# HEALTH NEEDS OF THE ROMA POPULATION IN THE CZECH AND SLOVAK REPUBLICS

**A LITERATURE REVIEW**

**A PROJECT COMMISSIONED BY THE WORLD BANK**

## FINAL REPORT

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This report on health needs of the Roma population in the Czech and Slovak Republics was commissioned by the World Bank, who were also consulted on the conception of the project. The views and conclusions expressed in this report, however, are the responsibility of the authors.

The report has been written by the European Centre on Health of Societies in Transition (ECOHOST). The project team was led by Ilona Koupilová and Martin McKee. Ilona Koupilová co-ordinated the running of the project, drafter several chapters and undertook the overall editing of the report. Martin McKee conceived the project, contributed to drafting of several chapters and assisted with the editing of the report. Helen Epstein made many of the essential contacts, drafted the chapter on health status in the Czech Republic and Slovakia and assisted with editing of other chapters. Steve Hajioff undertook the literature review on health of Roma in other countries and drafted the chapter on international aspects of health of Roma. Ilona Koupilová and Martin McKee work in ECOHOST. Helen Epstein and Steve Hajioff were visiting fellows in ECOHOST at the time of their work on this project.

The literature searches in the Czech and Slovak republics were conducted by a team based at the Department of Social Medicine & Health Care Administration at the Masaryk University in Brno. The team was led by Jan Holčík. Zuzana Blažková, Pavlína Káňová and Helena Malenová performed the literature searches and conducted surveys among the Roma organisations. We are grateful to Květa Rimárová of the Department of Hygiene at the Šafařík University in Košice for providing us with access to data and information and assisting us with the survey. We would also like to thank Zuzana Brázdová of the Department of Preventive Medicine at Masaryk University in Brno, Libuše Nesvadbová of the Department of Geographical Medicine at Charles University in Prague, and colleagues from universities, research institutions and agencies in the Czech and Slovak Republics, for providing us with much useful information and encouragement. We wish to thank Ross Pavis of the World Bank for comments on an earlier version of this report.

# ABSTRACT


## Background

Both the Czech Republic and Slovakia have a substantial Roma population, the exact size of which is uncertain. Uncertainties are due to several factors such as distrust in and disregard of the minority for official matters, and hiding of identity due to the negative social connotations that it is associated with. Whilst it is widely believed that the health of Roma people is often poorer than the majority population, these inequalities remain largely unresearched. This project aims to bring together the available information and facilitate the future collaboration between researchers involved in studies on Roma health in the two countries.

## Methods

Comprehensive literature review based on relevant papers on the topic published in Czech or Slovak or by authors from the two countries. The team performed systematic searches and made contacts with institutions and subjects potentially involved in studies of Roma health in the Czech Republic and Slovakia. Information from both formal and informal sources was used in producing this report.

## Results

What limited evidence exists indicates that the health needs of the Roma population are considerable. With very few exceptions, the evidence suggests that health status of Roma is worse than that of non-Roma population in the Czech Republic and Slovakia.

Much published literature concentrates upon communicable disease or reproductive health. The burden of infectious disease among Roma in the Czech and Slovak Republics seems to be high for a population living in an industrialised country. Diseases associated with poor hygiene seem to be particularly important. The limited evidence suggests increased morbidity from non-communicable disease, but there is little published on this topic. Evidence on health care, though fragmentary, suggests poor communication between Roma and health workers and low uptake of preventative care.

The health needs of the Roma population lack visibility, not only because of the absence of research but also the absence of advocacy on their behalf. Since 1989, Czech and Slovak researchers have largely turned away from health research on particular ethnic groups. This probably reflects a growing sensitivity about stigmatising Roma, but it also makes it more difficult to know how their circumstances might be improved.

## Conclusions

Published research on the health needs of the Roma population is sparse. The topics that have received attention suggest a focus on concepts of contagion or social Darwinism, indicating a greater concern with the health needs of the majority populations with which they live. There is a need for both further research into the health of Roma people; with particular emphasis on non-communicable disease; and also for interventions that would improve Roma health. Such research must, however, be handled with sensitivity, recognising the social and political context of the society concerned.

# 1 Introduction and aims of the project

Roma, or Gypsies, are an ethnic minority of northern Indian origin living in many countries throughout the world. Gypsy populations are particularly numerous in central and eastern Europe and the western part of the former Soviet Union where their presence has been documented since the eleventh century. Their history in this region can be characterised as a combination of peaceful coexistence and blatant discrimination, with multiple and complex causes among which are their remarkably preserved traditions and resistance to assimilation.

Both Czech Republic and Slovakia have a substantial Roma population, the exact size of which is uncertain. Uncertainties are due to several factors such as distrust in and disregard by the minority of official matters (like participation in a census), and hiding of identity due to the negative social connotations associated with it.

A brief glance in the scientific literature supports the commonly perceived notion that besides (or in relation to) social and financial problems this minority population have been struggling with considerable health problems.

The recent attempts by groups of Roma families from Czech Republic and Slovakia to seek asylum in Canada and Britain have focused more attention of the media and the governments on the needs of Roma people and stimulated activity within the research community. We have identified new research projects addressing the health needs of the Roma population that are currently under way or at the stage of preparation or piloting in the Czech Republic and in Slovakia (see Chapter 9).

## 1.1 Aims

In view of the pressing needs of the Roma people and the emergence of a favourable political environment, we believe that it is now timely to initiate a comprehensive programme of research on the health problems of the Czech and Slovak Roma populations. We recognise that success of any research or intervention programme dealing with the health of the Roma will depend crucially on the support of the Roma people themselves.

The first step in this process is a comprehensive literature review based on relevant papers on the topic published in Czech or Slovak or by authors from the two countries. Our initial search has indicated that there is likely to be a sizable volume of research that deals, at least in passing, with the health needs of the Roma population. Unfortunately this research has not been collated systematically.

The aim of this project was to carry out a literature review covering the following topics:

- Demography of the Roma population
- Epidemiology of leading communicable and non-communicable diseases and health behavior
- Sociological / anthropological research on the Gypsy minority regarding traditions / values / beliefs / social organization
- Publications or available information on interventions aimed at the improvement of their health / social / financial status

## 1.2 Health and transition in the Czech Republic and Slovakia

Czechoslovakia came into existence in 1918 when the Czechs and Slovaks together proclaimed their independence from the Austro-Hungarian Empire. At this time, Czech lands were the most industrialised part of the Empire. From 1948 to 1989, a strong Communist regime prevailed, until finally a new parliamentary democracy was formed with strong governmental policies of market orientation and economic and social restructuring. On January 1st 1993, Czechoslovakia separated into two countries: the Czech Republic and Slovakia.

Figure 1.1: Life expectancy at birth (in years) in the Czech Republic and Slovakia.

Source: WHO HFA data.

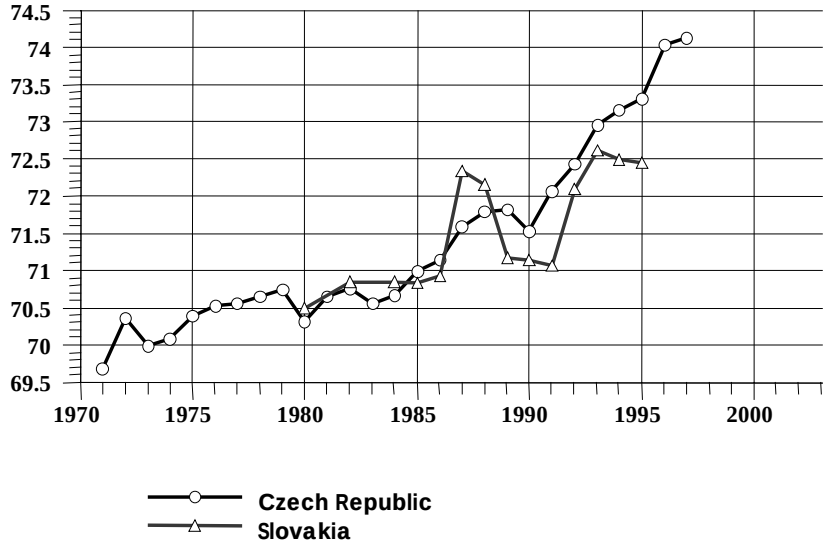
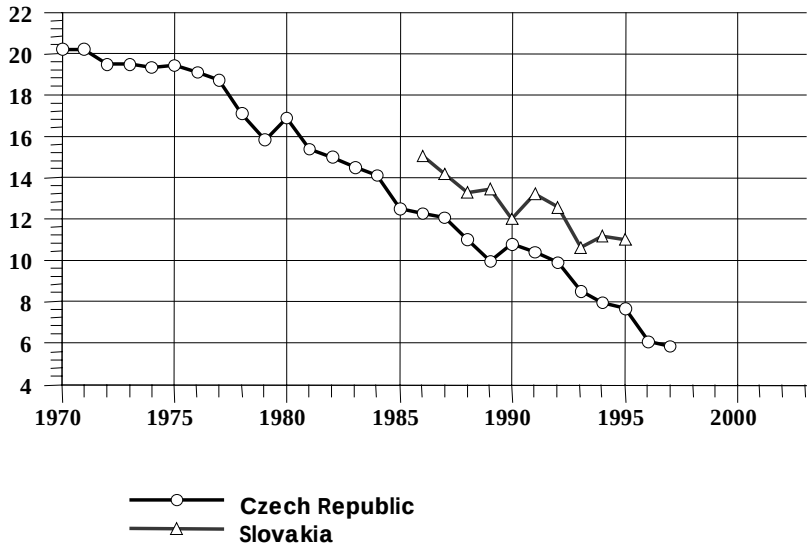


Figure 1.2: Infant mortality rate (per 1000 births) in the Czech Republic and Slovakia. Source: WHO HFA data.




Since the mid 1960s, the health of the people of central and eastern Europe has lagged behind that of those living in the west. The reasons for this gap are complex and there is still considerable debate about their relative importance, in particular the contributions of socio-economic circumstances and health care.[1] This situation has become more complex as the effects of transition affect countries differently, with some, such as the Czech Republic and Poland, experiencing improvements in mortality[2] [3] but others, such as Russia, experiencing marked deterioration. See Figures 1.1 and 1.2.

The average real income in the Czech Republic decreased by almost 20% between 1989 and 1993, and was still 10% lower in 1995 than in 1989; real wages followed a similar trend. In 1997, real wages in the Czech Republic were at the level of 102% of year 1989. The decline in real income and real wages in Slovakia was even more dramatic. The real wages declined by more than 30% between 1989 and 1993, and in 1997 were still 13% lower than in 1989.[4]

Although the registered unemployment remained relatively low in the Czech Republic (around 4% in 1997), the socio-economic differentials in the society clearly increased, as documented by an increase in the Gini coefficient (measure of the degree of inequality of the distribution of earnings; zero if total equality, 100 if total inequality) from 20.4 in 1989 to 25.9 in 1997. The registered unemployment rate is substantially higher in Slovakia (nearly 13% in 1997).

The income advantage of education is clearly becoming of increasing importance in both countries in recent years: less than 5% of university educated and as many as 35-40% of those with basic education declare subjective poverty in the Czech Republic. Although the current income differences are still smaller than in the West, their appearance at the time of declining average real income almost certainly increased vulnerability of some in the society,

including the less educated. This, together with the decline in social benefits, might have produced substantial hardship with a potential to affect health.

The transition towards the market economy has been accompanied by a series of fundamental changes in the Czech and Slovak health care systems. The main features of the changing health system included introduction of free choice of a GP, direct access to specialists and specialist departments, and an emergence of private health sector. [5 6 7]

Information on social variation in health of people in Central and Eastern Europe is limited. The available data suggests that considerable differences do exist and that the process of economic and political transition generally tends to lead to an increase in health inequality within countries.[8] We have previously reported an increase in social variation in birth outcomes in the Czech Republic and Estonia during the period of transition, as the groups with lowest education fail to benefit from the changes brought about by the transition. In both countries, there were also considerable differences in mean birth outcomes by marital status and nationality.[9 10]

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1 Bobak, M, Marmot, M. East-West mortality divide and its potential explanations: proposed research agenda. BMJ 1996;312:421-425.

2 Zatoñski, WA, Boyle, P. Health transformations in Poland after 1988. J Epidemiol Biostat 1996;1:183-187.

3 Walberg, P, McKee, M, Shkolnikov, V, Chenet, L, Leon, DA. Economic change, crime, and mortality crisis in Russia: a regional analysis. BMJ 1998;317:312-318.

4 United Nations Children's Fund. Women in Transition. Regional Monitoring Report No. 6. Florence: UNICEF, 1999.

5 WHO. Health Care Systems in Transition: The Czech Republic. WHO, 1996.

6 WHO. Health Care Systems in Transition. Slovakia. WHO, 2000.

7 Vienonen, MA, Wlodarczyk, WC. Health care reforms on the European scene: evolution, revolution or seesaw? World Health Stat Q 1993;46:166-169.

8 Shkolnikov, VM, Leon, DA, Adamets, S, Andreev, E, Deev, A. Educational level and adult mortality in Russia: an analysis of routine data 1979 to 1994. Soc Sci Med 1998;47:357-369.

9 Koupilova, I, Bobak, M, Holcik, J, Pikhart, H, Leon, DA. Increasing social variation in birth outcomes in the Czech Republic after 1989. Am J Public Health 1998;88:1343-1347.

10 Koupilova, I, Rahu, K, Rahu, M, Karro, H, Leon, DA. Social determinants of birth weight and length of gestation in Estonia during the transition to democracy. Int J Epidemiol 2000 (in press).

# 2 Methods for the literature review

Information from both formal and informal sources were used in producing this report. Each part of the information acquisition process was informed by and linked to the other parts of the process. For clarity, we have outlined our methods according to the information sources used.

## 2.1 Internet

The World Wide Web was one of our most important sources of information. A search of the World Wide Web using the HotBot search engine yielded a large number of hits of variable usefulness. We performed a search of the entire web using the search engine "Hotbot", and we also searched the websites of a number of relevant agencies, including:

### 2.1.1 National Institutions

- Institute of Health Information and Statistics in Prague
- Government of the Czech Republic
- Government of the Slovak Republic
- Czech Statistical Office
- Statistical Office of the Slovak Republic

While some of these sites contained general information about Roma rights, few contained useful data about the health status of Roma populations.

### 2.1.2 International Institutions

- United Nations Organization
- World Health Organization
- Organization for Security and Cooperation in Europe
- Organization for Economic Cooperation and Development
- World Bank
- United Nations High Commission for Refugees
- European Union
- Council of Europe

These sites also were usually not sufficiently specific with regard to Roma health to be of great use. However, they did provide some useful background information, particularly in the field of human rights.

### 2.1.3 Organizations dealing with ethnic minorities

- European Center for Minority Issues
- Federal Union of European Nationalities
- Minority Rights Electronic Service in Eastern Europe
- Minority Rights Group International

Some of these sites contained comprehensive analyses of the socio-economic status of Roma populations, but information on health and disease was sparse.

### 2.1.4 Roma Organizations

A large number of Roma organizations exist worldwide, and many of them have websites. While the content of the sites varied, they were often of a high standard, and some contained high quality source-referenced material. There was little health information available through these sites, although there was a wealth of information on history, culture and on human rights with regard to the Roma community. A number of the sites also carried informal estimates of the size of the Roma population in many countries. These differed markedly from national census data, which are believed to significantly underestimate Roma numbers.

### 2.1.5 Libraries

The World Wide Web-based catalogues of university libraries in the Czech and Slovak Republics were searched, and a list of locally published books on the subject of the Roma were obtained.

## 2.2 Roma organizations and newspapers

We contacted several Roma organizations including the Museum of Roma Culture in Brno. At each organization, the Roma staff were very helpful and seemed to appreciate our interest in the health of their communities. In the archives of the museum we found all the copies of Roma newspapers and magazines ever published in the Czech Republic and a few from the Slovak Republic. There were many articles on human health and disease, often accompanied by the advice of doctors. Issues related to women's health seemed to be frequent topics, as were drug abuse and smoking.

## 2.3 Bibliographic databases

We conducted two searches of the medical bibliographic database MEDLINE; one concentrated on papers originating in the Czech and Slovak Republics between 1981 and the present, and the other searched for publications world-wide, concentrating on English language publications. A search using the keyword "Roma" yielded a predominance of references that had nothing to do with Roma people, but rather to Rome. Because of the relative unfamiliarity of the term "Roma" in medical circles, it was believed unlikely that a paper about Roma health would contain none of the most common synonyms. For this

reason, the keyword “Roma” was discarded. Alternative keywords used were: gypsy, gipsy, gypsies, gipsies, romany, vlach, traveller. Interestingly, the misspelling “gipsy” yielded 37 references. Of the 693 citations identified, 378 were categorised as “human”. Individual case reports, news reports and articles tagged “comment” were excluded. Examination of the remaining citations showed a significant proportion relating to the genetic detection of Rom ancestry, or to arthropods. For this reason, papers including “moth” or “genetics” as keywords were also excluded.

A total of 175 papers were identified (of which 65 were in English and 110 were in other languages). The citations were assessed by the researchers, and those not referring to the Roma people or those not dealing with issues of health or healthcare were excluded. There remained 105 citations, 30 in English and 75 not. A search of the HealthSTAR database yielded 6 citations.

## 2.4 Libraries

Work within libraries was concentrated in the Czech and Slovak Republics. Key to the search was the Lékařský Dm library in Prague. Journals hand-searched by the researchers included:

- Čs. pediatrie (Czechoslovak Pediatrics),
- Čs. stomatologie (Czechoslovak Dentistry),
- Čs. gynekologie (Czechoslovak Gynecology),
- Vnitřní lékařství (Internal Medicine),
- Časopis lékařů českých (Journal of Czech Physicians),
- Demografie (Demography),
- Sociologický časopis (Sociology Review),
- Sociální politika (Social Policy).
- Slovenská gynekológia a pórodnictvo (Slovak Gynecology and Obstetrics),
- Detský lekár (Pediatrician),
- Slovenský lekár (Slovak Physician),
- Bratislavské lekárské listy (Bratislava Medical Journal).

The literature reviewed focused on the years 1989-1999 with a few publications from the years 1980-1989. Mention of the Roma minority appeared to practically cease after 1994. The reason for this is unclear.

## 2.5 Other information sources

The Czech Statistical Office in Prague was a major source of information on the Roma community, both in the Czech and the Slovak Republics. The data relating to those who claimed Roma ethnicity in the 1991 Census for both Republics were collected.

Finally, the daily papers in the Czech and Slovak Republics were scanned, and cuttings taken of articles relating to the Roma minorities in the Czech and Slovak Republics.

# 3 Health of Roma: an international perspective

## 3.1 History of Roma in Europe

By the twelfth century, the Roma were established in Asia Minor and groups had been recorded in Wallachia and Moldavia [1], the historic provinces of Romania. Their initial dispersion throughout the rest of Europe occurred in the aftermath of the Ottoman conquest of Byzantium.[2] At this time they acquired the label 'gypsies', arising from their invocation of the story that they were a tribe from Egypt who were compelled to undertake a seven year pilgrimage in penitence for once forsaking Christianity.[3]

Although initially welcomed, their subsequent reception varied greatly. In fourteenth century Ragusa (now Dubrovnik), they were free citizens (although they ranked low upon the social scale), whilst in Kosovo, Moldavia and Wallachia they were used as slave labour. With the advent of the nation state in the sixteenth century, intolerance became widespread. [4] Some nations, such as France and England, sought to prevent Roma people from entry, whilst others: Sweden, Denmark and Portugal: actively expelled them. Throughout the seventeenth century, punitive policies were widely adopted in Europe. Common sanctions included restrictions upon trade and shelter, prohibition of the wearing of traditional dress or the speaking of the Romani language and restrictions on the size of Roma gatherings. Penalties were often severe, including death or corporal punishment.

Throughout the eighteenth century, punishments continued to be exacted simply on the basis of their ethnicity. Slavery upon galleys and in colonial territories and corporal and capital punishment were commonplace. In the territories of Austro-Hungary, Roma children were taken away from their parents to be brought up by other families, a practice that continued in some countries until the twentieth century.[5]

The nineteenth century saw a general improvement in the treatment of Roma through most of Europe, with, in most cases, the abolition of slavery and the granting of legal rights and freedoms. The latter part of the nineteenth and the early part of the twentieth centuries, however, are characterised by the development of the theories of eugenics and social Darwinism which contributed to the extermination of half a million Roma in the Nazi camps.[6] Conditions for the Roma generally improved throughout Europe in the post war period but although many countries engaged in policies to encourage or compel Roma families to settle. The collapse of communism, however, had major implications for the Roma population in Central and Eastern Europe: with an upsurge in racist attacks, often with semi-official sanction, in states experiencing re-emergent nationalism.

## 3.2 Demographic characteristics

As will be shown later, there are many gaps in official data about Roma populations, not least the actual size of the populations involved. Estimates from different sources can vary widely,[7] for several reasons. The history of oppression and forced assimilation in some countries may have made people loath to declare their Roma ethnicity. Some countries have only recently recognised the Roma as a distinct ethnic group for the purposes of census.

Roma people are often amongst the most socio-economically deprived, and this, in addition to itinerant lifestyle and a mistrust of authority figures may further contribute to their under-ascertainment. Taking these issues into account, the Minority Rights Group [8] compiled estimates of the populations in various European countries in the early 1990s (Table 3.1), although these do not take account of more recent mass movements of population in the former Yugoslavia.

Table 3.1: Estimates of Roma population in various European countries, early 1990s.

| | Roma population (thousands) | | |
|---|---|---|---|
| Country | Official statistics | MRG* estimates | Total population (millions) |
| Albania | | 90-100 | 3.2 |
| Austria | | 20-50 | 7.9 |
| Bosnia-Herzegovina | | 40-50 | 4.0 |
| Bulgaria | 577 | 700-800 | 8.9 |
| Croatia | | 400-450 | 4.6 |
| Czech Republic | 146 | 250-300 | 10.4 |
| France | | 280-340 | 57.9 |
| Germany | | 110-130 | 81.5 |
| Greece | | 160-200 | 10.5 |
| Hungary | 400 | 550-600 | 10.3 |
| Italy | | 90-110 | 57.9 |
| Poland | 30 | 50-60 | 38.5 |
| Romania | 430 | 1,800-2,500 | 23.2 |
| Russia | 262 | 220-400 | 147.7 |
| Slovakia | 254 | 480-520 | 5.3 |
| Spain | | 650-800 | 39.2 |
| Turkey | | 300-500 | 63.8 |
| Ukraine | | 50-60 | 51.2 |
| United Kingdom | | 90-120 | 58.4 |
| Yugoslavia | | 400-450 | 10.6 |

* Minority Rights Group

## 3.3 Health of Roma worldwide

It is widely believed that the health of the Roma population lags behind that of the majority populations in the countries where they live, with some studies suggesting a fourfold increase in infant mortality and a 10-year deficit in life expectancy,[9] it has been noted previously that research on the health of the Roma is limited and difficult to access. This paper seeks to advance the discussion of this issue by examining in detail published research on the health of the Roma population in Europe. This presents many challenges. The paucity of published

literature limits the scope for direct comparison of the situation in more than one country, and the relatively small number of researchers in the field means that, for many countries, no information is available. Differences in definition and terminology are also problematic; the predominant term in UK research, traveller, would not necessarily be familiar in some eastern European countries and is significantly different from Rom, as it includes a large number of non-Roma people who have itinerant lifestyles. In addition, in some countries, the amount of published evidence may itself reflect the position that the Roma population occupy within society. Thus, it is important not to fall into the trap of equating an absence of evidence on Roma health with evidence of an absence of health inequalities.

### 3.3.1 Results of literature searches

There appear to be considerable variations in the number of citations identified and the country of study, and this bears little relationship with population size.

Table 3.2 shows the distribution of papers identified from bibliographic databases by the country in which they are set. It should be noted that some publications relate to more than one country, and are thus counted for each country concerned.

Table 3.2: Number of publications identified by country

| Country | Number of papers identified |
|---|---|
| Spain | 24 |
| Czech Republic | 19 |
| Slovakia | 16 |
| Hungary | 14 |
| United States of America | 8 |
| United Kingdom | 6 |
| Germany | 5 |
| Bulgaria | 5 |
| Other | 13 |

Thus some 70% of the publications found relate to just 4 countries: Spain (24 papers), Czech Republic (19 papers), Slovakia (16 papers) and Hungary (14 papers). Those nations classed as “other” included Sweden, Romania, France and Italy, each of which contributed 2 papers. There were a further five papers found, one from each of: Slovenia, Greece, Russia, Mexico and Jordan.

Turning to the subject matter dealt with, Table 3.3 shows papers grouped by care group or disease or subject area. Again, some papers covered more than one category: “children” and “communicable disease”, for example. These were counted in all relevant subject areas.

Table 3.3: Number of papers by subject matter

| Subject matter | Number of papers |
|---|---|
| Child Health | 34 |
| Older People | 2 |
| Communicable Disease | 32 |
| Non-communicable Disease | 5 |
| Reproductive Health | 13 |
| Accidents, Violence, Suicide and Poisoning | 4 |
| Mental Health | 6 |
| Healthcare | 14 |
| Immunisation | 5 |
| Sociology | 14 |
| Anthropometry | 6 |
| Demography | 5 |

A significant proportion of the papers found relate to child health (including congenital anomalies) or communicable disease. Only six of the studies related to chronic and non-communicable disease. The subject areas will be examined in more detail below.

### 3.3.2 Child health

Child health has attracted particular attention with regard to the Roma people. Many of the studies relate to communicable disease, but other aspects of health and healthcare have also been examined. From birth, there appears to be a differential in health indices between the Roma and majority populations. In Hungary, Roma infants were twice as likely to be born prematurely and there was a significant excess of births under 2,500g at most gestational ages, [10] a finding of concern not just because of the immediate consequences but also for potential associations with health in adulthood.[11] At least part of the difference may be explained by the association found in that study between birth weight and maternal education, given the marked difference in educational attainment of Roma and non-Roma mothers.

A Spanish study of congenital malformations [12] found that recessively inherited syndromes were seven times more common than in the reference population, a finding attributed to the high degree of consanguinity found in Roma families (about twelve times as common as in the non-Roma population). High rates of consanguinity have also been reported among Roma populations elsewhere.[13] The Spanish study, however, also reported a relative paucity of cases of chromosomal and of autosomal dominant disorders, with rate ratios of 0.68 and 0.80 respectively.

There has been very little research on the common disorders of childhood. One study from Spain [14] found a significant excess morbidity from secretory otitis media in Roma children but this was thought to be explained by socio-economic, rather than some other ethnic factors. Other research has been somewhat eclectic. For example, a study into childhood brain tumours in north-east Hungary [15] found a lower incidence in Roma children than in the

general population. Both lead poisoning [16] and burns [17] have been shown to be more common in Roma children, findings that are consistent with the environmental hazards to which they are often exposed. [5]

Moving to adolescent health, the Roma have traditionally had a low rate of substance misuse [18] but a 1993 case control study [19] appears to show an increase in the rate in neonatal abstinence syndrome in the offspring of young Roma mothers in Mexico between 1985 and 1991.

### 3.3.3 Reproductive health

Reproductive health is an important area, and one in which the Roma population fare badly. A study of the sexual culture of Roma women in Bulgaria [20] found that only 61% use contraception regularly, that terminations of pregnancy were more common than in the majority population – 2.41 abortions per woman, with 33% of women having had more than 3– and that Roma women, in general, had their first pregnancy at a younger age. A more detailed study of contraceptive practices in Spain [21] found that Roma women knew significantly less about barrier methods of contraception, about definitive methods such as vasectomy and tubal occlusion and about periodic abstinence (rhythm method). Their primary form of contraception was coitus interruptus. They were less likely to seek contraceptive advice than were non-Roma women, and had more pregnancies; leading both to significantly more live births and terminations of pregnancy.

Teenage pregnancy rates have also been reported to be high. A Bulgarian study [22] found nearly half of pregnancies where the mother was aged 13-16 to be amongst women of Roma origin. A study of commercial sex workers attending a sexually transmitted disease clinic in Plovdiv, Bulgaria [23] found more than half be of Roma origin. The authors noted that the average income of the parents of these women was US$60 per month, as opposed to the national average income of US$80 per month at that time.

Serological surveys amongst pregnant women have indicated high rates of hepatitis A [24] and hepatitis B [25]. Whilst these conditions will be dealt with later, it is important to note the latter at this point because of the potential for vertical transmission.

### 3.3.4 Non-communicable disease

Non-communicable disease in Roma adults has received very little attention. This review yielded only 3 citations relating to adult disease (the remainder related to paediatric conditions). A study from Massachusetts [13] found that, in an admittedly small sample of 58 Roma people, 73% were found to be hypertensive, 46% had diabetes, 80% hypertriglyceridaemia and 67% hypercholesterolaemia. Lifestyle related factors related to ischaemic heart disease were also prevalent in this sample: 86% were cigarette smokers and 84% obese. Of this small population, 39% had occlusive vascular disease and 20% chronic renal failure. A study of cultural factors among Roma children also found a high prevalence of diabetes mellitus and hypertension in family histories obtained. [18]

A few studies have examined mental health, finding an excess of suicide and parasuicide over the general population. [26] In contrast, suicidal ideation is reported as less common amongst Roma.

Oral health too is characterised by unmet need in Roma populations, as evidenced by a British study, which found considerable inequality in access to dental care and utilisation of preventative dental services between travellers and the general population. [27]

### 3.3.5 Communicable disease

A large proportion of the literature on Roma health is devoted to communicable disease. Many papers are reports of outbreaks or cases but do not report the broader epidemiology of the disease. There seems to an increased incidence and seroprevalence of many of the classic epidemic diseases as well as of some more newly identified infections.

Mycobacterial infection is reported as more common amongst Roma than in other populations, and also to be increasing at a faster rate. [28] Leprosy was also found to be more prevalent amongst Roma than the majority population in a study in the Spanish province of Jaen.[29]

Viral hepatitis appears to have attracted most attention among the common infectious diseases. Seroprevalence surveys in pregnancy discussed earlier [24] [25] show high levels of infection with hepatitis A and B. A study in Northern Spain [30] found a seroprevalence of HAV antibodies of 82% in deprived Roma children compared with 9.3% of more affluent non-Roma children. In another Spanish study, [31] three groups were compared; non-Roma children, Roma children, and orphanage children. From seven years of age upwards, there was an excess in age specific seroprevalence of hepatitis A virus of Roma children over the other groups. Overall seroprevalence was found to be 63% amongst the Roma, 46% in the orphanage group and 23% amongst the controls. Overcrowding seemed to be a key factor, as did poverty and sanitary practices. The excess in seroprevalence of hepatitis B in pregnant Roma women was also described in 1984. [32] One suggested reason for the relatively high seroprevalence in Roma people may be tattooing practices. [33] Hepatitis C too may be more prevalent in the Roma population. A seroprevalence survey of the prison population in North Eastern Spain [34] found an excess over other prisoners.

In the context of increased rates of other blood borne virus infections and the preponderance of non-barrier contraceptive practices, one might expect a relatively high rate of HIV infection. Two studies, however, one amongst the general prison population in a penal institution on north west Spain [35] and another limited to intravenous drug users [36], showed a significantly lower seroprevalence of HIV antibodies amongst Roma than non Roma inmates.

Poliomyelitis is of particular public health importance because of the major effort underway to eradicate it globally. Recently, infection due to wild rather than vaccine associated viruses has been concentrated among Roma populations in some countries. [37] [38] Immunisation coverage tends to be low, [39] with a study in Jordan [40] reporting only a 9% immunisation rate amongst Roma and one in Italy reporting 26% coverage, [41] although there is some evidence that targeted intervention can improve rates. [42] This may have significant implications for the eradication of the disease. [43]

## 3.4 Roma and health care

Several studies have found differential access to health care by Roma people. This is a complex issue. Health care is located within a complex set of beliefs in which some diseases

are seen as Roma, and thus appropriately treated by traditional healers, and others as due to contact with the outside world, requiring the services of the formal health care system. [5] Relations with the majority population, and thus the formal health care sector, are governed by rules about what is pure or impure. Thus some Roma adhering to traditional beliefs consider that sharing eating utensils with anyone, even a member of the immediate family, is impure. There are also specific rituals dealing with birth, death, and caring for the ill that can cause acceptance of some aspects of care and rejection of others. For some Roma a stay in hospital other than for childbirth is often associated with death. [5] These beliefs can easily lead to a rejection of the traditional methods of health care delivery. Health care professionals may then see this as irresponsible. [44] Attitudes of healthcare workers may further exacerbate matters. [45]

Ironically, in pre-industrial times Roma played an important role in the delivery of health care to the majority populations in many parts of Europe, acting as folk healers in the absence of trained physicians. As late as 1910 a German traveller in Kosovo described seeing Roma "giving quack remedies to the doctorless Albanians". [46] Beliefs with regard to luck, fate and predestiny may be a factor in the poor uptake of preventative services.

Access to care is not, however, simply a matter of culturally insensitive provision. Fonseca quotes a Roma physician in Bulgaria as saying that his Bulgarian contacts "do the absolute minimum" in the Roma community. She also describes several examples of outright discrimination. [5]

A single study was identified from the United Kingdom showing that provision of specialist link workers can improve understanding between Roma and medical staff, [47] and thus potentially ameliorate access to care.


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# 4 History of the Roma population in Czech and Slovak Republics

Roma, or Gypsies, are an ethnic minority of northern Indian origin living in many countries throughout the world. The written history of the Roma people dates back a thousand years. Research on linguistics and blood grouping suggests that they originated in Northern India, leaving their original home sometime during the first millennium AD, arriving in the Byzantine Empire at the beginning of the eleventh century, [1] [2] following prolonged periods in Iran and the Caucasus.

Gypsy populations are particularly numerous in central and eastern Europe and the western part of the former Soviet Union where their presence has been documented since the eleventh century.[3] Their history in this region can be described as a combination of peaceful coexistence and blatant discrimination, with multiple and complex causes among which are their remarkably preserved traditions and resistance to assimilation.

The Roma settled into what are today the Czech and Slovak republics sometime around the 15th century. Most of them turned to traditional craftsmanship or lived as nomads. Those who settled down anchored themselves in the local society. However, their traditions and language, their seemingly carefree attitude toward money and competitiveness and their communal lifestyle all served to cut them off from the rest of society.[4]

## 4.1 The Roma before World War I

With the rise of the nation state in Europe in the sixteenth century, intolerance towards the Roma became widespread. Throughout the seventeenth century, punitive policies were adopted throughout Europe. Common sanctions included restrictions upon trade and shelter, prohibition of the wearing of traditional dress or the speaking of the Romani language and restrictions on the size of Roma gatherings. Penalties were often severe, including death or corporal punishment. In the territories of Austria-Hungary, Roma children were taken away form their parents to be brought up by other families. The nineteenth century saw a general liberalisation in the treatment of Roma through most of Europe, with the abolition of slavery and the granting of legal rights and freedoms. The latter part of the nineteenth and the early part of the twentieth centuries, however, are characterised by the development of the theories of eugenics and social Darwinism which contributed to the extermination of half a million Roma in the Nazi camps (see below).[5]

## 4.2 From 1918 to 1989

Early this century, the Roma in Slovakia, as elsewhere in Europe, formed an ethnic community, living on the social periphery of the mainstream population. State policy nearly always focussed on the Romany population not as a distinct ethnic minority, but rather perceived it as a particularly anti-social and criminal group. This attitude was reflected in the policy of collecting special police evidence – e.g. fingerprint collections of members of Romany groups (1925).[6] In 1927, the Czechoslovak government passed the Law on Wandering Gypsies.

In March 1939 – two weeks before the German army's occupation of Prague and the establishment of the Nazi Protectorate of Bohemia and Moravia – the government passed an ordinance on the establishment of punitive labour camps for "Gypsy families and other wandering individuals". This collection centre was later replaced by concentration camps in

Lety u Pisku and Hodonin u Kunstatu, where many Roma perished or were held until they could be transported to Nazi death camps. Of the thousands of Roma who were sent to the concentration camps, only a few hundred survived. During the Second World War, approximately six to seven thousand Roma from Bohemia and Moravia died in a concentration camp at Auschwitz.

The Slovak State copied the racist legislation of the German Reich, establishing special labour camps for the Roma, who were forbidden to travel on public transport, were allowed admission to towns and communities only on limited days and hours, and had their settlement units separated from public roads. After the occupation of Slovakia by the German army, mass killings of Roma occurred in many parts of Slovakia.[6]

After World War II, the policy of the state was oriented toward assimilation of the Roma. The 1958, law "On the permanent settlement of nomadic and semi-nomadic people", forcibly limited the movement of that part of the Roma (perhaps 5%-10%) who still travelled on a regular basis. In the same year, the highest organ of the Communist Party of Czechoslovakia passed a resolution, the aim of which was to be "the final assimilation of the Gypsy population". The so-called "Gypsy question" was reduced to "problems of a socially-backward section of the population". The problem of the high number of children in Roma families was addressed with financial incentives for Roma women to undergo sterilisation. The state dealt with the problem of housing by liquidating backward Romany settlements and resettling the Roma to urban settings.

Although Romany cultural and ethnic identity was denied, organs of the state administration in communities and towns gave annual accounts of "the Gypsy population". This evidence was collected without the knowledge of the Roma, who were categorised according to the criteria of the social services. Similarly, when there was a census, people were not permitted to proclaim their Romany ethnic identity, but census officers nevertheless marked the forms without the respondents' knowledge to indicate that they were Roma.[6]

The communist regime aimed to "re-educate" the Romany people in its own image. In a society that no longer recognised private property and freedom of movement, the Romany people were forced out of their traditional occupations as musicians, blacksmiths, and basket-weavers and drafted as unskilled labourers at construction sites. According to the regime's social engineering projects, the Roma were moved from Slovakia to the Czech lands, from rural settlements to tenement housing blocks in the cities. This systematic uprooting of the Romany people resulted in a high crime rate, unemployment, alcoholism, and related problems.[4]

## 4.3 Roma and the transition

The fall of communism in 1989 opened up new opportunities for the Roma of Czechoslovakia, but also created new problems.

The Declaration of Basic Human Rights and Freedoms accepted by the Federal Assembly of Czechoslovakia on January 9, 1991, secured the Roma's right to freely decide their own ethnic affiliation. Individual ministries developed initiatives for the Romany minority, securing their rights in the fields of culture and education. In April 1991, the Government of the Slovak Republic accepted the demand for the equalisation of the Roma with the other ethnic minorities in Slovakia.

The division of Czechoslovakia into the Czech and Slovak Republics has created new problems for the Romany minority in both newly-formed countries. Since 1992, Czech society has been increasingly apprehensive about mass migration of Roma from Slovakia to

the Czech Republic. After the split, some Roma in the Czech Republic automatically acquired Slovak citizenship, even though they were born in the Czech Republic, had been living there for a long time, and had their places of permanent residence there. By this legal act they became aliens in their current homes and would have to apply for Czech citizenship. The procedures required were particularly difficult for the Roma, who were handicapped most seriously by the condition that citizenship could be obtained only by a person without a record of criminal activity in the previous five years. It was less difficult to acquire Slovak citizenship; everyone who had a permanent residence in the Slovak Republic before the dissolution of Czechoslovakia became a Slovak citizen.[6]

Since 1989, racist sentiments in Czech society have increased, and the social and economic gap between the Romany minority and the majority population has widened. At the same time the collapse of communism was accompanied by the loss of much of the welfare and social protection the Roma people had been afforded. Today the proportion of incarcerated persons in the Czech Republic who are Roma is very high, and Roma Human Rights organizations have claimed that the police unfairly persecute Roma youths, and are relatively lenient with ethnic Czechs. The Czech Republic has also seen the rise of the skin-head movement, a white supremacist youth group espousing fascist values. Over the past ten years there were several reports of Roma having been attacked by skinheads. The Roma also claim that they now face discrimination when applying for jobs and in schools.

In 1997, the Czech government published a report on the situation of the Roma community[7] and recommended a range of assistance measures. The report contained very little on the issue of health. In fact, very little is known about the particular health problems of Romany people in the Czech and Slovak Republics in general. Where data exists, it suggests that the health problems of Romany people are different, both in kind and in degree from those of ethnic Czechs and Slovaks. In any case, there is abundant literature from many countries indicating that the health status of underprivileged minorities is virtually always worse than that of the majority population. In this way, health and human rights can be seen as related to one another, and any effort at improving the human rights of minorities should consider their health status as well.

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# 5 Demography and anthropology

Both Czech Republic and Slovakia have a substantial Roma population, the exact size and demographic characteristics of which are uncertain. Uncertainties are due to several factors such as distrust in and disregard of the minority for official matters (like participation in a census), and hiding of identity due to the negative social connotations that it is associated with.

## 5.1 Population, age structure, fertility

The present manner of statistical ascertainment of the numbers of the Roma population, which is in keeping with the international recommendations adopted and with treaties in the sphere of human rights, does not enable a precise estimate of how many Roma citizens live in the Czech or Slovak Republic.

Table 5.1: Nationality structure of the population of the Czech and Slovak Republics in 1991. Data from Census.

| Nationality | Czech Republic | | Slovak Republic | |
|---|---|---|---|---|
| | n | % | n | % |
| Czech | 8363768 | 81.2 | 52884 | 1.0 |
| Moravian | 1362313 | 13.2 | 6037 | 0.1 |
| Silesian | 44446 | 0.4 | 405 | 0.0 |
| Slovak | 314877 | 3.1 | 4519328 | 85.7 |
| Hungarian | 19932 | 0.2 | 567296 | 10.8 |
| Roma | 32903 | 0.3 | 75802 | 1.4 |
| Polish | 59383 | 0.6 | 2659 | 0.0 |
| German | 48556 | 0.5 | 5414 | 0.1 |
| Rusin | 1926 | 0.0 | 17197 | 0.3 |
| Ukrainian | 8220 | 0.1 | 13281 | 0.3 |
| Russian | 5062 | 0.0 | 1389 | 0.0 |
| Other | 18812 | 0.2 | 3861 | 0.1 |
| Not known | 22017 | 0.2 | 8782 | 0.2 |
| Total | 10302215 | 100.0 | 5274335 | 100.0 |

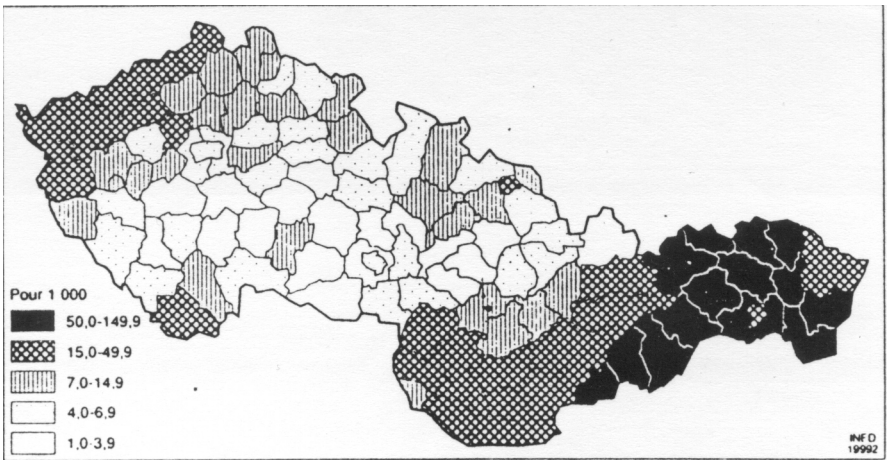
In the 1991 Census in the Czech Republic, only 32,903 people declared being Roma (Table 5.1). However, according to the registration by the districts, there were 150,000 Roma resident in the Czech Republic at the end of 1992, i.e. 1.5% of the total population of the Czech Republic. Another official estimate (based on unemployment and social services registers) puts the number of Roma population in the Czech Republic at 200,000. The estimates made by the Roma community themselves range up to 300,000.[1]

The exact number of Roma in Slovakia is also unclear. Unofficial estimates claim that as many as 750,000 Roma live in Slovakia but the official census shows only 75,802 who identified themselves as Roma in the 1991 Census (Table 5.1). It is usually believed that there are between 400,000 and 500,000 Roma in Slovakia, i.e. 8.5% of Slovakia's population.

In the Census of 1991, the term "Roma nationality" was used for the first time. Even though Roma are thus an officially recognised nationality, they tend to distance themselves from this

notion. It is likely that they perceive an official categorisation – being of Roma nationality - to be a potential threat for their everyday life. They are also in this way expressing their wish to be perceived as members of the majority in the society.[2]

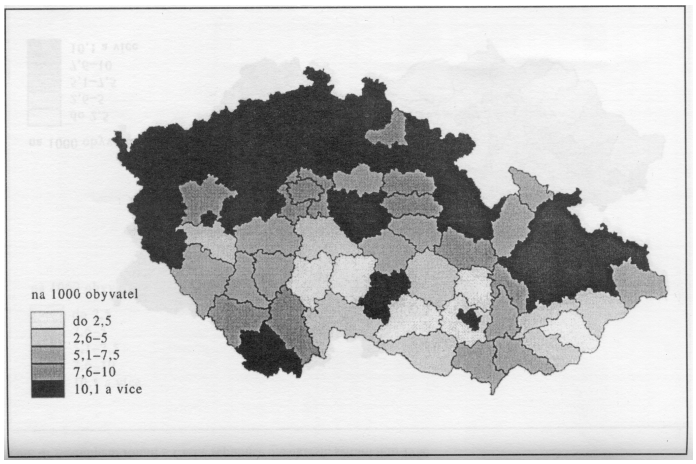
Map 5.1: Number of Roma per 1,000 population in the former Czechoslovakia in 1980. By district.




Source: Reprinted with kind permission from Rychtarikova and Dzurova, Population, 1992.

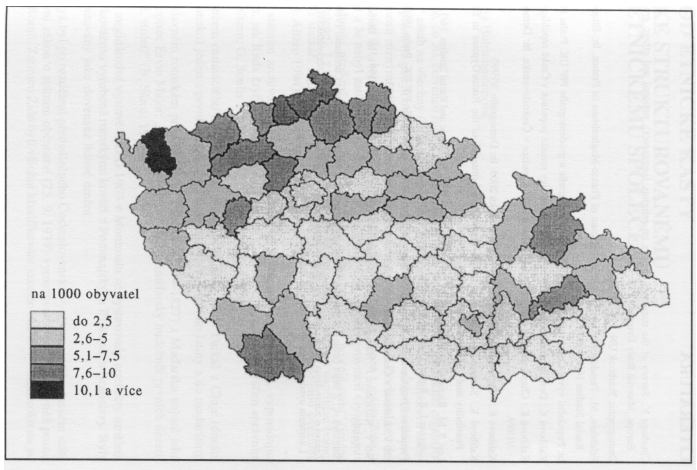
In the Czech Republic, there are substantial Roma populations living in Ostrava region, Prague, Northern Bohemia, South and Western Bohemia and in Brno. In Slovakia, most Roma live in the East, and the Roma communities tend to live in relative isolation from the rest of the villages there.[3] See Map 5.1. In the 1960s, there were four main sub-groups of the Roma population living in the Czech and Slovak Republics, the absolute majority of whom were settled. There are groups of Vlachike Roma living in both countries (Lovare and Kalderare in the Czech Republic; Rudari in East Slovakia). [4] Most of the Roma living currently in the Czech Republic migrated from Slovakia after 1945.

Map 5.2: Number of Roma per 1,000 population in the Czech Republic in 1989 based on data from municipal authorities.




Source: Reprinted from *Romove v Ceske Republice*, Praha: Socioklub, 1999. Legend: per 1,000 inhabitants; <2.5; 2.6-: 5.1-; 7.6-; 10.1+.

Map 5.3: Number of Roma per 1,000 population in the Czech Republic in 1991 based on data from Census.




Source: Reprinted from *Romove v Ceske Republice*, Praha: Socioklub, 1999. Legend: per 1,000 inhabitants; <2.5; 2.6-: 5.1-; 7.6-; 10.1+.

Figure 5.1: Age structure of Roma and total population in the Czech Republic in 1991. Source: Census data.

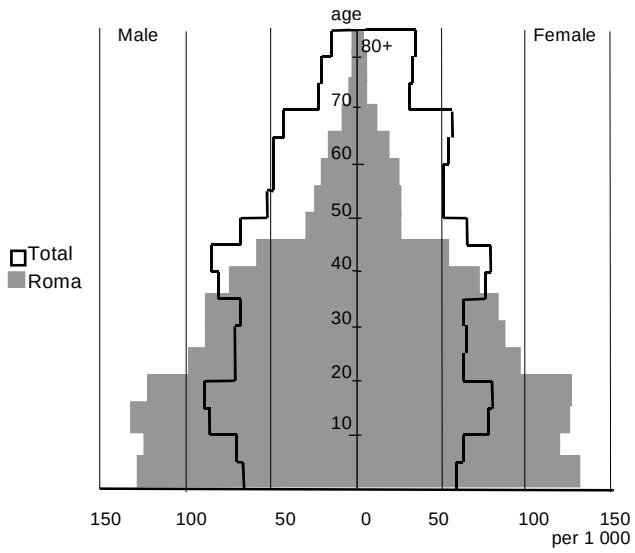
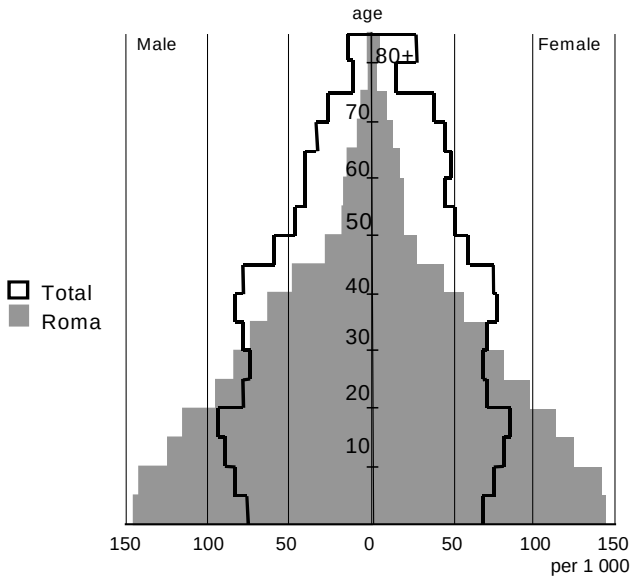



Figure 5.2: Age structure of Roma and total population in Slovakia in 1991.

Source: Census data.




Demographic studies show that the Roma people maintain a strongly progressive type of age structure (Figures 5.1 and 5.2) characterised by a high representation of the child population and a low representation of old people. In type it is close to the age structure of the populations of developing countries. In 1991, dependent persons represented almost half of the Roma community, while the respective proportion was only 28% in the total population of the Czech Republic.[5]

Census data indicate a birth rate among the Roma population that is higher than among other ehnic groups in each age band (Table 5.2).

Table 5.2: Number of live born children per woman by nationality. The Czech Republic, 1991. Data from Census.

| Number of live born children per 1000 women | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Nationality | Total | Age | | | | | | | |
| | | 15-19 | 20-24 | 25-29 | 30-34 | 35-39 | 40-44 | 45-49 | 50-54 |
| Czech | 1904 | 521 | 1035 | 1629 | 1985 | 2098 | 2104 | 2048 | 2026 |
| Moravian | 2037 | 494 | 1033 | 1685 | 2059 | 2182 | 2202 | 2184 | 2200 |
| Silesian | 2062 | 598 | 1065 | 1716 | 2050 | 2153 | 2200 | 2191 | 2250 |
| Slovak | 2364 | 665 | 1297 | 1839 | 2200 | 2366 | 2467 | 2495 | 2592 |
| Polish | 2034 | 382 | 994 | 1634 | 1959 | 2140 | 2123 | 2093 | 2139 |
| German | 2010 | 600 | 951 | 1550 | 1975 | 2087 | 2119 | 2047 | 2074 |
| Roma | 3430 | 955 | 1929 | 2716 | 3378 | 3656 | 4112 | 4858 | 5159 |
| Total Czech Republic | 1945 | 524 | 1045 | 1647 | 2008 | 2124 | 2135 | 2089 | 2085 |

## 5.2 Social characteristics of the Roma population

Any discussion of social and cultural characteristics of a particular ethnic group runs the risk of generalisation and stereotyping. Consequently, the following sections relate to those people living in traditional Roma families although, as will be noted, integration with the majority population has been very limited so that it is not unreasonable to focus on the traditional cultural attributes.

Figure 5.3: Education of Roma and total Czech male and female population, by age. Data from 1991 Census

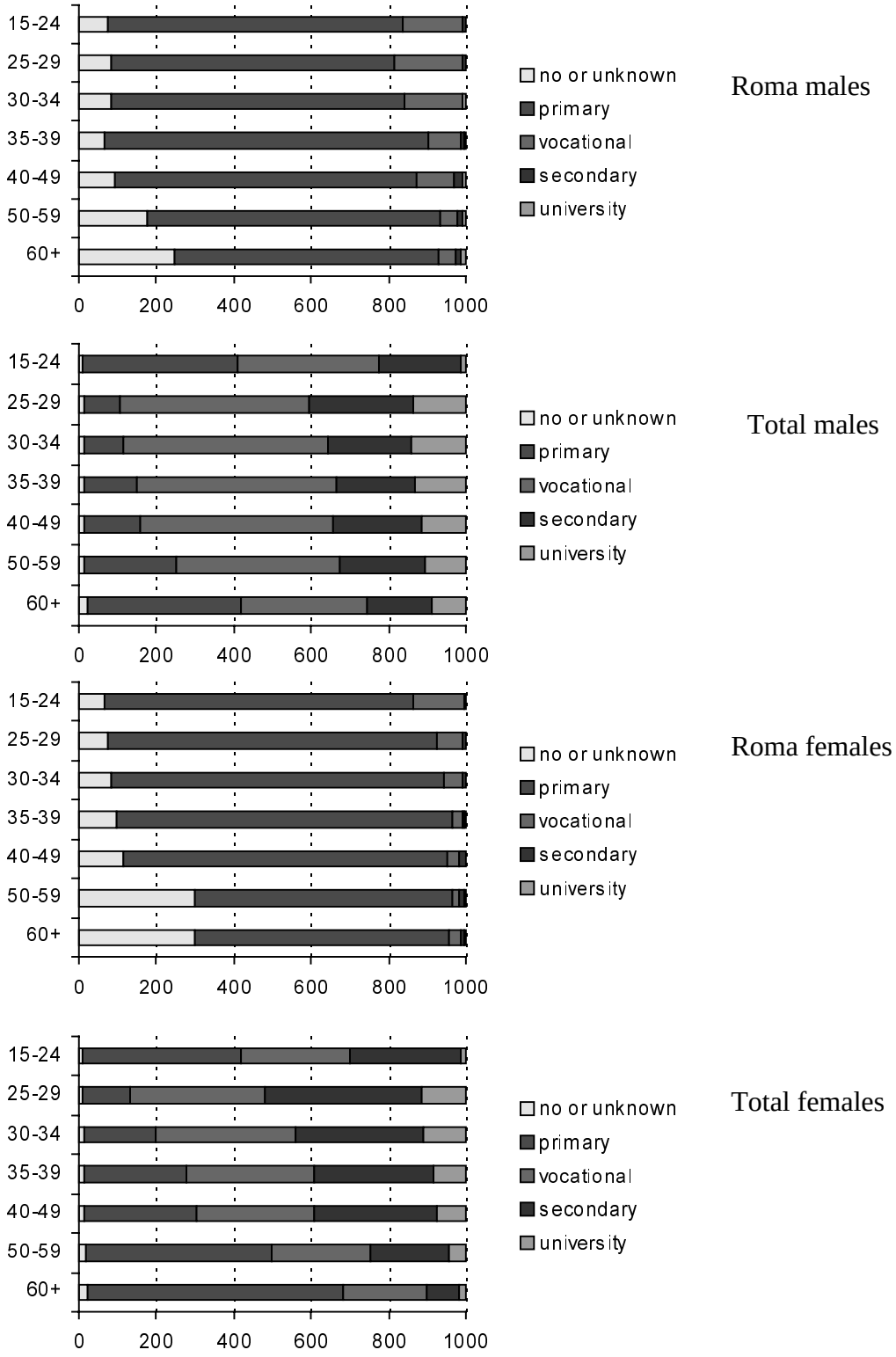
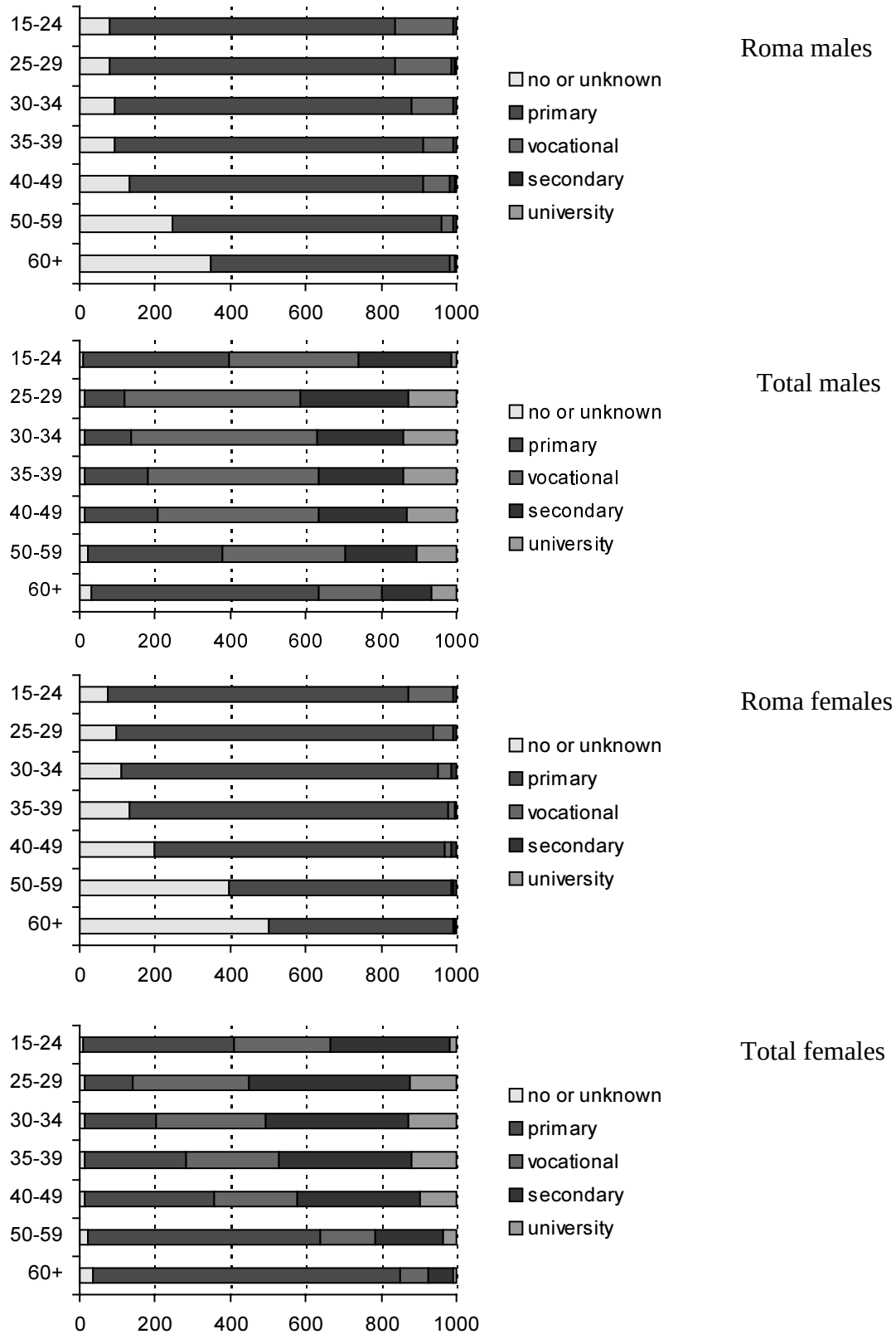


Figure 5.4: Education of Roma and total Slovak male and female population, by age. Data from 1991 Census.



Children in traditional Roma families are brought up in a completely different social and cultural environment than their counterparts from the majority Czech or Slovak population. Romany children generally have a very liberal upbringing, they are granted more freedom, and they are rarely punished. A quote from a book by Milena Hübschmannová illustrates the attitude to education of children "Romany children learn by what they see others doing. … They learn more or less on their own. No one forces them to learn anything which has not been granted to them by God…" [6]

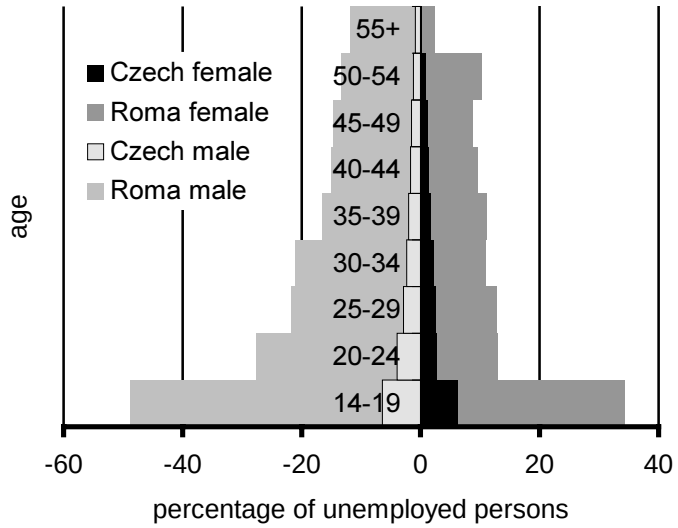
It is estimated that between 75% and 85% of all Romany children in the Czech Republic do not complete their education in the "mainstream" school system. Many Romany students drop-out and end up in "special schools" for children with disabilities. These schools typically mean a slower rate of progress, leaving the students behind those in "mainstream" schools. The result has been the creation of a segregated school system in which some special schools have a majority of Romanies and other are all Romany. The majority of Romany children finish their education on the primary level so their access to secondary education and vocational training is limited. They are largely cut off from the job market and severely limited in mobility and development. See Figures 5.3 and 5.4. This translates into social problems such as high unemployment, drug abuse, criminality, political marginalisation and dependency on the state.[7]

Holomek acknowledges that "… Roma still do not see education as an absolutely crucial starting point for their own advancement and for a fuller participation in the society." [3] Collective decision-making and collective responsibility are much more important in Romany families than individual responsibility and individual ambition. [6]

The unemployment among Roma is extremely high. Some authors estimate that only about a third of the Roma population of productive age is currently employed. Horakova [8] identified the following main factors as underlying causes of high unemployment among the Roma:

- reduction of number of jobs in state-owned enterprises during the early stages of the economic transformation when mainly people with no or low qualification were made redundant; subsequently it has been very difficult to find new jobs for people with low qualifications;
- social benefits for families with children often exceed the minimum wages people of low qualification would be earning; this is sometimes considered the main reason for Roma staying out of job; however as it is not possible to refuse such a job without loosing the entitlement to the social benefit, the person usually tries to find some "artificial" reason for refusing the job;
- growing competition at the job market with influx of cheap work force from abroad (mainly from the East) and generally lower demand for low-qualified workers.

Figure 5.5: Unemployment among Roma and Czech population in the Czech Republic in 1991. Source: Census data.




Necas reports that it is estimated that 20-30% of economically active Roma population in the Czech Republic make their living through illegal activities. Based on estimates by local police, in Teplice district, where Roma community makes up about 7% of the total population, 60% of crimes are committed by Roma. According to the data from the Brno police station, Roma commit 95% of pick-pocketing, 80% of theft with assault and 60% of prostitution related crimes.[9]

In an article published in a Romany newspaper, Jacak, the mayor of Spisska Nova Ves in Slovakia, notes that while the Romany community only makes up 2.5% of the population in the district, 40-50% of all crime in the district are committed by Roma.[10]

## 5.3 Roma traditions, values and social organisation in relation to health and health care

Roma typically live in household with somewhat fluid membership because they generally belong to large extended families. [4] Members of extended families will eat and sleep at each other's homes as if they were their own. In Roma culture, illness is not just the concern of the individual - it is a problem of broader social importance. A serious illness always elicits deep concern from a wide circle of relatives rushing to the bedside of the stricken. Families coming together when someone is ill, is one of the strongest values in Gypsy culture. This has often led to a clash with the norms of the majority population as when a relative is sick, members of the extended families may come to the hospital in alarmingly large numbers, disregarding visiting rules, and generally disrupt the normal functioning of the hospital.

There are many other examples of conflict between Roma beliefs and those of the majority population. For example the belief that the larger a person is, the luckier, healthier, and happier that person will be, may be frustrating for many physicians.[11]

1 Rican, P. We will live with the Roma – the question is how [in Czech]. Praha: Portal, 1998.

2 Anon. Roma: a Czech question, rather than a Roma question [in Czech]. S-Obzor (Charles University Prague) 1995;(5):43-46.

3 Holomek, K. Roma minority in the Czech Republic [in Czech]. In: Gabal, I, et al. Ethnic minorities in Central Europe [in Czech]. Prague: G plus G, 1999:153-171.

4 Davidova, E. Romano Drom 1945-1990 [in Czech]. Olomouc: Palacky University, 1995.

5 Nesvadbova L, Rutsch J, Kroupa A, Sojka S. Health and social aspects of migration. Project report. Prague: Charles University, 1998.

6 Jirincova, H. Hope for the future: Educating Romani Children. Patrin Web Journal. www.geocities.com/paris/5121/patrin.htm

7 The Romani Education Programme of the New School Foundation. Patrin Web Journal. www.geocities.com/Paris/5121/patrin.htm

8 Horakova, M. The Roma in the Czech Republic [in Czech]. Socialni Politika 1998;(4):9-12.

9 Necas, C. Roma in the Czech Republic yesterday and today [in Czech]. Olomouc: Palacky University, 1999.

10 Jacak R. Sociological problems of national and ethnic minorities in the Spis region [in Slovak]. Romano Lil 1993;3:91-93.

11 Sutherland, A. Cross-cultural medicine: a decade later. Patrin Web Journal. www.geocities.com/paris/5121/patrin.htm

# 6 Health status of the Roma in the Czech Republic and Slovakia

In the growing literature on the human rights of Roma people in Central Europe, their relatively poor health status is often mentioned. However, little concrete information exists about the contemporary health status of the Roma in the Czech and Slovak Republics. There are a number of scientific reports from pre-1989 Czechoslovakia that deal with this issue, and when outbreaks of infectious diseases occur in Roma communities, they are usually reported in the Czech, Slovak and Romany press. Since 1989, Czech and Slovak researchers have turned away from health research on particular ethnic groups. This probably reflects a growing sensitivity about stigmatising Roma, but it also make it more difficult to know how their circumstances might be improved.

## 6.1 Mortality and life expectancy

Statistics on death and morbidity among different ethnic groups are not officially collected in the Czech or Slovak Republic and the Roma population is not separately categorised in statistical research about health care[1]. However, data from before the 1989 revolution suggested that mortality was higher for Roma than for ethnic Czechs and Slovaks, and it is unlikely that the situation has been greatly improved in the last ten years. Kalibova [2] derived an estimate of the life expectancy of the Roma in Czechoslovakia by extrapolating from the 1970 and 1980 censuses. She found that life expectancy for the total population of Czechoslovakia was 66.8 years for men and 73.9 years for women, but life expectancy for the Roma population was only 55.3 years for men and 59.5 years for women. High death rates among Roma in infancy seemed to contribute significantly to this lowered life expectancy. In the Czech Republic, infant mortality was 23.9 per thousand live births for Roma, compared to 12.1 per thousand for non-Roma, i.e. nearly twice higher for Roma. In Slovakia, infant death rates were 34.8 per thousand for Roma and 14.6 for non-Roma, indicating that Roma infants in Slovakia were more than twice likely to die in their first year than were ethnic Slovak babies.

A recent study of the Roma population of the Prague 5 district also provides some information about mortality. Prague 5 is an urban district encompassing numerous contiguous Prague neighbourhoods including Smichov, Andel, Barrandov and Velka and Mala Ohrada. Most Roma live in the newer housing estates in these neighbourhoods, some built as recently as the early 1990s. A situation analysis was commissioned by the Minister of the Interior as part of an initiative to investigate the causes of and prevent criminality among the Roma population in Prague 5.[3]

Only 4% of Roma in the survey were above retirement age (about 60 years) whereas about 25% of ethnic Czechs were above retirement age, according to the most recent census.

The Prague 5 study found that among adults, men outnumbered women, which is unusual in an industrialized country. However, among children, girls outnumbered boys. Many Roma in Prague were born in East Slovakia and moved the Czech lands after the Second World War. It is possible that the greater number of men at older age groups might reflect the lower migration of women than men to the Czech Republic in the past. Another, more disturbing possibility is that, as is the case in many developing countries, Roma girls are less likely than boys to survive childhood, reflecting diversion of food to boys and lower standards of care. There is, however, no direct evidence that this occurs in Roma families now.

## 6.2 Perinatal outcomes and reproductive health

One recent study[4] suggested that perinatal death rates among Roma may also be high. A study in the Roznava Region in Slovakia found perinatal death rate among Roma was 1.5 to 2 times higher than among non-Roma in 1996-1997. The authors argue that the 'health conciousnes of the population' particularly the Roma, is the greatest handicap in reducing perinatal deaths in Slovakia.

One reason for higher rates of perinatal death rates among Roma may be low birth-weight. Seres studied the proportion of low birth weight among Roma and non-Roma population in the Roznava district in Slovakia from 1995-1997. The proportion of low birth weight births was generally lower and further decreased among non-Roma during this period, but remained high among the Roma.[4] See Table 6.1.

Table 6.1: Proportion of low birth weight in Roma and non-Roma population of Roznava district in 1995-1997.

| | Roma | | Non-Roma | |
|---|---|---|---|---|
| | Total births | % with birth weight <2500 g | Total births | % with birth weight <2500 g |
| 1995 | 277 | 13.7 | 481 | 5.2 |
| 1996 | 272 | 15.1 | 503 | 4.6 |
| 1997 | 311 | 13.2 | 459 | 3.3 |
| 1995-1997 | 860 | 14.0 | 1443 | 4.4 |

From: Seres, I. Slov. Gynek. Porod. 1998

Dejmek et al. found significantly higher prevalence of low birth weight and prematurity in Roma births in Teplice district in North Bohemia. In 1994-1995, there were 23.6% birth of less than 2500 grammes among Roma and 6.4% among non-Roma. The incidence of preterm births (gestation < 37 weeks) was 13.4/100 in Roma and 5.0/100 in non-Roma.[5] There are other studies suggesting that Roma newborns are lighter, smaller and shorter, even when born at term, than ethnic Czech or Slovak births. Based on data on singleton term births with no pathological symptoms in Kosice and Presov in Slovakia between 1968-1992, Bernasovska et al.[6] reported an average difference between Gypsy and non-Gypsy babies of 345 g in birth weight and 1,5 cm in length.

Based on anthropological studies and clinical experience, it has been suggested that different standards (birth weight < 2250 g) should be used to define low birthweight in term Roma births.[6] Nevertheless it does appear that even by their own standards, Roma births are more likely to be underweight. In a study of the paediatric population[7] around Roznava, in Slovakia, infant mortality was found to be consistently higher and birthweight consistently lower, among Roma compared to ethnic Slovak children. There is some indication that the gap in infant mortality and low-birthweight between Roma and other Slovaks is narrowing, but the data provided in the article are incomplete, suggesting that reporting may not have been entirely reliable.

Death rates after infancy and early childhood also seem to be high for Roma. Between 1981 and 1990 death rates of Roma children under three in three different regions of Slovakia, Bystrany, Spisske Tomasovice and Spissky Stvrtok were 47.1, 40.9 and 32.0 per thousand respectively.[8] These rates are considerably higher than e.g. under-5 mortality rate of 15.8 per thousand in Slovakia in 1989.[9]

Roma women in the Roznava district in Slovakia have been reported to have twice the rate of abortions compared to the non-Roma women in 1996.[4] The use of modern contraception among Roma women in the district was extremely low, much lower than among non-Roma. The authors argue that the use of contraception (mainly IUD and sterilisation) was highest among Roma in late 1980s and was partly related to financial stimuli to undergo sterilisation. After 1989, the prevalence of contraception among Roma decreased markedly. The authors argue that financial advantages of childbearing (social benefits) might be of importance at the time of mass unemployment and inflation.

## 6.3 Infectious diseases

The burden of infectious disease among Roma in the Czech and Slovak Republics seems to be high for a population living in an industrialised country. Diseases associated with poor hygiene seem to be particularly important. Information about infectious diseases among Roma comes from the scientific literature, mostly before 1989, and from more recent news reports of outbreaks.

There are indications that diseases such as hepatitis A, shigellosis, giardia and lice are still significant problems for some Roma communities. An evidence of a higher exposure to parasites, bacteria and viruses was found in a group of gypsy children aged 6-16 years when compared with ethnic Slovaks. [10] The same study found no difference between Roma and non-Roma children up to three years, all of whom lived in an institution (children's home).

Another study conducted in Nove Mesto nad Vahom in Slovakia[11] also found some indirect evidence of a higher exposure to parasitic, bacterial and viral infections among asymptomatic Roma volunteers than among a similar group of ethnic Slovaks (10.5% vs. 4.9%; RR 2.12, p=0.002).

Respiratory infections may also be a significant problem in Roma communities. During the 1960s, tuberculosis incidence fell sharply in Czechoslovakia. However, a study in Western Slovakia showed that the prevalence of active pulmonary tuberculosis was consistently higher, and fell more slowly among Roma, than among other Slovaks.[12] Tuberculosis was found to be particularly prevalent among older Roma men. The reasons given were lower social status, lower educational level and inadequate hygiene standards. A microepidemic of tuberculosis among Roma children in the Czech Republic was recorded in 1990.[13 14]

A number of pre-1989 studies provide information about a range of infectious diseases in Roma. A 1967 study found that the proportion of Roma treated for various conditions, including tuberculosis and parasitic diseases, at hospitals in Kosice and Bardejov districts was higher than that of other Slovaks.[15] One interesting exception was sexually transmitted diseases, perhaps corroborating the observation that, traditionally at least, Roma people have relatively conservative sexual values, and that prostitution is a relatively new phenomenon in Roma society. However, the evidence for this is not consistent (see Table 6.2).

Table 6.2: Frequency of treated morbidity in Roma and total population in two districts in Slovakia, 1960s.

| | Kosice | | Bardejov | |
|---|---|---|---|---|
| | Cases per 10,000 | | Cases per 10,000 | |
| | All inhabitants | Roma inhabitants | All inhabitants | Roma inhabitants |
| Tuberculosis | 146 | 343 | 134 | 325 |
| Sex. Trans. Diseases | 11 | 7 | 11 | 50 |
| Scabies | 16 | 199 | 22 | 219 |
| Other infectious and parasitic diseases | 268 | 329 | 167 | 233 |
| Asthma | 56 | 164 | 17 | 71 |
| Inflammation of the eyes | 295 | 432 | 139 | 212 |

From Stubna, J. et al. Cs. Zdravot. 1969.

A study conducted in Cheb district in the Czech Republic in 1982[16] compared hospitalization rates for Roma and non-Roma children. According to the authors, one in three children under one year who had to be hospitalized was a Roma infant although it was estimated that Roma constituted less than 3% of the population. The most common diagnoses for hospitalized Roma infants and toddlers were respiratory tract and middle ear infections, anaemia and diarrhoea. It is not clear whether the manifestations of these diseases in Roma were more serious and more likely to require hospitalisation.

Dr Kopecka, a head physician in Prague 5 [3] followed 129 Roma children and 107 ethnic Czech children "endangered by their family environment" between 1981 and 1984. She found that the Roma children had twice as many respiratory and skin diseases (often lice) as ethnic Czech children, and 1.5 times as many diseases of the gastrointestinal tract. Roma children however, were less likely to have flat feet, poor posture or back problems than their ethnic Czech peers. About three quarters of the Roma parents had some sort of serious health or social problem, and as many as 29% of Roma children had parents with a severe disability, or psychiatric problem or a criminal record.

During the 1990s, there have been several reports of outbreaks of hepatitis A in Roma communities. In 1990, there was a serious outbreak in an urban Roma population in Brno, in which mostly patients of Roma origin with mutual contacts were involved and the course of the disease was unusually protracted.[17] In 1999, more than forty children were bedridden from an outbreak of hepatitis A in central Moravia, most of whom were living in a Roma colony near the city of Prostejov or were in contact with those living there.[18] Hepatitis E, which, like hepatitis A, is associated with poor hygiene and sanitation seems also to be present among Czech Roma. A study in West Bohemia found that 4.8% of Roma hospital patients, who did not have symptoms of hepatic disease, carried antibodies to hepatitis E.[19]

It is well known that some Roma in both Republics live in crowded, unsanitary conditions. For example, a recent investigation by the Regional Office in Strakonice in the Czech Republic found that the average Roma apartment was occupied by more than seven people.[20] In one case, eight people were living in two rooms, and in another, fifteen people were living in three rooms. Similarly, a reporter visiting the Lunik 9 housing estate in Kosice, Slovakia, which has a large Roma population observed, "[a] substandard flat with two rooms has to be shared by 20 to 30 people or more. In every room two families have to share kitchen and hygiene facilities. In some of the houses, neither gas or water is working."[21] These

unhygienic conditions may arise at least partly from the difficulties some Roma have in paying rent,[22] [23] and the low level of home ownership among Roma. It is not unknown for landlords to deny essential services, such as water and garbage collection, to those whose rent is in arrears. Such conditions are ideal breeding grounds for epidemics of a range of diseases associated with poor hygiene.

Another important issue for the Roma is vaccination. In 1997, a measles outbreak occurred in and around Kosice, a Slovak city with a large Roma population.[24] Ten Roma and nine ethnic Slovaks were affected. Five of the patients had been vaccinated, three had not, because vaccination was not indicated in their respective age group, and there was no data concerning the vaccination status of the other eleven. The authors state that "…patients of Roma origin are, from the point of view of vaccination and health documentation, a problematic group" and "a proportion of Roma parents ignore the vaccination programmes". However, the authors do not indicate whether it was in fact the Roma patients whose vaccination status was undocumented. This outbreak may well indicate that vaccination rates and vaccine efficacy in Slovakia is inadequate, perhaps not only for Roma.

## 6.4 Congenital disorders

Much Czech and Slovak research on Roma health has focussed on genetic diseases. The attention paid to such studies may reflect a tendency to view all Roma health problems in terms of flaws in their individual dispositions, and there is the potential for considerable bias in such studies. Nevertheless, effective interventions can prevent or alleviate the effects of certain congenital conditions, so it is often very important to know if some Roma are at particular risk.

Seres reported an incidence of congenital anomalies of 2.15/100 births among non-Roma and 2.37/100 births among Roma in Roznava district in Slovakia in 1992-1997.[4] According to a study by Lescisinova et al.,[25] Roma newborns are nearly three times as likely to be born with congential hypothyroidism compared to non-Roma newborns in East Slovakia in 1985-1988. While the incidence of congenital hypothyroidism occurred in 1 in 6284 white births, its incidence in Roma births was 1 in 2192. The authors argue that the most likely cause is genetic. A study in the Kosice region in Slovakia found more than ten times higher incidence of craniostenosis (a congenital defect of the bones of the skull) in Roma compared to non-Roma children (1.1/1000 and 0.1/1000 respectively)[26]. Kvasnicova et al. studied prevalence of "mental retardation" among Roma and non-Roma children aged 6-14 years in the district of Banska Bystrica in Slovakia. They reported a prevalence of mental retardation of 21.5% among Roma and 0.9% among non-Roma children. The authors report that in about a third of the affected Roma children, there was an evidence of genetic aetiology (monogenic disease or chromosomal aberration).[27] There are a number of other reports of higher incidence congenital anomalies and genetic diseases among Roma including glaucoma [28] and phenylketonuria (an inborn error of metabolism that, in the absence of treatment with a special diet, leads to sever learning disability)[29]. Other authors[30] examined Roma blood groups to see if there might be any relationship between blood type and Giardiasis; none was found.

In 1987, Ferak et al presented data indicating an extremely high coefficient of inbreeding in the Roma population of Nitra district in Slovakia.[31] The authors argue that this may explain the high prevalence of certain genetic diseases in this ethnic group. It is not unknown for particular ethnic groups to carry a greater burden of certain genetic diseases, particularly populations that have spent many generations, even in the past, in reproductive isolation. For example, Tay-Sachs disease and genetic forms of breast cancer are more common among

Orthodox Jews; Huntington's chorea is particularly common among certain Pacific Islanders. The Roma in Central Europe have maintained their traditions and culture and have tended to marry other Roma. They have also long been subject to discrimination by the majority community. It is certainly possible that certain deleterious genes might be more common among Roma. However, the 'Gypsy Question', like the 'Jewish Question' in the past, has been a Central European preoccupation for hundreds of years. The large number of research articles devoted to genetic conditions among Roma health experts have been seeking an endogenous cause for Roma ill health, rather than examining the social and economic causes of their current predicament, which are almost certainly as important.

Having said this, if certain genetic diseases are more common among Roma, it becomes even more crucial to ensure that Roma are not alienated from the health care system. Many genetic conditions can be managed very successfully by diet or medication, e.g. phenylketonuria. However, if health personnel are perceived to be in any way unsympathetic to Roma children and their parents, the health consequences can be very damaging (see below).

## 6.5 Non-communicable diseases

Very little information about non-communicable diseases among Roma exists. In the Prague 5 study, many of the older Roma men were invalids, usually due to neurological causes, or joint and bone diseases or airway diseases.[3]

There were very few reports on cardiovascular diseases in Roma. Nozdrovicky followed a community of Roma in the village of Rakusy in Slovakia since late 1980s.[32] He reported that cardiovascular diseases were the most common cause of death among this Roma community and speculated about the reasons for high cardiovascular mortality among Roma. The author identified several factors of life style as the most important causes of high cardiovascular morbidity and mortality among Roma: high consumption of animal fat and low consumption of fruit and vegetables, obesity, high prevalence of smoking - often from a very early age, lack of physical activity and very high consumption of alcohol. Nozdrovicky also mentions an unwillingness of Roma to actively participate in disease prevention and general health promotion activities.

There are indications that chronic diseases such as heart disease and diabetes may become an increasingly important problem for Roma adults. The incidence of low birth weight is higher in Roma (see above), and evidence is emerging[33] that adults who were underweight at birth are more likely to contract heart disease and diabetes in later life.

## 6.6 Health behaviours

In much of the pre-1989 scientific literature on Roma health, there is a strong emphasis on health behaviour.[34] The importance of bathing, the cleaning of fingernails and the sanitary preparation of food are emphasised.[35] More recently researchers have noted, the health condition of Gypsy people is very bad and comes out of bad nutrition, unhealthy life style and reluctance to co-operate actively in treatment or prevention. [3] This statement comes from a report on the situation of the Roma population in Prague 5. The report provides no data or references to studies, but alleges that the Roma of Prague 5 have a range of behaviour-related health problems. According to the report, adult Roma smoked more and suffered more often from respiratory diseases. The report also states that Roma consumed more alcohol and consequently had more liver diseases and diseases of the digestive tract.

According to the paediatricians interviewed for the study the Roma in Prague 5, Roma mothers breast feed for shorter times, and smoke more. They also said that Roma toddlers suffered accidents (mainly scalds), diarrhoea and skin conditions, more frequently than did ethnic Czech children.

Widespread drug dependence among Roma is also cited as a problem. Until 1989, according to the report, drug prevention programs for school children used to be built into the framework of paediatric services, but with privatisation, these services are being dismantled (see below).

### 6.6.1 Nutrition and growth

There is widely available data describing the lifestyles and the diets of Czech children, but very little has been written about the nutrition of Romanies. The Romany minority has, with very few exceptions, a low socio-economic status and there are many reasons to suppose unhealthy dietary habits, often associated with poverty, are common. In addition, access in rural areas to fresh fruit and vegetable is often highly seasonal. The collection of data about the nutrition of the Romany minority presents many difficulties. These include: (i) language problems; (ii) the fact that some Romany parents seem uncomfortable answering questions about their children's nutrition because this kind of information is believed to be very intimate, and (iii) the fact that ethnicity is not recorded in official statistical data.[36]

Certainly the situation has improved since the 1950s and 1960s when there were occasional reports of kwashiorkor (protein-energy malnutrition), and other forms of malnutrition among Roma children, especially girls.[37] However, contemporary Roma seem to experiencing nutritional problems similar to other disadvantaged groups in industrialised countries.

In 1997, the first intervention project in the Czech Republic that focused on Romany children and their nutrition was initiated at the Masaryk University in Brno. Brazdova et al. [38] contacted a sample of 650 Romany children aged 9-13 years (of which 551 took part in the study) from several regions in the Czech Republic to record dietary habits and to evaluate their daily intake of the most important nutrients. They found inadequate consumption of vegetable (19% of recommended daily allowance (RDA)), fruit (20% of RDA), milk and milk products (32% of RDA), of cereals, pasta, bread and rice (63% of RDA) and the food groups of fish, poultry, meat and eggs (78% of RDA). The Romany children in the study consumed four and a half times the recommended daily allowance of various snack foods containing fat and sugar. These results may shed light on other data that show higher rates of obesity in Romany children.[39]

The estimated average daily intake of vitamins C (44% of RDA), E (44% of RDA), B2 (77% of RDA), B6 (79% of RDA) and calcium (57% of RDA) and iron (79% of RDA) was low in the Romany children.[39] The authors also compared the food consumption in Romany children with Czech children of similar ages. The surveys of Czech and Roma children were conducted a few years apart, and substantial differences were noted. While the Czech children consumed on average 2.6 daily portions of fruits and vegetables in 1992, the Romany children consumed on average 1.4 portions in 1997. In 1995, Czech children consumed on average 2.2 portions of milk and milk products, the Romany children, less than 1 portion in 1997.[38]

When asked what they would like to eat, as many as 90% of the Roma children told interviewers that they liked many healthy items including oranges, apples, bananas, tomatoes, cucumber, potatoes, but they rarely ate them. This is surprising, given that children's preferences usually influence food choice significantly. It is likely that this reflects the constraints on choice arising from low income,[40] as has been shown in other countries or

lower access to source of supply, especially in rural communities. This highlights the importance of addressing factors such availability and price rather than concentrating exclusively on education and information campaigns.

Brazdova and colleagues have suggested that social programs that would provide certain foods in place of a proportion of social benefits might be more appropriate and effective.[41] This should not, however, be seen as an alternative to policies that ensure that nutritious foods are available and affordable to all citizens, including the poorest.

There is evidence to suggest that poor nutrition may be having a harmful effect on the growth of Roma children. Bernasovsky et al [42] measured the skeletal growth of 300 Roma children from East Slovakia, and concluded that these children developed and grew more slowly than Slovak children of the same age. In addition, secondary sexual characteristics, including menarche appeared later. The authors do not attempt to explain their observations, except to say that the apparent delayed development of Roma children arose from a combination of genetic and environmental factors. The observed differences between Roma and non-Roma children are less marked at younger ages. The authors speculate that the retarded skeletal maturation of Gypsy children can be ascribed to poorer socio-economic factors as well as genetic factors.

Bernasovska et al.[43] studied growth and development in school age children in Eastern Slovakia in late 1970s. They reported that Gypsy children lag markedly behind the non-gypsy children in somatic development. They also reported an earlier average age of menarche in non-gypsy girls (12.8 years vs. 13.9 years).

Another study[44] found that Roma children from children's homes were smaller than either Roma children growing up in their own families, or non-Roma children in the general population. However, the growth of these children caught up as they approached adolescence.

### 6.6.2 Sexual behaviour, prostitution and drug abuse

Prostitution and drug abuse will be dealt with together in this report because they seem to be relatively new risk behaviours in Roma society and because they are associated with similar disease risks, including HIV, hepatitis, violence and suicide.

An article in a recent issue of the Roma magazine Amaro Gendalos[45] estimated that, out of a total of 40,000 prostitutes in the Czech Republic, as many as 25,000 are Roma women. They work mainly in Prague and in Northern Bohemia, near the German border along the international motorway E55. The author speculates that the combined income of the Roma sex workers in the Czech Republic may exceed $650 million. Roma women have entered prostitution in growing numbers since 1989. The Roma community maintains that this is a new phenomenon and there are some data to support this.

A study from the early 1980s found that[46] that Roma women had a 10-fold lower incidence of cervical cancer than ethnic Czech women in the Karlovy Vary district of the Czech Republic between 1953-79. The incidence of cervical cancer was 26.2 per 100,000 among Czech women, but only 2.4 per 100,000 among Roma women. The study was based on medical records, so it is possible that Roma women were underdiagnosed. The authors searched, but did not find, immunological clues as to why Roma women seems to have lower rates of cervical cancer. They were puzzled because they assumed that Roma woman would have more risk factors for cervical cancer, such as earlier age at first sexual intercourse, more frequent intercourse and more partners than Czech women. However, it is also possible that the data indicate that sexual behaviour among Roma women from the 1950s through the 1970s may have been more conservative than the authors assumed.

Monika Horakova, the only Roma member of the Czech parliament, wrote an article recently in one of the Roma publications about drug use.[47] She writes that she is worried, because, while there are no statistics, there seem to be a high number of Roma drug addicts. She encourages Roma addicts to seek out services for drug addicts, of which there are several in the Czech Republic, "…Roma addicts don't seek psychological services or drug centers which offer help. It is possible that the way these services are organised does not suit them, but it is also possible that the Roma simply don't know that these centres exist and that the Roma can obtain help there too…"

Prochazka notes some differences in the sexual norms of Romany compared to the majority Czech population. He refers to, for example, an earlier age at first intercourse in Romany males, rejection of homosexuality by the Romany community, and a high value placed on faithfulness in the Romany marriage. However, the author is very cautious about generalising to the Romany community as a whole as his information is largely based on contacts with individual patients.[48]

## 6.7 Self-reported health

Nesvadbova et al.[49] studied 432 adult Roma from several districts in the Czech Republic in 1998. The study subjects assessed their current status as "completely healthy" in 50.1%, as "not completely healthy" in 26.1% and as "not healthy" in 23.8%. Most frequently mentioned illnesses suffered by the study subjects "in the past" were diseases of joints, muscles and heart (15%); diseases of digestive system (12%), gynaecological disease (10%), respiratory diseases (9%) and diabetes (5%). Forty percent of the study group reported that they were suffering from a condition requiring medical treatment at the time of the interview. Most frequently mentioned conditions were disease of joints and muscles (22%); cardiovascular diseases (22%), diseases of digestive system (13%), respiratory diseases (10%) and diabetes (10%). Unfortunately, the results are not presented by age and it is not possible to compare the results with data for non-Roma population.

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# 7 Access to health care and use of health services

## 7.1 Contact with health services

In 1990, a small epidemic of tuberculosis occurred in a Roma neighbourhood in Prague.[1] Most cases occurred in children and two children died. All cases were institutionalised, but treatment was complicated by arguments between the doctors and the parents of the afflicted children. Within three years, two of these children relapsed, suggesting that the conflicts may have been serious enough to prevent some children from receiving proper care. Such lapses in care may have consequences not only for the children concerned, but also for others and for the development of resistant strains. There seems to be an urgent need to improve relations between the Roma and the health care system, so that such potentially dangerous situations can be avoided.

Another case of poor communication between the Roma and the health care system was in the treatment of congenital hypothyroidism [CH]. According to the authors, "…due to incomprehension of some parents the treatment of some Gypsy newborns with detectable CH could not be regularly continued as necessary to maintain a normal mental and somatic development."[2] It is quite possible that if there had been a Roma health worker present who could speak to the parents in their own language, perhaps these Roma children would have had a better chance of receiving adequate treatment.

A doctor writing from the 1980s reported, "A big problem in many paediatric departments are children of gypsy origin. There were times when gypsy parents did not want to leave even very sick children in the hospital, because the stay was connected with the feeling of losing their children… today the situation is mostly the opposite. The district paediatricians refer Gypsy children to the hospital when their parents cannot or do not want to take care of them."[3] The same source also quotes problems in communication and numerous cases when Roma parents refuse to leave their child in the hospital or, on the other hand, simply are not available when the child is to be discharged from hospital are also described. One can only suppose that the problem emerges from both sides, and that if the health of the Roma is to improve, a rapproachment between health workers and Roma patients will be essential.

Seres describes several "specific issues" in treating Roma women at his clinic of obstetrics and gynaecology in the Roznava district in Slovkaia. He identifies non-compliance with prescribed treatment regimes as the main issue. Several case studies of Roma women ignoring the doctor's advice are documented in detail (largely patients leaving the hospital immediately after having extensive life-saving surgery). Other issues identified by Seres are non-compliance with drug treatments, especially if these are prescribed as a "preventative measure" or when the patient is not currently suffering from symptoms, and unwillingness to undergo regular out-patient check ups.[4]

Nesvadbova et al.[5] studied 432 adult Roma from several districts in the Czech Republic in 1998 and in addition to measurement of health status also investigated factors influencing contact with health services. Ninety-five percent of the study population knew their GP and 89% said they "get on well" with their GP (the remainder were indifferent or did not like their GP). Sixty-nine percent felt they could confide in their GP, 24% did not know and 7% said they could not confide in their GP. Seventy-seven percent considered medical care they and their family receive to be sufficient, 19% felt it could be improved and 4% declared that the medical care was insufficient.

The above study included a questionnaire survey among GPs about Roma health and contact with health services. GPs reported that men of productive age pay more frequent visits to them than the non-Roma male population of similar age. GPs also pointed out a lower number of visits by Roma women to their surgeries compared with the males of the same population. They reported that Roma women come to accompany their partners but are reticent about their own problems. GPs reported that they often learn about health problems of elderly people very late, and usually are contact only when it is necessary to deal with a serious acute deterioration of health. Elderly Roma people tend to live in large families and are looked after by their female relatives.[5]

## 7.2 Research on Roma health

Relations between the Roma community and health researchers are also delicate. Recently a research team at Charles University received government funding to study the health status of the Roma population of the Czech Republic. The researchers sent questionnaires to general practitioners throughout the country, and asked them to report on the health of their Roma patients. Almost immediately after it was launched, the project started receiving a great deal of (mostly negative) publicity on TV and in main newspapers and was criticised on a number of grounds.[6] Some doctors believed the project was unethical because information about patients is confidential. In addition, some doctors allege that they have no way of knowing which patients are Roma. More importantly, Roma groups objected to the fact that lists of Roma names would be collected for the project, because they were very concerned that these lists might be misused. Emil Scuka, president of the Roma citizens initiative, said he found it puzzling that the Charles University study received funding from the Czech Ministry of Health when at the same time, so many schools and hospitals are currently underfunded.

In order to proceed with a study or intervention in the area of Roma health, investigators must avoid such protean conflicts. The design of studies and interventions might better be aimed broadly, at health issues, rather than particular ethnic groups. For example, it is suspected that certain infectious diseases associated with poor hygiene might be more common among Roma. An acceptable intervention might be to ensure that all apartments have adequate sanitation and plumbing services, even if tenants will not or cannot pay their rent. Finally, all proposals should have the approval of at least one, if not several Roma rights organisations.

One finding is apparent. Standard epidemiological methods that have not been adapted to the particular circumstances of the Roma population, and which do not build on work to achieve commitment and participation by the Roma population, are unlikely to give meaningful or valid results.

An improved understanding of the determinants of health among the Roma people is needed but the history of such research indicates the potential risks involved. It will only be successful if it is handled with great sensitivity. For example, the 1991 Census demonstrated how reluctant the Roma are to admit their ethnicity/proclaim themselves as belonging to "Roma nationality" to state or other officials. The success of any research or intervention programme dealing with the health of the Roma people in Central Europe will depend crucially on the support of the Roma people themselves.

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# 8 Health issues in the Roma media

There are several newspapers and magazines published for the Romany community in the Czech and Slovak republics in the Czech, Slovak and Romany languages. We reviewed the following titles: *Romano Kurko* (published monthly in Brno 1991-1999), *Romano gendalos* (1993-1996), *Amaro gendalos* (1997-1999), *Romano dzaniben* (1994-1999), *Kereka* (1998-1999) and *Romano hangos* (1999).

## 8.1 Romano Kurko

The magazine *Romano Kurko* includes a regular "Physician's advice" column and a special "Physician's advice to women" column and runs a series of other articles on health and health services issues. The topics covered in the most recent issues included:

- Physician's advice to women:

Diagnosis and treatment of various vaginal infections; methods of contraception – sterilisation, hormonal contraception and other; preventive health care in pregnancy – schedule and aims of preventive visits, ultrasound tests; information about aetiology, diagnosis and treatment of breast cancer including the explanation of the technique of self-examination; the importance of adhering to the prescribed drug regimes – including a warning about taking certain types of drugs in pregnancy, information and advice about menopause; detailed information how to prevent HIV infection and explanation about the modes of transmission. The readers are invited to write to the editor with their own suggestions and questions.

- Other health issues:

Very general information describing poorer health status of the Romany minority compared to the majority Czech and Slovak population. Advice on healthy drinking regime. Rather extensive information about alternative medicine techniques, a regular column on using herbs. Warning about the epidemics of viral hepatitis with explanation of symptoms. Information about hormonal contraception. Advice on how to prevent misuse of alcohol and drugs in children. Prevention of alcoholism. Symptoms and treatment of migrane, tic-born encephalitis. Information about harmful effects of smoking and advice on how to stop smoking. General information about major discoveries in medical science, genetics, articles on prevention of tuberculosis, cerebrovascular disease, passive smoking, male infertility, sleeping patterns, various types of cancer, skin diseases, child abuse.

- Articles about health services

The magazine also runs articles providing basic information about patient's rights, the schedule of preventive health checks for children, explanation about regulations concerning transport to and from a hospital, articles advising people on how to obtain a registration card for the health insurance etc.

We did not find any articles with concrete data on health status of the Romany community in the Czech or Slovak Republics.

## 8.2 Other Roma magazines

*Kereka*, a magazine for children and the youth, published monthly in Valasske Mezirici, has run a series of articles on prevention and treatment of drug abuse, prevention of sexually transmitted diseases including HIV, and child prostitution.

*Amaro Gendalos* and *Romano Gendalos* have also published several articles on prevention and treatment of drug abuse and contraception.

In 1996, *Romske listy* reported two microepidemics of tuberculosis among Roma children in Prague and Cesky Krumlov in 1990 and 1994.[1]

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1 Anon. More tuberculosis among Roma [in Czech]. Romano lil. 1996;6:3.

# 9 Interventions aimed at the improvement of health, education and social status of Roma

The recent attempts by groups of Roma families from the Czech Republic and Slovakia to seek asylum in Canada and Britain have focused attention of the media and of governments on the needs of Roma people and stimulated interest within the research community.

## 9.1 Governmental and EU initiatives

### 9.1.1 Czech Republic

The Government of the Czech Republic approved a "Report on the Situation of the Romani Community in the Czech Republic and Government Measures Assisting its Integration in Society" on 29 October 1997.

The preparation of the Report was based on collaboration of ministries, non-governmental organisations, Romani groups, state and local administration officials, members of the Council on Nationalities as well as ad hoc working groups, with the aim of obtaining the most objective and precise information about the current situation of the Romani community. The authors state that "… The seriousness of the problems connected with the Romani community comes primarily from the fact that a significant portion of the Romani minority in the Czech Republic belongs to the lowest social level, with high unemployment, a low level of education, and, compared to the total population, a disproportionately high crime rate. In addition, the proportion of the Romani population of the total population is increasing, and this group has difficulty fitting into processes which are standard for the majority." [1]

The chapter on health care and the problem of drug addition among the Vlax Roma is transcribed in full below:

> "The Romani population is not separately categorised in statistical research about health care. The Ministry of Health does not distinguish ethnic groups in providing health care, and so-called risk groups of the population are cared for without differentiation. Only in the records of infant and children's homes for children up to 3 years of age are children of Romani nationality initially classified. We can only empirically state that the Romani population has a different incidence and prevalence of a number of illnesses, which comes primarily from their life style. Their birth rate is higher than that of the non-Romani population, as is the rate of infant and child illness. The average life span among the Romani population – especially in light of lifestyle and dietary habits – is shorter.
>
> A relatively new and very negative occurrence, which can lead to destruction of traditional values and ties in the community, is abuse of hard drugs (in this case heroin) by the youth of the Vlax Roma in some large cities. It is generally known that this group is often connected to a network of various traders, and so it was basically merely a question of time, when the children and young people of the Vlax Roma, used as dealers, would succumb to the temptation to try the drug. As specific examples from Prague and Ostrava show, this leads to a situation in which the young generation gets completely out of control of older, traditional family authorities.
>
> It is indispensable for all the state government bodies (whether central or local) and local government to take steps which – apart from intervention directly with the children - will help those members of the Vlax community who could be intermediaries between the community and the authorities to regain their authority, and will also lead to protecting society from the familiar results of drug abuse."

In the resolution, the Government requested the minister of health to "ascertain the needs for specific health care for the Roma population in the Czech Republic, including suggestions regarding organisational and preventative measures".

A subsequent resolution on "Principles of the Government policy regarding the Roma community that should facilitate their integration in the society" was approved on 7 April 1999. Neither the background documents, nor the specific areas for action address health issues specifically. The resolution, however, includes a more general policy on tackling discrimination of Roma in access to public services. There are representatives of the Ministry of Health among the members of the Inter-ministerial commission for Roma community affairs. [2]

### 9.1.2 Slovakia

The Government of the Slovak Republic approved a "Strategy for or the Solution of the Problems of the Roma National Minority and the Set of Measures for Its Implementation – Stage I" at its meeting on 27 September 1999. [3]

In this official document, the Slovak government acknowledged a need to concentrate on creating conditions for the resolution of problems facing the Roma population in areas where the situation is perceived as critical - unemployment, housing, health status, social sector and the school system, or where there are grounds for improvement - human rights, rights of persons belonging to national minorities, co-operation with NGOs and regional development.

The areas for action include human rights, education and training, language and culture, employment, housing, social sector and health care. A specific set of measures to be implemented at stage I under the "Health Care" [NB This chapter is actually denoted as *zdravotny stav*, i.e. "Health Status" in the Slovak version of the document] heading are: [3]

- To continue the implementation of the project "Schools Supporting Health" which proved effective in areas with higher concentrations of the Romany population, in particular in the region of Banska Bystrica, Presov and Kosice.
- To prevent the occurrence and transmission of infectious diseases in Romany settlements through targeted preventive anti-epidemiological measures and increased hygiene supervision by relevant departments of the State Health Institute
- To support as a priority the establishment of home nursing agencies in the regions with high concentrations of Romany population, in particular in the regions of Kosice, Presov and Banska Bystrica
- To implement projects elaborated by the Institute of Health Education in Bratislava
- "Promoting health awareness of Romany children, aged 6 to 12". The goal of the project is to increase health awareness of Romany children
- "Promoting health awareness of Romany children, aged 10 to 15". The goal of the project is to influence basic hygienic and sanitary habits of Romany children through health education
- "Preparing Roma citizens for marriage and family planning". The plan of the Ministry of Health of the Slovak Republic is to implement these projects through the National Health Promotion Centre.

The background document assessing the health needs of the Roma population in Slovakia is reprinted in full below:

> "The health care in the Romany population has never been studied in detail and in a systemic way in the Slovak Republic, even though, this problem has a significant

social, societal and economic impact. It is generally known that the health status of the Romany population, including children, is much worse than the average health status of majority population. The consequence of this is a higher and earlier mortality. These statements result from several statistics.

Low level of education of the Romany population, the resulting low level of social awareness, low standard of housing and personal hygiene have also affected their health status. The Romany settlements have substandard municipal hygiene, polluted and devastated environment. Potable water supply is missing. Drug consumption, alcohol drinking and smoking proliferate increasingly. All these factors have a significant effect on the level of hygiene and the resulting morbidity and infectious diseases.

In order to improve the health status of the Romany population the Government shall provide for improved hygiene, health awareness and prevention through education and training. The Government shall provide for conditions that will change the dietary habits and generally influence the social, cultural and value orientation of the Romany population in the field of health.

The Government shall provide for conditions that will allow continuation of implementation of projects dealing with education for marriage, responsible parenthood and the use of contraceptives and preventive examinations of persons living mainly in settlements. It shall provide for better prenatal care, care for health of future mothers and their children. Under its education programme the Government shall provide for a targeted education in healthy diet, personal hygiene, education for parenthood, promotion of vaccination, prevention against drug addictions, etc." [3]

### 9.1.3 EU support for Roma communities in Central and Eastern Europe

As a part of the activities related to its preparations for enlargement, the European Union is paying more attention to the situation of Roma in the "candidate countries". In a recent report by the Directorate General for Enlargement it is acknowledged that "… Roma communities suffer from social and cultural exclusion in most European countries. The problems of marginalisation are particularly severe in the central and eastern parts of Europe, where Roma have suffered in the transition of the countries towards market economies. The problems most commonly faced by Roma populations are racism and discrimination, low levels of education, high unemployment (50-90%), health standards well below those of the mainstream population, and very poor housing conditions."

The European Union has supported the Roma population in Central and Eastern Europe mainly through its PHARE and TACIS programmes. All the programmes cover a range of activities from education and employment to legal and social initiative. Most fall within the education/training, cultural and media domains. [4] Projects supporting Roma-related legal, social, informational, health and gender activities are generally fewer in number and there are currently no Roma-related health programmes funded by PHARE in the Czech or Slovak Republics.

## 9.2 Examples of initiatives

Among the numerous activities by non-governmental organisations, foundations and Roma groups, aimed at improving the situation of Roma in the Czech and Slovak Republic, there is a notable absence of programmes specifically addressing health and health services issues. The exceptions are some new activities related to drug abuse and HIV prevention.

### 9.2.1 Education

We identified a considerable number of activities addressing the educational needs of the Roma people. These include for instance programmes on Romany studies, training of teachers for work in multicultural environments, education of Romany children, Romany language courses, courses on work with handicapped children and youth, courses in social policy, and training of Roma "teaching assistants".

The Romany Education Programme of the New School Foundation in the Czech Republic supports development of education programmes for the Roma people. The training is designed to resolve conflicts, improve protection of civil rights and further equal opportunity and non-discriminatory practices, including access to education, employment and full and equal participation in society for the Romany minority. The many activities under this scheme include: support for Romany teaching assistants in elementary schools, workshops for teachers of Romany children, monitoring discrimination against Romany students, information exchanges with organisations in Slovakia and elsewhere, and publication of textbooks, teaching materials and a bulletin.[5]

On 1 September 1998, the Romany High School for Social Affairs opened in Kolin, Czech Republic, as the first secondary school in the country established by and for Roma. The Roma community, Soros Foundation and the Canadian and British embassies all contribute to the funding of the project.[6]

### 9.2.2 Drug abuse

A charity, specifically aimed at helping Roma people reduce their risks of contracting HIV, hepatitis or other diseases associated with the use of narcotics has been operating in Prague.[7] The new program is known as Movement for Civic Solidarity and Tolerance (HOST), and it employs Roma street-workers to encourage use of needle exchange services and inform about methadone programs and other services for addicts. A similar program was established at around the same time in Ostrava, in Northern Moravia.[8]

## 9.3 Summary

This review provides some evidence that the health of the Roma population in now reaching the national agenda in both countries. The official documents do, however, substantiate the findings described elsewhere in this report, that there are large gaps in the available knowledge of the health of the Roma people.

In contrast, it has not been possible to identify any significant body of activity aimed specifically at methods to improve the health of the Roma people. There are, however, some encouraging developments in the education sector that may offer models that could be emulated by health professionals.

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1 Report on the Situation of the Romani Community in the Czech Republic and Government Measures Assisting its Integration in Society. 1997. www.vlada.cz/rady/rnr/cinnost/romove/zprava/zprava.eng.htm and www.vlada.cz/1250/vrk/komise/komise.htm

2 Resolution of the Czech Government on principles of the governmental policy regarding the Roma community with the aim to facilitate their integration in the society. [in Czech] 1999. http://www.vlada.cz/1250/vrk/rady/rady.htm

3 Strategy of the Government of the Slovak Republic for the Solution of the Problems of the Roma National minority and the Set of Measures for Its Implementation - Stage I. 1997. www.government.gov.sk

4 Anon. EU Support for Roma Communities in CEECs. December 1999. www.europa.eu.int/comm/dgs/enlargement/index.htm

5 The Romani Education Programme of the New School Foundation. Patrin Web Journal. www.geocities.com/Paris/5121/patrin.htm

6 Stroehlein, A. A school unlike any other. . Patrin Web Journal. www.geocities.com/paris/5121/patrin.htm

7 Anon. New project helps Roma drug users [in Czech]. Mlada Fronta Dnes 12/05/99: p. 1.

8 Anon. Roma get two places for advisors [in Czech]. Mlada Fronta Dnes 03/04/99: p. 1.

# 10 Conclusions

## 10.1 Validity of the results

The team have performed systematic searches and made contacts with institutions and subjects potentially involved in studies of Roma health in the Czech Republic and Slovakia. However, this review is inevitably subject to the usual limitations facing any literature searches, such as incomplete ascertainment of papers and publication bias.[1] The scale of the challenges is, however, greater than would be the case for many other topics.

The international part of this research examines the health needs of a single people who have been dispersed to countries as diverse as Jordan, Mexico, Slovakia and the United Kingdom. Although the Roma populations in many places have adhered strongly to traditional ways of life and share many common beliefs, the literature reviewed encompasses tremendous heterogeneity, making it extremely difficult to generalise.

Although the literature overall is fragmentary, the most striking finding is the almost complete absence of research on non-communicable diseases, despite evidence that the Roma have a substantially shorter life expectancy than the majority populations.

Several possible explanations exist but these have quite different implications. Some may simply reflect the difficulties of undertaking research in marginalised populations with well developed sets of health beliefs. Classical population based risk factor epidemiology is likely to be more difficult among Roma populations who, as well as being more difficult to gain access to, may regard researchers with hostility: often appropriately in view of their experiences at the hands of authorities. In addition, research on hospitalised patients may be difficult because of low access to and use of hospital facilities.

There are, however, other more problematic issues relating to the values underlying the research. The focus of existing research on communicable disease may reflect not so much a concern about the health needs of the Roma but more those of the majority population. The history of public health contains many examples of actions driven by such concerns about "contagion". This concentration on communicable disease also resonates, uncomfortably, with the Social Darwinist agenda, which viewed the excess of communicable disease in certain populations as a means for reducing the numbers of those considered to be constitutionally weak and socially undesirable. [2] Such beliefs might also be seen to underlie some research on reproductive health, and may represent the same blurring of the boundary between the population perspective and eugenics that led to the demonisation of the infirm and the polluters of racial purity that characterised Germany under National Socialism. [3]

In some societies, especially in parts of central and southern Europe where there has been a recent reawakening of strongly nationalistic sentiments, evidence of health inequalities may be interpreted very differently than it might be in more inclusive societies. Consequently some researchers have taken a view that these issues are best left alone for the present. It is in the context of this climate that one must take a view on the appropriateness of different forms of intervention. Notwithstanding the clinical evidence from the UK of the usefulness of interventions targeted at the Roma population, [4 5] any intervention which reinforces ideas of difference or separation from the majority community, may be politically divisive in some settings and cause net harm.

## 10.2 Health needs of the Roma population – way forward

What limited evidence exists indicates that the health needs of the Roma population are likely to be considerable. Recognising the need for great sensitivity because of the dangers arising from nationalism in some countries, there is a need to move this issue higher up the public health agenda. Unfortunately such action faces a wide range of obstacles, similar to those recently identified as constraining the development of effective policies on childhood injuries in central and eastern Europe. [2]

The health needs of the Roma population lack visibility, not only because of the absence of research but also the absence of advocacy on their behalf. In many of the countries with large numbers of Roma, the public health services that, in the west, might be expected to act as agents to promote policies focusing on the health needs of minorities, do not exist. Neither do the non-governmental organisations that have been effective in the west in raising the profile of otherwise ignored issues. Similarly there is little tradition of the inter-sectoral action that would be required to mount an effective policy response.

Perhaps the one opportunity on the horizon is the growing interest in the Roma among international agencies and similar bodies. Agencies active in reform of health and social care, such as the World Bank (as indicated by the commissioning of this report) and the Open Society Institute, have taken an increasing interest in this issue and the rights of minorities are increasingly the focus of discussions with countries hoping to accede to the European Union and are also a major issue for the Council of Europe, of which many countries in central and eastern Europe are now members.

## 10.3 Summary of results and conclusions

### Health status

- The existing evidence indicates that the health needs of the Roma population in both the Czech Republic and Slovakia are considerable.
- With very few exceptions, the evidence suggests that health status of Roma is worse than that of non-Roma population in the Czech Republic and Slovakia.
- Data from before 1989 suggested that mortality was higher for Roma than for ethnic Czechs and Slovaks, and it is unlikely that the situation has been greatly improved in the last ten years. In 1970-1980, life expectancy for the total population of Czechoslovakia was 66.8 years for men and 73.9 years for women, but life expectancy for the Roma population was only 55.3 years for men and 59.5 years for women. In the Czech Republic, infant mortality was 23.9 per thousand live births for Roma, compared to 12.1 per thousand for non-Roma. In Slovakia, infant death rates were 34.8 per thousand for Roma and 14.6 for non-Roma.
- Perinatal mortality is significantly higher and low birth weight and preterm births are more common among Roma than among ethnic Czechs or Slovaks.
- There is evidence to suggest that poor nutrition may be having a harmful effect on the growth of Roma children.
- The burden of infectious disease among Roma in the Czech and Slovak Republics seems to be high for a population living in an industrialised country. Diseases associated with poor hygiene seem to be particularly important.
- Virtually nothing is known about chronic adult diseases such as heart disease and cancer among the Roma people, although it is suspected that smoking and heavy drinking are prevalent in Roma communities.

- There is very little research on drug abuse among Roma in the Czech Republic and Slovakia, but newspaper reports and Roma groups themselves attest that it is a problem of considerable dimensions.
- It is not known how many Roma women work as prostitutes but it is perceived as an increasing problem among the Roma people.

**Research**

- Information on Roma health needs is patchy, and epidemiological studies on Roma health tend to suffer from poor methodology (absence of control groups, unrepresentative samples and other issues) combined with ethical and logistical obstacles to data collection.
- Since 1989, Czech and Slovak researchers have largely turned away from health research on particular ethnic groups. This probably reflects a growing sensitivity about stigmatising Roma, but it also makes it more difficult to know how their circumstances might be improved.

**Contact with health services**

- There is almost no evidence about the access of the Roma population to health services.
- There does, however, seem to be an urgent need to improve understanding among health care workers of the needs, beliefs and aspirations of the Roma people.

**Advocacy**

- There is no indication that health is perceived as a high priority by Roma organizations or other bodies representing and assisting the Roma community. An important reason is that some Roma who are now leaving the Czech Republic and Slovakia to seek asylum in Europe and North America fear that if the poor health status of their community becomes widely known, their immigration cases may be viewed less favourably.

**Transition and socio-economic situation**

- The Romany minority has traditionally had, with very few exceptions, a low socio-economic status. Since 1989, many Roma families have fallen further into poverty and social exclusion. There is evidence that health inequalities are generally increasing in the transition countries, as gaps in health between groups with different education levels, income or marital status are widening.
- Results from several other countries indicate that health status of the Roma tends to be poorer than that of the majority population.

## 10.4 Next steps

An improved understanding of the determinants of health among the Roma people is needed but the history of such research indicates the potential risks involved. It will only be successful if it is handled with great sensitivity. For example, the 1991 Census demonstrated how reluctant the Roma are to admit their ethnicity/proclaim themselves as belonging to "Roma nationality" to state or other officials. The success of any research or intervention programme dealing with the health of the Roma people in Central Europe will depend crucially on the support of the Roma people themselves.

One finding is apparent. Standard epidemiological methods that have not been adapted to the particular circumstances of the Roma population, and which do not build on work to achieve commitment and participation by the Roma population, are unlikely to give meaningful or valid results.

Two priorities flow from this finding. First, there is an urgent need for further primary research that will answer the following questions:

- To what extent is it possible to define those who are part of the Roma people, for the purposes of deriving sampling frames etc.?
- What does the term Roma mean in an epidemiological or health policy sense?
- How can the Roma population be defined in a way that not only avoids further stigmatisation but is also seen to do so by those involved?
- Given the many deeply held beliefs about public and private matters, such as dietary habits, what type of research might really be possible?
- How are concepts of health and disease interpreted?
- Are there ways in which research might be undertaken that would adapt to deeply held Roma concerns?

Second, and most importantly, there is a need for further work to understand how the Roma people can become genuine participants in this research rather that simply the objects of it.

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