

Health and the Roma Community

# Health and the Roma Community

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# HEALTH AND THE ROMA COMMUNITY

*Analysis of action proposals*

Directorate-General for Public Health  
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# I. INTRODUCTION

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This document is based on the conclusions reached by means of the qualitative analysis carried out by the “Group of Experts on Health and the Roma Community” within the framework of the collaboration agreement between the Ministry of Health and Consumer Affairs and the Fundación Secretariado Gitano in 2004.

The goal of this working group was to come with an initial diagnosis of the social-health status of the Spanish Roma population in order to pinpoint their principal needs and thus contribute to the elimination of existing health inequalities faced by this group. This work was based on the realisation that there was very little available data upon which to base tailored intervention with the Roma community. Until ad hoc research is available, it is up to the experts in the field who work with and meet the needs of the Roma population (in the areas of health and social action) to help raise awareness regarding the situation, prioritise actions and tailor methodologies.

Having taken stock of this situation, the Ministry of Health and Consumer Affairs (Directorate-General for Public Health) and the Fundación Secretariado Gitano (FSG) have put together a joint collaboration project aimed at promoting health-care equality for the Roma population of our country. On the European level, the FSG heads a project financed by the European Union and supported by the Ministry of Health and Consumer Affairs targeting the same objectives.

In keeping with this line of action, one of the initial work proposals was the start-up of a working group with the mission of formulating an initial diagnosis and a series of intervention proposals. This group, comprised of 18 professionals<sup>1</sup>, held four work sessions during the months of April and May.

This document is the outcome of the efforts of this working group and the contributions made at the seminar on “Health-care Equality and the Roma Community” held at the headquarters of the Ministry of Health and Consumer Affairs on 11 November 2004<sup>2</sup>. The content of this document, also based on secondary sources related to other studies in this field, is structured around the following sections:

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<sup>1</sup> See Annex II for a list of group participants.

<sup>2</sup> See Annex III for the seminar programme, objectives and participant list.

## - II. Health, Health Equality and Health Promotion

This section presents the theoretical framework used as a reference marker for reflection and proposals; a theoretical framework with health promotion as its main axis.

## - III. The Roma community and health: a diagnosis for action

This heading includes the diagnosis made by the group based on their reflections and analysis of existing studies. This diagnosis is not limited to an analysis of weaknesses but also seeks to highlight strengths, dangers and opportunities for the Roma community.

Two elements which have a bearing on all of the reflections expressed hereafter must be highlighted because they are basic premises in approaching the issue of health and the Roma community: first of all, the degree of diversity within the Roma community which is increasing on a daily basis. The exact same variables marking differences within the majority society also have an effect on Roma diversity: age, sex, gender-specific circumstances, place of residence, income level, type of job, cultural and academic level, etc. It is therefore difficult to arrive at valid conclusions which are applicable to all Roma. Second of all, there is very little available scientific information related to the Roma community and health that furnishes data on perceptions, demands, epidemiology, etc.<sup>3</sup>

Thus, the opinions expressed herein are a reflection of the experiences of the group of experts and a few local studies. The following quote captures very well what has taken place in this field of research: "An editorial in the *British Medical Journal* highlights the lack of studies done on the health of the Roma people. According to the article, in the *Medline* data base the keyword 'Gypsy' produces many more articles referring to the fruit fly *Drosophila melanogaster* (gypsy moth) than to the health of this cultural group."<sup>4</sup>

## - IV. The Roma community and health: recommendations for action

This section presents the action proposals and recommendations based on the needs diagnosis. In order to understand the proposals made one must bear two basic premises in mind:

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<sup>3</sup> F. Ferrer searched the body of works published over the last 20 years on the Roma Community and health. A presentation of this study may be found in the following article: Ferrer, F. "El estado de salud del pueblo gitano en España. Una revisión de la bibliografía". *Gaceta Sanitaria*. Vol. 17. 2003.

<sup>4</sup> Cabedo García, V.R. et. al. "Cómo son y de qué padecen los gitanos". *Journal Atención Primaria*. Vol. 26. No. 1. 2.000.

- First of all, it should be made clear that the object is not so much to get the health system to “*adapt*” to the Roma community by implementing parallel programmes but rather to INCLUDE in its operation the needs and characteristics of sectors<sup>5</sup> that, when it comes to certain aspects<sup>6</sup>, are different from the majority population. This inclusion process calls for the implementation of exceptional measures or strategies but always on a provisional basis so as to steer clear of paternalism and stigmatism.
- Second of all, it must not be forgotten that inclusion here does not imply assimilation. The goal, therefore, is to construct a society which is not based on one, single cultural identity but rather on dialogue and negotiation between all cultures.

The implementation of these recommendations would make an important contribution to the correction of weaknesses, the reinforcement of strengths, and the prevention of dangers and would help in taking full advantage of opportunities. This proposal is structured around the different agents involved in the health-Roma community relationship:

- Action taken by social work and health-care professionals;
- Training provided for social work and health-care professionals;
- Organisation of the health-care system;
- Intercultural mediation;
- Roma community capacity-building in the area of health;
- Health intervention programmes for the Roma community;
- Studies and research focusing on health and the Roma community.

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<sup>5</sup> The Roma community is one of these but our society is gradually becoming more heterogeneous.

<sup>6</sup> And in many other aspects they are quite the same which is why we reiterate that the objective is not to create parallel initiatives as if we were dealing with absolutely different and irreconcilable sectors of society.



## II. HEALTH, HEALTH EQUALITY AND HEALTH PROMOTION

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### 2.1. Bio-psycho-social concept of health

The broad concept of health affecting different aspects of human life is gradually becoming more and more accepted: physical, psychological and socio-cultural aspects and not only absence of disease. The 1948 constitution of the WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” The WHO considers health as a **fundamental human right** and therefore all people must have access to basic health-care resources.

Therefore, when we speak of health we refer to the process of interaction between human beings and their social and natural environment, a process by which said human beings maintain physical and psychological well-being allowing them to contribute fully to their community’s social life.<sup>7</sup> Health is conceived as the result of all the factors affecting the lives of individuals: those that are virtually unsusceptible to modification (sex, age or genetics) as well as those that are potentially modifiable (behaviour, ways of earning a living, cultural and socio-economic aspects, etc.). Health, therefore, is not an exclusively biological phenomenon.

### 2.2. Health and inequality

Inadequate housing, deficient education, insufficient income, etc. all have an important influence on health and are important factors determining the state of well-being and living standards of a population group living in a specific environment. The processes of exclusion and social marginalisation limit people’s access to health-care services and the use they make of them. Therefore, interventions aimed at improving living standards (reducing environmental pollution, improving access to high-quality food, potable water, eradication of shanty towns or sub-standard housing, etc.) contribute to improving health and promoting integration.

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<sup>7</sup> “La población gitana en Andalucía: un estudio exploratorio de sus condiciones de vida”. Regional Government of Andalusia. Seville, 1996.

In this sense, the most disadvantaged socio-economic groups exhibit characteristics making them susceptible to poor health. Other variables such as gender, age, ethnic background, social class or geographical area are also **risk factors** when it comes to health.

It appears to be clear that belonging to a minority ethnic group has a bearing on the emergence of specific health inequalities. These inequalities are not only rooted in socio-economic variables but are also the product of barriers blocking access to health-care services and ineffective use of such services due to poor adaptation or even discrimination.

The processes of social exclusion and marginalisation take a greater toll on these groups because, due to their condition as minorities, they do not actively participate in the different areas and facets of public life.

### 2.3. Equality and health for all

According to the WHO, inequality is a product of differences in health-care issues which are unnecessary, avoidable and unjust. In response to the above, the WHO proposes the concept of health-care equality. Health-care equality does not mean the same state of health for everyone but rather refers to the aim of providing all people with the same opportunities so that they can take full advantage of their health. In this sense, the WHO's global strategy of achieving *Health for All* basically pursues a greater degree of health equality between and within population groups and among countries. This means that all people should have the same opportunity to develop and maintain their health by means of fair access to health-care resources. Inequalities with respect to health status arise as a result of the lack of opportunities in life in general.

### 2.4. Health promotion

Health promotion, within the framework of public health, "is the process by which populations are provided with the means necessary to exert greater control over their own health and thus capacitating them to improve it."<sup>8</sup> Health promotion is a global political and social process which not only includes actions directly focusing on strengthening the skills and capacities of individuals but also encompasses those that seek to modify social, environmental and economic conditions with a view to mitigating their impact on public and individual health.

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<sup>8</sup> "International Conference on Health Promotion." Ottawa Charter, 1986.

It entails a whole set of strategies to be implemented by governments in an interdisciplinary fashion in order to raise living standards and equality in the area of health with participation playing a key role in sustaining actions of this nature.

The principal areas of action in health promotion are: public policy definition, creation of favourable health environments, reinforcement of community action, personal skills development and reorientation of health services.

From among the principal elements, special mention should be made of the involvement of the population as a whole and dealing with inequalities. This covers actions the purpose of which is to furnish information regarding the possibility of taking individual or family decisions and to foster responsible participation on the part of citizens in decisive community activities focusing on protecting the right to health.

The Jakarta Declaration on Leading Health Promotion into the 21st Century (July 1997) identifies five priorities:

- Promote social responsibility for health.
- Increase investments for health.
- Consolidate and expand development partnerships for health.
- Increase community capacity and empower the individual.
- Secure an infrastructure for health promotion.



# III. HEALTH AND THE ROMA COMMUNITY: a diagnosis for action

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## 3.1. Weaknesses

This refers to the elements that are currently not functioning properly or which have some negative repercussions on the health-Roma community relationship.

### *The Roma population's perception of health<sup>9</sup>*

In some sectors of the Roma community, health is not perceived as a top priority. Housing, finances or employment all come before health in terms of this group's perceived needs.

A large percentage of Roma conceive health as the absence of disease, and disease as an incapacitating phenomenon linked to death. This unique perspective on health and disease leads to several consequences:

- Health only becomes a concern in the presence of very dramatic symptoms and incapacitating consequences thus making it difficult to approach the concept of prevention.
- Once the individual (and his family) perceive the presence of disease, action taken must be immediate and definitive in light of the direct relationship existing between disease and death.
- The diagnosis is a matter of "*putting a label on one's affliction.*" Thus, the attitude adopted is ambivalent. Complete avoidance prevails in the absence of symptoms and incapacitating consequences (in these cases the diagnosis may be perceived as a manifestation of a disease that previously did not exist).
- If symptoms disappear under treatment, all other therapeutic guidelines are

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<sup>9</sup> Although based on the analysis of a very small, specific group of Roma, David Lagunas published an article on these issues in 1999: "Resolviendo la salud. Los gitanos catalanes" (Resolving Health Issues, the Catalan Roma). *Gazeta de Antropología*. No. 15.

generally ignored because from the perspective of this concept of health, the disease has vanished.

### **The status of the Roma community with regard to health-care<sup>10</sup>**

The close relationship between social inequalities (economic, educational, housing, etc.) and health inequalities is clearly highlighted by international health organisations (WHO, European Commission, etc.).<sup>11</sup> In this sense, if we bear in mind that a high percentage of the Roma population is in a situation of social exclusion or vulnerability,<sup>12</sup> we should be able to understand that the percentage of the Roma population affected by the lack of equality in health is also very relevant.

In general terms, the health-care status of the Roma community can be summarised as follows:

- Infant mortality is 1.4 times higher than the national average and life expectancy for the Roma population is between 8 and 9 years below the average.<sup>13</sup> In cases of extreme marginalisation, life expectancy is estimated to be 10 years below the average.
- Higher incidence of infectious disease<sup>14</sup>, mainly hepatitis B and C. Vertical or mother to child transmission has been observed frequently in the case of these diseases.<sup>15</sup> A higher incidence of HIV is also observed, mainly among intravenous drug users.
- Deficient child vaccination,<sup>16</sup> and generally inadequate follow-up on the "Healthy child" programmes, especially in areas with a low socio-economic level<sup>17</sup>.

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<sup>10</sup> As was indicated in the "preliminary note" to this chapter, the lack of studies done in the field of health and the Roma community is one of the main weaknesses detected. The studies consulted (all listed in the bibliography), and which for the most part have formed the basis of our analysis of the status of the Roma community with respect to health, use very small and geographically limited sample sizes. It would, therefore, be risky to generalise results.

<sup>11</sup> European Commission "Conclusions and recommendations of the Studies Commission on social inequalities in the field of health in Spain." 1996.

<sup>12</sup> The National Action Plan for Social Inclusion 2001-2003 estimates that over 30% of the Roma population is in a situation of social exclusion or vulnerability.

<sup>13</sup> Las claves del racismo contemporáneo (Key aspects of contemporary racism). Montoya, 1994.

<sup>14</sup> Cabedo, V.R. et. al. "Cómo son y de qué padecen los gitanos". Publication Atención Primaria. Vol. 26, No. 1. 2000; Fos, E. et. al. "Elevado riesgo de infección por el virus de la hepatitis B en la población de raza gitana". Publication Atención Primaria. Vol. 89, No. 13. 1987.

<sup>15</sup> Delgado, A. "Resultados y análisis de la investigación de AghBs en las embarazadas de un centro de salud durante 4 años". Publication Atención Primaria. Vol. 7, No. 8. 1990.

<sup>16</sup> Regional Government of Andalusia. La población gitana en Andalucía. 1996.

<sup>17</sup> Sastre, E. et. al. "Situación de salud entre niños gitanos y no gitanos de una comarca granadina". Publication Anales Españoles de Pediatría. Vol. 53, No. 3. 2000. Sánchez, F.J. et. al. "Diferencia étnica en la actividad asistencial de urgencias. Aproximación a la realidad gitana". Publication Anales Españoles de Pediatría. Vol. 56, No. 1. 2002.

- Deficient eating habits and nutrition, especially in the case of children (also affecting dental health).<sup>18</sup>
- Adult diets are characterised by excessive consumption of coffee and fats.
- Improper use of medicines: this tendency is directly related to the Roma population's use of the "scientific treatment model"<sup>19</sup> (explained further on in this report) and a desire to "solve the problem right here and now."
- There is a higher incidence of accidents and involuntary injury<sup>20</sup> such as: burns, falls, pedestrian traffic accidents, bone fractures, cuts, intoxications, etc.
- High-risk group for congenital malformations. The studies consulted make reference to genetic and cultural factors (endogamy).<sup>21</sup>

Turning specifically to the health of Roma women, special mention should be made of the incidence of certain diseases related to the traditional role assigned to mothers and wives. The following relevant characteristics merit attention:

- High fertility rate with pregnancies and births starting very young and continuing into older age.<sup>22</sup>
- On occasion, sparse information with respect to family planning. Some birth control methods are not used because they are unknown and also because a number of myths and faulty ideas still persist.<sup>23</sup>
- Very little gynaecological disease prevention.<sup>24</sup>
- Premature ageing with incidence of diseases which are atypical for the age groups affected such as diabetes, bone ailments, cardiovascular problems, etc.
- Excessive degree of responsibility both in and out of the home giving rise to symptoms of depression, anguish and anxiety in some cases.

In conclusion, and bearing in mind the indicators commonly used by the international scientific community to measure inequalities in the area of health,<sup>25</sup> it can be said that the health-care status of the Roma population is clearly deficient.

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<sup>18</sup> Mora, L. et. Al. "Prevalencia de caries y factores asociados en niños de 2-5 años de los Centros de Salud Almanjáyay y Cartuja de Granada capital". Revista Atención Primaria. Vol. 26. No. Publication Atención Primaria. Vol. 26, No. 6. 2000.

<sup>19</sup> That represented by the physician (sometimes private) and the pharmacist.

<sup>20</sup> Sánchez, F.J. "Diferencia étnica en la actividad asistencial de urgencias. Aproximación a la realidad gitana". Publication Anales Españoles de Pediatría. Vol. 56. No. 1, 2002.

<sup>21</sup> Martínez-Frías, M.L. "Análisis del riesgo que para defectos congénitos tienen diferentes grupos étnicos de nuestro país". Publication Anales Españoles de Pediatría. Vol. 48. No. 4. 1998; Martínez-Frías, M.L., et. Al. "Síndrome de Fraser: frecuencia en nuestro medio y aspectos clínico-epidemiológicos de una serie consecutiva de casos". Publication Anales Españoles de Pediatría. Vol. 48. No. 6. 1998.

<sup>22</sup> Dueñas, R. M. et. al. "Influencia de factores socioeconómicos en la evolución y seguimiento del embarazo." Publication Atención Primaria. Vol. 19, No. 4. 1997.

<sup>23</sup> Reig, S., et. al. "Anticoncepción : gitanas frente a payas." Publication Atención Primaria. Vol. 23, No. 2. 1999.

<sup>24</sup> Dueñas, R. M. et. al. "Influencia de factores socioeconómicos en la evolución y seguimiento del embarazo." Publication Atención Primaria. Vol. 19, No. 4. 1997.

Nevertheless, the opinion of the Group of Experts and that expressed in the scientific literature consulted, tends to confirm that this health-care situation has more to do with a lack of equality in terms of life opportunities and access to and use made of resources than with genetic factors intrinsic to the Roma minority (except in the case of congenital malformations).<sup>26</sup>

### **Cultural aspects of the Roma community which have a bearing on the health-Roma community relationship**

The concept of health and disease transcends the individual and extends into the realm of group and community issues (especially in terms of the extended family). This characteristic (which, as we will see later, does have positive effects) also implies a series of weaknesses in light of the fact that:

- The decisions taken by an individual with respect to his health are strongly influenced by his extended family. This makes the relationship with the health-care system more complex because it is no longer a relationship between the health-care system and one individual; it is between the system, the individual and his extended family. This characteristic has very visible and striking effects such as the presence of many family members at doctors' surgeries, emergency rooms or at hospital, which others can sometimes find very annoying. Other effects are less visible at the outset but have very clear consequences: the instructions that the health-care professional gives his patient may be subsequently "re-interpreted" by the extended family.
- The result of the prevailing concept of health and disease prevalent among an important proportion of the Roma population, together with this interaction between the individual and his family, is that many ailments are treated within the family rather than by the health-care system until symptoms and consequences become alarming. This makes early detection very difficult.

It is the woman's role to see that health is cared for. The next question is "who takes care of the caretaker?" Women's health tends to come last on the list of priorities. The following situations may arise:

- Out-patient home-based care for women is usually very difficult; first of all because this means that homes must be properly equipped and second of all because it is very difficult for women to take on the role of "patient" at home.

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<sup>25</sup> The most commonly used indicators are as follows: mortality rate, morbidity rate, perceived health, health-related behaviour, activity limitations and access to and use made of health-care services.

<sup>26</sup> Martínez-Frías, M.L. "Análisis del riesgo que para defectos congénitos tienen diferentes grupos étnicos de nuestro país". Publication *Anales Españoles de Pediatría*. Vol. 48. No. 4. 1998.

- In the case of mental health, women tend to abandon treatment prematurely.

The perceived immediate need to cure illness as quickly as possible is a product of the close association between disease and death. This means that the diagnosis of a health-care professional is urgently needed to determine the problem's degree of seriousness.

The improper use of some health-care services is another of the consequences of the above-mentioned concept of health and disease prevalent among an important proportion of the Roma population:

- Excessive use of emergency room services.
- Infrequent use of ambulance services; patients are generally transported by the family.
- Appointments at doctor's surgeries are not usually made.

The extended family usually has a very clear idea of the course family members' lives should take. If these ideas are very rigid and if the person in question does not want and/or cannot adhere to them, the consequences for the social, mental and even physical well-being of the person could be very negative.

### **Approaching health in the Roma community from the health-care system**

First of all, one must remain mindful of the lack of studies carried out or supported by health authorities in the field of health and the Roma community.

Second of all, it has become common practice for health-care planners and managers to overlook the diversity characterising the Roma community. In this sense, a lack of awareness on the part of health-care professionals is observed regarding the characteristics and culture of this minority, frequently giving rise to the emergence of prejudice and stereotypes. It is generally observed that these professionals are not able to differentiate between specifically cultural aspects and others which are more related with the socio-economic situation in which many Roma families find themselves. In other words, no distinction is drawn between what can be considered Roma culture and the "culture of marginalisation."

The Group of Experts reiterates time and again the existence of an important communication barrier between the health-care system and a large proportion of Roma citizens. This communication barrier may be rooted in a number of different factors:

- Failure to adapt or tailor messages communicated to the Roma population.

This lack of adaptation is related with the sort of vocabulary employed,<sup>27</sup> but it is also rooted in health-care professionals' predilection for the use of written communication while it is oral communication that prevails in the Roma community.

- Discrepancy as concerns criteria for the assessment of the quality of treatment. In the case of the Roma minority, quality of treatment is mostly based on the length of the visit, how they are treated as persons, perceived empathy, non-verbal communication, etc. These are difficult criteria to comply with in today's public health system.
- Mutual prejudice which, in many cases, leads to a relationship based on defensiveness and mistrust. These prejudices, charged with a powerful emotional component (and therefore tremendously difficult to change), are the product of a number of different circumstances:
  - Historical prejudices on which the relationship between the Roma community and the rest of society has been based.
  - Individual negative experiences which tend to fuel prejudice while positive experiences, perceived as exceptions to the rule, do not have a counterbalancing effect.
  - The formation of individual opinions based on the dissemination of negative rumours (snowball effect): "I heard that a Roma family punched the physicians at hospital X"; "Someone told me about a Roma child who died of pneumonia because in the hospital emergency room they told his family that he was fine", etc.

All of the above is related with two important weaknesses in the way the health-care system deals with this issue:

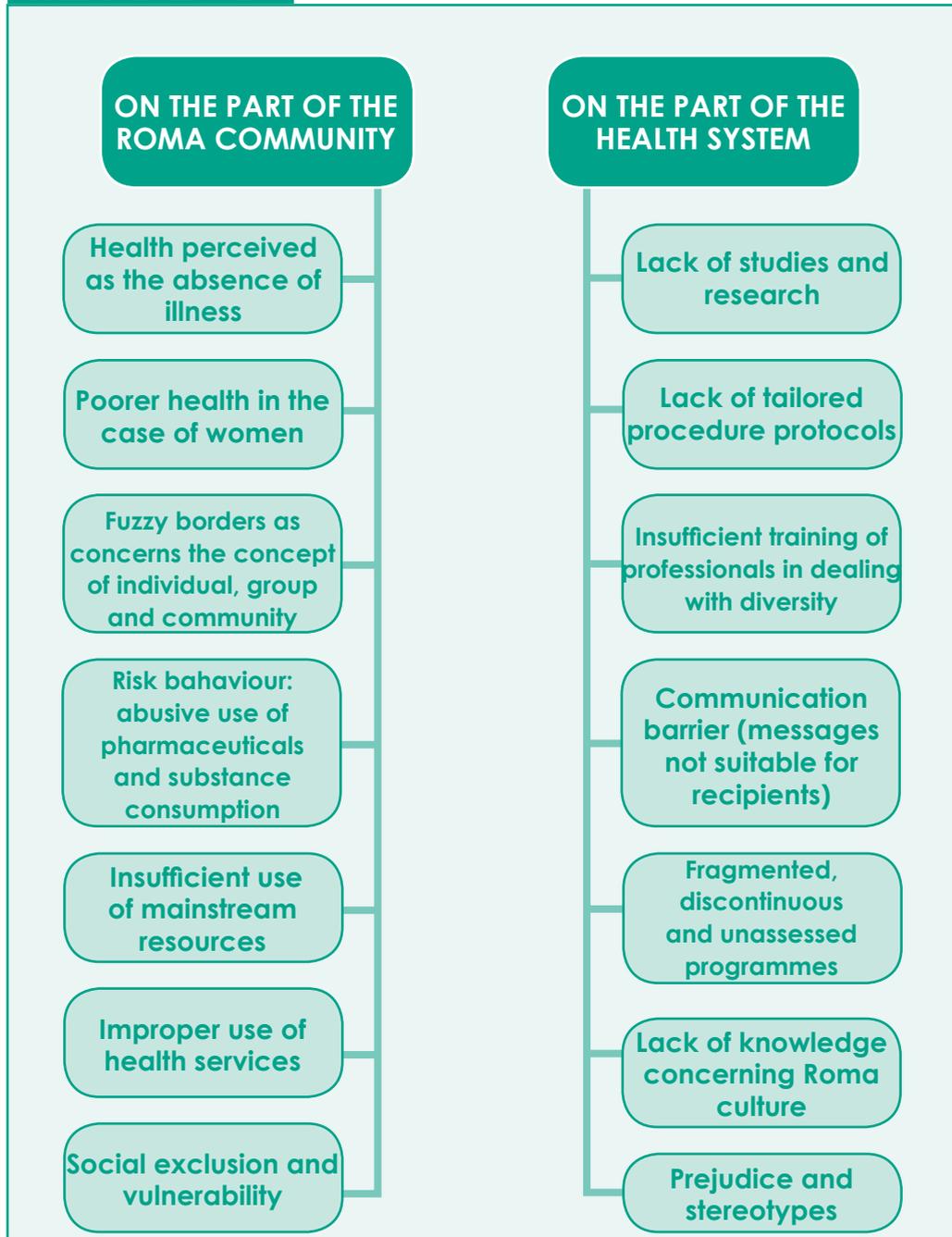
- Health-care services have great difficulties in employing flexibility in the face of "differences." The lack of tailored protocols is one of those difficulties. As long as procedural protocols are lacking, many professionals will continue to claim that they are complying with general protocols ("I'm just doing what I was told to do") while care tailored to the Roma community (or to any other minority groups for that matter) will continue to be perceived as something voluntary reserved for "sensitive service providers."
- The lack of empathy skill training and failure to address "cultural" aspects in university studies. The overall perception is that field professionals need mediator skill training if they are to effectively treat minority groups with special characteristics.

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<sup>27</sup> Especially bearing in mind the lack of formal schooling in the case of a large sector of the Roma population.

The few programmes implemented (with some exceptions) are characterised by their fragmentation, discontinuity and lack of evaluation. This observation does not refer exclusively to programmes implemented by government administrations but

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also to those launched by the associative world.

There are also a number of emerging issues which could have a significant effect on health but hardly any preparation or organised response has been observed. Special mention should be made of the following:

- Care for adolescents, a developmental stage that, until just recently, was virtually inexistent.
- The gender perspective, taking into consideration the specific health needs of women who also belong to an ethnic minority.
- Religious fanaticism.
- Traffic accidents and associated risk behaviours such as the consumption of alcohol or other substances.
- Gender violence perpetrated against women.

The figure of the professional mediator or Roma mediator is not very widespread and the health system is quite unaware that it even exists.

In some health promotion programmes, economic incentives for users have even been established with a view to encouraging use and/or continued use of healthcare services. However, this is not considered a suitable strategy because over the long term it leads to dependency on public institutions and fails to develop positive attitudes with respect to taking care of one's own health.

## 3.2. Threats

This section deals with those elements which could get worse or lead to negative future repercussions with regard to the health-Roma community relationship. The following aspects should be highlighted:

### *The relevance of other minority groups*

This is one of the threats that tends to come up in debate forums on intervention work with the Roma population. This concern focuses on the possibility that the Roma community will once again be “relegated” and “forgotten,” displaced by the needs of other emerging minorities (immigrants mostly) competing for benefits and niche areas of employment traditionally reserved for Roma workers.

### *Intervention programme design within the health-Roma community relationship*

Mention has already been made of the heterogeneity that exists within the Roma community. If planners and managers lose sight of this fact, the danger is that the programme will fail at the implementation stage due to the lack of tailored strategies.

Another mistake sometimes made is that of focusing entirely on existing weaknesses without considering the large number of strengths and opportunities. In this case, the danger is in creating service oriented, hierarchical and paternalistic programmes in which one group of individuals (non-Roma) “saves” the Roma people from their weaknesses but fails to give them a leadership role because they are not believed to have any strengths which can be built upon.

Along these same lines, if Roma men and women are not invited to take part in programme design, this could give rise to programmes which fail to meet the needs and expectations of the target population; programmes that do not respect their pace, their codes, their values, etc., in short, programmes that fail.

Moreover, if these programmes fail to take stock of the expectations and needs of other sectors (health-care professionals, for example) and do not include them in the design process, the danger of failure will also be imminent.

Also related to the above, if these programmes fail to adapt their language to that of the health-care sector, it is possible that the latter will not recognise that they are being called upon to participate in their development.

As for the theoretical model on which these programmes are based, if biology-

oriented models are chosen, it will be impossible to effectively respond to a multidimensional reality such as the health inequality of the Roma community. A biology-oriented model would also stand in the way of needed interdisciplinary work.

And finally, putting all the responsibility for intervention on the shoulders of the mediator is yet another important danger. As is always the case, delegating responsibility on one person (the mediator in this case) can lead to disinterest on the part of others (the rest of the health system professionals in this case). Mediation can be an important strategy but is certainly not the only option.

### **Development of Health and Roma Community Intervention programmes**

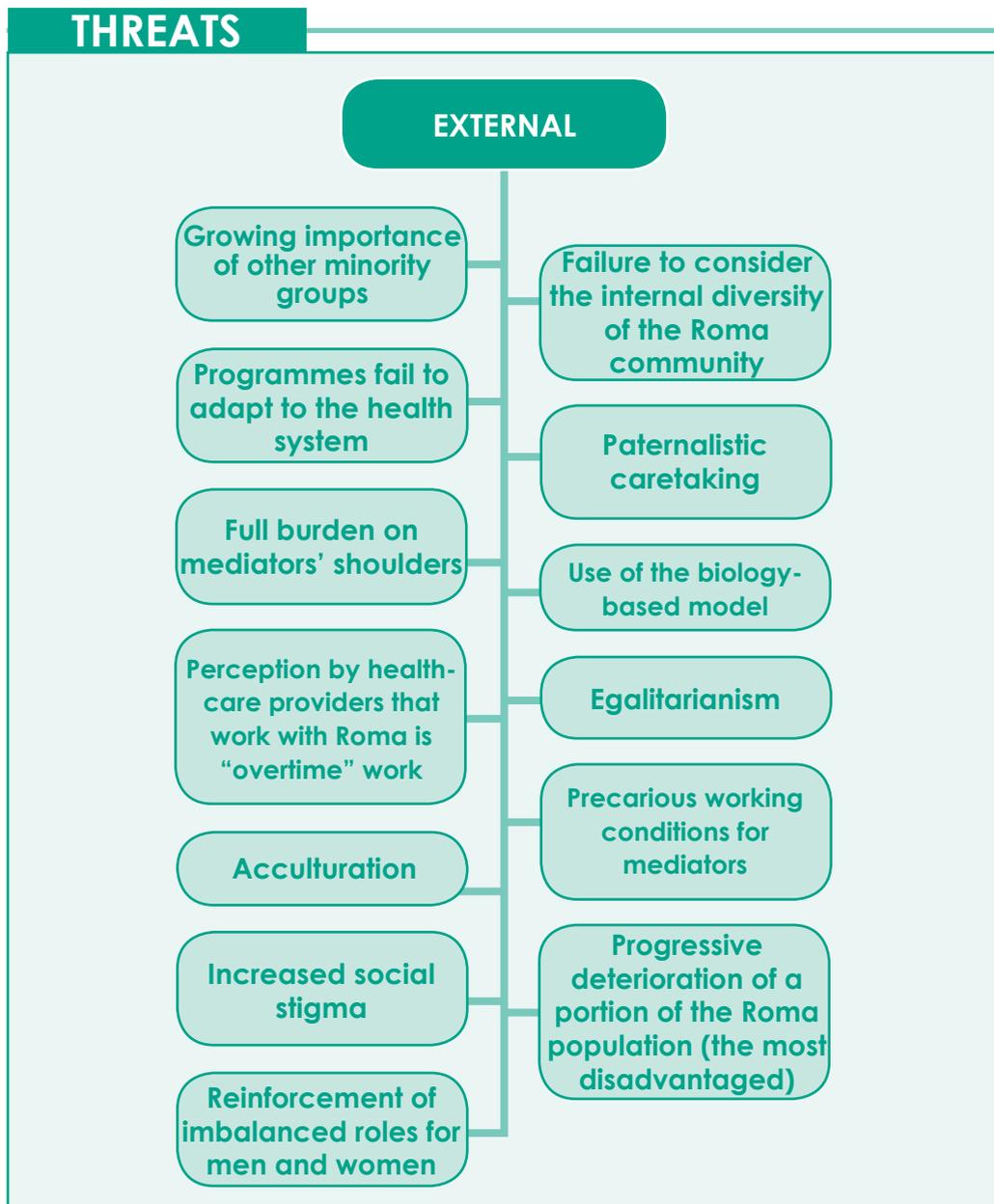
The idea of equality that many sectors of the majority society have is more like “egalitarianism” or “white coffee for everyone” and tends to show little respect for “difference” and diversity. This concept of equality, a far cry from the sort of health equality proposed by the WHO, is one of the most important dangers to the implementation of policies and programmes that assume flexibility and adaptation on the part of minorities and other groups with specific needs.

In the threats section mention has already been made of the lack of awareness that health-care professionals have of Roma culture and the absence of tailored protocols and programmes. However, the Group of Experts pointed out that when it comes to future training initiatives or tailored programmes, a number of different dangers should be kept in mind:

- Prevailing lack of awareness and therefore insufficient professional demand for these types of initiatives.
- If these types of programmes are not preceded by awareness heightening initiatives and are simply included as part of normal health-care activities, they may be perceived by field professionals as extra work rather than a resource to increase the effectiveness of intervention with the Roma population. In this case the threat lies in not making these interventions or programmes part of the routine, i.e. in not integrating them into the set of health system management tools.
- The society puts a great number of demands on professionals from the health-care sector. At certain times these professionals become saturated and feel that they are expected “*to know and do everything.*” In this case the danger lies in not defining exactly what course of action should be taken by professionals and in not having sufficient resources.

It is also important to point out that the precarious situation which some

mediators face in carrying out their professional duties (lack of clarity regarding functions and working conditions) also has a bearing on their failure rate which is often attributed to the mediation strategy employed rather than to the precarious conditions under which it is applied.



## **Repercussions of intervention programmes on Health and the Roma Community**

If, as mentioned above, programmes are designed and developed without promoting the participation of Roma community members, there is a danger of fostering acculturation given the difficulties involved in properly controlling unwanted side effects such as the adoption of majority society habits and values which have not been sufficiently internalised by the receiving culture.

If the development of specific programmes is not viewed as an intermediate strategy but rather is seen as a permanent alternative, there is a danger of reinforcing social stigmas reflecting negatively on this community.

It is important to bear in mind that Roma women are deeply involved in these issues. Traditionally, Roma women assume responsibility for everything related to family health. If these types of programmes continue to exclusively reinforce the responsibility and involvement of women, this could contribute to consolidating the disparate roles played by men and women with respect to health.

### **3.3 . Strengths**

What follows is a description of the elements that are currently functioning satisfactorily or which have some positive repercussion on the health-Roma community relationship.

#### **Cultural identity and community support**

Cultural identity is omnipresent in the Roma community and is the source of great pride and community self-esteem. According to scientific literature, community self-esteem is an important buffer offering protection from all types of bio-psychosocial problems.

Community support, in this case closely linked with a feeling of cultural identity, also offers important protection to individuals. This is especially true in the case of the extended family (despite possible negative effects already highlighted in the “weaknesses” section) offering material resources along with physical and emotional care compensating for the important risk factors to which large segments of the Roma population are subject. An important indicator in this respect is the low number of elderly Roma or those with a physical disability or mental disease who are institutionalised.

## **Norms, customs and habits of the Roma population**

Certain traditional norms such as a prohibition on the use of tobacco and alcohol in the case of women or the limiting of sexual relations to marriage (especially with regard to women), serve as health protection factors (despite the ethical issues involved).

Traditionally, the Roma population has adhered to a number of hygiene practices despite difficult environmental conditions such as the widespread use of bleach as a disinfectant, clear differentiation of unclean objects or areas from clean ones, etc.

As was also mentioned above, the extended family usually has a very clear idea of the course that family members's lives should take. If these projects are sufficiently flexible and the family member in question is able and wants to adopt them, they can provide a sense of security and serve as a protection factor for that individual.

## **Some characteristics of today's Roma community**

The reality facing the Roma population is still a pending issue in Spanish society because the "Roma issue" has yet to be given priority on the nationwide social policy agenda. There is a gradual trend towards improvement in living standards but a number of barriers still stand in the way to full participation in the different fields of public life.

However, the Roma community is not immune to the transformation characterising the society at large and this advancement process is being led by Roma women and young people.

Roma women play a key role within their communities. They are the educators, the ones that take care of the children and the elderly and are responsible for passing on the norms and values of Roma culture. They are more open to change in general, especially when it comes to health issues. To a large degree this is due to the fact that they have been the focus of the majority of the educational, social and health programmes implemented by institutions and associations.

Today, the leadership role of Roma women is increasingly recognised and not only within their home communities but also within the different sectors of public life. More and more women are breaking with the tradition of exclusive dedication to home and children and are making their way into the mainstream labour market or are enrolling in training courses.

One should not lose sight of the fact that Roma women are traditionally in charge of health care and this means that all work targeting them specifically, has a multiplying effect with repercussions for the other members of the family.

Notwithstanding the above, efforts must be made to continue encouraging Roma men to share in domestic and family responsibility and to also take charge of their own health. In this sense, problems are arising with respect to traffic accidents caused by the consumption of different substances.

Roma youth are also a driving force contributing to the changes taking place in the lifestyle of the Roma community in the area of traditional values and redefinition of identity. The fact that they are remaining in school longer and are increasingly convinced of the importance of playing an active role in society, makes them generally more open to health promotion.

With respect to access to employment, Roma men and women are gradually making their way into the mainstream labour market and are progressively giving up traditional trades (scrap metal collection, for example) which entailed a number of different health risks.

The evangelical churches (popularly referred to as “*El culto*” or worship) have recently grown in importance in the Roma community and now offer an alternative in terms of group support and conflict resolution. As concerns health, these churches constitute a protection factor for the Roma population in as far as they promote norms and behaviours related with taking care of personal health.

The following are some of the most characteristic **cultural features** of the Roma people which are essential to understanding their relationship with health and disease:

- Social organisation based on the **extended family**, the nucleus around which social and personal relations develop. That is why when a member becomes ill, the entire family and not just close family members accompany the infirmed or affected individuals
- Prevalence of the group over the individuality of each person.
- High value put on the spoken word which takes precedence over written communication.
- **Respect for elders**. The elderly are very present and valued within the community and they are cared for at home.
- The influence that **older Roma** members have on the younger members. It is important to seek support from influential and respected Roma members who are capable of accepting new aspects of community life which contribute to its development.
- **Mourning**: affects social and labour activities and imposes norms regarding personal appearance (black clothes and headscarf for women, beard for men, etc.) and community life in terms of expressions of joy or entertainment activities.

- The figure of the deceased is treated with great respect by the living. It is important to bear possible reactions in mind when the death of a close family member is confirmed or when physicians order the removal of a corpse or call for an autopsy.
- **The Evangelical Church of Philadelphia:** the majority of the Spanish Roma population (not all, however) are members of this church, the doctrine of which is rooted in Luther's 16<sup>th</sup> century Christianity reforms. Down through its history, the Roma people have had an intense relationship with the supernatural which has a number of different cultural manifestations: a profound respect for the dead, the practice of different arts for predicting the future, belief in curses, etc. Due to its peculiar relationship with religion, the Roma community has never been fully integrated into Spanish Catholicism. The evangelical church, however, has allowed the Roma people to practice a sort of religion more in tune with their culture. In evangelical celebrations, Roma can feely express themselves without feeling inhibited by rules governing behaviour, the pastors are members of the Roma community and during worship ceremonies parishioners can express themselves with total freedom by clapping, singing, chanting, etc. In short, they can actively participate. All of these factors have contributed to making the Roma population feel at home in this church and to their recognising it as their own.

This church affects the social dynamics of the Roma community in a number of different ways: it has motivated many Roma to learn to read and write in order to be able to read the bible, it has fostered the creation of a collective identity and social cohesion, it allows women to take part in activities outside of the home and exercises a degree of social control. It should also be mentioned, however, that each church has its own pastor whose influence over parishioners may vary.

- The **role of women:** women are responsible for know-how and treatment when it comes to illness and the sick.
- **Overprotection of young women.** As of a very young age, girls are prepared for marriage and to assume reproductive functions. Sex is sometimes viewed as taboo, a factor that must be borne in mind when approaching anything having to do with sexual education, family planning or the prevention of gynaecological diseases.

The co-existence of different medical models has been observed:

- **Traditional model:** still in vogue but has lost a great degree of prestige. Often times it is relegated to the treatment of certain popular pathologies, mostly childhood diseases. Traditional health-care providers who, for many years, were responsible for the diagnosis, prevention and treatment of many diseases

have increasingly been relegated to the treatment of ailments linked with “old-fashioned illnesses” or with problems not acknowledged by scientific medicine such as those related with “the evil eye”, “sunburst” (*golpe de sol*) or “the ligament” (*ligamento*).

- **Scientific model:** represented by the physician and pharmacist. Roma people visit physicians when their ailment is not very serious and in the case of more severe problems they tend to go directly to emergency health-care services. They often turn to private physicians. There is quite a bit of flexibility in the combined use of public and private medical institutions.
- **Evangelical church:** the church treats all the pathologies which medicine is unable to effectively deal with such as terminal or social diseases (cancer, addictions, HIV, etc.). Faith-based cure is the principal recourse. An important element to keep in mind is that in its ideological discourse, Pentecostal worship stresses health education guidelines such as the prohibition of drug use and in so doing lends support to the scientific medical recommendations thus serving as a vehicle for prevention.
- **Self-diagnosis** is also a very important health-care method practiced by Roma women (mothers and grandmothers). They are the caretakers of all medical knowledge (scientific medicine, traditional medicine, etc.) and it is thus in the home environment where one may more clearly observe the relationship among the different health-care practices.

Although these aspects may occasionally lead to certain difficulties, it is important to stress the most positive cultural traits and tailor messages to the Roma cultural framework.

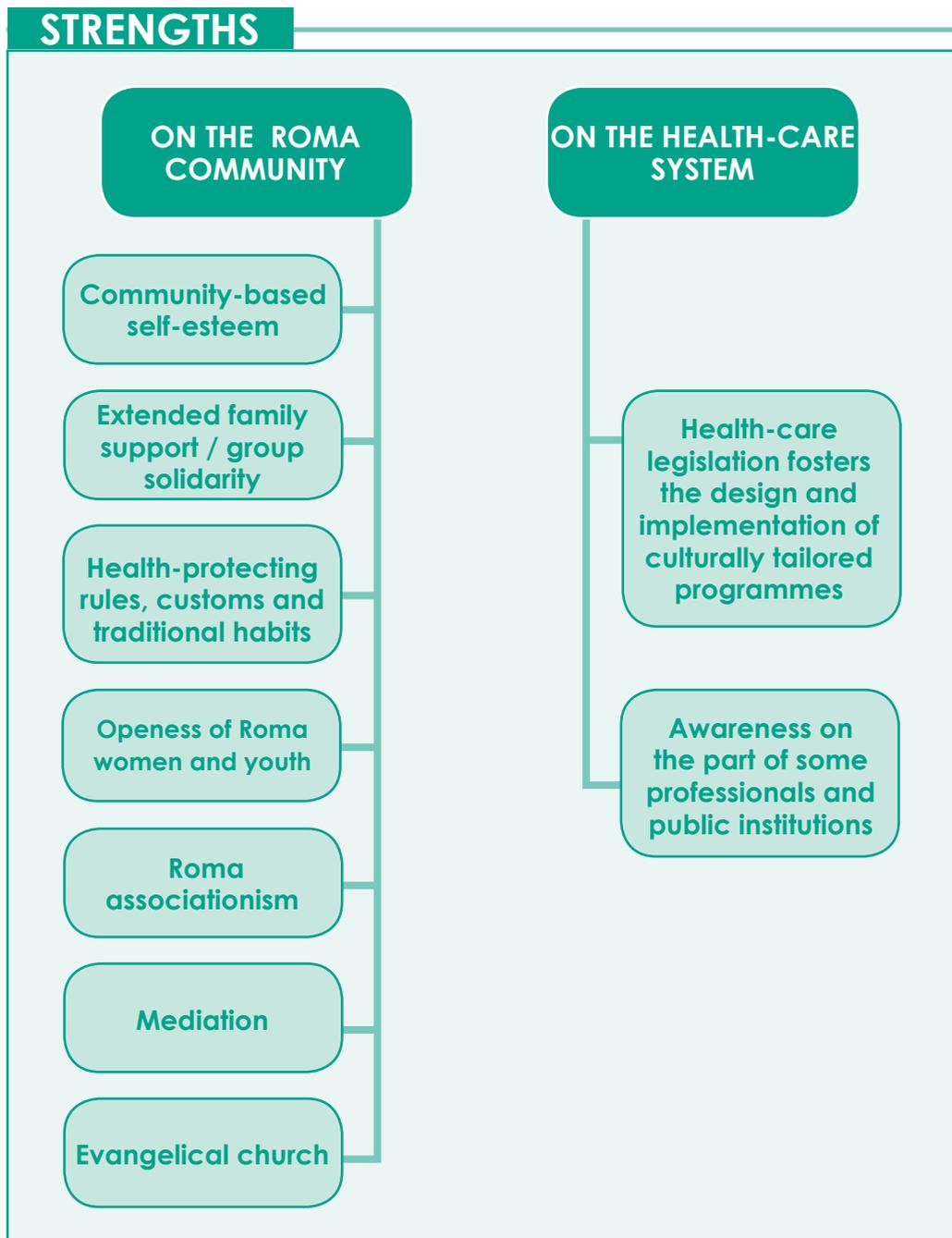
It has generally been observed that if the Roma individual perceives warm personal treatment from the health-care professional (as was mentioned in the section on weaknesses), he or she responds very positively indicating that this aspect has an enormous influence on adherence to treatment. Thus, if a good relationship is established with the health provider and the guidelines proposed by the latter are understood, response to treatment tends to be very positive.

### **The Roma associative movement and intercultural mediation**

The very existence of the Roma associative movement is an important element of strength which should be maximised because it can serve as a springboard for the implementation of actions providing the Roma population with reference models they can identify with. The associative movement is, therefore, a key element in prevention and advancement in health promotion and capacity building and in encouraging this population to take care of its own health.

The existence of professionally trained and experienced Roma mediators in the

field of health care is another strength factor. Their role as the link between the Roma community and mainstream health-care resources is also an element that should be optimised.



Furthermore, a significant proportion of health legislation sets both the theoretical and legal stage for the implementation of intervention programmes with minorities and groups suffering from exclusion.

### **Heightening the awareness of some social-health care professionals and legislation regarding health**

Special mention should be made of a number of strengths characterising today's health-care system:

- General Health-care Act 14/1986 of 25 April providing general regulation of actions contributing to the effective execution of the right to health protection recognised in article 43 of the Constitution.
- Awareness raising on the part of some groups of health-care professionals and some public institutions as to the situation facing the Roma people.

### **3.4. Opportunities**

When we speak of opportunities we are referring to those elements of the health-Roma community relationship which can be improved upon or have positive future repercussions.

#### **Today's political — social context**

The Spanish political context is particularly sensitive at this point in time to cultural identity and diversification because of the ongoing debates and tensions taking place among the nation's different territorial divisions. This context aids in the understanding (at least among certain sectors) of identity references and Roma cultural peculiarities.

The phenomenon of immigration can also spark interest in *cultural issues* as a variable to be kept in mind in intervention work thus increasing professional awareness of culturally tailored intervention.

In the European context, mention should be made of the incorporation of several countries with a large Roma population.

The new **European Directive 2000/43/EC** sets up a new legislative framework among member countries with respect to the enforcement of the principle of equal treatment among persons regardless of ethnic or racial origin. It requires member states to designate at least one specific organisation to actively promote the principle of equal treatment. This Directive, which presents an opportunity for

the establishment of intervention strategies the purpose of which is to diminish health inequalities affecting the Roma population, should have been transposed into the Spanish legal system prior to 19 July 2003 but instead, was transposed (to the dismay of the organisations affected) through Act 62/2003 of 30 December on Fiscal, Administrative and Social Order Measures (“Accompaniment Act”). Effective enforcement must get under way and the Royal Decree regarding the constitution of the specific equal treatment organisation must be published before passing judgement on the results of this Act. This organisation must be given the necessary independence and resources if it is expected to be effective in dealing with complaints lodged by eventual victims of discrimination in any of the fields which figure under the European Directive: education, employment, health care, access to goods and services, etc.

The transposition of this directive has special significance and scope for members of the Roma community who have been victims of historic discrimination provided for under legal regulations for centuries. Still today, 25 years after the abolishment of all discriminatory regulations thanks to the Spanish democratic constitution, the Roma population still falls victim to stereotypes and prejudice suffering both direct discrimination (when they are treated unfavourably due to their ethnic origin in comparison with how another person in similar circumstances would be treated) and indirect discrimination (when an apparently neutral practice or criterion puts an ethnic group at social disadvantage based on group characteristics). Therefore, equal treatment is an attempt to advance towards a more just society by means of greater legal guarantees and non-discrimination against minority ethnic groups.

### ***The institutional response to the health-Roma community relationship***

The existence of long-standing programmes which in some cases have been assessed, such as the Ethnic Minority Health Promotion Programme (Public Health Institute of the Regional Government of Navarre), can serve as vehicles to raise awareness among professionals and other administrations. These programmes have produced a group of trained and aware professionals thus providing an important opportunity for the furthering of specific actions in the area of health.

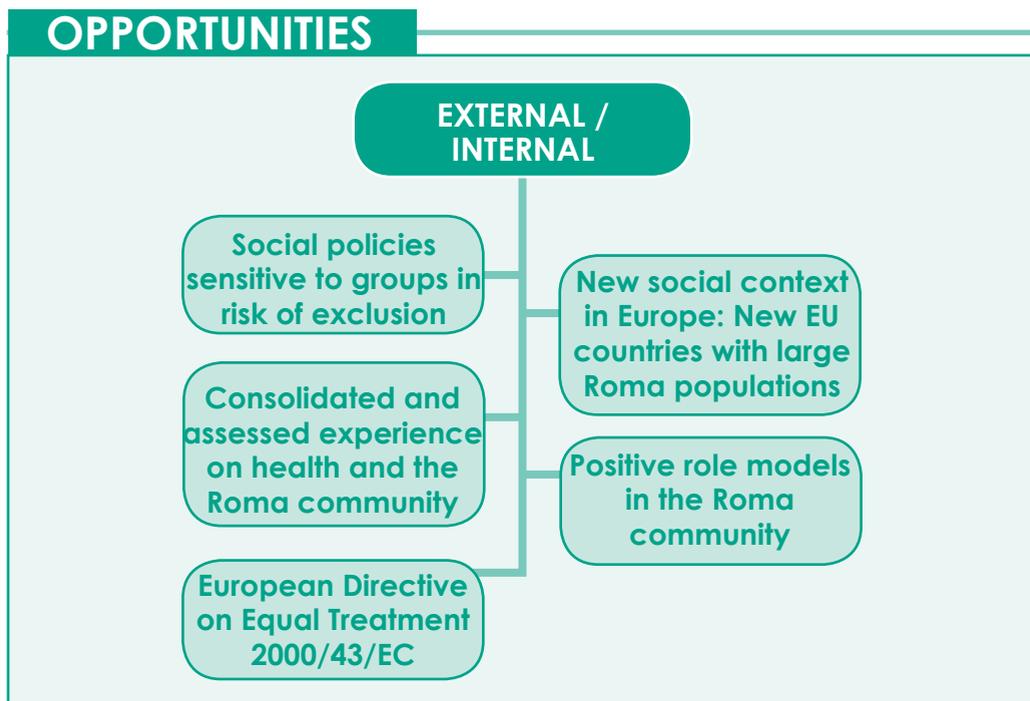
There are also numerous evaluation instruments that can be used to demonstrate the feasibility of these types of programmes and to make headway in improving their effectiveness.

### ***Aspects related to the Roma community itself***

Mention has already been made of the transformation that the Roma community is undergoing today. This calls for flexibility when it comes to certain norms governing Roma families which could facilitate greater and better use made of resources by

Roma women and youth. Therefore, health promotion programmes should mainly focus on women and youth.

A large proportion of the changes taking place within the Roma community are related to internal role models. In this sense, the presence of Roma mediators or Roma professionals working in other fields at least somewhat related with health (medicine, social work, nursing, etc.) are an opportunity for an ongoing cumulative process contributing to a decrease in inequality in the area of health.



# IV. THE ROMA COMMUNITY AND HEALTH: Recommendations for action

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## 4.1. Introduction

A proposal for recommendations contributing to the elimination of health inequalities among the Roma population implies identification of the actors involved in the health-Roma community relationship and the responsibilities attributable to each one.

If we take our legal system as an initial point of reference, article 9 of the Spanish Constitution states that “It is the responsibility of the public powers to promote conditions so that liberty and equality of the individual and the groups he joins will be real and effective; to remove those obstacles which impede or make difficult their full implementation, and to facilitate participation of all citizens in political, economic, cultural and social life.”

It should not be forgotten that socio-health service professionals are merely service providers and therefore their real ability to change or tailor structures is very limited.

The logical conclusion, therefore, is that it is the responsibility of the following institutions to deal with:

- Health equality: health-care system.
- Basic and specialised training of social-health care professionals: Universities, the Ministry of Education and Science and the Ministry of Health and Consumer Affairs.
- On-the-job training: The Ministry of Health and Consumer Affairs and the health-care system.

One should not lose sight of the fact that the Roma population as a whole should be the target group for the development of health education actions favouring skills acquisition and capacity building focusing on care of their own health and compliance with their obligations concerning the proper use of health-care resources.

## 4.2. Action taken by health-care professionals

The following essential tools should be used by health-care professionals:

### *Work with the network of family members*

Bearing in mind the close relationship among extended family members, when one approaches the subject of health we must be aware that the relationship established is not usually between the individual and the health-care system but rather between the individual who is ill, the extended family and the health-care system.

It is of the utmost importance to accept this fact as an opportunity and apply the contributions that social network and family theories and methodologies have to offer.

### *Group work*

Priority should be put on group work when dealing with the Roma community,<sup>28</sup> its perceptions, habits, knowledge or attitudes regarding health. Furthermore, participative group work should be the methodology of choice. Group work based on participative methodology facilitates reflection, creativity and the importance of the participants and therefore acts as a buffer to external indoctrination and a filter against the risks of acculturation.

### *Communication and the art of empathy*

The diagnosis indicated that factors such as human warmth in the treatment process, perceived empathy and the feeling of being listened to and understood were among the most important criteria for the Roma population in assessing the quality of health-care services. It is therefore essential that health-care professionals pay particular attention to these aspects especially when a relationship is first being established with the different members of the Roma community.<sup>29</sup>

### *Dealing with conflict and the development of a mediator's mindset*

Mutual feelings of prejudice and the influence of cultural differences when assessing a situation or interpreting certain codes, could give rise to significant conflict. If the health-care professional is familiar with and knows how to apply guidelines suited to conflict prevention and/or knows how to approach conflict in a suitable manner, and

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<sup>28</sup> Obviously this does not exclude work on an individual basis or the fact that, in certain circumstances, it may be necessary to prioritise individualised attention.

<sup>29</sup> Of course this should be a priority in providing care to any type of user.

if he also has a mediator's mindset in approaching conflict situations in which he is not directly involved, his contribution will be extremely valuable.

### 4.3. Training of health-care professionals

The compulsory educational system has done little to develop the communication skills needed for a healthy life and this translates into a more pronounced personal deficit when it comes to certain professional activities. Health care training has also been negligent in attention paid to communication skills and medical anthropological knowledge essential in the provision of effective services to multicultural populations.

One of the fundamental strategies in the reorientation of health-care services based on health promotion is that of strengthening the health promotion component in human resources training programmes in educational institutions and also as part of health professionals' on-the-job training.<sup>30</sup>

It should not be forgotten that training is an essential element in the proper and effective exercise of any professional activity. In the absence of such training, one would be hard-pressed to achieve proposed objectives and it would be harder still to satisfy needs. In this sense, and bearing in mind the lack of knowledge that social-health care professionals have with regard to the Roma community, priority should be put on including the following material in training schemes:

- Background knowledge on Roma culture.
- Knowledge as to the ideas that the Roma community has with regard to health.
- Awareness of the cultural elements involved in the relationship that exists between Roma men and women and health.
- Information regarding the health status of the Roma population.
- Insight into the internal diversity of the Roma community.
- Analysis of prior intervention experiences regarding the health-Roma community relationship.

This content material should be included at the different levels of training schemes:

- Initial or undergraduate training: as part of the core curriculum mainly in technical or full university degrees in social sciences, especially health sciences and education.
- Specialised or post-graduate training: masters degrees or other degrees specific to certain universities.

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<sup>30</sup> Training in Health Promotion and Education. Ministry of Health and Consumer Affairs. 2003

- Life-long learning schemes: as part of the training offered by government administrations with competency in health issues.

Notwithstanding the above, one must also be aware of some of the already mentioned “threats” when it comes to the training of professionals: awareness in this subject area is rather limited; professionals may perceive that they are being asked to “work overtime” and that they “*already know how to handle all sorts of situations.*” For that reason, the following types of messages should be constantly reiterated at training initiatives:

- It is not a matter of more work but rather of adopting new concepts, different ways of interpreting situations, new intervention methodologies, etc., allowing professionals to more efficiently carry out their functions thus obtaining better results in everyday work and reducing the possibility of emerging conflicts.
- Training will allow professionals to be more effective in their work with the Roma community, will contribute to reducing existing inequalities and to improving standard of living but they will also benefit in the form of improved results when addressing *differences* in general, i.e. training will help professionals advance towards more individualised attention. In short, it is not an issue of going through a training course to learn how to approach each *different group*. It is more a matter of (over and above some specific, specialised content) honing one’s tools of the trade such as empathetic communication, developing a mediator’s mindset, dealing with conflict, etc., which are universally applicable.

As for training methodology and bearing in mind the effect of historic prejudice with a strong emotional component, hands-on techniques should be given priority (role play, for example). Joint reflection exercises between Roma and non-Roma individuals (such as this Group of Experts) are proof of the ability to modify prejudice and stereotypes and therefore should be incorporated.

And lastly, supplementary to personal training (or as an alternative) it would be very useful to continue and broaden the line of work involving the drafting of manuals for professional self-training, teaching guides and audio-visual materials for group work.

Today, the Health-care Profession Regulatory Act (Spanish initials LOPS) has created a framework which envisions the incorporation of this sort of skills training and knowledge. The Family and Community Medicine programme has already included certain content which will come into force in 2005 and the Conference of University Deans, as part of a revision and revamping process of undergraduate studies, is assessing the skills and attitudes of health-care professionals with a view to making a new proposal which would enter into force in 2006. Moreover, within the Europe-wide scheme (the so-called Bologna Process) for the creation of a Single Education Area, a strategic opportunity has arisen to introduce changes in the social-health

care curriculum before 2010. In light of the importance of Europe's Roma population, the training aspects envisioned in this section should be tabled before the pertinent European authorities and ratified within the European project led by the FSG with a view to integrating them into the curricula of the health-care professions in all of the countries of Europe.

#### 4.4. Organisation of the health-care system

The essential challenge lies in including the consideration of *difference* in the organisation and operation of the health-care system, as well as in the laws and development or enforcement of regulations concerning health-care activities.

It should first of all be mentioned that protocols should envision "*alarm systems*" reporting inequalities arising within a target population (differences in the percentage of vaccinations, in the incidence of certain diseases, in the number of gynaecological check-ups or in the frequency of health centre conflicts, etc.). Once a situation of inequality has been detected, the health-care system's management tools should envision the following responses:

- *Active recruitment;*
- Tailoring of timetables to meet patients' needs;
- Tailored information schemes (specific teaching materials, organisation of educational groups, etc.);
- Compensatory services for good health habits;
- Inter-sectoral collaboration, with social services centres, schools, intercultural mediation professionals, Roma associations, other types of associations, etc.

The inclusion of these initiatives in the protocols and health system management tools<sup>31</sup> will also help in confronting an attitude (mentioned earlier in this report) which is very prevalent among certain professionals: "*they're calling on us to work overtime.*"

These alarm systems should be developed for individual cases but also for general situations. One of the functions that these systems would have on a large scale is that they would facilitate the development of *maps* which would be useful in identifying the areas most affected by health inequalities. Once these *maps* were developed, the incidence of inequalities by zones could be used as a criterion in calculating the ratio of the population being served by each centre. The degree of individualisation required if proper service is to be provided to a population group affected by health care inequalities means that each professional should have a lower patient load.

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<sup>31</sup> Nevertheless, it is important to recognise that these initiatives can and should only be spelled out on a small scale.

The “*Humanisation of Health-care*” philosophy already initiated in some hospitals would have a very positive effect on care provided to populations affected by health inequalities. As concerns the Roma community, the following proposals should be tabled:

- Each hospital should be able to design ad hoc strategies allowing for expressions of family support but which would not have a negative effect on the proper operation of the centre.
- “Health-care humanisation training” for responsible parties at hospitals in line with section 4.3.
- Initiate “pilot experiences” for the inclusion of the intercultural mediator figure in those hospitals that treat a large percentage of Roma patients.

The Regulation concerning mortuary sanitary police (Decree 2263/1974 of 20 July) is currently under review and it is possible to include necessary amendments to make this regulation sensitive to the cultural differences of the Roma minority.

#### 4.5. Intercultural mediation

*“Intercultural mediation is a resource available to individuals of different cultures and serves as a bridge with a view to promoting constructive change in intercultural relations. The main purpose of mediation in relations between culturally diverse individuals is to prevent cultural conflict by fostering recognition of differences, closing the gap between parties, fostering communication and mutual understanding, learning and developing techniques for coexistence, searching for alternative strategies for the resolution of cultural conflicts and community participation.”<sup>32</sup>*

Professional mediation is a resource bridging the gap between the Roma community and the majority society in order to promote constructive change in relations between the two. It is, therefore, a process and not a “fire extinguishing” tool to be used only when conflicts arise.

The following functions form part of mediation with the Roma community in the field of health care:

- Facilitate communication between health care resource professionals and the Roma community promoting equal opportunity in gaining access to said resources.
- Advise Roma service users as to how to best relate to health care service providers.

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<sup>32</sup> Several authors. “La mediación intercultural: un puente para el diálogo”. Desenvolupament Comunitari. Barcelona, 2000.

- Advise health-care providers as to how to suitably meet the needs and interests of the Roma population.
- Promote community empowerment.
- Provide personal support to Roma service users.

From the very outset it is important to point out that everyone must contribute to the intercultural mediation effort; i.e. mediation efforts must be made from all sectors of the community and all health-care service providers (in the case at hand) should receive training in mediation skills and attitudes.

On occasion, the presence of a specific mediator figure is needed. In work with the Roma population, a person belonging to this ethnic group with specific training and qualifications in intercultural mediation would be a good role model for the community, however being a member of this minority group is not a prerequisite. A professional with knowledge of the Roma culture and sensitivity towards this sort of work with the Roma community would also be capable of carrying out mediation functions.

The figure of the mediator has huge potential. In addition to all of the above, mediation can also contribute to progress in capacity building in the area of health with the Roma population because it allows for awareness-raising and training people to take care of themselves.

In practical terms, however, a number of limitations still need to be overcome:

Mediator training is anything but standardised. Some receive ample training before going out into the field while others may have only attended brief capacity-building courses. The topics covered at the different training initiatives also lack standardisation. Moreover, many mediators are also subject to precarious working conditions (part-time, seasonal, etc.) which has a negative influence on the quality of their efforts.

It should also be pointed out that many professionals in the field are unaware that mediators even exist and therefore cannot profit from their services. Other professionals have an erroneous idea about them and therefore make improper use of mediators such as:

- Offering them "*overflow work from other professions*": street work, door-to-door visits, etc.
- Call on them only when there is a conflict or a crisis situation losing sight of the fact that the mediator can and should take action at other pre-conflict stages or carry out prevention initiatives.
- Assigning them the most conflictive and difficult families and cases.

Therefore, proper use of mediator potential entails:

- Guaranteeing that mediators are provided with basic training and fostering further on-the-job training.
- Improving the working conditions of some mediators by implementing ongoing programmes.
- Providing professionals in the field with more information on mediators with a view to achieving multi-disciplinary, social-health intervention.

In short, the goal is for the mediator to find his/her niche in which:

- She/he does not act as a substitute for any other professional but rather bridges the gap facilitating the relationship between the Roma people and community resources.
- She/he does not contribute to the creation of permanent alternative itineraries for certain cases but rather works as part of a team with the rest of the professionals to improve health-care services provided by community resources in these cases.

### **Benefits of intercultural mediation in the social-health care sector**

The benefits of these professional initiatives have positive repercussions on social-health care system service providers as well as on the Roma population as users of these services:

#### **■ For health-care providers:**

- Enhanced interpersonal relations by breaking down communication barriers.
- Improved interpretation and comprehension of some cultural guidelines, as in the case of Roma girls of marrying age or widows.
- Avoidance of conflict; in the case of a death, for example.
- Better use of health-care services.
- Better results from medical treatment.

#### **■ For the Roma population:**

- Better understanding of diagnoses and medical treatment increasing the success rate in the treatment of disease.
- Greater integration of Roma in the health-care system.
- A sense of greater security and trust on the part of the Roma population.

In addition to these specific benefits, there is no doubt that they all contribute to improved standard of living and reduction of health inequalities for the Roma community.

## Challenges facing intercultural mediation

Intercultural mediation in Spain is an emerging profession and is still characterised by a lack of organisation at all levels. There is a need for rules and procedures to regulate training and interning. Work should be done on the following aspects of mediation:

- Basic training followed by on-the-job training should be provided for intercultural mediators;
- Training should be tailored to new needs as well as to existing problem areas;
- Efforts should continue towards standardisation of training at the national and European levels;
- Professional mediation should be subjected to a reflection and assessment process through research and participatory action;
- On the job support and supervision should be provided for mediators;
- Support should be given to professional associationism initiatives;
- Service providers in the field should be informed about this new resource for social intervention;
- Dialogue should be initiated with public institutions and services on the local, regional and national levels concerning recognition and viability of the mediator figure as a tool for social intervention.

### 4.6. The need for Roma community capacity-building in the area of health

Health education and skills acquisition as regards the development of health habits and prevention as well as instruction in the proper and rational use of health-care services should be the main goals of real and effective Roma community capacity building with respect to taking care of one's own health.

There is a danger, however, of taking on a paternalistic attitude overlooking the necessary participation and leadership role that Roma should play in their own development. This sort of attitude and behaviour can lead to failure because programmes thus conceived would not meet the needs and expectations of the target population and would fail to respect their pace, codes and values and could lead to acculturation. With a view to preventing the above, we offer the following proposals:

The **Roma community must participate and be given a leadership role** throughout all of the planning phases:

- In the diagnosis of needs;

- In the definition of objectives and methodology;
- In the implementation;
- In the evaluation.

Participation should take place at all levels:

- On a broad scale when defining strategic lines of action;
- On a more concrete level when assigning these strategic lines to specific areas and individual pockets of the population.

Participants should be diversified reflecting the diversification of the Roma population:

- Roma associations which are able to represent a certain sector of the Roma community (as opposed to others) and with which alliances can be established to work on certain aspects (as opposed to others);
- Evangelical churches which are able to represent a certain sector of the Roma community (as opposed to others) and with which alliances can be established to work on certain aspects (as opposed to others);
- Roma mediators in light of their wide-ranging and in-depth knowledge of the Roma reality;
- Members of the Roma community at large (who do not belong to any of the above-mentioned sectors) and who, given their training and sensitivity, can make important contributions;
- Health-care service users themselves who, through their contact with service providers and/or mediators, can collaborate at all of the planning stages. With respect to the above, we reiterate the importance of group work to facilitate participation and a leadership role.

#### **4.7. Intervention programmes focusing on the health-Roma community relationship**

Two fundamental ideas have already been underscored with respect to intervention programmes focusing on health and the Roma community: On the one hand, many of these programmes have been described as fragmented and discontinuous and as lacking evaluation. It has also been pointed out that there are other long-running programmes, some of which have been evaluated, which could serve as an important resource in raising awareness and getting other field professionals and government administrations to commit to action. The following proposals are related with these ideas.

Due to the complexity of the situation, short-term or intermittent initiatives are not an option. Stable programmes with a sufficient time horizon are needed.

However, specific initiatives (i.e. exclusively targeting the Roma population), should not be allowed to become permanent as this could exacerbate the stigma put on this community.

Therefore, the ultimate goal of programmes should be **mainstreaming**, meaning that the needs of the Roma population should be met by the same service providers and the same resources as the rest of the population. That should be the objective of the stable programmes referred to above: to guarantee that the specific needs and peculiarities of the Roma community can be met through the operation of these mainstream resources and the efforts of service providers.

Sufficient time perspective also means that programmes should set aside an ample amount of time for reflection, and not only internal reflection among team members but also reflection and negotiation with the target population itself, with other teams, associations, etc. This time should be made available before, during and upon completion of the intervention. Reflection and negotiation are the basic tools used to prevent the majority of the dangers outlined in the diagnosis.

If all of the requirements mentioned up to this point are not met, **evaluation** is jeopardised. Evaluation of an unstable and intermittent programme or one that fails to set aside time for reflection, would be a difficult task indeed. Moreover, in order to be evaluated a programme must have been properly diagnosed with design of assessable objectives and a sufficient level of coherence between diagnosis, objectives, methodology and actions.

It is also of prime importance to “break” from theme and sectoral-based limitations. This means favouring programme transversality including Roma issues in non-specific frameworks (for example: inclusion plans,<sup>33</sup> equal opportunity schemes, projects focusing on cultural diversity in a general sense, etc.) and including “health” issues in programmes that focus on other aspects of the Roma population. Inter-sectoral collaboration is essential if this is to be accomplished. Multi-disciplinary work is an undeniable pre-requisite within the health-care system and for the development of inter-sectoral intervention.

As for **programme content**, three very important subjects related to three population groups within the Roma community must be considered:

- The inclusion of gender in all activities and programmes, focusing on the specific health needs of Roma women with respect to the role that they play within their community (“Who takes care of the caretakers?”).
- An effort must also be made to find new strategies and subject areas that

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<sup>33</sup> Among other things, we cannot lose sight of the close relationship that in many cases exists between social inequalities and health inequalities.

link up with the interests of adult Roma men (prevention of work-related accidents, prevention of STDs, etc.).

- Roma youth (characterised by their open disposition) as a priority group in the advancement of the Roma community.

And lastly, the following **proposals related to the opportunities** described in the diagnosis:

- Develop initiatives which disseminate “good practices” already being implemented in this field such as the above-mentioned Ethnic Minority Health Promotion Programme of the Public Health Institute of the Regional Government of Navarre which was presented at the seminar on Health-care Equality and the Roma Community held on 11 November.
- Continue to develop initiatives which shed light on the strengths of the Roma community and reflect its heterogeneity.
- Take full advantage of the opportunities to develop new initiatives in Spain arising from the collaboration agreement between the Ministry of Health and the FSG and, on the European level, from the European Directive on equal treatment.

#### **4.8. Studies focusing on the health-Roma community relationship**

The lack of studies and research on the health of the Roma population is a factor which complicates the planning of specific programmes that can be tailored to the reality and needs of this group. The following considerations should be kept in mind:

##### **General criteria to bear in mind when carrying out studies and research projects:**

- Studies which constitute an affront to individual privacy should be avoided and efforts should be made to seek alternative techniques.
- Whenever Roma collaboration is requested for a study, participants must be “rewarded” by being sent the results.
- A number of questions must be posed prior to the start of any study: Are the expected results of the study going to be significant? In other words, is the information sought necessary for advancement in that sector? If the answer to the latter question is affirmative, do we have the necessary resources to carry out a sufficiently serious and high-quality study? If the answer to one or both of the above questions is negative, it would be better to dedicate our efforts and resources to other objectives.

Regarding the subject of studies and research, the following useful ideas emerged which could facilitate the subsequent design of health promotion programmes:

- Study of the factors which determine the health of the Roma community.
- Study of the life expectancy of the Roma population.
- Study of the traditional “healing” practices of the Roma community.

### **Registration of ethnic origin**

The advisability or not of registering ethnic origin as part of the paperwork involved in the different health-care and social resources is an aspect which generates quite a bit of controversy.

If we turn to the Spanish legal system, article **14 of the Spanish Constitution** states that all Spanish citizens “are equal before the law, without any discrimination for reasons of birth, race, sex, religion, opinion or any other personal or social condition or circumstance.” **Article 16.2** of the same text states that “No one may be obliged to make a declaration on his ideology, religion or beliefs.”

**Organic Law 15/1999 of 13 December on the Protection of Personal Data** states:

- Article 5. Right to information in data collection: “those from whom personal data is requested should be expressly informed beforehand:
  - of the existence of a file or personal data processing, of the purpose of such data collection and the caretakers of such information;
  - of whether response to questions is compulsory or voluntary;
  - of the consequences of providing data or refusing to do so;
  - of the name and address of the party responsible for data processing or that of his representative.
- Article 7.3 Specially protected data: “Personal data making reference to racial origin, health and sexual practice may only be collected, processed and delivered when, for reasons of general interest, the law thus stipulates or the affected party expressly agrees.”
- Article 7.4: “The creation of files the exclusive purpose of which is the storing of personal data revealing ideology, trade union membership, religion, beliefs, **racial or ethnic origin** or sexual practices is prohibited.”
- Article 7.6: “Notwithstanding the above paragraphs, the sort of personal data referred to in paragraphs 2 and 3 (racial origin, health and sexual preference) may be processed when such processing is necessary for prevention purposes or for a physician’s diagnosis, health-care services, medical treatment or the

management of health-care services, provided that such data processing is carried out by a health-care professional subject to professional secrecy regulations or by another person sworn to an equivalent degree of secrecy.”

Getting back to the topic at hand, it can be deduced that data regarding the ethnic background of an individual may legitimately be collected provided that the objective is the implementation of measures the purpose of which is the elimination of health inequalities and as long as the information giver is informed and applicable regulations concerning confidentiality and processing of such data are upheld.

Nevertheless, the following considerations should be kept in mind:

- While the professional gathering the information may do so with the best of intentions, it is easy to lose control over what others might subsequently do with that information.
- Many times a person’s ethnic origin fails to provide significant information and, on occasion, may even distort it. Given the heterogeneous nature of the Roma community, if a professional reads in a report that a person is Roma, he may come to conclusions based on the stereotypes that society has regarding the Roma community which could give rise to erroneous conclusions in that particular case.
- Instead of collecting data on the ethnic origin of a person for a report when the purpose of this data is to provide information regarding the characteristics of that person, it is better to describe such characteristics directly because they will differ from case to case.
- It is also important to get an explicit commitment from field professionals with regard to data protection.

# SUMMARY

## PROPOSALS FOR GOOD PRACTICES

### LINES OF ACTION

#### **1. TRAINING OF SOCIAL-HEALTH CARE SERVICE PROVIDERS**

- ✓ Include information on Roma culture and community at the different levels of training:
  - Initial or undergraduate training in technical or full university degree studies in the social sciences, health sciences and education.
  - Specialised or post-graduate training.
  - On-the-job training for professionals
- ✓ Create forums for reflection and debate among professionals in the social-health care sectors who work with the Roma population with a view to reviewing professional practices.
- ✓ Provide training and capacity building for Roma mediators in the area of health promotion.

#### **2. DRAFTING OF TAILORED MATERIALS**

- ✓ Manuals, teaching guides and reference documents for self-instruction of professionals.
- ✓ Information brochures and posters that are culturally tailored to the Roma population (simple, clear language, visual, etc.).
- ✓ Audiovisual material for group work.

#### **3. INCLUSION OF THE CONCEPT OF “DIFFERENCE” IN THE ORGANISATION OF THE HEALTH-CARE SYSTEM**

- ✓ Create alarm systems to identify health inequalities.
- ✓ Draw up maps identifying those areas where greatest health inequalities exist.
- ✓ Response actions from the “services menu.”

- ✓ Tailor protocols and procedures, making them more flexible (adaptation of schedules, active recruitment of users, etc.).
- ✓ Include the figure of the professional intercultural mediator in hospitals.
- ✓ Humanise health-care.

#### **4. CAPACITY BUILDING WITHIN THE ROMA COMMUNITY**

- ✓ The Roma community must participate and be given a leadership role at the different stages in the planning and execution of health promotion programmes.
- ✓ Awareness must be heightened in terms of taking care of one's own health, disease prevention, and the proper use of health-care resources by each and every one of the members of the Roma community.

#### **5. DESIGN, IMPLEMENTATION AND DEVELOPMENT OF ROMA COMMUNITY HEALTH PROMOTION PROGRAMMES**

- ✓ Include health promotion as a transversal element in other programmes and activities targeting the Roma population.
- ✓ Incorporate the gender perspective focusing on the specific needs of Roma women (gynaecology, family planning, mental health, etc.) in all health promotion programmes.
- ✓ Introduce the "Roma issue" with special emphasis on health inequalities, in other reference framework policies such as Inclusion Plans or Equal Opportunity Plans between Men and Women implemented by the different government administrations.
- ✓ Design stable programmes tailored to the real needs of the Roma population with a time horizon long enough to allow for evaluation of results and impact.
- ✓ Design assessable operational objectives in the programmes.
- ✓ Design and develop specific programmes for priority groups in the area of health care: young people and women.
- ✓ Design and develop specific programmes for Roma men focusing on the development of responsible behaviour in taking care of one's own health and with regard to emerging problems such as traffic accidents, work-related accidents or substance abuse.
- ✓ Design and develop programmes and activities allowing for the dissemination of good intervention practices and experiences developed in different areas.

## **6. DEVELOPMENT OF STUDIES AND RESEARCH REGARDING HEALTH AND THE ROMA COMMUNITY FOCUSING ON:**

- ✓ key factors determining the health of the Roma community;
- ✓ the life expectancy of the Roma population;
- ✓ traditional healing practices.

# **GENERAL ACTION CRITERIA FOR PROFESSIONALS**

1. Mainstreaming is the ultimate goal: use of the general health-care resource network by the Roma population;
2. Focus on priority health-care groups within the Roma community: women and youth;
3. Optimise intercultural mediation and support the incorporation of mediators in health-care resources;
4. Promote inter-sectoral and multi-disciplinary collaboration;
5. Optimise and showcase the strengths of the Roma community.



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# ANNEX I

## WORK METHODOLOGY APPLIED TO THE DEVELOPMENT OF THE DOCUMENT

An adaptation of a qualitative diagnostic method commonly used in organisational development and marketing, has been employed in the development of this Reference Document. **SWOT Analysis (\*)**<sup>34</sup>.

The dynamics of this technique involve bringing together a group of experts on a certain subject and structuring reflection and debate around the four axes formed by the words represented by the initials SWOT:

- ◆ Strengths
- ◆ Weaknesses
- ◆ Opportunities
- ◆ Threats

This technique offers added value in that, in addition to lending itself to a participatory and structured debate, it encourages the group to bear two sometimes forgotten dimensions in mind:

1. The time dimension. The present is analysed in the “weaknesses” and “strengths” categories (what is happening now) while the future is analysed in the categories “threats” and “opportunities” (what is expected in the future). The concept of future is what contributes dynamic power and a sense of advance to the analysis.
2. The positive / negative dimension. An analysis is made of the aspects that should be reinforced (“strengths”) or taken advantage of (“opportunities”)

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<sup>34</sup> Several authors (2002). Manual for Project Cycle Management. European Commission EuropeAID Cooperation Office.

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as well as those that should be remedied (“weaknesses”) or minimised (“threats”). Therefore, if the group is feeling discouraged, it does not focus exclusively on the negative aspects and, on the other hand, if it is feeling rather enthusiastic, it will not lose sight of the weak points.

The following specific process was followed in the application of the technique and the development of the Reference Document:

- A. Drafting of a Base Document from the prior bibliographical and documentary study.
- B. Formation of a group comprised of experts in public health and/or intervention with the Roma People (please find attached in the annex a list of group members).
- C. Distribution of Base Document to the individuals selected to participate in the group.
- D. Scheduling and development of an initial two-day work session. The group carried out the SWOT analysis at that first session.
- E. Drafting of a report on that meeting and distribution of said report to group members.
- F. Scheduling and development of a second two-day work session. At this session the group agreed on the recommendations to tackle the conclusions reached via the SWOT analysis.
- G. Drafting of a report on that meeting and distribution of said report to group members.
- H. Development of the first draft of the Reference Document based on the reports from the working group sessions and the incorporation of new bibliographical and documentary references.
- I. Distribution of the draft to group members and to other professionals at the Ministry of Health and the FSG.
- J. Incorporation of contributions to subsequent drafts of the Reference Document.
- K. Presentation of the Reference Document at a Working Session held at the Ministry of Health and Consumer Affairs, mainly targeting Health Managers from the Autonomous Communities (regions), technical experts from the Ministry and other professionals working in the field of Public Health and/or the Roma community.
- L. Incorporation of the main contributions coming out of this Working Session into the Reference Document.

## ANNEX II

### PARTICIPANTS IN THE “HEALTH AND ROMA COMMUNITY” GROUP OF EXPERTS

NAME	SPECIALTY	SERVICE
<b>Begoña Merino</b>	Public Health	Technical Advisor. Coordinator Health promotion Area. Directorate-General for Public Health Deputy Directorate-General for Health Promotion and Epidemiology MSC
<b>Mariví Librada</b>	Public Health	Health Promotion Section Head
<b>Angeloi Goya</b>	Health and ethnic minorities	Coordinator of Health Promotion Programmes targeting Ethnic Minorities. Public Health Institute of the Regional Government of Navarre
<b>Lucía San Juan</b>	Research	Universidad Autónoma Barcelona
<b>Pilar Bermejo</b>	Drug abuse	Director of the Drug Dependency Unit, Town Hall of Santiago de Compostela. Galicia
<b>Hervé Bertevas</b>	Primary Care Research	Physician
<b>Fernando García.</b>	Mediation	Mediator. FSG Area of Health Madrid
<b>Nadia Rodríguez</b>	Social Work	“Buenos Aires” Primary Care Centre Madrid
<b>M<sup>a</sup> Pepa Arcas</b>	Gynaecology Midwife	Granada Hospital
<b>M<sup>a</sup> Dolores Calvo Navarro</b>	Forensic physician	Malaga Judicial Medicine Institute Department of Justice and Public Administration Regional Government of Andalusia.

<b>Isabel Blázquez Jiménez</b>	Nurse	Cardiology “Doce de Octubre” Hospital in Madrid
<b>M<sup>a</sup> Carmen Bravo</b>	Emergency Room Nurse	“Gregorio Marañón” Hospital in Madrid
<b>Lorenzo Fernández Barriales</b>	Psychiatry	“Teatinos” Mental Health Centre. Oviedo, Asturias
<b>Enrique Negueruela</b>	Psychiatry	Mental Health Centre in Palencia
<b>Dovirgen Fernández Cortés</b>	Health-care Mediator	Barcelona
<b>Gracia Jiménez Lérica</b>	Physician	Physician Andalusian Health Service
<b>Javier Arza</b>	Social Worker	Universidad de Navarra
<b>Cristina García</b>	Social Worker	Head of the FSG’s Health and Women Area

# ANNEX III

## SEMINAR HEALTH EQUALITY AND THE ROMA COMMUNITY

### INTRODUCTION

The reduction of social inequalities in the area of health is an essential prerequisite for the achievement of well-being and progress on an individual, group and society-wide basis. In this sense, evidence shows that the implementation of integrated programmes developed on the community level involving a wide range of sectors and organisations and which are tailored to the specific characteristics of the target group, are very positive.

The Spanish Roma community is among the most vulnerable groups suffering from a health-care deficit due to its disadvantaged socio-economic situation. Based on this social reality, this seminar was developed by the **Directorate-General for Public Health of the Ministry of Health and Consumer Affairs** in collaboration with the **Fundación Secretariado Gitano** to make headway in the elimination of health inequalities within the Spanish Roma population.

Seminar objectives included:

- The drafting of an operational and consensus-based document providing strategies and key intervention tips for work with the Roma population from the perspective of mainstream health-care services.
- Contribution to the push for active policies which, from a regional perspective, contribute to the improvement of equal opportunities for Roma with regard to health and the use and benefit of community goods and services.

To accomplish the above, the approach of the seminar is based on the document entitled "**Health and the Roma Community**", the result of analysis and reflection work carried out by a group of social services / health-care professionals with experience working with the Roma population.

## PROGRAMME

### 10:30 Inauguration

- Fernando Lamata Cotanda. Health Secretary-General Ministry of Health and Consumer Affairs.
- José Manuel Fresno. Director of the FSG

### 11:00 Introductory paper and debate

"The health status of the Roma population in Spain" Cultural aspects

Speaker: Gracia Jiménez Lérida Physician at the Andalusian Health Service Malaga

### 12:30 Paper and debate

"Strengths, weaknesses, dangers and opportunities in the Health-Roma Community relationship"

Speaker: Lucía San Juan Universidad Autónoma Barcelona

### 13:30 Paper and debate

"Professional mediation as a strategy for the Roma population to gain access to the mainstream health-care resources network"

Speakers:

- Dovicgen Fernández Cortés Health Mediator Barcelona
- Fernando García García. Health Mediator Madrid

### 14:30 Lunch

### 16:00 Paper and debate

"Health Promotion Programmes targeting Ethnic Minorities" Public Health Institute Regional Government of Navarre

Speakers:

- Angeloi Goya Programme Coordinator of Health Promotion Programmes targeting Ethnic Minorities Regional Government of Navarre
- Fermín Castiella Lafuente. Director of the Regional Drug-dependency scheme Navarre
- Ana Hernandez. Health Mediator. Navarre

### 17:00 Paper

"Proposals and recommendations for the fostering of health equality in the Roma community"

Speakers:

- Begoña Merino. Technical Advisor Coordinator Health promotion Area. Ministry of Health and Consumer Affairs.
- Patricia Bezunartea. Director, Social Action Department FSG

### 18:00 Closing ceremony

# ANNEX IV

## SEMINAR PARTICIPANTS “HEALTH EQUALITY AND THE ROMA COMMUNITY”

NAME	SURNAME	ORGANISATION	POST
Ana	Hernández	NAVARRRE REGIONAL DRUG DEPENDENCY SCHEME	Health Mediator
Angeloi	Goia	HEALTH AND ETHNIC MINORITIES PROGRAMME GOVERNMENT OF NAVARRRE	Programme coordinator Health Promotion among Ethnic Minorities
Antolina	Expósito Alburquerque	PUBLIC HEALTH DEPARTMENT, REGIONAL GOVERNMENT OF ANDALUSIA	Public Health Expert
Begoña	Merino	MINISTRY OF HEALTH AND CONSUMER AFFAIRS	Technical Advisor Coordinator Health promotion Area.
Carmen	Bravo	GREGORIO MARAÑON HOSPITAL	Nurse
Cristina	García	FSG	Coordinator of the Women and Health Area
Dovirgen	Fernández Cortés		Health Mediator
Elena	Buceta	FSG	Coordinator of European Projects
Enrique	Negueruela	PALENCIA MENTAL HEALTH CENTRE	Psychiatrist
Estibaliz	Ramos Díaz	GAO LACHO DROM ASSOCIATION OF VITORIA	Psychologist
Fermín	Castiella	NAVARRRE REGIONAL DRUG DEPENDENCY SCHEME	Technical Director of the Department

NAME	SURNAME	ORGANISATION	POST
Fernando	García	FSG	Health Mediator
Francisco Javier	Rubio Rodríguez	MINISTRY OF HEALTH AND CONSUMER AFFAIRS	Deputy Director-General of Professional Planning
Gracia	Jiménez Lérica	ANDALUSIAN HEALTH SERVICE	Physician
Guillermo	Domenech Muñoz	HEALTH DEPARTMENT OF CASTILLA Y LEON	Head of the Health Promotion and Prevention Programme Service
Herbé	Bertevas	MALAGA	Physician
Inés	Palanca	DIRECTORATE FOR PUBLIC HEALTH, FOOD AND CONSUMER AFFAIRS	Physician
Isidro	Rodríguez	FSG	Deputy-director of programmes
Javier	Blanco Aguilar	HEALTH AND PARTICIPATION DEPARTMENT, REGIONAL GOVERNMENT OF ANDALUSIA	Technical advisor
Jesús	Loza	FSG	Physician FSG Board member
José Alfonso	Cortés Rubio	MINISTRY OF HEALTH AND CONSUMER AFFAIRS	Deputy Director-General Services Portfolio and New Technologies
Jose Antonio	Jiménez Jiménez	UNGA DE ASTURIAS ROMA ASSOCIATION	President
José Manuel	Freno	FSG	Managing Director
Jose Miguel	Mata de la Torre	GOVERNMENT DELEGATION, NATIONAL DRUG PLAN	
Juan Antonio	López Blanco	MINISTRY OF HEALTH AND CONSUMER AFFAIRS	Technical Advisor, Deputy Directorate-General for Professional Planning
Juan Ivan	Cruz	MANAGEMENT, EXTREMADURA HEALTH SERVICE	Director of Primary Care Nursing

NAME	SURNAME	ORGANISATION	POST
Julio	Zarco Rodríguez	SPANISH RURAL MEDICINE SOCIETY	President
Lorenzo	Fernández Barriales	TEATINO MENTAL HEALTH CENTRE, OVIEDO	Psychiatry
Lucía	San Juan	UNIVERSIDAD AUTÓNOMA DE BARCELONA.	Research
Luis Ignacio	Gómez López	DEPARTMENT OF HEALTH AND CONSUMER AFFAIRS, GOVERNMENT OF ARAGON	Director-General of Public Health
Luz María	Fernández Regatillo Ruiz	HEALTH AND PARTICIPATION DEPARTMENT, REGIONAL GOVERNMENT OF ANDALUSIA	Section Head: Health Promotion and Education
M <sup>a</sup> Rosa	Munugarren	CARLOS III HEALTH INSTITUTE; NATIONAL SCHOOL OF HEALTH	Section head
Manuel	Moya Mir	SEMES-MADRID	President
María Luisa	Martínez Blanco	MADRID HEALTH DEPARTMENT; INSTITUTE OF PUBLIC HEALTH	Public Health Expert – Programme for underprivileged groups
María Luisa	Rodríguez Monroy	DEPARTMENT OF HEALTH AND SOCIAL SERVICES – LA RIOJA	Section Head: Health Promotion and Education
Marina	Pollán	NATIONAL EPIDEMIOLOGY CENTRE, MADRID (SESPA)	
Mariví	Librada	MINISTRY OF HEALTH AND CONSUMER AFFAIRS	Health Promotion Section Head
Marlen	Menéndez Menéndez	UNGA ROMA ASSOCIATION	Mediator
Mayte	Abaurrea	GAZ KALO FEDERATION OF ROMA ASSOCIATIONS OF NAVARRE	Health Programme

NAME	SURNAME	ORGANISATION	POST
Miguel	Dávila	MINISTRY OF HEALTH AND CONSUMER AFFAIRS	Deputy-Directorate General for External Health
Nadia	Rodríguez	INSALUD OF MADRID	Social Worker
Patricia	Bezunartea	FSG	Coordinator of the Social Action Department
Pilar	Bermejo González	MUNICIPAL DRUG TREATMENT UNIT SANTIAGO DE COMPOSTELA TOWN HALL	Director of UMAD
Rafaela	Jiménez Jiménez	GAO LACHO DROM ASSOCIATION	Social Worker
Ramón	Repullo Labrador	SPANISH SOCIETY OF PUBLIC HEALTH	President
Ricardo	Hernández	GAZ KALO FEDERATION OF ROMA ASSOCIATIONS OF NAVARRE	Mediator
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# ANNEX V

## Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin

THE COUNCIL OF THE EUROPEAN UNION,

Having regard to the Treaty establishing the European Community and in particular Article 13 thereof,

Having regard to the proposal from the Commission <sup>(1)</sup>,

Having regard to the opinion of the European Parliament <sup>(2)</sup>,

Having regard to the opinion of the Economic and Social Committee <sup>(3)</sup>,

Having regard to the opinion of the Committee of the Regions <sup>(4)</sup>,

Whereas:

(1) The Treaty on European Union marks a new stage in the process of creating an ever closer union among the peoples of Europe.

(2) In accordance with Article 6 of the Treaty on European Union, the European Union is founded on the principles of liberty, democracy, respect for human rights and fundamental freedoms, and the rule of law, principles which are common to the Member States, and should respect fundamental rights as guaranteed by the European Convention for the protection of Human Rights and Fundamental Freedoms and as they result from the constitutional traditions common to the Member States, as general principles of Community Law.

(3) The right to equality before the law and protection against discrimination for all persons constitutes a universal right recognised by the Universal Declaration of Human Rights, the United Nations Convention on the Elimination of all forms of Discrimination Against Women, the International Convention on the Elimination of all forms of Racial Discrimination and the United Nations Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights and by the European Convention for the Protection of Human Rights and Fundamental Freedoms, to which all Member States are signatories.

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(1) Not yet published in the Official Journal.

(2) Opinion delivered on 18.5.2000 (not yet published in the Official Journal).

(3) Opinion delivered on 12.4.2000 (not yet published in the Official Journal).

(4) Opinion delivered on 31.5.2000 (not yet published in the Official Journal).

(4) It is important to respect such fundamental rights and freedoms, including the right to freedom of association. It is also important, in the context of the access to and provision of goods and services, to respect the protection of private and family life and transactions carried out in this context.

(5) The European Parliament has adopted a number of Resolutions on the fight against racism in the European Union.

(6) The European Union rejects theories which attempt to determine the existence of separate human races. The use of the term "racial origin" in this Directive does not imply an acceptance of such theories.

(7) The European Council in Tampere, on 15 and 16 October 1999, invited the Commission to come forward as soon as possible with proposals implementing Article 13 of the EC Treaty as regards the fight against racism and xenophobia.

(8) The Employment Guidelines 2000 agreed by the European Council in Helsinki, on 10 and 11 December 1999, stress the need to foster conditions for a socially inclusive labour market by formulating a coherent set of policies aimed at combating discrimination against groups such as ethnic minorities.

(9) Discrimination based on racial or ethnic origin may undermine the achievement of the objectives of the EC Treaty, in particular the attainment of a high level of employment and of social protection, the raising of the standard

of living and quality of life, economic and social cohesion and solidarity. It may also undermine the objective of developing the European Union as an area of freedom, security and justice.

(10) The Commission presented a communication on racism, xenophobia and anti-Semitism in December 1995.

(11) The Council adopted on 15 July 1996 Joint Action (96/443/JHA) concerning action to combat racism and xenophobia<sup>(5)</sup> under which the Member States undertake to ensure effective judicial cooperation in respect of offences based on racist or xenophobic behaviour.

(12) To ensure the development of democratic and tolerant societies which allow the participation of all persons irrespective of racial or ethnic origin, specific action in the field of discrimination based on racial or ethnic origin should go beyond access to employed and self-employed activities and cover areas such as education, social protection including social security and healthcare, social advantages and access to and supply of goods and services.

(13) To this end, any direct or indirect discrimination based on racial or ethnic origin as regards the areas covered by this Directive should be prohibited throughout the Community. This prohibition of discrimination should also apply to nationals of third countries, but does not cover differences of treatment based on nationality and is without prejudice to provisions governing the entry and residence of

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(5) OJ L 185, 24.7.1996, p. 5.

third-country nationals and their access to employment and to occupation.

(14) In implementing the principle of equal treatment irrespective of racial or ethnic origin, the Community should, in accordance with Article 3(2) of the EC Treaty, aim to eliminate inequalities, and to promote equality between men and women, especially since women are often the victims of multiple discrimination.

(15) The appreciation of the facts from which it may be inferred that there has been direct or indirect discrimination is a matter for national judicial or other competent bodies, in accordance with rules of national law or practice. Such rules may provide in particular for indirect discrimination to be established by any means including on the basis of statistical evidence.

(16) It is important to protect all natural persons against discrimination on grounds of racial or ethnic origin. Member States should also provide, where appropriate and in accordance with their national traditions and practice, protection for legal persons where they suffer discrimination on grounds of the racial or ethnic origin of their members.

(17) The prohibition of discrimination should be without prejudice to the maintenance or adoption of measures intended to prevent or compensate for disadvantages suffered by a group of persons of a particular racial or ethnic origin, and such measures may permit organisations of persons of a particular racial or ethnic origin where their main

object is the promotion of the special needs of those persons.

(18) In very limited circumstances, a difference of treatment may be justified where a characteristic related to racial or ethnic origin constitutes a genuine and determining occupational requirement, when the objective is legitimate and the requirement is proportionate. Such circumstances should be included in the information provided by the Member States to the Commission.

(19) Persons who have been subject to discrimination based on racial and ethnic origin should have adequate means of legal protection. To provide a more effective level of protection, associations or legal entities should also be empowered to engage, as the Member States so determine, either on behalf or in support of any victim, in proceedings, without prejudice to national rules of procedure concerning representation and defence before the courts.

(20) The effective implementation of the principle of equality requires adequate judicial protection against victimisation.

(21) The rules on the burden of proof must be adapted when there is a prima facie case of discrimination and, for the principle of equal treatment to be applied effectively, the burden of proof must shift back to the respondent when evidence of such discrimination is brought.

(22) Member States need not apply the rules on the burden of proof to proceedings in which it is for the court

or other competent body to investigate the facts of the case. The procedures thus referred to are those in which the plaintiff is not required to prove the facts, which it is for the court or competent body to investigate.

(23) Member States should promote dialogue between the social partners and with non-governmental organisations to address different forms of discrimination and to combat them.

(24) Protection against discrimination based on racial or ethnic origin would itself be strengthened by the existence of a body or bodies in each Member State, with competence to analyse the problems involved, to study possible solutions and to provide concrete assistance for the victims.

(25) This Directive lays down minimum requirements, thus giving the Member States the option of introducing or maintaining more favourable provisions. The implementation of this Directive should not serve to justify any regression in relation to the situation which already prevails in each Member State.

(26) Member States should provide for effective, proportionate and dissuasive sanctions in case of breaches of the obligations under this Directive.

(27) The Member States may entrust management and labour, at their joint request, with the implementation of this Directive as regards provisions falling within the scope of collective agreements, provided that the Member States take all the necessary steps to ensure that they can at all times

guarantee the results imposed by this Directive.

(28) In accordance with the principles of subsidiarity and proportionality set out in Article 5 of the EC Treaty, the objective of this Directive, namely ensuring a common high level of protection against discrimination in all the Member States, cannot be sufficiently achieved by the Member States and can therefore, by reason of the scale and impact of the proposed action, be better achieved by the Community. This Directive does not go beyond what is necessary in order to achieve those objectives,

HAS ADOPTED THIS DIRECTIVE:

## CHAPTER I

### GENERAL PROVISIONS

#### Article 1

#### **Purpose**

The purpose of this Directive is to lay down a framework for combating discrimination on the grounds of racial or ethnic origin, with a view to putting into effect in the Member States the principle of equal treatment.

#### Article 2

#### **Concept of discrimination**

1. For the purposes of this Directive, the principle of equal treatment shall mean that there shall be no direct or indirect discrimination based on racial or ethnic origin.

2. For the purposes of paragraph 1:

(a) direct discrimination shall be taken

to occur where one person is treated less favourably than another is, has been or would be treated in a comparable situation on grounds of racial or ethnic origin;

(b) indirect discrimination shall be taken to occur where an apparently neutral provision, criterion or practice would put persons of a racial or ethnic origin at a particular disadvantage compared with other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary.

3. Harassment shall be deemed to be discrimination within the meaning of paragraph 1, when an unwanted conduct related to racial or ethnic origin takes place with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment. In this context, the concept of harassment may be defined in accordance with the national laws and practice of the Member States.

4. An instruction to discriminate against persons on grounds of racial or ethnic origin shall be deemed to be discrimination within the meaning of paragraph 1.

### Article 3

#### Scope

1. Within the limits of the powers conferred upon the Community, this Directive shall apply to all persons, as regards both the public and private sectors, including public bodies, in relation to:

(a) conditions for access to employment, to self-employment and to occupation, including selection criteria and recruitment conditions, whatever the branch of activity and at all levels of the professional hierarchy, including promotion;

(b) access to all types and to all levels of vocational guidance, vocational training, advanced vocational training and retraining, including practical work experience;

(c) employment and working conditions, including dismissals and pay;

(d) membership of and involvement in an organisation of workers or employers, or any organisation whose members carry on a particular profession, including the benefits provided for by such organisations;

(e) social protection, including social security and healthcare;

(f) social advantages;

(g) education;

(h) access to and supply of goods and services which are available to the public, including housing.

2. This Directive does not cover difference of treatment based on nationality and is without prejudice to provisions and conditions relating to the entry into and residence of third-country nationals and stateless persons on the territory of Member States, and to any treatment which arises from the legal status of the third-country nationals and stateless persons concerned.

## Article 4

### **Genuine and determining occupational requirements**

Notwithstanding Article 2(1) and (2), Member States may provide that a difference of treatment which is based on a characteristic related to racial or ethnic origin shall not constitute discrimination where, by reason of the nature of the particular occupational activities concerned or of the context in which they are carried out, such a characteristic constitutes a genuine and determining occupational requirement, provided that the objective is legitimate and the requirement is proportionate.

## Article 5

### **Positive action**

With a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantages linked to racial or ethnic origin.

## Article 6

### **Minimum requirements**

1. Member States may introduce or maintain provisions which are more favourable to the protection of the principle of equal treatment than those laid down in this Directive.

2. The implementation of this Directive shall under no circumstances constitute grounds for a reduction in the level of protection against discrimination already afforded by Member States in the fields covered by this Directive.

## CHAPTER II

### REMEDIES AND ENFORCEMENT

## Article 7

### **Defence of rights**

1. Member States shall ensure that judicial and/or administrative procedures, including where they deem it appropriate conciliation procedures, for the enforcement of obligations under this Directive are available to all persons who consider themselves wronged by failure to apply the principle of equal treatment to them, even after the relationship in which the discrimination is alleged to have occurred has ended.

2. Member States shall ensure that associations, organisations or other legal entities, which have, in accordance with the criteria laid down by their national law, a legitimate interest in ensuring that the provisions of this Directive are complied with, may engage, either on behalf or in support of the complainant, with his or her approval, in any judicial and/or administrative procedure provided for the enforcement of obligations under this Directive.

3. Paragraphs 1 and 2 are without prejudice to national rules relating to time limits for bringing actions as regards the principle of equality of treatment.

## Article 8

### **Burden of proof**

1. Member States shall take such measures as are necessary, in accordance with their national judicial systems, to ensure that, when persons who consider

themselves wronged because the principle of equal treatment has not been applied to them establish, before a court or other competent authority, facts from which it may be presumed that there has been direct or indirect discrimination, it shall be for the respondent to prove that there has been no breach of the principle of equal treatment.

2. Paragraph 1 shall not prevent Member States from introducing rules of evidence which are more favourable to plaintiffs.

3. Paragraph 1 shall not apply to criminal procedures.

4. Paragraphs 1, 2 and 3 shall also apply to any proceedings brought in accordance with Article 7(2).

5. Member States need not apply paragraph 1 to proceedings in which it is for the court or competent body to investigate the facts of the case.

#### Article 9

### **Victimisation**

Member States shall introduce into their national legal systems such measures as are necessary to protect individuals from any adverse treatment or adverse consequence as a reaction to a complaint or to proceedings aimed at enforcing compliance with the principle of equal treatment.

#### Article 10

### **Dissemination of information**

Member States shall take care that the provisions adopted pursuant to this

Directive, together with the relevant provisions already in force, are brought to the attention of the persons concerned by all appropriate means throughout their territory.

#### Article 11

### **Social dialogue**

1. Member States shall, in accordance with national traditions and practice, take adequate measures to promote the social dialogue between the two sides of industry with a view to fostering equal treatment, including through the monitoring of workplace practices, collective agreements, codes of conduct, research or exchange of experiences and good practices.

2. Where consistent with national traditions and practice, Member States shall encourage the two sides of the industry without prejudice to their autonomy to conclude, at the appropriate level, agreements laying down anti-discrimination rules in the fields referred to in Article 3 which fall within the scope of collective bargaining. These agreements shall respect the minimum requirements laid down by this Directive and the relevant national implementing measures.

#### Article 12

### **Dialogue with non-governmental organisations**

Member States shall encourage dialogue with appropriate non-governmental organisations which have, in accordance with their national law and practice, a legitimate interest in contributing to the fight against discrimination on grounds

of racial and ethnic origin with a view to promoting the principle of equal treatment.

### CHAPTER III

#### BODIES FOR THE PROMOTION OF EQUAL TREATMENT

##### Article 13

1. Member States shall designate a body or bodies for the promotion of equal treatment of all persons without discrimination on the grounds of racial or ethnic origin. These bodies may form part of agencies charged at national level with the defence of human rights or the safeguard of individuals' rights.

2. Member States shall ensure that the competences of these bodies include:

- without prejudice to the right of victims and of associations, organisations or other legal entities referred to in Article 7(2), providing independent assistance to victims of discrimination in pursuing their complaints about discrimination,
- conducting independent surveys concerning discrimination,
- publishing independent reports and making recommendations on any issue relating to such discrimination.

### CHAPTER IV

#### FINAL PROVISIONS

##### Article 14

##### **Compliance**

Member States shall take the necessary measures to ensure that:

- (a) any laws, regulations and adminis-

trative provisions contrary to the principle of equal treatment are abolished;

(b) any provisions contrary to the principle of equal treatment which are included in individual or collective contracts or agreements, internal rules of undertakings, rules governing profit-making or non-profit-making associations, and rules governing the independent professions and workers' and employers' organisations, are or may be declared, null and void or are amended.

##### Article 15

##### **Sanctions**

Member States shall lay down the rules on sanctions applicable to infringements of the national provisions adopted pursuant to this Directive and shall take all measures necessary to ensure that they are applied. The sanctions, which may comprise the payment of compensation to the victim, must be effective, proportionate and dissuasive. The Member States shall notify those provisions to the Commission by 19 July 2003 at the latest and shall notify it without delay of any subsequent amendment affecting them.

##### Article 16

##### **Implementation**

Member States shall adopt the laws, regulations and administrative provisions necessary to comply with this Directive by 19 July 2003 or may entrust management and labour, at their joint request, with the implementation of this Directive as regards provisions

falling within the scope of collective agreements. In such cases, Member States shall ensure that by 19 July 2003, management and labour introduce the necessary measures by agreement, Member States being required to take any necessary measures to enable them at any time to be in a position to guarantee the results imposed by this Directive. They shall forthwith inform the Commission thereof.

When Member States adopt these measures, they shall contain a reference to this Directive or be accompanied by such a reference on the occasion of their official publication. The methods of making such a reference shall be laid down by the Member States.

#### Article 17

##### **Report**

1. Member States shall communicate to the Commission by 19 July 2005, and every five years thereafter, all the information necessary for the Commission to draw up a report to the European Parliament and the Council on the application of this Directive.

2. The Commission's report shall take into account, as appropriate, the views

of the European Monitoring Centre on Racism and Xenophobia, as well as the viewpoints of the social partners and relevant non-governmental organisations. In accordance with the principle of gender mainstreaming, this report shall, inter alia, provide an assessment of the impact of the measures taken on women and men. In the light of the information received, this report shall include, if necessary, proposals to revise and update this Directive.

#### Article 18

##### **Entry into force**

This Directive shall enter into force on the day of its publication in the Official Journal of the European Communities.

#### Article 19

##### **Addressees**

This Directive is addressed to the Member States.

Done at Luxembourg, 29 June 2000.

For the Council  
The President  
M. Arcanjo