitimacy of the mediator** were also mentioned.

The same optimistic tendency of evaluation is registered concerning the perception of the relationship with the direct coordinator from the city hall: 84.7% are very happy or happy, 7.9% neither happy nor unhappy, while 0.8% state that they are unhappy or very unhappy. The relationship is regarded as satisfactory when the coordinator understands their attributions and recognises their competence and need of a health mediator; when they reach an agreement concerning the number of hours to be spent by the mediator at the city hall and the number of hours to be spent for field work or when the coordinator is open towards the problems of the Roma and contributes to the improvement of their situation.

Despite this optimistic presentation of the relationship with the representatives of the city hall, the action of the local authorities to take over into their subordination the mediators is regarded as a difficult process in some of the situations. Out of the 258 valid answers to the question "Were there any problems regarding your employment with the City Hall?" almost a quarter (23,6%) indicated the existence of such issues. (Graph no. 4). Among the mentioned problems were the refuse of local authorities to take over the mediators during the decentralisation process, taking them over after a period of time (which led to discontinuity on their work card), modifying their work contract and employing them for a determined period. According to the mediators, the local authorities invoked as main reason of their refuse to take over the mediators, the absence of funds (although the funds came from other sources than the City hall budget or that of the Local Council). In some cases, the authorities became receptive only when they learned that the health mediation programme is financed by the Ministry of Health, but in other cases, the regional centres had to intervene. A mediator mentioned that her employment was conditioned by her husbands' resignation; he was working as local Roma expert at the City Hall. More mediators mentioned that they were employed exclusively for the periods for which the salaries were paid from other source



Graph no. 4. Problems of employment at the City Hall

**The transfer from the Department of Public Health to the local authorities was achieved with a lower salary, changes in the work schedule and in their attributions.** The lack of information of the local authorities regarding the purpose of the health mediation system for Roma was a frequently mentioned problem and it is most likely to have contributed to the difficulties faced by the health mediators upon employment.

9% of the mediators consider that the activity that they conduct after the decentralisation is not in accordance with their job description. The former perform different administrative activities (archiving), supply information on the social welfare offered by the City hall, fill-in the files for social welfare conduct social investigations and solve various punctual administrative issues. Changing their job description significantly reduces the allocated time for health mediation:

Until September I conducted my activity in accordance with the job description but from October on things changed... I must do anything else but my work: receive files on woods and fill them in, files on gas... My field work is not respected. I only managed to visit the community twice during the last two months and that hurts a lot. The people in the community need me there.

The present questionnaire included questions regarding the receptivity of the City Hall coordinator concerning the problems that the health mediators face, the frequency of the interactions of the two and the number of visits of the coordinator to the Roma community serviced by the mediators. A number of 268 mediators answered the question: “How receptive is the City Hall coordinator to the problems that you face?” Three mediators out of four, (74.6%) assessed the person from the City Hall who coordinates their activity to be generally receptive, while only 1.9% believe the contrary, and 9.3% do not know or would rather not answer the question.

An open question of the questionnaire requested an example that would illustrate the relationship between the respondent and the coordinator of the City Hall. As positive examples, the mediators mentioned different situations in which the mediator identified a social or economic problem in the community serviced, presented it to their coordinator and the latter did his best to solve it, even if it was not necessarily part of his attributions:

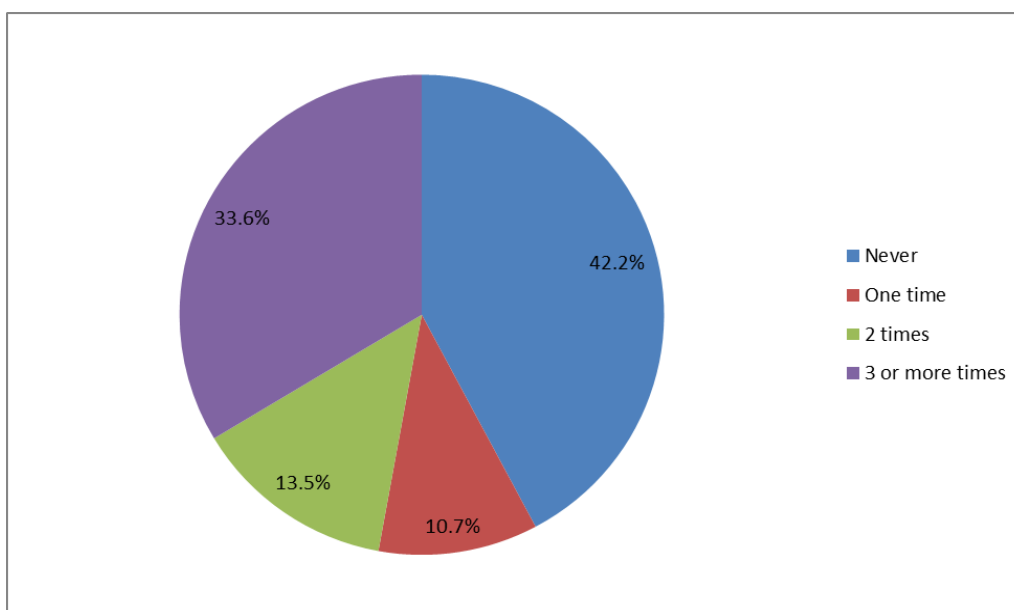
A handicapped under aged was in difficulty, his parents being unconcerned with his state and fate, and he, (the coordinator) visited his family and acted in a way that allowed an escape from the difficult situation. The under aged now benefits from social protection.

Negative examples of collaboration mentioned referred to indifference, lack of preoccupation towards the problems of the Roma and not recognising the occupational legitimacy of the health mediator:

I waited for him in front of the office for 3 hours and when he came he told me that he did not have any time and that I should leave the reports to his secretary. I do not consider this a normal employer – employee behaviour.

Concerning the communication between the mediators and the coordinator of the City Hall, it takes place as an average at least 3 times per month in 61.9% of the cases. 14.4% of the respondents mentioned that they communicated with their coordinator 4 to 8 times during the three months period prior to the application of this questionnaire, while 10.4% of the mediators asserted that they communicated with the mediator 1 to 3 times during the same period. Only 4.1% of the mediators never communicated with their coordinator during the past 3 months.

To the question: “During the past 3 months, how many times did your coordinator accompany you when performing fieldwork?” 244 valid answers were registered (Graph no. 5). A polarization of the answers may be observed: the coordinators tend not to accompany the health mediator when performing fieldwork (42.2% of the cases), or to accompany her once a month (33.6% of the cases).

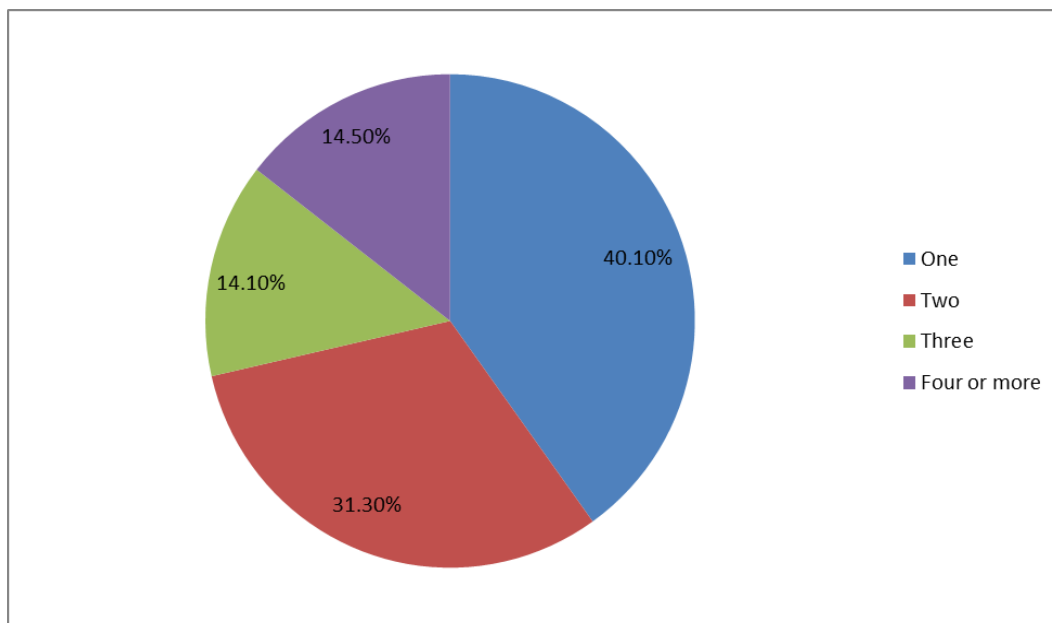


Graph no. 5. Number of visits to the Roma community during the past 3 months, performed by the City Hall coordinator together with the health mediator.

## THE RELATIONSHIP OF HEALTH MEDIATORS WITH MEDICAL AUTHORITIES

Most of the mediators collaborate with only one family doctor (40.1%) or two family doctors (31.3%) (Graph no. 6). A larger number of the mediators who activate in rural areas collaborate with one or two doctors as compared to the mediators from rural areas. (77.2%, as compared to 64.6%). The statistically significant difference (chi-square = 8,26; df = 3;  $p < 0.05$ ), is probably based on a higher dispersion of the Roma communities in rural areas in comparison with urban areas.

A slight positive correlation may be observed ( $R=0,03$ ) between the number of patients serviced by the health mediator and the number of doctors with which the latter collaborate. In consequence, 75.2% of the mediators working with 750 beneficiaries at most collaborate with one or two doctors, as compared with 69.1% in the case of mediators who service between 751 and 1500 persons, and 68.9% of the mediators who work with more than 1500 persons. The difference is not statistically significant.



Graph. no. 6. Distribution of the health mediators according to the number of family doctors that they collaborate with.

To the question "During the past 30 days how many hours did you spend at the doctors' office?" 248 valid answers were registered. More than half of the mediators (56.4%) spend less than 10 hours per month at the doctors' office, while almost one third (32.3%) spend more than 16 hours per month.

An analysis of the mediators' profile that spend 5 hours or less in the doctors' office shows a difference between mediators whose job description suffered changes following the decentralisation and the ones who still have the same attributions. In consequence, 56.5% of the mediators whose job description was changed spend 5 hours or less at the doctors' office in comparison with 39.1% of the mediators who have the same job description. The difference may be explained by the City Hall administrative attributions of the mediators, imposed by the changes of their job description, by which they were requested to perform social assistance activities (e.g. social enquiries for the beneficiaries of the subventions granted by the City Hall) or to spend a considerable part of their time at the office. All these requirements led to a reduction in the time dedicated to health mediation, an indicator being the decreased length of interaction with the medical staff.

The questionnaire included two questions designed to measure communication with the medical staff. The first question targeted the quality of the communication whereas the second question enquired on the efficiency of the communication. To the question "How well do you communicate with the medical staff?" 271 valid answers were registered; 91.1% of the respondents considered their communication with the medical staff as being good or very good. To the question "How efficient do you communicate with the medical staff?" 34.7% of the mediators answered "Efficient", and 53.9% answered "Very efficient".

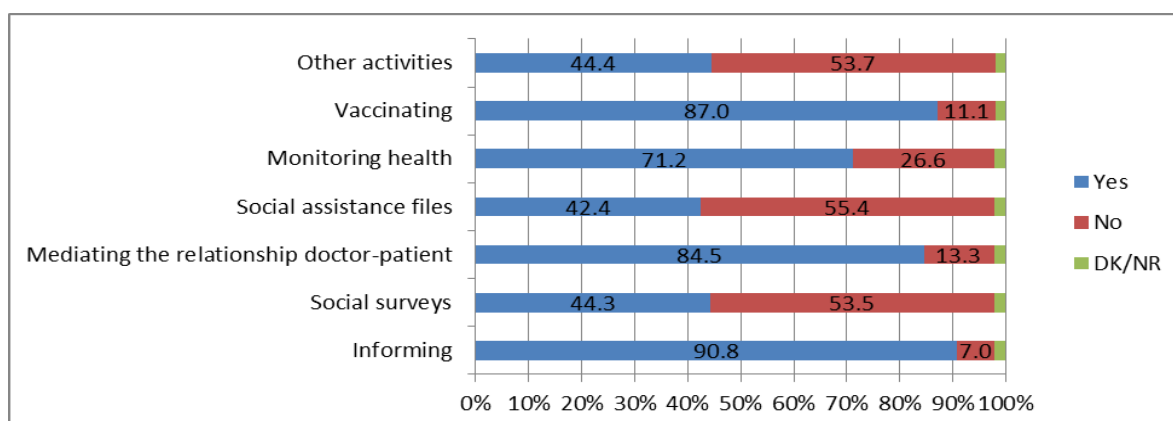
As positive aspects of the collaboration with the medical staff, the mediators mentioned the field work visits on which they were accompanied, receiving relevant information concerning the main affections and prevention and treatment, the possibility of calling the doctor to the community outside of his working hours when the necessity arises, and their agreement with certain doctors regarding free-of-charge examinations of uninsured Roma patients. On the other hand, the mediators mentioned

situations in which the doctors refused to enrol on their lists certain Roma patients, and situations in which Roma patients have been treated with indifference.

## THE RELATIONSHIP OF HEALTH MEDIATORS WITH THE MEMBERS OF THE ROMA COMMUNITY

The relationship of the mediators with the members of the community that they service has been operated by a set of questions concerning the frequency of their visits to the community, the purpose of their visits, and their relationship with the local leaders, the voluntary actions deployed. 87.2% of the mediators declare that they performed an average of 5 visits per month to the community that they service during the period of three months prior to the application of the questionnaire, while only 4.8% declare that they visited their serviced communities on average of 3 times or less during the same time interval.

More than three quarters of the community visits targeted the increase of the information level of the Roma concerning aspects related to health, mediation of their interaction with the medical staff or immunisation activities.



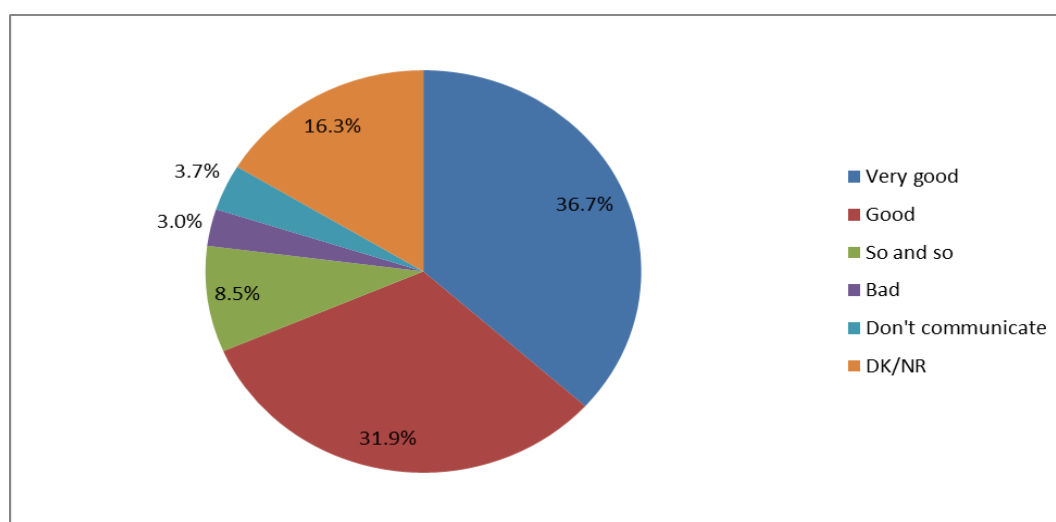
Graph no. 7. Purpose of the health mediators visits to their serviced communities

The activities of informing the Roma were conducted on subjects such as: family planning and methods of contraception (80 cases), personal hygiene and of the household (58 cases), importance of vaccination (55 cases), seasonal flu and respiratory viruses (38 cases), tuberculosis (35 cases), AH1N1 flu (32 cases), sexually transmitted diseases (21 cases), importance of breastfeeding (18 cases), hepatitis (15 cases), cervical cancer (11 cases), breast cancer (8 cases), cancer in general (5 cases), healthy alimentation (4 cases), diabetes (3 cases), correct administration of antibiotic (2 cases), harmful consequences of alcohol and tobacco (2 cases), child obesity (1 case) and osteoporosis (1 case). During the visits, different informational materials have been distributed from doctors and assistants with whom they collaborate, the Public Health Authority and non-governmental organisations (the Romanian Association against AIDS – RAAS).

At the same time, the mediators covered other issues faced by their serviced communities during their informational visits such as the importance of school attendance, domestic violence, discrimination, eradication of begging activities, child abandon in maternities and early marriages.

Some of the health mediators willingly perform volunteer activities not contained in their job description for the community that they service such as: helping out people with social problems; school mediation actions; observational participation to social enquiries; participation to cleaning and hygiene activities, collection and distribution of cloths and food supplies, fund-raising for a surgery.

To the question concerning the relationship with the informal leaders of the Roma community two-thirds of the respondents (68.6%) stated having a good or very good relationship. At the same time, 3.7% declare that they do not communicate at all with the leaders of the community, and the percentage might be even higher taking into account the proportion of those who did not answer (16.3%).



Graphic 8. The relationship of the health mediators with the leaders of the community that they service

## THE NEEDS OF THE HEALTH MEDIATORS

The health mediators indicated **three types of needs – material, of stability and of professional development**. The category of material needs includes: reimbursement of transportation costs or ensuring transport subscriptions (59 cases), receiving supplies/materials supplies (53 cases), receiving phone cards or reimbursement of phone communication expenses (51 cases), increased salaries and/or receiving financial stimulants (16 cases), receiving cellular phones (12 cases), receiving food vouchers (6), receiving computers (6 cases) and ensuring a work space/office (2 cases). The category of the need for stability includes: the desire to have a permanent work contract, (15 cases) full-time work contract (1 case). The category of professional development the wish to benefit from trainings in fields related to health mediation was included (10 cases) the wish to receive leaflets and other informational materials (2 cases).

To the question regarding continuous formation (“Enumerate five domains in which you would need continuous training”) 144 mediators answered. Training courses on legislation (especially regarding the law of public administration and human rights) were invoked by the participants (78 mentions), followed by first aid trainings and initiation in informatics (each of them mentioned 22 times). We grouped the answers on three categories: information regarding the main affections,



methods of prevention and treatment (107 references); personal and professional development (100 references) and legislation and combat of discrimination (84 references):

Medical information	Personal and professional development	Legislation and combat of discrimination
Cancer (cervical, breast, prostate) – 28	First aid – 22	Legislation and human rights– 78
TBC – 13	Initiation in informatics – 22	Combating discrimination – 6
Reproductive health – 12	Communication – 16	
Neonatal care – 11	Project drafting – 12	
Family planning – 11	Social assistance – 7	
Sexually transmitted diseases – 10	Health mediator training – 6	
Hepatitis – 4	Training on public administration – 5	
Diabetes – 4	Conflict mediation – 3	
AH1N1 – 4	Medical assistance – 3	
Immunisation – 4	English – 1	
Drug abuse – 2	Roma history – 1	
Chronic diseases – 1	Psychology – 1	
Nursing care – 1	Issue of identification papers – 1	
Paediatrics – 1		
Heart diseases– 1		

**Table no. 1. Domains in which mediators appreciate that they would need continuous training**

To the question „In your opinion, what should Romani CRISS do to support you?” 142 mediators answered. The first identified need is that of offering support to the mediators in their activity (41 references) and ensuring a permanent work contract (19 cases), lobby to the Ministry of Health for the continuation of the programme (44 references), and collaboration with the city halls the Mayors’ Associations (9 references). The second direction concerns organising trainings (32 references). Collaboration between Romani CRISS and the mediators, by having frequent meetings and fieldwork was specified 27 times. Other answers targeted financial support from Romani CRISS, by

reimbursement of transport costs and granting of financial stimulants (12 references); granting financial support, cell phone SIM cards (5 references); involvement of the mediators in other projects conducted by Romani CRISS (6 references); and ensuring the evaluations of the activity of the mediators (2 references).

To evaluate us (not by questionnaires) but by tests from the medical and social domain; to centrally present their wishes, results of the work in order to be permanently employed; visits to the serviced community; to ask for information about me to the local authorities, to support me in the relation with the family doctor, by explaining my attributions to the latter; the salary is of 650 lei, they should insist regarding the pay scale.

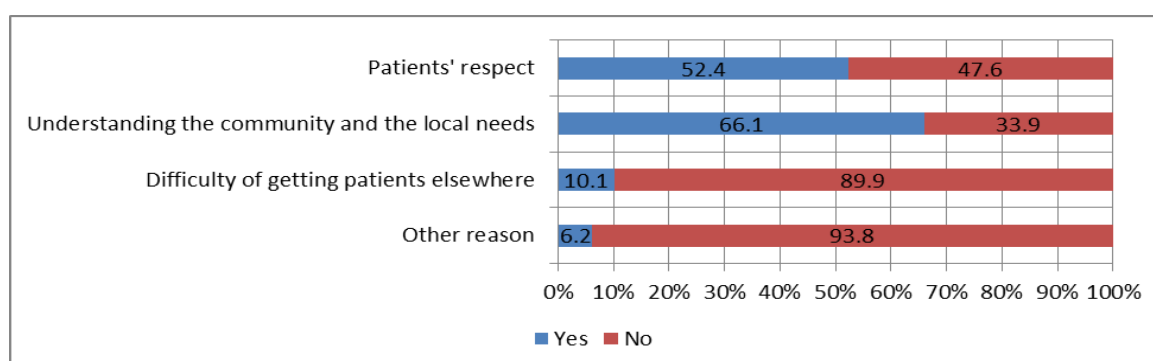
## PROFILE OF THE RESPONDENTS

The questionnaire dedicated to doctors has been applied on a nationally representative sample of doctors who service Roma communities or have more than 100 hetero-identified Roma patients of their list. The volume of the sample is of 935 subjects, and the highest admitted standard deviation is  $\pm 3.1\%$ . 52,2% of the doctors (488 cases) belong to the urban area and 47,8% (447 cases) to the rural area. The area of residence refers to where the doctor works and not to his/her home address. The questionnaire did not include questions on the area of residence, domicile of the doctor or distance between his domicile and the office where he operates.

More than three quarters of the subjects (75.8%) are women, the same tendency being observed both in rural (75.4%), and urban areas (76.2%).

The number of years of work with Roma patients is higher than 10 years for 68.9% of the doctors in the sample; 7.6% have Roma patients for less than 3 years. 1.9% of the doctors did not supply any information regarding their work experience with Roma beneficiaries.

To the question “What motivates your fidelity as a family doctor towards the Roma community that you service now?”, a multiple choice question, two thirds of the subjects (66.1%) mentioned a good knowledge of the community and of peoples’ needs, and 52.4% insisted on the respect shown by the patients:

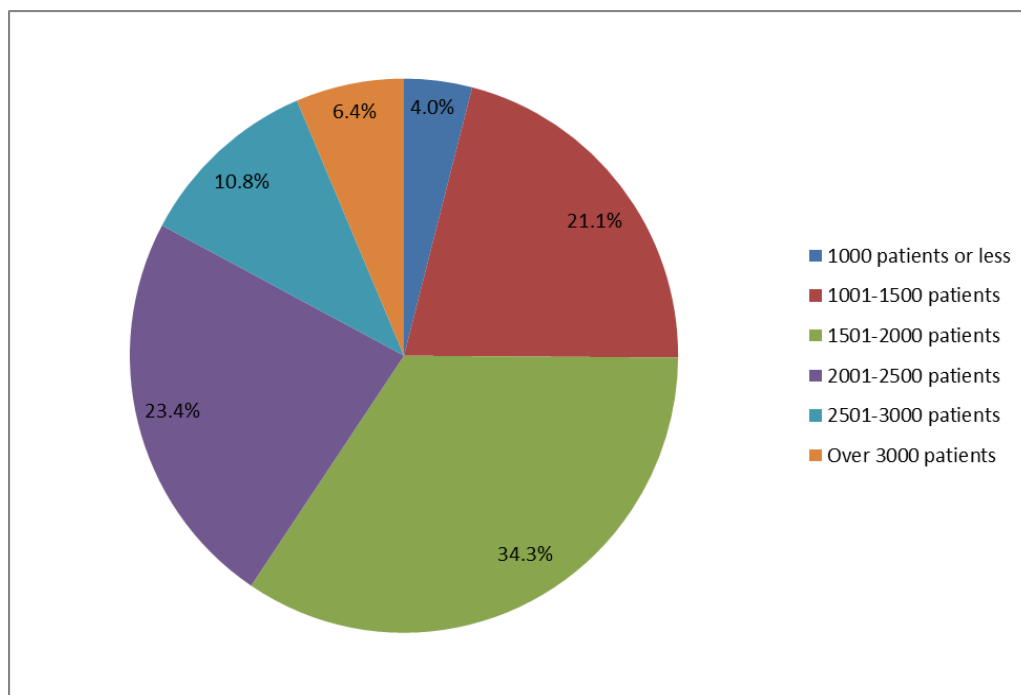


Graph no 1. Motives of the doctor's fidelity towards the serviced community

The ones who invoked other reasons made reference to the pleasure of working in the serviced community and to the absence of prejudice (33 cases); the habit of working with the patients he has (12 cases); short distance between their domicile and the doctors' office (3 cases); age (3 cases) the desire to help the community (2 cases). They also mentioned very good communication with the health mediator, the pleasure of working in the specific locality, financial remuneration, religious precepts, and diverse pathology in the community.

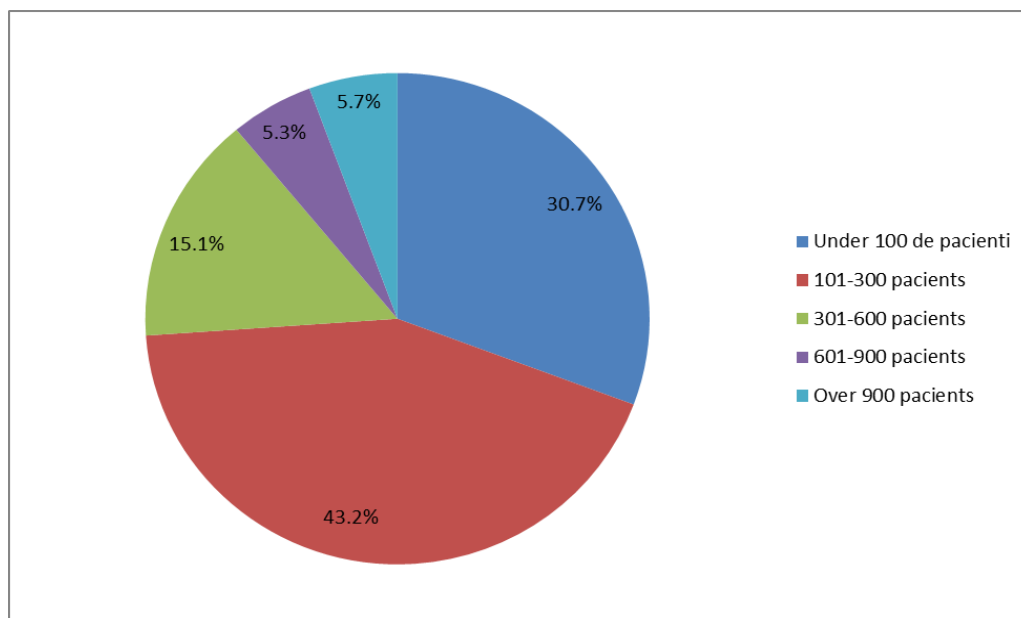
## SERVICED ROMA PATIENTS

The lists of patients of the doctors from the sample number between 100 and 5500 persons, with an average of 1983 persons on the list. 78.8% of the doctors have enrolled on their lists between 1001 and 2500 patients:



Graph no 2. Distribution of family doctors according to the total number of patients on their lists, regardless of their ethnicity

The number of Roma persons on the list of patients as declared by doctors, ranges from 10 to 3000 persons, with an average of 288 persons. Almost three quarters of the doctors, (73.9%) declare that they have on their lists 300 Roma patients at most, while one out of 20 doctors (5.7%) states to have over 900 Roma patients enlisted



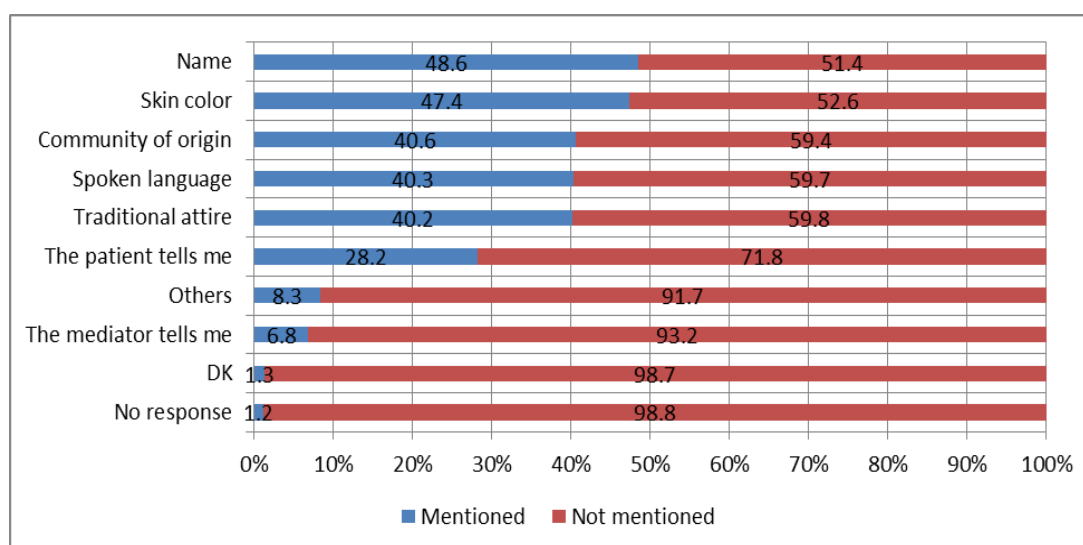
Graph no 3. Distribution of the family doctors according to the number of their enlisted roma patients

The percentage of Roma persons out of the total of the listed patients is situated between the values of 0.4% and 93.3%, with an average of 15.1%. The percentage was calculated by dividing the declared number of Roma patients to the total number of Roma patients on the list, and the result was multiplied by 100. The Roma patients represent at most 5% of the total of the list of patients for almost

a quarter of the doctors (24.4%); between 5.01% and 10% for almost a third of the doctors (31.5%); between 10.01% and 25% for 26.2% of the doctors; between 25.01% and 50% for 13.9% of the doctors. Only 4% of the family doctors who service Roma persons have a percentage of patients higher than 50% of their total list of patients.

## IDENTIFICATION ELEMENTS OF ROMA ETHNICS

**Identifying the affiliation to the Roma ethnicity is generally based on name, skin colour, community of origin, spoken language, and attire** (Graph no. 3). More than a half of the family doctors who activate in the urban areas use skin colour as indicator of the Roma identity (50.4%, as compared with 44.1% in the case of rural area doctors). The difference is found at the limit of statistic significance ( $\chi^2=3,759$ ;  $df=1$ ;  $p=0.053$ ). Choosing skin colour to identify Roma patients is not correlated with the number of communities serviced by the doctor neither with the percentage of Roma patients who are found on the lists of patients.



Graph no 4. Elements by which doctors determine whether their patients are roma or not

Also, almost half (49.5%) of the family doctors who service Roma persons state that they have discussed about Roma history and traditions with their patients. The way in which the question was conceived does not allow us to approximate the percentage of doctors who have discussed about traditional healing methods or about the cultural provisions that maintain the healthy state of people belonging to Roma communities.

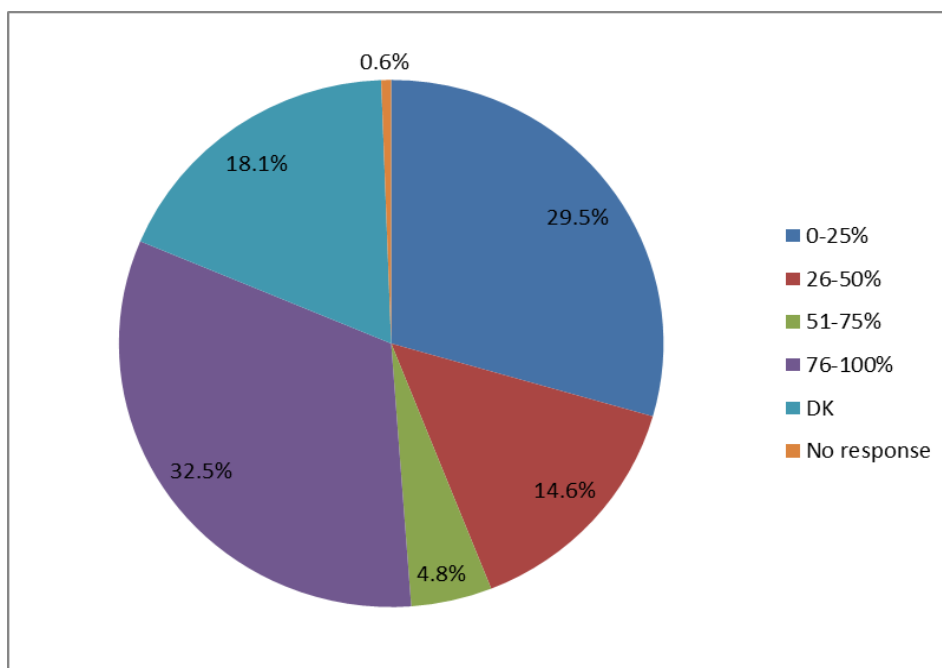
## THE ROMA POPULATION EXAMINED DURING THE PAST MONTH

The questionnaire included questions regarding the number of Roma patients examined, and the approximated percentage of Roma ethnics, both in the case of the insured as well as for those who were not insured. The percentage of Roma in both cases was estimated by the family doctor.

During the month previous to the study, a quarter of the doctors (25.8%) examined as much as 300 insured persons; 60.1% examined between 301 and 700 patients; and 14.1% have examined more than 700 patients. The percentage of Roma patients out of the total of the insured patients examined during this interval was below 20% in the case of 59% of the doctors; between 21% and 60% in the case of 24.4% of the doctors, and higher than 60% in the case of 4.9% of the doctors. 11.7% of the respondents were not able to offer an answer to this question.

Concerning the uninsured persons, 8.9% of the doctors declared that they did not examine such patients. 61.3% of the doctors examined at most 50 uninsured patients, 10.3% of the doctors examined between 51 and 100 patients and 4.2% of the doctors examined more than 100 patients. 15.7% of the doctors were not aware of, or preferred not to answer the question concerning the number of uninsured patients examined during the past month.

Out of the doctors who declared that they offered medical services to the uninsured, appreciatively 10% did not examine any Roma patients, while 25.5% estimated that all patients who benefited from medical examination and did not have medical insurance were Roma.



Graph no 5. Estimated percentage of Roma patients out of the total number of uninsured patients examined during the previous month

## REASONS THAT DETERMINE THE ROMA TO SEE A DOCTOR

Over two thirds of the doctors, (69.7%) consider that the main reason for which Roma people come to the doctor is for emergency affections. At the same time, 13.7% of the doctors consider that Roma patients mostly undergo prevention medical examinations (9.2%) or routine medical examinations (3.9%).

## HEALTH CONDITION OF ROMA PERSONS

### MOST FREQUENTLY DIAGNOSED AFFECTIONS

Given the nature of the research instrument used (questionnaire-based enquiry) the state of health of the Roma has been identified based on the most frequently diagnosed affections by the responding family doctor. All percentages indicated in this subchapter refer to the doctors who identified affections as being the most frequently occurring in practice, and not to the persons suffering from the affection in question. In order to offer a more complex image of the health condition, the

questions related to the first affection target both the Roma population and the total population enlisted with the family doctor.

In the case of **all patients**, regardless of their ethnicity, hypertension has been identified by more than two thirds of the family doctors included in the sample, (more precisely, 67%) as main diagnosed affection. One doctor out of 6 (17.6%) faces acute respiratory or digestion diseases. Doctors also identified as main diagnosed health problems heart affections and angina pectoris (6.6%), lung affections (2.5%), diabetes (0.9%), liver diseases (0.6%), rheumatic affections (0.6%), urogenital affections (0.5%).

Hypertension represents the main diagnosed affection in the case of more than three quarters, 75.4% of the family doctors who activate in rural areas, and more than 59.4% of the family doctors who service urban communities. Acute respiratory or digestion diseases have been mentioned as main affections in a higher percentage for urban areas 22.1% as compared to rural areas 12.8%. The same tendency has been registered in the case of heart affections and angina pectoris, 8.6% in rural areas and 4.5% in urban areas, and lung affections – asthma, chronic bronchitis, BPOC, tuberculosis, 2.9% for urban areas and 2.0% in rural areas.

In the case of **Roma patients**, hypertension was mentioned as main diagnosed affection by most of the family doctors (37.5%), followed by acute respiratory or digestion diseases (31.7%), lung affections (11.7%), heart affections (5.3%), rheumatic affections (1.8%), gastric ulcer, duodenal ulcer and gastritis (1.6%), diabetes (1.4%), liver or billiary diseases (1.3%), dermatological affections (1.2%), parasites (1.0%) and urogenital affections (1.0%). In comparison with the rest of the patients on the lists, in the case of the Roma patients, acute respiratory and digestive affections occur more frequently (31.7%, in comparison with 17.6%). Lung affections also have a higher incidence as main diagnosed affection among Roma patients (11.7%, as compared to 2.5%).

For Roma patients, just like for the total population of patients, hypertension is identified as main affection in rural areas in comparison to urban areas, 43.4%, respectively 32.2%. On the other hand, heart diseases and angina pectoris appear as more frequently occurring affections for the doctors in urban areas (7.2% in comparison with the doctors in rural areas 3.4%).

In the case of **adult male persons**, hypertension represents the main diagnosed affection by the family doctors both for the total population of patients 53.5%, and for the Roma patients 34.7%. Lung affections are diagnosed in a higher proportion as main affection in the case of Roma male patients, 16.8%, rather than in the case of all men on the list 4.8%. In the case of Roma male patients the following diseases have been mentioned as main affections: acute respiratory or digestive affections by 13.8% of the doctors, heart affections or angina pectoris 7.6%, liver or billiary diseases including cirrhosis and chronic hepatitis, 3.6%, affections of the prostate 3.3%, gastric or duodenal ulcer and gastritis 3% and trauma 2.6%.

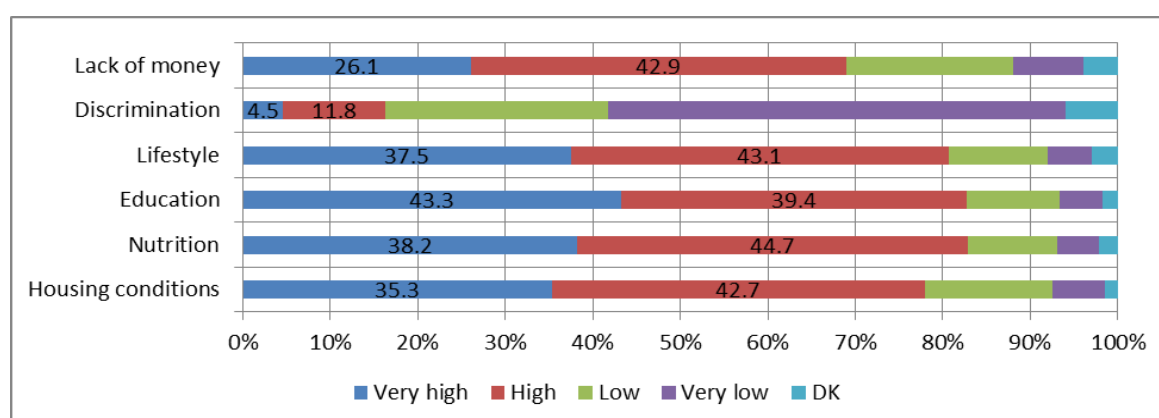
In the case of **adult female persons**, hypertension is also considered by the family doctors as the most frequently occurring affection both for Roma women 28.3% and for all the women on the list of patients, regardless of their ethnicity 49.5%. In the case of Roma women, the main mentioned affections were acute respiratory or digestion affections 18.8%, genital affections 15.3%, lung affections (asthma, chronic bronchitis, chronic obstructive pulmonary diseases, tuberculosis) – 7.3%, heart affections and angina pectoris 3.7%, rheumatic affections 3.5% and bone articulation diseases 2.8%.

In the case of **children**, most of the doctors identified acute respiratory or digestion affections 74.7% of all cases and 72.5% in the case of Roma children. Lung affections are considered to be the main affection of Roma children by 6.3% of the doctors, and of the total number of children on the list

by 7.9% of the doctors. Parasites are regarded as main affection by 5.6% of the doctors in the case of Roma children and by 3.3% of the doctors in the case of the total number of enlisted children.

## PERCEPTION OF THE DOCTORS CONCERNING FACTORS AFFECTING HEALTH

More than 80% of the doctors consider that the alimentation, education and life style influence to some extent, the state of health of their enlisted Roma patients. The housing conditions have been mentioned by 78% of the respondents, while the lack of money has been indicated by 69% of the doctors. On the other hand, only one doctor out of 6 considers that discrimination influences to some extent the state of health of their Roma patients.



Graph no 6. Doctor's perception concerning factors influencing the health condition of Roma patients

The way in which the question was framed does not allow us to precisely identify the point of view of the doctors concerning the impact of discrimination on health. Two interpretations are theoretically possible: doctors appreciate that between discrimination and the state of health there is no connection, either they consider that their enlisted Roma patients are not discriminated against. The first interpretation is less probable, given the fact that the existence of discrimination is a limitation of the right of the victims to good-quality education and integration on the labour market, and it represents an obstacle in ensuring decent lodging conditions. The second interpretation presents two possible ramifications in its turn: either Roma patients are not victims of discrimination in their relationship with the medical staff, or they are not victims of discrimination in our society in general. A future research will have to enquire on the perception of the doctors who service Roma communities concerning discrimination against Roma patients. The following could be assessed in this regard: experience of the discrimination against Roma in day to day life, discrimination in relation with the state authorities, discrimination in relation with the medical staff, the direct and indirect impact of discrimination on the health condition, the consequences that it generates, the health condition itself, responsibility of discrimination against the Roma, etc.

## ACCESS TO HEALTH SERVICES AND THE DOCTOR PATIENT INTERACTION

### ENLISTING TO A FAMILY DOCTOR

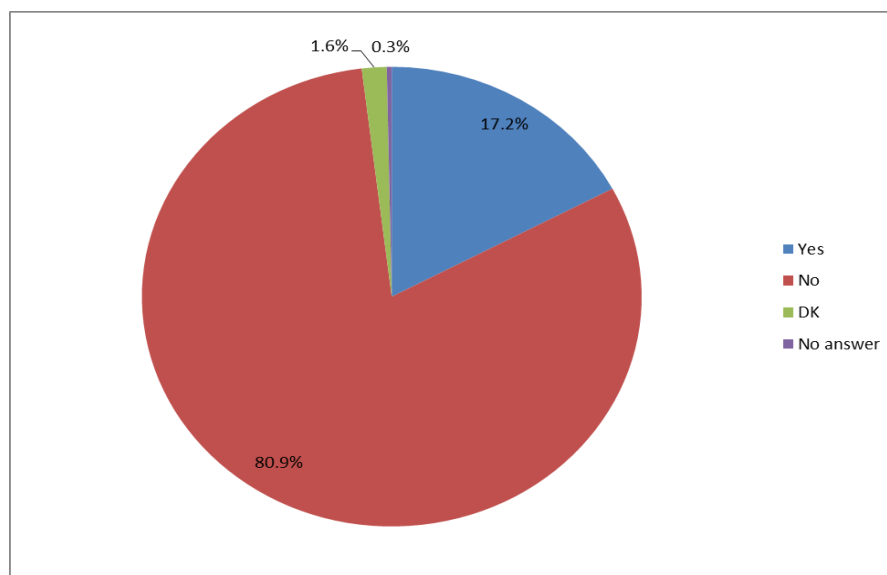
**All patients, regardless of their ethnicity.** To the question “Did it happen for you not to enlist patients on your lists although they would’ve have wanted to enlist?”, 935 subjects answered. Four



doctors out of five (81,2%) declared that they never faced the situation of not enlisting somebody on their patient list, while 18,2% admit to have refused to enlisting patients. Not enlisting patients is a phenomenon that occurs more frequently in the urban area where 22,1% of the doctors declare that they have not enlisted on their lists wilful patients, than in rural areas, where only 13.9% of the doctors faced such a situation. The difference is statistically significant (chi-square = 11,402; df = 2;  $p < 0.05$ ).

Out of the 170 de doctors who have not enrolled on their lists persons who would have wished to enrol, 37.6% invoked the lack of their medical insurance; 35.3% stated that they already had a large number of patients that did not allow enrolling new patients; and 28.2% have declared that the persons willing to enrol had no identification papers, and for this reason, they could not be enrolled. Other reasons not to enrol them were inadequate behaviour of the persons in relation with the medical staff (22.9%) and the presumed lack of education of the persons in question which would have rendered communication difficult (8,2%). There were some isolated cases in which patients had withdrawn from the lists and then wished to re-enrol but were not received anymore (4 cases); situations in which the doctor did not want start a conflict with his fellow colleagues on whose lists the patients in question would have been previously enrolled (3 cases); situations in which the person who wished to enrol did not have his/her domicile in the serviced locality (one case); and situations in which the doctor appreciated that the parents do not bring their children for examination periodically (one case).

**Roma patients.** To the question „Did it happen not to enrol Roma patients on your lists although they wished to enrol?” 935 subjects answered. 17,2% o them declared that it happened not to enrol Roma patients.



Graph no 7. Experience of the refuse to enlist Roma patients

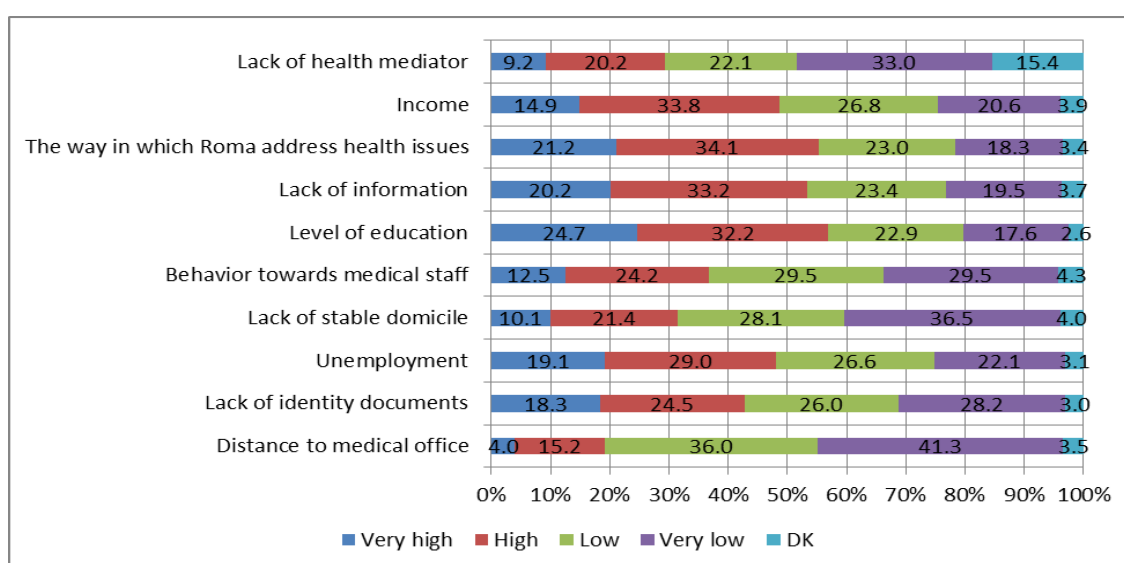
Not enlisting Roma persons is more frequently occurring in urban areas, where 21.5% of the doctors mentioned such situations, rather than in the rural area where only 12.5% of the doctors did not enlist Roma patients on their lists.

Out of the 161 doctors who declare that they did not enlist Roma persons who had expressed their desire to be enlisted, 49.7% motivated that the latter did not have medical insurance; 32.3% mentioned the lack of identification papers, that made their enlistment impossible; and 28% declared that the volume of the patients already enlisted did not allow them to enlist new patients. The doctors have explained not enlisting a Roma person due to their inadequate behaviour (26.7%) and their low level of education, which led to misunderstandings (6,2%). Isolated, it has been brought into discussion

that the parents do not bring their children for periodical examinations (4 cases) and situations in which the patients had withdrawn from the lists, and then wished to come back but they were not accepted any more (2 cases).

## FACTORS LIMITING THE ACCESS TO PRIMARY MEDICAL SERVICES

Doctors believe that the main factors that limit the access of Roma persons to primary medical assistance services are their level of education (56,9%), the way in which the Roma population treat their health issues (55,3%), lack of information (53,4%), their income level (48,7%), and the absence of an occupation (48,1%). On the other hand, there is also the distance between the patients' house and the doctors' office which is regarded as an obstacle by 19.2% of the respondents. It has been remarked that 15.4% of the doctors don't know in what measure the absence of the health mediator influences the access to primary medical services, percentage that could be interpreted as lack of knowledge of the health mediation programme or in lack of knowledge of its efficiency in general.



Graph no 8. Factors that limit the access to assistance services

## VACCINATION OF ROMA CHILDREN

The research covered 5 dimensions of the immunisation: frequency of occurrence of the problems faced by doctors concerning the vaccination of Roma children; the type of problems faced; the problems faced when vaccinating Roma children in comparison with children of a different ethnicity; the main cause of not vaccinating them in the perception of family doctors; and vaccines that the Roma parents do not wish to administer to their children.

38.3% of the doctors declare that during the past year they frequently faced problems when trying to vaccinate Roma children, while 58.2% assert that they rarely or never came across such problems. There are no major differences according to the residence areas (often or very often problems are stated to happen by 37.5% of the urban area doctors and 38.9% of the ones activating in the rural area) and the collaboration with the health mediator for the Roma (frequently occurring problems are

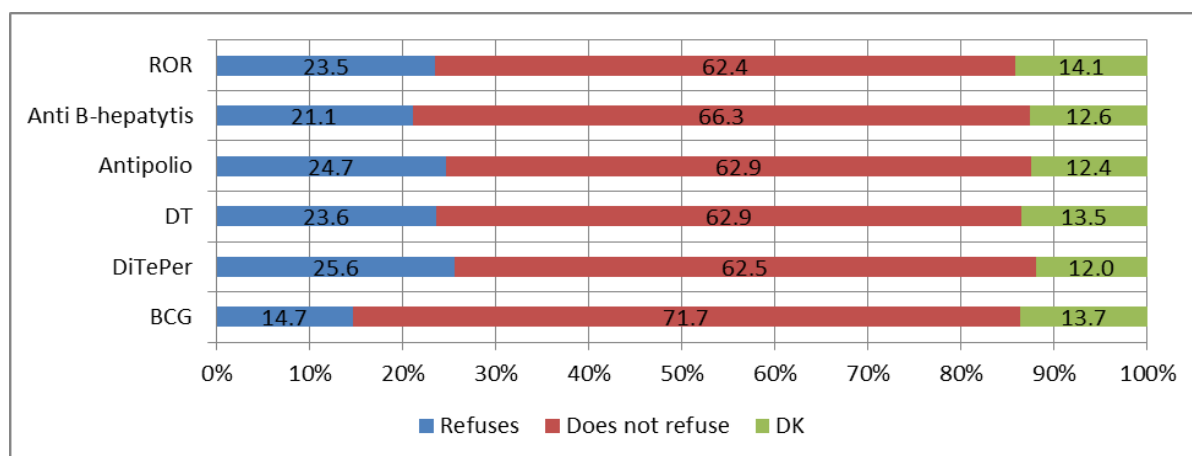
mentioned by 41.4% of the doctors working with a health mediator and 40% of the doctors who don't collaborate with a health mediator)<sup>22</sup>.

The main problems that occurred when vaccinating children were not following the schedule by the Roma parents (mentioned by 39.1% of the doctors) and the refuse of the family to accept the immunisation program (mentioned by 36.8% of the doctors). The problems with reduced incidence are losing the vaccination bulletin (5.1%), lack of free of charge vaccines (4.8%), and changing the domicile to another city or country (2.2%).

Most of the doctors (41.8%) consider that the problems occurring concerning the vaccination of Roma children are the same with those experienced by other ethnics, while 38.7% believe that the problems faced are more frequent for Roma. 8.7% of the respondents were unwilling or not able to offer an answer to this question.

To the question „What is the main cause for non-vaccinating Roma children?“ almost half of the respondents (47.8%) invoked the indifference of the parents towards this health measure. The second most frequent answer was the absence of information concerning the risks and benefits of vaccination (21.8%). 3.9% of the doctors believe that a cause is the less fortunate financial situation of the parents of these children, while 3.4% blamed it on the absence of a health mediator in the locality. 7.9% of the doctors considered that the vaccination problems have other causes than the ones previously enunciated; the proposed explanations, in the order of their frequency were the following: the fear of vaccine and secondary effects (23 cases), absence of the family from the locality (15 cases), lack of free vaccines (13 cases), Roma traditions do not encourage parents to go to the doctor's (4 cases), not respecting appointments (3 cases), repeated acute affections (1 case), lack of documents (1 case) and lack of stable domicile (1 case).

Concerning the vaccines that the parents refuse to accept in general the following distribution of the answers was obtained:



Graph no 9. Types of vaccines refused y Roma parent in general

<sup>22</sup>To the question „Do you work directly with the health mediator?“ only 384 subjects answered while to the question „during the past year how frequently did you face problems when vaccinating Roma children 935 answers were registered.

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## THE APPOINTMENT WITH THE DOCTOR

The questionnaire included two questions related to the moment of the visit to the doctor of Roma patients. The first of them was concerned with the stage of the disease that the patients were being examined for, while the second question targeted the perception of the doctors regarding the motives that determine some of the patients to wait until their affection reaches such an advanced stage.

52% of the respondents (486 doctors) appreciate that Roma patients come to the doctor's office during the early stage of their disease, 34.5% consider that they only visit the doctor when the disease has reached an advanced stage, while 9% believe that the Roma usually come for examination without presenting any symptoms of a disease. 4.3% of the subjects do not know in what phase of their affection Roma patients come for examination and 0.2% refuse to answer the question.

Out of the 323 doctors who believe that Roma patients only come for medical examination during the advanced stages of their affections, more than half (52.6%) attribute this to their tendency of self-medication and/or on the traditional/alternative medical practices, 15.8% consider that the lack of money represents the main reasons for which they are late for examination, while 8% consider that the main cause is not having the persons in question enlisted to a family doctor. The refusal of the family to allow them to go to the doctor's was mentioned by 2.8% of the respondents. 11.8% of the doctors who consider that the Roma usually see a doctor in the advanced stages of their disease, consider that there are other causes than the ones mentioned in the answer variants; these include indifference, ignorance, negligence (23 cases), absence of a medical education (13 cases), leaving the locality (1 case) the tendency to present to a family doctor in order to avoid being hospitalised (1 case).

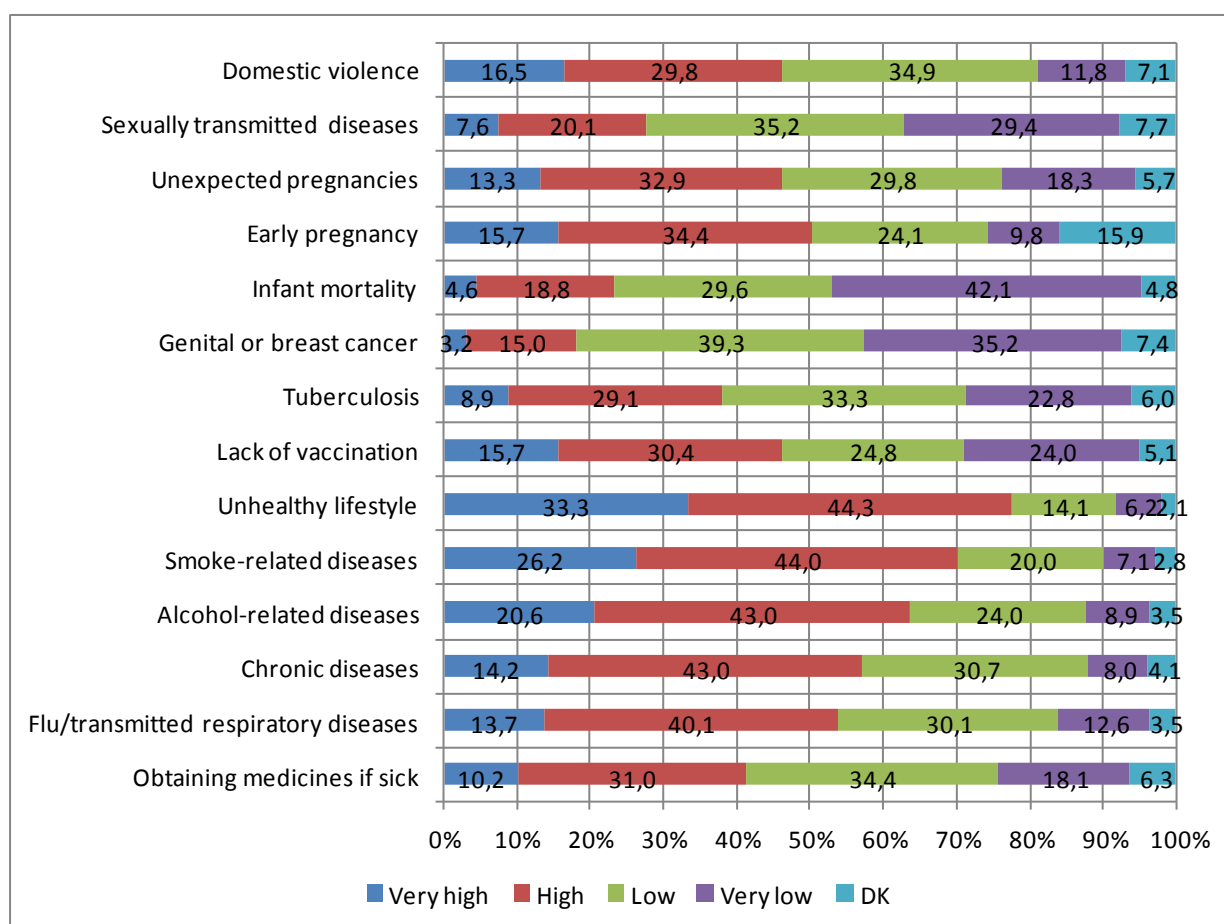
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## THE VULNERABILITY OF THE ROMA POPULATION

In the design of the questionnaire, the concept of vulnerability has been interpreted as susceptible by the Roma population facing health issues or social and economic issues that impact the state of well-being of its members. The question "To what extent do you consider that the Roma population in your locality is vulnerable towards the following aspects?" applied to 14 items: domestic violence, sexually transmitted diseases, including HIV/AIDS; unwanted pregnancies, early pregnancies (for non-adults); infantile mortality; genital or breast cancer; tuberculosis; lack of vaccination of the children; unhealthy life style (poor personal hygiene, incorrect alimentation, etc); diseases provoked by excessive smoking; diseases provoked by excessive alcohol drinking, chronic diseases (diabetes, hypertension); contacting flu or other contagious respiratory affections and purchasing the necessary medicine. Obviously, the questionnaire does not directly measure the vulnerability of the Roma population towards the above mentioned problems, but rather the perception of the family doctors that service Roma communities concerning the medical risks faced by the members of these communities.

More than half of the respondents appreciate that the Roma population that they service is vulnerable and prone to an unhealthy life style, poor personal hygiene, incorrect alimentation (77,5%); affections caused by smoking (70,2%) and alcohol (63,6%); chronic diseases like diabetes and hypertension (57,2%); flu or other contagious respiratory diseases (53,8%) pregnancy of under aged (50,1%).

On the other hand, less than a third of the doctors consider that the Roma population to which family medical services are being offered is vulnerable in great measure to sexually transmitted infections (27,7%), infantile mortality (23,4%) genital and breast cancer (18,2%).

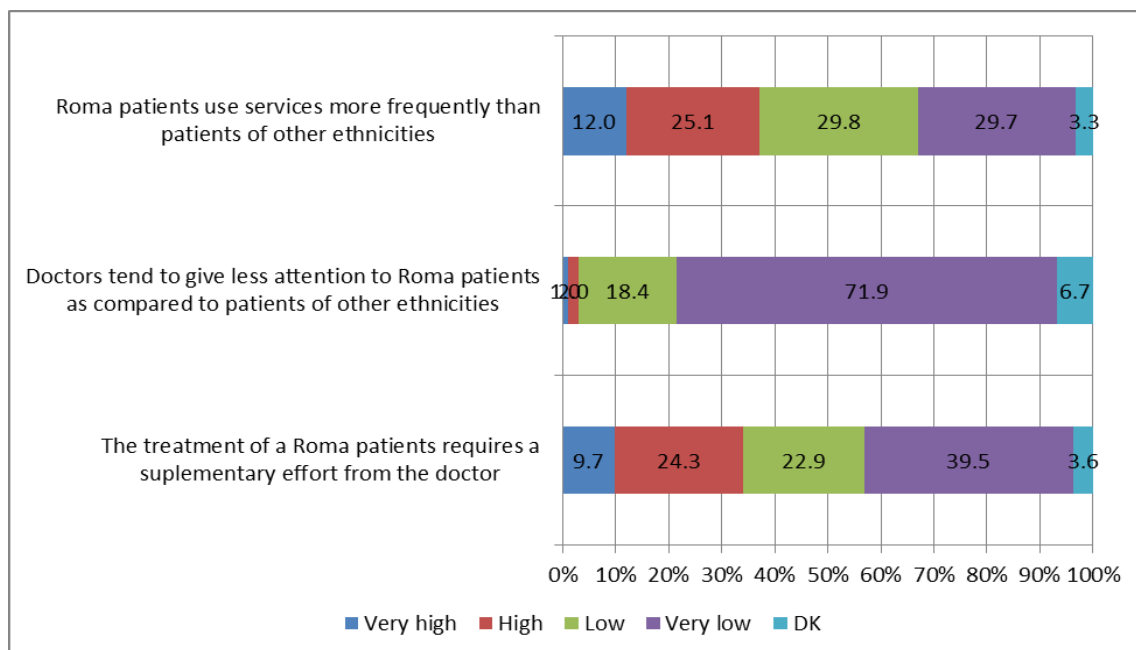


Graph no 10. Perceived vulnerability of the Roma towards various problems

## THE DOCTOR –PATIENT INTERACTION

The section of the questionnaire concerning the interaction between family doctors and Roma patients covers various dimensions: frequency of accessing medical services by Roma patients in comparison with patients of other ethnics; appreciation of the effort that the examination of a Roma patient requires in comparison with a patient of another ethnicity; the time allocated in general to a Roma patient in comparison with the time allocated to non Roma patients; causes for which some doctors allocate less attention to Roma patients than to non Roma patients; level of involvement of Roma patients in establishing the treatment method; problems faced in the relationship with Roma patients; to what degree elements belonging to Roma culture are thought to be upsetting for doctors.

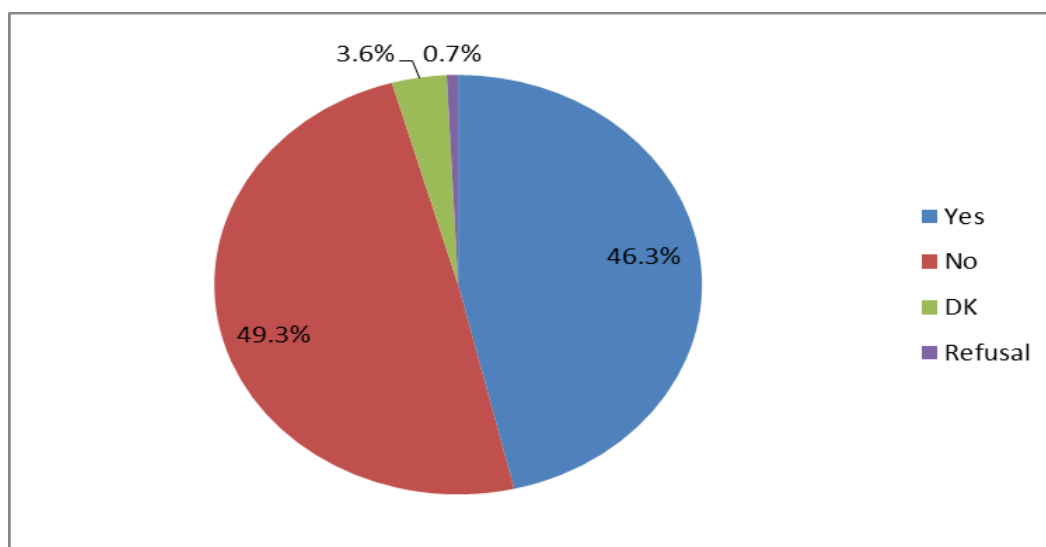
**Most of the doctors (59.5%) consider that the Roma patients do not access family medical services more frequently than other patients.** Only a third of the doctors agree in great measure that treating a Roma requires more effort in general from the part of the doctor. Concerning the attention granted to Roma patients, nine doctors out of ten, (90.3%) do not agree with the fact that Roma patients receive less attention than the patients of other ethnicities do.



Graph no 11. Perception of the doctors regarding the frequency of visits of Roma patients, time granted to them and the effort required for their examination in comparison with non Roma patients

The doctors who agreed at least to some extent that Roma patients are granted less attention than to non Roma patients, consider that this is a consequence of the inadequate behaviour of the Roma patients (31 cases), absence of personal hygiene (18 cases), low educational level (15 cases) and violent language or behaviour (14 cases).

To the question „In general, do you involve Roma patients when choosing the treatment variant that you prescribe to them?” less than half of the doctors (46.3%) answered positively (Graph no 12). Doctors whose patients are Roma, at least half of their total number of enlisted patients, answered positively in greater measure (72.2%).



Graph no 12. Distribution of the answers to the question “Do you generally involve Roma patients in choosing the treatment variant?”

Concerning the problems faced in the relation with Roma patients, less than a quarter (more precisely 22,5%) of the doctors declared having faced such issues during the past year. The aggressive behaviour and/or verbal violence were the main problem that was mentioned (46 cases), followed by inappropriate behaviour (40 cases), refuse of medical controls and of treatment (38 de cases), not respecting the schedule and the indications of the doctor (25 cases), low educational level of the patients (21 cases), absence of personal hygiene (4 cases), absence of identification documents (3 cases), coming for examination under the influence of alcoholic drinks (3 cases) and lack of cooperation (3 cases).

The doctors are generally open towards the Roma culture. Therefore, only 2.4% of the respondents feel greatly or very uncomfortable when a Roma women wearing traditional cloths comes for examination while 9.7% feel a little uncomfortable, and 86.2% don't feel at all uncomfortable or in a very little. Also, to the question, "To what extent does a Roma women bother you when she asks her relatives to participate to her medical examination?" 16.8% of the doctors asserted that they are very uncomfortable with this practice, 26% feel a bit uncomfortable about this and 55.3% do not feel uncomfortable at all.

The continuous formation of the medical staff in the intercultural domain has been covered in the questionnaire by questions relating to the participation of the subjects or meetings concerning the ethnic/cultural specificity of Roma, participation to such activities during the last year, perception of the utility of such activities as well as the best moment to conduct them throughout a doctors' career.

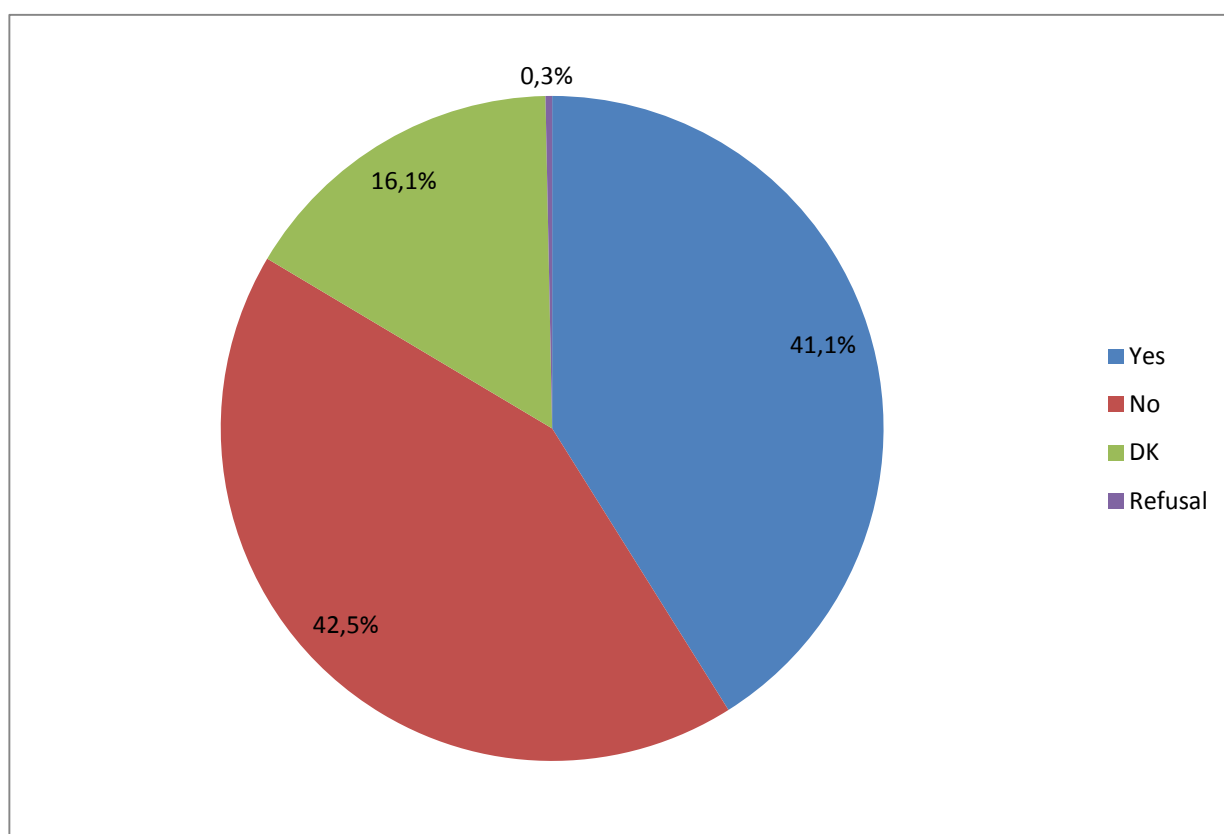
17% of the respondents, (159 persons) declare to have participated to trainings or meetings on specific Roma themes. Two thirds of them, (105 persons) participated to at least one such activity during the past year. The doctors who have participated to trainings on the specific of the Roma culture appreciate in a proportion of 85,.5% their being very useful or useful, whereas 5% consider that they are little or not at all useful.

To the question „In what moment of your medical career do you consider that such trainings/meetings are useful?", most of the respondents (54.5%) have chosen the moment when they begin their medical practice period while 17.8% consider that the intercultural preparation should take place from the moment of the initial training (during university) and 9.2% consider that the right timing would be during their traineeship.

## **THE RELATIONSHIP WITH THE HEALTH MEDIATOR**

### **EXISTENCE OF THE HEALTH MEDIATOR IN THE LOCALITY**

To the question „In the locality in which you work, is there any health mediator?" 41.1% of the respondents answered positively while 42.5% declared that there is not. It is curious that one doctor out of six (16.1%) is not able to offer an answer in this regard:



Graph no 13. Existence of a health mediatory in the locality

A higher percentage of the doctors in urban areas (44.5%) in comparison with those in rural areas (37.4%) declare that the locality in which they activate has a health mediator. As expected, the percentage of doctors from urban areas answered that they didn't know in comparison with those from the rural areas (22.3%, and 9.4%).

Positive answers to the question regarding the existence of a health mediator for the Roma in the locality were registered from at least half of the doctors who have at least 300 Roma patients enlisted and for the doctors where the percentage of Roma patients is of at least 25%.

Out of the 397 doctors who answered at present, there is no health mediator in their locality, 21.2% were not in measure to state whether during the past five years the local community has been serviced by a mediator while 12.8% offered a positive answer (we observe here a disparity in terms of residential environment: the proportion is higher for the rural area than for the urban area – 15.2%, in comparison with 9.4%).

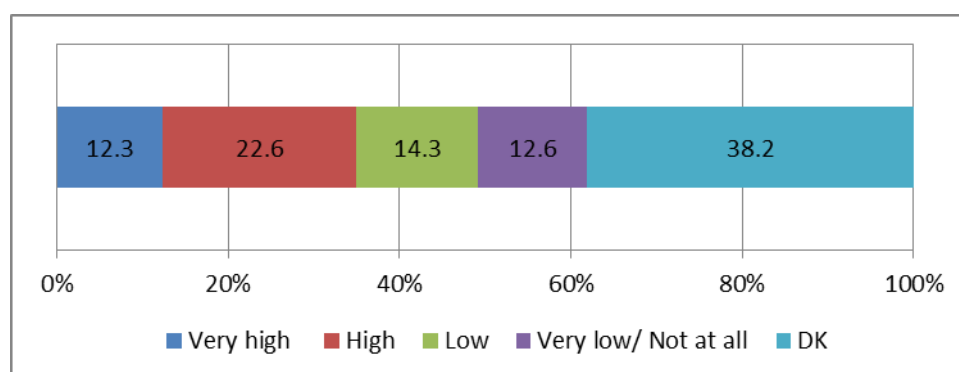
#### COLLABORATING WITH THE HEALTH MEDIATOR

254 family doctors (27.2% of the sample) stated that they work directly with a health mediator. 94.5% of them consider having a good or very good collaboration with the health mediator while 4.3% consider it to be a not good or not at all good collaboration.

Also, 92.1% of the doctors working with mediators declare themselves happy or very happy with the activity of the health mediator reported to the social and health needs of the Roma community.



On the other hand, to the question „To what extent do you consider that the activity of the health mediators led an increase in the access of Roma persons to medical services?” only one third of the doctors (34.9%) chose the answer variants „greatly” or ”largely”, while 38.2% were not able to offer a general appreciation:



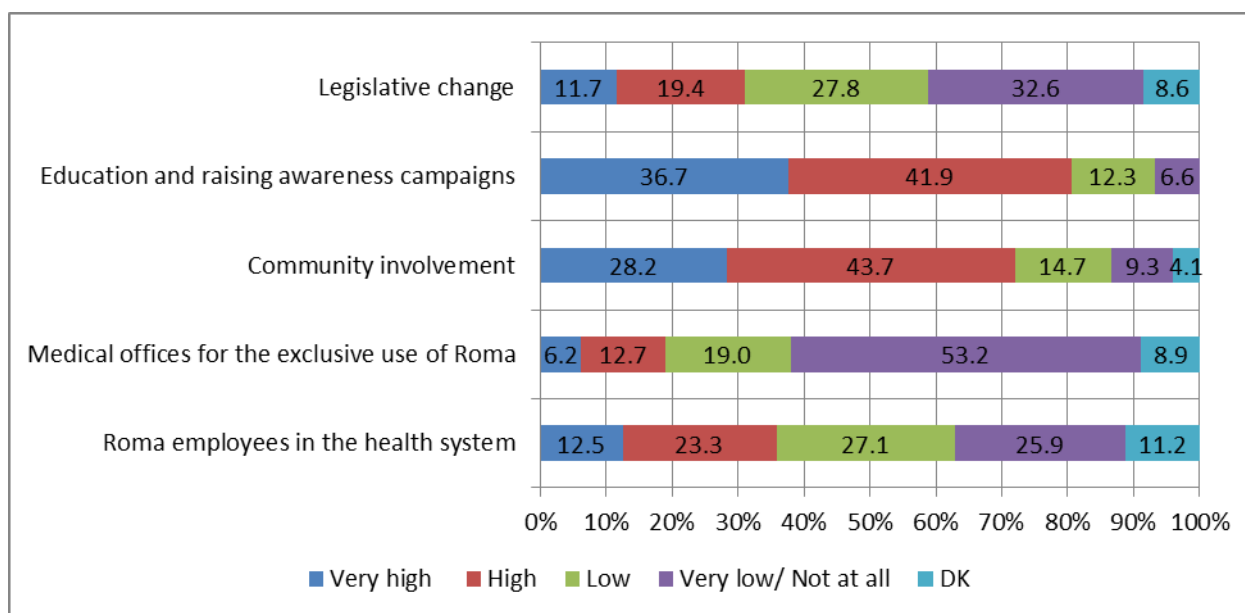
Graph no 14. Measure in which the activity of the mediators increased Roma access to medical services

#### ACTIVITY OF HEALTH MEDIATORS AFTER DECENTRALISATION

The respondents were asked how they appreciated the activity of the mediators after decentralisation in comparison with the previous period. More than half (58.3%) don't know if the decentralisation influenced in any way the activity of the mediators, the tendency of answering being attributed to the short period in which the mediators were transferred to the local authorities and the occupational situation that prevents comparative evaluation of the mediators. 16.6% believe that the activity of the mediators has improved after the decentralisation 17.6% consider that the activity is the same while 7% feel that their activity is weaker.

#### SOLUTIONS FOR THE IMPROVEMENT OF THE ACCESS OF ROMA PERSONS TO HEALTH SERVICES

The questionnaire was meant to measure the perception of the subjects regarding the efficiency of 5 measures of improving the Roma access to medical (changing the legislation and introducing new legislative measures specifically for Roma people; conducting education and formation campaigns for the Roma; involving the community in solving these problems; setting-up doctors' offices only for Roma patients; increasing the number of Roma employees in the public health system), but it also offered the possibility to identify other necessary measures by including an open question.



Graph no 15. XXXXXXXXXXXXXXXXXXXXXXXX

From the distribution of the answers, we may observe that the doctors consider that the responsibility for the limited access of Roma persons is of Roma members; the solutions to which most of the doctors adhered are conducting education and information campaigns targeting Roma persons (78.6%) and involvement of the community in solving the problems (71.9%). The increase in the number of Roma employees in the health system is regarded as a good or very good measure by 35.8% of the respondents, while changing the legislation and introducing specific legislative measures addressed to the Roma population is considered to be an efficient measure by 31.1% of the subjects. The less popular method among family doctors who service Roma communities is creating doctors' offices that offer services exclusively to Roma patients – only 18.9% consider this a good or very good method, and 72.2% believe that setting-up this offices would slightly or not all improve the problem of Roma access to health services.

To the open question, only 15 doctors answered; 7 of them underlined the integration of the Roma on the labour market, 6 proposed the increase of the education level, a doctor mentioned the increase in the number of health mediators for the Roma and a doctor referred to transportation subventions.

“They don’t even look at him! Gypsy, tin-pot, no matter how you are, they should look at you.” The voice of the elder woman breaks the overwhelming silence of the corridor. A middle-aged man sitting next to her nods in resignation: it is beyond them to make things happen in a different way. The emergency room of the hospital A is packed with people waiting to have their name called by a doctor from the “Minor emergency” room. They have all passed the initial examination at the triage and were assigned to the doctors in charge with cases that are not life-threatening and do not require immediate monitoring or treatment. Two elder women wearing headscarves sit next to each other but do not talk. Close to them, an intoxicated man contemplates a point on the wall and, from time to time, repeats a monologue about going to have a drink if no doctor comes to check his health. At first, his idle talk attracts some smiles from patients and companions; after a while, no one seems to pay any attention to him. It is a sizzling hot July afternoon and the sun rays passing through the window blinds fill the room with greenish hues. The crowded waiting room is a turned-on boiler, where pungent smell of body and medical odors inhibits any chitchat. There is no room for anything but waiting. Every time a person in uniform crosses the corridor, a voice asks about the long time before being admitted in the consultation room. Doctors and nurses are the most expedient – they ask patients to be patient and move on in a choir of complaints. Orderlies seem more talkative; especially when they carry wheelchairs or gurneys, they stop for a while and empathically agree that it takes too long before being admitted in the consultation room. As soon as they leave, the room dips again into uninterrupted, hostile silence. Suddenly, a Roma male in his early 50s precipitately walks the narrow corridor, opens the saloon-like door of the “Minor emergency” room and shouts to the doctor that his tests are ready but no one goes to pick them up. The doctor escorts him outside and tries to cool him down, explaining that the number of major emergencies that day exceeded the initial expectation and, as a consequence, there was not enough staff to deal with minor injuries. As soon as a nurse would be free, s/he would go and pick his results. Apparently, the man came earlier to minor emergencies, and the doctor ordered some specific tests to be performed in the hospital lab. The results were available, but the regulations prohibited the disclosure of results to patients. At that point, in a sudden burst of solidarity passing beyond the ethnicity and class divides – as I would witness many in the days to come –, an elder middle class woman sitting in the waiting room exclaims: “They don’t even look at him! Gypsy, tin-pot, no matter how you are, they should look at you.”

Wright Mills’ (2000/1959:14) claim that social scientists do not have monopoly on sociological imagination holds true. The woman’s astute remark that cases are handled in the emergency ward based on informal criteria established by the medical staff is consistent with the idea of a clash between the logic of the institution and the logic of the patient, which employ different criteria for assessing the severity of a condition and the ranking of the individuals on the waiting list (Vassy 2004:69). The “moral evaluation” of patients has been advanced as an explanation for the departures from official regulations at the triage of the emergency wards. Moral evaluation refers to the assessment of cases based on non-clinical characteristics, such as the perceived social value/worth of the patient (Glaser and Strauss 1964; Sudnow 1967; Roth 1972). The evaluation of patients is both retrospective and prospective and is embedded in a largely utilitarian discourse. It is retrospective insofar as the presumed moral character of the person in need is based on a series of factual data and more or less legitimate inferences regarding the person’s past (employment status in the period preceding the visit, social security, familial situation, social life, level of education, or position in the social hierarchy). At the same time, the judgment is prospective, for it predicts a life path after the moment of the visit to the emergency room. This anticipatory look works for the largest share of persons presenting at the emergency room triage – those whose deteriorating health is not irreversible or would not result in a prolonged or permanent incapacitation. For persons inscribed on a dying trajectory (Glaser and Strauss 1965), the social valuation considers not the expected behavior after the recovery, but the loss society

incurs in case the medical attempts to save patient's life are unsuccessful (Glaser and Strauss 1964; Sudnow 1967:71-76). The staff appraisal of the social characteristics of patients often translates into their categorization as “deserving” or “undeserving” of care (Roth 1972), which, in turn, serves to organize the handling of cases in the medical facility and to determine the appropriate amount of resources deployed to improve their condition. The underlying logic in the practice of preferential allocation of resources follows the idea that the interest of the society at large should prevail over the equalitarianism of official regulations. Vassy (2001) considered that triage staff apply a local theory of justice when establishing informal rules of access and ranking of patients on the waiting list.

Despite acknowledging social valuation as an important determinant of the way in which patients are handled in the emergency rooms of public hospital, recent scholarship on access to healthcare focused on providing a more complex picture of the phenomenon. In a study on the organization of pre-hospital emergency work in Paris and New York, Nurok and Henckes (2009) emphasized that the perceived professional value of cases shapes to a large extent the attitude and behavior of medical staff. Patients whose condition allows emergency practitioners to exhibit prowess in the use of medical devices and mastery of resuscitation techniques are professionally rewarding. Liminal situations are also widely appreciated, because the life-saving occurs in front of an audience and the performer of the intervention is credited with success. Novice doctors and nurses tend to appreciate cases not previously encountered, for they can allow the expansion of the realm of competence, whereas more experienced members of the team prefer cases that are very complex, because they allow the display of medical expertise. Nurok and Henckes sustain that a competition between the social valuation of the patient and the judgments on the professional satisfaction a case entails takes place at the level of pre-hospital emergency services; therefore, the evaluation of patients relies on a ‘fluctuating economy’ (2009:505). Drawing from extensive ethnographic fieldwork in a Parisian suburb hospital, Vassy (2001) considers that patient categorization realized by emergency room staff relies on clinical, organizational, moral, and social criteria. Organizational criteria refer to the need of keeping the emergency service functional at times of great affluence of patients. Patients displaying trivial symptoms are more likely to be denied access or to be redirected to other medical facilities in proximity during rush hours, whereas most patients arriving at night, regardless of severity, are consulted by a doctor (Vassy 2001:624-5). The distinction between moral and social criteria is grounded in the individual responsibility for the trouble it creates to the functioning of the emergency ward. Patients whose disruptive behavior is imputable to some inner flows (such as laziness, annoyance) are subject to negative moral appraisal and particularly exposed to the practical consequences deriving from this judgment - delay in providing care, lower ranking on the waiting list, less time with hospital staff, orientation to other healthcare providers, or direct denial of treatment. Social evaluation is based on objective failures for which the individual is not (or not necessarily) accountable: lack of social security, lack of affiliation to a family doctor, insufficient knowledge of how does the medical system function, or limited economic resources. Although they represent the most vulnerable category of patients, Vassy found out that this peculiar vulnerability makes them more suitable for access to the emergency room. An “informal system of positive discrimination” (2001:629) is put in place to provide the most deprived members of the society with care they would not be able to procure elsewhere. Other studies, conducted in France (Dodier and Camus 1998) and Spain (Rey Pino et al. 2008), emphasize that negative evaluation of patients by triage nurses and staff does not necessarily translate into denial of treatment. Spanish nurses justify the indulgent admissions through fear of responsibility in case the state of the patient deteriorates. Given that official regulations do not establish clear cut boundaries between minor emergencies and trivial cases, they prefer to categorize most patients with non-severe symptoms as “minor emergencies,” thus entitling them to receive treatment (Rey Pino et al. 2008:174-5).

While various works raise awareness on the non-clinical evaluation of patients in the medical system, its underlying assumptions and practical consequences, “categorization is often analyzed with a structural and static approach, not with an interactionist one.” (Vassy 2001:617; Kelly and May 1982) The present research aims to fill this vacuum. Although examining the perceived patients’ social worth based on personal characteristics explains to a large extent the different allocation of resources in the

emergency wards, several questions remain unanswered: Why do people sharing similar characteristics and having similar medical conditions are treated differently? What makes triage staff change the ranking on the waiting list when there is no deterioration of the patients' symptoms? Based on empirical data gathered mainly through non-participant observation, I argue that categorization is contingent not only upon social characteristics, but also upon patients' ability to perform the patient role in front of medical practitioners and auxiliary staff at the emergency ward. However, there is no formal agreement on what constitutes an appropriate patient role as there is no clear demarcation of how should a patient act during his stay in the hospital or how should s/he conduct various conversations with hospital personnel. Therefore, my research will provide a representation of appropriate patienthood leaving from the evidence accessible to an observer: the visual artifacts displayed in the emergency rooms and the interactions between hospital staff and patients.

## **METHODOLOGICAL CONSIDERATIONS**

This paper draws from 18 days of observation<sup>23</sup> in the emergency rooms of 6 county hospitals<sup>24</sup>. A certain amount of secrecy characterized the data gathering in order to increase the accuracy of the observation<sup>25</sup>. Thus, no formal or informal request for carrying on fieldwork in the hospitals was made. This drastically limited the access to information. Regularly, a visit to the emergency room consists in four moments: assessment of the condition at the triage desk; waiting in the lobby for consultation; medical consultation; and redirection of the service recipient to a different medical service or exit (Dodier and Camus 1997). I was only able to assist to the first two moments, and even then I had to gather information in a surreptitious manner. Moreover, no discussions were realized with the hospital personnel, patients, or persons accompanying them, in an attempt of uncovering the "procedural base of the events" (Sudnow 1967) instead of dealing with "vocabulary of motives," retrospective accounts, prescriptive norms, and perceptions. In order to increase the reliability of the empirical data gathered, I used investigator triangulation: I asked a fellow graduate student in sociology to accompany me on the field and independently gather data about the handling of patients.

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<sup>23</sup> Observation was considered appropriate for the purpose of the research for several reasons: is less obtrusive than other methods of collecting data; provides access to information people are reluctant to offer during interviews or surveys; facilitates the understanding of relevant issues that might have been ignored while designing the research; and exposes the observer to situations with heuristic potential that would not have been otherwise accessible (Kluckhohn 1940; Becker and Geer 1957; Trow 1957).

<sup>24</sup> The period of data gathering was July-August 2010. Hospitals were randomly chosen from the list of county hospitals in order to obtain a higher variation of contexts. The price paid for this sampling preference was the difficulty to enter the emergency room lobby in one hospital, and the impossibility of entrance in another. In the latter case, I tried to turn this handicap into an opportunity by closely observing the behavior and talk of people accompanying the sick. Like me, they were not allowed to enter the hospital premises, but had to wait in an improvised area in front of the main gate until the exit of the person accompanied. This could take from a couple of minutes to several hours.

<sup>25</sup> Like Roth (1962), I consider the dichotomy secret – non-secret improper for the description of the social researcher's approach of the field. More accurate would be the positioning of the researcher on a continuum between complete secrecy and total non-secrecy, as ideal-typical constructs. As regards my presence in the emergency room lobbies, it tended towards secrecy: I maintained limited verbal contact with medical staff, potential patients and others; I did not inform anyone about the reason of my presence in the hospital; and I did my best for my presence to get unnoticed. However, after several hours of staying in the hospital lobby, it became obvious that I was there neither as a patient nor as a relative or friend. To my surprise, in the hospital A, the nurse working at the triage initiated contact with me in the form of cracking a joke with a patient on a gurney and then winking at me and waiting for my reaction. (I replied with a cordial smile.) This was the only form of communication with the staff at the triage. The benevolent reaction to my presence there was unlikely to have been shared by other nurses or doctors, who had a more neutral, indifferent attitude. Occasionally, when the flow of events surrounding me was too quick to be able to accurately remember it, I used to take notes on a small notebook. Thus, I gave a certain indication about my position and interests.

The aforementioned methodological constraints informed to some extent my area of interest: having to rely on what could be seen by a casual observer, I paid peculiar attention to the entrance into the patient role. More specifically, I was interested in the framing of the situation by the person claiming medical care and by triage personnel; the norms of appropriate conduct in the emergency room as delineated in the visual artifacts existing in the emergency care unit and the small talk occurring in the waiting room; and the practical ways of enforcing these norms and sanctioning transgressions.

## **SICK ROLE AND PATIENT ROLE**

Prior to engaging in the discussion of appropriate patienthood in the emergency wards, a theoretical distinction between the 'sick role' proposed by Talcott Parsons (1951a, 2005/1951b) and the 'patient role' needs to be drawn. Parsons envisaged illness as a legitimate deviation from societal orderliness, leading necessarily to a reconfiguration of the set of rights and duties the sick person is expected to comply with. Briefly stated, the incumbent of the sick role is entitled to exemption from the responsibility for the health condition and discharge of the ordinary duties and responsibilities. In return, he should recognize illness as undesirable, have the will to get well, and thus "seek technically competent help." (Parsons 1951b:294) Illness is perceived as a temporary condition which can (and has to) be eliminated; consequently, the sick role itself is confined to a limited temporal horizon, before "the restoration of capacity to play social roles in a normal way." (Parsons 1951a:146)

Parsons' theoretical model stirred up intense debate in medical sociology. The abstract prescriptions of appropriate behavior once sick status was granted were challenged by empirical examinations of the concept (Twaddle 1969, Segall 1976, Levine and Kozloff 1978, Wolinski and Wolinski 1981). Findings of these studies identified several shortcomings in the ideal-type representation of the sick role. The model was considered appropriate for acute diseases, but could not be applied to many chronic illnesses. Particularly, the idea that the sick should be exempted from responsibility for his condition would be difficult to apply to conditions that can be linked to undesirable lifestyle (smoking, drinking, unbalanced diet) and poor management of health. (Levine and Kozloff 1978:321, Wolinski and Wolinski 1981, Charmaz 1999:212) As compared to acute illness patients, persons suffering of chronic diseases tend to have little legitimacy for entrance into the sick role. Another objection raised to Parsons' model – mostly in recent studies – was concerned with the asymmetrical relation between medical providers and beneficiaries in terms of information and decision-making. Shilling (2002) and Varul (2010:83-4) point out that the increased access to scientific knowledge in the nowadays society breaks the monopoly of medical practitioners on health expertise and tends to balance the relationship between providers and recipients of care. Charmaz (1999:218) rejects the idea of almost complete dependency of patients, who are required to give up any involvement in the decision making process. Ethnographic studies published in the aftermath of Parsons' theory point out that although the doctor is the social actor having the last say on the diagnostic and treatment, the patient usually assumes an active role, asking for alternatives, negotiating treatment, and questioning some medical decisions.

In spite of the prescriptive character, inherent shortcomings, and partially obsolete provisions, the 'sick role' retains the ability of making the handling of some cases at the triage of emergency rooms apprehensible. However, albeit overlapping, the 'sick role' and the 'patient role' do not coincide. Both roles are linked to a perceived illness, and the entrance in the role requires the prior validation from a specialist. However, there are at least two major differences between them. First, 'sick role' refers to the incumbent's relation with the society at large, whereas 'patient role' is confined to the social arrangement of the hospital and to individuals relation with the persons taking part in that arrangement (doctors, nurses, orderlies, aides, security guards, other patients, visitors, companions, policemen and so forth). Second, all sick are patients, but not all patients are sick. Parsons argues that one's claims of sickness need to be confirmed by a professional in order for the sick status to be bestowed, so that only patients are entitled to being recognized as sick, with the subsequent reallocation of rights and obligations as member of the society. At the same time, there are patients who are not in the position of

requiring a readjusting of their position in the social system – such as patients who seek medical advice for family planning, or patients accessing medical services for health prevention and monitoring. A case of particular importance for the purpose of the present study is that of people presenting with disturbing symptoms at the emergency room triage, who pass the initial examination and are in the waiting room. They acquire a temporary patient status, but the diagnostic is preliminary and instrumental, relies on a limited set of medical procedures and a not very accurate stock of information about the actual situation of the person. A comprehensive medical inquiry in the “minor urgency” section of the ward is needed in order for a diagnostic to be established and further actions to be set. For the duration of their waiting, they are patients, without being entitled to claim “sick role”.

## ACCESS TO CARE

Medical staff at emergency room triage normally comprises one doctor and one or two nurses. Depending on the size of the hospital and the number of clients, adjustments take place in order that waiting time be reduced and major emergencies be handled as soon as they arrive. During my fieldwork, I haven't experienced any case in which people presenting life-threatening symptoms be denied access or required to wait. Regardless of social characteristics, insurance status, or way of coming to the hospital (using an ambulance or not), major emergencies were immediately transferred to the special section of the ward where life-saving procedures take place. The triage encounter was brief and consisted in gathering succinct information about the identity of the patient, the symptoms, and the circumstances in which the deterioration of health had produced. When the condition rendered the patient unable to sustain a conversation, the companion or the ambulance staff was required to provide the relevant information. A sense of urgency was conveyed throughout the encounter from the way questions were formulated, the expeditious recording of data, and the absence of any display of emotion from the part of the staff. Also, no comments regarding the patient or the condition were made, and the staff refrained from giving a preliminary diagnostic to the family or making predictions regarding the patient's chances of survival. No moral evaluation affects the decision of triage staff in the case of persons with life-threatening symptoms.<sup>26</sup>

For other patients, the situation is more complex. Triage doctors and nurses are entitled by law to refuse access to persons presenting without an “acute crisis” (Ministry of Public Health Order 1640/2007). However, this is very seldom the case even for persons with trivial symptoms. Similarly to the case of Spanish hospitals studied by Rey Pino et al. (2008), the initial assessment of the condition seemed to be in most situations favorable to the patient. The practice of redirecting patients to other medical facilities in proximity, which is so widespread in other medical system that slang terms were dedicated to it – ‘turging’ (Caldicott 2007) and ‘circule’ (Mirhosseini and Fattahi 2010) – was uncommon in the hospitals I observed. As Dodier and Camus (1998) remarked in a French hospital, patients who do not seem to qualify for access to emergency services stir up negative remarks from the practitioners at the triage, but are ultimately accepted in the facility. A particular situation is that of persons lacking medical insurance. At hospital A, an uninsured woman who could not use out-of-pocket money to support the cost of the visit was verbally admonished by a doctor, who told her “I wish I could go to a shop and buy goods without paying them.” Nonetheless, the woman was assigned a position on the waiting list and was allowed to see a specialist. The metaphorical representation of the hospital as a supermarket indicates the conflicting ideologies supporting emergency care. Historically, hospitals were initially organized as charity institutions providing free of charge support to the persons in need – “the poor, old, and unwell” (Porter 2002:137). The medicalization of illness and the development of technological instruments for addressing disease led to the reconfiguration of hospitals as places aimed at healing, to which only the deserving share of the sufferers was entitled (Rosenberg 1977:430). The confusion surrounding the aims of and entitlement to emergency care is further

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<sup>26</sup> However, moral evaluation is likely to inform the medical procedures in the intervention room, such as the resuscitation maneuvers, as Sudnow (1967) and Timmermans (1999) documented.

increased by the replacement of the equalitarian organization of the health system during socialism with the equity-based model in the aftermath of the fall of socialism. For the uninsured woman, the existence of disturbing symptoms was considered sufficient to grant access to immediate care, whereas for the doctor access was contingent on the ability to repay the service received. Negotiations over the meaning and scope of emergency departments were also common in the handling of the ‘social cases’ – persons who present at the hospital without a clinical condition justifying their presence on the premises. At hospital C, for example, an elder male asked to be hospitalized because he allegedly suffered of asthma. The triage doctor recognized him and remembered the fact that he also came with the same request a few days earlier, but the request had been denied by the consultation doctor. He insisted that he feels bad and needs continual monitoring. The doctor told him that asthma does not represent a disease requiring hospitalization; he should have a more severe illness in order to be admitted into the hospital. The patient required to have his situation reassessed by a different doctor. At that point, the triage doctor broke the veneers of medical conversation and asked him if he wants to stay in the hospital because he doesn’t have where to spend the night elsewhere. The man acknowledged the situation and after that the doctor allowed him to go to the waiting room.

## **SOCIAL CHARACTERISTICS AND ROLE PERFORMANCE**

For reasons that are beyond the reach of my data-gathering methods, triage personnel are reluctant to refuse the access to emergency services. Also, major emergencies are handled following the official procedures, without any moral judgment projected upon the patient. The only resource that is disposed of in a manner that seems to be discretionary is the ranking of non-major cases on the waiting list. Categorizing patients as ‘deserving’ and ‘less deserving’ seems to be informed to a certain extent by the social characteristics of the individual, but the categorization is subject to change according to the individual’s performance of the patient role in the interaction with the hospital staff and the overall demeanor in the waiting room.

Among the social characteristics, age has been identified by most studies on the moral evaluation of patients as a salient criterion for assessing worth. Youngest members of the society tend to receive the most favorable treatment, and efforts to save their life go beyond the application of standard procedures. Elderly patients, on the contrary, elicit less enthusiasm from the part of the medical staff. The differential treatment of the aged was explained through the cultural valuation of “full life” (Glaser and Strauss 1964:119), the decreased reliance of other family members on them (Sudnow 1967:68), and the organizational problems associated to providing them with care. In the French hospital studied by Vassy (2004:72), elderly patients are frequently denied hospitalization because their problems are generally numerous and, consequently, their handling involves the mobilization of more resources than in the case of the younger ones. In the hospitals where I conducted observation, aged patients were generally received with sympathy by the triage staff, who employed gentle smiles when addressing them, reframed the questions several times if the interlocutor was unable to grasp the meaning or provide an adequate answer, and acted with conspicuous politeness. On the other side, the sympathy for elders did not translate too often into assigning them priority positions on the waiting list. The most notable exception was related to extrinsic conditions – in days of excessive heat, older patients tended to be among the first recipients of care at the “minor emergency” section. Probably, this was related to the presumption that spending too much time in the waiting room might further deteriorate their state of health. Another factor influencing the handling of elders was the perceived social worth of their companions.

Inebriation represents another characteristic of peculiar importance in the moral evaluation of patients. Intoxicated patients are often denied access to medical services or are receiving the minimum of care regulations allow (Roth 1972, Mondragon et al. 2007, Biener 1983). I witnessed three types of reactions to the drunken people or people whose condition was considered to have been caused by excessive alcohol consumption: refusal of surgical treatment, in spite of claims of intense suffering; overt admonishing for their vice; and long waiting time before being admitted to the consultation room.



The first reaction was rendered clear by a doctor in hospital E who informed the patient that if he wasn't drunk, he would receive the micro-surgical intervention he asked for. (The case will be presented at length in the next section of the article, because it involves the interplay between social characteristics and role performance in the handling of emergency cases by medical personnel.) At the same hospital, a patient coming with a liver-related illness was subject to a harsh moralizing discourse from the triage doctor for his alcoholic relapse. Staff attitude towards intoxicated patients reflects in the language used to refer to them: a slang term ("pretty ones") was intensively used in one medical setting, and in another hospital an inebriate patient was refused the label of "gentleman" ("domn") and deemed unqualified for care:

*(The triage doctor mocking the 112 call): "A gentleman who fell on the street!"*

*(The aide who carries the intoxicated man on a wheelchair): "A gentleman! If he is gentleman, I must be king!"*

*(The triage doctor repeating the initial claim, with an emphasis on the term considered inappropriate in the context): "A fallen gentleman. Great emergency!"*

However, the most often encountered method of dealing with persons under the influence of alcohol was to ignore them for lengthy periods of time. This strategy has been identified to create an uncomfortable experience for patients in an attempt to make them willing to leave the premises before being consulted (Mirhosseini and Fattahi 2010:316-7) and discourage their return. (Rey Pino 2008:177) A possible explanation for the negative assessment and treatment of inebriates is furnished by Parsons' 'sick role': people who suffer of alcohol-related illness or who do not live a healthy lifestyle cannot be exempted from responsibility for their deteriorating health, and are not legitimate in their claim for being granted a sick status.

In the emergency room, social characteristics matter. They inform staff's appraisal of a person's worth and influence his/her trajectory in the hospital. Nonetheless, it is obvious that not all persons sharing a set of characteristics are treated in a similar fashion. Moreover, the same patient can be initially put on the lower end of the waiting list but after a while can increase his position without any alteration in the clinical condition. In order to better understand the influence of patient role performance and its ability to correct the initial moral evaluation, I will present a situation encountered at hospital E.

## **A CASE OF 'UNDESERVING'**

An intoxicated person in his early 30s comes to the Emergency Room requesting to have a suture removed because it was causing severe pain. After taking his identity card for filling the necessary paperwork, the triage nurse directs him to a room adjacent to the lobby. On the door, it is written "Monitoring." Most other cases either have to wait in the lobby, or are directed to the Minor or Major Emergency rooms. After about 15-20 minutes, a female doctor goes to see him and asks for his name. He swears. The doctor leaves angrily, saying "You are so stupid!" ("Prost ești"), then calls him a "rascal" in a conversation with a nurse. After a few minutes, the intoxicated person returns to the triage desk asking for his identity papers to be released. The nurse conforms to the demand and brings him the provisory ID card. She holds it with the top of her nails, wearing an expression of disgust. Then, he refuses to take the paper and, in an angrily, loud voice, asks for medical care. The nurse throws the ID on the seat close to him and asks him to leave. The man waits for a good few seconds, then goes to the triage desk and, using a more polite tone, repeats the claim; this time, he frames it into a more complex (though not necessarily coherent) story, including references to his native place (Dorohoi); the destruction of the house during the recent flood; the long travel he made in the past few days; and the unbearable pain he feels. The nurse tells him to return to the seat in the lobby and wait. A security agent is called, and he is charged with accompanying the man into the "Monitoring" room. Five minutes later, another doctor enters the room and starts a dialogue with him. In asking about his perceived health condition, she makes reference to the influence of alcohol. After briefly talking about the medical history of the patient, the doctor leaves the room and returns with a colleague. She informs the man that blood needs to be harvested for a laboratory test. He agrees. He is reluctant to accept a perfusion,

nonetheless, and is warned that otherwise he won't receive the intervention he requires. Another doctor and a nurse approach the room. The nurse tells the patient to sit down, whereas the recently arrived doctor tells him to take his belongings and leave the hospital. Then, doctors have a brief discussion about his condition. The woman tells him that were he not drunk, she would perform the surgery to remove the suture. Then, she asks the male doctor whether they *could* operate him. The male doctor says "Yes," smiles to her, but after that repeats the request for him to leave. The security guard escorts the patient to the exit door and makes sure he would not get in again.

Four temporal sequences of particular significance can be identified in the aforementioned case: the first encounter with a doctor and the subsequent exit; the reframing of the case presentation upon return; the second encounter with a doctor and the performance of a medical procedure; and the reassessment of the situation by the medical team leading to the refusal of on the spot treatment. Although his drunkenness permeates the entire story, it does not seem to be the only factor impacting the handling of the case. Instead, his actual conduct in relation with the medical staff appears to shape to a larger extent the moral evaluation and the passage from one category ('undeserving of care') to another ('deserving') and vice-versa. Swearing attracts the emotional outburst of the first doctor who asks him to leave. His apparently improved demeanor after coming back to the triage (using polite language, proving cooperative through excessive details on his situation, and recognizing the asymmetry of power in relation with the medical providers) ends up in readmission. The second doctor seems genuinely willing to perform the suture removing surgery, and her good intentions are revealed by initiating the blood harvesting procedures. However, the lack of cooperation and unpredictable behavior of the patients makes her look for a second advice from another doctor. Although intoxication is the reason invoked for denial of treatment, it is more likely that failure to comply with the requirements of the patient role was the actual reason behind the decision.

#### **VISUAL RHETORIC OF EMERGENCY WARDS AND CONSTRUCTION OF APPROPRIATE PATIENTHOOD**

The spatial organization of the emergency ward lobby and/or waiting room(s) establishes the framework in which interactions between medical staff and patients and interactions among patients occur. Despite different spatial arrangements, the hospitals in which I carried fieldwork share a striking similarity regarding the visual artifacts displayed – most of them included pointers, posters and printed sheets of paper containing institutional rules and norms of conduct, advertising various health-related projects, and indicating monitoring and surveillance. For the purpose of this thesis, I refer here exclusively to the semantic of patienthood as constructed through the visual artifacts, its relevance for the study of the moral evaluation in hospitals, and the ways in which it is enforced by institutional agents of socialization (such as nurses, orderlies and security agents). In other words, I explore the ways in which a person coming into the emergency room gets familiar with the ideology of the hospital unit and, more importantly, with a set of norms, obligations, and expectations associated to the patient role.

The visual rhetoric of the emergency rooms provides a coherent discourse centered around four, largely overlapping, themes – medical authority and competence; patient's responsibility for the health condition; patient's dispossession of the control over his/her body; and the need to adjust one's behavior to the institution's norms. In all hospitals, medical authority is explicitly asserted through the display of the Ministry of Public Health's Order 1706/2007 indicating that the qualified staff (nurses) is the only instance entitled to assess the condition of the patients, decide on the priority of the case and establish the order of entrance into the consultation room:

*"Within this unit, the access to the treatment area is based on the triage, which establishes the priorities from a medical standpoint. In case the triage does not consider your case to be a priority from a medical standpoint, it is possible to wait for a longer period, until a seat in the consultation room and a doctor are available. Other patients can be transferred immediately, even if they came much later than you, if they had a more urgent medical priority. You are requested not to try in any way to influence the medical staff in order to secure a more rapid access."*

The use of the adjective “medical” four times in the four sentences of the notice provides a clear idea of separation between the hospital and the outer space, and indicates the asymmetrical power relation between the medical practitioners and patients. The authority of the staff derives from a particular type of educated knowledge confirmed and supported by bureaucratic regulations.<sup>27</sup> The social organization of the emergency wards relies on this knowledge, and any attempts to ignore or contest it are firmly rejected. During my stay in the emergency wards, there was no situation in which a patient contesting the order of entrance or complaining about his/her prolonged waiting managed to obtain faster access to the doctor. In addition to the promotion of medical ideology, the establishment of clear rules about the management of cases suggests another important aspect of the emergency ward culture – the dispossession of the individual of the control over his/her body. Part of the patient role is built on the expectancy that the person looking for medical examination accepts a temporary delegation of control to the members of the hospital staff who are sole legitimate actors in putting a diagnostic, deciding the priority of the case, evaluating the potential treatment, and deciding on the future actions.<sup>28</sup>

Another way of asserting medical authority consists in the use of specialized language and a particular system of abbreviations. A printed A4 page displayed on the window of the triage office in the hospital D required visitors not to enter the hospital premises in case they presented a series of symptoms including “rhinorrhea” and “dry irritated cough.” The message was posted by the “Service for Surveillance and Control of Nosocomial Infections.” For the average visitor, the aforementioned symptoms and the object of activity of the Service are likely to remain obscure. Using scientific terms for describing common health states serves to claim an epistemic authority rather than to convey an indication. Moreover, the same emergency ward displayed a whiteboard with a series of rules regarding the handling of cases, expressed in a coded way, with capital letters followed by numbers: D2, D3, M1, I2, C1-C4. Albeit addressed to the staff, these signs were not shown in the area reserved to the staff, but on a back wall in the view of all people in the waiting room.

Many posters exhibited in the emergency wards focused on raising awareness on the determinants of illness, and were realized as part of projects implemented by the Ministry of Health and various NGOs. Smoking cessation and respect of hygiene norms represented the two central themes of these visual artifacts. Patients and companions represented the most likely audience, and they were generally depicted as potential wrongdoers: “(in black characters) 5 out of 10 Romanians do not wash their hands after using toilet. (In red) Are you one of them?”<sup>29</sup>; “Learn to live in a clean environment”<sup>30</sup>; “A space without smoke. We respect your right to health, do not irritate your eyes and do not cause you coughing, but we offer you air.”<sup>31</sup> The representation of patients as potential culprits is in conflict with

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<sup>27</sup> As a matter of fact, we can distinguish between two forms of authority – epistemic (knowledge-based) and deontic (practically-based). The former is more obvious and characteristic to the highly qualified staff, whereas the latter is discrete and characteristics to the staff occupying lower positions in the hierarchy of the emergency ward. Deontic authority can be observed in the control over non-medical resources existing in the public space of the hospital – such as air conditioners and TV sets. Deciding whether to use or stop using electronic devices, choosing channels, tuning up or down the volume of the television, or making use of fixed telephones are forms through which deontic authority is exhibited.

<sup>28</sup> Patients who wanted to retain a degree of control over their bodies and the ways they are handled within the emergency unit were overtly admonished. For example, at E a group of young males came and informed the triage nurse they were bitten by a dog and requested rabies vaccination. Although the cause of their medical condition was evident, the nurse angrily told them that only the medical staff is able to put a diagnostic and decide on a treatment. The dispossession of the individual of the control over their own bodies could also be a resource for the patient. During the presentation of the case at the triage, some of them took advantage of this rule, by exaggerating their state and claiming they were unable to hold control over themselves. A middle-class lady came to A with a reddish inflamed foot and, also there were no other symptoms, she told to the nurse she was afraid not to be the victim of a “black widow” spider. By framing the illness as a life-threatening one and by asserting the competence of the medical team, she created a script based on the myth of the savior. Needless to say, the nurse was eager to assume the role and comforted the woman telling her that she was going to be alright and would be soon seen by a doctor.

<sup>29</sup> Project developed by the Ministry of Health and the Inspectorate of Public Health.

<sup>30</sup> Campaign for promoting the norms of personal and environmental hygiene, Ministry of Public Health and the Inspectorate of Public Health.

<sup>31</sup> Material realized by the Ministry of Health and the Marius Nasta Institute of Pneumology.

Parsons' (1951) theoretical model, which states the patient's exemption from responsibility for his/her medical condition as integral part of the sick role, but is consistent with the empirical research on the moral evaluation of patients in the emergency rooms. In my fieldwork, I witnessed various instances in which people displaying unhealthy lifestyles or whose illness was related to "moral flaws" such as alcoholism and lack of hygiene were disregarded by the medical staff and spent longer time than other patients in the waiting rooms. Moreover, derogatory language was used to refer to drunkards in the medical slang – in the hospital E they were referred to as "pretty ones."

Other visual artifacts (pointers and printed sheets of papers) provided the persons in the waiting room with a clear delimitation of the public space from the private space of medical practitioners and with rules of conduct to be respected while on the hospital premises. In hospital D, the space destined for medical staff was marked by signs written in capital letters conveying the message: "STOP – ENTRANCE FORBIDDEN." Transgressions were rare, but when they occurred (most likely by mistake), the culprit was immediately sanctioned verbally. A particular case was that of people discontent with the lengthy waiting time during the rush hours in the hospital A. They voiced their anger and tried to enter the consultation room for minor injuries, but a doctor went out and explained that the cases under examination require lengthy work. Security agents later came in and restored order. Based on the empirical data gathered, I can say that the surveillance of patients by security agents was instrumental in preventing the transgressions of space in all six hospitals.

Descriptions of appropriate behavior on visual media included general recommendations (smoking prohibition; discouraging informal payments; accepting the authority of the hospital personnel), specific procedures at work in that unit ("All radiographies with referrals are realized in the ambulatory", hospital E; instructions in case of earthquake), and instructions about the appropriate use of space ("Don't lean on the heating elements", hospital D). In fact, they covered only superficially the code of conduct in the emergency rooms. Other rules, not explicitly stated, became clear only after patients and companions failed to respect them. The main sources of information in this respect were conversations among patients, conversations among members of the medical staff, and interactions between members of the medical staff and patients. People were expected, among others, to sit in the waiting rooms<sup>32</sup>, not to speak loudly, to be clean<sup>33</sup>, to use cell phones outside<sup>34</sup>, not to consume food products,<sup>35</sup> and to respect the order of priority assigned to them at the triage. The surveillance was realized both electronically, using close-circuit television (CCTV), and classically, by most institutional actors (security agents, but also nurses, orderlies, and cleaning ladies).

## CONCLUSIONS AND CAVEATS

The aim of this thesis was to challenge with empirical evidence the prevailing idea that moral evaluation of patients relies almost exclusively on characteristics of the individual, such as age, socio-economic status, level of education, and family situation. Instead, I argued that non-clinical assessment of cases at the triage of emergency rooms is also to a large extent grounded in the patient's ability to act in a manner that is deemed appropriate by the medical staff. I organized my argument around the concepts of 'patient role' – referring to the set of rights and obligations medical practitioners consider a patient has – and 'appropriate patienthood,' understood as successful performance of the patient role. After delimitating the 'patient role' from the related concept of 'sick role,' I examined the ways in which its prescriptions are rendered apprehensible through visual artifacts and interaction.

To my knowledge, there has been no previous sociological exploration of the handling of patients in the emergency rooms of Romanian hospitals. This represents a remarkable constraint: I have no opportunity to compare the data gathered with other studies to check the reliability of my findings. Another limit of my study lies in the collection of data in a turbulent period, marked by the

<sup>32</sup> At A and C, security agents targeted persons not standing still and invited them occupy a seat.

<sup>33</sup> At E, a nurse told a woman that her dirty clothes are polluting the air.

<sup>34</sup> At E, the rule was respected not only by patients and companions, but also by doctors, nurses, and orderlies.

<sup>35</sup> At D, nurses passing by a woman eating a sandwich joked about "people having a picnic here."

reorganization of the medical system, massive lay-offs, and wage cuts. It is likely that these phenomena disrupted to a certain extent the regular flow of events in the emergency rooms, including the handling of patients. A third potential shortcoming is inherent to the data collection approach – relying exclusively on the information that would be available to an outsider, I was unable to get a complex representation of the social organization of the emergency services in the hospitals under scrutiny. In order to get to a more accurate understanding of the categorization of patients, methodological triangulation would be necessary.

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The World Health Organisation defined health as a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.<sup>36</sup> The state has a certain responsibility concerning the health of the citizen. Obviously, the state is not responsible for the state of health of the citizen, but there are a series of institutions and other authorities of the state that have the responsibility to create certain basic conditions that protect and improve the health condition of the citizen.

In the introduction we will enumerate the relevant instruments at a national, international and regional level that determine the right to health as a human right.

At national level, the article no. 34 of the *Constitution of Romania* determines the right to preserve one's health (line 1) and foresees a series of correlative obligations of the state towards this right: to take measures in order to ensure hygiene and public health (alin.2), to organise medical benefit and the system of social insurance for disease, accidents, maternity, recovery and to ensure the control of the exercise of medical professions and that of paramedical activities as well as other measures that physically and mentally protect the citizen, according to the law (line 3). *Law no. 95/2006 concerning the reform of the health domain* regulates in detail the health system of Romania starting from the fundamentals foreseen by the Constitution. *Law no. 46/2003 on the rights of the patient*, statutes the rights of the patients and the principles on which the relationship between the medical staff and the patient is built. The Romanian legal frame is completed by the deontological codes of the medical professions and the regulations adopted by the Ministry of Health, regarding various aspects of medical assistance. The protection of a non-discriminatory treatment in accessing healthcare is regulated by the *Government Ordinance no. 137/2000 regarding the prevention and sanction of all forms of discrimination*. If the infringement of the right to health of the person takes the shape of a deed which is sanctioned by criminal law than the provisions of the *Criminal Code* may also be incident in the healthcare field.

At international level, The Universal Declaration of Human Rights devotes article no. 25 to the right to health of the person. This right is foreseen in the International Pact on economic, social and cultural rights, the main international document for the defence of the right to health. Article no 12 recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (line1). In the pursuit of a complete fulfilment of this right the states are called upon to adopt all necessary measures in order reduce the stillbirth-rate and of infant mortality and for the healthy development of the child, to improve all aspects of environmental and industrial hygiene to prevent treat and control epidemic, endemic, occupational and other diseases and to create conditions which would assure to all medical service and medical attention in the event of sickness; (line.2). Moreover, *The Convention on the elimination of all forms of racial discrimination* (art.5.(e).(iv)), *The Convention on the elimination of all forms of racial discrimination against women* (art.11.1.(f) and 12) and *The Convention on rights of the children* (art.24) foresee that the right to health must be guaranteed without discrimination regardless of race, gender age or ethnic affiliation.

At an European level, the right to health is regulated by the *Revised European Social Charter* Article 11 on the right to protection of health, resides in the obligation of the state to remove as much as possible the causes of ill-health, to provide advisory and educational facilities for the promotion of

<sup>36</sup>See the Preamble of the UN Constitution of the World Health Organization adopted by the International Conference on Health, New York, 19-22 June, 1946; signed on the 22nd of July 1946 by the representatives of 61 states (Official documents of the World Health Organization, no. 2, pag. 100) and adopted on the 7th of April 1948.

health and the encouragement of individual responsibility in matters of health; to prevent as much as possible epidemic, endemic and other diseases, as well as accidents Article no. 13 on the right to social and medical assistance stipulates the obligation of the state to ensure among others, that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition.

Starting from the nowadays international and regional provisions, we will develop in this chapter a series of themes examined throughout the sociological research on the right to health among the Roma, showing how to combat the potential infringements of the right to health, with juridical arguments. In the first part we will describe the spread of the right to health; we will approach the issue of the determining factors of the right to health as well as education, and information for health, access to drinkable water, basic sanitation, etc. In the second part, we review the basic content of the right to life and we will underline the maternal medical assistance, emergency medical assistance, immunization and prophylactic measures to which everyone is entitled to regardless of their being insured, access to primary medical assistance via the family doctor. In the third part, we describe the driving lines of the right to health, we will approach the issue of acceptability of the health services by adapting them to the cultural values of the Roma community and by respecting the deontological codes. The last part, examines the correlative obligations of the state towards the right to health, and we will point out the role of the medical staff as representatives of the state responsible with the abidance of the right to health for Roma, in equal measure with those of other patients and the fulfilment of the obligation of protection by adopting the legal framework and the commitment of those who infringe the right to health of a person.

## THE EXTENT OF THE RIGHT TO HEALTH

The Committee for economic, social and cultural rights, the UN organism mandatory to interpret the *International Pact on economic, social and cultural rights* and to monitor the way in which the signatory states, among which Romania, fulfil their obligations, has interpreted the right to health in the *General Comment no.14 – the right of everyone to the enjoyment of the highest attainable standard of physical and mental health* Consequently, the Committee for economic, social and cultural rights statuated that

*...the right to health must be perceived as being the right to enjoy a variety of units, goods and services necessary to the attainment of highest possible standard of health*<sup>37</sup>

Moreover,

*... the right to health ... is an inclusive right, that covers not only medical assistance provided in a timely and adequate manner, but also the determining factors of the state of health like the access to drinkable water, to hygiene, sure and adequate alimentation and lodging, healthy work conditions and environment and access to education and information on health, including sexual and reproductive health. Another important aspect is the participation of the population in all decisions that affect health, taken in the community, at a national or international level.*<sup>38</sup>

In consequence, the right to health encompasses the right to adequate medical assistance as well as access to a series of determining factors for the state of health like drinkable water, sanitation, sure

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<sup>37</sup>The Committee for economic, social and cultural rights, General Comment no14 The right to the highest attainable standard of health, paragraph. 9, E/C.12/2000/4.

<sup>38</sup>The Committee for economic, social and cultural rights, General Comment no.14 The right to the highest attainable standard of health, paragraph. 11, E/C.12/2000/4.

and adequate alimentation, adequate housing conditions, an not harmful environment to the health, education, information on health, including sexual health and reproduction.

Since the problem of the access to medical assistance will be widely discussed in this chapter, we will refer to the determining factors of the state of health by describing some Decisions of the Court of Law obtained in relation with regional or international human rights protection mechanisms that directly or indirectly addressed the right to health.

The impact of environmental conditions on health were indirectly examined by the European Court for Human Rights in the case *López Ostra against Spain*, through article no. 8 of the European Convention on Human Rights – the right to private life.<sup>39</sup> The European Convention on Human Rights does not protect the right to health. On the 14<sup>th</sup> of May 1990, Mrs. Gregoria López Ostra filed a complaint to the European Commission on Human Rights in which she was stating the lack of measures from the part of Spain concerning the contaminated smell, noise and smoke coming from a warehouse nearby her house, containing liquid and solid waste Mrs. López Ostra stated that the lack of action from the behalf of the Spanish State led to an infringement of her physical integrity right, (Art.3 of ECHR) and of the right to a private life and of domicile (art.8 of ECHR). The European Court for Human Rights decided that the art 8 of the ECHR was infringed. The Court motivated that neither the displacement of Mrs. López Ostra, nor shutting down the warehouse would not solve the fact that she and her family have been living for several years a few meters away from an environmental contamination source, which is harmful to the well-being of humans. The Court decided that the State was responsible for the infringement of the right private life and domicile since pollution was affecting the state of well-being of the individual and limit the way in which the latter enjoys her domicile, which in its turn affects her private and family life. The Court statuated that the State failed in finding the equilibrium between the adequate promotion of the economic development of the city and the actual exertion of rights from the part of the plaintiff.

On the other hand, the Court decided that the damage caused by the situation does not reach the level of intensity of degrading treatment and therefore there has been no infringement of Article no 2 of the ECHR (prohibition of torture and of inhuman or degrading treatment). The importance of the case is to emphasise the interdependence between the right to health and other civil and political rights, showing that by defending the right to private life and that of residence the right to health is also defended. Throughout the proceedings before the Inter-American Commission on Human Rights, the American equivalent of the European Court of Human Rights, there was an indirect approach to the importance of the **access to drinkable water**, remuneration and necessary medical treatment following the pollution of a river that affected the indigenous population of the Mapuche Paynemil and Kaxipayiñ of Argentina. In this regard, the children's right to special protection due to the statute of minority offers the right to effective remedies which were invoked before the Commission. At a national level, the regional child protection authority won a lawsuit that ordered the local authorities to provide for the community, within two days time, drinkable water that would last for a period of 45 days, to conduct research through which to determine the cause of contamination with heavy metals of the river, to fix all the damages done and to prevent future environmental damage. The complaint to the Inter American Commission on Human Rights was filed as a result of non compliance of the Argentinean state to the orders disposed by the national Court. Throughout the proceedings before the Commission, the state has committed to provide treatment for the affected children, to build a water treatment plant in the area, to inform the public concerning the potential contamination sources from the area.<sup>40</sup> The case is important because it shows the role of the international protection mechanisms for the human rights, in warning the states when the latter ignore the rights of the vulnerable categories of the population, even when these rights are baked up by Decisions of the National Court of Law.

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<sup>39</sup>See *López Ostra v. Spain*, 9 December 1994, Series A no. 303-C.

<sup>40</sup>See the Inter-American Commission on Human Rights, Mapuche Paynemil and Kaxipayiñ Communities, Case N° 12.010, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=405939&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=405939&focus=13991,13992,14020).



In the African system of protection of human rights, the importance of the determining factors of the state of health has been asserted. The African Commission for Human Rights and Peoples has decided in 2001 in the cause *SERAC against Nigeria* that the Ogoni population of Nigeria has suffered from infringements of their guaranteed rights. The Commission decided that the right to health and to an **environment favourable to development** have been infringed due to the failure of the government to prevent pollution and environmental degradation produced by the activity of private oil companies found in the land of the Ogoni. The Commission decided that the **right to housing** has been infringed by forced evacuations, destruction of the houses and harassment of the inhabitants who returned to rebuild their houses. In the end, the Commission decided that the destruction and contamination of the crops by state and non-state actors led to an infringement of the **right to nourishment**<sup>41</sup> The case is very important because it underlines the negative obligations as much as the positive obligations of the state, in connection with the economic, social and cultural rights, as well as the implications of the rights to nourishment and housing.

In the cause *Moldovan and others against Romania (no.2)* the **housing conditions** and their impact on mental health are analysed indirectly. In this cause, the European Court of Human Rights examined the remaining of unsolved matters from September 1993, targeted against a Roma community from Hădăreni, Mureș County, which ended with losses of human lives, setting the houses on fire and banishment from the village in the Roma community. The Court decided that the multitude of facts to which the Roma were subjected led to the violation of Article 3 (prohibition of torture and of inhuman or degrading treatment) and Article no 8 (right to private life and family) of the ECHR. In the analysis of the deeds, the Court emphasised as a contributing factor to the inhuman and degrading treatment, the living conditions of the past ten years of the plaintiffs following the loss of the houses of the latter, and especially: the overpopulated environment and lack of hygiene and their negative effects on the health of the applicants and their well being, combined with a long period in which the applicants had to live in such conditions and the general attitude of the authorities, which must have caused them significant mental suffering, leading to the destruction of dignity and making them feel humiliation and inferiority<sup>42</sup>

Concerning the **information and education in the health domain, including sexual health and the health of reproduction** as determining factors of the state of health, the European Committee for Social Rights decided in 2009 that the information and education policies of the population concerning certain aspects of health to be part of the right to health (art.11 line (2) of the Revised European Social Charter). In this regard, the Committee statuated that education for health should be conducted in school throughout all the education process, and that it must include the following subjects: prevention of smoking and alcohol abuse, education regarding the sexual and reproductive health, especially the prevention of sexually transmitted diseases and of AIDS, security of circulation and promotion of healthy eating habits.<sup>43</sup>

In Romania, the *Case „Miercurea Ciuc”*, documented by Romani CRISS and Amnesty International shows the impact of not assuring the determining factors of the state of health in the case of Roma communities. In June 2004, around 75 Roma, including families and children were moved by the local authorities from the buildings in the centre of Miercurea Ciuc city near a water treatment plant, in mobile metal containers. Although this was supposed to be a temporary measure, for six years, the community is in the same place, living in inadequate housing and living conditions according to the human rights. Although at present the containers are connected to electricity, there is a water source with drinkable water for all the community and the hygiene is ensured by the authorities, the children

<sup>41</sup>See the African Commission on Human Rights and Peoples, Social and Economic Rights Action Center & the Center for Economic and Social Rights against Nigeria, Communication No. 155/96, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=404115&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=404115&focus=13991,13992,14020).

<sup>42</sup>See the European Court of Human Rights, *Moldovan against Romania (no.2)*, no 41138/98 și 64320/01, §110, ECHR 2005-VII.

<sup>43</sup>See the European Committee on Social Rights, Complaint no.45/2007, INTERIGHTS against CROAȚIEI, 30 March 2009, §§43-50, available at [http://www.coe.int/t/dghl/monitoring/socialcharter/Complaints/CC45Merits\\_en.pdf](http://www.coe.int/t/dghl/monitoring/socialcharter/Complaints/CC45Merits_en.pdf).

are taken to school by bus, the housing conditions remain inhuman and endanger the health of the persons – the metal containers are overpopulated, the number of toilettes does not suffice and are inadequate, the containers do not offer protection against the cold, heat, rain and wind. The metal containers are found nearby the water treatment plant which exposes the community to toxic danger and the smell of human debris is spread throughout the community and it is felt inside the lodgings.<sup>44</sup>

The above summarised examples of Decisions prove that there are arguments in order to start conducting actions in order to defend the right to health, for the cases in which Roma persons face difficulties in accessing determining factors of the state of health such as drinkable water, hygiene, secure and adequate alimentation, adequate housing conditions, healthy work conditions, an environment harmless for the health and education and information on health, including sexual and reproductive health.

## THE BASIC CONTENT AND PROGRESSIVE ACHIEVEMENT OF THE RIGHT TO HEALTH

The right to health, as a right belonging to the categories of economic, social and cultural rights presumes that some of its elements are likely to be achieved immediately, regardless of the available resources, while some other of its elements are the object of progressive achievement.

### 1. THE BASIC CONTENT

The elements of the right to health that must be fulfilled immediately are part of the basic content of the right to health, such as non-discriminatory treatment in accessing units, goods and health services available at a given time. In 1978, the World Health Organisation has outlined during the *International Conference concerning primary medical assistance* a list of essential, basic, medical services, showing “that there is a border line concerning the state of health, line under which no individual of any country should find himself.”<sup>45</sup> Therefore, concerning medical assistance, the WHO identified that at least the following should be guaranteed: maternity medical assistance of the child and family planning, immunisation against infectious diseases, adequate treatment of diseases and injuries as well as access to essential medicine. Concerning the factors that determine the state of health, the WHO identified that at least the following should be provided for: education concerning the most frequently occurring health problems and the methods of prevention and control, promotion of food resources and adequate alimentation, access to drinkable water and basic hygiene.<sup>46</sup>

The aspects that are part of the basic content of the right to health have been emphasised and recognised by National Courts of various countries as well as by regional or international mechanisms concerned with the protection of human rights. Hereinafter a few examples are presented

In 2010, the National Council Against Discrimination, (NCAD), the Romanian authority against discrimination, sanctioned a gynaecologist for **discrimination against a Roma woman**, because the doctor granted her less attention than to the other patients and he verbally offended her concerning her ethnicity. The NCAD qualified the facts as harassment (art.2 line (5) of the GO 137/2000, concerning the prevention and sanctioning of all forms of discrimination). The NCAD statuated that taking into account the disadvantaged result from a socio-economic point of view and educational of the Roma

<sup>44</sup>See Amnesty International, Romania: Roma in Miercurea Ciuc continue to suffer violations of their right to adequate housing, 18 octombrie 2010, EUR 39/005/2010, available at <http://www.amnesty.org/en/library/asset/EUR39/005/2010/en/b67ca5d6-b8cb-439c-99e3-e7253b7c978f/eur390052010en.html>.

<sup>45</sup>World Health Organisation, Primary Health Care: Report of the International Conference on Primary Health Care, Alma-Ata, URSS, 6-12 September 1978, Health for All Series Nr.1, 1978, Chapter 3, paragraph.50.

<sup>46</sup>World Health Organisation, Primary Health Care: Report of the International Conference on Primary Health Care, Alma-Ata, URSS, 6-12 September 1978, Health for All Series No. 1, 1978.

community in comparison with that of the majority of the population, as well as the special state of vulnerability of the women because of her pregnancy, the reaction of the doctor was disproportioned towards the fact that the patient did not have a file, did not ask to be hospitalised and had no proof of an examination in order to show her medical condition. The NCAD disposed the sanctioning with warning.<sup>47</sup> A similar complaint has been filed in parallel to the Doctors' College, on disciplinary grounds, but the territorial college decided that it was not a matter of discrimination and sent the case for re-examination to the national level college.

The Supreme Court of India decided in 1996 on the obligation of ensuring the free **emergency medical assistance** as part of the right to life. The case is about a gentleman who suffered severe injury after falling off the train and his treatment was refused one after the other, by six public hospitals either because the units did not dispose of the equipment needed for the treatment or because they did not have any free places. The Court decided that the obligation to defend human life is of primary importance, regardless of the financial constraints that a state might encounter at a certain moment. The refuse to offer medical treatment in due time in order to save a life represents an infringement of the right to life.<sup>48</sup> It is the first case in which the national Court held that providing timely emergency medical assistance in order to save a life is covered by the right to life.

Also in India the problem of **maternal medical assistance** was analysed as part of basic content of the right to health. Mrs. Shanti Devi, who lived under the limit of the minimum guaranteed wage for the country, deceased after being repeatedly refused maternal medical assistance, despite the fact that she was eligible for free of charge services according to the state financing scheme; her husband was not able to prove it with the card. The Supreme Court of Delhi, decided in 2010 that the lack of an effective implementation of the financing scheme in order to guarantee the access to health services lead to the denial of the right to life as it is guaranteed by the international conventions of human rights and recognised that the right to life and the right to health are interconnected.<sup>49</sup>

**Producing an efficient vaccine** against a disease that affects a large number of persons has been qualified by the Argentine Federal Court of Appeal as being an infringement of the right to health stipulated in Art. No 12 of the "International Pact concerning economic social and cultural rights". Mariela Viceconte filed an action to the National Court of Justice, in which she explained the infringement of the right to health, her own and that of other people, by the fact that the Argentinean state does not produce the "Candid 1" vaccine against the Argentine hemorrhagic fever which affects almost 3,5 million people in Argentina. The vaccine is approved by the WHO, is 95% efficient and does not produce a profit for the medicine producers.<sup>50</sup> This case shows the positive role that the Courts of Law may have in monitoring public policies and budgetary execution. The Decision reasserts the role of the state in guaranteeing the right to health in situations in which certain services are not profitable or do not represent an interest for private suppliers from the health domain.

**Access to adequate and timely surgical treatment for children** is a fundamental element of the right to health, as it has been decided by the Caracas Juvenile Court, Venezuela in 2001. Several non governmental organisations filed a complaint concerning the precarious clinical and surgical treatment of children suffering from heart affections, in the speciality hospital of the capital. They complained about the long waiting lists, the fact that some children would die before their turn to be operated on arrived due to reduces allowances and lack of personnel that ensured adequate and timely

<sup>47</sup> See the National Council Against Discrimination, Decision No.149 of 07.07.2010, Decisions concerning the existence of discrimination classified on criteria issued in 2010, available at <http://cncd.org.ro/noutati/>.

<sup>48</sup> See the Supreme Court of India, *Paschim Banga Khet Mazdoor Samity & Ors against the State of Western Bengal Vest and Anor* (1996), AIR SC 2426/ (1996) 4 SCC 37, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=401236&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=401236&focus=13991,13992,14020).

<sup>49</sup> See the Supreme Court of Delhi, *Laxmi Mandal against Deen Dayal Harinagar Hospital & Ors*, W.P.(C) Nos. 8853 (2008), 4 June 2010, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=1370523&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=1370523&focus=13991,13992,14020).

<sup>50</sup> See the Federal Administrative Court of Appeal, Argentina, Viceconte, Mariela against Estado Nacional (Ministerio de Salud y Ministerio de Economía de la Nación) s/ Acción de Amparo, 2 June 1998, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=419811&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=419811&focus=13991,13992,14020).

medical services. The National Court admitted the sanction on the grounds of the right to health and to life, and disposed that the operation room be fully equipped, that there should be a permanent dialogue between the local administration and the members of the medical association and patients under the surveillance of the Peoples' Advocate and of Child Protection in order to identify and find solutions for the present and future problems. Throughout the dialogue an agreement was signed, by which the local administration committed to guarantee among others, a minimum of 5-7 surgical interventions per week. The Ministry of Health promised to acquire and maintain the new equipment and to completely renovate the cardiology service, to reimburse the cost of 86 surgical interventions and to ensure a continuous circulation of money so that it would finance surgical interventions in order to avoid the situations in which patients must pay for the necessary medical materials. Following this case, a negotiation framework with the state has been created concerning the very serious deficit in granting medical services. Even if not all the clauses of the accord have been respected, the children suffering from congenital heart affections have been identified as vulnerable group in need of special measures from the part of the state, and a new cardiology centre is now under construction.<sup>51</sup>

In Romania, a series of recent documents of some international organisms or non-governmental organisations have reported infringements of the basic content of the right to health to which Roma persons are exposed. In August 2010, the Committee for the Elimination of Racial Discrimination has noticed the presence of racist stereotypes and of racial discrimination against Roma, in accessing health services in Romania. The Committee recommended to the Romanian state to promote Roma health mediators and to find the responsible for the discrimination against Roma in accessing public services.<sup>52</sup> The problems identified by the Committee are mentioned in the 2009 Report on Human Rights of the State Department of the USA, and in the 2010 report of Amnesty International.<sup>53</sup> A particular aspect related to the right to health is the sexual and reproductive health. In this regard, a report from 2010 financed by the European Commission showed that "frequent early pregnancies of Roma women expose the latter to particular risks concerning their health, fact aggravated by precarious access to healthcare and poverty, with negative influences on the life expectancy of Roma women."<sup>54</sup>

The fact that above-mentioned problems have been recognised in justice as belonging to the basic content of the right to health attracts the possibility of an immediate execution in justice of the obligations of the state in order to ensure the medical services in question. This could be a remedy to this situation, as in the above stated examples of the Decisions of National Courts, and of the mechanisms for the protection of international and regional human rights presented above.

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## 2. PROGRESSIVE ACHIEVEMENT

The progressive achievement of certain elements of the right to health means that the state may gradually achieve these elements by adopting the necessary measures, including legislative, administrative, budgetary measures, etc. Through the elements passive for the progressive achievement of the right to health, stand the creation of high quality facilities and services that imply larger

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<sup>51</sup>See Juvenile Court of Caracas, *Programa Venezolano de Educación-Acción en Derechos Humanos (PROVEA) y otros contra Gobernación del Distrito Federal s/ Acción de Protección*, 16 July 2001, Expediente N° 3174, disponible en [http://www.escribnet.org/caselaw/caselaw\\_show.htm?doc\\_id=414358&focus=13991,13992,14020](http://www.escribnet.org/caselaw/caselaw_show.htm?doc_id=414358&focus=13991,13992,14020).

<sup>52</sup>See the Committee for the elimination of racial discrimination, *Observations and conclusions for Romania*, 27.08.2010, paragraf.14, CERD/C/ROU/CO/16-19, available at <http://www.ohchr.org/EN/countries/ENACARRegion/Pages/ROIndex.aspx>.

<sup>53</sup> See the US Department of State, 2009 Human Rights Report, published in 2010, available at [HTTP://ROMANIA.USEMBASSY.GOV/2009\\_RHR\\_EN.HTML](http://ROMANIA.USEMBASSY.GOV/2009_RHR_EN.HTML). See also Amnesty International 2010 Report, *The State of the World's Human Rights*, pag.267, available at [http://thereport.amnesty.org/sites/default/files/AIR2010\\_AZ\\_EN.pdf#page=214](http://thereport.amnesty.org/sites/default/files/AIR2010_AZ_EN.pdf#page=214).

<sup>54</sup>See Marcella Corsi, Chiara Crepaldi, Manuela Samek Lodovici, Paolo Boccagni, Cristina Vasilescu, *Ethnic minority and Roma women in Europe: A case for gender equality?*, Synthesis report, European Union, 2010, p.114, available at [http://www.google.bg/url?sa=t&source=web&cd=1&ved=0CBQQFjAA&url=http%3A%2F%2Fec.europa.eu%2Fsocial%2FblobServlet%3FdocId%3D4833%26langId%3Den&rct=j&q=Ethnic%20minority%20and%20Roma%20women%20in%20Europe%3A%20A%20case%20for%20gender%20equality%3F%20Synthesis%20report&ei=pPGsTNnLBcbGswbL0JTKDQ&usq=AFQjCNEwC746V0EjaawGbdYDp7c\\_mpkm-g](http://www.google.bg/url?sa=t&source=web&cd=1&ved=0CBQQFjAA&url=http%3A%2F%2Fec.europa.eu%2Fsocial%2FblobServlet%3FdocId%3D4833%26langId%3Den&rct=j&q=Ethnic%20minority%20and%20Roma%20women%20in%20Europe%3A%20A%20case%20for%20gender%20equality%3F%20Synthesis%20report&ei=pPGsTNnLBcbGswbL0JTKDQ&usq=AFQjCNEwC746V0EjaawGbdYDp7c_mpkm-g).

investments in comparison with the number of potential beneficiaries, creation of new professions and specialisations, building new hospitals or departments, etc.

The progressive achievement of the right to health was an issue approached by the Constitutional Court of South Africa in 2005, in the cause *Soobramoney against the Ministry of Health (Kwazulu-Natal)*. Mr. Thiagraj Soobramoney suffered from acute renal failure, he needed dialysis otherwise his life would be endangered. When he ran out of private resources for the dialysis, Mr. Soobramoney requested free medical assistance from the public health system in Durban. Mr. Soobramoney was refused (because he was not eligible for treatment due to his general health condition (it did not allow his recovery in a short time by dialysis, nor did he qualify for a kidney transplant). Mr. Soobramoney filed appealed to the National Court of Law, requesting an order for the hospital by which he would benefit from free dialysis. The National Courts, including the Constitutional Court of South Africa decided that even if the situation of Mr. Soobramoney was related to the exercise of the right to health, there had been no infringement of this right. In consequence, the Court showed that the **access to dialysis** of Mr. Soobramoney is not an emergency medical treatment, accessible to anybody, but a **continuous medical treatment in order to maintain the state of health**. The Constitutional Court made the difference between these two categories of medical services, from the perspective of the obligations of the state to ensure access to public health services. In comparison with the emergency medical treatment, that must be immediately secured by the state, regardless of the available resources, the medical treatment which is not an emergency depends on the available resources. Therefore, the Court agreed to the eligibility criteria of the public hospital imposed due to limited resources. Moreover, the Court declared that it could not interfere in the good-faith decision making process of the political body and of the medical authorities concerning the budgetary allocation and financing priorities. Although this decision tends to grant transition to the administrative decisions, invoking the separation of the executive and the judicial powers, it lets us understand that the administrative decisions may be censored by the Court of Law in case the policies of the executive are unreasonable or their application is not correct and reasonable.<sup>55</sup>

Romania was highlighted on an European level through the health mediator programme<sup>56</sup> They conduct their activity in the community in order to improve the access of the Roma to the available public health services, especially to the primary medical assistance services. The measures adopted by the Romanian state in order to create and make the health mediators work, may be included in the progressive achievement of the right to health – taking legislative, administrative and budgetary measures in order to create and support a new profession in order to assist the access of the population to public health services. An important aspect of the obligations of the state connected to the progressive achievement of the right to health is that once adopted, the measures in question must be continued; any registered regress must be justified thoroughly by the state, otherwise it may be regarded as an infringement of the right to health. The situation during 2009-2010 of the health mediators in Romania may represent such a progress. In 2009 there were about 500 health mediators employed by the Ministry of Health. Following the decentralisation process of the medical services in Romania, starting with the 1<sup>st</sup> of July 2009, the employment contracts of all the health mediators had to be taken over by the City Halls of the 41 counties, but still being financed by the Ministry of Health. Nevertheless, around 200 health mediators faced difficulties in continuing their activity – they were either not hired by the City Halls or other persons without the necessary training were hired in their place, they were given attributions which were not connected to the activity of health mediator, which prevents them from conducting their health mediator activity.<sup>57</sup> At that time, the need of the community for health mediators was still of actuality, and the budgetary resources were not a problem, because the

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<sup>55</sup>See the Constitutional Court of South Africa, *Soobramoney against the Ministry of Health (Kwazulu-Natal)*, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=673074&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=673074&focus=13991,13992,14020).

<sup>56</sup>See Open Society Institute. *Mediating Romani health: policy and programme opportunities*. New York: Open Society Institute, 2005, pag.19-21.

<sup>57</sup>See Romani CRISS, *Civic Alliance of the Roma in Romania, Shadow Report for the Committee on the Elimination of Racial Discrimination*, 27 iulie 2010, disponibil la <http://www.romanicroiss.org/Shadow%20report%20CERD%20Romania%20-2010.pdf>.

Ministry of Health had allocated funds in order to continue this activity, the interruptions, obstacles or malfunctions faced at the level of local public administrations cannot represent a thorough justification of the regress registered in the health mediators programme.

## GUIDELINES OF THE RIGHT TO HEALTH

The Committee for economic, cultural and social rights statuated on four guidelines of the right to health: availability, accessibility, acceptability and quality.

### 1. AVAILABILITY

Availability implies the medical units, goods, services and medical programmes to be offered in sufficient quantity throughout the country, including drinkable water, adequate hygiene, hospitals, clinics and other buildings for medical assistance, trained medical and auxiliary staff receiving competitive wages at a national level and essential medicine.

### 2. ACCESSIBILITY

Accessibility presumes that the medical units, goods and services be accessible to all persons found on the territory of a state, without discrimination. The accessibility has four overlying dimensions: non-discrimination, physical and economic accessibility and the access to information.

By **non-discrimination** in exercising the right to health it is understood that the medical units, goods and services are accessible to everyone both in theory and in practice, especially to vulnerable or marginalised groups.

For example, in Canada, in 1997 a case was trialled, which raised the problem of **unequal access to medical services of the people suffering from hearing affections**, in the context in which the hospitals in the country did not ensure sign-language communication for these patients. The two plaintiffs, persons who were born with a hearing deficiency held before the Supreme Court of Canada that because of the fact that they are not ensured the interpretation of the sign-language, they are exposed to a risk being incorrectly diagnosed and inefficient treatment, which leads to an infringement of the right to equality on the criterion of disability guaranteed by the Constitution. The Court decided that the right to equality imposes correlative obligations on the public authorities which must allocate resources in order to ensure the complete access of disadvantaged groups to public services. Because of the fact that the government did not prove to have a reasonable justification not to include interpreting services, the Court gave a deadline of six months to the government to ensure these services in order to comply with the principle of equality in practicing the right to health on the criterion of disability.<sup>58</sup> The Decision offers a base for advancing the right to health and other economic, social and cultural rights for the vulnerable groups through the right to equality and non-discrimination.

In Romania, discrimination by race or ethnicity in exercising the right to health is forbidden and sanctioned by Art.1 line (2) and Art.10 letter b of the *GO 137/2000 concerning the prevention and sanction of all forms of discrimination*, by Art.62, 98 and 652 line (2) of *Law 95/2006 concerning the reform in the health domain*, by Art.3 and 27 of *Law 46/2003 on the rights of patient*, by Art.3, 4 and 5 of the *Medical Deontological Code of the College of Doctors in Romania* of the 30<sup>th</sup> of August 2008 and by Art.3 letter e and Art.21 of the *Ethical and Deontological Code of the medical assistant of the general practitioner, of the midwife and of the medical assistant in Romania* of the 9<sup>th</sup> of July 2009. In

<sup>58</sup>See the Supreme Court of Canada, *Eldridge against British Columbia (Attorney General)* [1997] 3 S.C.R. 624, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=399162&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=399162&focus=13991,13992,14020).



the cases presenting an increased social risk, in which the deed or consequences are very serious may become the incidence of criminal law, for example Art. 184 (physical injury), Art.247 (Abuse of office rights by restraining certain rights) and rt.250 (Abusive behaviour) of the *Criminal Code*.

**The physical accessibility** of the right to health presumes that the medical units, goods and services may be addressed physically and territorially, by all the segments of the population, especially by vulnerable or marginalised groups, such as ethnic minorities, women, children, teenagers, elderly people and people suffering from HIV/AIDS. Physical accessibility presumes drinkable water and basic hygiene to exist in rural areas and that the access to medical buildings be realised by disabled people.

**Economic Accessibility** of the right to health means that any person can afford to access medical units, goods and services. Payment of the medical assistance services as well of other medical services connected to determining factors of the health condition must be founded on the principle of equity, ensuring that their financial accessibility in either the private or public environment for the socially disadvantaged groups. Equity implies poor segments of the population not to be subjected to disproportionate medical expenses in comparison with wealthier segments of the population.

The European Committee for Social Rights decided in 2004 that by **stopping the coverage from public insurance funds** of health of medical assistance for poor illegal represents an infringement of the right to health in the case of children but not in the case of adults, since they have access to certain types of medical assistance (emergency medical assistance and for the situations in which their life is endangered, and after three months of residence and other forms of medical assistance). The decision is much more important since it has been adopted in the context in which the rights of the European Social Charter only apply to the citizens of other member states, who work and live legally in another member-state. The Committee decided that unlike other rights, in the case of the right to health, which is closely connected, to the right to human dignity “the legislation and practices that refuse the right to medical assistance of the foreign citizens found even illegally on the territory of a member state are contrary to the provisions of the Charter”. Consequently to the decision of the Committee the French government changed its policy.<sup>59</sup>

In 2005, the UN Committee for the rights of the child issued a series of recommendations to Ecuador in which it showed that there might be an incompatibility between the right of the child to health contained in the Convention concerning the rights of the children and the free trade treaties negotiated by Ecuador, Columbia and Peru with the United States. In particular, it was about the inability of the State of Ecuador to ensure **access to inexpensive medicine**, including common medicine. Similar recommendations were issued by the Committee for other states, and the UN Committee for Human Rights started issuing itself similar recommendations concerning the impact of the free trade agreements on the economic, social and cultural rights. Even if their character was not compulsory, these recommendations may be used at a national level in wider campaigns against the practice of such agreements.<sup>60</sup>

In Romania, apart from the persons who contribute to the public insurance system – employees and the unemployed who have signed an insurance contract with the health insurance house – there is a vast list of categories of persons insured by the public health insurance system by law, without their bringing any personal. These categories are the following: husband/wife and parents found in the maintenance of the insured person, young people between 18 and 26 years old on the period of their studies and another 3 months after they finished their studies, young people under 26 years old without incomes from the child protection system, some persons persecuted during the communist regime, the disabled with no income sources, those suffering of affections included in the national health programs,

<sup>59</sup>See the European Committee for Social Rights, *International Federation of Human Rights Leagues (FIDH) against France*, Complaint No. 13/2003, available at

[http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=400976&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=400976&focus=13991,13992,14020).

<sup>60</sup>See UN Committee for the right of the children, *Observations and conclusions for Ecuador*, CRC/C/15/Add.262, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=408597&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=408597&focus=13991,13992,14020).

pregnant women and women lately confined, persons on medical leave due to temporary work incapacitation following a work accident or professional disease, persons on maternity leave until the age of 2 years old or in the case of disabled children until the age of 3 years old, persons executing a sentence that deprives them of liberty or are found in remand, persons benefiting from unemployment allowance, expatriated persons or victims of human traffic found under the procedures required in order to establish their identity, persons part of a family entitled to social welfare, according to Law no.416/2001, with the all the ulterior amendments, the retired, for their retirement income up to the imposed limit of the income tax; persons who carry out the measures stated in Art.105, 113, 114 of the Criminal Law; persons found in the period of delay or interruption of execution of the sentence that deprives them of their liberty, if they don't register any income.<sup>61</sup> It is important to remember that this quality of insured is not automatically acquired through the simple fact that the person belongs to the category in question, but they must file a request in this regard to the insurance house in their city of domicile, and prove that they belong to the category in question.

From the sociological study presented in this publication it shows that among the interviewed Roma population, out of the 58% insured by the public insurance system, a high percentage, (61%) represent unemployed persons who benefit from health insurance because they are members of a family entitled to social welfare, according to Law no.416/2001, and 7,3% are insured as wife or husband of an insured person. Consequently, it is very important for the Roma population to hold on to these social benefits that ensure free access to the **basic package of services** annually by the standard contract adopted by the National House of Health Insurance and the Ministry of Health.<sup>62</sup> The remaining 48% Roma interviewees are not insured by the public health insurance system, and therefore only have free access to the **minimum package of services**, which includes medical services only in the case of surgical emergencies and of diseases with endemic-epidemic potential, including the ones foreseen by the National Immunisation Programme, monitoring of pregnancy evolution and of confinement, family planning services established by the standard contract.<sup>63</sup>

*Access to information* concerning the right to health implies that anybody has the right to request, receive and spread information and ideas on health.

In Romania, *Law no. 46/2003 on the rights of the patient* dedicated an entire chapter, (Chapter II) to the right of the patient to be medically informed, be it concerning available medical services and the right to use them, or of his being informed on the identity and professional status of the suppliers of health services available or they way in which he may dispose of those, or on the rules and habits that he should respect during hospitalisation, or his being informed about his health condition, proposed medical interventions, potential risks of every procedure and the existing alternatives, diagnose data and forecast.<sup>64</sup> In order to respect the principle of the access to information in exercising the right to health is that the information presented be understood by the patient, "brought to his knowledge clearly, in a respectful language and by minimising the use of specific terminology".<sup>65</sup> If the patient does not speak Romanian, as in the case of Roma patients, part of traditional groups of some specific regions, the law offers them the right to learn about these information in their mother tongue, or any language that they know or according to the case another mean of communication will be used".<sup>66</sup> In addition, the patient has the right to ask and receive another medical opinion.<sup>67</sup> Respecting these legal provisions is important because every person should fully enjoy their right to health, without any difference by ethnicity or any other criteria. Moreover, in the case of the persons exposed to discrimination, respecting these standards may lead to an increase in the trust of the medical system and an increase in addressability. Therefore, informing the parents and the community on the importance of the

<sup>61</sup>See Law no.95/2006 concerning the health reform, art.211-213.

<sup>62</sup>See Law no..95/2006 concerning the health reform, art.210 lit.c and art.217. The basic package of medical services

<sup>63</sup>See Law no.95/2006 on the rights of the patient, art.210 lit.e and art.220.

<sup>64</sup>See Law no.46/2003 on the rights of the patient, art.4-6.

<sup>65</sup>See Law no 46/2003 on the rights of the patient art.8.

<sup>66</sup>See Law no 46/2003 on the rights of the patient art.8.

<sup>67</sup>See Law no 46/2003 on the rights of the patient, art.11.



immunisation of the children and on the secondary effects inherent to every vaccine, may work as an efficient encouragement of the increase in the number of vaccinated Roma children.

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### 3. ACCEPTABILITY

Acceptability in exercising the right to health implies that all medical units, goods and service respect the medical ethics and be adequate from a cultural point of view, that they respect the culture of individuals, minorities, populations and communities, to pay attention to gender and age and be projected in such a way as to respect confidentiality and improvement of the health condition of the persons in question.

In 2003, the European Court on Human Rights decided in the cause *Y.F. against Turkey* that any action affecting the physical integrity of the person must be regulated by the law and conducted only **with the consent of person** in question. The cause refers to a Kurd woman who was in preventive arrest and when she was released, she was subjected to a gynaecological examination without her consent. The examination was performed by a forensic doctor with the purpose to prove that she had not been raped by the police officers who had arrested her, and in order to avoid future accusations towards the police from the part of the woman in question. This type of treatment has been considered an infringement of Art. 8 of the Convention (the right to private life), the right to physical integrity.<sup>68</sup>

In 1997, the European Court of Human Rights decided in the cause *Z against Finland* that the national law must ensure adequate protection guarantees of the **confidentiality of the patient**. The communication of personal data within the medical system or between the medical system and the juridical system by the medical personnel, contradicts the standards foreseen by Art.8 of the Convention (the right to private life). Moreover, the Court statuated that the communication of personal medical data [as in the case of the HIV positive result of the person] may dramatically affect the family and private life of the person, as well as the social position and work relations by enhancing the stigmatisation of the person.<sup>69</sup>

A case similar to the previous one has been decided in 2009 at the Court of Sector 1 Bucharest. This case was about **communicating personal medical data**, not between public systems but to the public, on the website of the city hall in question. The Court of Sector 1 Bucharest disposed moral damages amounting 10.000 euro to be paid to a person affected by the infringement of confidentiality.<sup>70</sup>

In 2009, the European Court of Human Rights decided in the cause *K.H and others against Slovakia* that the right to **access to the personal medical file** and that of **obtaining a photocopy** of the personal medical file is protected by Art.8 of the Convention (the right to private life). Eight women, members of the Roma community in Slovakia received gynaecological treatment in Eastern Slovakia. Following that treatment, all eight women were unable to remain pregnant. They were asked to sign various documents when leaving the hospital but could not identify the content of the signed documents. Although the women empowered lawyers to protect their interests, the Ministry of Health did not recognise their warrants and refused the access of the latter to their medical files. The National Courts of Justice maintained the decision of the Ministry of Health. The Court decided that the right to private and family life must be effectively ensured in practice therefore the access to the personal files must be ensured. The Court decided that apart from Art.8 and Art.6 line1 (the right to a fair trial) has been infringed because limiting the access to the file creates a disproportionate duty on the individual who tries to efficiently present his case to the Court. This case is part of a series of cases decided by the

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<sup>68</sup>See the European Court of Human Rights, *Y.F. against Turkey*, no. 24209/94, 22nd of July 2003, ECHR 2003-IX.

<sup>69</sup>See the European Court of Human Rights, *Z against Finland*, 25 February 1997, § 95, *Reports of Judgments and Decisions* 1997-I.

<sup>70</sup>See vedea The Court of Sector 1 București, Sentința civilă din 16.03.2009, available at <http://www.juridice.ro/100724/judecatoria-sectorului-1-daune-morale-pentru-publicarea-pe-internet-a-datelor-personale.html>.

European mechanisms of defence of human rights, which are meant to pressure the governments of Eastern and Central Europe in order to stop discrimination against the Roma citizens.<sup>71</sup>

Concerning the informed consent, in Romania, Law no. 46/2003 on the rights of the patient is in accordance with the international standards of human rights establishing that mainly the decision concerning a certain medical treatment belongs exclusively to the major patient, with capacity of exercise and discernment, except for the emergency cases when the patient cannot express his will, and the intervention is to the best interest of the patient. He may refuse or stop a medical intervention if he wishes to.<sup>72</sup> In addition, the consent of the patient is obligatory when it comes to sampling, keeping or using all biological drawn products of his body, the participation of the patient to the medical education and scientific research or photo shooting or filming in a medical unit.<sup>73</sup> These regulations must be respected and applied in practice by rendering the patient more responsible with regard to the fact that the decision concerning the medical act belongs to him and not to the medical personnel, and that by complete information of the patient he would be able to decide after knowing all the details.

Concerning the insurance of confidentiality, Law no. 46/2003 on the rights of the patient guarantees that all information concerning the state of the patient, the results of the investigations, the diagnosis, the forecast, the treatment, and personal data are confidential even after the death of the patient and may only be communicated to relatives or other persons only with the consent of the patient. Furthermore, the information can only be divulged to the accredited suppliers of medical services involved in the treatment of the patient, if the information in question are necessary in this regard.<sup>74</sup> The guarantee of confidentiality must not be understood in the sense of limiting the access to the personal medical file. The same Law on the rights of the patient guarantees the right of the patient to access personal medical information and when leaving the hospital to receive a resume of his investigations, diagnosis, treatment and medical care throughout his hospitalisation.<sup>75</sup> These rights are important to the information of the patients but are essential in building a case in the event of an action against an infringement to the right to health.

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#### 4. QUALITY

The quality in exercising the right to health implies that the medical units, goods and services be scientifically and medically adequate and of the best quality. This implies among others, the existence of well-trained medical personnel, medicine, equipments that must be scientifically approved and valid, of drinkable water and of adequate hygiene.

It is useful to examine the elements of the right to health from the point of view of all directing lines of the right to health as mentioned above, because it helps identify the possible flaws in ensuring the right to health and to plead for their remediation.

#### CORRELATIVE OBLIGATIONS OF THE STATE CONCERNING THE RIGHT TO HEALTH

The right to health, like all human rights, implies three types of correlative obligations of the state – to respect, protect and achieve. The obligation to respect is a negative obligation on the grounds of which the state must abstain from directly or indirectly affecting the practice of the right to health by the individuals. The positive obligations of the state, of protection and achievement, imply that the state acts in order to protect the individual against the actions of third parties, by facilitating, offering and

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<sup>71</sup>See the European Court of Human Rights, *K.H. and others against Slovakia*, no32881/04, 28 April 2009.

<sup>72</sup>See Law no. 46/2003 on the rights of the patient, art.13-17.

<sup>73</sup>See Law no. 46/2003 on the rights of the patient, art.18-20.

<sup>74</sup>See Law no. 46/2003 on the rights of the patient, art.21-23.

<sup>75</sup>See Law no. 46/2003 on the rights of the patient, art.12 și 24.

promoting the content of the right to health. In private, the obligation to achieve implies adopting adequate legislative, administrative, judicial measures of promotion and other measures in order to achieve at its most the right to health.

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## 1. THE OBLIGATION TO RESPECT

On the grounds of the obligation to protect the right to health, the state is held not to forbid or limit equal access to health services, not to apply discriminatory practices as a public policies, not to impose discriminatory practices or policies concerning the health of women and their needs, and to abstain from acts that have a negative effect on the population.

The UN Committee for the elimination of discrimination against women sanctioned Hungary because a doctor from a public hospital performed a **forced sterilisation** on a Roma woman, without previously informing her and without her consent. The Committee stated that this type of discrimination was discrimination on the criterion of ethnicity concerning her right to decide the number and time interval of birth of her children, sexual and reproductive education and information on family planning. Mrs. A.S., member of the Roma community, reached the hospital when she was in labour and required immediate caesarean operation. Immediately after the surgery, a doctor asked Mrs. A.S. to sign a form of consent for sterilisation. Between the moment of her arrival to the hospital and the moment the form was signed, 18 minutes had passed. Mrs. A.S. did not understand what was written on the file and found out that she had been sterilised after the sterilisation. This case of sterilisation of a Roma woman is the first of this kind, which has been solved in Central and Eastern Europe.<sup>76</sup>

The medical personnel employed in the public health system represent the state in the relation with the patients, and is a state actor. In consequence, the state is held responsible for any action of the medical personnel of the public system following which the right to health of the patient is affected.

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## 2. THE OBLIGATION TO PROTECT

On the grounds of the obligation to protect the right to health the state is held to adopt legislative measures as well as other types of measures in order to ensure that the persons have equal access to health services offered by third parties, to adopt legislative measures and other types of measures in order to protect the persons from the infringements of the right to health by any third parties.

In 2008, the Constitutional Court of Columbia decided on the fact that some **structural problems faced by different levels of the Colombian public health system** that originate mainly in essential regulation mistakes, infringe the obligation of the state to respect, protect and achieve the right to health. Among the remedies disposed by the Court, we find actualising, clarifying and uniting the coverage plans of health insurances, urgent allocation of financial resources towards the insurance system and strengthening the evaluation and surveillance system of the private companies that supply health materials to the public health system. By this decision the Court impedes the health system to continue with unsustainable measures and corrects the structural mistakes that affect the access of the beneficiaries to health services.<sup>77</sup>

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<sup>76</sup>See the UN Committee for the elimination of all forms of discrimination against women, A.S. against Hungary, Communication Nr. 4/2004, 14.August 2006, CEDAW/C/36/D/4/2004, available at <http://www.un.org/womenwatch/daw/cedaw/protocol/decisions-views/Decision%204-2004%20-%20English.pdf>.

<sup>77</sup>See the Constitutional Court of Columbia, Decision T-760 of the 31st of July 2008, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=985449&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=985449&focus=13991,13992,14020).

In 2010, the Administrative Court of Justice of Egypt decided that the Order of the Ministry of Health no. 373/2009 by which a new medicine pricing system was established, infringes the right to access to medicine as part of the right to health, by the significant increase in the price of medicine. The old system established the price of the generic medicine according to their production cost to which the profit margin was added. The new system adjusts the prices to the global market prices, by establishing prices for medicine of renowned brands with 10% cheaper than the cheapest prices on other markets for the same product. The court motivated that the new system will have inevitable repercussions mainly on the price of the medicine, which will lead to the impossibility of the citizens to purchase medicine. The Court disposed the abeyance of the order on the period of the trial. The Supreme Court of Egypt is now judging the appeal.<sup>78</sup>

The medical personnel of the private system or the other patients are third parties towards the state in what concerns the right to health – they are not state actors. In order to protect the right to health the state must adopt the legal and institutional framework that would allow the sanctioning of these third parties, in case this right is infringed. In Romania, the medical personnel is responsible if by their actions they affect the right to health of the patient, regardless of their being employed by the state or in the private sector.

Hereinafter we will refer to the disciplinary responsibility of the doctors. The disciplinary responsibility does not exclude the criminal, civil or contravention responsibility.<sup>79</sup> According to the Romanian legislation, a patient who considers himself harmed by a doctor may file a complaint against that doctor to the College whose member the doctor in question is. The complaint is valid if the harm produced is a consequence of non-compliance to one or more of the following: the laws and regulations of the medical profession, the Deontological Medical Code, the rules of professional practice or of the Statute of the College of Doctors in Romania, the non-compliance to the compulsory decisions adopted by leading organisms of the College of Doctors in Romania or any other deeds in relation with the profession which prejudice the honour and prestige of the profession or of the College of Doctors in Romania. The complaint must be filed within a maximum of 6 months from the date the deed was committed or of the acknowledgement of the prejudicial consequences.<sup>80</sup> The Bureau of the Territorial Council decides whether to start or not a disciplinary investigation.<sup>81</sup> The disciplinary investigation is conducted by the persons designated by the College.<sup>82</sup> The plaintiff and his witnesses will attend a hearing during the investigation.<sup>83</sup> After the investigation of the deed, the disciplinary file together with the proposal of sanction or annulment of the disciplinary action is forwarded by the Professional Jurisdiction Commission to the Commission of Discipline where other procedures and new hearings follow.<sup>84</sup> The Commission of Discipline takes the decision and may apply the following disciplinary sanctions: admonishment, warning, blaming vote, fine from 100 lei to 1500 lei, interdiction of exercising the profession or certain medical activities on a period from one month to one year or withdrawal of the quality of member of the College of Doctors in Romania.<sup>85</sup> Against the decision of the Commission of Discipline on a territorial level an impugment can be made within 15 days from the communication of the decision. The impugment is filed to the Executive Bureau of the Territorial Council that must send it to the Executive Bureau of the National Council.<sup>86</sup>

<sup>78</sup>See the Court of Administrative Justice of Egypt, Case No.2457/64, Challenging the New Drug Pricing System, 27th of April 2010, available at [http://www.escri-net.org/caselaw/caselaw\\_show.htm?doc\\_id=1312208&focus=13991,13992,14020](http://www.escri-net.org/caselaw/caselaw_show.htm?doc_id=1312208&focus=13991,13992,14020).

<sup>79</sup>See Law 95/2006 concerning the health reform, Art.442 and the following. See the Statute of the 25th of March 2005 of the College of Doctors in Romania, published in the Official Monitor no. 418 of the 18th of May 2005 stipulates in the 2nd section the Procedural rules concerning the disciplinary investigation of doctors.

<sup>80</sup>See Law 95/2006 concerning health reform, Art.449.

<sup>81</sup>See the Statute of the 25th of March 2005 of the College of Doctors in Romania, Art.110.

<sup>82</sup>See Law 95/2006 concerning health reform, Art.450 and the Statute of the 25th of March 2005 of the College of Doctors in Romania, Art.112.

<sup>83</sup>See the Statute of the 25th of March 2005 of the College of Doctors in Romania, Art.112.

<sup>84</sup>See the Statute of the 25th of March 2005 of the College of Doctors in Romania, Art.113 -114.

<sup>85</sup>See the Statute of the 25th of March 2005 of the College of Doctors in Romania, Art.104 and Law 95/2006 concerning health reform, Art.447.

<sup>86</sup>See Law 95/2006 concerning health reform, Art.443.

In order for a state to carry-out its obligations, to respect and protect the right to health, it is not enough to adopt a legal and institutional framework by which to establish a disciplinary procedure, but it should take all necessary measures so that the procedure in question be successfully correctly and efficiently applied, to be known and accessed in case of infringement and the applied sanctions to be effective, dissuasive and proportionate.

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### **3. THE OBLIGATION TO ACHIEVE**

On the grounds of the obligation to achieve the right to health, the state must adopt policies concerning health at a national level, and to allocate a sufficient percentage of the budget for health, to offer the necessary health services or to create the conditions that allow adequate and sufficient access of the persons to health services, especially including medical care services and access to drinkable water and adequate hygiene.

The non-compliance to any of the three correlative obligations of the state concerning the right to health, are regarded as solid grounds to start an action in the Court of Law in order to defend the right to health at a national, regional or international level, as shown by all the decisions presented in this chapter.

In conclusion, we consider that in Romania we adopted important measures in order to defend the right to health, especially from the legislative point of view. Nevertheless, recent studies and reports, including the sociological study presented in this publication, uncovered a series of difficulties in exerting the right to health, especially in the case of Roma people. This situation, is either a consequence of racist stereotypes such as racial discrimination in accessing health services, lack of access to some determining factors of one's state of health, such as awareness and health education, drinkable water, living-conditions and adequate housing, etc; either a consequence of a regression in the health mediators' programme or the existence of a significant percentage of Roma persons that are not medically insured. Consequently, the Romanian state must continue with the positive policies and programmes promoted, such as the health mediators' programme, and it should apply the current laws using the following types of measures: administrative, budgetary, awareness-raising, education and promotion of the right to health both for the general population and for the medical staff. The decisions taken by international, regional and national Courts, by which the infringement of the right to health has been acknowledged and sanctioned, are strong arguments that determine the need to support similar actions in the case of Romania, in order to ensure access to the right to health for the Roma.

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