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Breaking the Barriers – Romani Women and Access to Public Health Care

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Breaking the Barriers – Romani Women and Access to Public Health Care

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This report has been prepared by an independent researcher on behalf of the project "Romani Women and Access to Public Health Care" undertaken jointly by the Office of the OSCE High Commissioner on National Minorities (http://www.osce.org/hcnm/), the Council of Europe's Migration and Roma/Gypsies Division (http://www.coe.int/T/E/Social_Cohesion/Roma_Gypsies/), and the European Union's European Monitoring Centre on Racism and Xenophobia (EUMC) (http://eumc.eu.int).

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Cataloguing data can be found at the end of this publication.

Luxembourg: Office for Official Publications of the European Communities, 2003

ISBN 92-95008-14-6

Printed in Luxembourg

PRINTED ON WHITE CHLORINE-FREE PAPER

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Foreword

The situation of the Romani community in various parts of Europe has become a benchmark of our development in the field of fundamental rights and social justice. As this report demonstrates, the situation of Romani women in relation to health care is poor and emphasizes how much needs to be done. Numerous other reports in a whole host of fields from employment to education also highlight the plight of members of the Romani community. Advances in social protection, health, housing availability, educational attainment and similar indicators of development will remain tarnished if they are not to the benefit of all members of society. The right of all individuals to equality before the law and to the protection from discrimination is a bedrock of democratic societies. Inequality, discrimination, exclusion on the basis of a person's racial or ethnic origin or social status is wrong not only in legal terms, but also in moral and social terms, including with implications for economic development. It is to all our benefit when all members of society can participate freely and equally and realize their full potential as individual human beings, members of communities and as citizens.

The impetus for this study arose from the suggestion of the Director of the Office of the OSCE High Commissioner on National Minorities to build upon the findings from the High Commissioner's April 2000 *Report on the Situation of Roma and Sinti in the OSCE Area* which identified a number of issues from a public interest perspective and offered a range of recommendations aimed largely to remove the obstacles to full enjoyment of equal treatment. Health stood out for the lack of information available, and for the apparent interplay between gender and racism. This study builds on that initial OSCE report by drawing attention to the overall situation of Romani women and their healthcare concerns.

The project on Romani Women and Access to Public Health Care, of which this report forms a central part, was the first collaborative effort between the OSCE's Office of the High Commissioner on National Minorities, the Council of Europe's Migration and Roma/Gypsy Division and the European Union's European Monitoring Centre on Racism and Xenophobia − an example of successful cooperation at the regional level between inter-governmental organizations pooling their expertise and resources. This joint undertaking drew upon the common concern for Roma in relation to which different areas of expertise and experience − ranging from human rights analysis to knowledge about health and education strategies to experience of combating racism and xenophobia − was useful in addressing Romani women's health concerns. It is the conviction of the three organizations that policy-making based on comprehensive information, reliable data and international standards, informed by the views and desires of those directly affected, can make a substantial difference to people's lives. Indeed, effective implementation of such policies can close the gaps in opportunity among various groups and contribute to the construction of cohesive communities where all members have a stake and can contribute.

If discrimination is to be eliminated, it requires action by all of us. Certainly, governments hold the principal responsibility and have the central role in tackling these issues through adoption and implementation of policy and law, and by directing State institutions in action. But without the active engagement of civil society, and the vital support of the Romani Women themselves,

even the best policy and law will risk failure. As such, this report outlines a set of recommendations ranging from legislative action, capacity building of Roma and health authority structures, health education and public awareness-raising.

In the course of this study, two independent experts were engaged to conduct country visits and individual interviews: Ms. Anna Pomykala, assisted by Ms. Mariana Buceanu. We would like to thank all those who were involved in this project, including Ms Pomykala also for having drafted this report and all those who were involved in the interviews, editing, consultation process and otherwise contributed their support leading to the full realization of the project. We would especially like to thank the Romani women themselves for their involvement and contributions to this project, in particular at the NGO Meeting on Romani Women and Access to Health Care held in Vienna on 28-29 November 2002, hosted by the EUMC. In addition, we are grateful to the Government of the United Kingdom and to the EUMC for having made substantial financial contributions to this project, along with The Themis Foundation which provided a small but important grant to Ms. Pomykala at the very beginning of this project which enabled her to attend two international conferences where vital contacts were established.

We intend this report to assist policy and law makers to better understand the complex and interrelated nature of the healthcare issues and to assist them to improve the design and implementation of policies on Romani women and health. It has been a much neglected aspect of the work on Roma and hopefully will contribute to the design and implementation of concrete and practical policies, strategies and programmes which may inspire further action into related areas upon which the report touches. This will be to the benefit not only of Romani women and their families, but all of us.

31 July 2003

Executive Summary

i. Introduction

This project aims to build upon on the findings of the Organization for Security and Cooperation in Europe (OSCE) High Commissioner on National Minorities' (HCNM) Report on the Situation of Roma and Sinti in the OSCE Area (April 2000). Specifically, the inadequacy of available information relating to this self-evidently important subject merited a substantial study and report with a policy orientation. As such, the project sought to reveal and understand better the situation of Romani women with regard to the vital subject of health care, to examine it in terms of applicable standards and the genuine needs of the population, and to draw appropriate conclusions and to propose practical recommendations. The project thus sought to stimulate the interest and action of others, especially governments, and to contribute momentum to a nascent European-wide movement of Romani women for their own empowerment as free and responsible citizens.

Administered by the Council of Europe, the project has been overseen by an advisory group consisting of representatives of the Council of Europe, OSCE HCNM, OSCE Office for Democratic Institutions and Human Rights, the European Union's European Monitoring Centre on Racism and Xenophobia (EUMC), and the World Health Organization Regional Office for Europe.

The report is based primarily on interviews conducted by the principal author in Bulgaria, Finland, France, United Kingdom, Greece, Hungary, Ireland, Lithuania, Moldova, The Netherlands, Poland, Romania, Serbia and Montenegro, Slovakia, and Spain. In each country, interviews were held with representatives of governments, non-governmental organizations (NGOs) and other institutions working on behalf of Roma, and with Romani women themselves.

The report also draws on primary documentation collected in the course of country visits, through questionnaires sent to governmental authorities as well as secondary research. Numerous ministries and non-governmental organizations responded to questionnaires aimed at elucidating the situation of Romani women and access to health care in their countries. This cooperation was appreciated and greatly facilitated the author's work. Of particular use were the written comments received from the Governments of those States visited or substantially addressed in response to advance circulation of an initial draft of this report. Comments were received from the following States: Hungary, Lithuania, Greece, Ireland, Romania, and Spain. To the extent possible, and as appropriate, the substance of Government responses has been incorporated within the text of this report.

The countries visited were selected with the aim of seeking to understand the situation of access to health care in diverse settings, for diverse Roma populations, and where initiatives to address this situation are at different stages of development or implementation. In this way, a range of good practices as well as areas of future intervention could be identified. Given that this study did not aim to be exhaustive, and given the fact of limited funds and time available for the study,

only a selection of countries could be visited.

The issues discussed below reflect some of the major concerns in accessing health and other public services of Romani communities across Europe. They do not represent an exhaustive list of the ways in which State responsibility to ensure equal access to health care on a non-discriminatory basis may be concerned. Furthermore, the lack of mention of a particular country in the context of discussing a specific practice is not intended to suggest that this practice does not occur there. Nor is it meant to imply that there are no efforts in a particular country to address this practice.

It is hoped that this report will stimulate closer examination of the specific ways in which discrimination in access to health care and related public services may affect Roma, particularly women. Such awareness should lead to the reform, development and implementation of effective State policies to guarantee access to public services on a non-discriminatory and culturally sensitive basis for Romani women and their communities. It should also lead to the heightened participation of Romani women in all policymaking, and its implementation, on their behalf.

ii. Overview

This report aims to contribute analysis and policy options to eliminate discrimination in and improve access to health care for Roma,[1] Gypsy and Traveller women and their communities. Examples of good practice are provided throughout with the aim of aiding States to develop effective targeted policies in consultation and cooperation with those affected.

Non-discrimination and equal treatment in the provision of health care form part of State obligations under international law. The right of all persons to be treated equally is a basic principle of fundamental human rights recognized at the international and national levels and a corner stone to developing free and fair societies. Rights are more than legal obligations and they open doors to realizing the full potential of all members of society and building more socially cohesive communities. This is to the overall benefit of the State both economically and socially. As this report highlights, Romani individuals and communities are in many ways excluded from the opportunity to realize their full potential and contribute on an equal basis with the rest of their society. Families form an important component of creating socially cohesive societies and the living conditions of families are therefore a crucial element in supporting inclusion. Romani women play a central role in health related matters of their families and communities, and so ensuring their free and equal access to public healthcare becomes a key aspect to the broader advancement of Romani individuals and communities, and thus of the

[1] Hereafter, use of the term "Roma" shall refer to ethnic groups who identify themselves as "Romani" or those such as Sinti, Gypsies and Travellers in the United Kingdom, Ireland and elsewhere who share similar aspects of culture, history, and, most importantly, confront similar issues of discrimination and social exclusion. Mention of Sinti, Gypsies, Travellers, and other groups has been retained where the source materials discussed focus specifically on these groups.

entire society. In order to achieve these goals, greater attention to health is required in the planning and implementation of government strategies to improve the situation of Roma. Special measures[2] may be necessary to provide Romani women with equal opportunities to enjoy access to health care on a non-discriminatory and culturally sensitive basis. Specifically, the participation of Romani women at all stages of policy-making and implementation needs to be enhanced.

Part I explains the rationale behind this report, including reasons why Romani women and access to health care have not yet received much needed attention at the national and international levels. A brief overview of the health status of Romani populations is provided in order to demonstrate the gravity of the problem and the context in which interventions and further research should be developed. Legal standards are presented, with a focus on the relevance of anti-discrimination norms to realizing the right to the highest attainable standard of health and to enhancing Romani women's participation in improving their own access to public services. Also discussed is the importance of ethnic data collection additionally disaggregated on the basis of sex, with emphasis on the need for safeguards and, where appropriate, participation of Roma at all stages of the data collection process.

Part II describes types of direct and indirect discrimination by health care workers and institutions that Roma may confront in accessing health care. These issues are approached within the framework of information, physical and economic access provided by the General Comment[3] of the United Nations (UN) Committee on Economic, Social and Cultural Rights (CESCR) on the right to the highest attainable standard of health. Forms of discrimination discussed include refusal of care by general practitioners and health care institutions, segregation in health facilities, verbal abuse and degrading treatment, and difficulties in accessing emergency care. The importance of effective monitoring and sanctions is stressed throughout. Additional and specific barriers for Romani women are explored, including gender dynamics within Romani communities that may impede access to care. Emphasis is placed on the need for a holistic approach to Romani women's health through a gender perspective and with attention to changing attitudes and practices detrimental to women's health and well-being. A call is made for greater openness towards and concrete actions to address domestic violence, mental health care and substance abuse treatment.

Part III emphasizes that access to health care is both a precondition to and inseparable from access to a legal identity, adequate social protection, education, minimum living conditions and housing. Some of the relationships between these entitlements and access to health care are examined, with a focus on eliminating direct and indirect discrimination that may impact adversely on access to health care. Previously under-explored issues such as the specific needs of Romani girls and women in education and housing are elucidated, with the aim of encouraging their routine consideration in policy-making and programme development.

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[2] The use of the term "special measures" in this report includes the provision under article 5 for positive action as described in the EU's Council Directive 2000/43/EC of 29 June, 2000 implementing the principle of equal treatment between persons irrespective of racial or social origin (Racial Equality Directive). More generally on special measures, *see infra* at Part I, B.2.

[3] CESCR General Comment 14 on the right to the highest attainable standard of health, UN Doc. E/C.12/2000/4.

Part IV examines existing government strategies to improve the situation of Roma with the aim of identifying components essential to improving access to public services generally, and to health care for Romani women, specifically. These include: the role and activities of specialized bodies to combat discrimination and promote equal treatment; the development of a multi-sectoral approach to health that recognizes the role of discrimination in impeding access to health care; the consideration of a broad range of Romani health interests; and designation of a women's rights and gender adviser to incorporate a gender perspective and ensure the inclusion of Romani women's needs within mainstream services. The institution of Romani health mediators is discussed in terms of existing programmes and future potential to promote integration into health services and enhance the public role of Romani women. The importance of increasing health care workers' and authorities' familiarity with Romani culture is explored. Intergovernmental initiatives to improve access to health care are described as a source of ideas for and complements to local and national programmes with similar objectives.

Part V presents policy recommendations aimed at improving access to health care and related public services, with particular attention to creating conditions for the full participation of Romani women. Concrete actions to improve access to health care can improve health status and living conditions as well as heighten integration with a broad range of mainstream services. Specific commitments are thus expected to contribute to the broader goal of inclusion of Roma, particularly women, in the fabric of the larger society.

iii. Key findings

To date, inadequate attention has been paid to Romani women and access to health care at either national or international levels. The health status of Roma is generally very poor across Europe, and there is little information about the needs and interests of Romani women. For many reasons, Romani women tend not to prioritise attention to their own health; at the same time they are often the primary caregivers in their families and communities. The collection of ethnic data additionally disaggregated on the basis of sex, as well as inclusion of Roma in research on women, adolescents, rural or isolated, and mobile populations, is needed in order to develop effective policies and programmes to guarantee access to health care and other public services on an equal basis.

There is a need for increased familiarity among health care workers and authorities with diverse Romani cultures and practices as they relate to health care. Greater openness to making accommodations for these practices is required to ensure that Roma enjoy access to health care without discrimination and on an equal basis with non-Roma.

Information, physical, and economic barriers to accessing health care for Roma result from the inter-related effects of discrimination and poverty. Roma may experience various kinds of direct and indirect discrimination in accessing health care. These include: refusal of assistance by general practitioners or health care institutions; segregation in health care facilities; inferior and degrading treatment; and difficulties in accessing emergency care imposed as a result of their ethnicity. The short and long term consequences of this discrimination include unattended health

problems, decreased trust in public services, and heightened social exclusion.

Difficulties for Romani women in accessing health care are compounded by attitudes and community practices that draw attention away from women's health and may constitute sex discrimination. Consequently, many women regard health services, particularly preventive care and family planning, as inapplicable or unavailable to themselves. There is a dearth of information about reproductive and sexual health among Romani women and men, especially adolescents, despite marriage and childbearing at a young age in many communities. Difficulties in accessing family planning services may account in large part for the generally high rates of fertility and abortion among Romani women.

Gender dynamics may combine with poverty and discrimination to enhance Romani women's vulnerability to domestic violence, mental ill-health and substance abuse. Information about and access to treatment for these problems are not readily accessible. There exist few possibilities for Romani women living with domestic violence to access culturally sensitive support services, and concerns arise about discriminatory treatment by authorities when assistance from outside the community is sought. Greater attention to the gender dimensions of women's health and well-being is required, particularly through raising awareness among Romani men of their role in promoting and protecting women's health.

While not a cure-all for the systemic and systematic barriers to accessing health care often confronting Roma, the institution of Romani mediators may have a significant impact on promoting integration with mainstream services and heightening women's participation in all matters pertaining to their own health. Existing programmes have focused primarily on training and employing Romani women as mediators. However, the poor health status of many Roma, the extent of difficulties in accessing care, and the need to address the gender dimensions of women's health suggest that other actions are required, and that more Romani men might become involved.

Many Roma lack identity cards, birth certificates and other official documentation of their legal status. Such documents are often required to access public services. Statelessness, and the lack of status within the State of residence, as well as problems with documentation impede access to a range of rights including access to health care. These situations are created by a variety of factors, including information and financial barriers, eligibility criteria that have a disproportionate impact on Roma, and discrimination by local authorities. There is need for greater awareness among authorities of the situation of Roma, and greater flexibility in application of legal status requirements for Roma (as for other discriminated groups) in order that they may enjoy equal access to public services.

Access to social protection includes access to non-contributory health insurance and other health-related benefits. Many Roma lack access to information about social benefits, including the fact that access to a doctor often depends on registration with and periodic visits to an unemployment office as proof of entitlement to care. Eligibility criteria that have a disproportionate impact on Roma as well as abuse of social worker discretion may further impede access. In countries where Roma constitute a disproportionate number of the unemployed and impoverished, the high cost of obtaining identity documents may pose additional barriers. Roma who follow semi-

nomadic or nomadic lifestyles often face a *de facto* loss of access to social benefits. Payments are normally made to a permanent residence, and forced mobility may impede access through a combination of instability, stress, lack of information, and discrimination on the basis of travelling lifestyle.

Attention to the relationship between decision-making capacity about personal health and gender dynamics in many Romani communities which may impede access to education for Romani girls and women is required. Schools are a key source of information on hygiene, nutrition, disease prevention and how to access the health system. Research and advocacy has been carried out on access to education on a non-discriminatory basis for Roma youth generally. But greater attention is required in addressing the particular difficulties a Romani girl may confront, e.g. withdrawal from school by her parents to protect her virginity, prepare for marriage, or assume household duties. These girls may not acquire adequate literacy and critical thinking skills to care for themselves and their families, as well as to modify cultural practices that adversely impact on their health and well-being. In effect, they may suffer both ethnic and gender discrimination.

Poor living conditions, problems securing a permanent domicile, lack of services, and forced evictions all impact negatively on access to health care. As the primary users and maintainers of housing, Romani women have the most at stake and the most requirements for adequate housing. Unfortunately, many Roma are forced to live in conditions that pose health and safety hazards. Health care and other service providers may intentionally or inadvertently avoid these areas. For Roma living in rural or isolated communities, public services may not be readily accessible. Such gaps in mainstream services must be filled.

Where proof of residence is required to access public services, Roma may be disadvantaged by the improper use of discretion on the part of authorities in providing such documentation, or by laws or policies that provide for legal halting sites in a manner that does not satisfy existing need. Romani communities may be particularly vulnerable to forced evictions, which impact health and access to other services in numerous ways. In this connection, legalization of settlements and other places of residence need to be addressed as a matter of urgency.

iv. Recommendations

Concrete action to promote equality and ensure non-discrimination in access to health care must be taken at the State and local levels, and can be supported with the cooperation of inter-governmental and non-governmental initiatives. International and regional anti-discrimination norms should be implemented including through comprehensive national anti-discrimination legislation that expressly prohibits direct and indirect discrimination and against victimization, supported by express instructions against discrimination in access to health care and other public services. States should also consider supporting equal treatment by establishing a legal duty for their public authorities to promote equality.

States should examine the need for special measures to ensure full equality in practice and create

the conditions for equal enjoyment of access to health care for Roma, particularly women. Special measures may also be required to ensure that traditional and cultural attitudes do not impede Romani women's rights to the highest attainable health and to take part in the conduct of affairs affecting them. These measures should be combined with mutually re-enforcing capacity building of targeted actors within the Romani community and awareness-raising campaigns of the goals of these measures among the wider population.

Where they do not exist, governments should consider the establishment or designation of specialized bodies which can act independently to promote the equal treatment of all persons without discrimination including on racial or ethnic grounds. These bodies should give consistent attention to the field of health care and take account of gender related issues. Such bodies could play a key role in heightening awareness among health care workers and authorities on the various types of discrimination to which Roma may be subject, investigating and supporting complaints as appropriate, undertaking independent research and surveys, and helping to enact and enforce comprehensive anti-discrimination legislation, particularly at the local level. Greater dialogue and cooperation are required among representatives of health systems, specialized bodies, treaty-monitoring and inter-governmental bodies on the issue of access to health care.

States should establish an official system of data collection based on recognized international standards for data collection and protection with appropriate oversight and safeguards to document the situation and needs of Roma and to record all types of discrimination. Where feasible, Roma should be involved in the stages of data collection, disaggregation and analysis. The purpose and use of the data, along with the rules regarding its storage and access, should be made clear to those persons from whom data is collected. Since there exists relatively little information on the health status and needs of Roma, States should take steps to include Roma health status and needs in health research, with a focus on women, adolescents, rural or isolated and mobile populations.

Government strategies to improve the situation of Roma should recognize and include concrete actions to address the role of discrimination in impeding access to health care. They should include consultative mechanisms to ensure consideration of a broad range of Romani health interests in the policy- and law-making processes, and take a holistic approach to women's health. The appointment or involvement of a women's rights and gender adviser should be encouraged to ensure integration of these issues into policies affecting Roma, as well as their integration into national health strategies and mainstream services.

More generally, government strategies should reflect a multi-sectoral approach, taking into consideration the ways that access to documented legal status, social benefits, education, living conditions and housing affect health status and access to care, particularly for women. In this regard, States should provide adequate authority and resources for strategy development, implementation and review, particularly at local levels.

Participation of Romani women in improving their own access to health care and other public services must be enhanced. Their participation at all stages of policy- and law-making affecting Roma should be ensured on an equal basis with men, in part through formal consultative mechanisms and heightened transparency in recruiting and decision-making processes.

The institution of Romani health mediators should be supported at local levels and on a national scale. Mediators could help to combat stereotypes by educating Romani communities and health institutions about each other, and to promote changes in gender dynamics in the community that have an adverse effect on women's well-being. They might also encourage greater attention among women to their own health while, more generally, encouraging women's participation in education and in public affairs concerning them.

Combating discrimination by health care workers and institutions should be undertaken in several ways. Prohibitions against direct and indirect discrimination, and against victimization should be enacted, monitored and enforced, including by professional associations. Health care workers and authorities working among Romani communities should be educated about diverse Romani traditions, cultures, living conditions, and mobility patterns with a view to combating discrimination on the basis of race, ethnicity, and associated factors such as a travelling lifestyle. Provision should be made for use of the Romani language to improve prevention and attain optimal care. Incentives should be created for health care personnel to work in Romani communities with the aim of integrating these communities into mainstream services. Romani health mediators could help to identify and diminish discrimination in health and related public services.

Information, physical, and economic access to health care, including emergency services, should be guaranteed. This can be supported by awareness-raising campaigns in the Romani communities and among local authorities, the provision of adequate roads, communication, and services for Romani communities, and programmes to include low-income persons. For mobile populations, client-held records and other non-territory based systems should be considered.

Victims of alleged discrimination should be encouraged to bring complaints, such as through awareness-raising about recourses and the use of mechanisms provided by specialized bodies with assurances that confidentiality and access to health care will not be compromised on account of bringing a claim. Complaint mechanisms should place the primary burden of proof on health care workers rather than victims to demonstrate whether the principle of equal treatment has been breached.

Romani women confront many barriers to promoting their own health needs. Health care workers and authorities should create programmes incorporating a self-empowerment component to improve women's awareness of and access to preventive, reproductive and sexual health care. Concrete steps should be taken to address elements of Romani culture that may impede access to services. A women's rights and gender adviser could help devise such programmes. Access to health information and services throughout the lifecycle should be available to all Roma, including adolescents, rural or isolated and mobile communities. Attention should be given to educating adolescent Romani women, their sexual partners, and parents on the risks associated with early pregnancy. More broadly, education about the right to autonomy and freedom of choice in all decisions relating to sexuality should be a central component of community-wide interventions to improve access to care. Concrete measures to address the gender dimensions of women's health and well being in the larger society should include Romani communities, e.g. through awareness-raising among Romani men concerning their role in protecting women's health and preventing domestic violence.

Efforts should be made to ensure that interventions in the larger society concerning domestic violence, mental health, and substance abuse address the needs of Romani women. The need for anti-discrimination, gender and culture sensitivity training for authorities, health and other personnel who provide support services for Romani women should be evaluated. Information and services should be provided on a culturally sensitive basis and with attention to the special ways in which Romani women experience these problems. The situation of adolescents, as well as women living in rural, isolated or mobile communities should not be overlooked.

Discriminatory barriers to accessing legal status, identification documents and social benefits impact directly on access to health care and should be removed. Criteria that have a disproportionate impact on Roma should be amended and abuse of discretion by civil servants should be investigated and sanctioned. The particular situation of mobile populations should be included in any changes to policy and practice. In the interim, access to health and other public services for which official documentation is required should be provided to persons in need, regardless of race or ethnicity. Where differences of treatment exist based on nationality or legal status, these should be regularly re-examined with a view to promoting equal treatment as appropriate.

Improving access to health care for Romani girls and women is inseparable from fulfilling their right to education. Measures to change attitudes and practices that impede their access to education should be adopted, along with reasonable accommodations for girls and women who have left school for a period to return as married and/or as mothers. Cooperation among teachers, authorities and parents should be encouraged to promote girls' continued education, particularly as a prerequisite for their exercise of free choice and responsibility in health care. Incentives and support systems should be created to encourage Romani women to pursue tertiary and vocational education.

Ensuring access to legal, habitable, culturally adequate and safe accommodation is paramount to improving health as well as access to the public services for which proof of domicile is required. Romani women should be consulted in policy- and law-making to develop and rehabilitate housing for their families and community. Special attention should be given to guaranteeing access to public services on an equal basis and without discrimination for Roma in rural or isolated and mobile communities. Registration of residency should be facilitated. Priority should also be given to the non-discriminatory application of sanitary checks and evictions policies, with due concern for preserving access to public services and preventing homelessness.

PART I

A. Introduction

1. Inadequate attention to Romani women and access to health care

The April 2000 *Report on the Situation of Roma and Sinti in the OSCE Area* recognized inadequate health care as one of two principal elements of generally poor living conditions suffered by Romani communities. Particularly adverse effects were noted for Romani women, who often bear the double burden of ethnic discrimination by majority society and gender discrimination from within their communities. Many factors influencing Romani women's health were identified, including poor housing and sanitary conditions, lack of education, unemployment, and legal status. Discrimination in access to health care raised particular concern:

> Discriminatory and prejudicial attitudes are one of the key factors in the marginalization and sometimes exclusion of many Roma from public health campaigns and programmes; lack of practical access to health care generates specific concerns for Romani women.[4]

While *access* is only one of many dimensions of health,[5] its improvement is a key step towards narrowing gaps in health care between advantaged and disadvantaged groups. Access to health care is a right and a prerequisite for good health without which full participation in social, economic and political life cannot be enjoyed: it is inseparable from access to public services such as education, housing, and social protection, and a precondition to accessing and maintaining employment. Ensuring access to health care for Romani women is thus a key element in ensuring their broader social and economic engagement and social inclusion. For both moral and practical reasons it is in the interests not only of Roma women themselves, but their families, communities and the wider society that their good health is assured. Commitment to providing the conditions for a healthy, educated, and integrated Romani population on the part of the authorities and wider society will reap benefits for the whole population.

Romani women tend to be the primary caregivers in their families and communities. They are also often intermediaries between their families and public services. At the same time, Romani women may neglect their own health while being excluded from education, housing, and other public goods. These factors inhibit Romani women's own personal development as well as that of their communities.

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[4] Organization for Security and Co-operation in Europe, High Commissioner on National Minorities, "Report on the Situation of Roma and Sinti in the OSCE Area", The Hague, April 2000, p. 117, available at: http://www.osce.org/hcnm/documents/reports/.

[5] The Committee on Economic, Social and Cultural Rights recognizes four elements of the right to health: availability, accessibility, acceptability and quality. *See* CESCR General Comment 14, *supra*, note 3, para. 12.

Despite documented cases of discrimination, relatively little attention has been paid to Romani women or health compared to other issues affecting Romani communities. Several factors contribute to this reality. Family and home responsibilities combined with adherence to rigid gender roles in some Romani communities prevent many women from addressing these issues in the public sphere and over a sustained period. Romani women are often overlooked in Roma integration and empowerment efforts. Where national strategies to improve the situation of Roma address health, it is often limited to education initiatives or in the narrow context of maternal health. Greater attention to the discriminatory and gender-related dimensions impeding Romani women's access to health is required.

More generally, the translation of government intentions into concrete actions is often impeded, whether by a lack of resources, enforcement authority, or political will (whether at national, local or regional level). As a consequence, the particular experiences of Romani women's interaction with health institutions and related public services are not often heard, either at national or international levels. Nonetheless, many Romani women and organizations at all levels have made significant contributions to addressing their health and the health of their communities. The work of some of these groups is described herein.

This is a period of health reforms especially throughout Central and Eastern Europe, with growing challenges of accommodating migrants and responding to increasingly multicultural societies in the West. Candidate countries for European Union accession have been called upon to remedy poor living conditions and social discrimination of Roma, as well as to improve Roma integration into social development strategies.[6] The World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance recently recognized the need to develop a more systematic and consistent approach to evaluating and monitoring racial discrimination against women, as well as the disadvantages, obstacles and difficulties women face in the full exercise and enjoyment of their rights because of racism and related intolerance.[7] At this time, a sharing of experience may be particularly useful to identify problems, propose solutions, and exchange lessons learned in improving access to health care and related public services for Romani women and their communities.[8] With this awareness, States can progress individually and in cooperation to achieve these goals.

2. Health status of Romani populations: an overview

Virtually all strategies in both Eastern and Western Europe designed to improve the situation of Roma have recognized that Roma generally exhibit a higher rate of illness and have lower access

[6] Towards the Enlarged Union: Strategy Paper and Report of the European Commission on the progress towards accession by each of the candidate countries, SEC (2002) 1400 – 1412 (COM (2002) 700 final), Brussels, Oct 9 2002, Annex 1: Conclusions of the Regular Reports.

[7] World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, Durban, South Africa, Aug 31- Sept 8 2001, Declaration, para. 70, available at: http://www.unhchr.ch/html/racism/Durban.htm.

[8] *See* "Implementing Good Intentions", Address to the conference on Equal Opportunities for Roma and Sinti: Translating Words into Facts, by Rolf Ekeus, High Commissioner on National Minorities, Organization for Security and Cooperation in Europe (OSCE), Bucharest, Romania, 10 September, 2001.

to care than the wider population.[9] Though there is relatively little information on the specific health status of Romani women, existing studies on Roma health create a broad picture upon which interventions and further research should be developed.

Noted health trends include the following; these will be discussed in greater detail below and throughout the report. Many Roma are highly susceptible to certain ailments on account of poor living conditions and poverty. These factors both cause and further exacerbate illness by impeding access to preventive care, proper nutrition, hygienic materials and medications. For a combination of reasons, including discrimination, they may fall completely outside the ambit of public health programmes that could provide health education, testing and treatment. High rates of smoking, stress or mental ill-health, and chronic diseases like heart and asthmatic ailments are common problems for which help is not easily found. Romani women have on average higher fertility rates and bear children at a young age. They are less likely to have access to preventive, reproductive and sexual health information and care. As a result, Roma have lower life expectancies, higher infant mortality, a high rate of sickness, and low rates of vaccination. Discrimination in access to health care makes remedying these widespread problems very difficult, either on a community or national scale.

The lower life expectancy of both male and female Roma, compared to the general population has been widely noted in both Western and Eastern Europe. In Slovakia, for instance, the life expectancy of Roma women is 17 years less than for the majority population; for men, it is 13 years less.[10] For Irish Travellers, life expectancy is between 10-12 years less than for the settled population.[11] Infant mortality rate (IMR) for Roma has also been found to be notably higher than national averages throughout Europe. In 1991 the IMR for Roma in the then Czechoslovakia was over twice the national average; in Bulgaria (1989) it was six times greater; in Italy (1991) almost three times the rate of the wider population; in Eastern Slovakia, where there is a high concentration of Roma, the rate is 3 times higher than for the population at large;[12] in Hungary and Ireland, it is double the national average.[13]

To varying degrees, communities of the most poor and marginalized Roma across Europe lack proper sanitation, including garbage collection, running water and electricity. For example, in many of the Romani settlements of Eastern Slovakia where an estimated 120,000 Roma live,

> there is no running water and no electricity. Some have no roads linking them with the outside world. When roads exist, they are often so scarred by potholes and clogged by mud that no bus or ambulance can use them. Rat infested garbage dumps are frequently located [nearby]. The water in the wells is often contaminated, because the settlements

[9] *See* Open Society Institute, "Minority Protection in the EU Accession Process", CEU University Press, Budapest, Hungary, 2001, at p. 37. In Moldova, 18.6% of Roma are estimated to have a "very serious disease" such as tuberculosis or poliomyelitis. "Situation of Roma in the Republic of Moldova (public opinion poll), Chisinau, 2001, Project CORDAID, p. 28. (On file with author.)
[10] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 448.
[11] Rachel Morris, "The Invisibility of Gypsies and Other Travellers", Traveller Law Research Unit, Cardiff Law School, 1999, p, 2.
[12] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 448.
[13] Id., 42; "Disability, Social Care, Health and Traveller People", Traveller Law Research Unit, Cardiff Law School, Wales, 2001, p. 59.

> lack adequate sewage systems. Tuberculosis breeds in overcrowded houses that have no heat in the wintertime. The deplorable conditions of rural ghettos are only matched by urban ones...[14]

These factors encourage the breeding of bacteria and infection while reducing opportunities to access and maintain adequate hygiene and curative conditions. It is no surprise that there exist higher rates of contagious diseases such as tuberculosis, hepatitis, scabies, pediculosis, and other skin problems throughout Roma settlements.[15] Overcrowded conditions make eradication of these problems an extremely difficult task. The lack of, or poor quality of, water promotes the spread of contagious disease while heightening the occurrence of conditions such as urinary tract infections and intestinal ailments. Adult and children's health and safety may be compromised by a range of factors, e.g. "dirt, fast traffic, rats, lack of safe play areas, difficulty drying clothes, overcrowding, mud, dogs, broken glass, a site getting 'used up' with toilet holes, lack of education, noises from factories, and smells from nearby sewage works."[16]

Conditions may be particularly acute for Roma and Travellers living in rural areas or on poorly maintained caravan sites or camps (whether legal or illegal). A survey of a sample of Traveller women living on Council sites or roadside in the area of Bristol, England, found that 39% had no access to fresh water on their site; 41.5% did not have access to a toilet; and 43.9% lacked refuse collection.[17] In some rural areas of Romania, sources of hygiene problems include poorly organized latrines which undergo no disinfectant maintenance; animal manure; generally poor water quality which carries Hepatitis A and perhaps B to certain regions; as well as uncollected, non-treated, and non-recycled garbage.[18] Living conditions for Roma who have migrated and may be living without legal status in Western Europe generally lack any sanitary equipment, refuse collection is exceptional, and accommodations constructed of found objects such as boards, plastic sheets or tiles, are particularly susceptible to rapid deterioration.[19] Among this group, 54% of women and 40% of men have been found to have a health problem.[20] In Aspropyrgos, outside of Athens, Greece, Roma dwellings exist "in the midst of a garbage dump."[21] The European Commission against Racism and Intolerance has noted the living conditions in camps in Italy inhabited by Roma/Gypsy families with concern:

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[14] Ina Zoon, "On the Margins: Roma and Public Services in Slovakia", Open Society Institute, New York, New York, 2001, pp. 78-79.

[15] 31.98% of Roma women living in settlements in Belgrade were found to be infected by pediculosis, 10.66% by scabies. "Report on Medical Issues", Autonomous Women's Centre, Belgrade, Serbia. (On file with author.)

[16] Compilation from interview with Traveller mothers of under five-year-old children by Pahl in 1998, as cited in "Disability, Social Care, Health and Traveller People", *supra*, note 13, p. 61. *See also* "The Invisibility of Gypsies and Other Travellers", *supra,* note 11, and "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", The Rroma Centre for Social Intervention and Studies (Rromani CRISS) and UNICEF Romania, April-May 1998.

[17] "Women's Health Report", Travellers' Health Project and United Bristol Health Care NHS Trust, 1998, Questionnaire Results.

[18] "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, section IV: hygiene.

[19] "ROMEUROPE Project Final Report, 1999-2000", Médecins du Monde, Paris, France, March, 2001, pp 15-16.

[20] Id., p. 25.

[21] Theodoros Alexandridis, "Not enough action: government policy on Roma in Greece", Roma Rights No. 2/3, 2001, European Roma Rights Center, Budapest, Hungary, p. 74.

> [conditions] "are extremely harsh, due to the lack of basic infrastructure and facilities, including access to energy, heating and lighting, sanitation as well as washing facilities and refuse disposal, site drainage and emergency services. Although the situation is particularly worrying for unauthorised camps, the living conditions in many authorised camps are not significantly better."[22]

For poor Roma, there is generally little knowledge about proper nutrition, and a lack of means to secure it. In particular, many Romani women are not aware of the need to modify their lifestyle and diet during pregnancy.[23] Fifty one percent of women aged 16-50 in settlements near Belgrade were found to be undernourished; their diet was found to consist of potatoes, rice and pastry: meat, milk, fruits and vegetables are rarely consumed.[24] Roma children in Romania have been found to suffer vitamin deficiencies, malnutrition and anaemia to a greater degree than non-Roma.[25] Parents' lack of money for the daily meal at school has been noted as a significant factor in absenteeism among Roma youths in Romania.[26]

Low rates of vaccination among Roma are evident across Europe as well. This means that Roma continue to be afflicted by diseases that could be prevented through vaccination, and that morbidity rates for such diseases among Roma children may be particularly high. In Slovakia, poliomyelitis and meningitis threaten to break out in Romani communities because of a lack of systematic vaccination programmes.[27] Roma children in Bulgaria are disproportionately affected by polio and diphtheria.[28] Among Traveller children, 43% were found not to have received pre-school vaccinations, compared to 97.3% of Scottish children.[29]

High rates of smoking have been reported among Roma of all ages. A WHO study of Roma teenagers in Hungary found that 69% of women and 71% of men were smokers; 71% of all the youths surveyed said they smoked daily.[30] Sixty eight percent of men and 54 percent of women among forced migrant communities in Western Europe were found to have use tobacco, many since the age of 14.[31] Almost all women in Roma settlements around Belgrade smoke tobacco; many begin at the age of 11 or 12, sometimes earlier.[32]

Some studies have addressed mental health issues among Roma; stresses associated with precarious living conditions and discrimination might be considered significant risk factors.

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[22] European Commission Against Racism and Intolerance (ECRI): Second report on Italy, CRI (2002) 4, Adopted on 22 June 2001, para. 61.
[23] *See, e.g.,* "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, section 5b.
[24] "Report on Medical Issues", *supra,* note 15.
[25] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 398.
[26] Advisory Committee on the Framework Convention for the Protection of National Minorities (FCAC) Opinion on Romania, adopted 6 April 2001, para. 57.
[27] Minority Protection in the EU Accession Process, *supra,* note 10, p. 450.
[28] Id., p. 91.
[29] Bancroft (1996) as cited in "Disability, Social Care, Health and Traveller People", *supra,* note 13, p. 60.
[30] "Training for gypsy peer educators", Summary of Final Report prepared by Tibor Szilagyi, Rapanuli, Ltd. A WHO Regional Office for Europe project, 1998-99, p. 7.
[31] "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 24.
[32] "Report on Medical Issues", Autonomous Women's Centre, *supra,* note 15.

Indeed, 12% of migrant Romani men and 21% of women studied by Médecins du Monde were found to suffer depression;[33] the rate among women in Belgrade settlements was found to be 11.39%. Also common among these women – many of who suffer war trauma in addition to precarious living conditions – are strong and frequent states of mood disorders, anxiety and somatizations such as headache, back pain, and breathing problems. Higher rates of depression have been noted among Travellers living in poorly located or maintained caravan sites than among settled populations.[34]

Physical barriers to health care are common in both urban and rural settings. One study has revealed that most inhabitants of the Fakulteta Roma neighbourhood in Sofia, Bulgaria, have never been under the supervision of public health authorities; medical facilities in this neighbourhood have closed down entirely.[35] In Balta Arsa, a rural area near Botosani town, Romania, women have not been able to access gynaecological care and family planning due to a lack of doctors and nurses; women generally cannot afford transportation to seek these services in a nearby town.[36] Such problems exist in Western Europe as well. Traveller women near Bristol, England, have maintained access to family planning that had been restricted under health reforms only through the negotiations of health providers associated with a mobile clinic.[37] Sixty five percent of migrant Roma living in irregular circumstances surveyed by Médecins du Monde have never had recourse to contraception.[38]

The high infant mortality, birth and abortion rates among Romani women have been attributed in large part to a lack of access to family planning and natal care.[39] In Central and Eastern Europe the ratio of children ages 0-4 to women ages 15-49 among Roma is 120% that of the total associated population.[40] Of 272 women ages 16-50 in settlements in Belgrade, 27.77% had 6-10 children and 6.7/% over 10 children.[41] Almost half of these women had had induced abortions: 83.5% of the women had had up to 5 abortions; 9.1% had had between 6 and 10 abortions, and 7.4% had had over 10 abortions.[42] Traveller women in some parts of England tend to have at least 4 children, with an average number of 6.5 pregnancies.[43] Almost half of the women interviewed for a report by the Travellers' Health Project reported problems with family planning.[44]

Initiatives to address substance abuse among Roma in a culturally sensitive manner are increasing, and will be discussed below. There appears to be little public attention to domestic

[33] "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 2.
[34] "The Invisibility of Gypsies and Other Travellers", *supra,* note 11, p. 2.
[35] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 91.
[36] "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, section 5, Balta Arsa.
[37] "Women's Health Report", Travellers' Health Project, *supra,* note 17, Background.
[38] "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 45.
[39] "Children of Minorities: Gypsies", UNICEF, Innocenti Insight 1, 1993, p. 41.
[40] The Demographic Characteristics of National Minorities in Certain European States, Volume 2. Population studies no. 31, Council of Europe, January 2000, p. 187.
[41] . "Report on Medical Issues", Autonomous Women's Centre, *supra,* note 15.
[42] Id.
[43] "Women's Health Report", Travellers' Health Project, *supra,* note 17, Background.
[44] Id., Questionnaire results.

violence, though Romani women are increasingly willing to speak out on this issue.[45] Few studies appear to exist concerning sexually transmitted diseases and HIV/AIDS.[46] But greater emphasis on this issue is likely with the observations such as the fact that 96 of the 300 Roma children in the town of Marasesti, Romania, are thought to be HIV positive.[47] Existing data and initiatives in these areas should be publicized to add momentum for further research and action.

While this report focuses on access to health care over health status, it is important to understand the many factors that must be addressed to ensure a healthy, educated, and integrated Romani population. Thus the report makes suggestions for concrete, practical interventions that can help to improve the current situation, as well as make proposals for further research.

[45] *See* "Roundtable: Romani activists on women's rights", Notebook, Roma Rights, No.1, 2000, European Roma Rights Centre, Budapest, Hungary.
[46] *See, e.g.,* "HIV/AIDS Situation and Response Analysis, Romania, 1999", HIV Analysis and Evaluation Commission (AEC), Romania; Simone Ridez, Yves Léglise "HIV and Drug prevention among Roma", ("Prévention VIH-Toxicomanie en milieu gitan",) Études Tsiganes: Tsiganes et santé: de nouveaux risques?, Vol. 14, second semester 2000, Paris, France, at 71.
[47] "Minority Protection in the EU Accession Process", *supra,* note 10, at 398.

B. Legal standards

1. Principles of non-discrimination and equality

Numerous legal instruments widely ratified by European Union, Council of Europe and OSCE participating States guarantee the right of access to public services such as health care free from racial or ethnic discrimination. Under these instruments, States have a positive obligation to ensure equal access to all: this might require undertaking special measures in order that certain groups achieve full equality in terms of rights and opportunities.

The principles of non-discrimination and equal protection irrespective of race, ethnicity, social or other status are enshrined in several international conventions, most notably the International Covenant on Economic and Social Rights (ICESCR), the International Covenant on Civil and Political Rights (ICCPR) and the Convention on the Elimination of All Forms of Racial Discrimination (CERD).

The ICESCR and the ICCPR guarantee respect for the rights enunciated therein without, respectively, discrimination and distinction as to, *inter alia*, race.[48] The ICESCR specifically recognizes a right to health, and will be discussed below in section 3. Additionally, these Covenants articulate other rights and freedoms that relate directly or indirectly to access to health care. These include the rights to food, housing, education, access to information, a child's right to birth registration and nationality, the right to take part in the conduct of public affairs, freedom from cruel, inhuman or degrading treatment, freedom to choose one's residence, and others.[49] The relationship of some of these rights to access to health care will be discussed below. Moreover, article 26 of the ICCPR prohibits discrimination on any ground with regard to policy or law.

Under CERD, States Parties are obliged to pursue, by all appropriate means and without delay, a policy of eliminating racial discrimination in all its forms and promoting understanding among all "races".[50] Specifically, States Parties must guarantee the right of everyone, without

[48] Under Article 2(1) of the ICCPR, "Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

Article 2(2) of the ICESCR declares: "The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

[49] *See* ICCPR Arts. 7, 12, 17, 24 (2)(3), 25(a). *See also* CESCR General Comment 14, *supra,* note 3, para. 3.

[50] ICERD Article 2(1). To this end:

> (a) Each State Party undertakes to engage in no act or practice of racial discrimination against persons, groups of persons or institutions and to ensure that all public authorities and public institutions, national and local, shall act in conformity with this obligation;

distinction as to race or ethnicity, to equality before the law in the enjoyment of economic, social and cultural rights. This obligation applies expressly to the right to public health, medical care, social security and social services.[51]

Recent developments in the pan-European context strengthen the opportunities to combat discrimination against Roma in access to health care and related fields. These include the Council of Europe's Framework Convention for the Protection of National Minorities (Framework Convention), and Protocol No. 12 to the European Convention for the Protection of Human Rights and Fundamental Freedoms (discussed below).

Within the Council of Europe framework, Protocol No. 12 to the European Convention on Human Rights and Fundamental Freedoms (ECHR) on entry into force will provide improved protection against discrimination for Roma and other vulnerable groups. Before adoption of the Protocol, Article 14 of the ECHR prohibited discrimination only with regard to the enjoyment of the rights and freedoms set forth in the Convention. The Protocol strengthens the ECHR's guarantees with regard to equality and non-discrimination by providing an independent prohibition of discrimination on a non-exhaustive list of grounds. Article 1 provides:

1 The enjoyment of any right set forth by law shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

2 No one shall be discriminated against by any public authority on any ground such as those mentioned in paragraph 1.

This additional scope of protection is intended to address cases where a person is discriminated against:

> i. in the enjoyment of any right specifically granted to an individual under national law;
>
> ii. in the enjoyment of a right which may be inferred from a clear obligation of a public authority under national law, that is, where a public authority is under an obligation under national law to behave in a particular manner;
>
> iii. by a public authority in the exercise of discretionary power (for example, granting certain subsidies)...[52]

> (c) Each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists;
>
> (d) Each State Party shall prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization.

[51] Id., Article 5(e)(iv).
[52] Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms, Explanatory Report, paras. 21-22.

Throughout Europe, access to health care and related public services is often guaranteed in national constitutions or other national legislation, is provided primarily by the State or by private persons providing an essentially public service and may involve or depend on the discretion of public authorities. In effect, Protocol No. 12 opens these dimensions of access to health care to scrutiny[53] and allows for the European Court of Human Rights to monitor compliance with Article 1 when a case is deemed to fall within its jurisdiction.

Ratification by 10 States is required for Protocol No. 12 to enter into force; States can demonstrate their commitment to ensuring access to public services for Roma on a non-discriminatory basis by their signature and ratification.

The European Union (EU) has also acted to reinforce fundamental rights. The Treaty of Amsterdam[54] amended Article 6 of the EU Treaty, making it explicit that the European Union is founded on the principles of liberty, democracy, human rights, fundamental freedoms and the rule of law. In Article 7, it laid down a political mechanism for preventing violations of the principles mentioned in Article 6 by the Member States. This mechanism is reinforced under Article 7 of the Treaty of Nice[55] which gives a greater role to the European Parliament. These standards are applicable to candidate countries for EU membership. In addition, the Copenhagen criteria require these States to achieve stability of institutions guaranteeing democracy, the rule of law, human rights and respect for and protection of minorities.[56]

The European Union proclaimed the Charter of Fundamental Rights on 7 December 2000[57]. The Charter aims to strengthen the protection of fundamental rights and make those rights more visible to the people residing within the EU. In respect of universalism, the rights set forth in the Charter (except those linked to citizenship of the EU) are generally granted to all persons irrespective of their nationality or residence. Article 1 guarantees the respect and protection of human dignity, article 20 recognizes that everyone is equal before the law, article 21 prohibits discrimination based on any ground including colour, ethnic or social origin, language and religion or belief and article 22 provides for respect of cultural, religious and linguistic diversity.

In addition, as a result of the introduction of a non-discrimination clause (article 13) in the European Community Treaty, in 2000 the Council of the European Union adopted a Council Directive to combat discrimination on the grounds of racial or ethnic origin (Racial Equality Directive) [58]. By the end of 2003, all Member States of the European Union should have

[53] On the extent of positive obligations of the State under Protocol No. 12 *vis a vis* relations between private persons, the Explanatory Report states that these "would concern, at the most, relations in the public sphere normally regulated by law, for which the state has a certain responsibility (for example…to services which private persons may make available to the public such as medical care or utilities such as water and electricity)." Id., para. 28.
[54] Treaty on European Union as amended by the Treaty of Amsterdam, Article 6. Signed on 2 October 1997. Available at: http://europa.eu.int/eur-lex/en/treaties/dat/eu_cons_treaty_en.pdf.
[55] The Treaty of Nice, signed on 26 February 2001, entered into force on 1 February 2003.
[56] Copenhagen European Council, 21-22 June 1993. Section 7.A.(iii): Presidency Conclusions: Relations with the Countries of Central and Eastern Europe: The Associated Countries.
[57] European Union Charter of Fundamental Rights, Official Journal (2000/C 364/01). Signed at Nice, 7 December 2000.
[58] *Supra*, note 2.

incorporated the Racial Equality Directive into national legislation, thereby re-enforcing the fight against racial discrimination at the national and European level. The Racial Equality Directive covers a broad range of fields including employment, education, social protection, including social security and healthcare, and access to and supply of goods and services which are available to the public, including housing.

The Directive includes the express prohibition of both direct and indirect discrimination.[59] Direct discrimination is defined 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." Indirect discrimination occurs "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."[60]

As examples throughout this report suggest, direct and indirect discrimination may be central to the experience of many Roma in accessing health care and other public services. Of additional significance for Roma is the fact that harassment related to racial or ethnic origin falls under the type of discrimination prohibited by the Racial Equality Directive. Defined as "unwanted conduct related to racial or ethnic origin [that] 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,"[61] such behaviour sometimes characterizes the interaction of Roma with public services. Thus, the Racial Equality Directive has the potential to protect Roma and other groups against a broader range of treatment than was previously encompassed under the concept of discrimination.

Additional provisions important to ensuring equal access to health care include Article 8, which requires the respondent in civil cases to prove that there has been no breach of the principle of equal treatment. This shift in the burden of proof should have particular resonance in the health care context. Evidence of discrimination might be found in medical records or internal rules that are not easily accessible to complainants. The unequal power dynamic traditionally ascribed to the doctor-patient relationship and patient dependency on health care as an essential service may dissuade individuals from bringing complaints. Article 8 can help to overcome these barriers to rectifying cases of discrimination.

In addition to guaranteeing access to remedies through judicial, administrative, or conciliation procedures,[62] the Racial Equality Directive requires that domestic law impose effective, proportionate, and dissuasive sanctions.[63] The Directive also calls for the establishment of a specialized body to promote the equal treatment of all persons without discrimination on the grounds of racial or ethnic origin.[64] Its competencies should include the capacity to provide independent assistance in pursuing victims' complaints, conduct independent surveys, and

[59] Id., Article 2(2).
[60] Id.
[61] Id., Article 2(3).
[62] Id., Article 7(1)(2).
[63] Id., Article 15.
[64] Id., Article 13(1).

publish reports and recommendations concerning discrimination.[65] This requirement provides an historic opportunity to ensure that State commitments to equality and non-discrimination are realized for Roma in access to a range of public services and at all levels.[66]

Significant precursors to these legally binding European instruments are found, *inter alia,* in the political commitments of OSCE participating States concerning the protection of national minorities and the eradication of discrimination against Roma and Sinti.

In the Copenhagen Document, CSCE participating States recognized that "persons belonging to national minorities have the right to exercise fully and effectively their human rights and fundamental freedoms without any discrimination and in full equality before the law."[67] Condemning "racial and ethnic hatred…xenophobia and discrimination against anyone," participating States specifically recognized the particular problems of Roma.[68] The Copenhagen Document also reaffirmed the States' conviction that "the promotion of economic, social and cultural rights…is of paramount importance for human dignity and for the attainment of the legitimate aspirations of the individual."[69]

At the 1992 Helsinki Summit meeting, OSCE participating States emphasized the importance of enforcing domestic laws to protect against racial and ethnic discrimination[70] and reaffirmed "the need to develop appropriate programmes addressing problems of their respective nationals belonging to Roma."[71] More recently, in the 1999 Istanbul Summit Declaration, OSCE participating States committed themselves to ensure that laws and policies fully respect the rights of Roma and Sinti.[72] In the Charter for European Security, they further recognized "the need to undertake effective measures in order to achieve full equality of opportunity" for persons belonging to Roma and Sinti.[73]

[65] Id., Article 13(2).

[66] States may introduce or maintain provisions which are more favourable to the protection of the principle of equal treatment than those laid down in the Racial Equality Directive. At the same time, implementation of the Racial Equality Directive shall not constitute grounds for a reduction in the level of protection against discrimination already afforded by Member States. *See* Id., Article 6 – Minimum Requirements.

[67] Document of the Copenhagen Meeting of the Conference on the Human Dimension of the CSCE, 1990, para. 31.

[68] Id., para. 40.

[69] Id., para. 23. States thus reaffirmed the commitment taken in the Document of the Bonn Conference on Economic Co-operation in Europe to pay special attention to problems in the areas of health, as well as housing, social security, education, culture and employment. *See* CSCE Conference on Economic Co-operation, Bonn, 19 March - 11 April 1990.

[70] CSCE Helsinki Document, 1992 para. 33.

[71] Id., para. 35.

[72] Istanbul Summit Declaration, 1999, para. 31.

[73] OSCE Charter for European Security, Istanbul, November 1999, para. 20.

2. Special measures

A human rights approach intends to guarantee formal and substantive equality. It requires States not only to protect against discrimination, but also to take positive action in order to ensure the equal enjoyment of rights.

In some instances, guarantees of the enjoyment of rights and freedoms on equal footing may call for differential treatment. Indeed, the principle of equality sometimes requires States to take positive action in order to ensure equal opportunities to groups who have been historically and systematically disadvantaged and where the resulting conditions impede their enjoyment of human rights. In such cases, special measures may be required to diminish or eliminate conditions that cause or help to perpetuate discrimination and so redress the imbalance.

Numerous international commitments provide support for positive action in the interest of bringing disadvantaged groups such as Roma to a level of enjoyment of rights on a par with the rest of the population.

States Parties to CERD are required to take special measures "to ensure the adequate development and protection of certain racial groups or individuals belonging to them when the circumstances so warrant…for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms."[74] The Racial Equality Directive provides that "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.[75] And the Framework Convention makes clear that measures adopted to promote full and effective equality between persons belonging to a national minority and those belonging to the majority, and which "take due account of the specific conditions of the persons belonging to national minorities", shall not be considered an act of discrimination.[76]

The Framework Convention makes legally binding many of the commitments made by OSCE States concerning minorities. Indeed, the Framework Convention is the first of its kind devoted specifically to the protection of minority rights. States Parties "undertake to guarantee to persons belonging to national minorities the right of equality before the law and of equal protection of the law," and to "take appropriate measures to protect persons who may be subject to threats or acts of discrimination, hostility or violence as a result of their ethnic, cultural, linguistic, or religious identity."[77] They furthermore undertake to "adopt, where necessary, adequate measures in order to promote, in all areas of economic, social, political and cultural life, full and effective equality between persons belonging to a national minority and those belonging to the majority. In this respect, they shall take due account of the specific conditions of the persons belonging to national minorities."[78] Among the principles enshrined therein are those that may be implicated in access

[74] ICERD Article 2.
[75] Racial Equality Directive, Article 5.
[76] Framework Convention, Article 4(2)(3).
[77] Framework Convention for the Protection of National Minorities, Strasbourg, 1/2/1195, Council of Europe Doc. ETS 157. Article 4(1), 6(2).
[78] Id., Article 4(2).

to public services such as health care: non-discrimination, promotion of effective equality, education, and participation in public life. States Parties are committed to implementing these and other principles through national legislation and government policies.[79] Those States which have not yet signed or ratified the Framework Convention are encouraged to do so with the aim of extending the protections therein to Roma in access to health care and other public services.[80]

In the particular context of equality for Roma, OSCE participating States have affirmed their readiness "to undertake effective measures in order to achieve full equality of opportunity between persons belonging to Roma ordinarily resident in their State and the rest of the resident population."[81]

Specifically in relation to health, States have a duty to facilitate the enjoyment of the "highest attainable standard of physical and mental health" on an equitable basis, as is discussed below. The State also has a role to play when obstacles to accessing public health care derive from the Roma community itself, such as through unequal gender relations. This obligation is based in the State's responsibility to ensure equal access for all groups within society, regardless of their ethnic or cultural background and specific associated barriers such as language. Under the ICCPR, States Parties are obliged to ensure that "traditional, historical, religious or cultural attitudes are not used to justify violations of women's right to equality before the law and to equal enjoyment of all Covenant rights."[82]

In situations where States pursue special measures – including preferential treatment – with the aim of guaranteeing full equality of opportunity for Romani women, attention should be given to raising the awareness of the wider population to the fact that such measures serve not to place Romani women in an advantageous position. Rather, they are intended to bring Romani women to a level of equal enjoyment of rights with majority society. Acknowledgment of the extent to which discrimination is a cause of existing inequalities should be clear.

Under article 5 of the Racial Equality Directive, EU Member States can also act in the field of positive action "with a view to ensuring full equality in practice …[by] maintaining or adopting specific measures to prevent or compensate for disadvantages linked to racial or ethnic origin".

[79] Id., Preamble.
[80] The Convention is open to signature and ratification by non-Council of Europe Member States.
[81] Report of the Geneva Meeting, as cited in the "Report on the Situation of Roma and Sinti in the OSCE Area", *supra*, note 4, p. 28.
[82] Human Rights Committee, General Comment 28, Equality of rights between men and women (article 3), U.N. Doc. CCPR/C/21/Rev.1/Add.10 (2000), para. 3.

3. The right to the highest attainable standard of health

The human right to health is recognized in numerous international instruments, including the Universal Declaration of Human Rights,[83] ICESCR,[84] the ICERD,[85] Convention on the Elimination of All forms of Discrimination against Women[86] (CEDAW), and the Convention on the Rights of the Child[87] (CRC). It is also enshrined in Article 11 of the Revised European Social Charter.[88] Many constitutions codify a right to health or at least a State commitment regarding people's health.[89]

The ICESCR provides the most comprehensive article on the right to health in international human rights law[90] in its recognition of "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[91] As the Committee responsible for monitoring compliance with the ICESCR explains,[92] the right to health is not a right to be *healthy*.[93] Rather, the right to health comprises legally enforceable freedoms and entitlements, most notably a right to "a system of health protection which provides equality of opportunity for

[83] Article 25(1) of the Universal Declaration of Human Rights declares: "Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services."
[84] In Article 12(1) of the International Covenant on Economic, Social and Cultural Rights, States parties recognize "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."
[85] Article 5(e)(iv) of ICERD provides: "States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of…The right to public health, medical care, social security and social services."
[86] Article 12(1) of CEDAW declares: "States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning."
[87] Article 24(1) of the CRC proclaims: "States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services."
[88] Article 11 of the Revised European Social Charter states:

> With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organizations, to take appropriate measures designed *inter alia*:
> 1 to remove as far as possible the causes of ill-health;
> 2 to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
> 3 to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

[89] Brigit C.A. Toebes, "The Right to Health as a Human Right in International Law", Intersentia, Antwerp, 1999, p. 79.
[90] UN Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14, *supra,* note 3, para. 2.
[91] ICESCR Article 12(1).
[92] The Committee on Economic and Social Rights monitors implementation of the ICESCR by States parties. The Committee also assists Governments in fulfilling their obligations under the Covenant by issuing specific recommendations such that economic, social and cultural rights are more effectively secured. Among these recommendations are General Comments, considered to be authoritative interpretations of Articles of the Covenant.
[93] CESCR General Comment 14, *supra,* note 3, para. 8.

people to enjoy the highest attainable level of health."[94] Thus the notion of a "highest attainable standard" takes into account both the individual's biological and socio-economic preconditions, and a State's available resources."[95]

As with other economic and social rights, the right to health is a fundamental right unto itself, indispensable for the exercise of other human rights, and related to, if not dependent upon, the realization of rights such as the rights to human dignity, life, non-discrimination, equality, privacy, access to information, and freedom of movement. Thus the individual factors and State resources encompassed by the right to health include not only those related to "timely and appropriate health care," but also to "underlying determinants of health," such as:

> access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.[96]

As General Comment 14 explains, States are under an immediate obligation to guarantee that the right to health will be exercised without discrimination of any kind.[97] It also outlines general legal obligations of States Parties to respect, protect, and fulfil the right to health.[98]

In relation to Romani women, the obligation to respect the right to health might by achieved, *inter alia*, by ensuring that policies do not discriminate against Romani women's health status and needs. Protecting the right to health might involve monitoring for discriminatory treatment of Romani women by health providers. Offering education programmes to address issues such as gender-based violence or community norms that deny Romani women full reproductive rights are other ways to protect this right.[99] In turn, the obligation to fulfil the right to health might require that States parties give sufficient recognition to the health needs of Romani women in strategies to improve the situation of Roma as well as to integrate them into national health plans. Such measures might be taken in the context of integrating a gender perspective into State health policy and programmes, i.e. in giving adequate consideration the biological and socio-cultural factors that influence women's and men's health.[100] Development of strategies to address women's health across the life span[101] and which reflect the needs of women from various minority or ethnic groups are additional and essential components of fulfilling the right to health.

The General Comment also sets out core obligations for States to ensure the satisfaction of minimum essential levels of the right to health. These include the following:

> (a) ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;

[94] Id., para. 8.
[95] Id., para. 9.
[96] Id., para. 11.
[97] Id., para. 30.
[98] Id., paras. 34-37.
[99] Id., para. 35
[100] Id., para. 20.
[101] Id., para. 21.

> [...]
> (c) ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;
> [...]
> (e) ensure equitable distribution of all health facilities, goods and services; and
>
> (f) adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence…the process …and content [of which] shall give particular attention to all vulnerable or marginalized groups.[102]

More broadly, and regardless of "the conditions prevailing in a particular State party," States should aim to provide health facilities, goods, and services with consideration of the following four elements: availability, accessibility, acceptability and quality.[103]

This report is limited to a focus on *accessibility*, though discussion of its dimensions will inevitably overlap with the other three issues. For instance, problems in availability of health facilities, goods and services for Romani women may result from intentional allocation of resources away from Romani communities or from oversight of Roma needs in planning public health campaigns. Health care workers or institutions may provide inferior quality care to Roma on the basis of ethnicity, or inferior care may be one consequence of the lack of access to health facilities for isolated Romani communities. For Romani women who adhere to various purity traditions, incorporating culturally acceptable care may be critical to ensuring that they have opportunities to access services on an equal basis to non-Romani women.

The dimensions of *accessibility* identified in the General Comment are non-discrimination, physical accessibility, economic accessibility, and information accessibility:

> *Non-discrimination*: health facilities, goods, and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.
>
> *Physical accessibility*: health facilities, goods, and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups such as ethnic minorities…women, children, adolescents… Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas.
>
> *Economic accessibility*: health facilities, goods, and services must be affordable for all…including socially disadvantaged groups...
>
> *Information accessibility*: the right to seek, receive and impart information and ideas concerning health issues, and to have personal health data treated with confidentiality.

Access to information as well as physical and economic access to care on a non-discriminatory

[102] Id., para. 43.
[103] Id., para. 12.

basis provides a useful framework with which to approach an examination of the experiences of Romani women relating to health care. (Future research focusing specifically on availability, quality and acceptability may be useful based on the findings of this and other reports.) Alongside the protections against racial and ethnic discrimination outlined above, State legal obligations and guidelines for the full realization of women's right to health provide the key standards against which protections against discrimination of Romani women should be measured. Above all, they form the basis upon which access to health care for Romani women and those in their care can be improved.

4. Participation of Romani women in improving access to health care

"Perhaps no principle is more essential to the success and legitimacy of initiatives to alleviate the concerns of Romani communities than that Roma themselves should be centrally involved in developing, implementing and evaluating policies and programmes. The basic democratic principle that individuals should have a say in how they are governed requires nothing less, and pragmatic considerations counsel the same approach."[104]

Romani women are beneficiaries of health care services, and are often the main interlocutors between their communities and these services. Thus an awareness of their culture and needs is important for effective policymaking in these areas. It is also a precondition to earning the confidence and commitment of Roma, while helping to ensure that programmes do not "create or perpetuate a classic syndrome of dependency and passivity"[105] through paternalistic or social care approaches.[106] More broadly, Romani women's participation in policy-making is integral to the full realization of their individual rights, the development of their communities, and the larger society.[107]

European Union, Council of Europe and OSCE participating States have recognized the importance of including Roma in decisions concerning initiatives on their behalf. More recently, special attention has been given to the participation of Romani women. For example, a recent project undertaken by ODIHR and funded by the European Commission[108] includes the empowerment of Roma women as one of its activities. Indeed, the inclusion of Romani women in policies to improve access to health care and other public services can be understood to form part of State obligations under international law, as follows.

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[104] "Report on the Situation of Roma and Sinti in the OSCE Area" *supra*, note 4, pp. 5-6.
[105] Id., p. 6.
[106] *See* Dimitrina Petrova, "The denial of racism." Roma Rights No. 4, 2000, European Roma Rights Centre, Budapest, Hungary, p. 32.
[107] *See* CEDAW Committee, General Recommendation No. 23 on Political and Public Life, adopted at the Sixteenth session, 1997, paras. 2, 13 and 14.
[108] "Mainstreaming, empowering and networking Roma as full participants in post crisis management, good governance and development of sustainable civil society in south-eastern Europe", Roma under the Stability Pact for South Eastern Europe, ODIHR Project February 2001-February 2003.

Under ICCPR Article 3, States Parties undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights enshrined therein.[109] This extends to the right to take part in the conduct of public affairs, directly or through freely chosen representatives.[110] The Human Rights Committee has indicated that enabling steps include adoption of protection measures as well as positive measures in order to achieve the effective and equal empowerment of women.[111] Moreover, States Parties are obliged to ensure that "traditional, historical, religious, or cultural attitudes are not used to justify violations of women's equality before the law and to equal enjoyment of all Covenant rights."[112] In this regard, the Committee requests that States furnish information on those aspects of tradition, history, cultural practices and religious attitudes which jeopardize, or may jeopardize, compliance with Article 3, as well as indicate what measures they have taken or will take to overcome such factors.[113]

States Parties to CEDAW commit to ensuring women's participation in the political and public life of a country on equal terms with men: specifically, the right to participate in the formulation and implementation of government policy.[114] In order to give full effect to these rights, States Parties are encouraged to consider a range of measures, including those:

- to ensure the equal representation of women in senior decision-making roles and as members of government advisory bodies, implementing temporary special measures where necessary[115]

- to consult and incorporate the advice of groups which are broadly representative of women's views and interests[116]

- to overcome barriers such as traditional and customary attitudes that discourages women's full participation in public life.[117]

In the context of national minorities, OSCE participating States agreed in the Copenhagen Document to "respect the right of persons belonging to national minorities to effective participation in public affairs, including participation in the affairs relating to the protection and promotion of the identity of such minorities."[118] In turn, the Framework Convention legally binds States Parties to "create the conditions for the effective participation of national minorities in cultural, social, and economic life and in public affairs affecting them."[119]

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[109] ICCPR Article 3 provides: "The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights set forth in the present Covenant."
[110] Id., Article 25(a).
[111] Human Rights Committee, General Comment No. 28 *supra,* note 82, para. 3.
[112] Id., para. 5.
[113] Id.
[114] CEDAW, Article 7(b).
[115] Id., para. 26, 29, 43.
[116] Id., para. 26.
[117] Id., para. 27.
[118] Copenhagen Document, para. 35.
[119] Framework Convention, Article 15.

The specific relationship of political participation to creating conditions to assure health care to all is identified in The General Comment on the Right to the Highest Attainable Standard of Health. The normative content of the right to health is said to include "the improvement and furtherance of participation of the population in the provision of preventive and curative health services, such as the organization of the health sector, the insurance system and, in particular, participation in political decisions relating to the right to health taken at both the community and national levels.[120] Significantly, the General Comment points out that States are required to adopt a national strategy to ensure to all the enjoyment of the right to health[121] in a manner that respects the right of individuals and groups to participate in decision-making processes which may affect their development.[122]

These international commitments in the fields of women's and minority participation in policymaking are supported by recommendations focused uniquely on combating discrimination against Roma.

The OSCE HCNM has put forth extensive recommendations to ensure effective Roma participation in policymaking on their behalf.[123] Roma should be involved in the development, implementation and evaluation of programmes aimed at Romani communities through formal and informal consultations and with Roma participation at all levels of governance. These measures should be combined with training in policy-making skills and transparent procedures that permit input from a broad range of Romani interests.

Council of Europe States are called upon by the European Commission against Racism and Intolerance (ECRI) "to develop institutional arrangements to promote an active role and participation of Roma/Gypsy communities in the decision-making process, through national, regional and local consultative mechanisms, with priority placed on the idea of partnership on an equal footing."[124] In its reports on the situation of racism and intolerance in Council of Europe States, ECRI has drawn attention to the need for empowering the Roma/Gypsy community to play an active part in initiatives aimed at improving its position in society, such as through the representation of their communities throughout the structures of society.[125]

Both the CERD Committee and the Advisory Committee on the Framework Convention (FCAC) have made specific mention of the need to include Romani women in policy-making. The CERD Committee recommends that States parties "initiate and implement programmes and projects in the field of health for Roma, mainly women and children…and to involve Roma…communities and their representatives, mainly women," in their design and implementation.[126] Specific proposals include: employment of Roma in public administration;[127]

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[120] CESCR General Comment 14, *supra,* note 3, para. 17.
[121] Id., para. 53.
[122] Id., para. 54.
[123] "Report on the Situation of Roma and Sinti in the OSCE Area", *supra,* note 4, pp. 162-163.
[124] *See* ECRI general policy recommendation No. 3 on Combating racism and intolerance against Roma/Gypsies, adopted in Strasbourg, 6 March 1998.
[125] ECRI Second report on Italy, *supra,* note 22, para. 68; Second report on Slovakia, CRI (2000) 35, Adopted on 10 December 1999, para. 40; Second report on the Netherlands, CRI (2001) 40, Adopted on 15 December 2000, para. 39.
[126] CERD Committee General Recommendation 27 on Discrimination against Roma, Adopted at the Fifty seventh session, 2000, para. 34.

securing of equal opportunities for the participation of Roma minorities or groups in all central and local governmental bodies;[128] promoting awareness of the need among Roma for more active participation in public life, and providing training in this regard.[129] In a separate Recommendation, the CERD Committee has committed itself to monitor and evaluate the gender related dimensions of racial discrimination.[130] And the FCAC proposes that States Parties give particular attention to the situation of Romani women when intensifying efforts to ensure effective participation for Roma in public affairs and social and economic life.[131]

Interpreting together the legal standards and recommendations discussed above allows for the identification of a series of measures to improve participation of Romani women in policy-making:

- States should take all necessary steps to secure equal opportunities for the participation of Romani women in all stages of policy-making on matters concerning them and their communities.

- States should adopt special measures to identify and promote the participation of women representatives of Romani communities in governmental bodies, including through the employment of Romani women in public administration and services.

- States should undertake training to improve Romani women's political, policy-making and public administration skills, and to raise awareness among Romani women of the need for their more active participation in public and social life.

- Consultation mechanisms should be developed to include Romani women in policy-making at local, regional, national and international levels.

- Transparency in proposals, election of representatives, and decision-making procedures should be ensured at all levels.

Two organizations working to promote Romani women's participation in public life include The Network Women's Program of the Open Society Institute of the Soros Foundations Network, and the National Traveller Women's Forum in Ireland. The Network Women's Program is deeply engaged in building the advocacy and organizational capacities of Romani women's associations and individual activists across Central and Eastern Europe. Activities have included a conference to examine elements of Romani culture that may have adverse impacts on Roma

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[127] Id., para. 28
[128] Id., para. 41.
[129] Id., para. 44-45.
[130] *See* CERD Committee, General Recommendation 25 on Gender related dimensions of racial discrimination, adopted at the Fifty-sixth session, 2000, para. 3-6. *See also* paras. 28 and 41-45.
[131] *See* Proposal for Conclusions and Recommendations by the Committee of Ministers In respect of Article 15, in the FCAC Opinion on Slovakia, adopted 22 September 2000. *See also* FCAC Opinion on Romania, *supra,* note 26; FCAC Opinion on Italy, adopted 14 September 2001; and, in respect of Article 4, *see* FCAC Opinion on the Czech Republic, adopted 6 April 2001.

rights[132] and a conference to develop a strategy for the future of Romani women in civil society.[133] Key priorities identified were the mainstreaming of Romani women's issues into the Romani and women's rights movements, and onto the agendas of governments and international organizations.[134] The National Traveller Women's Forum in Galway, Ireland is an alliance of Traveller women and Traveller organizations that seek to promote women's public participation, challenge racism and sexism experienced by Traveller women, and realize the fulfilment of Traveller women's rights on a non-discriminatory basis.[135] It is hoped that States will support such initiatives as well as further the goal of increasing Romani women's political participation through their own efforts, taking into account the guidelines set out above. In this regard, models for participation in the development and delivery of health services developed in Ireland might be considered for replication elsewhere. These include the establishment of active partnerships between representative organizations and health service personnel and of "Traveller Health Units" comprising Health Board staff and Traveller representatives with responsibility for planning and implementing the Strategy in each Health Board.[136]

In particular, States may consider whether Roma health mediators provide a key avenue for enhancing women's participation in public affairs affecting them.[137] (Mediator programmes are discussed in greater detail below.) By virtue of their close links with Romani communities, mediators can help prevent and address the consequences of discrimination in access to public services. They have the potential to provide rights education and empowerment to community members to challenge cases of discrimination and identify and correct gaps in existing services – both on their own and in partnership with authorities. In these and other ways, mediator programmes can empower Romani women to improve access to public services for themselves and their communities.

[132] International Conference of Romani Women, Budapest, Hungary, June 1998.
[133] Public Policies and Romani Women in Central and East European Countries, 3-5 December 1999, Bucharest, Romania.
[134] *See* http://www.soros.org/osi.html.
[135] Interview, Dublin, Ireland, 5 December 2001.
[136] Comments prepared by the Government of Ireland (on file with the Council of Europe).
[137] *See* CERD Committee: General Recommendation 27, *supra,* note 126, para. 8: To develop and encourage appropriate modalities of communication and dialogue between Roma communities and central and local authorities.

C. The importance of ethnic data collection to improving access to health care

Equality before the law may not always be adequate to ensure the equal enjoyment of human rights – particularly economic, social and cultural rights – by certain minority groups in a country.[138] Special measures based on concrete evidence of needs may be required to achieve this goal. A commitment to improving the situation of Roma requires that policies be formulated on the basis of reliable data and information on Romani needs and interests. Specifically, policies focused on improving the situation of Romani women should be founded upon data disaggregated on the basis of both ethnicity and sex. Collection of data on the health status and needs of Romani women is indispensable to improving access to health care and other public services.

Data collection on the basis of ethnic identity serves several purposes that together promote genuine equality. It can reveal the needs and interests upon which social policies are developed and their progress evaluated. Information on the situation of a population – e.g. rural, urban, settled, migrant – can help to ensure good policy-making.[139] Knowing the particularities (number, concentration, specific needs, etc.) of a minority population can substantially affect policy and assist, for example, in setting targets for employment in government structures or locating public services. Statistical data is also an essential tool to support claims of indirect discrimination in judicial proceedings.[140] Data on the situation of Roma disaggregated on the basis of sex would provide valuable information on the complicated relationships among sex, gender dynamics in Romani communities, and majority perceptions of Roma that affect Romani women's experience in accessing public services. Such data may provide the evidence to sustain successful policy implementation over a longer term. In addition, the official collection and development of comparable data, combined with information and awareness-raising campaigns, can help explain the priorities of targeting policy at a particular disadvantaged group and help counter unfounded interpretations and the misuse of information collected unofficially and systematically which fail to present a comprehensive socio-economic picture of a particular group or situation.

There is growing support among international bodies for the collection of ethnic data. The World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance has invited States to design policies aimed at combating discrimination against Roma based on reliable statistical data collected in accordance with data protection regulations and privacy

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[138] *See, e.g.,* Concluding Observations of the Committee on Economic, Social and Cultural Rights: France. 30/11/2001. E/C.12/1/Add.72, para. 15.

[139] Since censuses would not include persons in situations such as refugees and migrants, then insofar as Roma comprise a significant proportion of such populations, surveys complementary to censuses might also be required in order to obtain a more accurate picture of the situation of Roma. "Roma and Statistics", Strasbourg, 22-23 May 2000, Council of Europe, MG-S-ROM (2000) 13, para. 49.

[140] *See, e.g.,* "The Importance of Race/Ethnic Statistics for Combating Discrimination" Statement by the European Roma Rights Centre on the Occasion of the OSCE Conference "Equal Opportunities for Roma and Sinti: Translating Words into Facts", 10-13 September, 2001, Bucharest. *See* also ECRI Second report on the Netherlands, *supra,* note 125, para. 10, in which ECRI "welcomes the fact that test-methods…and statistical data are also accepted as the proper means of substantiating a claim [of discrimination.].

guarantees, and in consultation with the persons concerned.[141] The UN Committee on the Elimination of All Forms of Racial Discrimination has committed itself to examining the links between Racial discrimination and gender.[142] ECRI has called for disaggregation of data on Roma based on sex.[143] The European Union's recognition of the importance of data collection to analysis and policy-making is evident in the establishment of the European Monitoring Centre on Racism and Xenophobia (EUMC).[144] The EUMC's primary objective is to collect data on racism, xenophobia and anti-Semitism with a view to establishing reliable and comparable information for EU Member States and institutions to act on. The importance of gathering reliable data for policy-making is therefore recognized by relevant international organizations. A concerted effort to gather reliable data on health status and access to services would assist these supervisory bodies to monitor health related aspects of discrimination.

Despite such support, States and Roma express legitimate concerns over the practice. These are due in part to past and continuing abuses, particularly in the context of law enforcement. Such concerns are reflected in the low participation of Roma in population censuses. For example, fewer than 10% of the estimated Roma population in the Czech Republic declared themselves as Roma in the 2001 census.[145] It is therefore important that States and Roma are made more fully aware that the rights implicated in data collection – to privacy, information, and equal treatment – can be protected with appropriate safeguards[146] and that independent and secure mechanisms can be established to collect and store the data. In addition, reliable and thorough ethnic data benefits both Romani communities and the larger society by facilitating appropriate and precise integration policies which stand a greater chance of success. Some States do, however, increasingly recognize the need for ethnic data to inform health policy development. In Ireland, for example, an ethnic identification question on the hospital in-patient inquiry and perinatal systems is being piloted as a part of the National Traveller Health Strategy 2002-2005.[147]

Recognizing the importance of ethnic data to improving the situation of Roma, the Council of Europe held a conference to discuss different perceptions of the issue among Roma and institutions, data protection in international law, and population censuses.[148] From these discussions, as well as suggestions by ECRI and the FCAC on methods and safeguards, a series of recommendations can be gathered to address many of the concerns around ethnic data collection as well as demonstrate its potential for improving access to public services.

States should create an official system of data collection[149] to document the situation and needs of Roma, and to record indirect and direct discrimination, ethnicity or Racial-based violence, and

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[141] World Conference Against Racism Racial Discrimination, Xenophobia and Related Intolerance, Programme of Action, *supra,* note 7, para. 44.
[142] CERD Committee, General Recommendation 25, *supra*, note 130.
[143] ECRI Second report on Slovakia, supra, note 125, para. 43.
[144] *See* http://eumc.eu.int/
[145] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 31.
[146] "The Importance of Race/Ethnic Statistics for Combating Discrimination", *supra,* note 140.
[147] Comments prepared by the Government of Ireland (on file with the Council of Europe).
[148] "Roma and Statistics", *supra*, note 139.
[149] *See, e.g.,* ECRI Second report on Bulgaria, CRI (2000) 3 adopted on 18 June, 1999; Second report on Greece, CRI (2000) 32, adopted on 10 December, 1999; Second report on Croatia, CRI (2001) 34, adopted on 15 December, 2000.

harassment, as defined in the Racial Equality Directive. ECRI recommends that States establish a specialized body in the field of racism and intolerance: this body could be responsible for overseeing the collection of data.[150] It might also undertake to assist health care institutions in ways to sensitise health care workers and patients on the importance and proper handling of ethnic data. One way of commencing this process might be to call authorities' attention to ECRI's general Policy Recommendation No. 4 on national surveys on the experience and perception of discrimination and racism from the point of view of potential victims.[151]

For acceptance and participation amongst Romani communities, certain steps and safeguards are required. In accordance with Article 3 of the Framework Convention, the principles of self-identification and informed consent must be respected.[152] This is significant not only in the initial stage of data collection but for subsequent applications, such as communication to third parties.[153] Anonymity should be guaranteed; in this respect States' attention is directed toward the Council of Europe Committee of Ministers' Recommendation Concerning the Protection of Personal Data Collected and Processed for Statistical Purposes.[154] More generally, European Union member States as well as candidate countries are reminded of the obligation to adapt national legislation to comply with EU directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data.[155]

Above all, Roma and other groups affected by the data collection should be included in preparing, implementing, and monitoring of the collection process. The experiences of the European Population Committee (CDPO) of the Council of Europe have led to (informal) recommendations on this topic in the context of administering population censuses. Similar suggestions might be applied, where feasible, to other forms of data collection:

- Elaboration of the census law in conformity with, among others, the international standards on this subject and guarantees that the data collected would not be used for any purposes other than those provided for by the census

- Setting up of census committees, made up of representatives of the minority groups at national and local levels who are appropriately trained

- Printing of the census form in a language that can be understood by the respondent; the census interviewer should be able to speak the respondent's language

[150] *See* ECRI general policy recommendation No. 2 on Specialized bodies to combat racism, xenophobia, anti-Semitism and intolerance at national level, CRI (97) 36.
[151] ECRI general policy recommendation No. 4 on National surveys on the experience and perception of discrimination and racism from the point of view of potential victims, CRI (98) 30.
[152] Article 3(1) provides: Every person belonging to a national minority shall have the right freely to choose to be treated or not to be treated as such and no disadvantage shall result from this choice or from the exercise of the rights which are connected to that choice.
[153] *See* Recommendation No. R (91) 10 of the Committee of Ministers of the Council of Europe to Member States on the Communication to Third Parties of Personal Data Held by Public Bodies, adopted 9 September 1991.
[154] *See* Recommendation No. R (97) 18 of the Committee of Ministers of the Council of Europe to Member States Concerning the Protection of Personal Data Collected and Processed for Statistical Purposes, adopted 30 September 1997.
[155] Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data, adopted 24 October 1995, Official Journal L 281, 23 November, 1995, pp. 0031-0050.

- The first page of the census form, which contains personal data permitting individuals to be identified, should be destroyed as soon as the reliability checks for the census process (such as for possible double-counting, etc.) are completed

- Representatives of the minorities [affected] should be present during the counting and the analysis of the data.[156]

A specialized body could undertake awareness-raising campaigns to encourage Roma, including women, to participate in the census process and other data collection efforts. In cooperation with Romani women, this body could help to guarantee that data is disaggregated on the basis of sex and properly analysed. Together, these steps could measurably improve understanding of and attention to the needs of Romani women with respect to a broad range of public services.

The establishment of institutions and safeguards for proper data collection are not sufficient, however, to ensure that information is collected upon which policies can be made to improve the situation of Roma. These measures must be linked with the requisite political will. In France, efforts by the NGOs Les Amis des Voyageurs de la Gironde and Médecins du Monde to call attention to the unique ways in which Roma and *Tsiganes* are vulnerable to lead poisoning – e.g. through scrap metal collection – have largely been dismissed on the ground that this is too different and particular a problem to devote resources to.[157] A recent Citizenship Survey in the United Kingdom was unlikely to capture the experiences of many Gypsies and Travellers because it was household based.[158] Answers to many of the questions would have yielded valuable information on the experiences of discrimination and needs of caravan dwellers.[159] And the "most extensive survey on the health of minority ethnic groups ever carried out in England" did not include these groups[160] despite the fact that Roma, Gypsies and Travellers are classified as racial groups and protected under the Race Relations Act (1976).

Researchers at the University of Sheffield seek to address some of these shortcomings in a new project to measure the health status of Gypsy-Traveller populations in the United Kingdom and compare this with settled populations and other low income and ethnic minority groups.[161] Ultimately, however, responsibility lies with the State to ensure that data is gathered and applied in a manner that ensures equal opportunities for all to achieve the highest attainable standard of health.

The 1994-1996 edition of "Why Mothers Die: Report on Confidential Enquiries into Maternal Deaths in the United Kingdom," expressed commitment to examining the risks confronting

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[156] "Roma and Statistics", Strasbourg, 22-23 May 2000, *supra,* note 139, para. 43.
[157] Interview, Talence, France, 11 December 2001.
[158] Interview, London, England, 25 October 2001.
[159] *See* "Home Office Citizenship Survey: People, Families and Communities 2001" Final Questionnaire, Home Office, United Kingdom, 19 March, 2001.
[160] *See* "Health Survey England: The Health of Minority Ethnic Groups '99, Summary of Key Findings", Department of Health, United Kingdom, 1999.
[161] Interview, Sheffield, England, 24 October 2001.

women of different ethnic groups in a future issue.[162] Indeed, recommendations therein call upon Commissioners and trusts to provide those least likely to use services - the socially excluded, the very young, or those from some minority ethnic groups - with the opportunity to gain acceptable professional and social support during their pregnancies.[163] Already, these suggestions should have stimulated action on the local and regional level for these groups. Hopefully, Romani, Gypsy and Traveller women will also be a target of the Health Department's future inquiries. More broadly, these examples from the United Kingdom demonstrate how States' commitment to addressing the needs of minority groups, including Roma, could benefit from ethnic data collection in health and related fields.

[162] "Why Mothers Die: Report on Confidential Enquiries into Maternal Deaths in the United Kingdom 1994-1996", Executive Summary and Key Recommendations, Department of Health, United Kingdom, November 1998, p. 3.
[163] Id., p. 5.

PART II

A. Discrimination against Roma in access to health care

Attitudes and actions of health care workers have a profound impact on access to health care for Roma. Members of Romani communities may be subject to verbal abuse, delayed care, segregation, or outright denial of services on grounds of their ethnicity. Romani women are disproportionately affected by such treatment given their generally higher interaction with health services. This concern extends also to the rights of children to access health-care services which may be negatively affected by discriminatory behaviour on the part of health care workers.[164] Where such practices persist, States may be implicated in failing to protect citizens' access to health care on a non-discriminatory basis. These harms must be remedied in order to raise Roma's poor health status and to instil trust among Roma in mainstream services.[165] Only then will the conditions be ripe for the successful integration of Roma into the larger society.

1. Physicians' refusal to treat Romani patients

Physicians may have wide latitude to refuse patients onto their rosters. Since General Practitioner (GP) referrals are often a prerequisite to tests and specialized care, such refusals raise special concern because they effectively preclude access to a health system.

In some countries it is common for Roma to be rejected from the rosters of GPs. GPs may have various bases to refuse patients: ethnicity may be the deciding factor, though assumptions about a patient's ability to pay or potential burdens on a physician posed by an itinerant lifestyle may be other grounds for refusal. In each one of these cases, the practice may be discriminatory.

Health reforms in Bulgaria in 1999 gave general practitioners (GPs) the right to choose clients. Reportedly, GPs there have refused to register Roma patients, due to an unwillingness to visit Roma neighbourhoods or take on the burden of dealing with the severe health conditions faced by poorer Roma communities.[166] Also in Bulgaria, where GPs are paid a per capita fee for patient care, there are claims of physicians campaigning to get Roma on their rosters without the intent to treat them on a basis equal to non-Roma patients, if at all.[167] In Romania, the reluctance by doctors to receive Romani patients is among the reasons cited for the fact that 30% of Roma are not registered with GPs.[168] These situations are not unique to Eastern Europe: a London survey revealed that 10% of GPs would not accept Travellers; a study in Avon, England found that 80% of Travelling families on a specialist health visitor's caseload had been refused health

[164] See, for example, UN Committee on the Rights of the Child, Concluding Observations: Italy, CRC/C/15/Add.198, 18 March 2003, para. 54; and CRC/C/15/Add.201, 18 March 2003, para. 67.
[165] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 399.
[166] Study conducted by Romani Baht Foundation as cited in Minority Protection in the EU Accession Process, *supra,* note 10, at 92.
[167] Interview, Sofia, Bulgaria, 19 November, 2001.
[168] Ina Zoon, *supra*, note 14, p. 83.

treatment of some kind.[169] A sample by Save the Children Fund in Scotland demonstrated that over 25% of Travellers had been refused registration with one or more family doctor, despite the existence of vacancies on physicians' rosters.[170] Refusal to register any Travellers from a particular Council site has also been documented.[171]

Professional codes of ethics and legislation may provide for refusal of initial assistance while generally obliging doctors to attend to patients without discrimination.[172] But sanctions may not be in place to make these rules effective. For instance, while the Czech Republic does not have an anti-discrimination law pertaining to health care, its Ethical Code of the Medical Chamber obliges doctors to "preserve health and life [and] reduce suffering regardless of nationality, race, skin colour…".[173] Nevertheless, there exist no specific sanctions to address Code violations. The same shortcoming applies to Hungary's Act on Health Care which prohibits discrimination in access to health services and entitles individuals to bring complaints against health care providers or regulating bodies which are obliged to respond, but does not embody a system of sanctions.[174] The law on the Hungarian Chamber of Medicine (which is the official body of the medical profession and is obliged to investigate all complaints), does, however, provide for the sanction of doctors breaching those laws governing equal access to health care services, including the Act on Health Care.[175]

The provision in the Racial Equality Directive calling for a shift in the burden of proof onto respondents to demonstrate that the principle of equal treatment has not been breached, when persons who consider themselves wronged can establish facts, before a court or competent authority, from which it may be presumed that they have suffered direct or indirect discrimination,[176] might be translated into local procedures for assigning to GPs persons who have been repeatedly refused onto rosters. In Ireland, for example, the local Health Board will appoint a GP for an individual upon presentation of refusals in writing from three GPs. The onus is placed on prospective patients to approach physicians for a letter, however, which is often not forthcoming.[177] Burdens upon individuals could be greatly eased, and health care could be resumed more quickly, if the onus fell onto a GP to demonstrate to the Health Board that a particular individual was not refused on discriminatory grounds. The same Health Board could facilitate investigation and sanctions for discrimination on prohibited grounds, as well as to ensure that the prospective patients are assigned to a GP who is easily accessible.

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[169] *See* Sarah Cemlyn, "Traveller Children and the State: Welfare or Neglect?", Child Abuse Review, Vol. 4, 1995, pp. 278-290.
[170] Michelle Lloyd, Richard Morran, "Traveller Health Issues in Scotland – Submission to the Secretary of State's Advisory Committee on Scotland's Travelling People", Save the Children Fund Scotland, February 1999, p. 6.
[171] Id.
[172] "Women of the World: Laws and Policies Affecting their Reproductive Lives: East Central Europe." Centre for Reproductive Law and Policy, New York, New York, October 2000, p. 181.
[173] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 148.
[174] Id., p. 231.
[175] Hungarian Chamber of Medicine sanctions apply also to the breach of the following laws: Law No. 107 of 2001 on the provision of public health care services; Law No. 34 of 2001 on the forms of medical activities; Law No. 35 of 2001 on obligation of the special health care provision; Law No. 83 of 1997 on obligatory health insurance provisions; Law No. 28 of 1994 on the Hungarian Chamber of Medicine. *See* Comments prepared by the Government of Hungary (on file with the Council of Europe).
[176] Racial Equality Directive, Article 8(1).
[177] Interview, Dublin, Ireland, 6 December 2001.

Another way in which Roma can be excluded from physicians' rosters is through their inability to pay tips demanded in exchange for "normal" quality service, or the imposition of an administrative fee for persons entitled to free care.[178] The health consequences may be particularly grave when this requirement precludes access to a specialist. Where statistical evidence can demonstrate that such "requirements" have a disproportionate effect on access to service because of the larger rates of poverty or unemployment among Roma, then such practices may constitute indirect discrimination. Concrete steps should be taken to inform health care workers, authorities, and Roma about the concept of indirect discrimination; specialized bodies and professional associations should be prepared to investigate complaints in the health care context.

Because of difficulties in securing registration with a family doctor, Roma may seek to continue care with a health care worker who had accepted them in the past, even if they or the health care worker have since left the area, even the country.[179] Not only does this practice have serious consequences in the case of a health emergency, it places huge demands on health care workers and is likely to result in unfulfilled expectations for Roma patients.

Patient-held records have helped where individuals or families change doctors with some frequency.[180] But insofar as Roma have difficulty being accepted by a doctor, access to such records should not be conditional upon registration with a particular doctor. More broadly, territory-based health services should better accommodate mobile, including migrant populations.[181] Many Roma claim that their health needs are ignored when they seek help outside their home areas. At the same time, some health care workers justify this on the basis that they believe these patients to be "someone else's responsibility" or out of fear that they will heighten expectations for service. In other words, to provide service would be to encourage visits from mobile communities and thus increase the burdens on health care workers.

In Romania, England, and elsewhere, salaried GPs have been proposed in regions where Roma, Gypsies and Travellers have difficulty accessing health care.[182] These and other incentives for health care workers to assist Roma may be required to regularize access to mainstream services. Undoubtedly beneficial in the shorter term, care should be taken to avoid institutionalising a parallel and inferior system of care.

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[178] Interviews, Budapest, Hungary, 9 November; Dublin, Ireland, 6 December; Toulouse, France, 11 December, 2001. *See also* "Minority Protection in the EU Accession Process", *supra,* note 10, p. 232.

[179] *See* Sarah Cemlyn,, note 169; Interview, Amsterdam, Netherlands, 12 October 2001.

[180] Patrice Van Cleemput, "The Health Care Needs of Travellers", Specialist Health Visitor for Travellers in Sheffield, Community Health Sheffield NHS Trust, pp 11-12.

[181] *See, e.g.,* Proposed objectives and actions to promote the health of migrant Roma through improvement of living conditions, access to health care, and mother and child care, in "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 44.

[182] In Romania, a plan for financial stimulation of GPs that perform activities in very poor regions inhabited by Roma has been elaborated by the Ministry of Health and Family and the National Health Insurance Fund. Submitted by the Counsellor on Roma of the Minister of Health and Family, Romania, to the Roma/Migration Division, Council of Europe, for the Romani Women and Access to Public Health Care Project; Interview, Plovdiv, Bulgaria, 20 November, 2001; *See also* Sarah Cemlyn, "From Neglect to Partnership? Challenges for Social Services in Promoting the Welfare of Traveller Children." *Child Abuse Review*, Vol. 9, 2000, p. 237.

2. Health care institutions' refusal to assist Roma

Refusal to assist Roma may constitute direct discrimination, and takes many forms, including denial of entry into medical facilities, limits on when Roma patients can be seen, and denials of assistance to their family members or visitors.

In some cases, Roma have been barred physically from entering health care centres on the basis of ethnicity. A decision by the Fund for Social Security and Health office in Iaşi, Romania, had declared that Roma who could not afford to pay for their medical treatment or prove they had state medical insurance could not enter the Iaşi County Hospital.[183] This practice apparently ceased after being brought to the attention of the Ministry of Health, Department for the Protection of National Minorities, and the National Office on Roma.[184] Monitoring by competent authorities should take place to make certain that similar prohibitions are not instated in Romania or elsewhere.

Also common are limits on the days and times when health care workers see Romani patients, allegedly on the basis of ethnicity. An example concerning access to gynaecological care for Romani women in Kosice, Slovakia, reportedly typifies stories heard from women in different areas:

> In Lunik IX, a community of roughly 4,000 Roma citizens in the city of Košice, Romani women are systematically deprived of consistent access to health care. In this community, which has often been noted as the largest Roma ghetto in Central Europe, Romani women are restricted to gynaecological care on Fridays only. This state clinic is open to other clients Monday – Thursday, but women from Lunik IX are not permitted access on these days.[185]

Allegations of this sort exist not only in the context of routine care, but emergency assistance as well. When visiting local doctors, Roma from the settlement of Kerinov in Slovenia reportedly are often told to return later or the next day; when seeking assistance in the emergency ward at night, they are told that the staff cannot wake up the doctors. Patients believe they are treated in this way because of their ethnicity.[186]

Concerns also arise with respect to the accommodation afforded to relatives or visitors of Roma patients. One Romani man reported that he was refused a bed to sleep on while spending the night alongside his sick child in a hospital in Hungary. The hospital denied him a bed not on the grounds that beds are generally unavailable for family members, but because 'beds are not for

[183] "State of Impunity: Human Rights Abuse of Roma in Romania", European Roma Rights Centre Country Reports series No. 10. European Roma Rights Centre, Budapest, Hungary, September 2001, p. 96.
[184] Id.
[185] "Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001", Roma Rights Centre, Koŝice, Slovakia, p.10.
[186] "Minority Protection in the EU Accession Process", *supra,* note 10, p. 506.

Roma."[187] He was further told that offering to pay would not change this fact.[188] In other words, as a Roma he was not entitled to the same service available to non-Roma.

Health care institutions should take measures to prevent, monitor and sanction such behaviour. At the same time, Romani patients and those caring for them should be encouraged to bring complaints, in part through confidential mechanisms and assurances that their access to health services will not be threatened or revoked because of their coming forward.

3. Segregation of Roma in health care facilities

A particularly disturbing example of direct discrimination by health care institutions is that of segregating Romani patients. Segregation in health care centres – in Roma-only rooms, showers, eating rooms, and other facilities – has been documented in prior research,[189] and allegations were heard in the course of researching this report.[190] This practice seems particularly common in maternity wards. Romani women perceive the reasons for separation into "Roma" and "white" rooms to be based on racial stereotypes: Romani women are "anti-social," "undisciplined," "dirty," or "thieves." These justifications are often hidden by health care workers' claims that Romani women would be more comfortable sharing rooms with each other. However, when individual Romani women ask to be placed in mixed rooms, they are often denied.[191] Upon being challenged on the grounds for this practice, individual health care workers may indicate they are powerless to transfer a patient because a higher authority in the institution takes such decisions.[192]

For reasons such as location, many Roma (as well as members of the wider population) do not have a choice of health care institutions. Thus they may be unable to avoid a particular health clinic despite allegations that it segregates patients according to race.[193] But segregation often leads to less attention from medical staff as well as inferior treatment, as those who experience it believe.[194]

The Roma Rights Centre in Slovakia obtained testimony concerning segregation of women in Vranov nad Toplu, Slovakia, as follows. There are five delivery rooms in the local maternity ward. Of these five**,** two rooms are reserved for Roma patients. When these two rooms are occupied, Romani women are not sent into one of the other three rooms, but rather into the hallway.[195] Presumably, treatment in the hallway is neither sanitary, private, nor properly equipped. Another example comes from Hungary, where a Romani woman complained that nurses in a nearby hospital avoided treating her child, letting a day go by without administering

[187] Interview, Budapest, Hungary, 9 November 2001.
[188] Id.
[189] *See, e.g.,* Zoon, *supra* note 14, p. 95.
[190] Interview, Vidin, Bulgaria, 18 November 2001.
[191] Interview, Vidin, Bulgaria, 18 November 2001.
[192] Id., Interview, Hermanovice, Slovakia, 2 October 2001.
[193] Interview, Vranov, Slovakia, 3 October 2001.
[194] *See* Zoon, *supra,* note 14, p. 43.
[195] "Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001", *supra,* note 185, p. 10.

prescribed medication.[196] In a case concerning possible discrimination against a child, another woman in Eastern Slovakia alleges that her baby daughter's death was due in large part to having been placed into a segregated room for Romani children where she was left unattended and unmonitored.[197] The woman additionally claims to have been treated with hostility, suspicion and disrespect herself, as well as denied information about her daughter's health status in a timely manner. Above all, she believes this treatment was based on her Roma identity.[198]

A group of Roma in Vidin, Bulgaria, attempted to remedy the problem of perceived inferior care at a health institution by collecting money from the Romani community to buy the attention of health care workers.[199] Such further indignities can be spared for this community and elsewhere if concerted efforts are made by local authorities and professional bodies to enact and publicize anti-discrimination norms and to provide effective monitoring and sanctions. A laudable initiative with such objectives is the Maternity Services Code of Practice put forth by the Commission for Racial Equality in the United Kingdom. Encouraging all purchasers and providers of maternity services to adopt racial equality policies, the code suggests several key components: vesting of responsibility for the policy at a senior level; regular monitoring to ensure that services do not discriminate directly or indirectly against ethnic minorities or otherwise put them at a disadvantage; and the inclusion of ethnic minority communities on committees established to perform ongoing reviews of the policy.[200]

Whether or not claims of discrimination are substantiated in specific cases, the importance of the perception of Roma that they are being discriminated against should not be underestimated. Thus, it is essential that proper mechanisms to ensure against and to sanction discrimination are seen to be in place and to function effectively if trust is to be developed.

4. Inferior and degrading treatment of Roma

Claims abound of inferior treatment of Roma on the basis of ethnicity, such as denial of certain treatment options or verbal abuse. Where such behaviour exists it amounts to direct discrimination. Furthermore, it may discourage Roma from seeking medical help out of fear of harassment and humiliation. For discouraged patients, access to preventive health information and services becomes less likely. As a consequence, care at later stages of illness may be more difficult and costly.

Romani women have sometimes been made to wait for what seemed to them like excessively long periods before receiving assistance, or until all non-Roma patients had been helped.[201] In one clinic, this was allegedly explained by the reluctance of non-Roma patients to sit in the same

[196] Interview, Imréné, Hungary, 10 November 2001.
[197] "Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001", *supra,* note 185, p. 9.
[198] Id., p. 10.
[199] Interview, Vidin, Bulgaria, 18 November 2001.
[200] United Kingdom, Commission for Racial Equality Maternity Services Code of Practice, Racial Equality Policies. Available at: www.cre.gov.uk/gdpract/health.html
[201] Interview, Jarovnice, Slovakia, 2 October; Hermanovice, Slovakia, 2 October; Patras, Greece, 13 November; Toulouse, France, 11 December, 2001.

chairs that Roma used.[202] In Ireland there are allegations of Gypsy-Travellers being given double-doses of vaccinations on the assumption that they do not take care of their health and are therefore unlikely to have been vaccinated.[203] A woman in the Kirtimai settlement outside of Vilnius was told by a doctor that since Roma are a vital people, she should come back to seek medical help only when her pain becomes unbearable.[204] Such behaviour is discriminatory if carried out on the basis of race or ethnicity. Regardless, they are humiliating, careless, and have potentially life-threatening consequences.

Verbal abuse by health care workers on the basis of ethnicity is a commonly cited experience among Roma. It takes many forms, including being laughed at, told dirty comments, yelled at for being unable to read, and reprimanded for living in dirty conditions. One woman in Madrid whose large family came to visit her in a maternity ward recounted how a nurse asked if "she brought the whole tribe with her" then demanded that she get out of bed despite being in pain to "get the tribe out" of the ward.[205] In another case of maternity ward segregation, a woman in Eastern Slovakia stated that during the delivery she was verbally attacked with racial slurs by both the nurses and the doctor. These slurs included terms such as "gypsy" and "gypsy whore."[206] Staff at health centres in Hungary have been known to treat Roma patients in an openly biased and rude manner.[207]

Roma health mediators could be instrumental in identifying discriminatory behaviour and helping health care workers to dispel prejudices that underlie inferior and degrading treatment. They could also raise awareness in Romani communities about complaint mechanisms and alternative sources of health care.

5. Discrimination in access to emergency care

Access to emergency medical services is an integral element of the right to health.[208] In practice, however, discrimination, physical, economic, and information barriers (see the dimensions of accessibility in General Comment 14 on the Right to the highest attainable standard of health as discussed above in Part I, Section B. Legal Standards, Sub-section 3) as well as stereotypes of Roma held by health workers and authorities, which impede access to health care generally, not only for individual Roma but for entire communities, may be particularly acute in cases of emergency

[202] Interview, Kovil, Serbia, 6 December 2001.
[203] This situation arises because of a special Mobile Vaccination Clinic for Travellers that does not routinely provide information to GPs about services rendered. Either the clinic or doctor may assume that a Traveller has not been vaccinated if the Traveller is uncertain about his or her vaccination record. This problem might be solved by mandatory information exchange and patient-held records. Interview, Dublin, Ireland, 6 December 2001.
[204] Interview, Vilnius, Lithuania, 16 October 2001.
[205] Interview, Madrid, Spain, 27 November 2001.
[206] "Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001", *supra,* note 185, p. 10.
[207] The Health Status of Romas in Hungary, World Bank Regional Office Hungary, NGO Studies No. 2, Roma Press Centre, Puporka, Lajos, and Zsolt, Zadori, p. 59.
[208] "The right to treatment includes the creation of a system of urgent medical care in cases of accidents, epidemics and similar health hazards." CESCR General Comment 14, *supra*, note 3, para. 16.

Poor road conditions or a lack of telephone service prevent many Romani communities from receiving emergency care. While these physical impediments may be symptomatic of hardships affecting the wider population, research is required to determine whether lack of attention to such problems in Roma communities is motivated by discriminatory grounds.

The Roma Rights Centre in Eastern Slovakia documented one of many examples of the difficulties in accessing a Roma settlement:

> "Moldava has a relatively large hospital that services many of the outlying towns and villages in the area. The Roma did not report any problems with the service and staff at the hospital. They did mention that if an ambulance needs to be called, it will not drive into the settlement, but it will wait at the top of the hill on the main road. From our own experience, we concluded that an ambulance would not be able to fit through the narrow pathway leading into the settlement and that it would be very difficult for it to get up and down the steep and decrepit path. The residents of the settlement shared with us that they have had to wait up to two hours for an ambulance to arrive."[209]

The unpaved, flooded, hole-strewn roads of many Roma settlements and lack of telephones suggest that many residents find themselves waiting excessively long for medical assistance. These problems may have a disproportionate impact on Roma, who are thought to seek emergency assistance with greater frequency and for less serious conditions than other subgroups of a population. If evidence can demonstrate this fact, then failure to address these problems may constitute indirect discrimination.

In fact, the poor reception that many Roma receive when seeking routine medical care may explain their "overuse" of emergency care.[210] Another explanation may be the distance from health care centres that makes access to regular services impracticable due to a lack of economic or transport means. For Roma in these situations, emergency services may be their singular source of medical advice.

As a consequence of this perception of overuse, individual health care workers or entire emergency care departments may not want to assist Roma; they may demonstrate this reluctance in slower or denied care. Roma commonly complain of having to call several times for an ambulance because the operator does not believe there is an emergency or assumes that the request is a "crank" call if such calls have been made from that community in the past.[211] Sinti women in Stein, the Netherlands, for instance, do not trust that ambulances will respond to calls from their caravan site because of their ethnicity. Though they do not commonly drive, the women feel forced to do so in order to access emergency services. As a consequence of their

[209] "Human Rights Report on the Situation of Roma in Moldava nad Bodvou", March, 2001, appendix D in "Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001", *supra,* note 185.
[210] *See, e.g.*, "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 41.
[211] Interviews, Szaflary, Poland, 4 October; Vidin, Bulgaria, 18 November; Plovdiv, Bulgaria, 20 November; Strasbourg, France, 4 December; Patras, Greece, 13 November, 2001.

lack of trust in the dependency of the emergency services, they must put themselves and others on the road in danger.[212]

Denying access to emergency services in these ways effectively punish Roma twice: on the basis of race or ethnicity and for having suffered discrimination in a primary care context. While it is reasonable to seek verification that there exists an emergency situation, to do so multiple times is unreasonable and contrary to the purpose of availability of emergency assistance. Anti-discrimination legislation that includes the provision of emergency care and effective sanctions within its ambit could help to avoid such situations.

Emergency care for Roma is reportedly sometimes made conditional on the provision of money or other guarantees not demanded of majority populations. Dispatchers of ambulances to the Roma settlement at Hermanovice in Slovakia, for example, are alleged to ask whether the patient in need of care is Roma, and to condition sending an ambulance upon provision of the identification numbers of non-Roma social workers often present in the community.[213] In other cases, Roma are forced to pay extra charges for emergency services, sometimes being refused transport if they cannot pay immediately.[214] For communities that cannot afford access to mainstream health care, forced donations for emergency services function to block access to most, if not all aspects of a health system.

Fear of aggression or theft in a particularly community – by Roma or non-Roma, whether in general or directed at health care workers specifically – may also result in denial of emergency services and night calls by doctors.[215] In these situations, authorities should take steps to protect health care workers rather than deny care to entire communities. Attention should also be given to breaking down stereotypes held by service providers of aggressiveness based on ethnicity.

The harmful medical consequences of delayed or denied care are obvious and cannot be justified. Furthermore, the consequences of denying emergency services to Roma may block access to the only kind of medical attention to which many Roma realistically have access. Admittedly, there is a need for education of Romani communities on what types of medical problems warrant emergency attention, and on the fact that emergency services are a limited resource. Indeed, mediators could take on this task. But these lessons are of little value unless they are combined with efforts on the part of mainstream health services to receive Roma without discrimination.

[212] Interview, Stein, Netherlands, 10 October 2001.
[213] Interview, Hermanovice, Slovakia, 2 October 2001.
[214] Interview, Hâncesti, Moldova, 18 September 2001.
[215] Interviews, Nis, Serbia, 6 November; Strasbourg, France, 4 December; Toulouse, France, 11 December; Belgrade, Serbia, 5 November; Vilnius, Lithuania, 16 October; Zefyri, Greece, 12 November, 2001.

B. Improving access to health care for Romani women

Information, physical and economic barriers that Roma may confront in accessing health care result from the complex and inter-related effects of poverty, discrimination, and reciprocal unfamiliarity *vis-à-vis* government institutions generally and health care services in particular. For Romani women, these difficulties are compounded by attitudes and community practices that draw attention away from women's health. As a result, women may exhibit defiance or resignation towards health care institutions. They may be unable to break away from "invisible" traditions that cause them to neglect health needs.[216] Improvement of Romani women's health status and access to care requires that their needs and interests be reflected in health policies and services.

1. Access to preventive care and Romani women's attitudes towards health

Systemic and systematic discrimination, degrading treatment and difficulties in accessing a family doctor may combine with various socio-cultural and psychological factors to discourage Romani women from paying attention to their own health and seeking appropriate care. For instance, Romani women are often reluctant to seek medical attention until pain is intolerable.[217] Many factors bear on this reluctance. These include:

- Insufficient information about treatment options (perhaps on account of language difficulties)[218] compounded by associations of illness with an immutable state rather than an alterable physiological process[219]

- a poor understanding of the value of preventive screenings or what constitutes a serious health risk or problem

[216] "The definition of health applied to a woman – and the resources allocated for this – have been influenced by social perceptions of women's status and role, which in turn interact with class, caste, and ethnicity. Many women accept ill-health as their lot in life, often ignoring painful and debilitating symptoms because in their culture a woman is expected to endure without complaint; or because taboos and myths have led them to believe that their health problems stem from some sort of reproachable behavior on their part; or simply because they have no alternative." WHO/FHE/95.9 – "Women's Health: Fourth World Conference on Women. World Health Organization, Geneva, 1995, p. 1.

[217] *See, e.g.*, "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, Section 5.a; "ROMEUROPE Project Final Report, 1999-2000", *supra* note 19, p. 25.

[218] The OSCE Parliamentary Assembly has suggested that European States which comprise Romani communities support the professional use of the Rromani language in medical prevention and care, judicial advisory and other fields where the use of the mother tongue optimises the effect of undertaken action. OSCE Office for Democratic Institutions and Human Rights, Human Dimension Implementation Meeting, Warsaw, 9-19 September, 2002, Working Session 4: Tolerance and Non-discrimination I (National minorities; Roma and Sinti). Available at: http://www.osce.org/odihr/documents/reports/hdim/hdim2002_fr.php3

[219] *See* "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, Section 4.b.

- shame to seek help, especially if this requires a break in purity traditions or modesty codes

- resignation about possibilities for their own future despite concern for their children's upbringing[220]

- postponing attention to personal well-being in the interest of attending to family care and maintaining the home.

For these and other reasons, many women do not prioritise preventive care, and regard health services generally as inapplicable or unavailable to themselves. At the same time, many Romani women are in particular need of access to health services because of living conditions, generally poor health status, and practices that pose specific health risks. (See Health status of Romani populations: an overview, above.)

Government strategies are increasingly acknowledging the relationship between poor living conditions and health status. In turn, many non-governmental organizations have sought to improve Romani women's attention to and ability to act on improving their own health, especially through preventive care. Significantly, many of these measures involve a self-awareness and empowerment component, affirming the notion that Romani women's health should be prioritised alongside family and community needs. A woman's programme run by the *Asociación Secretariado General Gitano* in Madrid, for instance, encourages Romani women to think not only about health prevention, but also to identify and express their personal needs and goals.[221] In Zephyri, outside of Athens, Greece, the organization Klimaka takes advantage of women's commitment to their children's health by offering gynaecological care from a female doctor after a paediatric's visit.[222] Each of these programmes provides women with the personal and cultural capital required to promote their own health needs.

2. Access to reproductive and sexual health care

As described in Part I, Section B on Legal Standards above, provisions in international conventions such as the ICESCR, Convention on the Elimination of All Forms of Discrimination against Women, and the Convention on the Rights of the Child, protect women's reproductive and sexual health. In practice, however, reproductive health is still often narrowly defined in relation to pregnancy and maternity; comparatively few resources are devoted to the reproductive health of women throughout their entire life cycles.[223] Generally, there is far less commitment to funding family planning services in support of women's choice of the number and spacing of

[220] Id.
[221] *See* "Guide to health for Gitana women" ("Guía de salud para mujeres gitanas"), Carmen Arbex Sánchez, Instituto de la Mujer y Asociación Secretariado General Gitano, Madrid, 2000.
[222] Interview, Zefyri, Greece, 12 November 2001.
[223] "Women of the World: Laws and Policies Affecting their Reproductive Lives: East Central Europe." Centre for Reproductive Law and Policy, *supra,* note 172, p. 183.

children, than to promoting safe motherhood.[224] Worldwide, relatively little attention is paid to women's right to safe sexuality and to autonomy in all decisions relating to sexuality.[225] These trends have particularly adverse effects on Romani women whose attempts to access reproductive and sexual health care may be impeded by the combined effects of poverty, discrimination and physical, economic or informational barriers. Gender discrimination within Roma communities may also be a significant detractor to accessing care.

a. Access to maternal health care

Under Article 12 of the ICESCR steps should be taken by States Parties to fully realize the right to health, including those necessary "for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child."[226] As the General Comment on the Right to Health explains, this provision may be understood as requiring: "measures to improve child and maternal health, sexual and reproductive health services, including access to family planning, pre- and post-natal care, emergency obstetric services and access to information, as well as to resources necessary to act on that information."[227]

For complex reasons, many Romani women do not have access to information on the importance of monitoring a pregnancy and how to care for themselves during this period.[228] The Flemish Centre for Minorities reports that in its cooperation with the official preventive child care service – Kind en Gezin – it has found that Roma mothers rarely come for maternal health consultations, often because they "believe more in "luck" than in preventive care, and because fathers, who provide transportation, are uninformed of the benefits of making time for such consultations."[229] Purity traditions and other customs may deter women from asking questions about reproductive health matters, or from seeking any care at all during or after pregnancy.[230] Some women claim that doctors do not provide this information.[231] Research should be done to determine the cause of this lack of communication. More broadly, in the interest of providing equitable access to care, health care institutions should identify the various causes that detract from promoting women's health, and to make reasonable accommodation in the provision of services.

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[224] Id.
[225] "Human Rights, Women, and HIV/AIDS", Fact Sheet no 247, World Health Organization, June 2000.
[226] ICESCR Article 12 (2)(a).
[227] CESCR General Comment 14, *supra* note 3, para. 14.
[228] *See, e.g.,* "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, section 5.b.
[229] The office addresses this problem through health care workers who visit mothers and fathers over long periods of time, encouraging them to attend consultations. Submitted by Flemish Centre for Minorities, Travellers and Gypsies branch, to the Roma/Migration Division, Council of Europe, for the Romani Women and Access to Public Health Care Project.
[230] Purity concerns and other traditions may be maintained after birth as well: a woman may uphold a tradition of not being able to see anyone for 6 weeks after birth; this practice may pose a challenge to clinics or home health visitors interested in following up on mother and child health. Interview, Budapest, Hungary, 9 November 2001.
[231] Interviews, Jarovnice, Slovakia, 2 October; Vilnius, Lithuania, 16 October; Szaflary, Poland; 4 October; Amsterdam, The Netherlands, 11 October, 2001.

Problems in accessing reproductive health information for young women may have a disproportionate impact on Roma due to the high rate of births before the age of 18 in some Romani communities. Women who give birth before age 18 are three times more likely to die in childbirth than women over 18.[232] This is attributable to the combined factors of insufficient physical maturity to bear pregnancy and deliver safely, and inadequate emotional and intellectual maturity to seek necessary assistance for personal and natal care.[233] The age of marriage and childbearing may be increasing in some Romani communities with awareness of the importance of education and economic independence to successful parenting.[234] In order to support this trend, there is a need for widespread and systematic efforts to educate young Romani women, their sexual partners and parents on the risks of early pregnancy.

The Children's Convention defines a child as a human being below the age of 18 years.[235] Further, it provides that "States parties shall strive to ensure that no child is deprived of his or her right of access to … health care services"[236] The interdependence of mother and child is recognized in Article 24(2)(d), by which States agree to take measures "[to] ensure appropriate pre-natal and post-natal care for mothers."[237] Ensuring non-discrimination on the basis of age in the realization of reproductive rights may require that States develop public health campaigns and provide special services to reduce mortality and morbidity where it affects young Roma women.

Romani women may also face economic barriers to accessing health care. Under CEDAW, States Parties are required to ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary as well as adequate nutrition during pregnancy and lactation."[238] Where free or reduced cost care is provided to uninsured women during pregnancy and delivery, concern arises over discriminatory treatment of Romani women based on their ethnicity. Despite the availability of such care in Macedonia, Romani women in Skopje were reportedly made to pay, sometimes being refused urgent treatment if they were unable to comply.[239] Monitoring and enforcement of the application of this provision may be required to ensure access to maternal health care on a non-discriminatory basis for Romani women.

In some cases, NGOs have stepped in to address some of these potentially discriminatory barriers to accessing maternal care. In Plovdiv, Bulgaria, a local health centre and municipal services have collaborated with the Social Foundation Stolipinovo to promote a holistic approach to motherhood and integration with mainstream health and social services through a workshop for 120 mothers on baby care, living conditions and budget maintenance.[240] The multi-sectoral

[232] Rebecca J. Cook, Bernard M. Dickens, *et .al.,* "Advancing Safe Motherhood through Human Rights", World Health Organization, 2001 (WHO/RHR/01.5) p. 54, citing to "World Development Report 1993 – Investing in Health", World Bank, Oxford University Press, New York, 1993, pp. 84-117.
[233] Id., p. 38.
[234] Interviews, Granada, Spain, 30 November; Amsterdam, The Netherlands, 11 October 2001.
[235] Convention on the Rights of the Child, Article 1.
[236] Id., Article 24(1), as cited in Cook and Dickens, *supra*, note 232, p. 54.
[237] Id.
[238] CEDAW Article 12(2).
[239] Zoon, *supra*, note 14, p, 105.
[240] Interview, Plovdiv, Bulgaria, 20 November 2001.

and empowerment aspects of such an initiative can promote women's autonomy in decisions about health care and related aspects of daily life.

Ultimately, however, the responsibility falls on States to ensure safe motherhood. Adaptations to mainstream services may be required to ensure equal access for Romani women. Again, mediators can help to achieve this goal. They might be employed to provide education and training to reinforce safe motherhood as a human right; negotiate for improved maternal health services and for other enabling conditions to improve maternal health; and monitor access at local and other levels.[241]

b. Access to family planning

Many factors contribute to impeding access to family planning for Romani women. Nevertheless, article 12(1) of CEDAW provides that States Parties should take "all appropriate measures … to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning." Under Article 16(e), States Parties must ensure women's "rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights." Special measures might be required to ensure for Romani women equal opportunities to realize these rights.

As among majority women, there exists a broad range of views on the acceptability of contraceptive use among Romani women. Concern arises, however, that the views of some Romani women may be uninformed since various barriers to accessing health care (as discussed above) may impede access to information about the various methods, efficacy, and availability of contraception. Without regular access to health care, the likelihood is higher of obtaining incomplete information and risking unwanted pregnancies or other health problems. To the extent that doctors are the primary source of family planning information and women the primary beneficiaries, Romani women are at particular disadvantage if they do not have regular access to family doctors. In effect, they may suffer both ethnic and sex discrimination.

Incomplete information may also lead women to use contraceptive methods they are less comfortable with, cannot access as easily, or which might pose more health risks than others. Of special concern are situations where health care workers may be reluctant to give Romani women information on the basis of ethnic stereotypes. A stereotypical view that Romani women do not think about the future might cause health care workers not to offer family planning information. They might provide information only on certain kinds of contraception on the assumption that Romani women are unable to follow directions to use all available methods properly. Or they could give information in an insensitive manner, for example by promoting those methods that are less easily detected by sexual partners on the assumption that just because some Romani women – like majority women – have difficulty discussing contraception with their husbands, then this extends to all Romani women. In so doing, health care workers are complicit not only in reinforcing ethnic stereotypes, but gender inequality as well.

[241] Cook and Dickens, *supra*, note 232, p. 67.

Another concern arises in the context of fears about coerced sterilization – a sensitive topic among Romani women in places where there exists a documented history of, or rumours about, sterilization campaigns and where allegations in individual cases continue to be made, such as those recently arising from Slovakia.[242] The Beijing Platform for Action developed at the 1995 Fourth World Conference on Women affirms that "the principle of informed free choice is essential to the long-term success of family planning programmes [and that] any form of coercion has no part to play."[243] Public health campaigns and health care workers should be sensitive to how family planning is promoted to Romani women who may be aware of claims of coercion. [244]

Perhaps most significant for Romani women's access to family planning are various traditions associated with religious beliefs, purity practices, and maintaining family honour through vigilance over a daughter's virginity. Again, adherence to such traditions and their consequences for communication about family planning vary among and within Romani communities. The increasing popularity of Evangelism or Pentecostalism in some Finnish and French Roma communities, among others, may result in pressure on women to conceal their interest in and efforts to obtain family planning and abortion services.[245] As among majority communities, religious traditions may lead to a denial of access by parents and community leaders to family planning programmes for adolescent girls. Such practices may increase health risks because they do not allow adolescent girls to learn about warning signs of reproductive health problems, or about the side effects of various methods of contraception.

The right to liberty and security of the person, as enshrined in the International Covenant on Civil and Political Rights,[246] can be applied to require that positive measures be taken to ensure respect in the delivery of reproductive health services to women who are at particular risk.[247] These women include adolescent girls presenting with stigmatising conditions such as unmarried or extra-marital pregnancy, or incomplete abortion: such factors may make them reluctant to seek reproductive health services out of fear that their confidentiality might be breached.[248] Special measures may be required to ensure the protection of confidentiality when Romani adolescents seek family planning services, including appropriate training of health personnel who work with these groups. One NGO that seeks to aid young Romani women is the Roma Women's Association in Kovil, Serbia. The Association provides weekly workshops for women ages 13-22 that may be reluctant to seek gynaecological care through mainstream services. The

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[242] *See* Joanna Wells, "Silent attack: a campaign of sterilization of Romani women", Roma Rights No 1, 2000, *supra*, note 45. *See also* "Body and Soul; Forced Sterilization and Other Assaults on Roma Reproductive Freedom in Slovakia", Centre for Reproductive Rights and Poradna pre obcianske a ludske prava in consultation with Ina Zoon.

[243] Para. 7.12, as cited in "Considerations for formulating reproductive health laws", Human Rights and Reproductive Self Determination, Part 1. 2000 - WHO/RHR/00.1, available at: http://www.who.int/reproductive-health/publications/RHR_00_1/RHR_00_1_Chapter3part1.html

[244] The Bulgarian Family Planning and Sexual Health Association has three centres in Roma districts, but often finds it difficult to encourage Romani women to attend because of fears of sterilization; Interview, Sofia, Bulgaria, 20 November, 2001.

[245] Interviews, Talence, France, 11 December; Helsinki, Finland, 20 October 2001.

[246] ICCPR Article 9(1): "Everyone has the right to liberty and security of person…No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law."

[247] Cook and Dickens, *supra* , note 232, p. 31.

[248] Id.

organization provides health information as well as access to a paediatrician and pregnancy counsellor in a culturally sensitive and confidential manner.[249]

Even when women do possess information on family planning, they may lack physical or economic access to services. Especially in Central and Eastern Europe, family planning services are limited in availability and accessibility.[250] For women living in isolated communities or halting sites, a clinic offering family planning services is often inaccessible because of distance, cost of transportation, or stigma associated with the location.[251] Research should be conducted to examine whether the location, cost, and variety of reproductive health services are accessible to Romani communities on an equal basis with others.

One result of information, physical and economic barriers to accessing family planning is a high rate of abortions, often perceived as the only realistic method of birth control.[252] Abortion remains a popular and necessary means for many Romani women's exercise of reproductive autonomy. The CEDAW Committee has observed that "the large numbers of couples who would like to limit their family size but lack access to or do not use any form of contraception provide an important indication for States parties of possible breaches of their duties to ensure women's access to health care."[253] Thus, the Committee has called on States Parties "to ensure that women are not forced to seek unsafe medical procedures such as illegal abortion because of lack of appropriate services in regard to fertility control."[254] Noting the high cost of contraceptives, rates of abortion, and low level of education on family planning in Hungary, the CEDAW Committee requested the government to offer sex education programmes to all young people, and to subsidize contraceptives in order to promote family planning and reduce the number of abortions.[255] The same recommendations could be reiterated for all States with significant, marginalized Roma populations.

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[249] Interview, Kovil, Serbia, 5 November 2001.

[250] The abortion rates per woman in the ECE region are among the highest in the world. These rates reflect women's lack of access to modern methods of family planning. Since 1989, little progress has been made towards increasing access to modern contraceptive methods. Most contraceptives are still imported. Many countries in the region also lack the infrastructure to distribute contraceptives effectively, especially in rural areas. "East Central Europe Abortion Laws and Policies in Brief", Centre for Reproductive Law and Policy, New York, New York, August 2000.

[251] Interviews, Mizil, Romania, 14 September; Vilnius, Lithuania, 16 October; Toulouse, France, 11 December, 2001.

[252] *See, e.g.,* "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra*, note 16, at section 5.b.

[253] CEDAW Committee, General Recommendation 24: Women and health, para.17, as cited in Cook and Dickens, *supra* , note 232, p. 52.

[254] CEDAW Committee, General Recommendation No. 19: Violence against women, adopted 11th session June 1992, para. 24(m).

[255] As cited in "Considerations for formulating reproductive health laws", Enforcement of Legal Standards and Human Rights Obligations: Part II: International Enforcement, *supra,* note 243.

c. Access to sexual health care

The Beijing Platform for Action reaffirms the definition of reproductive health developed at the 1994 UN International Conference on Population and Development,[256] while advancing the wider interest of sexual health. The Platform's focus on women makes explicit that:

The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behaviour and its consequences.[257]

One key issue in advancing Romani women's access to sexual health care is access to information about and treatment for sexually transmitted diseases (STDs) including HIV/AIDS.

Generally, there is little access to information among Roma on prevention and treatment of STDs and HIV/AIDS. There may be little awareness about symptoms, the fact that condoms or other methods can help prevent their spread or that HIV can be transmitted sexually. A study in two Roma communities in Romania – one urban and one rural – found that only 28% of the population had correct information about HIV/AIDS. This was attributed in large part to low levels of, and restricted access to, education: only 57% had finished primary school.[258] Irregular access to health care exacerbates these shortcomings in education.

Information on STDs including HIV/AIDS is of special interest to women. They are more vulnerable to STDs than men, and the consequences are more serious. Many STDs are asymptomatic in women so they go untreated; the presence of untreated STDs is a risk factor for HIV; as with STDs, women are at least four times more vulnerable to HIV infection, (and very

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[256] "Reproductive health is a state of complete physical, mental and social well- being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. In line with the above definition of reproductive health, reproductive health care is defined as the constellation of methods, techniques and services that contribute to reproductive health and well-being through preventing and solving reproductive health problems. It also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases." United Nations International Conference on Population and Development (ICPD), 5-13 September, 1994 Cairo, Egypt Section A. Reproductive rights and reproductive health, Basis for action, para. 7.2.

[257] The Platform for Action, 1995 Fourth World Conference on Women in Beijing, para. 96, as cited in **"**Considerations for formulating reproductive health laws, Challenges to Sexual and Reproductive Health", *supra,* note 243.

[258] "HIV/AIDS Situation and Response Analysis, Romania, 1999", *supra,* note 46.

young women are more vulnerable).[259] More research is needed to establish whether the lack of information on STDs and HIV among Roma is the consequence of public health campaigns or health care workers that overlook or in effect fail to reach Romani communities.

Unequal gender relations may also impede women's access to sexual and reproductive health care. Gender relations within any community or individual couples are dynamic and complex, and few generalizations can be made. However, rigidly defined gender roles, including the subordination of women to men in many aspects of daily life, are characteristic of many Romani communities.[260] In this context, it is less likely that Romani women will be allowed to choose "when, with whom, and with what protection, if any, to have sex."[261] A significant number of Romani women cannot suggest their partners use condoms: this may be understood as an accusation of infidelity, or an expression of reluctance to bear children according to the timing and number desired by her husband. In turn, refusal of sexual relations may be interpreted as a sign that a woman is "cheating" with another partner. Also, a significant number of Romani women do not feel free to choose the method and timing of contraception for themselves. Without a doubt, some women are equal partners with their husbands on these decisions. Others feel more comfortable raising the issue after having given birth to a child or having an abortion.[262] At the other extreme, a Romani man may be perceived as "master of [his wife's] belly" [263] who might abuse or otherwise shame her if she uses contraception without his agreement. A consequence of such dynamics may be heightened stigma around seeking care for STDs or HIV. Women might not seek medical attention if they fear violence, abandonment, neglect (of their health and material needs), destitution, or ostracism from their sexual partner, family and community.[264]

Romani adolescents may be particularly affected by traditions and gender roles that impede access to information on sexual health. Generally, ignorance about STDs and HIV are likely to be widespread among adolescents and young people – the very groups who are likely to be more sexually active than others, and who have poor access to STD services.[265] Romani girls whose families or communities adhere to traditions that equate a girl's virginity with family honour, and which place the responsibility for sex education on a mother-in-law or sister of a husband, may have particular difficulty accessing this information. Given the stigma in many Romani communities associated with non-heterosexuality,[266] the same is true for youth and adults who seek information on other sexual orientations.[267] For instance, information on reproductive and sexual health relevant to bisexual or lesbian women may be difficult to come by.

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[259] "Women and HIV/AIDS" Fact sheet 242, June 2000, World Health Organization.
[260] *See*, *e.g.,* "Women's Rights", in Roma Rights No. 1, 2000, *supra,* note 45; Etudes Tsiganes: "Femmes Tsiganes", Paris, Vol 10, Second semester, 1997; "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, at 19.
[261] "Human Rights, Women, and HIV/AIDS", *supra*, note 225.
[262] Interviews, Zefyri, Greece, 12 November; Plovdiv, Bulgaria, 20 November 2001.
[263] Interview, Stein, the Netherlands, 10 October 2001.
[264] "Human Rights, Women, and HIV/AIDS", *supra*, note 225.
[265] "The public health approach to STD control", UNAIDS Technical Update, May 1998, p. 5.
[266] *See, e.g.,* "Everything we don't want to hear!", Notebook, Roma Rights No. 1, 2000, *supra,* note 45.
[267] The Foundation for Promotion of the Roma Youth in the Fakulteta district of Sofia, Bulgaria, organized in Spring of 2002 a seminar for young homosexual Roma on the social issues they confront related to their sexuality. Correspondence, Foundation for Promotion of the Roma Youth, 28 August 2002.

The CEDAW General Recommendation on Women and Health calls on States parties to "ensure the rights of female and male adolescents to sexual health education by properly trained personnel in specially designed programmes that respect their rights to privacy and confidentiality."[268] Ensuring that such services are available to Romani youth in a non-discriminatory manner might entail identifying traditions and gender dynamics in local communities in order that programmes are developed in ways that will reach these groups.

Government-linked initiatives have begun to address these issues. Finland's Ministry of Social Affairs and Health proposes that school nurses act as a liaison between young Roma and teachers on issues of sexuality.[269] In Hungary, the WHO Regional Office for Europe, Ministry of Health and Minority Office of the Prime Minister organized a peer education project for Roma teenagers who do not attend school. Roma youths attending secondary school were trained to collect data on tobacco and alcohol use, self-acceptance, and sexual health among their peers, with the objective of improving knowledge of and access to health services.[270] They are hoped to become the core of a future Roma peer educator system in Hungary.

NGOs have also addressed Romani adolescents' need for information in various ways. The NGO Romano Missio in Helsinki, Finland, is developing health education programmes for adolescent girls that provide the opportunity to ask questions of Roma or non-Roma Finnish women which, for various reasons, they cannot ask their mothers.[271] In the Fakulteta district of Sofia, Bulgaria, the Foundation for Promotion of the Roma Youth has organized discussions on prevention of STDs and HIV/AIDS. These seminars addressed issues such as the importance of knowing about one's body and about contraception, particularly in the context of changing traditions around marriage where Romani youth are more likely to engage in pre-marital sex.[272] And the Autonomous Women's Centre in Belgrade has translated the groundbreaking women's health information book "Our Bodies, Our Selves: A Book By and For Women"[273] into Serbian.[274] Access to such programmes and resources should be prioritised to assist adolescent youth, particularly girls, to acquire information and sexual health assistance for themselves.

To improve access to sexual health care, States should consider adopting, among others, the UNAIDS "public health package" approach. This includes promoting safer sex behaviour and condom use; promoting general health care seeking behaviour; and the integration of culturally sensitive STD control into health care services.[275] For women, information and service provision should be coordinated with education and employment opportunities that empower them to control sexual relations and other aspects of their lives.[276] Specific interventions should also be aimed at Roma men, whose participation and assumption of responsibility is integral to

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[268] CEDAW Committee, General Recommendation 24: Women and health, adopted at 20th session, 1999, Article 18.

[269] "Strategies of the Policy on Roma", Ministry of Social Affairs and Health, Finland, Reports 2000:8 (Eng) p 89.
[270] "Training for gypsy peer educators", A WHO/MTP project, *supra*, note 30.
[271] Interview, Helsinki, Finland, 19 October 2001.
[272] Correspondence, Foundation for Promotion of the Roma Youth, 28 August 2002.
[273] "Our Bodies, Ourselves: A Book By and For Women", Boston Women's Health Book Collective. Available at: http://www.ourbodiesourselves.org/adapt.htm for information on translations and adaptations.
[274] Interview, Belgrade, Serbia, 5 November 2001.
[275] "The public health approach to STD control", *supra,* note 265.
[276] "Women and HIV/AIDS", *supra* note 259, p. 2.

protecting women's health.[277] (Most Roma mediators are women; whether men should be trained to work especially on issues of sexuality and gender might be considered. For example, the Foundation for Promotion of the Roma Youth has engaged Roma boys as peer educators on issues of contraception and STDs.[278]) More research is needed to identify the elements of successful programmes with these aims, and to explore opportunities for government-NGO collaboration.

Health mediators could assist with STD/HIV prevention and control in various ways. They might devise creative approaches to educate members of Romani communities about the dangers of unprotected intercourse, symptoms and treatment available for STDs/HIV. Mediators could encourage adults and youth of both sexes to engage in dialogue about the value of virginity and everyone's right to autonomy and freedom of choice in all decisions relating to sexuality.[279] To improve adolescents' access to sexual health care, mediators might explain to parents the ways in which information can empower young girls to make responsible and healthy choices.

3. Domestic violence and Romani women

The Council of Europe's Steering Committee For Equality between Women and Men defines violence against women and its consequences to include:

> "…all forms of coercion and means of intimidation, punishment, relegation to gender-stereotyped roles, undermining of self-esteem or personality and impairment of physical or intellectual capabilities. Comprising physical, sexual, and psychological violence, it threatens the fundamental rights, individual freedom and bodily integrity of the victims."[280]

By definition, violence detrimentally affects women's health, therefore it violates the right to the enjoyment of the highest attainable standard of physical and mental health enshrined in Article 12 of the ICESCR. Specifically, violence has a direct negative impact on several important health issues, including safe motherhood, family planning, and the prevention of sexually transmitted diseases and HIV/AIDS. More generally, violence causes extensive suffering and negative health consequences in the form of physical injuries, mental health problems, fatalities or suicide.[281] As a consequence, women experiencing violence may have reduced potential for self-realization, contributions to their community and the larger society.[282]

For all women, the consequences of violence on health are immense. For Romani women who face numerous barriers to accessing health care, protection from or remedies against violence,

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[277] Id., p. 4.
[278] Correspondence, Foundation for Promotion of the Roma Youth, 28 August 2002.
[279] "Human Rights, Women, and HIV/AIDS", *supra* note 225, pp. 1-2.
[280] "Ending Domestic Violence: Actions and Measures", Proceedings of the Forum (Bucharest (Romania), 26-28 November 1998, Council of Europe, EG/BUE(99)1, p 86.
[281] "Violence Against Women: A Priority Issue", Violence Against Women Information Pack, World Health Organization, p. 4. *See also* pp.12-15. available at:
http://www.who.int/violence_injury_prevention/vaw/infopack.html
[282] Id., p. 15.

the consequences can be especially grave. The need to "bring [the phenomenon of violence against women] out of the closed family environment"[283] as it relates to Romani women is thus particularly urgent.

The sources of violence against Romani women are complex, varying among and within communities where it takes place. Nevertheless, they can be summarized as violence in reaction to women's failure to adhere to traditional gender roles as defined by her partner or community, as well as to impoverished, stressful living conditions. Behaviors that challenge traditional conceptions of Romani men's authority and women's submissiveness and self-sacrifice for her partner and family[284] are frequently cited as justifications for domestic violence: challenging a husband's opinion, refusing to do what he asks, cursing, failing to procreate, refusing sex, or behaving contrary to a boyfriend's or father's wishes.[285] With regards to living conditions, Romani women identify financial worries, unemployment, fear for the future, forced settlement, insufficient food, and alcohol abuse as sources of men's anger and frustration that are expressed through violence.[286]

Studies have found that a woman steeped in patriarchal traditions may take for granted that failure to adhere to her assigned roles as wife, mother and woman justifies violence against her.[287] Dependence on her partner for economic support and community ties may inhibit a woman from speaking out against abuse.[288] A lack of alternative examples of marital relations may lead women to believe that being hit is a sign of love or affection. Indeed, numerous interviews with Romani women have supported these views.[289]

Other factors contributing to the silence around violence against women in Romani communities include a low level of awareness of the rights associated with freedom from violence, and little empowerment to apply this knowledge. This is particularly likely among women with low levels of education. As a result, the root causes of violence are not addressed – only the symptoms, if at all. Some women described typical family or community interventions to consist of questioning whether a husband's reasons for hitting his wife were valid, and not whether he had

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[283] "Rationale", European Campaign to Raise Awareness of Violence against Women, the European Commission. http://europa.eu.int/comm/employment_social/equ_opp/violence_en.html. As per decision no. 293/2000/EC of the European Parliament and of the Council, 24 January 2000, "adopting a programme of Community action (the Daphne programme) (2000-2003) on preventive measures to fight violence against children, young persons, and women."

[284] "Ending Domestic Violence: Actions and Measures." *supra*, note 280, p. 85.

[285] Interviews, Paris, France, 10 December; Dublin, Ireland, 6 December; Stein, The Netherlands, 10 October; Chisinau, Moldova, 18 September; Nis, Serbia, 6 November; Plovdiv, Bulgaria, 20 November; Vidin, Bulgaria, 18 November, 2001.

[286] Interviews, Toulouse, France, 11 December; Ploiesti, Romania, 14 September; Sofia, Bulgaria, 19 November; Chisinau, Moldova, 18 September, 2001.

[287] "Ending Domestic Violence: Actions and Measures", *supra*, note 280, p. 85.

[288] "Lack of economic independence forces many women to stay in violent relationships. The abrogation of their family responsibilities by men can be a form of violence, and coercion. These forms of violence put women's health at risk and impair their ability to participate in family life and public life on a basis of equality." CEDAW Committee, General Recommendation No. 19, *supra,* note 254, at para. 23.

[289] Interviews, Plovdiv, Bulgaria, 20 November; Nis, Serbia, 6 November; Ploiesti, Romania, 14 September; Vilnius, Lithuania, 16 October; Chisinau, Moldova, 18 September; Zefyri, Greece, 12 November, 2001.

a right to hit her.[290] Where women are aware of these concepts, concern with preserving family honour or an interest in maintaining smooth relations between the family and community are significant deterrents to seeking help. Like majority women, Romani women may refuse to intervene on behalf of a neighbour living with domestic violence, or withdraw a complaint made to the authorities in the interest of avoiding such tensions.[291]

The lack of resources such as counselling or shelters can further contribute to Romani women's silence around domestic violence, as it would for majority women. Research is required to determine whether existing services are accessible to Romani women on an equal basis. Ireland's National Strategy for Traveller Health includes monitoring of access to women's refuges to ensure that no barriers exist for Travellers and that they are inclusive of Travellers' needs.[292] Moreover, any research projects undertaken on the issue of violence against women will include a Traveller dimension.[293] Other States should consider incorporating such measures into their Roma strategies.

In many Romani as in other communities, domestic violence is addressed by members of the community – family members, neighbours, elders, or a community judge; help from public authorities is rarely sought. In cases where authorities have been contacted, some women describe what may constitute discriminatory treatment by authorities of their complaint. Authorities may be reluctant to arrest a perpetrator on the assumption that since some Romani women (like majority women) withdraw a complaint, then all women are likely to do so.[294] The National Traveller Women's Forum in Ireland has expressed concern that police may take advantage of a call to a Traveller community to search for illegal conduct or unregistered vehicles.[295] In a Romani community in Romania, women expressed fear that a complaint to authorities might result in the imposition of a fine on both the woman and man involved for disturbing the peace, or eviction for failing to make available proof of a rent contract or permanent domicile.[296] Such practices may constitute both ethnic and gender discrimination and should be investigated. Moreover, they may have potentially dangerous consequences for the woman who sought police intervention if the community perceives the visiting authorities as a threat.

Despite the difficulties described above, Romani women are challenging rigid gender roles and their consequences for women's well-being. At the same time, organizations working on their behalf are taking action against violence against women in the home. Pavee Point, in Dublin, Ireland has undertaken to train Traveller women as refuge/crisis workers, and to work with young Traveller men to challenge domestic violence against women in their community.[297] In

[290] Interviews, Chisinau, Moldova, 18 September; Zefyri, Greece, 12 November, 2001.
[291] Interviews, Strasbourg, France, 4 December; Toulouse, France, 11 December; Chisinau, Moldova, 18 September; Niš, Serbia, 6 November, 2001.
[292] Traveller Health – A National Strategy 2000-2005, Ministry for Health and Children, Ireland, 2002, item 36.
[293] Id., point 38.
[294] Interviews, Nis, Serbia, 6 November; Ferenesti, Romania, 14 September; Chisinau, Moldova, 18 September, 2001.
[295] Interview, Dublin, Ireland, 6 December 2001.
[296] Interview, Ferenesti, Romania, 14 September 2001.
[297] *See* Fay, Ronnie. "Pavee Beoirs Breaking the Silence: Racism and Violence Against Women." Pavee Point Traveller's Centre, Dublin, Ireland.

England, the Community Health Sheffield Trust, in cooperation with health visitors for Travellers, has produced a leaflet to explain elements of Gypsy and Traveller culture and customs to help personnel who assist women and children living with domestic violence.[298] The leaflet addresses some of the difficulties women face in leaving close-knit communities as well as problems that might arise in refuges between Traveller and non-Traveller women. Physicians from Mizil, Romania, have sought training and information exchange on responses to domestic violence from colleagues elsewhere in Romania and abroad.[299]

Whatever the efforts of civil society, the State has ultimate responsibility to prevent violations of rights, investigate and punish acts of violence, or provide compensation.[300] Such obligations exist under CEDAW, and extend to private actors.[301] Nevertheless, where States are not yet doing so, they should seek to coordinate responses with existing efforts by Romani women to combat violence against women in their communities. In this way, States can come to understand the unique dimensions of domestic violence in diverse Romani communities and develop effective interventions.

The CEDAW Committee's recommendations indicate that State measures to address the health and rights issues implicated in violence against women must encompass a multi-sectoral response.[302] In the context of assistance for Romani women, these can be interpreted to require public information and education programmes to change attitudes in Romani communities concerning the roles and status of men and women.[303] Support services – refuges, specially trained health workers, rehabilitation and counselling – should be established and maintained, with special attention to cultural sensitivity and accessibility for isolated Romani communities and rural women.[304] (In Slovenia, women's refuges have reportedly refused entry to Roma women out of fear of conflicts due to the "differing approaches to hygiene of Roma and non-Roma."[305]) Law enforcement and judicial officers should undergo anti-discrimination, gender and cultural sensitivity training,[306] and there should exist effective complaints procedures and civil remedies that consider gender dynamics and dispute resolution within Romani communities.[307] State action to combat domestic violence should also be coordinated with women's economic empowerment programmes.[308] In all these cases, special measures may be

[298] "Supporting Gypsy and Traveller Women and Children Living with Domestic Violence", N7877, Community Health Sheffield Trust, 1998.
[299] Interview, Mizil, Romania, 14 September, 2001.

[300] CEDAW Committee, General Recommendation No. 19, *supra,* note 254, para. 9.

[301] Id.
[302] *See* General Recommendation No. 19, *supra,* note 254.
[303] Id., para. (d), (f).
[304] CEDAW Committee, General Recommendation No. 19, *supra,* note 254, para. (k), (o). Ireland's National Traveller Health Strategy also includes a provision to encourage refuges to develop and adopt anti-racist codes of practice and to provide in-service training in anti-racism and interculturalism. Traveller Health – A National Strategy 2000-2005, *supra,* note 292, item 40.
[305] Minority Protection in the EU Accession Process, *supra,* note 10, p. 505.
[306] On training on violence against women for the criminal justice system, *See also* A Focus On Women, WHO/MSA/NAM/97.4, World Health Organization, 1997.
[307] CEDAW Committee, General Recommendation No. 19, *supra,* note 254, para. (b), (i).
[308] *See* Id., para. 24(p).

required to guarantee that Romani women have equal access to rights training, protection services and remedies

For Romani women who do not seek authorities' assistance, health workers may be the only point of contact with public services that can offer support and information.[309] Health workers should therefore establish contacts with governmental agencies and NGOs that offer support, counselling and legal assistance in a manner sensitive to the needs of diverse Romani women.

Finally, the intimate nature of domestic violence and the likelihood that Romani women will not seek state intervention provides an opportunity for mediators to work on a range of initiatives to address this problem. Mediators might assist state authorities and health care workers to identify adequate responses according to the traditions and needs of particular communities. They can support women living with violence in their assertion of rights, as well as in obtaining counselling, protection, and legal remedies. Also, mediators might engage the community in dialogue with the aim of changing conceptions of marriage to a model based on gender equality between partners.

4. Access to mental health care

Access to mental health care is an integral component of the right to health: "the creation of conditions which would assure to all medical service and medical attention in the event of sickness, both physical and mental, includes the provision of … appropriate mental health treatment and care.[310] In describing States Parties obligations, the General Comment on the Right to the Highest Attainable Standard of Health declares:

> States have to ensure the appropriate training of doctors and other medical personnel, the provision of a sufficient number of hospitals, clinics and other health-related facilities, and the promotion and support of the establishment of institutions providing counselling and mental health services, with due regard to equitable distribution throughout the country."[311]

Clear links have been established between poverty, poor living conditions, women's subordinate social status, and heightened risk of mental illness.[312] Among women generally, both depression and post-traumatic stress disorder are reported to be twice as common as in men.[313] These observations signal a need for access to mental care for the most vulnerable members of society, particularly women.

[309] "Violence Against Women: A Priority Issue", *supra,* note 281, p. 3.
[310] CESCR General Comment 14, *supra,* note 3, para. 17.
[311] Id., para. 36.
[312] Jill Astbury, "The State of the Evidence: Gender Disparities in Mental Health", WHO Collaborating Centre in Women's Health, School of Population Health, University of Melbourne, p. 74.
[313] Id., p. 78.

In many communities visited for this report, Romani women spoke of the overwhelming nature of economic worries, caretaking responsibilities, relations with their partners, and interaction with public services. These observations coincide with those of NGOs working in the field. Among migrant Roma in irregular situations, Médecins du Monde has found that 12% of men and 21% of women suffer from neuro-psychic illnesses.[314] One study in Romani settlements in Belgrade has found that "a large number of [Romani] women suffer the consequences of strong and frequent states…of stress like mood disorders, anxiety and somatisations such as headache, back pain, breathing problems."[315] Amongst Travellers, stress resulting from poorly equipped stopping sites or forced mobility because of a lack of legal sites has been noted as a significant potential source of depression.[316] Compounding factors include the hostility of settled populations and a sense of containment and restriction by "apparently needless" rules, for example, on the number and type of caravans and visitors.[317] The potentially widespread occurrence of these problems indicates that urgent attention is required to ensuring access to mental health services for Romani communities as well as addressing the root causes of these problems.

A project to examine access to mental health services for Gypsy-Travellers has recently been undertaken by Sheffield University in England.[318] Research such as this is required to encourage mainstream services to accommodate to the needs of these groups in a culturally sensitive and non-discriminatory manner.

Mediators can promote research and service provision efforts by helping to familiarize mental health professionals and Romani communities with each other. Mediators might be of special assistance in identifying members of a Roma community who require professional care, since the close emotional bonds and safety net on which many Roma communities pride themselves may inadvertently delay recognition of such cases. Special attention might be given to adults who have heard of psychological assistance only in the context of institutionalisation or correction of child behaviour. For example, where Roma parents have felt the need to defend their often-discriminated-against children as "not crazy," they might need assistance to understand the breadth and benefit of available services.[319] In devising interventions, care should be taken to avoid stigmatising Roma, Gypsies, and Travellers: efforts should be devised with the aim of integration into mainstream health services.

[314] "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 25.
[315] "Report on Medical Issues", Autonomous Women's Centre, *supra,* note 15.
[316] Lloyd and Morran, "Traveller Health Issues in Scotland – Submission to the Secretary of State's Advisory Committee on Scotland's Travelling People", *supra,* note 170, p. 5.
[317] Id.
[318] Interview, Sheffield, England, 24 October 2001.
[319] Interviews, Amsterdam, The Netherlands, 11 October; Vidin, Bulgaria, 18 November 2001.

5. Access to substance abuse treatment

Like mental ill-health, substance abuse is more common in circumstances of poverty, discrimination, and socio-economic disadvantage – those in which a disproportionate number of Roma find themselves. Moreover, substance abuse poses particular difficulties for, and may require different treatment for, women.

There exist varying degrees of awareness about alcohol abuse among Romani communities. Some Romani women's experiences have led them to believe that it is normal to have alcoholic husbands; many men and women may be unaware of the potential harms of alcohol abuse; a few individuals may know where to seek help and are familiar with persons who have been treated successfully. The need for accurate information is urgent, however: a WHO study found that 41% of Roma teenagers in Hungary consume alcohol regularly;[320] the Autonomous Women's Centre NGO in Belgrade found that while alcohol consumption was low among Roma women living in settlements, it was very high among men.[321]

With respect to drugs, there seems to be markedly less awareness about rates of abuse, let alone access to information about harms or possibilities for treatment. More investigation is required to determine the need for drug abuse treatment among Roma in various communities, and whether these communities have equal access to information and rehabilitation resources.

Research has shown that women drug users generally have fewer options for supporting themselves and their families and are at greater risk of violence and HIV infection.[322] In light of these observations, the International Harm Reduction Development Program of the Open Society Institute has targeted Romani women through several initiatives. These include: organizing a seminar for Roma social care providers in Prague to learn about harm reduction and exchange strategies for service delivery; providing training on the needs of minority communities for harm reduction organizations that serve a large Roma population; and working with Roma leaders to develop culturally appropriate service models.[323]

The extent of home, child care and other responsibilities borne by Romani women nevertheless suggests that men are more likely to suffer from substance addiction within Romani communities.[324] Awareness-raising about prevention and treatment is necessary among men, and raises the question of whether Roma mediator programmes, originally conceived around female mediators, could be more active and effective in combating substance abuse with male counterparts. At the same time, the stress and instability that men's drug abuse is likely to cause their partners and families suggests a need for outreach to support women and children as well.

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[320] "Training for gypsy peer educators", *supra,* note 30, Annex 1: Summary of the closing report of the survey: Alcohol consumption.
[321] "Report on Medical Issues", Autonomous Women's Centre, *supra,* note 15.
[322] Submitted by the Open Society Institute to the Roma/Migration Division, Council of Europe, for the Romani Women and Access to Public Health Care Project.
[323] Id.
[324] "Working with the Gitana Community: A guide for social services providers on substance abuse intervention" ("Actuar con la comunidad Gitana: Orientaciónes para la intervención en drogodependencias desde los servicios asistenciales"), Asociación Secretariado General Gitano, Madrid, 1996.

Programmes do exist to assist Roma with substance addictions through preventive and treatment measures. With the aim of improving substance abuse services for Roma, the Asociación Secretariado General Gitano (ASGG) in Madrid has established programmes to sensitise health and other professionals to the Gitano community. Access to care, contact with personnel, maintaining participation in treatment, work with families, and prevention are among the topics discussed. Examples of drug intervention programmes organized by ASGG include education on how parents can take a proactive role in preventing drug use in their families and a mediator-led comic book for children on drug prevention. These programmes form part of "Sastipen" – the European Network for Drug Abuse and HIV/AIDS prevention in the Roma community.

The WHO European Alcohol Action Plan 2000 – 2005 recommends support for programmes that strengthen community mobilization, development and leadership for the prevention of alcohol-related problems.[325] Where they do not already address substance abuse issues, mediators – women and men, and of varying age groups – could have a significant impact on shaping attitudes towards alcohol and drugs, guiding community members in need to treatment and providing support for Roma and their families.[326]

[325] *See* "European Alcohol Action Plan 2000 – 2005" WHO Regional Office for Europe, 2000 Available at: http://www.euro.who.int.
[326] Interview, Madrid, Spain, 27 November 2001.

PART III

A. Access to documented legal status

1. Access to legal status

Of fundamental concern to accessing health care and public services is acquisition of documented legal status since it is a prerequisite for obtaining a whole range of rights and freedoms. In many countries, Roma comprise a significant number of persons who do not possess legal status or documentation of it. This situation is generally the result of one or more interrelated factors: a lack of information and/or understanding of the procedures or time period within which legal status may be secured (including a lack of awareness registration requirements), difficulties in proving nationality, discriminatory treatment, mistrust of the authorities or a combination of these factors.[327] As has been noted by ECRI in the context of Croatia, certain groups such as minorities, the displaced, and those who encounter difficulties in validating documents or obtaining citizenship – among whom Roma number a high proportion – are all susceptible to difficulties and discrimination in obtaining health care and other benefits.[328]

Under the 1954 United Nations Convention relating to the Status of Stateless Persons, States are called upon to naturalize stateless persons in the interest of ensuring their enjoyment of fundamental rights and freedoms without discrimination.[329] In the interest of avoiding greater economic, social, and political exclusion of persons who already find themselves in marginalized conditions, the OSCE HCNM has recommended that "laws on citizenship and aliens should be drafted and then implemented in such a way as to not increase the number of stateless persons, to take into account extensive if not life-long residence in the country, and to serve as the basis for loyal citizenship bonds to the state."[330] Because of the critical link between legal status and access to services, States are encouraged to provide legal identity with due consideration to humanitarian concerns when implementing citizenship [and other status] requirements. [331]

In some countries Roma may experience problems in accessing legal status (including citizenship) because the authorities do not recognize their place of residence or because they lack legal tenure. In Italy, authorities have been known to deny residence papers to Roma dwelling in unauthorized camps, thus effectively precluding Roma from acquiring Italian citizenship.[332] Likewise, in the Czech Republic many Roma encounter difficulties in producing proof of

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[327] Paivi Hernesniemi, Lauri Hannikainen. "Roma Minorities in the Nordic and Baltic countries - are their rights realised?" Juridica Lapponica No. 24, Northern Institute for Environmental and Minority Law, University of Lapland, 2000. *See also,* Zoon, *supra,* note 14 at pp. 37 and 107.

[328] ECRI, Second report on Croatia, *supra,* note 149 at para. 32.

[329] Preamble, Convention relating to the Status of Stateless Persons, Adopted on 28 September, 1954 by a Conference of Plenipotentiaries convened by Economic and Social Council resolution 526 A(XVII) of 26 April, 1954.

[330] Roma (Gypsies) in the CSCE Region Report of the High Commissioner on National Minorities, Conference on Security and Cooperation in Europe, 1993. Section 3.3. Migration, para. 8.

[331] Id., Section 5.2, General Recommendations, para. 4.

[332] "Campland: Racial Segregation of Roma in Italy", Country Report Series No. 9, European Roma Rights Centre, Budapest, Hungary, October 2000, p. 20, footnote 47.

residence required to acquire Czech citizenship. They may also confront discrimination by local officials, in the form of discouragement or misinformation in pursuing legal status applications.[333] High administrative fees, among other factors, have been noted as an obstacle to acquiring citizenship of the Former Yugoslav Republic of Macedonia for many Roma and members of other ethnic groups who suffer from especially high levels of unemployment and poverty.[334] In Serbia, where large numbers of Roma are not registered and lack personal documents such as identity cards this has been cited as a key reason for Roma's failure to resettle effectively and gain even temporary access to services: in Novi Sad, Roma are reported to have been denied medical aid if they lacked updated health cards.[335] Internally displaced persons from Kosovo face additional problems. Unable to officially register their stay due to the fact that they live in unlegalised settlements, they experience problems in gaining not only ID or Social Security cards, but also IDP cards which are necessary to receive humanitarian aid.[336]

A broad range of measures might be implemented to remove these obstacles. These include: flexibility in administrative rules concerning proof of residency; strict central government supervision over local officials, and awareness-raising campaigns among Roma of the importance and methods of acquiring legal status – preferably in cooperation with Roma organizations.[337] State efforts to facilitate acquisition of legal status include steps by the Ministry of the Interior of the Former Yugoslav Republic of Macedonia to heighten transparency in the citizenship application process, liberalize naturalization requirements, waive fees for individuals receiving state social assistance, and to take special initiatives to assist the Roma community.[338] An NGO in Belgrade – Bibija Rroma Women Centre – has launched a European Community supported project with two local NGOs to improve local Roma settlements. A significant component of the project is to secure the legal status of the inhabitants, many of whom are victims of the Balkan conflicts, and to integrate them into city services.[339]

In addition to ensuring that the procedures for acquiring legal status are developed and implemented in a non-discriminatory manner, States should ensure that non-discriminatory and culturally sensitive practices are followed in the course of procedures relating to migrants and immigrants, with particular attention to the problems of women. Where health care is made available, fears of excessive surveillance, complicity of health care workers in migration

[333] ECRI Second report on the Czech Republic, (CRI (2000) 4), adopted 18 June 1999, para. 6.
[334] ECRI Second report on the Former Yugoslav Republic of Macedonia, CRI (2001) 5, adopted 16 June 2000, para. 6-7.
[335] Fitzpatrick, Catherine A., "Forgotten Refugees: Roma in the Balkans", Radio Free Europe/Radio Liberty (Un)Civil Societies, Vol. 3, No. 43, 23 October 2002, available at: http://groups.yahoo.com/group/balkanhr/message/4709, citing the European Roma Rights Centre report on observations by the Novi Sad Humanitarian Centre.
[336] Serbian Draft Strategy for the Integration and Empowerment of the Roma, 13 December 2002, p. 13. *See also*, Bibija-Rroma Women's Centre, Alternative Report on the Implementation of the Framework Convention for the Protection of National Minorities: the Situation of Roma Women in Serbia and Montenegro, 27 March, 2003, submitted to the Council of Europe May 2003.
[337] *See* ECRI Second report on the Former Yugoslav Republic of Macedonia, *supra,* note 334 para. 7-9; ECRI Second report on Croatia, *supra,* note 149 at para. 32; ECRI Second report on the Czech Republic, *supra,* note 333 at para. 6.
[338] ECRI Second report on Macedonia, *supra,* note 334, para. 8-9.
[339] Interview, Belgrade, Serbia, 5 November, 2001; *See also* "Rroma Women Centre Bibija Annual Report", Belgrade, Serbia, 2001, p. 34.

proceedings, and lack of information on the documents required to access services all pose practical barriers to receiving assistance.[340]

Some States have taken action in this regard. In France, health care insurance has been extended to everyone living in the national territory and provides 100% coverage to persons with a very low income.[341] The Convention on the Rights of the Child can be interpreted to guarantee health care insurance to children, including children with parents with irregular legal status; this should be fulfilled by all States Parties.[342]

2. Access to identification documents

Proper identification documents such as birth certificates, personal identity documents, local residence permits, marriage certificates, work booklets, passports, and others are generally mandatory for access to a broad range of rights and services. For a variety of reasons, however, many Roma do not possess such documents. "In many instances, the lack of one document can lead to a "chain reaction", in which the individual at issue is unable to secure a number of such documents. In the extreme case, a Romani child without a birth certificate may wind up in a situation of complete paralysis with respect to the exercise of basic rights: precluded access to basic health care, effectively hindered freedom of movement (including the right to leave one's own country), denial of the right to vote, exclusion from state housing provided to persons from socially weak groups, and others.[343] Among the obstacles are cost and other administrative barriers, a lack of information, and discrimination by authorities. Insofar as official registration and associated documents provide information upon which appropriate policies and provision of public services are determined, States are encouraged to prioritise registration and documentation for all.

In Moldova, identity documents may be prohibitively expensive for as much as 30% of the population, a disproportionate number of who are Roma.[344] Since identity documents are a

[340] "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 24.
[341] Concluding Observations of the Committee on Economic, Social and Cultural Rights: France, *supra,* note 138, para. 11.
[342] Article 2 of the CRC ensures that the rights set forth in the Convention will be guaranteed to each child without discrimination of any kind. Under Article 22, States Parties agree to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, whether unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the Convention; this would include the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health (Article 24(1)). According to Médecins du Monde, these obligations are fulfilled only by Spain. "ROMEUROPE Project Final Report, 1999-2000", *supra,* note 19, p. 15.
[343] "ERRC: Personal Documents and Threats to the Exercise of Fundamental Rights among Roma in the Former Yugoslavia", Press Release for conference held 6-8 September, in Igalo, Montenegro. The conference called for systematic attention by authorities to this issue, and recommended that states of the former Yugoslavia work proactively to design and implement strategies to end statelessness among Roma on their territories, as well as to alleviate the crisis of rights deprivation generated by a widespread lack of basic documents among Roma. Available at: http://www.errc.org/publications/letters/2002/montenegro_sept_18_2002.shtml.
[344] Interview, Chisinau, Moldova, 18 September 2001.

prerequisite for the enjoyment of other rights, States confronting a similar situation should consider special measures to assist persons who cannot pay applicable fees.

Identity documents are usually issued on the basis of birth certificates. For various reasons, individuals may not possess birth certificates: children born at home may not be registered by their parents, whether out of neglect, lack of funds or information on the importance of doing so.[345] The cost of securing legal assistance for an ex-post-facto registration and any fines may also be prohibitive to some parents.[346] These circumstances may be particularly common for Roma who do not have regular access to medical care or social benefits, through which birth registration could be facilitated. The Advisory Committee of the Framework Convention has expressed concern with regard to credible reports from various sources that maternity units in some Romanian hospitals have denied birth certificates to new mothers – many of them Roma – because they are unable to pay medical costs for childbirth.[347] According to the Romanian Government, the real problem lies in the fact that hospitals in Romania cannot issue birth certificates to new mothers without a certificate from the city hall, where the newborn baby must first be registered. If the mother has no identification documents herself, the city hall cannot issue the certificate the hospital needs. To obtain identification documents for the mother of a newborn baby in this situation is a costly process for the family (in terms of both money and time), leading some Roma to give up hope of obtaining a birth certificate.[348] A bureaucratic cycle is thus perpetuated whereby parents who are not fully in the system are unable to register their offspring.

Roma have also been refused treatment at some public hospitals in Romania on the basis of their inability to prove that they are covered by medical insurance.[349] The UN Committee on the Rights of the Child recently expressed concern that the right to official birth registration in Greece is not being respected for Roma children as a result of lack of information on procedures, lack of legal representation, and the lack of sufficiently decentralized services.[350] States should take measures to facilitate and enforce birth registration; here too, special measures might be considered for parents who have difficulty providing the necessary information or paying applicable fees. Preventive measures, including documentation campaigns and staff training, are urgently required to ensure access to health care on a non-discriminatory basis and to avoid potentially dire health consequences.

In Romania, the Department for the Protection of National Minorities and the Inter-Ministerial Commission for National Minorities have begun to address the lack of identification documents among Roma in cooperation with the Working Group of Roma Associations.[351] The Framework Convention Advisory Committee encourages the broadening of this effort to address the situation of children of the persons assisted, as well as that of persons detained by police because they

[345] *See* Zoon, *supra,* note 14, pp. 35-37.
[346] Zoon *supra* note 14, p. 36**;** correspondence**,** Greek Helsinki Monitor, Athens, Greece, 13 January, 2002.
[347] FCAC Opinion on Romania, *supra,* note 26, para. 28.
[348] Comments prepared by the Government of Romania (on file with the Council of Europe).
[349] Id.
[350] Concluding Observations of the Committee on the Rights of the Child : Greece. CRC/C/15/Add.170, 1 February, 2002, para. 40(a).
[351] *See* Zoon, *supra*, note 14, pp. 37-39.

lacked identity documents.[352] In Bulgaria, the Romani Baht Foundation has undertaken to assist Roma from the Fakulteta District of Sofia to obtain identity documents as well as to clarify their rights with respect to these documents.[353]

In the interim, measures should be taken to improve access to health care for persons who do not have proper documents to access mainstream health and other public services. In contexts where family physicians are the primary source of health information, public health officials should provide alternative sources of assistance to persons without the documentation normally required to access a physician. Some States are taking such steps. For example, one element of Portugal's recently promulgated National Plan of Inclusion[354] makes provision for mobile health units to improve access to health care for vulnerable groups. Roma who are not Portuguese citizens can access the National Health system in this way.

NGO efforts include the "Lifesaving Vouchers" project in Sofia, Bulgaria to assist seriously ill Roma without proper documentation. This effort has been organized by Romani Baht, the Foundation for Assisting Charity in Association with the Vth Sofia City Hospital and Foundation for Promotion the Roma Youth. The two foundations provide money for medical care of these patients in exchange for the right to monitor treatment and request statistics on the needs and outcomes.[355] Near Vilnius, the Lithuanian Children's Fund seeks to assist integration of the many unregistered Roma living in the isolated and impoverished Kirtimai camp through the provision of medical visits for mothers and children, as well as pre-school education in a new Community Centre.[356] Governments that have not yet taken steps to address documentation issues might explore similar initiatives.

[352] FCAC Opinion on Romania, *supra,* note 26, para. 42.
[353] Interview, Sofia, Bulgaria, 19 November, 2001
[354] *See* National Plan of Inclusion, Resolution of the Council of Ministers, 91/2000, Government of Portugal.
[355] Interview, Sofia, Bulgaria, 19 November, 2001; Zoon, *supra*, note 14, p. 93.
[356] Interview, Vilnius, Lithuania, 16 October 2001.

B. Access to social benefits and health

Access to social benefits is directly linked with access to health care in that it includes access to non-contributory health insurance and other health-related benefits. Roma often confront numerous barriers to accessing social protection, some of which may be discriminatory.

States are reminded that international and regional legal instruments prohibit distinction among recipients on the basis of race. The ICESCR recognizes the right of everyone to social security, including social insurance, and States Parties undertake to respect and ensure its enjoyment without discrimination on the basis of race or other status.[357] The anti-discrimination provisions set out in the Racial Equality Directive extend to social protection, including social security and healthcare, and social advantages;[358] and the General Comment on the right to the highest attainable standard of health prohibits derogation from the core obligations of minimum services and non-discrimination in the distribution of goods and services.[359] As in the context of health care, special measures may be required to ensure access to social protection for Roma on an equal basis.

Unexamined stereotypes colour many Roma's interaction with local or national social welfare systems. In various countries, civil servants and majority populations may assume that Roma are wealthy and attempt to cheat the welfare system and the "real" poor by seeking benefits. A myth that Roma do not want to work like everyone else but seek money "the easy way" continues to circulate.[360] These stereotypes obscure the reality that the vast majority of Roma are over-represented among the people in need of social protection because of a combination of poverty, and exclusion from the mainstream economy and larger society.

While many European countries currently confront high unemployment rates, Roma may face additional barriers to securing employment because of information, physical or economic barriers. Such barriers may include racial or ethnic discrimination by prospective employers or in accessing education, or vocational training programmes. As a result, Roma constitute a high proportion of the long-term unemployed.[361] Those Roma who are engaged in "black-market" labour generally do not have access to health insurance and social protection; others may engage in informal or formal jobs such as street cleaning, scrap metal or refuse collection which pose health hazards, and against which Roma may not be protected. Persons who become ill under conditions where they lack health insurance or official documentation have difficulty gaining

[357] ICESCR Articles 9 and 2.1, respectively.
[358] Racial Equality Directive, Article 3.1(e).
[359] General Comment 14, *supra,* note 3, para. 47.
[360] A recent study by the World Bank on "Roma in an Expanding Europe: Breaking the Poverty Cycle" at p. 36 found that contrary to popular stereotypes, Roma do actively seek employment – more so than the majority population in some cases.
[361] *See generally* "Minority Protection in the EU Accession Process", *supra,* note 10. The high proportion of Bulgarian Roma among the long-term unemployed and the dependence of a majority of Roma households on social support for survival have been noted in Bulgaria. Minority Protection in the EU Accession Process, *supra,* note 10 at 92. ECRI calls for monitoring of the situation of various minority groups in the labour market to identify possible areas of discrimination, particularly in light of the high rate of unemployment among Roma – 71.8% compared to 32.4% among the general population, according to a 1999 survey. ECRI Second report on Macedonia, *supra,* note 334, para. 30.

access to health care. In turn, a state of poor health is not conducive to securing employment.[362] Thus the need for access to social protection for many Roma may be especially high, and the call to address shortcomings in this area, particularly urgent.

In fact, many Roma lack access to information about social benefits. Some are unaware of the benefits to which they are entitled and the methods for accessing them: for instance, they may not be informed that registration at an unemployment office entitles them to non-contributory health insurance, or that they must return periodically to this office to maintain their entitlement. Frequently access to a doctor depends on registration with an unemployment office as proof of entitlement to care. The low registration rate of unemployed Roma has been noted at Labour Exchange offices in Lithuania, on official social welfare lists in Bulgaria, and elsewhere.[363] Among the consequences are a lack of access to health insurance and thus medical treatment, if not an ineligibility for any kind of social support altogether.

The Social Foundation Stolipinovo, in Plovdiv, Bulgaria, has estimated that 80% of the local Roma population – a majority of whom are unemployed – was not registered with a general practitioner because of unfamiliarity with procedures.[364] Thus the organization has engaged volunteers from the community to assist with registration for both unemployment and access to physicians. Furthermore, it has supported Romani Chai – a local Romani women's group – to arrange with local authorities for a space where two general practitioners – funded initially from Foundation resources – can serve poor community residents.[365] States confronting a similar situation should prioritise identification of the information barriers to registration with a view towards facilitating access to the health and other benefits for which registration is required.

For some Roma, access to social benefits is precluded because of the high cost of identity documents such as birth certificates and proof of civil marriage. Failure to check-in periodically at unemployment offices because of a lack of money for a bus ticket may result in a loss of social support, either because this is (mis-)interpreted by social workers as a lack of desire to seek employment, or because there is a lack of adequate provisions to guarantee practical access to social support.[366] ECRI has expressed concern that changes in Slovakia's welfare legislation that replaced financial support with food vouchers have prevented many Roma, among others, from using public transport, impeding their search for employment.[367] Thus ECRI has stressed that the allocation of various forms of welfare benefits should be decided upon on an individual basis and in a non-discriminatory fashion.[368]

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[362] *See,* "Report on the Situation of Roma and Sinti in the OSCE Area", *supra,* note 4, p. 120.
[363] Minority Protection in the EU Accession Process, *supra,* note 10, pp. 323 and 92, respectively.
[364] Interview, Plovdiv, Bulgaria, 20 November, 2001.
[365] Id.
[366] Transport services may be complicit in this loss: taxi drivers reportedly refuse clients from the Kirtimai camp outside of Vilnius who cannot show identification cards. Perhaps justified in their desire to avoid involvement in illicit activities reported to take place in the area, the drivers who are aware that many Roma lack identification may nevertheless be engaged in ethnic discrimination by denying them services. Interview, Vilnius, Lithuania, 16 October 2001.
[367] ECRI Second report on Slovakia, *supra,* note 125, para. 38.
[368] Id.

Access to social benefits may be denied to Roma on direct or indirect discriminatory grounds. Eligibility criteria such as age of motherhood or limitations on the number of children covered may have a disproportionate impact on Roma who constitute a significant portion of the population of young mothers and large families. In Bulgaria, denial of child allowances to mothers under sixteen years of age has been documented: insofar as Romani women constitute the majority of young mothers, this criterion would have a disproportionate impact.[369] In Romania, additional benefits for families with children introduced in 1997 limited benefits to a fixed amount for families with more than four children. But it was found, for example, that Romani women between the ages of 35 and 39 were responsible for five children on average, while women of the same age in the larger population had responsibility for only 2.1 children. Thus the facially neutral programme would have a disparate impact on Romani women.[370] Couples who follow a tradition of common law marriage may face multiple administrative barriers to accessing social protection. The name of a biological father on his child's birth certificate is generally required for the father to exercise parental rights such as collecting a child allowance. Many Roma are unfamiliar with the required procedures or unable to pay the associated costs.[371]

Social worker discretion may improperly deny access to benefits on discriminatory grounds. The following case from Slovakia represents an allegedly common type of experience of benefits denied on the basis of ethnicity:

> In May 2001, Peter Oračko came to the Roma Rights Centre to complain of what he believed to be the denial of medical services to his wife, Eva Oračkova, on the basis of racial prejudice. Mr. Oračko stated that his wife, who had recently undergone a hysterectomy, was denied access to a medical spa (a common post-surgery procedure in Slovakia) by the state institution responsible for payment. Eva Oračkova had been told by her doctor that this spa treatment was an essential part of her recovery, and words to that effect had been included in her file. After receiving notice of the unsuccessful application, Mr. Oračko went to the Social Insurance office to find out why she had been denied. Mr. Oračko was given his wife's paperwork, at the top of which was written the word, "Romka" (Roma woman). It is his belief, as well as that of the Roma Rights Centre, that Eva Oračkova may well have been denied access to the treatment she had been prescribed by her doctor on the basis of her ethnic Roma identity.[372]

Potential abuse of social worker discretion has also been alleged in determining qualification for single parent benefits,[373] or, more generally, for demanding payment from Roma for explanations of benefits and procedures.[374] These claims raise particular concern where clients are illiterate; identification documents that reveal a potential beneficiary's illiteracy may provoke further differential and inferior treatment.[375] Organizations such as the Romani Baht Foundation

[369] Zoon, *supra,* note 14, p. 49.
[370] Id., p. 32.
[371] Id., p. 37.
[372] "Human Rights Report on Situation of Roma in Eastern Slovakia, 2000-2001", *supra,* note 185, p. 11.
[373] Zoon, *supra,* note 14, pp. 62-65.
[374] Interview, Vidin, Bulgaria, 18 November, 2001.
[375] Correspondence, Greek Helsinki Monitor, Athens, Greece, 13 January 2002.

in Sofia, Bulgaria, seek to minimize abuse of discretion by mediating between social welfare offices and Roma clients.[376]

More generally, the non-discriminatory distribution by local authorities of social protection requires monitoring and enforcement. In Romania, claims have been made that less funding is allocated for social protection programmes in districts and settlements where the majority of the potential beneficiaries are Roma.[377] Local government negligence in disbursing child support, an unconstitutional moratorium on the payment of temporary support in a village inhabited by Roma, and a requirement of unpaid labour for social support applicants that was found to have a disproportionate impact on Roma, have all been noted by the Ombudsman's office in Hungary.[378] This office, and others similarly charged with investigating such reports, should be provided with sufficient resources and prosecutorial authority to investigate and enforce any remedial action.

Roma who follow semi-nomadic or nomadic lifestyles often face a *de facto* loss of access to social benefits, since payments are normally made to a permanent residence. (Access to public services in relation to mobility is further discussed in the section on Access to housing and health, below.) When a lack of adequate halting sites results in forced mobility, the consequent instability, stress, potential discrimination, and loss of access to information have been found to have extremely adverse impacts on access to social benefits and related social services.[379] An assumption of mobility and related stereotypes may also provide a basis for discriminatory treatment. For instance, Travellers living in the area of Dublin have been required to collect social welfare allowances at one central office, while Travellers and the general population elsewhere can collect benefits at local offices. The requirement in Dublin is estimated to affect almost one quarter of Ireland's Travellers, whether or not they are mobile. Since Traveller sites are often poorly linked to public transport, beneficiaries face difficulty in accessing this central location. In addition, they must wait outside the building regardless of weather conditions – a factor that may compromise not only health but confidentiality with respect to the services sought. This experience is particularly difficult for women with small children, who may have difficulty in accessing childcare. For Travellers in crisis situations, access to benefits is effectively precluded by these onerous rules.[380]

The Committee on the Rights of the Child recently expressed concern that many Roma families in Greece do not receive childcare allowances "at all."[381] Research is required to determine the reasons for this situation in Greece and elsewhere, with a focus on the ways in which direct and indirect discrimination may play a role. Attention might be given to determining whether social welfare departments adequately consider the needs of Roma when developing and publicizing the assistance available; whether assistance is withheld from Roma on discriminatory grounds; and how preventive measures can be taken to ensure access on an equal basis. For nomadic or

[376] Interview, Sofia, Bulgaria, 19 November, 2001.
[377] Zoon, *supra,* note 14, p. 41.
[378] Minority Protection in the EU Accession Process, *supra,* note 10, p. 233.
[379] *See* Sarah Cemlyn, "Health and Social Work: Working with Gypsies and Travellers." Practice Vol. 6 No. 4, 1994, p. 246-261.
[380] Interview, Dublin, Ireland, 6 December 2001.
[381] Concluding Observations of the Committee on the Rights of the Child : Greece, *supra*, note 350, para. 48(c).

semi-nomadic populations, client held records or other non-territory based systems might be explored to preserve access to entitlements.

It is notable that Roma comprise a significant number of internally displaced persons, refugees and asylum seekers throughout Europe. As such, they often face particular difficulty in accessing social benefits and health care on account, both of their legal status and of their ethnicity. The UN High Commissioner for Refugees has called upon States to include non-nationals such as asylum seekers, refugees, returnees and stateless persons in equality and non-discrimination legislation.[382] Ireland's National Consultative Committee on Racism and Interculturalism has recently undertaken to ensure that the needs of Roma are included in broader refugee and asylum policy,[383] in part through support of a study on the needs of Roma refugees and asylum seekers in Ireland. In the context of access to health care, this study has identified discriminatory treatment by some health providers as well as language difficulties.[384] States might follow such an approach in combination with public awareness campaigns to make clear that asylum seekers and refugees are entitled to access health care and other public services without regard to their ethnicity.

The lack of knowledge among many Roma of social benefits, combined with their frequent distrust towards social workers, indicate an opportunity for mediators to assist Roma in navigating the social welfare system while educating both groups about each other. With mediator assistance, the "mutual distrust that permeates the relationships among most social workers and their Romani clients"[385] could be broken down, and with it the discriminatory acts and attitudes that often define their relations.

[382] *See* UN High Commissioner for Refugees, Written Recommendations, Session 5, Summary, ODIHR Human Dimension Implementation Meeting, 17-27 Sept 2001, available at: http://www.osce.org/odihr/documents/reports/hdim/hdim2001_fr.php3

[383] Progress Report, 1998-2001, National Consultative Committee on Racism and Intolerance, Ireland, p. 13.

[384] Phyllis Murphy, "Roma in Ireland: A Profile and Initial Needs Analysis, Background Paper for Romani Support Group, Pavee Point, NCCRI and FAS", (Draft). November 2001.

[385] Zoon, *supra* note 14, p. 65.

C. Access to education and health

Barriers to accessing education for Roma have drawn attention across Europe. In both East and West, low attendance in primary schools and little or no participation at secondary and higher levels characterize the interaction of many Roma, Gypsies and Travellers with the education system.[386] Poverty, discrimination, unfamiliarity with mainstream education and abuse in schools together has brought about this situation. The segregation of Roma children has been noted in countries like the Czech Republic, Hungary, Poland, Romania, and Slovakia, whether through assignment to special schools designated for the mentally handicapped, exemptions from normal school attendance, or other bureaucratic obstacles. In addition to violating the principles of equality and non-discrimination,[387] such practices have the effect of excluding Roma from secondary or higher education and virtually eliminate opportunities for employment and social integration.[388]

In its General Policy Recommendation N° 3 on combating racism and discrimination against Roma/Gypsies, ECRI recommends that member States "vigorously combat all forms of school segregation towards Roma/Gypsy children". The OSCE HCNM has called on governments to eradicate practices that tend toward involuntary segregation of Romani children in schooling, and to commit resources to programmes that enable Romani children to succeed in regular schools.[389] The EU's Racial Equality Directive includes education within its scope to combat racial discrimination. In its Programme of Action, the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance calls upon States to ensure that Roma/Gypsy/Sinti/Traveller children and youth, especially girls, are given equal access to

[386] For example, according to the Annual Report for the year 1997 published by Hungary's Parliamentary Commissioner for National and Ethnic Minorities, the percentage of the Roma population in elementary schools corresponds to their percentage in the population (around 5%), but decreases at secondary school level to less than 1% and at university level to around 0.1%. ECRI Second report on Hungary, CRI (2000) 5, adopted 18 June 1999, para. 33. *See also* ECRI Second report on Romania, CRI (2002) 5, adopted 22 June 2001, para. 34; ECRI Second report on Italy, *supra,* note 22 at para. 63; ECRI Second report on Croatia, *supra,* note 149 at para. 41; ECRI Second report on Poland, CRI (2000) 34, adopted on 10 December 1999, para. 37; ECRI Second report on Ireland, CRI (2002) 3, adopted 22 June 2001, at para. 66; ECRI Second report on Slovakia, *supra*, note 125 at para. 65; "Traveller children: Educational and health deprivation", by Luke Clements and Rachel Morris, Traveller Law Research Unit, Cardiff Law School, *Childright Journal*, Children's Legal Centre, University of Essex, September 2001, vol 179, pp 7-9.

[387] Obligations to respect the principles of equality and non-discrimination in education are enshrined in instruments such as: ICERD, Article 5(e)(v): The right to education and training; Article 2 of the Convention on the Rights of the Child, and Article 2(2) of the ICESCR. Under the Framework Convention, the Parties undertake to promote equal opportunities for access to education at all levels for persons belonging to national minorities. Framework Convention, Article 12(3). The Racial Equality Directive extends to all persons, as regards both the public and private sectors, including public bodies, in relation to education. Racial Equality Directive, *supra,* note 53, Article 3(g).

[388] *See e.g.,* Claude Cahn, David Chirico, et. al, "Roma in the educational systems of central and eastern Europe", Roma Rights, Summer, 1998, *supra,* note 19; ECRI Second Report on the Czech Republic, *supra,* note 328 para. 32; ECRI, Second Report on Hungary, *supra,* note 379, para. 30. *See generally* Roma Rights: Roma and the Right to Education, Summer 1998, European Roma Rights Centre, Budapest, Hungary.

[389] Report on the Situation of Roma and Sinti in the OSCE Area", *supra,* note 4, at Recommendations: B. Education, p. 161.

education.[390] Governments, NGOs and others are paying increasing attention to the serious problem of segregation of Roma children in schools. In Hungary, for example, a new office responsible for integrating Roma pupils into mainstream education was established in 2002. A National Educational Integration Network has also been established to this end.[391]

To date, however, there has been little attention to the relationship between education and access to health care, specifically on the adverse effects of barriers to education on Romani women's health. Insofar as improved education and health enhance the well-being, productivity and development of a population. States are encouraged to identify and promote the links between improved education and health, particularly for women.

The right to education includes availability and accessibility to all by appropriate means, particularly for girls who have not completed primary education. The ICESCR obliges States Parties to fulfil realization of the right to education for all, in part by providing compulsory and free primary education, making secondary education accessible to all by every appropriate means, and encouraging fundamental education for those persons who have not completed primary education. (Art 13.2.)

The Convention on the Rights of the Child, Article 24(2), requires States Parties to ensure that all segments of society, in particular parents and children, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents.[392] More broadly, States are obliged to develop preventive health care, guidance for parents and family planning education and services.[393]

Under CEDAW, States Parties are obliged to take all appropriate measures to ensure, on a basis of equality of men and women, access to the same quality of education and programmes of continuing education, and to specific information to help ensure the health and well-being of families, including information on family planning.[394] States Parties should also reduce female student dropout rates and organize programmes for girls and women who have left school prematurely.[395]

Prerequisites to caring for one's physical and mental well-being include some knowledge of what that well-being entails and access to the means to achieve it. Schools often provide information on hygiene, nutrition, disease prevention, and how to access the health system – whether through health education, access to school nurses, vaccinations, or other means. Romani children are thus at a disadvantage when they confront various factors inhibiting access to education, such as difficulties accessing kindergarten[396] (where healthy habits begin to be acquired); a lack of money for school materials and clothes; poor command of the local language;

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[390] World Conference Against Racism Racial Discrimination, Xenophobia and Related Intolerance, *supra,* note 7, Programme of Action para. 39.
[391] Comments prepared by the Government of Hungary (on file with the Council of Europe).
[392] CRC, Article 24(2)(e).
[393] Id., Article 24(2)(f).
[394] CEDAW Article 10(b)(e)(h).
[395] CEDAW Article 10(f).
[396] *See, e.g.,* ECRI Second report on Hungary, *supra* note 386 at para. 31.

under-trained or prejudiced teachers; lower standards; and attendance not enforced on a basis equal to that of non-Roma.

In addition to facing the health consequences of racial or ethnic discrimination in education, attitudes within their own communities may further serve to reduce their access to education. For Roma parents who are isolated from or feel powerless *vis-à-vis* majority society, or who did not acquire extensive education themselves, mainstream education may represent a threatening culture. School may be considered an intellectually or physically polluting place, especially for Romani girls. Some parents fear their daughters will be exposed to disagreeable elements of majority culture, subject to sexual violence or "stolen" by a young man intending to marry her – either without the parents' permission, or when they believe their daughter is not ready.[397] Some parents may condition a daughter's school attendance on safeguards for her protection and to maintain virginity, such as by being accompanied by a brother. Otherwise, they may withdraw a Romani girl from school around the age of puberty.

Parents may also remove girls from school to help at home and care for younger siblings, prioritising her preparation for marriage and childbearing over completing an education the value of which they are uncertain. They may be unaware that a tradition of early marriage may deprive girls of their personal freedom, force them into non-consensual sex and diminish their educational development and individual life-choices.[398] A lack of education themselves may not allow parents to recognize that early childbearing exposes young women to life-threatening health problems because their bodies are often insufficiently mature to go through pregnancy and birth.[399]

Insofar as such cultural practices reduce or deny young Romani girls access to education, they are detrimental to the girls' health and well-being. Literacy skills are indispensable to access information on health prevention and hazards: this information is most frequently offered in written pamphlets and texts that have to be read and reread to be effective.[400] Adequate education, especially concerning human rights and gender equality, is key to empowering women to exercise self-determination in their sexual relationships: it can prepare women to take informed steps to protect themselves from sexually transmitted infections and HIV/AIDS. Through education, women acquire critical thinking skills that can help them in the choice, timing and spacing of pregnancies, as well as protection of child health.[401] The likelihood of safe maternity and a healthy family is thus increased. Ultimately, education empowers women to modify customary practices that have an adverse effect on their personal autonomy and community well-being.[402]

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[397] Interviews, Aspropyrgos, Greece, 12 November; Nieuwegein, The Netherlands, 10 October; Strasbourg, France, 4 December; Plovdiv, Bulgaria, 20 November, 2001.

[398] "Forum on Marriage and the Rights of Women and Girls", November 2001, International Planned Parenthood Federation, p. 6.

[399] Id.

[400] Cook and Dickens, *supra,* note 232, p. 61.

[401] Id. *See also* discussion of education as a "passkey for unlocking other human rights", Annual report of the Special Rapporteur on the right to education, Katarina Tomasevski, in E.CN.4/2001/52, 9 January 2001, para. 11-13.

[402] For discussion and examples of women's changing roles in Romani communities, their contestation of traditional practices and role as forces for change, *See, e.g.,*: Liegeois, Jean-Pierre, "Roma, Gypsies, Travellers", Council of Europe Press 1994; Acton, Thomas, "Gender Issues in Accounts of Gypsy Health and Hygiene as Discourses of

There is growing awareness among Romani women that education holds the key to their future by empowering them to help themselves. Many women desire their daughters' continued education, and recognize a need for vocational training to broaden opportunities for future employment. Indeed, States are obliged both to accommodate and challenge traditions affecting Romani girls' access to education. In addition to the obligations outlined above, CEDAW obliges States Parties to take "all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women."[403] In turn, the Convention on the Rights of the Child requires States Parties to take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.[404] These obligations can be understood to require not only encouragement of kindergarten education and enforcement of school attendance, but also the taking of measures to change attitudes to encourage delayed marriage and school attendance for Romani girls and women.

With respect to kindergarten education, ECRI encourages government authorities to take measures such as information and incentive campaigns to improve the attendance of Roma/Gypsy children at this level. In response to concerns that diminished educational opportunities for Roma children deny them the tools with which to integrate into society, Finland's National Board of Education Romani Educational Unit has undertaken a project to support Roma children and their families in pre-school and comprehensive education. On the basis of a nationwide survey, the Unit aims to develop networking among children, families and school authorities to improve school measures in support of Romani students.[405] The Ministry of Education of Portugal has undertaken actions to educate Romani parents on the advantages of kindergarten education.[406] Noting the success of "zero-grade" year-long programmes in the Czech Republic intended to prepare disadvantaged Roma for their first year in school and thereby, to encourage their continued education, ECRI has urged authorities to expand such initiatives by ensuring adequate resources and publicity.[407]

More broadly, ECRI has recommended in its General Policy Recommendation N° 3 that governments should ensure the effective enjoyment of equal access to education. Efforts in this regard could include: encouraging parent participation in educational decisions affecting their children; special training for children who have failed to reach academic levels required for further education; initiatives specially designed for adult members of the Roma population; ensuring admission and attendance to schools, particularly for higher education; and allocating resources for part-time or home education.[408] Such initiatives should be planned with specific

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Social Control", (on file with author); "Roundtable: Romani activists on Women's rights", Roma Rights No. 1, 2000, *supra*, note 45.

[403] CEDAW Article 2(f).

[404] CRC Article 24.3.

[405] "Comprehensive School and Pre-School Education Project for Roma Children, 2001", Finland's National Board of Education, Romani Educational Unit. (On file with author.)

[406] Information submitted to the Migration and Roma/Gypsies Division, Council of Europe, by Portugal's High Commissioner for Immigration and Ethnic Minorities (ACIME) and the Ministry of Health.

[407] ECRI Second report on the Czech Republic, *supra,* note 333, para. 34.

[408] ECRI Second report on Slovakia, *supra,* note 125, para. 65-66; ECRI Second report on the United Kingdom, CRI (2001) 6, adopted 16 June 2000, para. 40; ECRI Second report on Romania, *supra,* note 386, para. 35.

attention to the needs of Romani girls, adolescents and women. Primary and secondary education programmes should be prepared to accommodate girls who have left for a period, perhaps to return as married, and/or mothers. Special incentives and support systems should be created to encourage Romani women to pursue studies at the tertiary level.

Several NGOs have sought to fill the specific gap left by education institutions in Romani girls' education, including the following. The Roma Project in Amsterdam Zuid-Oost seeks to engage married Romani girls around the ages of 13-15 in weekly sessions on childcare and empowerment.[409] In Granada, Spain, the *Asociación de Mujeres Gitanas* "ROMI" helps Romani girls, young women and their families to understand the ways in which continued education is not only compatible with but also can help to strengthen Roma values and culture.[410] Whenever possible, States should coordinate with existing efforts and encourage partnership with Romani women and organizations with similar concerns in order to achieve these objectives.

States' attention is also directed towards the ECRI Practical Examples in Combating Racism and Intolerance Against Roma/Gypsies, which comprise examples of good practice in fields such as Roma empowerment, education and youth. Initiatives such as the Education Support Project in Timişoara, Romania (a programme for children who abandoned school and which includes support for girls who are not allowed to attend school) and the Alternative Vocational School in Szolnok, Hungary (providing remedial education and vocational training) – provide an existing framework within which to integrate healthcare.[411] States are encouraged to seek out initiatives already underway in education and other fields where a healthcare component can be added.

The role of mediators in helping to fulfill girls' right to education should also be considered. With parents, mediators might engage in dialogue about the importance of education to girls' exercise of free choice and personal development, including the advantages of delayed marriage. They could promote parent-school relations, particularly on the issue of identifying how education authorities can help to promote girls' safety and dignity as they continue their studies. Mediators might also be instrumental in sensitising teachers to gender dynamics in the local Romani community, while helping to ensure that teacher-held stereotypes and prejudices – particularly those that lead to lower expectations of Roma children generally and of girls, specifically – are broken down. Through confidence-building measures and rights education, mediators could support Romani girls and women to identify and pursue their educational goals.

[409] Interview, Amsterdam, The Netherlands, 11 October 2001.
[410] Interview, Granada, Spain, 30 November 2001.
[411] ECRI Practical Examples in Combating Racism and Intolerance Against Roma/Gypsies, CRI (2001) 28, Strasbourg, October 2001, pp 35, 41.

D. Access to adequate housing and health

Access to health care on a non-discriminatory basis is linked in many ways to the improvement of living conditions and to adequate housing.[412] As the primary users and maintainers of housing – the locus of many Romani women's employment, child-care, and social interaction – Romani women often have the most at stake and the most requirements for housing.[413] Among the housing-related factors affecting their health are poor living conditions and a lack of public services appropriate for rural and caravan dwellers, problems securing a permanent domicile, and forced evictions. These factors also detract from women's ability to give attention to their own health. If States are committed to improving the health of Romani women and their communities, attention must be given simultaneously to securing access to adequate housing.

1. Inadequate living conditions

The right to adequate housing is recognized in numerous international covenants, most notably the International Covenant on Economic Social and Cultural Rights. Article 11(1) of the ICESCR provides:

> The State parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and for his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions.[414]

The CESCR Committee's General Comment No. 4 on the Right to Adequate Housing delineates seven elements of adequate housing, including: habitability; the availability of services, materials, facilities and infrastructure; cultural adequacy; and legal security of tenure.[415] Many Roma are

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[412] Use of the term *housing* is intended to apply to various forms of accommodation, including caravans and halting sites. It is also intended to encompass the broader environment – in essence, "living conditions" – in which housing is situated, such as infrastructure, public services, environment, etc. These applications are consistent with the definition of the right to housing as enshrined in the ICESCR and delineated in the CESCR General Comment on the Right to Adequate Housing (see below.) However, CEDAW, for instance, recognizes a right to adequate living conditions in Article 14(h), under which housing is subsumed. While the CESCR definition provides the framework for this section, references to housing and living conditions from other sources will maintain the original language.

[413] Ina Zoon, "The Right to Adequate Housing", Roma Rights No. 2, 2000, *supra,* note 21, p. 46.

[414] ICESCR Article 11.

[415] Habitability: Adequate housing must be habitable, in terms of providing the inhabitants with adequate space and protecting them from cold, damp, heat, rain, wind or other threats to health, structural hazards, and disease vectors. The physical safety of occupants must be guaranteed as well.

Availability of Services, Materials, Facilities and Infrastructure: Adequate housing requires access to potable drinking water, energy for cooking, heating and lighting, sanitation and washing facilities, food storage, refuse disposal, site drainage and emergency services. When one or more of these attributes of adequate housing are not available, the right to adequate housing is not fully in place.

Cultural adequacy: The way housing is constructed, the building materials used and the policies supporting these must appropriately enable the expression of cultural identity and diversity of housing. Activities geared towards

forced to live in conditions that fall far short of satisfying these elements. In addition, the EU's Racial Equality Directive prohibits discrimination in access to and supply of goods and services which are available to the public, including housing. The availability of adequate housing on an equal basis can be one of areas examined to ensure non-discrimination and that Romani communities have the same rights as others.

Whether urban or rural, settlement after settlement lacks adequate and clean water, heat, sufficient electricity, paved roads, refuse collection,[416] or sanitation. Structural and health hazards abound – from overcrowding, leaking roofs, infestation by rodents, half-demolished buildings, and heavily trafficked roads. Roma communities may also suffer from disproportionate exposure to environmental hazards, often living in closer proximity to industrial factories, legal and illegal hazardous waste sites, municipal garbage dumps, incinerators and other sources of harmful pollution.

In rural areas, lack of regular garbage removal and sanitation services may force residents to dispose household garbage and human waste in woods and rivers, creating health hazards and higher risk of diseases such as hepatitis.[417] For various reasons, such living conditions may be the only option for Roma. They may feel compelled to move to structurally dangerous or polluted places upon experiencing harassment or discrimination elsewhere, on the assumption that they are less likely to be bothered in such areas. They may not be able to afford other housing. Alternatively, they may be at the mercy of local authorities with regards to where they are able to live. In Italy, reportedly not a single segregated camp for Roma, many of which are government authorized, has an adequate sewage system in place.[418] In Lower Hrušov, Ostrava, the Czech Republic, Roma reportedly live among rats in mouldy apartments where there is no regular garbage collection and waste is placed in neighbouring buildings. Local authorities have been unwilling to provide Roma with housing outside this area despite declaring the area unsuitable for human habitation. At the same time, authorities reportedly have charged Roma

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development or modernization in the housing sphere should ensure that the cultural dimensions of housing are not sacrificed, and that, inter alia, modern technological facilities, as appropriate are also ensured.

Legal security of tenure: Tenure takes a variety of forms, including rental (public and private) accommodation, cooperative housing, lease, owner-occupation, emergency housing and informal settlements, including occupation of land or property. Notwithstanding the type of tenure, all persons should possess a degree of security of tenure which guarantees legal protection against forced eviction, harassment and other threats. States parties should consequently take immediate measures aimed at conferring legal security of tenure upon those persons and households currently lacking such protection, in genuine consultation with affected persons and groups

Committee on Economic, Social and Cultural Rights, General Comment 4, The right to adequate housing (Article 11 (1) of the Covenant) Sixth session, 1991, para. 8(a)(b)(d)(g).

[416] Women may be more exposed than men to some forms of contact with wastes or with pollutants emanating from wastes due to their social roles. Women's domestic responsibilities and their level of interaction with the local environment increases their exposure to and contact with uncollected wastes….Certain occupations that are dominated by women, such as scavenging, increase their exposure. "Impact on Women's Health of Waste Mismanagement", World Health Organization Environmental Health Newsletter, No 25, Dec 1995, p. 11, available at: www.who.int/peh/ehn/ehn25e.doc

[417] "Improving Primary Health Care: Public Health and Cultural Research with Rroma Communities in Romania", *supra,* note 16, section 6.a, Appropriate cultural strategies to increase the access of the Rroma to health care.

[418] "Campland: Racial Segregation of Roma in Italy", *supra,* note 332, p. 21.

relatively high rents because the apartments in which they live are somehow regarded as high quality.[419]

These inadequate conditions may also be the consequence of discrimination in the provision of other public services. One example is the need for Roma occupying flats in the Ferentari district of Bucharest to bribe sanitary workers to collect the garbage, while being forced to live among trash dumped from other parts of the city near these flats.[420] Another is the alleged delay in action by local authorities to relocate *Tsiganes* from a caravan park outside of Toulouse where they had been moved after floods, to a permanent and larger site. This delay is attributable in large part to the presumption that property values will decline wherever the caravans are moved.[421]

Some authorities have taken extensive steps to relocate Roma families from uninhabitable or illegal conditions to adequate accommodations. An example is the *Instituto de Realojamiento e Integracion Social* (IRIS) in Madrid, Spain, which relocates families living in *chabolas* to flats on the basis of a negotiated rent contract and clear, detailed manual of tenant rights and responsibilities. Significantly, the IRIS programme includes attention to education, health and social benefits, as well as social workers to assist in integration with neighbours.[422]

Remote location of housing presents another problem of particular concern for Roma. According to the CESCR, for housing to be adequate it must be situated so as to allow access to employment options, health care services, schools, childcare centres and other social facilities. It must not be located in polluted areas.[423] Under CEDAW, States Parties are required to ensure to women in rural areas the right to enjoy adequate living conditions, particularly in relation to housing, sanitation, electricity and water supply, transport and communications and to have access to adequate health care facilities.[424] Nevertheless, the isolation of many settlements and caravan sites, combined with the stigma often associated with the fact that Roma are the inhabitants, are potential sources of considerable economic, physical, and psychological hardship. Indeed, research has shown that there is a higher rate of accidental injury, depression, and other illnesses on poorly located, poorly equipped caravan sites.[425]

Public and private services may refuse to offer their services to residents of "Roma neighbourhoods." Where Roma live far away from public services, such stereotyping may result in further difficulties accessing those services. For example, there may be discrepancies even in delivery of the post, through which social benefits are received: mail carriers may leave the post at a nearby shop or give it to children in the neighbourhood rather than deliver to individual homes.[426] Salespersons of various goods and services may avoid visiting caravan sites.[427]

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[419] Eva Sobotka, "Life under the bridge: ghettoizing Roma in Lower Hrušov, Ostrava, Czech Republic." Roma Rights No. 2, 2000 – Housing; *supra,* note 21, pp. 52-55.
[420] Interview, Bucharest, Romania, 20 September 2001.
[421] Interview, Toulouse, France, 11 December 2001.
[422] Interview, Madrid, Spain, 28 November 2001.

[423]CESCR, General Comment 4, *supra,* note 415, para. 8(f): Location.

[424] CEDAW Article 14(2)(b) and (h).
[425] Id.
[426] Interview, Toulouse, France, 11 December, 2001.

Women whose roles and responsibilities prevent them from leaving their residential area may find these stresses and isolation especially hard to bear.

In recognition of the many difficulties confronting women living on isolated sites, the Traveller's Health Project in Bristol, England organized a mobile well-women's clinic to provide on-site care for screenings, contraception, and chronic illnesses, and devise creative multifaceted solutions to ease their isolation. In particular, the clinic sought to address the fact that family doctors often did not visit caravan sites, and that depression resulting from difficult living conditions may result in women's decreased attention to their own health. Upon recognizing that certain women were "smoking themselves to death" in reaction to their isolation, lack of opportunities for activity, and depression, the Health Project also assisted the women to acquire driver's licenses.[428] This measure provided the women with greater access to services while reducing the stress induced by local police who, it has been alleged, would target women leaving the site in cars on the assumption that they did not possess valid licenses.[429] Despite the clinic's successes, funding for the programme has been discontinued. It is hoped that recognition of the potential for such efforts both to fill gaps in mainstream services for Roma and to become an integral part of them will lead to continued support of this kind of outreach in the future. The Greek Ministry of Health and Welfare is also piloting a programme of fifty "Medico Social Centres" for Roma living in settlements, as well as two mobile units for moving populations. The Centres provide preventative health services and basic first-degree health and social care, as well as facilitating access for Greek Roma to the National Health System and helping to familiarize them with available public services. Similar services are provided to moving populations by mobile units. The treatment of Roma is provided in most cases for free, since the overwhelming majority hold proof of financial hardship. Furthermore, the uninsured population has unimpeded and free access to the services of the National Health System in case of emergency.[430]

2. Residency requirements

Identification documents are one requirement for registration as residents, and thus, for access to housing. As discussed above in Part III, Section A, Access to Documented Legal Status, disproportionate numbers of Roma may lack identity cards or other documents, and thus may be denied a range of benefits related to housing, social protection and health care. In Italy, problems in securing residence permits for Roma has been documented, whether because of abuse of authority discretion, lack of information, or burdensome eligibility requirements.[431] Some municipalities in Greece have refused to register Roma if they want to move their place of residence,[432] presumably to avoid providing benefits to which the new residents would otherwise be entitled. The recent declaration by the mayor of Bucharest that all persons without proper residence permits are to be expelled from the city has been deplored by ECRI.[433]

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[427] Interviews, Stein, Netherlands, 10 October; Dublin, Ireland, 6 December; Toulouse, France, 11 December, 2001.
[428] Interview, Bristol, England, 26 October 2001.
[429] Id.
[430] Comments prepared by the Government of Greece (on file with the Council of Europe).
[431] "Campland: Racial Segregation of Roma in Italy", *supra,* note 332, pp 18-19.
[432] ECRI Second report on Greece, *supra,* note 149, para. 33.
[433] ECRI Second report on Romania, *supra,* note 385, para. 41.

The legality of housing is another precondition for permanent resident status. Insofar as Roma are over-represented among people who live in substandard, unlawfully situated or constructed housing, the domicile requirement may have a disproportionate impact on their access to services for which it is required. In the Fakulteta district of Sofia, Bulgaria, the high proportion of inhabitants who lack residence permits face not only a constant fear of eviction, but extensive corruption and bribery in the local housing administration around obtaining legalization of housing.[434] Authorities may also deny renewal of rent contracts to Roma who live in "uninhabitable" dwellings, though this situation may have been overlooked in the past. In fact, Roma already living in precarious conditions may fear that authorities will use sanitary checks as an excuse to evict them rather than to improve conditions, often without provision of adequate shelter elsewhere.[435]

Where proof of residence is required to access public services, particular concern is raised by laws or policies that provide for legal caravan sites in a manner that does not satisfy existing need. A January 2001 count of caravans on unauthorized sites in the United Kingdom showed 2,608 caravans.[436] While some of these caravans may belong to persons who have access to authorized sites elsewhere,[437] the need to address availability of sites is particularly significant in light of England's 1994 Criminal Justice and Public Order Act: this bill removed a duty on local authorities to provide sites while increasing the eviction powers of authorities and police (including placing criminal sanctions on persons who fail to move on when asked to do so by authorities).[438] A combined effect of these changes is to push caravan dwellers onto unsafe roadside sites with less access to public services, whether because they lack a legal address or find it impossible to access these services. Thus the results of England's Committee of Ministers' Deputies inquiry into the adequacy of existing sites, as well as policy proposals based on these results, are eagerly anticipated.[439]

France's 1990 Loi Besson – requiring communes with more than 5000 inhabitants to provide sites for *gens du voyage* – appears to have resulted in only about 10,000 sites, although it is estimated that needs could be much higher. A Year 2000 amendment shifts this burden to the State if communes do not comply with their planning responsibilities.[440] At the same time, it allows authorities to ban caravans from entire municipalities for unauthorized camping in one place, although the unauthorized camping may have been a direct response to a lack of space on

[434] "Mihail Gheorgiev, "Fighting for Fakulteta: advocating Roma housing rights in Bulgaria", Roma Rights No. 2, 2000 – Housing; *supra,* note 21, pp. 49-50.
[435] Interview, Budapest, Hungary, 9 November 2001.
[436] Comments of the Government of the United Kingdom on the Opinion of the Advisory Committee on the Report on the Implementation of the Framework Convention for the Protection of National Minorities in the United Kingdom, adopted 22 May, 2002, re: Article 5: Paras. 40 and 41-42: Roma, Gypsy and Traveller site provision.
[437] Id.
[438] Rachel Morris, "The Invisibility of Gypsies and Other Travellers", *supra,* note 11, p. 2.
[439] FCAC Comments of the Government of the United Kingdom on the Opinion of the Advisory Committee, *supra,* note 436, para. 112.
[440] *See* Law No. 2000-614, France, adopted 5 July, 2000, concerning the reception and housing of *gens du voyage* (relative à l'acceuil et à l'habitat des gens du voyage), section (1).

existing sites.[441] Even if the Amendment is eventually complied with, the two years given to municipalities to develop and implement site plans suggest that many families will continue to live in precarious conditions for some time while being deprived of a permanent domicile and the public services that follow from it.

In response to the difficulty in securing a permanent domicile, NGOs such as the *Association pour une Recherche Pédagogique ouverte en milieu Tsigane* (ARPOMT) in Strasbourg, France, have stepped in to provide a permanent address for nomadic populations, thus facilitating access to public services.[442] Solutions such as these should be temporary, however, until States fulfil their obligations as explained in General Comment No. 4 on the Right to Adequate Housing, to provide, *inter alia*, housing that is habitable, legally situated and culturally adequate. These obligations should apply equally to Roma who choose to live in caravans and other mobile accommodation, whether to pursue settled, semi-nomadic or nomadic lifestyles.[443] Furthermore, States should take measures to ensure that access to public services is not denied because of a failure to satisfy these and other elements of adequate housing.

The 2000 Amendment to the *Loi Besson* makes provision for a consultative committee to elaborate its implementation.[444] This committee should include representatives of *gens du voyage* and associations working on their behalf. Integral to satisfying the elements of adequate housing for the populations that this law and others like it are meant to serve is the participation of individuals who will be affected by it. Romani women's primary role in using and maintaining the home indicates that their input is invaluable to determining what constitutes adequate sites. Every effort should be made to identify and support Romani women in their contributions to site location, design and rehabilitation.[445]

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[441] « Loi du 5 juillet 2000 sur l'accueil et l'habitat des gens du voyage, » Groupe de travail « Gens du Voyage, » Commentaires, 5 July, 2000, La Ligue des Droits de l'Homme, Paris, France, available at: http://perso.wanadoo.fr/ldh/actions/commissions/gdv/comment_loi050700.html

[442] Interview, Strasbourg, France, 14 December 2001.

[443] The Framework Convention Advisory Committee has expressed concern that the difficulties Roma/Gypsies and Travellers confront in finding places to stop on account of England's Criminal Justice and Public Order Act have contributed to many Roma/Gypsies and Irish Travellers having to give up their travelling life-style. FCAC Opinion on the United Kingdom, adopted 30 November 2001, para. 41.

In its judgment in the case of *Chapman v. the United Kingdom* (18 January, 2001, application no. 27238/95) the European Court of Human Rights points to an emerging consensus among Council of Europe States recognizing the special needs of minorities and an obligation to protect their security, identity and lifestyle (para. 93). The Court was not, however, persuaded that the consensus is "sufficiently concrete…for it to derive any guidance as to the conduct or standards" applicable in a particular situation. In this case, the Court considered the applicant's occupation of her caravan to be "an integral part of her ethnic identity" (para. 73), and reiterated its intimation in the *Buckley v. the United Kingdom* judgment that "there is a positive obligation on Contracting States by virtue of Article 8 to facilitate the Gypsy way of life" (para. 96). The Court was not convinced, however, despite the undoubted progress in international law with regard to the protection of minorities, that Article 8 can be interpreted to involve a positive obligation of general social policy which would demand the provision of places in authorized caravan sites to match the statistical numbers of Gypsies (para. 98).

[444] Law No. 2000-614, 5 July, 2000, concerning the reception and housing of *gens du voyage*, *supra* note 440, Article 1, para. IV.

[445] Noting women's lack of control over environmental health, whether in urban or other settings, WHO recommends helping women to negotiate a better environmental health situation. WHO Environmental Health Newsletter, *supra,* note 416, p. 18.

3. Forced evictions

Forced eviction is defined as the "permanent or temporary removal against their will of individuals, families, and/or communities from the homes and/or land which they occupy, without the provision of, and access to, appropriate forms of legal or other protection."[446] Many informal and often illegal settlements and communities lack security of tenure;[447] therefore they lack protection against arbitrary forced eviction, harassment, and other threats.

While not all evictions are forced evictions, the non-discrimination provisions of Articles 2(2) and 3 of the ICESCR impose an obligation upon governments to ensure that, where legal evictions do occur, appropriate measures are taken to ensure that no forms of discrimination are involved. General Comment No. 7 on Forced Evictions, put forth by the UN Committee on Economic, Social, and Cultural Rights, further specifies that "evictions should not result in rendering individuals homeless or vulnerable to the violation of other human rights. Where those affected are unable to provide for themselves, the State party must take all appropriate measures, to the maximum of its available resources, to ensure that adequate alternative housing, resettlement or access to productive land, as the case may be, is available."[448]

Organizations working on behalf of Roma recognize their particular vulnerability to mistreatment in the context of evictions. Many Romani communities are situated illegally, and/or are disfavoured by the local population. At the same time, inhabitants may be unfamiliar with laws and regulations governing housing and evictions, while seeking to avoid interactions with authorities given the already precarious conditions in which many of them live.

Forced evictions have been found to impact the psychological, physical, and safety aspects of health, including trauma, disruption of daily living and childcare routines, health risks from unsuitable and dangerous areas which may have to serve as emergency stopping places, and loss of access to health care services.[449] Fear of eviction may give rise to a perception of futility concerning attempts to register with a local doctor. When clinics are located, appointments may have to be missed because of a lack of control over movement.[450] Insecurity and lack of knowledge about clinic locations make access to even minimal services difficult.

It is widely recognized that women, children, youth, older persons, indigenous people, ethnic and other minorities, and other vulnerable individuals and groups all suffer disproportionately from the practice of forced evictions.[451] Women in particular are most likely to suffer the first-hand trauma of an eviction, as they are the ones most likely to be at home when an eviction occurs; they are also more vulnerable to physical and sexual violence both during and after an eviction.

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[446] CESCR, General Comment No. 7: The Right to Adequate Housing: Forced Evictions: E/C.12/1997/4, para. 3.
[447] "Why housing rights?", Centre on Housing Rights and Evictions, Geneva, Switzerland, available at: http://www.cohre.org/hrframe.html
[448] General Comment No. 7, *supra,* note 446, para. 17.
[449] Sarah Cemlyn, "Traveller Children's Right to be Treated with Common Humanity." *Childright*. November 1995, No. 121, p. 5.
[450] Cemlyn, "Health and Social Work: Working with Gypsies and Travellers." *supra,* note 379, p. 249.
[451] Id., para. 10.

Gender also structures the way evictions are experienced, with women often assuming care-giving roles toward other family members, attending to others' health needs and not their own. Feelings of instability and anxiety may have especially strong effects on women who cope with their own stress while assuming the role of the emotional centre and stabilizing force of the family.[452] More broadly, forced evictions and the displacement of Roma communities may result in the breaking down of social networks and personal relationships. These disruptions can have a negative impact on both physical and emotional health, and affect women in unique ways.

Despite the acknowledged disproportionate effect of evictions on women and other vulnerable persons, regulations that consider the effects of eviction on access to local health and other public services are neither widespread nor commonly used. Research in Scotland for the period 1995-1996 has shown that 48% of women had been moved on or evicted while pregnant.[453] Data from 1990 revealed that 43% of Councils in England would evict a woman who was close to giving birth.[454] Raids by authorities comprising the destruction of property and makeshift dwellings, beatings, verbal abuse, abusive use of firearms, and resulting in evictions without provision of adequate shelter elsewhere, are reportedly a "regular feature of camp life" for Roma in Italy.[455] Women and children are routinely the victims.[456] In Hungary, evicted families are often separated as children are frequently taken into state custody if no alternative accommodation is found.[457] Moreover, a May 2000 amendment to Hungary's Housing Act authorized notaries to evict squatters and unlawful tenants within a matter of a few days, even if an appeal were pending, and during the winter months, for which a moratorium on evictions previously had been accepted.[458] Demolition of the huts of Roma in Aspropyrgos, Greece on the future site of sports facilities for the 2004 Olympic Games took place without the authorization or presence of a public prosecutor, as is required under law.[459] Reportedly, seven or eight Greek Romani families with family members too ill to move were given 3 days to leave the site.[460]

A 1998 "Good Practice Guide on Managing Unauthorised Camping" published in England recommends that local authorities and police provide a written statement of their policies towards unauthorized encampments. These should include an assessment on the impact of eviction for education and health services, identification of emergency stopping places, and a description of the circumstances in which Roma and Travellers would be permitted to stay on

[452] Farha, Leilani, "Home is Where the Hurt Is: An Economic and Social Rights Perspective on Violence Against Women" (Draft) Submitted to the Special Rapporteur on Violence Against Women, Ms. Radhika Coomaraswamy, June 1998, p 26.
[453] Lloyd and Morran, *supra*, note 170, pp. 4-5.
[454] Id., p. 5, citing Durward, L. (ed), "Traveller mothers and their babies: Who cares for their health?" Maternity Alliance, London, England, 1990.
[455] "Campland: Racial Segregation of Roma in Italy", *supra,* note 332, p. 23.
[456] Id., at 29-30.
[457] "Violent evictions of Roma in Hungary", Roma Rights, No. 4, 2000, *supra,* note 106, snapshots from around Europe.
[458] Id.
[459] "Greek authorities evict Roma", Roma Rights No. 3, snapshots from around Europe, 2000, European Roma Rights Centre, Budapest, Hungary.
[460] Id.

unauthorized sites without eviction.[461] Local policies should also "take full account of considerations of common humanity."[462]

Such guidelines are a useful step towards reducing the likelihood of evictions and promoting a rights and humanitarian approach to such situations.[463] Nevertheless, there exist many ways to harass, threaten, and intimidate persons to leave a site, in which case the policies in question would not come into effect. Widespread animosity towards Roma raises an additional concern that the application of humanitarian principles by administrative discretion is insufficient to guarantee non-discriminatory treatment and protection of evictee's rights to health, housing, education, and social protection.

The NGO National Travellers Organization, (NTAG) in Bedfordshire, England, has recently established a Gypsy liaison with the County of Bedfordshire. The aim of this liaison is to negotiate on behalf of Gypsies threatened with eviction from roadside pitches in cases of extreme need, and to protect access to education and health care.[464] Such mediation or monitoring may be indispensable to ensure that guidelines such as those described above are adhered to in a non-discriminatory manner.

In all cases of proposed evictions, the guidelines established in General Comment No. 7 on Forced Evictions should be applied. These include the exploration of "all feasible alternatives in consultation with affected persons, with a view to avoiding, or at least minimizing, the need to use force," adequate and reasonable notice for all affected persons prior to the date of the eviction, provision of legal remedies, and the prevention of homelessness.[465] Adequate measures should also be taken to ensure that Roma women are also meaningfully included in this process, in order that their specific needs are addressed. When interpreted in conjunction with the non-discrimination provisions of the ICESCR, these should lead to clear mandates for the protection of Roma, Gypsy and Travellers' right to access health care and other public services.

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[461] Work with the Romani Community, Race Equality Unit, England, p.3. (On file with author.)
[462] Id.
[463] In a dissenting minority opinion in the European Court of Human Rights judgment in *Buckley. v the United Kingdom*, concern is raised over the deliberate accumulation and superimposition of administrative rules employed only against Gypsy families to prevent them from living in certain areas, in part by making it impossible for the family "to make suitable arrangements for its accommodation, social life and the integration of its children at school" and for enmeshing the family in a "vicious circle" of bureaucracy reaching across different government departments. Dissenting opinion of Judge Pettiti, Case of *Buckley v the United Kingdom*, 25 September 1996, application no. 00020348/92.
[464] Interview, Bedfordshire, England, 27 October 2001.
[465] General Comment No. 7, *supra,* note 446, para. 14-17.

PART IV

A. Health and government strategies to improve the situation of Roma

Recognition of the grave socio-economic differences between many Roma and majority populations throughout European states and their general exclusion from society has given rise to government-sponsored efforts to remedy these disparities. Many States have taken steps to improve the Roma situation in fields as diverse as criminal law, housing, education, employment and citizenship. Others, such as Italy, have been encouraged to adopt a national strategy.[466] It is important that health is a major focus.

This section does not aim to provide an exhaustive critique of existing Roma strategies in the field of health care. Rather, it shall describe several components of government strategies that are a precondition to successful programmes in health care as in other areas, as well as identify elements that should be included in all government strategies related to Roma health. (The presence or absence of examples from a particular national plan is not intended to indicate endorsement or criticism of the overall strategy.) Through a discussion of existing government plans, this section seeks to promote the development and re-evaluation of strategies to improve access to health care by providing some considerations with which to approach the issue.

1. Components of government strategies essential to improving access to public services

The legal standards and recommendations described above, as well as broader moral and practical imperatives to address Roma needs and interests indicate that certain undertakings at the national level are preconditions to the success of Roma integration programmes. These include an acknowledgment of the role that discrimination plays in the Roma's relatively poor socio-economic conditions, combined with capacity building of Roma organizations to undertake action to combat discrimination and public awareness campaigns to promote corrective measures and publicize complaint mechanisms; the participation of Roma in all stages of policymaking on their behalf; and the need for effective implementation and monitoring of comprehensive anti-discrimination legislation, as well as all aspects of the strategy itself. Such measures will be discussed here in relation to their significance for improving access to health care and other public services.

[466] ECRI Second report on Italy, *supra*, note 22, para. 68. *See also* FCAC Opinion on Italy, Proposal for Conclusions and Recommendations by the Committee of Ministers, in respect of Article 4, *supra*, note 131.

a. Recognition of the role of discrimination in impeding access to health care

The OSCE HCNM's Report on the Situation of Roma and Sinti in the OSCE Area identified discrimination and prejudicial attitudes as key factors underlying the poor socio-economic status of Roma, serving to limit or sometimes preclude access to employment, education and public serves, including health care for many Roma.[467] ECRI, in numerous reports, has called upon States to examine the extent to which racism underlies the large socio-economic differences between Roma and majority societies.[468] The European Union, acting through the European Commission has drawn attention to these issues in its activities related to Roma and the EUMC has included the situation of Roma communities in the European Union in its Annual Reports. Evidence of disparities in many fields of life would suggest that attention to the causes and manifestations of discrimination should comprise a significant part of any strategy to improve the situation of Roma. Guidelines such as the ECRI general policy recommendation no. 3 on combating racism and intolerance against Roma/Gypsies indicate the breadth of initiatives that might be required.[469] However, various government strategies attribute the poor state of Romani health almost entirely upon Roma, appearing to ignore the cumulative significance of discrimination for limiting access for Roma to a wide range of goods and services.

In the Strategy of the Government of the Slovak Republic for the Solutions of the Problems of the Roma National Minority, the disparity between Roma and majority health status is attributed to low levels of education, social awareness, standards of housing and personal hygiene, drug and alcohol consumption.[470] Interventions are thus focused on improving Roma hygiene, changing Roma dietary habits, and "influencing the social, cultural and value orientation of the Romany population in the field of health."[471] Poland's Pilot Government Programme for the Roma Community in the Małopolska Province (Małopolska Programme) recognizes multiple causes of the serious health situation of Roma, including low levels of hygiene, "disastrous" living conditions, and limited access to health services.[472] Yet it suggests that the source of these problems is found in Roma's unusual inability to cope with the "systemic transformations" which Poland has undergone.[473] Despite its acknowledgement of the Second Report of ECRI, which calls upon Poland to address discrimination against Roma in everyday life, the Małopolska Programme does not reflect this objective in its health-related proposals.

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[467] "Report on the Situation of Roma and Sinti in the OSCE Area," *supra,* note 4, pp 25, 31 and 122-123.
[468] *See, e.g.,* ECRI Second report on Slovakia, supra, note 125, para. 39; Second report on Bulgaria, *supra,* note 149, para. 39; Second report on Italy, supra, note 22, para. 65; Second report on Poland, *supra,* note 386, para. 59.
[469] ECRI general policy recommendation No. 3, *supra,* note 124.
[470] Strategy of the Government of the Slovak Republic for the Solutions of the Problems of the Roma National Minority and the Set of Measures for Its Implementation, Stage 1, approved 27 September, 1999, Part 2 Explanatory Report: Health Status.
[471] Id.
[472] Pilot Government Programme for the Roma Community in the Małopolska Province for the Years 2001-2003.National Minorities Division, Public Administration Department, Ministry of the Interior and Administration, Republic of Poland, Section 3: Health.
[473] Id., Section III: Objectives of the Programme, p. 7.

Stereotypes, combined with a narrow view of acceptable ways of living, often underlie attributions of fault primarily to Roma in these and other State plans. Though individual government representatives, policy-makers and health care workers may not hold consciously racist views, the importance of identifying and eliminating any underlying racism is obvious: it has tremendous impact on the success of programmes implemented by state institutions. Without acknowledging and combating racism, any results achieved will only mask continued marginalization and propagate the need for state intervention into the indefinable future.

In contrast to the Slovak, Polish and other government plans, Hungary's Roma strategy does address the link between Roma health and discrimination in its health initiatives and the need to examine Roma health in the context of Roma relationships to health institutions, and negative discrimination is acknowledged.[474] In this context, a survey was carried out by the Ministry of Health in cooperation with the National Insurance Fund to investigate the health status of the Roma population and their relationship with healthcare service providers. The results of this survey were incorporated into the national public health care programme. In addition, the training of health care workers and of Roma social workers, as well as the appointment or Roma officials and leaders whose role is to liaise with the organizations representing the target groups, local governments and health care service providers, serve to improve relations between Roma and non-Roma and to combat discrimination.[475] Strategies without an anti-discrimination element to their health and other initiatives should seriously evaluate the appropriateness of incorporating such a focus.

b. Public awareness campaigns to ensure implementation of special measures

In addition to taking practical measures to combat discrimination as it relates to poor health status and problems in accessing services, States should undertake public campaigns to ensure that Roma and the larger society understand the context and content of measures to integrate Roma, including preferential treatment/positive action to promote equality in specific cases. Attention is required to the ways in which majority behaviour and attitudes are implicated in the marginalization of Roma in order to avoid the misinterpretation that special measures are intended to place Romani communities at an advantage rather than to fulfil the goal of equitable access to care. In turn, meaningful access to institutional and complaint mechanisms should be promoted in order to guarantee that the objectives of special measures are met. Guides on legal rights and information on how to access complaint mechanisms should be prepared.

Lithuania's Roma Integration Programme for 2000-2004 identifies a "hostile attitude" toward Roma by Lithuanian society, recognizing the problem of negative public opinion concerning measures to integrate of Roma. Changing majority attitudes does not appear to be a component

[474] "Middle-Term package of measures for the improvement of the living conditions and social situation of the Roma population", Government of Hungary, May 1999, Appendix to Government Resolution No. 1047/1999 (V.5.), point 4.1.
[475] Comments prepared by the Government of Hungary (on file with the Council of Europe).

of the Programme, however: mere implementation of the Programme is expected to eradicate these attitudes.[476] But public support is required at all stages of integration policy and this requires an understanding that building healthy societies, based on principles of democracy, equality and mutual respect, without exclusion or marginalization, benefits everyone. ECRI encourages States to undertake awareness campaigns on the existence of racism and intolerance within their societies, its negative impact on minorities such as Roma, and the need to respect the principle of equality and human dignity in all aspects of daily life.[477] Where victims of racism and discrimination are perceived as "outsiders," educative measures should focus on tolerance, the benefits of a multicultural society, and the special measures that may be required to achieve equal opportunities for the entire population.[478]

Existing initiatives demonstrate state institutions' potential to affect public opinion on the issue of discrimination. Recognizing that majority society still discriminates against Irish Travellers in a manner unacceptable towards other ethnic groups, Ireland's National Consultative Committee on Racism and Interculturalism has recently expanded its public anti-discrimination campaigns to include Irish Travellers.[479] These efforts are being implemented alongside attention to Traveller complaints of denial of public services,[480] and work with the Eastern Regional Health Authority on cultural diversity awareness and sensitivity training towards Travellers.[481]

In recognition of the vicious cycle of discrimination that confronts many Roma, the Rector of the state-funded University of Patras, in Greece, has made a commitment to improve the situation of a group of Roma living in extremely poor conditions in the Riganokambos settlement on university property.[482] The University is interested in cooperating with the relevant state agencies to carry out this objective, in part by incorporating the Romani community into educational research programmes.[483] This commitment should also include provisions for non-discriminatory and culturally sensitive reception at the University's health centre.[484] It is hoped that the leadership demonstrated by the Rector will provide momentum for the Greek government to address the situation of the many Roma throughout Greece living in similarly precarious conditions.[485]

The United Kingdom's Commission for Racial Equality has produced codes of practice for primary care and maternity services to promote equal opportunities and combat racial harassment in care in accordance with the UK Race Relations Act. The codes propose, *inter alia,* measures

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[476] Lithuanian Government Roma Integration Programme for 2000-2004, "Other Issues", p. 5.
[477] *See, e.g.,* ECRI Second report on Slovakia, *supra,* note 125, para. 47; Second report on Italy, *supra,* note 22, para. 58; ECRI Second report on the Czech Republic, *supra,* note 333, para. 45.
[478] ECRI Second report on Greece, *supra,* note 149 at para. 36; ECRI Second report on the Czech Republic, *supra*, note 333, para. 45.
[479] Interview, Dublin, Ireland, 7 December 2001.
[480] Id.
[481] "Meeting the Challenges of Cultural Diversity in the Irish Healthcare Sector", Speech by Mr. Micheal Martin TD, Minister for Health and Children, given 6 November 2001. National Consultative Committee on Racism and Interculturalism, Ireland.
[482] Interview, Patras, Greece, 13 November 2001.
[483] Id.
[484] Id.
[485] *See* Greek Helsinki Monitor /MRG-G Press Release, 13/6/2001, available at: http://www.greekhelsinki.gr/bhr/english/organizations/ghm/ghm_13_06_01.doc

to inform patients, staff and the larger community that health institutions are committed to eradicating racial discrimination while providing services that meet the needs of all sections of the community.[486] Establishment of a complaints procedure is a key component, and comprises arrangements to liaise with relevant health, law enforcement, law and other agencies, as well as publication of materials in all the relevant languages on the help available to patients and the local community.[487] Applicable to health authorities, National Health Service trusts, hospitals, general practitioners and others, these good practice codes may provide guidance for other health systems seeking to implement and raise awareness of anti-discrimination measures in health services.

c. Coordination and supervision of the overall integration programme, especially at the local level

While the ultimate responsibility for implementation of official policy lies with governments, the objectives laid out in national strategies on Roma are often intended for elaboration and implementation at the local level. For various reasons – primarily resistance of local communities – local authorities may be reluctant to implement initiatives on behalf of Roma. The unwillingness of some local communities in Greece to welcome Roma was noted by ECRI;[488] Romania's Prime Minister recently lamented the poor implementation of the country's Roma strategy, calling on prefects to recall their obligations under the plan and become more involved in its implementation;[489] in Kosovo, municipalities' readiness to discriminate against internally displaced Roma in allocation of assistance has been observed.[490]

Supervision and coordination, if not a re-conception of existing methodology, may be required to ensure that steps are taken.[491] This may be the case with respect to Poland's Małopolska Programme, for instance, which places all responsibility for identifying and implementing activities that fit within the Programme's objectives onto local governments.[492]

Coordinating implementation at the local level is one element of a larger need for effective oversight. Strong results are more likely to be achieved when a Roma strategy is implemented in various fields of life in an integrated fashion.[493] Indeed, ECRI has suggested that establishment of a government oversight body with adequate authority and resources can help to guarantee implementation at all levels.[494] Spain's Roma Development Programme has fallen under

[486] United Kingdom, Commission for Racial Equality Maternity Services Code of Practice, *supra,* note 200, Racial Equality Policies.
[487] United Kingdom, Commission for Racial Equality Primary Health Care Services Code of Practice, Countering Racial Harrassment. Available at: www.cre.gov.uk/gdpract/health_care_cop_harass.html
[488] ECRI Second report on Greece, *supra,* note 149, para. 36.
[489] "Situation Not So Fine in Implementing Roma Strategy", Prime Minister, Bucharest, MINELRES: Romania: Ethnic Diversity Briefs, NO. 23, available at: http://relay.delfi.lv/pipermail/minelres/2002-September/002299.html
[490] Fitzpatrick, Catherine A., "Forgotten Refugees: Roma in the Balkans", *supra,* note 335.
[491] *See* ECRI Second report on Greece, *supra,* note 149, para. 35-36.
[492] "Pilot Government Programme for the Roma Community in the Małopolska Province", *supra,* note 472, Section IV. Aims of the Programme, p 9.
[493] *See* ECRI, Second report on Italy, *supra,* note 22 at para. 63.
[494] *See* ECRI general policy recommendation No. 2, *supra,* note 150.

continued criticism for a lack of systematic evaluation and information on outcomes or good practices,[495] although the Spanish Ministry of Employment and Social Affairs has indicated that an evaluation study on the Roma Development Programme will be published shortly.[496] There is no mechanism in Bulgaria's Framework Programme to require the necessary commitment of staff or resources by different government ministries; as in Slovakia's Government Strategy,[497] these bodies have no obligation to report on measures taken to fulfil their responsibilities under the Programme.[498] Similar shortcomings are found in Hungary's middle-term programme.[499] Priority should be given to providing sufficient resources for the timely and effective functioning of such bodies.

d. Adequate anti-discrimination laws enforced by a specialized body

Adequate and effectively enforced anti-discrimination laws can provide the impetus for and assurances that strategies on behalf of Roma will be carried out. The role of a specialized body in the enforcement of anti-discrimination legislation has also shown to increase the effectiveness of the law and to act as a deterrent to discriminatory practices. Within the Council of Europe, ECRI and the Framework Convention Advisory Committee have called on States which have not already done so to develop or strengthen a comprehensive body of criminal, civil and administrative legislation prohibiting racism and discrimination in all fields of life.[500] ECRI has published its General Policy Recommendation No. 7 on national legislation to combat racism and racial discrimination which was adopted on 13 December 2002. The EU's Racial Equality Directive should be transposed into the national legislation of its member states by the end of 2003. Taken together they both provide a framework for all governments to draft legislation that prohibits racial discrimination and promotes equal treatment. As discussed above, this legislation should, among other requirements, apply to direct, indirect discrimination and harassment, explicitly address access to health care and related services, and provide for the reversal of the burden of proof in cases of prima facie discrimination. It should provide sanctions for and effective remedies against acts of discrimination by public authorities in the exercise of their duties.[501]

Romania's recently adopted Government Order 137/2000 On Preventing and Punishing All Forms of Discrimination does specifically address access to health services.[502] While the Order

[495] See, e.g., "Spanish Policy and Roma", Fernando Villarreal, Roma Rights No. 2/3 2001, *supra,* note 21 at p. 59.
[496] Comments prepared by the Government of Spain (on file with the Council of Europe).
[497] Minority Protection in the EU Accession Process, *supra,* note 10, p. 432.
[498] Id., at 115.
[499] Id., at 217.
[500] *See* ECRI Second report on Poland, *supra*, note 386 at para. 16; ECRI Second report on Bulgaria, *supra,* note 149, at para. 15; ECRI Second report on Greece, *supra,* note 149 at para. 8; ECRI Second report on Hungary, *supra,* note 386, para. 13; ECRI Second report on the Czech Republic, *supra,* note 333 para. 10; FCAC Opinion on Slovakia, *supra,* note 131; FCAC Opinion on the Czech Republic, *supra,* note 131.
[501] *See* FCAC Opinion on Hungary, adopted 22 September 2000, para. 15; FCAC Opinion on the Czech Republic, *supra,* note 131; ECRI Second report on Poland, *supra,* note 386 at para. 59.
[502] Article 11 - Under the ordinance herein, denying the access of a person or of a group of persons to public health services (choice of a family doctor, medical assistance, health insurance, first aid and rescue services or other health services) on account of their appurtenance to a race, nationality, ethnic group, religion, social category or to a

does not clearly prohibit indirect discrimination nor shift the burden of proof to defendants, it does provide for individual damages and administrative sanctions in the form of fines.[503] These differences may render it less effective in some situations related to health care access, such as alleged discrimination in the location of health clinics and allocation of other resources. Nevertheless it represents a positive step, in conjunction with the Government Strategy, to bring about meaningful change in access to health care and other public services for Roma. In the future, the Romanian government, as well as others, should aim to adopt comprehensive anti-discrimination legislation that meets all the requirements set out in the Racial Equality Directive.

The Racial Equality Directive calls for a specialized body to promote the equal treatment of all persons without discrimination on the grounds of racial or ethnic origin and outlines the minimum three areas of competence for these bodies.[504] In its General Policy Recommendation No. 2, ECRI provides guidelines for the establishment of independent bodies to oversee and monitor the effectiveness of anti-discrimination legislation.[505] In the context of access to health care, specialized bodies to combat racism could fulfil several key roles. Insofar as attention to rights and obligations associated with health services is relatively recent, special efforts might be required to train public authorities, members of professional medical associations, the legal profession, and Roma themselves concerning all aspects of discrimination in this field.[506] Awareness-raising campaigns might be required to inform the public that the specialized body is competent, for example, to investigate and seek recourse to judicial authorities for complaints related to health care. Above all, since problems of social exclusion generally, and concerning access to health care specifically, arise most often in the local context, then specialized bodies such as ombudsmen institutions should also be adequately represented at local levels.[507]

e. Measures to ensure the consideration of a broad range of Romani health interests

The participation of a broad range of Roma interests throughout the policy-making process is integral to the success of programmes devised on their behalf. This applies not only to Romani women, but also to Roma with distinct, identifiable interests in access to health and other fields. Broad representation is indispensable in the context of primary health care, which is foremost a local phenomenon:

> Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the

disfavoured category, on account of their beliefs, sex or sexual orientation, shall constitute an offence. Romanian Government Order 137/2000 On Preventing and Punishing All Forms of Discrimination, Article 11, available at: http://www.romanothan.ro/eng/documente/internal/0_137_2000.htm

[503] Id., Article 20-21.

[504] Racial Equality Directive, Article 13(1).

[505] ECRI general policy recommendation No. 2: Specialised bodies to combat racism, xenophobia, anti-Semitism and intolerance at national level, *supra,* note 150.

[506] ECRI Second report on Romania, *supra,* note 385, para. 53.

[507] ECRI Second report on the Czech Republic, *supra,* note 333, para. 50.

> community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.[508]

In the interest of integration at the community level, efforts should be made to understand the various needs that should be accommodated to provide equal access to services for all.

The Bulgarian and Romanian government strategies, among others have been lauded for including the Roma community in their preparation.[509] But these and other government plans offer few provisions to outline the ways in which diverse members of Romani communities can participate in policymaking. Specifically, there is little attention to ensuring that the needs of Romani women or of groups with particular requirements concerning the fields addressed by the strategy are considered. Without attention to, *inter alia*, adolescent, rural, nomadic, elderly, or disabled Roma – arguably the most marginalized or socially excluded and yet with specific health needs – these groups are likely to be overlooked. In this regard, Ireland's National Traveller Health Strategy does declare an emphasis on flexibility and innovation to respond to differing circumstances and health needs as identified by Travellers in each area.[510] In the interest of mobile populations, the Strategy includes measures to implement patient and family held records for use by Health Boards nationwide.[511]

The Hungarian Long-Term Strategy identifies the need for participation by the wider society, including Romani social organizations and members of the majority.[512] It also recognizes the rivalry among organizations and individuals representing Roma interests, and the need to include Roma interest organizations in operations at the local and regional levels.[513] Transformation of these considerations into concrete action plans may provide guidance to States confronting similar dynamics. In the interest of implementing far-reaching and efficient programmes to achieve equal access to services for all Roma, States should take measures to identify the diverse groups that should benefit from their health strategies, as well as articulate in detail the ways in which these groups' participation in policy-making can be facilitated.

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[508] Para. VI, Declaration of Alma-Ata**,** International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. Available at: http://www.who.int/hpr/archive/docs/almaata.html

[509] *See* Zoon, *supra,* note 14, pp. 28 and 44; Rumyan Russinov, "The Bulgarian Framework Programme for Equal Integration of Roma: participation in the policy-making process", Roma Rights No. 2/3, 2000, *supra,* note 20; ECRI Second report on Bulgaria, *supra*, note 149, para. 45.

[510] Traveller Health – A National Strategy 2000-2005, *supra,* note 292, item 46.

[511] Id., items 50, 51.

[512] Long-Term Government Strategy Guidelines for Roma Society and Minority Policy Discussion Paper, Abbreviated version, compiled by the Office for National and Ethnic Minorities, Hungary. Budapest, 2001, Preamble.

[513] Id. *See* Section 1.2 The emergence of Roma representation and Section 4.2.2, Strengthening the role of the Roma in public life.

2. Components of government strategies essential to improving access to health care for Romani women

Improving access to health care for Romani women and their communities is more likely to be achieved if several key components are included in strategies with this aim. Programmes should be developed on the basis of adequate research of needs and interests of women, beyond their maternal and care-giving roles. They should focus on integration into mainstream health services through the incorporation of a women's rights and gender perspective in the development of all programmes. As well, strategies should reflect a complementary approach across diverse fields that impact upon health, such as citizenship, social benefits, housing, and education.

a. A holistic approach to women's health with a gender perspective

A sincere commitment to effecting change in health status and access to services for Romani women demands solid research into a wide range of their needs and interests. Majority impressions of the problems of the Roma community are an insufficient basis for action. Presumably in this light, ECRI has encouraged the Slovak government to move away from a paternalistic towards an empowerment model for improving the situation of Roma.[514] With respect to Romani women, the perceptions of Romani communities as reflected through the values of a subset of its members – such as male leaders or members of older generations – are also inadequate bases of policy and programmes. In the interest of guaranteeing equal attention to the health issues of Romani women, and of promoting their individual personal, social and economic development in the manner that they see fit, States should take measures to ensure a holistic approach to Romani women's health that reflects the principles of equality and human dignity.

Romani women may be the primary care givers in their communities, but their health needs are much broader than those related to their care-giving and maternal roles. Nevertheless, government programmes intended to benefit Romani women focus largely on maternal health care and family planning. For instance, Hungary's medium-term action programme alludes to women's health only by reference to proposed training for mother and child health nurses, and a study on "Pregnancy, Birth, and Childcare in Cultures in Hungary."[515] (In fact, it is not clear that either programme is targeted primarily towards Romani women.) Poland's Małopolska Programme also does not appear to target women's health for its value to the women themselves: it mentions the need to encourage pregnancy monitoring among Roma women as a way of "curing congenital defects of children."[516]

[514] ECRI Second report on Slovakia, *supra,* note 125, para. 40.
[515] Government Measures to Improve the Living Conditions of the Roma in Hungary, Information paper compiled by the Office for National and Ethnic Minorities, Budapest, 2001, p. 10.
[516] "Pilot Government Programme for the Roma Community in the Małopolska Province", *supra,* note 472, p. 14.

Though, as the Integration Plan for the *Gitana* Community of Andalucia puts it, "the mother and child are an inseparable vulnerable unit,"[517] this is only a starting point for a variety of strategies targeted to empower women in various spheres of life. These include promotion of education as a means for women's personal, social and economic development, and measures to improve access to the labour market and income-generating activities.[518] The Bulgarian Framework outlines similar measures in education and employment.[519]

As for men, women's health concerns include preventive, reproductive and sexual health issues throughout the life cycle. Furthermore, conditions that affect both women and men may require different types of treatment to be effective. Above all, effective solutions may require changes in men's behaviour: combating domestic violence is one such context. These considerations demand that a women's rights and gender perspective inform all aspects of policymaking that affects Roma.[520] Indeed, this consideration might be satisfied through the designation of a women's rights and gender adviser to all policy-making bodies concerned with Roma. This adviser should be familiar with the situation of women, particularly of gender dynamics, in diverse Romani communities. Moreover, such an adviser should be afforded adequate resources and authority to guarantee meaningful participation in the policy-making process.

In light of the need to address gender-based concerns, an initiative in the Bulgarian Framework calling for "establishing attitudes of cultural equality among Roma women so that they can participate fully and equally in all aspects of public life" might be amended to include attention to Romani men's attitudes that inhibit women's participation.[521] Laudably, one of the many initiatives in Ireland's National Traveller Health Strategy to combat domestic violence reflects gender considerations in its proposal to work with Traveller men perpetrating violence.[522]

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[517] Integration Plan for the Gitana Community of Andalucia – Regional Ministry for Social Affairs (Plan Integral Para La Comunidad Gitana de Andalucia, Junta de Andalucia – Consejeria de Asuntos Sociales,) Health (Área de Salud), p. 48.

[518] Id., objectives 7.1, 7.3, pp. 51-53.

[519] Framework Program for Equal Integration of Roma in Bulgarian Society, adopted by the Bulgarian Council of Ministers on 22 April 1999. Part II, section VIII: The Roma Woman.

[520] On incorporation of a gender perspective into policymaking, the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance (2001) declared: "convinced that racism, racial discrimination, xenophobia and related intolerance reveal themselves in a differentiated manner for women and girls, and can be among the factors leading to a deterioration in their living conditions, poverty, violence, multiple forms of discrimination, and the limitation or denial of their human rights, [The World Conference] recognizes the need to integrate a gender perspective into relevant programmes of action in order to address multiple forms of discrimination. World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, *supra,* note 7, Declaration, para. 69.

[521] Framework Program for Equal Integration of Roma in Bulgarian Society, *supra,* note 519.

[522] National Traveller Health Strategy, *supra,* note 292, item 41.

b. Integration of women's needs into mainstream health and related services through a multi-sectoral approach

Roma health initiatives should reflect the complementary goals of reducing health disparities and integrating Roma into mainstream services. Attention to one without the other results, at best, in a failure to foster integration: at worst, the institutionalisation of a segregated system of aid. The "points of immediate medical aid" envisioned in Poland's Małopolska Programme, for example, are not clearly associated with eventual integration into regular services.

At the same time, consideration of Romani women's health status and access to care should be reflected in the policies of government sectors whose work impacts upon health, such as those responsible for provision of documented legal status, social benefits, education, and housing. Maximum benefit will be achieved by strategies across institutions that are mutually supportive in their objectives to improve the situation of Roma health.[523] The Greek Government's Inter-ministerial Committee, for example, in an effort to improve the living conditions of the Roma as well as their social integration, has developed a Complete Action Programme that applies to the sectors of housing, training, employment, education, health-welfare, culture and sports.[524] In a similar vein, the Irish Government have taken steps to improve inter-departmental coordination through the establishment of a permanent liaison mechanism between the Department of Health and Children and the Department of the Environment and Local Government – and including representatives from Traveller organizations – to address issues of common concern relating to Travellers.[525]

To conclude, in the long term, policies for a multicultural society should reflect routine consideration of a population's diverse needs across a range of fields. Several States are moving towards this goal. While Bulgaria's Framework Programme places little emphasis on Roma health, the need for serious efforts to improve access to health care for Roma is recognized in Bulgaria's 2001 National Health Strategy.[526] Ireland's Traveller Health Strategy requires "Traveller-proofing" – a review, with the participation of Travellers, of national and regional health initiatives to ensure that their interests are reflected.[527] The Integration Plan for the Gitano Community of Andalucia seeks, in part, to ensure that the equality initiatives of the regional Institute for Women reach Romani women.[528]

[523] *See* ECRI, Practical Examples in Combating Racism and Intolerance against Roma/Gypsies, *supra,* note 411, Integrated Strategies, p. 69.
[524] Comments prepared by the Greek Government (on file with the Council of Europe).
[525] Comments prepared by the Irish Government (on file with the Council of Europe).
[526] National Health Strategy: Better Health for a Better Future of Bulgaria. Republic of Bulgaria, Ministry of Health, April 2001, p. 28.
[527] National Traveller Health Strategy, *supra,* note 292, items 5 and 27.
[528] Integration Plan for the Gitana Community of Andalucia, *supra,* note 517, The Woman (Area de la mujer), p. 53.

Spain's National Plan of Action for Social Inclusion, in its Programme for Marginalized Women, proposes a programme to benefit rural women, as well as to combat domestic violence.[529] It remains to be seen whether these programmes will be coordinated with the "plan for the excluded Gitana population or at risk of exclusion," the health component of which is purely an educative one.[530] The challenge confronting policymakers is to find a balance between incorporating Roma women's needs into mainstream programmes and identifying where special measures are required to ensure that Romani women benefit from these programmes on an equal basis with other women. In seeking out this balance, consistent attention to Romani women's needs and interests are required.

[529] National Plan of Action for Social Inclusion of the Kingdom of Spain, June 2001-June 2003 (Plan Nacional de Acción para la Inclusión Social Del Reino de Espana, Junio 2001-junio 2003.) Improving the situation of marginalised women (Mejorar la situación de las mujeres desfavorecidas), points 1 and 2, pp. 29-30.
[530] Id., Improving the situation of the Gitana population that is excluded or at risk of exclusion (Mejorar la situation de la población gitana excluida o en riesgo de exclusión), pp 31-32.

B. Improving access to health care through greater familiarity with Romani culture

Health care institutions, policymakers, and workers are often unfamiliar with diverse Romani cultural practices, particularly if they serve an isolated, transient, or changing population. This unfamiliarity is often combined with negative images of Roma propagated by the media, politicians, or through hearsay.[531] Institutional approaches to culture influence access to care because they may discourage a patient to return or affect the quality of care. In both cases the approaches may be discriminatory.

Keeping in mind that Romani culture varies as widely as majority culture,[532] some common complaints from civil servants and health care workers have included: surprise at traditional cures of giving garlic to newborns to hold or hiding depictions of saints in babies' clothing; annoyance when numerous family members accompany or visit a Romani patient; dismay when Romani families seek to take home from the hospital the body of a deceased family member to mourn; or confusion when a Romani woman refuses to remain in a hospital for purity concerns as well as obligations in the home. As patient populations diversify in terms of traditions and lifestyles, institutions must take on the challenge to guarantee access to care in a non-discriminatory manner.[533]

Increasingly, States are acting on this realization. France's Commission Nationale Consultative des Gens du Voyage aims to assist national ministries in accommodating their services to the particular needs of nomadic or semi-nomadic populations.[534] Ireland's NCCRI recently held a conference in partnership with the Irish Health Services Management Institute to examine cultural diversity in the health sector from the perspectives of health and staff.[535] More specifically, the National Traveller Health Strategy provides for awareness training for health personnel in relation to Traveller culture, including Traveller perspectives in health and illness. Provision of designated Public Health Nurses in each Health Board to work specifically with Traveller communities should also contribute to increased intercultural understanding.[536] In its programmes to relocate *Gitanos* and other inhabitants of *chabolas* to adequate housing, Madrid's Departamento de Realojamiento e Integración Social (IRIS) takes as a starting point that cultural practices and expectations of Gitanos and non-Gitanos that impede integration can be modified to the benefit of both sides.[537] The Romanian Government Strategy, among others, proposes to

[531] *See* discussion in Zoon, *supra,* note 14, at pp. 81-82, 93-94. *See generally,* comments in ECRI country reports on racism and intolerance in the media and in the rhetoric of political parties.
[532] For an overview of Romani culture and lifestyle, including that of women and in relation to health, *See, e.g.*, Jean-Pierre Liegeois, "Roma, Gypsies, Travellers", Council of Europe, 1994; Etudes Tsiganes: "Femmes Tsiganes", *supra,* note 255; Études Tsiganes: Tsiganes et santé: de nouveaux risques?" *supra,* note 46.
[533]For instance, ECRI has noted increasing recognition by high-level authorities of the existence of numerous minority groups in Greece with diverse needs and problems. At the same time, ECRI has called for raising awareness of lower level authorities and the wider population, of the reality and benefits of a multicultural society. Monitoring of the effective application of constitutional guarantees and governmental policy, particularly at the local level, is also recommended. ECRI, Second report on Greece, *supra,* note 149, para. 30.
[534] Interview, Paris, France, 10 December 2001.
[535] Speech by Mr. Micheal Martin TD, *supra* note 481.
[536] Comments prepared by the Irish Government (on file with the Council of Europe).
[537] Interview, Madrid, Spain, 28 November 2001.

train Roma health care workers within Roma communities, as well as setting aside special openings for Roma in medical universities.[538]

In recognition of ethnic minorities' diverse health problems, their relatively less frequent use of the health system, and the failures of an ad hoc approach, The Netherlands' Ministry of Health has begun to examine implementation of recommendations to "stimulate the interculturalization of health care."[539] An acknowledgment that Roma and Sinti are often excluded from programmes and consultations (these tend to focus primarily on recent immigrants) is an important step towards remedying this shortcoming.[540] And Finland's National Board of Education, in cooperation with the Advisory Board on Romani Affairs, has prepared "The Romani People and Health Care Services: A Guide for Health Care Professionals."[541] This book describes beliefs and expectations around health services in the context of the history and culture of Romani people in Finland.

In the past, Romania's Ministry of Public Information supported traineeships for Romanian communities on racism, including sensitisation to negative representations of Roma in the media. Exchange programmes with Roma children visiting the homes of rural Romanians were also organized and apparently well received.[542] Though these programmes have since ended, the long-term, value of anti-stereotype and cultural sensitisation efforts that reach the wider society suggests they might be re-considered in Romania and elsewhere.

At the same time, non-governmental organizations are helping to sensitise Roma and the health care system to each other. Among them are Les Amis des Voyageurs de la Gironde, which trains public health professionals in Roma culture and combating stereotypes through a case specific approach. This permits audiences to examine and re-interpret their understanding of *Tsigane* customs and actions.[543]

[538] Strategy of the Government of Romania for Improving the Condition of the Roma, Ministry of Public Information, Bucharest, 2001, Section D. Health Care, points 2 and 8.
[539] "Interculturalization of Care", summary document, Ministry of Health, The Netherlands. (On file with author.)
[540] Interview, Amsterdam, The Netherlands, 12 October 2001.
[541] "The Romani People and Health Care Services: A Guide for Health Care Professionals." National Board of Education, Finland. This book will soon be published in English (demonstration example and table of contents on file with author.)
[542] Interview, Bucharest, Romania, 13 September 2001.
[543] Interview, Talence, France, 12 December 2001.

C. Improving access to health care through Romani health mediators

Various kinds of mediators are engaged in forging linkages between Romani communities, public services, and local authorities throughout Europe. Promoting intercultural dialogue, improving access to public services, and encouraging parents to send their children to school are among the many issues mediators address. They may fulfil these functions within or outside formal institutions, on a paid or voluntary basis. Their origins may be in the local Romani community or majority society. Qualifications for such a position may include special training administered by public authorities or NGOs.

In the health context, mediator programmes have the potential to inform health care workers and authorities about the culture and needs of a particular Romani community, provide community education on basic health and hygiene, facilitate access to public services, and improve awareness of Roma rights and responsibilities. A survey of these diverse arrangements and evaluation of their effectiveness is beyond the scope of this study. Here, various components and experiences of several existing health mediator programmes will be described. Throughout the report, possibilities for mediator intervention are proposed: these may be of interest to States or localities considering such an initiative.

A key factor leading to the health mediator system in Romania was the lack of data on Romani women's health and a specific problem of low infant immunization.[544] In 2001, the Ministry of Health and Family (MHF) of Romania concluded an agreement with a Bucharest-based NGO – Romani Centre for Social Intervention and Studies (Romani CRISS) – to implement a health mediator system in Romani communities within the government's Strategy for Improving the Roma Situation for the period 2001-2004. This agreement represents a joint commitment to the training, operation, monitoring and evaluation of the system.

The MHF has agreed to support mediator training and the institutionalisation of the health mediator as a recognized occupation in Romania. Along with local public health directors, the MHF coordinates, monitors and evaluates the mediators' activities. In turn, Romani CRISS selects potential mediators from Romani communities and collaborates with Public Health Directors to organize a network of mediators, and participate in monitoring and evaluation. Romani CRISS also has permanent consultative status with right of veto to the MHF-Ministerial Commission for Roma meetings. The Office for Democratic Institutions and Human Rights of the OSCE provides further support to this joint effort by agreeing to facilitate the sharing of experience of Romania's system at local, regional, and international levels.[545]

Mediators in the Romanian programme are primarily women who work in their own communities to provide basic health and hygiene information and services. Mother and childcare is a particular focus: this includes, for example, educating husbands on the importance

[544] Submitted by the Counsellor on Roma of the Minister of Health and Family, Romania, to the Roma/Migration Division, Council of Europe, for the Romani Women and Access to Public Health Care Project.

[545] *See* "Agreement on the Implementation of the Health Mediator System in Romani Communities" within the Romanian Government Strategy for Improving the Roma Situation, Approved by Government Decision No. 430/2001, points 1 and 2.

of increased food intake and decreased workload during pregnancy. Mediators also help to forge links between local health centres and the community, for instance by promoting participation in vaccination campaigns and arranging medical appointments.[546] Proposals for a new law on health insurance include providing general practitioners the opportunity to hire Roma health mediators in certain contexts.[547]

In addition to increasing the number of Roma on the rosters of general practitioners and the uptake of infant vaccination, a significant outcome of the system has been to provide work opportunities for Romani women in their communities. As a result, many of these women have become more visible, vocal, and respected in articulating community needs.[548]

In Finland, an association of Roma mediators, Rhydys, existed since 1994.[549] The likelihood that many participants had taken on a mediator position on the basis of their status in the local community and regardless of education level pointed to the need for training programmes to ensure adequate reading, writing, and information technology skills.[550] Though the programme had been supported through yearly state grants, mediators suffered unemployment due to lack of municipal cooperation and funding.

The Romani Educational Unit within Finland's National Board of Education, in cooperation with Rhydys, began in 1999 to undertake longer and more systematic training of mediators.[551] Extensive written materials have been prepared on a range of topics to be taught over approximately one year; upon passing an exam, mediators receive a diploma from the Romani Educational Unit and credentials from Rhydys.[552] These changes have been made with the aim of encouraging local councils to employ mediators for official positions in the community administration.[553]

In Dublin, Ireland, the NGO Pavee Point has engaged Traveller women in identifying Travellers' health needs and the means by which to address them through its Primary Health Care for Travellers Project. This project was initiated in partnership with authorities from the Eastern Health Board. At the project's inception, eight Traveller women, seven of whom were pre-literate and had little schooling, were selected to become familiar with local health services, identify community needs, plan interventions, and undergo training to implement them. Liaisons with local schools, clinics and health authorities were among the interventions aimed at

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[546] *See* Joyce Schoon, "Project Description: Rroma Mediators Training for Health Education and Social Rights in RRomani communities of Romania", Romani Centre for Social Intervention and Studies (Romani CRISS) Bucharest, Romania.

[547] Submitted by the Counsellor on Roma of the Minister of Health and Family, Romania, to the Roma/Migration Division, Council of Europe, for the Romani Women and Access to Public Health Care Project.

[548] Interview, Botosani, Romania, 15 September 2001.

[549] "Background information on the Roma mediator activities." Romani Education Unit, National Board of Education, Finland. (On file with author.)

[550] Id.

[551] Id., "Mediator training in 2001."

[552] Current and future topic areas include: the Finnish education system, Finnish citizenship, childcare and upbringing; basic health care in communal health centres, history, language and culture presentation skills, basic computing skills, knowledge on tenants' rights and duties, social care and services, illness, drugs, leisure time and hobbies, unemployment, starting an entrepreneurship, information on the European Union. Id.

[553] Id.

identifying and filling gaps in existing services.[554] The project's efficacy in complementing and improving access to mainstream services has been recognized by the Department of Health.[555]

For the Traveller women trained as community health workers, one consequence of the heightened confidence, knowledge, and communication skills they acquired over the course of these experiences has been the motivation to represent Travellers issues through a wider range of actions and in various forums.[556]

Mediators are not a cure-all for the complex systemic barriers to accessing health care often facing Roma. Thus the fact that a health assistant initiative is the primary health component of the Czech Republic's Concept of Roma Integration might require re-evaluation.[557] However, concern that mediators or other specialist health workers are a drain on resources may be dispelled with evidence of savings on specialized or urgent health care costs through greater attention to preventive care. The significance of avoiding misunderstandings and confrontations that cause Roma to distrust public services while fostering good relations with local authorities should not be underestimated. At the same time, measures should be taken to ensure that mainstream services respond to mediators' findings and take steps to transform accordingly.[558] The existence of specialized health workers must be viewed as a way to promote rather than excuse other health care workers from engaging with the community the mediator aims to help.[559] To do otherwise risks institutionalising a segregated system of assistance.

[554] "Primary Health Care for Travellers Project Report for year ended October 1995", Pavee Point Travellers Centre, pp. 10-11.
[555] Id., p. 28.
[556] Id.
[557] *See* The Concept of Roma Integration of the Czech Republic, approved by the Government on 23 January, 2002, Section 4.6: Affirmative Action in Social and Health Care.
[558] *See* Sarah Cemlyn, "From Neglect to Partnership? Challenges for Social Services in Promoting the Welfare of Traveller Children", *supra,* note 182, pp 359-361.
[559] Concerns about overburdening specialist health visitors and weakening their capacity to assist patients has arisen: "Specialist health visitors working with Travellers come under pressure to assume not only "health" tasks such as mental health issues but also those of other agencies such as housing or social services. This can lead to a dependency culture and dilute the health care input." Cleemput, *supra,* note 180, p. 16.

D. The potential of intergovernmental initiatives to improve access to health care for Romani women

Intergovernmental initiatives can contribute significantly to improving access to health care for Romani women and those in their care. Through attention to the health and rights of marginalized groups, and with a focus on participation of Romani women, certain initiatives have begun to create conditions for the elimination of discrimination and improved access to health care in a culturally sensitive manner. Enhanced relations among health care systems, inter-governmental and specialized bodies will advance these objectives.

The Constitution of the World Health Organization states that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic, or social condition."[560] The recently adopted WHO Gender Policy: "Integrating gender perspectives into the work of WHO," recognizes that there are differences in the factors determining health and the burden of ill-health for women and men.[561] The WHO has also drawn attention to the links between gender, health, and poverty, with a focus on improving planning and implementation at the national level.[562] Recognition of distinct patterns of health and illness in women belonging to minority and migrant groups has been highlighted as well.[563] The WHO's commitment to health and human rights for all in the 21st century[564] should provide for the inclusion of marginalized groups on all health improvement agendas.

Several European Union funding initiatives support minority protection and civil society development. The Phare programme seeks to improve minority protection in light of EU accession requirements, and has provided over 23 million Euro to Roma-related initiatives since 1999.[565] In turn, the EU Access programme focuses on enhancing the social sector, with emphasis on promoting sustainable health and social support for marginalized groups.[566] Initiatives in South Eastern Europe to support capacity building for officials, NGOs and minority communities on minority protection issues are supported by the European Initiative for Democracy and Human Rights.[567] Through the Stability Pact, the EU promotes these goals in cooperation with and among Balkan states as well as other international organizations. Thus the EU has an extensive framework within which to deepen its involvement in improving access to

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[560] Constitution of the World Health Organization (July, 1946), Preamble.

[561] WHO, April 2002. *See also* "Gender and Health", Technical Paper, WHO/FRH/WHD/98.16, World Health Organization, 1998; "Women's Mental Health: An Evidence-Based Review", World Health Organization, 2000; "Mental Health: New Understanding, New Hope. World Health Report 2001", World Health Organization, 2001

[562] *See* "Integrated Planning Framework on Gender, Health, and Poverty", (Draft). Department of Health and Sustainable Development, World Health Organization, September 2000.

[563] *See, e.g.,* "Consultation on Health Indicators of Minority Women in Europe", (Draft Report) World Health Organization Regional Office for Europe and the Danish Centre for Human Rights, 12 April 2000.

[564] *See* "Director-General Sets out WHO Stance on Health and Human Rights, Press Release WHO/93, 8 December, 1998.

[565] *See* The European Commission: External Relations at: http://europa.eu.int/comm/external_relations/

[566] Id.

[567] *See* The European Initiative for Democracy and Human Rights, Available at: http://europa.eu.int/comm/europeaid/projects/eidhr/index_en.htm

health care and related services. Additionally, the European Monitoring Centre on Racism and Xenophobia (EUMC) works with international organizations to collect, review and disseminate data on racism, xenophobia and anti-Semitism in EU Member States as well as candidate countries, with the aim of promoting "best practices."[568] Its role as a central database places the EUMC in a strong position to enhance awareness of the ways in which racism affects access to health care and of initiatives that have succeeded in combating this phenomenon.

The Council of Europe has long understood that health is an integral determinant of social cohesion, and has demonstrated a commitment to addressing a broad range of health issues: access to care for vulnerable groups, citizen and patient empowerment, health promotion and disease prevention, data protection, and others.[569] The European Committee for Equality between Women and Men (CDEG) provided a public forum to Roma and Gypsy women where a need was identified for action to improve access to public services in the context of ethnic and gender discrimination.[570] Under the European Health Committee, an expert group – SP-SPM – was established to examine the adaptation of health care services to the needs of people in marginal situations. Its recommendations emphasize preventive action, the creation of supportive environments for social re-integration, improvement of health knowledge and avoidance of stigmatisation.[571] Training to assist health and social professionals to respond to the needs of marginalized groups is suggested, and the needs of women living in insecure conditions are identified as requiring special attention.[572] The Committee has also acknowledged the value of positive discrimination measures in the interest of promoting equitable access to services and with the aim of integration into mainstream services.[573]

Recognizing that health is a factor in stability maintenance and peace promotion, the SP-SPM, in cooperation with WHO, have recently undertaken to examine obstacles, opportunities, and gaps in knowledge concerning access to health and social services for vulnerable groups in South Eastern Europe.[574] This initiative aims to promote the reconstruction and development of health infrastructure and services through regional cooperation and international support, throughout and beyond the European Union accession process.

Under the Stability Pact, the OSCE Office of Democratic Institutions and Human Rights (ODIHR) has undertaken capacity building for Romani women's associations throughout the

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[568] *See* The European Monitoring Centre on Racism and Xenophobia, http://eumc.eu.int/about/index.htm.

[569] *See* Recommendation Rec(2000)18 of the Committee of Ministers to member states on criteria for the development of health promotion policies, adopted 21 September, 2000; and Recommendation Rec(2001)12 of the Committee of Ministers to member states on the adaptation of health care services to the demand for health care and health care services of people in marginal situations, adopted 10 October 2001.

[570] *See* "Hearing of Roma/Gypsy Women of West, Central, and Eastern Europe", Conclusions of the General Rapporteur Ms. Ana Gimenez Adelantado, Council of Europe, EG/TSI (95) 2.

[571] *See* "The Adaptation of Health Care Services to the Demand for Health Care and Health Care Services of People in Marginal Situations, Recommendation Rec(2001)12 and explanatory memorandum", adopted by the Committee of Ministers, Council of Europe, 10 October, 2001.

[572] Id., pp. 16, 19.

[573] Id., pp. 15-16.

[574] *See* "South East Europe Strategic Review on Social Cohesion Health Network Concept Note: Preparation of a methodological survey to improve access to health care for vulnerable and marginalised persons", SEER/Health (2001)2; *See also* "Executive Summary on Access to Health Care for Vulnerable Groups in South East Europe", Strasbourg, 20 August, 2001, prepared by Jeffrey Levett, National School of Public Health, Athens, Greece.

region. A regional training for Romani women activists was held in Ohrid, Former Yugoslav Republic of Macedonia, in October 2000. Future activities should include mainstreaming of Romani women into the other two chapters of ODIHR responsibilities under the project. These are: 1) addressing the difficulties of Roma in crisis and post-crisis situations, including refugees and internally displaced persons, and 2) generating a "Roma to Roma" process of self-organization, sustainable community development and participation in civil society.[575]

In the interest of improving access to health care for Roma and other vulnerable groups in a coordinated and multifaceted manner, special attention should be given to enhancing dialogue and cooperation among these and other specialized bodies. Furthermore, as these initiatives expand, care should be taken to ensure that the needs and views of Romani women are taken into consideration at all stages. Sustained political will and commitment of sufficient resources at international as well as national and local levels will be required to achieve these goals.

[575] Newsletter on activities within the Project "Roma under the Stability Pact" Number 2, June 2001, Council of Europe Migration and Roma/Gypsies Division, Directorate General III – Social Cohesion, pp. 14-15.

PART V Recommendations

A. Legislation and Institutional Mechanisms to Promote Non-discrimination and Equality in Access to Health Care

States, intergovernmental and specialized bodies should take steps to promote non-discrimination and equality in access to health care for Roma, as follows:

- States should implement fully and effectively at national level comprehensive anti-discrimination legislation that includes the express prohibition of direct and indirect discrimination in access to health care and related public services, provides provision for a shift in burden of proof, combats victimization, supports positive action, allows legal entities to support complainants in judicial or administrative proceedings, provides for effective and proportionate sanctions and remedies. Implementation should also build regular review and assessment of the legislation with a view to strengthening it to ensure that anti-discrimination and equal treatment provisions are in line with further positive developments on racism and racial discrimination. The law should also impose a legal duty on public authorities to promote racial equality. Adequate authority and resources should be allocated to guarantee proper implementation and enforcement, particularly at the local level.

- States should establish or designate specialized bodies which acting independently have a role and responsibility in reviewing and enforcing anti-discrimination legislation, supporting victims of discrimination, undertaking research, surveys and awareness-raising activities. Members of the specialized bodies should reflect the broad population. The role and responsibilities of these bodies should be in line with ECRI's General Policy recommendation No. 2 : Specialized bodies to combat racism, xenophobia, anti-Semitism and intolerance at national level.

- States should create an official system of data collection in line with international standards on data protection to document the situation and needs of Roma and to record all types of discrimination. Statistical, documentary or technical information processed or produced must help give regional and international organizations an overview of the situation, its extent, causes and manifestations, as well as effects of measures already taken to address the situation. Such data should be disaggregated on the basis of ethnicity and gender. The data and information so gathered must be such that it enables the receivers to draw meaningful comparisons between States and assists States and bodies working on the issues to develop policies and courses of action to address the specific needs of Romani women, including accessing public services.

B. Government Strategies Improve Access to Health Care

Governments should develop and implement comprehensive and proactive national strategies to improve access to health care for Roma women as follows:

- Government strategies to improve Roma health should raise awareness on health and health related issues on the part of health care workers and Roma community, develop their capacity to combat discrimination, involve them in the design of strategies.

- Consultative mechanisms should be included in government strategies to improve Roma health in order to ensure the consideration of a broad range of Romani health interests in the policy-making process, e.g. those of female/male, rural/urban, adolescent/elderly, sedentary/nomadic, and disabled Roma.

- Strategies should adopt a multi-sectoral approach to address the impact of documented legal status, social benefits, education, living conditions, housing, and other factors on health status and access to care. States should consider establishing an inter-ministerial body in order to coordinate activities.

C. Enhancing Participation of Romani Women in Improving Access to Health Care

Governments, and inter-governmental organizations charged with supporting governments by funding national and transnational programmes and projects, should take steps to ensure that Romani women have the right to participate, on equal terms with Romani men, in all stages of policy-making on behalf of Roma. Taking special measures where necessary, governments should:

- Target Romani women to raise their awareness on the importance of participation in health care matters, build their capacity to participate and ensure their participation on an equal basis with men in all consultative mechanisms established and in the stages of policy-making on matters concerning Roma, in part through ensuring transparency in proposals, decision-making, and recruiting processes subject to appeal.

- Designate a women's rights and gender adviser to ensure incorporation of a women's rights and gender perspective into policy-making and programmes on behalf of Roma. This adviser should be familiar with the situation of women and gender dynamics in diverse Romanic communities, and be afforded adequate resources and authority to ensure meaningful participation in the policy-making process.

- Design and undertake training to improve Romani women's advocacy skills in order to enhance their effectiveness in policy-making and public administration.

- Support the institution of Romani health mediators at local levels and on a national scale.

D. Combating Discrimination by Health Care Workers and Institutions

Governments should take steps to ensure equal access to public health care for Roma on a non-discriminatory and culturally sensitive basis. Taking special measures where necessary, governments should:

- Ensure the enactment, monitoring, and enforcement of prohibitions against discrimination on the part of health care workers and institutions, including by professional associations.

- Educate as appropriate health care workers and authorities about diverse Romani traditions, cultures, living conditions and mobility patterns, and to recognize indirect and direct discrimination on the basis of race, ethnicity, and associated factors such as a travelling lifestyle.

- Create a system of incentives for health care personnel to work in Romani communities with the aim of integrating these communities into mainstream services.

- Ensure physical access to health care, including emergency care, through the provision of adequate roads, communication, and services for Romani communities.

- Ensure access to health care for mobile populations, with consideration for client-held records and other non-territory based systems.

E. Improving Access to Health Care for Romani Women

Governments should take steps to ensure equal access to public health care for Romani women without discrimination on the basis of ethnicity or gender and on a culturally sensitive basis. Taking special measures where necessary, governments should:

- Include Roma, particularly women, in research on health status and needs, with attention to the situation of adolescents, rural and mobile populations.

- Ensure access to preventive health information and services throughout the life cycle, in part through access to free or reduced-cost care for eligible women.

- Ensure access to reproductive and sexual health information and services with respect for privacy and confidentiality, and particular attention to the needs of adolescents, rural or isolated and mobile communities.

- Ensure access to complete and accurate sexual health education for all members of Romani communities, with attention to gender equality in decisions about sexuality and the role of Romani men in promoting and protecting women's health.

- Ensure access to human rights education for all members of Romani communities, with particular attention to those rights associated with control over and freedom to decide on matters related to reproduction and sexuality.

- Ensure access to mental health and substance abuse information and services, with particular attention to the needs of adolescents, rural or isolated and mobile communities.

F. Identification Documents, Citizenship and Health

Governments should take steps to ensure equal access to identification documents and citizenship on a non-discriminatory basis. Taking special measures where necessary, governments should:

- Adopt proactive and concrete measures to raise awareness among the Roma community of the importance and methods of acquiring documented legal status.

- Streamline and facilitate access to documented legal status through the flexible application of eligibility requirements such as administrative fees or proof of residency that may be difficult for Roma to satisfy.

- Ensure interim access to health information and services for persons who lack documentation required to access mainstream services.

- Ensure access to identity cards, birth certificates, and other official documents through provision of adequate information, reduced or no-cost registration for low-income persons, and monitoring of local authority discretion.

G. Social Benefits and Health

Governments should take steps to ensure equal access to social protection on a non-discriminatory and culturally-sensitive basis. Taking special measures where necessary, governments should:

- Identify, assess and review information, costs and barriers to accessing social benefits, particularly non-contributory health insurance, such as those associated with registration at unemployment bureaus, and eligibility criteria with the aim of combating discrimination and promoting equality.

- Create and publicize effective appeals mechanisms to challenge assessments of eligibility for benefits.

- Ensure access to social benefits for mobile populations, with consideration for client-held records and other non-territory based systems.

H. Education and Health

Governments should take steps to ensure equal access to education without discrimination on the basis of ethnicity or gender by encouraging cooperation among parents, teachers and education authorities to promote the education of Romani girls and women. Taking special measures where necessary, governments should:

- Adopt reasonable accommodations in primary and secondary education for girls who may have left school for a period, in part through allocation of resources for part-time or home education.

- Ensure access to literacy training and specific information to help promote the health and well-being of women and their families, including information on reproductive and sexual health, human rights and gender equality.

- Ensure access to information on the personal and health risks of early marriage and childbearing, and to the education and means for Romani women to exercise their rights to decide freely and responsibly on the number and spacing of their children.

- Create incentives and support systems to encourage Romani women to pursue tertiary or and vocational education.

I. Housing and Health

Governments should take steps to ensure access to adequate housing and living conditions on a non-discriminatory and culturally sensitive basis. Taking special measures where necessary, governments should:

- Ensure access to adequate housing, i.e., that which is habitable, has adequate availability of services, materials, facilities, and infrastructure, and has legal security of tenure. Particular attention should be given to rural or isolated communities and halting sites.

- Ensure the inclusion of Romani women in the planning, implementation, monitoring and evaluation of housing and caravan site development and rehabilitation.

- Recognize the actual dwellings of Roma as their permanent domicile for the purposes of access to public services.

- Legalize Romani settlements for the purpose of access to public services.

Ensure access to health care and other public services for members of mobile populations without access to legal caravan sites.

European Monitoring Centre on Racism and Xenophobia

Breaking the Barriers — Romani Women and Access to Public Health Care

Luxembourg: Office for Official Publications of the European Communities

2003 — v, 118 pp. — 21 x 29,7 cm

ISBN 92-95008-14-6

The European Monitoring Centre on Racism and Xenophobia (EUMC) is an agency of the European Union. Its primary objective is to provide the European Community and its Member States with objective, reliable and comparable data at European level on the phenomena of racism and xenophobia in order to help them take measures or formulate courses of action within their respective spheres of competence. It also studies the extent and development of the phenomena and manifestations of racism and xenophobia, analyses their causes, consequences and effects and highlights examples of good practice in dealing with them.

The European Union undertakes a variety of activities related to fundamental rights and anti-discrimination which form a basis for addressing issues related to the situation of members of the Roma community. It also finances and supports projects through its PHARE programme, a pre-accession instrument to assist the applicant countries of central Europe in their preparations for joining the European Union.

Additional information is available from the following websites:

http://europa.eu.int/comm/employment_social/fundamental_rights/index_en.htm
www.stop-discrimination.info
http://europa.eu.int/comm/justice_home/fsj/rights/fsj_rights_intro_en.htm
http://europa.eu.int/comm/enlargement/pas/phare/index.htm

Information on related activities by the Organisation for Security and Cooperation in Europe (OSCE) and Council of Europe is available from the following websites:

http://www.osce.org/hcnm/
http://www.osce.org/odihr/
http://www.osce.org/odihr/cprsi/

http://www.coe.int/T/E/Social_Cohesion/Roma_Gypsies/
http://www.coe.int/T/E/human_rights/Ecri/

From the foreword:
This report is intended “to assist policy and law makers to better understand the complex and interrelated nature of the healthcare issues and to assist them to improve the design and implementation of policies on Romani women and health. It has been a much neglected aspect of the work on Roma and hopefully will contribute to the design and implementation of concrete and practical policies, strategies and programmes which may inspire further action into related areas upon which the report touches. This will be to the benefit not only of Romani women and their families, but all of us”.

31 July 2003

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Publications.eu.int

à ajouter code à barres:
ISBN 92-95008-14-6