# EUROPEAN ROMA GRASSROOTS ORGANISATIONS (ERGO) NETWORK

Case Studies 2021

## "Roma access to quality, inclusive and affordable health and long-term care in the Czech Republic 2022"

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# 1 Introduction

## 1.1 Description of the organization

Vzájemné soužití (Life Together) was founded in 1997 after catastrophic floods that had a disproportionate impact on the Roma of Ostrava. From that time onwards, Life Together has been trying to build up the Roma Community, organize, and support it so that the Roma can come to enjoy the same rights and opportunities as any other person in Czech Society. We have created educational and social services that are accessible to the Roma and other needy people. We have established bases within communities and have created Roma-Czech teams there to make our work meaningful and helpful, appropriate and easily accessible. We have thus been fortunate to take up hundreds of individual cases, group cases and community issues, and make them mainstream. In 1999, we established Ostrava's first free Legal and Social Advise Office. We have a full time lawyer and several teams of social workers to serve the people and influence institutions. Dignity of all and respect for each other is a cornerstone of our work. Life Together has expertise in many fields: Housing, Education, Health, Human rights, Employment. We have been involved in many field researches and studies. For example:

- 2007 UPR submission on Housing of the Roma

  https://lib.ohchr.org/HRBodies/UPR/Documents/Session1/CZ/COHRE_CZE_UPR_S1_2008_CentreonHousingRightsandEvictions_uprsubmission.pdf

- 2009 SASTIPEN survey. Health and the Roma Community, analysis of the situation in Europe Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain. The analysis of the health situation was prepared by Life Together (Vzájemné soužití) on behalf of the Czech Government Office.

  http://www.gitanos.org/upload/78/83/Health_and_the_Roma_Community.pdf

  https://www.vlada.cz/assets/ppov/zalezitosti-romske-komunity/dokumenty/Sastipen.pdf

- 2012 We worked with prof. Kevin Browne, Nottingham university on: The Problem of Child Abandonment and its Prevention.

  https://bettercarenetwork.org/sites/default/files/attachments/Child%20Abandonment%20and%20Its%20Prevention%20in%20Europe.pdf

- 2014 We prepared the Shadow Report on Segregation of the Roma in Czech Education

  http://www.dare-net.eu/cms/upload/file/shadow-report-on-roma-segregation-in-education-czechrepublic-english-2014.pdf

- 2015 We prepared the Methodology for monitoring Roma national strategies for education.

  http://www.dare-net.eu/cms/upload/file/national-methodology-for-monitoring-the-plans-on-education-within-the-national-strategies-for-roma-czechrepublic-english.pdf

- 2015 Strategies and Tactics to Combat Segregation of Roma Children in Schools - Case studies from Romania, Croatia, Hungary, Czech Republic, Bulgaria and Greece

  https://ec.europa.eu/research-roma-children/?publications/366/

  https://www.nottingham.ac.uk/research/groups/cffp/documents/childabandonment/czech/brochure.pdf

We have also successfully organized demonstrations against harmful laws that sought to put unconstitutional bars on accessing housing benefits: https://www.idnes.cz/ostrava/zpravy/petice-za-schvaleni-doplatku-na-bydleni.A150615_161515_ostrava-zpravy_jog

## 1.2 Methods and tools

Our research is based on our many years of experience in working with families and children. Since 2006, we have provided support to 1,137 predominantly Roma families with children. Throughout the years, we still solve the same problems. Problems with housing, finances, children's education, health care, etc. Most families have very low competencies for both raising children and for education, health care and they're lacking in financial literacy. Since 2006, the problems of families have not changed in any way. On the contrary, currently the problems in families are increasing.

In the research, we used the method of quantitative research with the help of questionnaires and from the data of family file documentation and also the method of qualitative research, namely case studies. The research took place within the city of Ostrava of the respondents and its socially excluded localities (hereinafter referred to as SEL). The respondents were Roma families with children under the age of eighteen. We distributed 400 questionnaires to families with children in socially excluded localities and hostels /see below/. The return was 72%. The research sample includes 286 adult respondents with children /approximately 400 children/. Furthermore, the aim of the research is to reveal systemic weaknesses in the field of health care faced by Roma in the Czech Republic.

## 1.3 Socioeconomic situation of Roma in the Czech Republic

According to the analysis of the Ministry of Labor and Social Affairs, in 2015 there were more than 606 excluded localities in the Czech Republic and their number is still rising. In Ostrava and in hostels /see below/.

Today, more than half of the Roma in our country live in excluded localities. Excluded locality means a place where people affected by social exclusion are concentrated. Such a place can be a city district, a street, several houses or a settlement. By concentrating the Roma with economic problems in one place, a situation arises where the places start to differ significantly from other parts of towns and villages and an excluded locality is created.

Roma with economic problems often end up in houses for the socially disadvantaged or in houses for non-payers of rent, which again leads to involuntary concentration, from which they cannot get out. It is also necessary to state that people from the majority groups often end up in excluded localities, namely people without work, people with disabilities or single mothers. The quality of life is deteriorating in excluded localities, including the health of children and adults. In addition, there is contact with people on the margins of society outside the Roma community and thus further negative influence.

Our research is focused on Roma living in Ostrava in socially excluded localities and in hostels of the city of Ostrava.

Strategic Plan for Social Inclusion Ostrava, 2015-2018 estimates that there are about 12,000 to 13,000 Roma living in the SEL in Ostrava who meet the conditions for social exclusion. The localities also include about 42 hostels, in which an estimated 7,000 people live. The majority of their population is Roma. According to estimates, this is 60% of the population of SEL and up to 100% of hostels. (source: Report on the state of the Roma minority in the region in 2017).

- Mariánské Hory: 2 socially excluded localities /hereinafter only SEL/, approx. 370 persons, 7 hostels 400 persons,
- Moravská Ostrava a Přívoz: 2 SEL, approx. 1500 persons, 7 hostels approx. 100 persons,
- O-Jih: 12 hostels and hotel houses, approx. 2850 persons /Hrabůvka, Zábřeh/
- Poruba: 1 SEL approx. 1200 persons, 2 hostels approx. 50 persons,
- Slezská O: 6 SEL 2150 persons, 4 hostels 430 persons, /Hrušov, Kunčičky../
- Vítkovice: 2 SEL, approx. 620 persons, 8 hostels Approx. 590 persons (source: Strategic plan).

In the excluded localities, but also in the hostels, the families live in unhealthy and unsuitable flats. High rents and housing-related services absorb most of the monthly income. Families often do not have financial resources left for basic food. If someone in this family falls ill, paying for medicines and medical supplies is a serious economic problem.

Another big problem is the area of Roma employment. They often perform menial, low-paid work and often move in the gray economy, are often unemployed, and the only income for families is material deprivation benefits. The administration of these benefits is difficult for many Roma. Roma are often unable to document the number of required documents and thus remain without these benefits.

The poor economic situation also affects the education of Roma children. Many of these children do not even complete primary education. It is true that in an urban environment, Roma children achieve better results than in rural areas and attend not only school but also preschool facilities to a greater extent. Social assistance is more accessible to them than in the countryside, where Roma families find themselves in greater isolation.

As stated in the Strategy for Social Inclusion 2021-2030 issued by the Ministry of Labor and Social Affairs, different groups of society are exposed to different levels of poverty and social exclusion. However, one of the most vulnerable groups in terms of poverty and social exclusion is the Roma. In 2016, more than 58% of Roma in the Czech Republic were at risk of income poverty, which is six times more common than the threat to the majority society. The highest share of Roma at risk of poverty or social exclusion is in areas where all or most of the population is of Roma origin, which confirms the situation in socially excluded localities, where up to 80% live Roma. The risk of Roma social exclusion is associated with educational, employment, health or housing disadvantages, and access to these areas is significantly affected by discrimination and anti-Gypsyism.

Situation of the Roma minority is still one of the most most urgent problems of social development after the year 1989. The Strategy for Equal Inclusion and Participation of the Roma 2021 - 2030 follows the strategy until 2020 and the aim is to reverse the negative trends in the development of the situation of the Roma, especially in the areas of housing, education, employment and health. The aim is to accelerate positive change, ensure effective protection of Roma against discrimination and anti-Gypsyism, and encourage the emancipation of Roma, the development of their culture and language.

Together with low education, poor financial literacy, lack of work habits and low legal awareness, in many cases they do not even know the appropriate tool to deal with their situation. There is absolutely no long-term planning and setting of personal goals for development. This resigned attitude is then passed on between generations as a learned pattern of behavior, which leads to the emergence of future generations of people without sufficient competencies to successfully participate in the life of the majority society and improve their current situation.

The life of the target group in socially excluded localities is frustrating. The locals are not able to help themselves, they often do not even know how. Families or individuals very often find themselves below the poverty line and at the bottom. These people often do not solve their problems, they cannot identify their causes. He chooses short-term life strategies, aimed only at satisfying basic needs. They do not understand the social environment and social norms. They live in a sense of danger and fear of change and new things, they fall into the vicious circle of life problems, and they often do not know which one needs to be solved first. They have no idea where to start. Frustration leads to resignation. The reason for their problems is low education, long-term unemployment, lack of financial literacy, low competences for the upbringing and education of children and ignorance of the means or institutions where they could solve their situation. Fear of discrimination or distrust in the surrounding world also prevents the inhabitants of SEL from finding suitable strategies for solutions. The problems also arise from the very environment in which they live. Unsatisfactory conditions.

There is absolutely no long-term planning and setting of personal goals for development. This resigned behavior is passed on between generations as a learned pattern of behavior. This creates next generations without the necessary competencies necessary for successful social inclusion and the ability to effectively solve their problems on a personal and local level. People in financial need often resort to illegal collection and sale of metals, they are victims of so-called "moneylenders", they borrow for "intereš". Children do not go to school, etc. As a result of these aspects, these people are a more vulnerable group, either becoming people with risky behavior or easy victims. Residents live in a small space, often spending their time with others outside in front of the house, trying to cover up their frustration with the means that are their own.

The reason for their problems or possible social exclusion is also the possible fear of discrimination, which leads to distrust of the outside world and institutions. The effect of the specific environment of SEL on their inhabitants leads to the fact that they are no longer able or do not have enough strength and motivation to change their current situation. Negative patterns of behavior of the population themselves then lead to tensions between the majority and the minority. The media, social networks, contribute no less to this. The Strategy for Equal Inclusion and Roma Participation 2021 - 2030 uses the term anti-Gypsyism.

The aim of our case study is to point out the often different treatment of Roma patients in the Czech healthcare system. The problem of Roma patients is often their low level of education - very low competences in education. In the Czech healthcare system, there is not enough space to pay increased attention to Roma patients. Roma patients have their specific needs. They would need paramedics to devote more time to them. The interviews showed that Roma patients do not understand what doctors or nurses tell them. They are ashamed, so they prefer to nod that they understand their situation. However, it is often necessary to explain to Roma patients several times their diagnosis, the treatment procedure, how to take medication, or when they should come for further examination. It happens that these patients come to us and ask us not only for advice but also for escorts. In some hospitals, there are social workers who deal with escorts at the time of illness, but Roma patients either do not know about them or do not use them.

It would be appropriate to focus on the Roma ethnic group in primary, secondary and higher education institutions, because the Roma live among the majority and have the same health problems. Roma have their differences, perceptions of values, their culture, customs. If health professionals knew their differences, then they would be better able to empathize with them and be better able to help them. In healthcare, we only rarely see Roma nurses or doctors.

# 2 Roma access to health and long-term care in the Czech Republic

The questionnaire survey and interviews with respondents show that 56% of Roma rate their health as good. 16% of respondents rated their health as poor. Some respondents sometimes feel good and sometimes worse, 28% of respondents rated their health in this way.

Respondents stated that 4% suffer from diabetes. 10% have problems with the spine. 15% have varicose veins. 10% suffer from high blood pressure. Because the research sample was families with children, which are adults at a younger age, it is not yet possible to objectively assess the shortened life expectancy.

## 2.1 The impact of individual factors on the health of Roma

When asked whether respondents think that health care is important, 80% of respondents answered in the affirmative.

When asked whether respondents think that neglected health care can lead to a shortening of life, the vast majority of respondents answered in the affirmative.

When asked whether respondents rate their housing as defective, 54% of respondents said that they have mold in their apartment or if the housing is otherwise unhealthy.

When asked whether the respondents perform strenuous work or work in unsatisfactory conditions, 13% of respondents answered in the affirmative.

When asked whether respondents can afford to buy enough food - meat, vegetables, fruits, 80% of respondents answered that they can not buy enough of these foods.

When asked if the respondents did not have money for medicines, 76% of respondents answered in the affirmative.

When asked whether respondents are taking medication, most respondents are not taking medication because they do not see a doctor or do not have the money for medication. 21% of respondents answered that they take medication every day.

When asked whether respondents have a general practitioner, 63% of respondents answered in the affirmative. But most of the respondents had a big problem finding a doctor. They answered the question in the same way for family members.
Although the respondents have a larger degree of their general practitioner, the majority /65%/ do not go for preventive medical examinations.

## 2.2 Social determinants of Roma health

Poverty, lack of education, social exclusion, unemployment, inadequate housing and lifestyle and eating habits contribute to the social determinant of Roma health from the sample obtained.

Due to the financial shortage, respondents have to choose between buying basic food or buying medicines.

In terms of food quality, shortcomings can be found in the examined Roma sample. Respondents often have to adapt their diet to their financial possibilities and thus cannot provide regular food for themselves and their children. An irregular diet can be observed among Roma respondents. Respondents often use food humanitarian aid. In addition to poverty, it is also possible to observe low financial literacy, they live from day to day. When they receive social benefits from the state, they buy more food and buy many sweets for children. They do so, according to them, because they do not have the opportunity to improve the children for a whole month. Such eating habits will subsequently affect the health of Roma families.

The questionnaire survey also shows that respondents have a problem finding a general practitioner and pediatrician. Respondents also complain that pediatricians often reject families with more children.

It was found among selected respondents that respondents attend preventive examinations if they suffer from a chronic disease. If they are healthy, they usually do not use preventive examinations, there are no doctors. The statement further showed that most Roma do nothing for their health preventively and many do not even know what they could do for their health. They don't have enough information. They do not go for preventive check-ups because they do not remember the days of visits, most of them have more children and then it is very difficult for them to go to the doctor. In Ostrava, health care is available for everyone without distinction.

Direct quotations from some respondents:

*"…I had a referral to a doctor for a preoperative examination, but she refused me. I have to go to surgery and they need an examination, I don't know what to do…?" "… When the doctor found out I had more children, she told me that if I did, I should take care of them…" "…My doctor is biased against me…" "… Whenever I looked for a doctor and saw me, she immediately rejected me because I have a lot of children…" "… I don't think doctors like Roma. I have seven children and therefore no one wants to take me…" "… Before I found my doctor, they always told me that they were not taking Roma. I think they take us differently. But my diabetic takes me as a human…" "…Luckily, my children have their doctor. I don't, so I go to the emergency room…" "…The doctor is arrogant, he said he was full. But he will take the others. I can't do anything without money…"*

### 2.3 Coverage of Roma health insurance

When asked whether respondents currently have health insurance, 80% of respondents answered in the affirmative, 20% of respondents currently have no health insurance. Most, however, did not know which insurance companies they were registered with.

When asked whether the family members of the respondents currently have health insurance, the majority replied that as far as children are concerned, they have the same insurance as their parents and do not know about the others.

When asked whether the respondents had changed their health insurance company in the last year, most of them said yes.

When asked if the respondents know someone in their area who changed the health insurance company in the last year, over half of the respondents said that they thought so.

When asked why people change health insurance, most respondents said that it is financially advantageous for them at the moment.

The Roma in our country have the opportunity to be covered by insurance. The reason for uninsured respondents is their low level of education and low awareness of insurance conditions and change of insurance company. Most of the respondents stated that they are changing their insurance company because it is financially advantageous for them at the moment. For the change of the insurance company, the financial amount offered to the respondents is paid immediately in cash. This is welcomed by our respondents as a major contribution to the financial budget. Many are willing to change insurance companies several times a year without respecting the terms of the insurance. Eventually, when respondents visit the doctor, they find out that there is no insurance anywhere and the doctor refuses to treat them. In our country, policyholders can change the insurance company only once a year. In addition, not every doctor is contractually bound to all insurance companies in the Czech Republic.

The story of Mrs. N.

"*…Mrs. N. came to the pediatrician with her daughter. The doctor asked which insurance company the daughter was insured with. Mrs. N. mentioned the name of the insurance company with which she thought her daughter was insured. The doctor verified Mrs. N.'s statement and found it to be untrue. The doctor did not treat Mrs. N.'s daughter and told the respondent that she should come when she had her daughter's insurance in order. Mrs. N. subsequently admitted that she had changed the insurance company for all children several times. She immediately received 300 CZK /12 EUR/ from the new insurance company. The financial amount received helped her a lot, because it often happens that she does not have money even for basic foodstuffs…*"

### 2.4 Access to health/care services in Roma communities

When asked whether respondents have a family member in a long-term care facility, the majority of Roma answered that it is not common in the Roma community to place their relatives in a hospital for the long-term ill (hereafter referred as LDN) or in homes for the elderly.

When asked whether respondents have a dentist, 14% of respondents answered in the affirmative.

Most respondents, including children, do not have a dentist. They also answered the question of family members,

When asked if the respondents have a family doctor, the respondents did not understand the meaning of the term.

When asked whether respondents ever lacked funds to pay for a medicine, medical aid or dentist, 85% of respondents answered in the affirmative, 15% had no problem with reimbursement.

In our country, we do not have LDN facilities set aside for the Roma community, or homes for the elderly or nursing homes, or care services directly coming to families, is not only set aside for Roma. In our country, care in facilities or care for the long-term sick is provided to all inhabitants of the Czech Republic, regardless of ethnicity.

There are only non-profit organizations in which field nurses work, who come mainly to Roma families and provide various education and assistance. Most Roma take care of their sick family members who need long-term care at home. The research shows that there are enough health facilities and aftercare services in the Czech Republic, but interviews with the Roma have shown that they believe that they are not very welcome as patients. In homes for the elderly - which is a facility for the elderly, Roma are also not usually accommodated because they remain in the care of family members. Family ties are very important for the Roma, it is not always common for seniors to live out their lives in homes for the elderly, unlike the majority.

Prefab houses began to be built in the Czech Republic in the 1950s, when families with children moved into prefab apartments. The apartments were mostly two or three rooms, there was no "place" for old people. The cult of youth was practiced. People still live in the apartments today. Seniors of the majority group go to the elderly homes because they often leave their apartments to their children or grandchildren. This is not the case with the Roma. They mostly don't own any flats, they live in sub-letting. Moreover, they are used to living in a large community in small spaces. The costs in healthcare facilities and social services are high, but depending on the type of self-sufficiency, all people are entitled to care allowance /see below/ and can pay for the service. According to the statements of the respondents, it also turned out that there are only "gadjas" in the homes and they prefer to be among their own.

Another important factor is that the Roma live to a lower age than the majority people. It is due to lifestyle, habits and other factors. Roma live an average of 18 years less than the majority. Minority men live an average of 57 years and women 65 years /sasteroma.com/o-projektu/. Majority men live an average of 76.1 years and women 81.9 years /czso.cz/csu/czso/umrtnost-tabulky-za-cr-regiony-soudrznosti-a-kraje-2020 a 2021/.

Dental care is a very expensive affair in the Czech Republic. Especially for groups of people living on benefits and thus also for the Roma community. There is a great shortage of dentists and the majority group is also experiencing difficulties. The problem of finding your dentist is not only the majority but also the minority and concerns both adults and children. It is quite visible that many Roma with whom we normally work have decayed teeth. Even children at an early age have decayed deciduous teeth. Romani children do not even observe basic dental care because they are not guided to do so by their parents. Many mothers think that they do not have to take care of their baby teeth because the children's teeth fall out and new ones grow. This is a myth common not only among the Roma.

The same is true for close family members. If their teeth are in disarray, Roma use emergency services, partly because they do not have their own dentist and partly because they pay CZK 90 /approx. 3.6 Euro/ in the emergency room, which is many times lower than what they would pay for dentist. A seal costs about CZK 3,000 /EUR 121/, they would pay even more for a dental prosthesis. Equally, many prescription drugs have to be paid for by families. They lack the money for this. Often then the Roma literally MUST choose between drugs, or food, or diapers, sunar, etc.

In the Czech Republic, a family doctor is not usual, we use our general practitioners or directly specialists in a certain field. Adults use a general practitioner for adults and pediatrician for children and, in the case of specific diseases, visit various specialists on the recommendation of their general practitioner or pediatrician.

The Roma do not use the services of health mediators or more or less do not know about their activities. This profession is not subconscious even for the majority. If a person is ill for a long time, the state provides financial support, the so-called care allowance, which is graded according to the type and amount of disability. In our experience and from interviews with Roma, families apply for care allowances so that they can care for their loved ones at home. In our country, mediators are known as medical assistants. These are outreach workers who are educated in the field of healthcare. These go to localities and accompany people from the community to doctors, look for doctors, advise people in the community. Their work is very beneficial and effective.

The role of so-called mediators should be to: provide people with preventive examinations, monitor vaccinations, accompany people to doctors, specialists, and dentists, emotionally support them, explain things to them or refer them to other services or experts. The mediator should be in the locality to gain people's trust. It would certainly be advisable to have a mediator in the locality to deal with children and another with adults.

The problem is that in our country, if we want a health assistant or a mediator to be in the localities, this activity is carried out by non-profit organizations if there is a call for this position. Projects are for one year and a maximum of three years. It would be more appropriate for the mediator to be an employee of one of the healthcare facilities and financed by the Ministry of Health, or to be an employee of the given municipality. Only in this way can stability be ensured and the position of the mediator strengthened.

Mediator is one of the very important positions in localities where Roma live. The Roma live their specific way of life, they often do not know how to eat healthily, they do not know that various types of vaccinations are mandatory in our country, they do not know or are afraid to seek a doctor, etc. An important fact is also that there is a greater incidence of infectious diseases in localities and the mediator can to be an intermediary between local residents, a health professional or hygiene service. What's more, the localities lack the necessary education and prevention. It is often possible to prevent various diseases through prevention. Ex. During the peak of Covid-19, non-profit organizations visited the sites and replaced the work of health assistants.

Amount of care allowance /valid from 1st of January 2022/

Under 18 years
Degree of dependence Amount of contribution
I. (slight dependence) 3300 CZK
II. (moderate addiction) 6600 CZK
III. (severe addiction) CZK 13,900
IV. (complete dependence) CZK 19,200

Older than 18 years
Degree of dependence Amount of contribution
I. (slight dependence) 880 CZK
II. (medium addiction) 4400 CZK
III. (severe addiction) CZK 12,800
IV. (complete dependence) CZK 19,200

The research shows that Roma people face problems in accessing health care and paying for medicines. They are often unable to obtain the medicines prescribed by the doctor at all or in limited quantities because they do not have the funds for the medicines. They often have to choose between buying food before buying medicine. If a patient visits a doctor, the doctor gives the patient a prescription for medication. Although the drugs are prescriptions, most of them are co-paid by the patient, some drugs are fully covered. medicines are written on a prescription, usually families pay extra for the medicines. We suggest that families ask their doctor to prescribe drugs from the same group, which may be free of co-pays. This is fully within the competence of the doctor himself, because it is not always the preparations that are effective for the given specific disease. Many medicines, syrups, drops are sold over the counter on the market and people have to buy them themselves.

Many mothers are unable to breastfeed their newborns, they are prescribed Nutrilon, which costs approx. 480 CZK / approx. 19.4 euros/. There are many reasons why mothers do not breastfeed their children. For one thing, mothers don't produce or lose milk because they immediately leave the hospital after giving birth, leave their baby in the hospital, and then come back for him a few days later. They do this for their children and their husband. Another reason is health problems.

We have noticed that it is becoming a trend that young Romani women do not breastfeed their children and prefer artificial nutrition without any valid reason. In the past, it was the other way around. On the contrary, mothers from the majority currently breastfeed their children for longer and longer.

Because many Roma families don't have medicine, they don't get treatment, they don't visit their doctor or dentist regularly, there are many reasons. *The mom has 6 more kids, she has to take them to school or one of the kids gets sick, the kids don't have proper clothes, the mom is ashamed, they don't have phones to apologize to the doctor… if she goes to the doctor, she goes with her kids…..* . then some doctors perceive Roma patients as not taking enough care of their health and not heeding the doctor's instructions. Roma families are then removed from the doctors' records after a certain period of time. Doctors are not trained, they don't take into account the specifics of the Roma ethnicity, so especially Roma mothers with children can look like "naughty patients" who don't care about their health.

The story of Mrs M.

*"…Mrs. M's son was born in the sixth month of pregnancy, he still had several intestinal inflammations in the maternity hospital and became an ostomy patient. The boy could receive nutrition only by probe and needed special nutrition. This special dairy nutrition was very expensive, CZK 24,000 per month. All maintenance costs were covered by the health insurance company. Mrs. M received instructions from a gastronomy doctor on how to dose the food to the child and also received milk for a whole month. The problem was that Mrs. M required a specific approach. She had difficulty counting hours and dosing special nutrition. She was also afraid that the son would be hungry, so she preferred to feed him more. Mrs. M, but after three weeks, she ran out of a monthly dose of milk, so she went to the children's gastronomy department to ask the doctor for more nutrition for her son. The doctor shouted at Mrs. M, insulted her, told her that she was a stupid Roma woman and did not care what her son would eat. Mrs. M's son had not eaten since yesterday, and the respondent still asked the doctor for milk for her son. After about three hours of futile pleas, Ms. M went to another children's ward for help. The doctor from the*

*children's ICU came and arranged for the doctor from the gastronomy. After further insults, Mrs. M finally wrote nutrition for her sons. Mrs. M has two older children at home and is still struggling to finance medical supplies for her son…"*

### 2.5 Roma with disabilities

When asked whether respondents have someone with a physical or mental disability in their family, 33% of respondents answered in the affirmative.
67% of respondents answered that they do not have such an experience, they do not know what it means.

When asked whether respondents think that Roma have access to a disability pension and long-term care, 76% of respondents answered in the affirmative.
24% of respondents think that this is not the case.

When asked whether respondents think that people with disabilities should live in facilities designed for this purpose, most Roma were in a negative opinion.

We managed to obtain information from the research sample that most of the respondents take care of their handicapped themselves. More than half of respondents believe that Roma have access to disability pensions and long-term care. Most respondents also think that people with disabilities should live in a home environment. For several years now, the government of the Czech Republic has been abandoning the institutionalization approach and striving for social and health rehabilitation of the handicapped. The mission of social and health rehabilitation is to help patients learn to live permanently with their health limitations and to overcome some adverse effects of limitations in practical life, thus reducing the risk of social exclusion. The target group is people with reduced self-sufficiency due to disability. Research and interviews show that most Roma from excluded localities have no information about this service.

The invalidity pension replaces the income if the state of health does not allow him to continue to do work and other gainful activities.

Disability pension is one of the four types of pensions in the Czech pension system (in addition to old-age, widow's, widower's and orphan's pensions). Depending on the degree of invalidity found, the invalidity pension is now divided into a first, second and third degree invalidity pension. The difference between the individual degrees of disability lies in the rate of decrease in the citizen's working capacity (a decrease of 35% to 49% means first degree disability, 50% to 69% second degree disability and 70% or more third degree disability). The conditions for entitlement to a disability pension are set out in the Pension Insurance Act (Act No. 155/1995 Coll., The Pension Insurance Act).

### 2.6 Sexual and reproductive health of Roma and their rights in this area

When asked whether planned parenthood makes sense, most did not comment on this.

When asked if contraception can help many families, most did not want to talk about contraception, they have no experience with it, they do not know how to answer it. Most think so.

When asked whether contraception is affordable for the Roma, most did not know how much it cost and what the options are. They know one option that was free in the past.

When asked whether respondents have a family or know someone who had to undergo forced sterilization, 30% of respondents answered in the affirmative and 70% of respondents do not know anyone like that.

Roma attitude to sexual issues is greatly influenced by their culture, mentality and way of life. Families do not talk about sex education and contraception is taboo for them. From their point of view, a woman should have children so that a man can respect her. Roma mothers are often viewed negatively in the maternity hospital because the mothers give birth to a child and leave the hospital immediately. The reason they do so is that they have to take care of other children at home and they are worried that their husband or partner will leave to see another woman. Roma mothers then return to the maternity hospital for the child. If the medical staff knew the mentality of Roma women, they would have a better understanding of them and would look at them with a different approach. Roma mothers would appreciate if Roma workers were also in hospitals.

It is interesting that working Roma have fewer children and are more informed about the possibilities of contraception and sex education, they can talk about it and they are more positive about the issue of contraception.

Forced sterilization was a practice that affected the Roma community under the previous regime. From 2004, women affected by involuntary sterilization began to meet and set basic points to prevent further involuntary sterilization and demand compensation. Two women were compensated by a hospital that performed involuntary sterilization. Through demonstrations, women drew attention to the importance of changes in legislation and pointed out discrimination in the maternity hospital. The Government of the Czech Republic has approved compensation for involuntary sterilization. Currently, 200 women in the Moravian-Silesian Region are applying for financial compensation.

The story of Mrs. S.

*"…Mrs. S is in a different condition, but she is looking in vain for her gynecologist. Mrs. S has already bypassed several surgeries, but they reject her everywhere. Mrs. S has valid insurance in the Czech Republic, but she is a Slovak citizen, the doctor recommended that she go to Slovakia to see a doctor. After such an experience, Ms. S lost the courage to continue her search for a doctor. Mrs. S asked for help from a non-profit organization and subsequently managed to find a gynecologist. At the examination, the doctor found out that Mrs. S was already in the seventh month of pregnancy. Mrs. S confided to us that even in her previous pregnancy she had not been able to find a doctor, so the first gynecologist who examined her was a doctor in a maternity hospital…"*

The story of Mrs. E.

*"…Mrs. E. was sterilized without her own knowledge at the age of 21, after the birth of her second son. The procedure was performed by caesarean section during childbirth. Although both her husband and I wished for a large family and especially a little girl, she was left at such a young age without the possibility of getting pregnant again…"*

Since 1972, a birth control policy has been introduced in Czechoslovakia to enable public authorities to support the sterilization of Roma women and women with disabilities placed in institutions. Women were often sterilized, without giving their informed consent, during obstetric and gynecological services provided for other purposes (childbirth, abortion), or were forced to consent. Some women have been misled by medical staff that sterilization is only temporary. Other women were told that if they did not choose to sterilize, they could die during the next birth.

Forced sterilization also had serious consequences for the personal lives of those affected. The sterilized women suffered from psychological problems as well as a lack of acceptance and understanding on the part of the community and the partners who blamed them for the sterilization, because they did not believe that they were forced to do so by institutional pressure, manipulation or concealment of essential information. This led to multiple victimization of Roma women. The official policy on birth control came to an end in 1991, but cases of involuntary interventions were recorded long after that date.

In 2015, the then Minister for Human Rights, Equal Opportunities and Legislation submitted to the Government the substantive intent of the Act on Compensation to Victims of Illegal Sterilization, on which, however, the government expressed a negative opinion and the draft substantive intent of the Act was withdrawn from further legislative process. Since 2015, efforts have continued to introduce tools to compensate illegally sterilized women, especially at the non-governmental level, and the Czech Republic has long been criticized by international institutions such as the Council of Europe for the absence of fair compensation tools.

In 2019, the topic of compensation was first opened on the premises of the Chamber of Deputies, within the Standing Commission on the Family, Equal Opportunities and National Minorities. This created the substantive intent of the Act on Compensation for Illegally Sterilized Women. The plan included a proposal to provide a lump sum to persons sterilized in violation of the law by which illegal sterilization was performed in the period from 1st of July 1966 to 31st of March 2012 in a medical facility in the territory that is part of the Czech Republic. (The bill was submitted to the Chamber of Deputies on 27th of September 2019 and approved on 4th of June 2021; the Senate discussed and approved the bill at its meeting on 21st of July 2021; after the President's signature, it was published in the Collection of Laws and will enter into force on 1st of January 2022) .

### 2.7 Roma and Covid-19

When asked whether the Covid-19 pandemic had a health impact on respondents and their families, 35% of respondents answered in the affirmative. According to their answers, 65% of respondents were not affected by the pandemic.

When asked whether respondents died during the Covid-19 pandemic, they did not want to comment on this question. About 4% said someone close to them had died, but they didn't know if it was related to Covid-19.

When asked whether respondents have a positive attitude towards vaccination against Covid-19, 8% of respondents answered yes and 92% of respondents have a negative attitude towards vaccination.

The government of the Czech Republic very often changed government measures and many Roma did not understand the measures. Therefore, our Mutual Coexistence organization provided enlightenment by explaining the term Covid-19, passing on information about new measures. We provided drapes, protective and disinfectants for SEL.

Most Roma initially had a negative attitude. They were greatly influenced by misinformation from the media, Facebook. Often they did not have enough information or did not understand them. For this reason, our organization educated the SEL by distributing leaflets about preventive measures and vaccinations that we created. We provided a doctor who answered their questions about vaccination and COVID-19.

Subsequently, we provided vaccinations directly in the SEL, because some Roma did not know where they could come for vaccinations, and it was also a problem for mothers with more children to get vaccinated. However, they used this option only minimally.

The story of Mrs. A.

*"…During the Covid-19 pandemic, the son of Mrs. A became seriously ill. The respondent was a vaccine opponent due to misinformation on social networks. The problem occurred when the respondent wanted to visit her son in the hospital. On each visit to the hospital, she required a negative test for Covid-19. And Mrs. A. had to pay for it from her already limited budget. The respondent first visited her son every day, but eventually had to limit the visits because she could no longer fund the Covid-19 tests. The respondent had remorse for her son and her bad feeling was further exacerbated by the hospital staff, who showed her that she was a bad mother and that she explained her son a little to his lack of interest in the child…"*

### 2.8 Elderly Roma and their health needs

When asked whether respondents think that older Roma are well taken care of in the field of health and long-term care in our country, most of them said that they took care of their relatives at home.

As mentioned above, Roma take care of their older relatives. Older Roma are rare in retirement and LDN homes.

People in our republic, regardless of ethnicity, have an income depending on the job in which they work or if they are registered at the labor office, they are guaranteed benefits by the state /for living, housing.../. In order for a senior citizen to be entitled to a pension, he must complete the period of social insurance for 35 years and the pension is calculated according to the years of service and the amount of earnings. The calculation is very complicated. Pensions in our republic are very below average considering the level of inflation, high costs and expenses. The average old-age pension amounts to CZK 16,300 /664 Euros as of September 13, 2022/. If people do not have enough funds to provide medical care, then depending on the amount of the pension, they can receive material hardship benefits, or if they are sick, they can receive care allowances. This is completely individual and each case is assessed and evaluated separately.

According to our findings, the communities are mostly inhabited by young families with children and the middle generation. Seniors live in communities as well, but not in such numbers. However, we do not have any studies for this finding, but we assume that Roma people do not live as long as the majority people.

### 2.9 Mental health of Roma

In the research, respondents were unable to describe their mental state. Mental health is affected by their difficult situation in which they find themselves, eg: inadequate housing, lack of funds to cover basic needs, unemployment. The Roma family is trying to solve the problems on their own. But families are very frustrated, which depends on their psyche and especially this has a negative effect on children, parents are irritable, irritable. They vent their helplessness on children but also on us workers and their surroundings.

There is a shortage of psychiatrists and psychologists in the Czech Republic. If the Roma decide to deal with their mental health with an expert, the ordering time is several months, which makes their problems and frustrations worse. In our organization, we mainly have experience in finding psychologists or psychiatrists for children. The waiting time is up to several months, from our experience up to about 10 months, or if we manage to arrange a psychiatrist, then outside our region. This deficiency is felt not only by the minority but also by the majority.

In the Czech Republic, there are private psychologists who have shorter order dates, but the price for one consultation ranges from 500 CZK /20.2 Euros/ up. The Roma, who are in a difficult financial situation, cannot afford it.

### 2.10 Discrimination and anti-Gypsyism

Most Roma have bad experiences, they feel discriminated against especially in the area of housing and employment /*"… I am Roma, they do not take me to work…", "…. they do not move me to the gadjas…".*/ leads to mistrust for the outside world and institutions. The effect of the specific environment of SEL on their inhabitants leads to the fact that they are no longer able or do not have enough strength and motivation to change their current situation. Negative patterns of behavior of the population themselves then lead to tensions between the majority and the minority. The media, social networks and the designation of free zones contribute no less to this. The Strategy for Equal Inclusion and Roma Participation 2021 - 2030 uses the term anti-Gypsyism. Interviews with respondents showed that they face discrimination, but because they do not always report this to the appropriate institutions and authorities, data and statistics on discrimination are not as accurate. /see stories above/

We cannot fully claim that anti-gypsyism is present in the healthcare sector. In our study, we describe the statements of the respondents. We have no possibility of comparison. Perhaps in the future it would be appropriate to ask both sides how they view certain things. This is only a one-sided view.

In our opinion, it is a misunderstanding on both sides. As we mentioned above, doctors do not know the specifics of the Roma ethnic group, so they do not understand them, they cannot empathize with their situation or role. On the contrary, Roma people perceive "gadjas" as people who are superior to them, exalt themselves over them, then fear them, are ashamed of them, and above all, there is no mutual trust between them. Often both sides are based on prejudices and common stereotypes.

## 3 Conclusion and recommendations

### 3.1 Findings and reasons for accelerating the improvement of Roma health care

The research and especially the interviews showed us that it is necessary to increase the health education of Roma, inform them more, talk to them about health prevention not only for themselves but also their children, emphasize the importance of healthy nutrition, lifestyle changes, but this can be achieved only if families live in adequate conditions and are financially secure.

Most of the Roma we work with have very low competencies, so the information needs to be adapted to their needs. Only in this way can access to the Roma be improved, not only in the health field.

It is important to support non-profit organizations staffed by field nurses, who come mainly to Roma families and provide various education and assistance.

Roma mothers would greatly appreciate Roma workers in hospitals.

The mental health of the Roma needs to be monitored and the necessary professional assistance provided in a timely manner.

It is also necessary to support pediatricians who are in the care of families with more children.

The Roma face problems mainly in accessing health care. Families have multiple children, often a pediatrician cannot accept them for the reason of full capacity. Then the children in one family have several pediatricians outside their region where they live.

As mentioned above, parents have low competencies and children are often excluded from the doctor's register because parents with children do not attend preventive check-ups, there are no vaccinations, etc. Mothers do not remember the exact data. If they have more children on the day they are to see a doctor, some of the children are ill because they do not have a phone, they cannot even apologize and are then excluded. It also happens that the mother visits a doctor with 5 to 10 children. The children are then alive in the surgery and the doctor then feels that he has a difficult job and shows it to his mother. Then the mother will not come to the same doctor several times after such a negative experience. Today, it is up to each person to take care of these things himself. (In the past, schools were visited by dentists, vaccinations were often provided directly in schools, and children were invited for preventive check-ups).

The Roma are struggling with paying for medicines, buying baby food, especially Nutrilon. Doctors often prescribe medications that families have to pay for. Families do not know that they can request drugs from the same drug group without co-pay, but this is not always possible. /See above/. Some medicines have to be bought without a prescription. Many mothers only trust certain medicines that they have already tried and then ask the doctor for them themselves.

### 3.2 Attitude towards the National Strategic Framework for Roma

The purpose of the Roma Integration Strategy 2021 - 2030 is to create a framework for measures that develop the positive changes that have been achieved in some areas of Roma integration and for measures that will lead to the reversal of negative trends where negative trends persist or deepen. The aim is to eliminate all unjustified and unacceptable differences between the situation of a large proportion of Roma and the majority population, to ensure effective protection of Roma from discrimination and anti-Gypsyism, and to encourage Roma emancipation, Roma culture, language and Roma participation. The main goals of the Strategy thus closely follow the goals of the Roma Integration Strategy until 2020 and reflect the fact that these goals have not been achieved in a number of areas.

Based on the identified problems, the following strategic goals were set:
- Support and development of civic, socio-economic, political and cultural emancipation of the Roma national minority, ie. Promoting equality, inclusion and participation
- Reduce the level of anti-Gypsyism
- Increase the level of achieved education of Roma
- Ensure equal access for Roma to quality housing
- Ensure equal access to employment for Roma
- Ensure equal access of Roma to quality health care and social services. We specify equal access to health care in more detail.

• Ensure further development, personnel stabilization and systemic anchoring of funding of Regional Health Support Centers and activities of health support mediators.

- Their activity is comprehensive health support for people at risk of poverty, including Roma. At the community level, they integrate socially disadvantaged Roma by facilitating registration with primary care doctors, help to find specialists and increase people's competence in health literacy. The goal is sustainable behavior change in favor of a healthy lifestyle.

• Introduction of the compulsory subject "culturally sensitive health care" following the example of foreign university educational models (e.g. the Netherlands, Austria, Germany, UK) for students of medical faculties.

- It follows from practice and strategic documents that socially disadvantaged Roma often feel humiliated or otherwise discriminated against by the behavior of health professionals, and as a result, health institutions do not enjoy their trust. This problem arises, among other things, as a result of the fact that male and female medical students in the Czech Republic do not have any compulsory education in intercultural and intersocial communication. Education must also be introduced for already working doctors who have completed their studies.

• Support for activities focused on education and prevention in the field of health (e.g. planned parenthood, healthy lifestyle, preventive examinations and screenings, prevention of drug use and addictive behavior, etc.)

- We know from practice and experience that the Roma often do not have sufficient awareness of topics related to a healthy lifestyle, preventive examinations, childcare, planned parenthood, harmfulness of drugs, etc. Based on this experience, it is necessary to support the implementation of educational activities also within the activities of NGOs and school facilities, within the framework of subsidy programs intended to support the integration of the Roma minority.

• Creation of a multidisciplinary team at the level of each region for a comprehensive solution to health and related problems.

- The connection of social and health care in one multidisciplinary team, whose work is focused on supporting the client in his path to disease prevention and a beneficial life, increases efficiency in solving serious health issues and related problems. The goal of the measure is to create a multidisciplinary team that spends at least half of its time in the natural environment of people from the target group.

• Create conditions for detecting and punishing discrimination on the grounds of nationality, ethnicity, social status, place of residence, age, etc. in access to health care.

- In the Czech Republic, at the moment, there is no quantification of the "optimal" number of doctors per given number of inhabitants according to individual territorial units and fields of health care, as well as a legal regulation or regulation that would treat this issue. The last publicly available material containing indicative capacity numbers is from 1996. For example, when traveling to see a doctor, people find themselves dependent on public transport, which does not cover the territory evenly in space or time, or are rejected by doctors because of the excess of patients assigned to one doctor or even rejection for other reasons, some of which are considered discriminatory, and whose provenance is problematic.

The cross-cutting strategic goal is: To ensure capacities and resources for the implementation of the Strategy. The strategy thus sets strategic goals in the areas of Emancipation, Anti-Gypsyism, Education, Housing, Employment and Health.

The strategic goals in the National Strategic Framework for Roma in the Czech Republic are based on the needs of the Roma.

### 3.3 Recommendations

In the Czech Republic, care is available by law for everyone without distinction. In practice, however, we encounter problems that should be addressed as soon as possible.

The recommendations are:

- Establishment of the position of Roma medical assistant in hospitals, especially in maternity hospitals and directly in families.
- The establishment of a Roma health assistant, a so-called mediator, who would come directly from the community, would be financed by the Ministry of Health or municipalities, would be an employee of the state administration or local government, not a worker of a non-profit organization.
- If the aforementioned function should be performed by an employee of a non-profit organization, the project should be 3 to 5 years long. Long-term, not one-year.
- Focus on education and prevention in the field of health care - healthy lifestyle, healthy nutrition, sex education, contraception, directly in Roma families - use terminology that they understand.
- Write materials in the Czech and Romani languages, create materials in the form of pictograms, which would be intended for people who cannot read and write.
- Materials to create in the form of a picture storybook, comics, leporelos...
- Introduce teaching about Roma culture at primary, secondary and higher education institutions, mainly where is the field of health care, nursing, social work, etc.
- Specify training and internships for medical staff and doctors on Roma issues - especially focusing on communication and differences of the target group.
- Make psychological help available to the socially weak, not only Roma.
- Involve Roma in health care facilities, social services not only in institutions, but also in organizations.
- Involve Roma in schools - teachers or counselors, assistants.
- In the media and social networks present more positive patterns from the Roma.
- Finally, solve the issue of socially affordable housing - suitable and affordable housing will solve many other problems /mental health, easier to find work, hygiene, space for children's learning…/.
- Alleviate the criteria for the availability of housing/high security, rent in advance, if a person is burdened with debts from the past for rent or services, or is burdened with foreclosure, usually does not reach the apartment.
- Introduce a clear card /booklet/ one intended for both children and adults, where preventive examinations /general practitioner, ophthalmologist, dentist.../, mandatory vaccinations would be recorded. The card should record when the patient visited and the next visit. Nowadays, every patient has a lot of cards, then it is very easy to mix them up, mix up the data, lose them and so on.

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# 5 List of abbreviations

ČR – Czech Republic

LDN – Hospital for long term sickness

NNO – Non-governmental non-profit organization

SEL – Socially excluded locality

Exchange rate 1 Euro - 24.74 CZK as of June 30, 2022