"Roma access to quality, inclusive and affordable health and long-term care in Bulgaria"

Case study, 2022

Introduction

Integro Association is a civic organization led by representatives of the Roma community in Bulgaria. It is composed of 10 local Roma civil society organizations from different parts of the country, united by their common cause to achieve an equal and respected position of the Roma community among the other members of Bulgarian society. Integro strives to make visible the problems and needs of the Roma from the remote settlements of Bulgaria. The organization's activities are aimed at community mobilization, creating an active Roma leadership capable of challenging the passivity of both Roma and public authorities, so that they can share the responsibility for overcoming inequality, social exclusion and poverty among Roma, and for achieving cohesion and prosperity at the local level and in society as a whole. The Association's guiding principles are the enforcement of human rights, democratic procedures, transparency, partnership and trust in the community and society.

Methods and tools used for the research

For the purpose of this research we conducted a documentary review and analysis, as well as 13 in-depth interviews with representatives of Roma communities from the following settlements. We conducted interviews with Roma communities in the town of Seslav, Kubrat municipality; the town of Senovo, Vetovo municipality; the town of Novi Pazar; the town of Botevgrad and the Nadezhda district in the town of Sliven. The interviewees were representatives of different groups of the Roma community: three (3) people with disabilities; one (1) mother of a child; three (3) pensioners; one (1) social welfare recipient, two (2) unemployed, uninsured persons and three (3) health mediators. In addition, the interviewees were from different types of locality - a small village, a small town, a medium-sized town, a regional town and a large tract with a large, segregated Roma neighbourhood.

Brief overview of the socio-economic situation of the Roma in Bulgaria

Despite more than 20 years of policy for Roma integration and social inclusion in Bulgaria, the socio-economic situation of the majority of Roma in the country is still dramatic. The lives of many Roma continue to be marked by extreme poverty, unemployment, low or poor quality education, inadequate housing, poor health and welfare.

The relative share of Roma at risk of poverty in 2020, according to the NSI, BG-SILC, is 66.2% and of Roma children under 18 years of age is 73.3%. The same data show that 64% of Roma children aged 0-15 live in material deprivation, 43.5% of Roma live in poor housing conditions, 76.9% live in overcrowded housing, 34.7% live in housing without a toilet and bathroom inside the home[1].

[1] Data taken from the National Strategy of the Republic of Bulgaria for Equality, Inclusion and Participation of Roma (2021-2030): https://ec.europa.eu/info/sites/default/files/national_strategy-_english_google.docx.pdf

Against the backdrop of the low level of overall unemployment (about 5%) and the demand for labour from private companies and firms in the country, the employment rate among Roma remains the lowest - only 47.2%. The main obstacles to Roma employment are low education and lack of adequate qualifications; insufficient, inadequate employability services and difficult access to them, if available; Roma involvement in the informal, informal economy, work without contracts and insurance payments; high levels of prejudice against Roma by employers and employees in the Labour Offices and discrimination in the labour market.

The low level of education of the Roma community is determined by the low proportion of Roma children attending kindergarten (27.7% of Roma children aged 0-4 years attend kindergarten or nursery); dropping out of school (86.2% of Roma children aged 7-15 years are enrolled in school and 13.8% do not study); early leaving the education system (68. 0% of Roma aged 20-24 have left education and training early and only 28% have completed at least secondary education); educational segregation, which is a major factor limiting access to quality education (63.5% of Roma children aged 6-15 attend schools where all or most of their classmates are Roma)[2].

Access to health care for many Roma of working age (18-64) is difficult due to the high proportion of Roma population with unpaid health insurance contributions, which excludes them from receiving medical care and preventive health activities from general practitioners and specialist doctors in the hospital and outpatient system. Children up to the age of 18 and people of retirement age, as well as people receiving monthly social benefits, are insured for health by the State. Even with health insurance, however, many Roma lack access to qualified medical care due to a lack of doctors and nurses in remote settlements and large urban Roma neighbourhoods. Access to emergency medical care for Roma is often compromised due to poor road infrastructure in Roma neighbourhoods, which makes it difficult for ambulances to access, and due to poor communication between Roma and staff in emergency medical centres, which is due, on the one hand, to a lack of cultural sensitivity to Roma on the part of medical staff, and on the other hand, to a lack of awareness among Roma about the range of medical conditions covered by emergency medical care in Bulgaria(The range of medical conditions covered by emergency medical care in Bulgaria is very limited and usually concerns conditions seriously threatening a person's health and life).

Aims of the case study

With this case study we aim to shed light on the situation of Roma in Bulgaria in terms of access to health care and long-term care, revealing the different barriers (systemic, circumstantial, personal) that hinder this access. The report will contribute to the definition of concrete recommendations to improve Roma access to quality, inclusive and affordable health and long-term care, as well as raise awareness of relevant stakeholders in the implementation of Roma equality, inclusion and participation policies at national and European level.

[2] The data are from a Thematic Report on the situation of Roma, carried out in the framework of the "New approaches for data collection on hard-to-reach population groups at risk of violation of their rights", https://www.noveleea.bg/wp-content/uploads/2022/04/Thematic_report_Roma_BG_22-04-26.pdf

Roma access to health and long-term care in Bulgaria

A number of studies, including those of the foundations "Minority Health Problems" - Sofia and "Roma Health" - Sliven, clearly show that the health status of the Roma in Bulgaria is severely deteriorated. These studies found that socially significant diseases such as diseases of the cardiovascular system, neoplasms, chronic lung diseases, infectious diseases, and some hereditary diseases are particularly prevalent among the community. According to these studies, in some neighbourhoods more than 10% of Roma suffer from arterial hypertension, 6% have ischemic heart disease, 2% have suffered a stroke, 8% have pulmonary diseases - bronchitis, bronchopneumonia, COPD, 7.4% suffer from diseases of the musculoskeletal system - discopathies and disc herniations affecting different stages of the spine. Among children, upper respiratory tract catarrhs, bronchitis, broncho-pneumonias, intestinal infections, helminthiasis, hypovitaminosis and hypotrophies are the most common diseases among infants and young children. In some neighbourhoods, hereditary diseases-epilepsy, muscular dystrophy-gamma-sarcoglycanopathy, or other malformations and abnormalities often neglected and untreated-are found among children.

The comparative analysis of community surveys conducted in the period 2017-2021 in 30 Roma neighbourhoods included in the ROMACT program show that more than 10% of Roma in these neighbourhoods suffer from some chronic disease and 1-3% of Roma have an expert decision issued by the Territorial Expert Medical Committees (TELK), which certify persons for permanent incapacity/type and degree of disability.

According to Eurostat 2018, life expectancy at birth in the EU is 78.2 years for men and 83.7 for women. For the Roma population, these projections are 10 years lower[3].

- ✓ **Impact of social determinants**

The health of Roma from marginalised and extremely poor neighbourhoods is particularly bad. Poverty prevents people from seeing a doctor or, if they do manage to see one, from buying the prescribed treatment due to the high cost of medicines:

"When I get sick, I can't go to the doctor, I have no money for the doctor, no money for gas to get to the doctor, no money for pills" (unemployed man, 63, Seslav).

In these poorest neighbourhoods, people live in extremely poor housing conditions, often without access to clean drinking water, without sanitation and street infrastructure, and stray dogs and cats roam the streets without the necessary immunizations and regular deworming. There is no regular garbage collection in Roma neighbourhoods and unauthorised dumpsites are a common sight, with children and adults digging in them. All this contributes to the frequent outbreaks of various infectious disease epidemics in these neighbourhoods - hepatitis A, dysentery, echinococcosis, etc.

[3] National Strategy of the Republic of Bulgaria for Roma Equality, Inclusion and Participation 2021-2030 https://nccedi.government.bg/bg/node/448

"Many people in the neighbourhood live in dilapidated homes, their roofs leak, there is mould on the walls. There are about 200 people living in one room - 8-9 people per 10-12 square meters. There is no plumbing because it is an illegal neighbourhood. People bring water with tubes and cans from wherever they can. I think people have not bathed there since they were born" (Sliven).

The majority of Roma eat an unhealthy, uniform diet. According to the interviewed health mediators from Botevgrad, in poor families the main food is bread, potatoes, beans, oil. Fresh meat, milk, fish and vegetables are rarely consumed. When they can afford it, families prefer to buy cheap sausages, frankfurters, minced meat. When possible, children are bought lots of snacks and confectionery such as waffles, chocolate desserts, etc. Many families struggle to provide adequate food for young children. Most often, if the mother is not breastfeeding and the family does not have funds for formula milk, the baby is given yogurt with sugar or boza. In the course of the restrictions imposed due to the 2020 Covid-19 pandemic, thousands of Roma families from the poorest neighbourhoods have been plunged into a humanitarian crisis. The Integro Association contacted the Minister of Labour and Social Policy and, through the Integro Association, the Social Assistance Agency (SAA) was involved. Together with several civil society organisations, over the course of a month, more than 12 000 people in need of food were identified from Roma neighbourhoods who, for one reason or another, were not registered with the social services and were not receiving social assistance and food parcels provided under the European Food and Basic Material Assistance Programme (FEAD). After identifying them, the ASP distributed food parcels under FEAD, but the food was not suitable for babies and young children. We then witnessed how dozens of Roma babies were fed a meal of bread and bean soup or water with starch dissolved in it.

Often Roma carry out hard physical labour from an early age. This affects their health, most often by damaging their musculoskeletal system early on. According to the mediators, many Roma at a young age suffer from various discopathies, disc herniations, arthroses of various joints, which often lead to their early disability.

- ✓ **Health insurance coverage of the Roma**

According to the State of health in the EU, Health profile of the country for 2021[4]. 1 million Bulgarians do not have health insurance. The same report identifies the main groups of the Bulgarian population who are uninsured: those living abroad; the long-term unemployed; people who have chosen not to make social health insurance payments and citizens without a valid ID card, which is a mandatory condition for social health insurance. The report goes on to say that the latter problem particularly affects the Roma population and illegal immigrants. According to data presented in a report by a coalition of civil society organisations, "Collection and analysis of additional information on persons without identity documents in Bulgaria. Analysis for the purpose of the advocacy campaign "The Invisible We See" from April 2021, about 244 000 people in Bulgaria are without ID cards, at least half of them unable to obtain an ID card due to problems with address registration due to legal restrictions. This concerns mainly Roma.

[4] State of health in the EU: https://www.oecd-ilibrary.org/docserver/df3f45dd-bg.pdf?expires=1661593753&id=id&accname=guest&checksum=7EBC4D11E51C696E560FA37A98DF1409

From 1 April 2022, people who pay their own compulsory health insurance contributions (e.g. long-term unemployed, who do not receive unemployment benefits and are not insured by the state, etc.) and are not registered as self-employed within the meaning of the Social Security Code, owe 28.40 BGN per month, which is equivalent to about 14 euros per month. The health insurance of people who receive monthly social assistance is covered by the state budget. In practice, those who are not insured are persons who work without employment contracts in the grey sector or long-term unemployed persons who do not receive unemployment benefits or monthly social benefits. In order not to receive monthly social benefits, it is likely that they do not meet the criteria set by the state for receiving the right to social assistance. They may not meet the household income criterion, exceeding its upper limit, or they may not sign in with the Labor Bureau every month, which is supposed to prove that they are actively looking for job.

The amount of 14 euros per month may not seem like such a big barrier for people who do not pay their health insurance. It becomes a barrier, however, when it accumulates. In order to re-join the health insurance system, these people must pay their health insurance dues for 5 years back in one lump sum. From the conversations we have with Roma from the neighbourhoods, we understand that the main reason why people do not pay for their health insurance is their lack of trust in the system and the cash payments that everyone has to make when needs medical services.

Also, it is important to emphasize that due to the very low amount of monthly social benefits and the rather restrictive eligibility criteria for social assistance in Bulgaria, many people from the most marginalized strata simply refuse to seek social assistance. In this way, they also give up monthly health insurance.

As of the second quarter of 2022, there are 49 800 long-term unemployed persons registered in Bulgaria (with more than 2 years of registration in the Labour Offices).

Taking into account the data from the April 2021 report of the Invisible We See campaign and the fact that among the long-term unemployed the share of Roma is the highest, we can safely say that about 150 000 Roma are without health insurance. The high proportion of uninsured Roma is confirmed by data from community surveys conducted in 30 municipalities participating in the ROMACT programme between 2017 and 2021, in which one in four Roma respondents reported having disconnected health insurance.

The reasons why a large number of Roma do not have health insurance are complex: the lack of regular employment contracts (work in the informal sector); distrust in the system; frequent travels abroad in search of work there interrupt the requirements for monthly registration at the Labour Office, which in turn is a condition for monthly social assistance. In Bulgaria, the state provides health insurance for children up to the age of 18, pensioners, people with disabilities and people receiving monthly social assistance.

"It doesn't matter if you have health insurance, you still pay out of pocket if you want the doctors to pay attention to you. I have a hernia and I need to have surgery, but they said they need money for a band-aid. I don't know how much they need, but I don't have any and I can't buy this cloth, so I don't have the operation" (unemployed man, 63, Seslav).

- ✓ **Access to health / care services in Roma communities**

Overall, the distribution of physicians in the state is uneven. According to State of health in the EU, State Health Profile for 2021, Doctors are concentrated in more urbanized areas with higher economic activity and with medical universities and hospitals. Remote rural areas and small towns experience a shortage of medical staff, and doctors are very busy.

In large urban Roma neighbourhoods, there is usually one or more primary medical practices for residents, while all residents share a rural medical practice. There is one general practitioner for all residents in the villages, while the general practitioners in the large Roma neighbourhoods are one or more depending on the number of the population.

In Bulgaria, there is a shortage of doctors (general practitioners and specialists) and nurses, especially in rural areas of the country. Research by the Institute for Market Economy in the period 2017-2019 reveals that there are significant inequalities between settlements regarding access to health services. It is clear from the research report that there are regions in the country where there are less than 100 people per doctor and regions where there are slightly less than 10,000 people per doctor. Generally, large regional cities with medical universities and large, well-equipped medical centres and hospitals have a higher number of doctors - both general practitioners and specialists, while in rural municipalities the number of doctors has decreased dramatically, and in 11 municipalities there are no even a doctor[5].

In the rural regions of the country, it is common to have private doctors who cover multiple localities and can therefore visit a locality once a week. In addition to the lack of a doctor, many villages are not visited by a nurse or other medical staff:

"The doctor only comes to the village on Thursdays and the nurse is only there until noon. If a person needs a doctor, we look for one in Kubrat, but it is difficult to get there by transport" (a woman of pensionable age, Seslav).

Sometimes, practices are occupied by very elderly physicians long past retirement age or physicians who have health or behavioural issues:

"Our doctor can no longer walk and hardly comes down to examine. Her accountant is in the health office and if there are referrals she gives them. We also have a midwife, she retired a long time ago, but when we pay, at least she measures our blood, gives us injections" (woman, 78 years old, Senovo).

Medical practices in villages and in Roma practices are poorly equipped. Doctors working in them can usually rely on their stethoscope, blood pressure machine and at best some quick laboratory tests.

Dental care is only available in large cities. It is expensive, and the insured benefit from a small package, usually including one or two examinations, a few fillings and treatment of one or two pulpitis. Very few Roma visit a dentist. They go to him in extreme cases, when a tooth has to be extracted or to treat an infection.

[5] Map: Population of one physician", Institute for Market Economy: https://ime.bg/bg/articles/karta-naselenie-na-edin-lekar/

There are not a few cases when Roma take out a sick tooth themselves. In Roma neighbourhoods, the majority of young people around the age of 30 already have several missing teeth. Children are also not provided with dental prophylaxis and early treatment of caries and other dental problems. The majority of Roma over the age of 60 have more than half of their teeth missing. The use of dentures by elderly Roma is extremely rare due to lack of means to access a dentist for examination and denture fabrication.

- ✓ **Are most Roma registered with a family doctor? What role for health mediators?**

Almost all Roma made a choice of GP at the beginning of the health reform in 2000. Over time, however, Roma with unpaid health insurance dropped out of the system and, regardless of the GP chosen, they do not receive free primary care.

Health mediators in Roma neighbourhoods support families with new-borns to make a choice of a personal doctor, as well as support the coverage of all children with mandatory vaccines. They support Roma communication with medical and social officials, support their access to various health and social services, conduct health promotion activities in Roma neighbourhoods, distribute health information leaflets on prevention of various diseases, support the dissemination of information for family planning, measure blood pressure, explain to people in the language they speak the doctors' advice, etc. Overall, national policy expectations of health mediators to address the health needs of Roma are too high, but in reality they are unlikely to be able to address the structural barriers that exclude Roma from the social and health system. Health mediators are highly valued by people in Roma neighbourhoods and by health professionals. The requirements for their activities are regulated in Regulation No. 1 of 19 August 2020 issued by the Minister of Health. Their appointments are regulated through a state delegated budget allocated each year through the Ministry of Health. For the time being, only mayors of municipalities have the right to appoint health mediators. Sometimes, in contravention of the regulations, mayors appoint unsuitable people for the job or assign the health mediators they have selected to non-specific activities. The low pay of health mediators, who are appointed at minimum wage, contributes to a high level of turnover in the profession.

- ✓ **Access to medicines and affordability of health and long-term care**

In Bulgaria, direct payments from patients account for a large share of healthcare spending. According to State of health in the EU, Country health profile for 2021, Direct payments from households account for 37.8% of healthcare spending in 2019 - the highest share in the EU and approximately 2.5 times higher than the share for the EU as a whole. A recent Eurobarometer survey shows that in December 2019, 10% of Bulgarians paid informally to a doctor, nurse or hospital (European Commission,2020).

For poor people in Bulgaria, direct payments are a major challenge to their equitable access to healthcare. Roma families, 66.2% of whom are at risk of poverty and social exclusion (NSI, BG-SILC, 2020), are particularly pressured by the need to pay health professionals by hand. Highly specialised tests and the purchase of medicines are also a problem.

"I have high blood pressure, I have to take heart pills, but I don't take them regularly because I don't have enough money and I can't always buy them. I was supposedly prescribed them for free, but only one of them is free, the others I still have to pay for. And the ones that are free cost 2-3 BGN and they don't give them in our pharmacy, so I have to travel to the municipal centre. When I did the calculation, I have to give at least 10 BGN for a car to go there and I gave up looking for these free pills" (woman, 67 years old, town of Senovo).

- ✓ **Roma with disabilities**

Roma with various disabilities are in a particularly tragic situation. According to the study "Health and the Roma community: an analysis of the situation in Europe", 12.6% of the entire Roma population, including children, is disabled or suffers from a serious chronic illness. According to the authors of the national report, who contributed to the report "Health and the Roma Community: Analysis of the situation in Europe", these figures appear to be underestimated due to the fact that the study only records cases of disability and severe chronic illness diagnosed by the TELK or the doctor with whom the person is registered. The national report also points out that a specific feature of the Roma is the very early onset of disability and the massive chronicisation of diseases already in middle age. The report reveals that one third of men and two fifths of women aged 45-60 have already lost part or all of their working capacity due to ill health. The proportion of people diagnosed with a chronic illness or disability in the oldest age group (those aged 65 and over) rises to 70% - three-fifths for men and three-quarters for women.

Very often early disability among the Roma occurs due to non-treatment of acute health conditions, chronicisation of diseases, non-monitoring of the chronically ill, etc. Not rare are the cases of severe hereditary diseases, various anomalies and malformations for which the necessary medical and genetic counselling was not done during pregnancy.

In the town of Senovo, during our research, we were told of a 67-year-old man with Alzheimer's manifestations for several years who had never been examined and diagnosed by a doctor, had not undergone a medical evaluation, and was not receiving any long-term care. The man lives with the family of his son, who is also disabled - he completely lost the sight in one eye as an elementary school student, and despite several attempts to be certified by the TELK, he has never been able to pass a medical evaluation. The family lives in tragic conditions, the only help they receive is from neighbours who sometimes bring them food.

In the same locality, we were told of a young man with two children who was born with an atresia of the anus and underwent several operations. As a child, thanks to the mother's activism, he had received monetary assistance, including the mother who cared for him. After reaching the age of majority, the man was certified by the TELK, which determined him to have a low degree of disability with the right to work. Unfortunately, the man still has problems and cannot do any work, and there are no suitable jobs around for his condition. He only receives monthly social assistance, for which he does 14 days of community service every month. His family is in misery. The sister of the same man, since childhood suffered from deaf-mute and kyphosis developed after antibiotic treatment. After reaching the age of majority, she was certified by the TELK and received a disability pension, but they removed her mother's pay because of the lower degree of disability that the TELK assigned her.

Again in the town of Senovo we were informed about a young man of about 20 years with Down Syndrome who is being raised by his mother. He has been certified by the TELK and receives the first degree of disability with the right to a companion as he also has profound mental retardation. The family receives the statutory cash benefits, but the mother is involved with her son on a daily basis, without being able to leave him in a day centre or other form of community-based social service.

There is a lack of community-based services for people with disabilities in Senovo, as well as in most small towns in Bulgaria. It would be a good practice if community-based day centres or rehabilitation centres were established, at least in the municipal centres, providing special transport to villages where people with various disabilities live.

In Bulgaria, unfortunately, the provision of institutional care for people with physical or mental disabilities and for the elderly still prevails. Our observations show that few Roma are willing to place their disabled relatives or elderly parents in an institution. This is due to the patriarchal way of life in the community, in which the young and healthy are obliged to care for the elderly and sick members of the household. Therefore, opening day-care centres and ensuring access to them, including through specialised transport and affordable fees for families, is crucial for the social inclusion of disabled and elderly Roma people, as well as for the family members caring for them. It should be borne in mind that just by building a day centre, people are unlikely to be motivated to use it. It is necessary to take into account that Roma speak a different language, have a different way of life and culture and if, because of their condition, they have been isolated within their family and community since birth, they are unlikely to feel comfortable in a day centre. We need to provide the necessary training for professionals so that they gain the trust of both disabled people and their carers. Last but not least, the use of a day centre or rehabilitation centre must be made available for a reasonable fee. Very often, the high fee that users have to pay restricts Roma families from using this type of service, especially when other members in the household are unemployed and the family generally relies on the social payments of the person with a disability.

- ✓ ***Roma mental health***

In November 2021, the Council of Ministers of the Republic of Bulgaria adopted the National Strategy for Mental Health of the Citizens of the Republic of Bulgaria 2021 - 2030. 'Severe' disorders are those that require professional health and social care support. They have a chronic course and lead to loss of social skills and some degree of disability. Severe mental disorders include schizophrenia, severe bipolar disorder, dementias, mental retardation and severe personality disorders. Severe psychiatric disorders have a lower incidence but are chronic and debilitating in nature. They require lifelong care, treatment, rehabilitation and resocialisation by multidisciplinary teams and in continuity settings.

'Frequent' mental disorders are those that take a toll on an individual's well-being over a relatively short period of time. They affect the active part of the population, are widespread, and are most often a consequence of stress. In the recent past they were called neurotic disorders[6].

[6] National Strategy for Mental Health of the Citizens of the Republic of Bulgaria 2021 – 2030 https://www.mh.government.bg/media/filer_public/2021/11/02/21rh388pr1.pdf

According to the latest nationally representative epidemiological study (2017), the lifetime prevalence of common mental disorders in Bulgaria is as follows:

- Anxiety disorders - 8.4%;
- Mood disorders - 4.5%;
- Alcohol and Drug Abuse and Dependence - 4.76% (with the proportion of alcohol abuse and dependence being 4.4%).

According to the health mediators we interviewed, some elderly Roma suffer from domestic ethylism.

"There are not many who drink too much alcohol. There are a few older Roma who drink too much. They drink one or two brandies and get drunk quickly. But they drink every night and then harass the wife and children. It's hard with them. Neither is there a place for them to be treated, nor does it cross their minds that they should be treated" (health mediator, Botevgrad).

Data from a nationally representative survey conducted in 2017 among students in Bulgaria (grades 9-12) show that more than a quarter of respondents indicated that they had used a drug in their lifetime, and a significant proportion of them had used it relatively regularly.

In the course of our research, both the health mediators and the Roma interviewed said that in recent years the entrance for drug dealers has been absolutely unimpeded both in Roma neighbourhoods in the cities and in small villages. Unlike in past years when the poorest used glue and bronze as opiates, nowadays young people in Roma neighbourhoods have unhindered access to a wide range of mostly synthetic drugs and marijuana.

"Little kids are already smoking pot. The dealers sell it to them, nobody stops them. The police don't react when we report to them. They always want to catch them on the spot. But they don't come when we call them..." (female, 58, Novi Pazar).

The National Strategy for Mental Health of the Citizens of the Republic of Bulgaria 2021 - 2030 highlights the lack of coordination between different professionals, services and institutions in the field of addiction as a problem. It also points to the insufficient number of places for addiction treatment, the uneven distribution of services and professionals in the country, which function "piecemeal", without being linked organizationally and technologically in a continuous treatment cycle ensuring adequate treatment effectiveness. Also, a number of treatment and rehabilitation services are not paid for in any way by the state and are left to the financial capacities of the addicts themselves and their families. This seriously violates the right of access to treatment.

The stigma attached to alcohol and especially drug addicts has an adverse impact on the development of a system of services that can operate throughout the country. In Roma neighbourhoods both adults and young people are not familiar with the effects of drugs on the human body. There is almost no awareness-raising in this regard, or if it is carried out, it is of low effectiveness due to its sporadic implementation, incomprehensible language, inappropriate channels for disseminating messages. Schools with an overwhelming number of Roma students also neglect to address the issue of drugs.

Only health mediators organise occasional talks with young people and parents and try to make them aware of the consequences of drug use. But topics such as the types of drugs, their impact on the development of the young organism and human health, on the social life of the individual and the community, the types of channels for drug distribution, ways for parents to recognise when their child is taking drugs, etc. remain unaddressed in the community and people have nowhere to learn about them.

In terms of severe mental disorders, there were 25 849 patients with schizophrenia under observation[7] . Of this group, between 10% and 15% (2,500-3,000 individuals) need support in the community. Of these, 1 000 are in long-term care institutions and around 230 are long-term residents in state psychiatric hospitals. There are 28 293 patients with mental retardation under observation. Of this group, those who are totally dependent on care and unable to cope independently in everyday life account for approximately up to 2% (severely and profoundly mentally retarded) or about 400 persons. They also need specialised medical care, which should be carried out in good coordination with outpatient specialists. The number of patients with dementia under observation is 2 408, but with the rate of dementia increasing from 1% to 30% in the upper age categories over the age of 60, the need for services for this target group will increase (NCDC data, 2018). There is no data available relating specifically to the Roma or other ethnic groups.

We can only assume that the Roma are more exposed to anxiety and depression because of poverty, hard living conditions, and an overburden of stress, but we do not have reliable survey data to prove the higher prevalence of anxiety and depression among poor Roma. It is likely, however, that the Roma do not pay attention and do not seek a doctor for these sufferings. What is remarkable about the Roma is that many of them, who have seriously ill family members, with extremely difficult access to health and social services, resign themselves and give up seeking help from the institutions.

- ✓ **Older Roma and their health needs**

Bulgaria is one of the leading countries in the EU in terms of ageing population. According to the National Statistical Institute (NSI), at the end of 2020 the number of people aged 65 and over in Bulgaria will be 1 504 048 or 21.8% of the country's population. The NSI forecasts that the relative share of the population aged 65 and over will continue to grow, reaching 29.6% of the total population in 2050[8]. According to data from the 2011 Census, Roma have the lowest rate of elderly people compared to other ethnic groups: just 1.9% of Roma reach 70-79 years old and only 0.4% of Roma reach 80+ years.

	60 - 69	70 - 79	80 +
Bulgarian	14,169	9,874	4,677
Turks	10,629	6,026	2,007
Roma	4,867	1,854	0,385

[7] National Strategy for Mental Health of the Citizens of the Republic of Bulgaria 2021 – 2030 https://www.mh.government.bg/media/filer_public/2021/11/02/21rh388pr1.pdf

[8] Thematic report on the elderly from a large-scale survey of the NSI and FRA, conducted within the project "New approaches for generating data on hard-to-reach population groups at risk of violation of their rights" https://www.noveleea.bg/wp-content/uploads/2021/11/Key_indicators_report_BG-21-11-26.pdf

In the thematic report on the elderly from a large-scale survey of the NSI and the FRA, conducted in 2020 within the framework of the project "New Approaches for Generating Data on Hard-to-Reach Population Groups at Risk of Violation of Their Rights", the following data are derived. In contrast, the proportion of Roma aged 65 and over who perceive their health as good or very good is 17.5% . These results are in line with findings from other studies noting the poor health status of the majority of the Roma population.

The elderly population increasingly needs services providing long-term care. In 2014, the State adopted a National Strategy for Twenty-Year Long-Term Care. It envisages "over the next 20 years, to improve access to community and family-based social services and to health services by expanding the country's network of these services, their diversity, volume and scope, improving their quality, and promoting interaction between them". The 2020 Social Services Act and its Implementing Regulations contribute to the implementation of this long-term objective. The strategy does not take into account the presence of elderly and disabled people from different ethnic backgrounds who might have different needs due to their different mother tongues and cultural identities.

The Roma of retirement age we interviewed reported poor health and difficult access to medical care and social services. Elderly Roma from villages have particularly difficult access to health and social services. One of the women interviewed said:

"Every time I have to go to the doctor or the pharmacy, I have to set aside 10-15 leva from my pension for a car, because there is no ride to the municipality, and you can never find the doctor in our village" (woman, 75, Senovo).

Interviewees from Seslav reported incredibly high fares for them to the municipal centre of Kubrat - BGN 4 one way or BGN 8 for a return ticket.

Due to their difficult mobility, the elderly would prefer to be visited at home by their GP or at least a nurse to take their blood pressure. Most Roma adults do not have their blood pressure taken regularly, despite reporting that they have high blood pressure. None of the localities in which we conducted the interviews reported having conducted preventive check-ups among Roma over 65 years of age.

Often, the only social service that exists for the elderly in the villages is the Home Social Patronage, through which hot meals are provided to pensioners living alone. According to our interviewers, Roma pensioners exceptionally rarely use this type of service because they usually live in an extended household where there are young people preparing meals for everyone.

Something we found in the course of our research is that few elderly Roma are left by their relatives in the Homes for the Elderly. Recently, however, the emigration of the young has prompted some elderly and sick Roma to consider an institution as a solution for the time when they can no longer manage on their own at home. Three respondents told us that they would go to an institution, but were worried about how they would be perceived there and whether they would be picked on for not knowing Bulgarian language well.

For hard-to-reach and remote regions, including segregated and marginalized Roma neighbourhoods with difficult access to medical services, a good way to monitor the health status of the elderly is the development of telemedicine. At this stage, this practice is being piloted by the BRC in only a small number of municipalities in Northwest Bulgaria. This service would be particularly useful if combined with the Home Social Patronage – so the elderly could stay at home instead of being institutionalized.

The Home Social Patronage is a community based social service that includes preparation and daily delivery of hot meal to the clients' homes. In addition, the service may include maintenance of personal hygiene and hygiene in the client's home of the service, assistance from social workers for preparation of documents for a labor-medical expert commission, accommodation in specialized social institutions, for submission of documents to the Social Assistance Directorate to receive energy and other social benefits, as well as for disability means. All old-age pensioners and persons with disabilities, who have been issued expert decisions for reduced 70 and over 70% working capacity, have the right to use the Home Social Patronage service.

In any case, it is necessary to take into account the linguistic and other cultural differences specific to Roma elderly over 65, which could create insecurity and anxiety for them and hinder their access to health and long-term care.

- ✓ **Roma sexual and reproductive health and rights**

Although the attitudes for one hundred percent marriage and for early childbearing are being overcome among Roma women with high education, the community still expects young people to be rehomed early and to have a child soon after rehoming. In recent years, more and more Roma women are adopting the family and reproductive model of Bulgarian women and giving birth to two children. A third child is usually born if the first two children are female. In some poor and extremely marginalized families, however, family planning is lacking and in these families the woman gives birth while she is able. A review of NSI data, BG-SILC, shows a correlation of data on the number of children in a family and the risk of poverty and social exclusion: families with more children are more at risk of poverty and social exclusion.

According to the health mediators, Roma women as a rule avoid visiting a gynaecologist. Our study found that Roma women's access to gynaecologists is hampered by a number of factors: the health insecurity of a large proportion of Roma women, the lack of gynaecologists within a short distance of women's homes, distrust of male gynaecologists, and rude and prejudiced attitudes from obstetricians during childbirth. Respondents told us that married young Roma women find it difficult to leave their homes on their own, even for a medical check-up. They are always accompanied by their husband, mother-in-law, mother-in-law or other relative.

Talking about preventing unwanted pregnancies is taboo in the community. Health mediators distribute information leaflets with family planning tips, conduct health talks with young Roma, and help to distribute contraceptives or motivate young women to take the contraceptive pill when implementing projects. Many women resort to unregulated, non-medical ways to terminate unwanted pregnancies, sometimes leading to life-threatening complications. Sex education takes place in a very small number of biology classes for Grade 8 students within the unit on human anatomy.

Forced sterilisation was not an issue in Bulgaria. During the communism time, families were encouraged to have more children to increase the country's population. Families with children, including Roma, benefited from family and child allowances and paid maternity leave lasting two years, and mothers who gave birth to a live child received a monetary award. From this period dates the myth that the Roma give birth to more children because of family and child benefits. In fact, the truth is that already in the mid-80s, many Roma families adopted a two-child family model. Large families continue to be characteristic of poorer, segregated and marginalized Roma groups.

- ✓ **Roma and Covid-19**

Covid-19 impacts extremely negatively on the health and lives of Roma. Already in the first days of the pandemic, many Roma in extreme poverty fell into a humanitarian crisis due to their inability to go out for daily subsistence. Their neighbourhoods were forcibly closed, even though in the first days of the pandemic not a single person from the neighbourhood fell ill. Apart from earning their livelihood, the Roma were unable to safely reach pharmacies, grocery stores and water in cases where they had no water in the neighbourhood and poured water from public taps and other water sources. Such restrictive measures were applied to the Roma quarters in Kazanlak, Sliven, Yambol, Sofia, and in Karnobat, the mayor ordered a plane to spray disinfectant over the Roma neighbourhood. At the same time, the mayor of Sliven shut down the quarter. "Nadezhda", inhabited by more than 10 thousand Roma population, from the public tender for a company to carry out disinfection of public areas of the city. Subsequently, thanks to private donors, the health mediators purchased disinfectant and with much pleading managed to convince the winning bidder to provide them with sprinklers so that they could disinfect the streets of the neighbourhood.

Due to the high proportion of chronically ill Roma, Covid lethally affected many Roma elderly and not so elderly. The first informational response to the pandemic was provided by the National Network of Building Mediators, which already in April 2020 produced a brochure on how people can protect themselves from infection. The brochure was also translated into Turkish and Roma languages and was used for dissemination among Roma as well as the rest of the population.

Unfortunately, fake news found ground among the Roma in Bulgaria and they did not believe in the vaccines' effectiveness, which is why they massively refused and continue to refuse to be vaccinated. This has led to the premature death of many Roma. Despite seeing the greater number of Roma deaths in 2020-2021, Roma still do not believe the vaccines and refuse to be vaccinated.

During the early Covid waves, a shortage of hospital beds made it difficult for everyone to access hospital treatment. Roma from small towns had particular difficulty accessing treatment. Even if they managed to get to the Covid wards, there was often a shortage of medication and they had to search for it all over Bulgaria through relatives and friends. Thanks to the decision to provide free treatment for Covid patients, regardless of their health insurance status, and the opening of Covid wards, hospital treatment became accessible to all, including Roma.

Unfortunately, however, a huge number of Roma believed the fake news that “they were killing Roma in the wards”, which is why Roma infected with Covid-19 massively refused to get tested and admitted to hospital. This is part of the phenomena where the Roma do not trust the state, given historical as well as present injustices against them. They usually sought emergency care and were admitted to hospital in a terminal stage when they could hardly be helped anymore. In the course of our research, we became aware of a case of aggression by a Roma family towards the attending doctor and a nurse, who is of Roma origin, due to the death of a relative of theirs who had died and was admitted to the ward in an extremely critical condition. He delayed until the last minute and refused to be admitted for treatment precisely because of fear of being killed in the hospital.

Misinformation among the Roma played an extremely bad role in their proper awareness of vaccines, treatment and prevention of the disease. The Roma were mainly informed about everything related to the disease from Facebook, where fake and misinformed news was apparently generated for them as a priority. The messages of the generally weak information campaign organised by the government did not reach the Roma at all, because they did not target the Roma, and channels were used to convey the messages that the Roma do not use - public television and radio.

There has also been little influence of health mediators and Roma medics in combating Roma misinformation about Covid-19. Health mediators were crucial during the pandemic, they were on the ground every day, spreading information, delivering food aid, making sure the quarantined people obeyed the quarantine, alerting organizations about discrimination during the pandemic, helping children without internet access to get schoolwork so they wouldn't be completely excluded from educational process. In some cases, for example in 'Nadezhda' neighbourhood in Sliven, they even carried out the disinfection of the streets in the Roma quarter, since the municipal mayor did not include the neighbourhood in the tender for disinfection of the streets and public spaces in the city.

However, their effectiveness was low in terms of persuading Roma to get vaccinated. This could be because in many localities the Roma rather begin to perceive health mediators and Roma doctors and nurses as part of the system, which they do not trust, because for centuries the system has rejected them, discriminated against them, excluded them, suppressed them. In some exceptional cases, such as in the village of Isperihovo, municipality of Bratsigovo, the health mediator was able to convince a substantial part of the Roma to get vaccinated. This is due, on the one hand, to the fact that the health mediator there is perceived as a leader by the community, and on the other hand, because the village mayor was personally committed to persuading people to get vaccinated.

It must also be said that even if there were Roma from small settlements who were willing to be vaccinated, it was impossible for them to do so, as in these settlements there were either no doctors to administer the vaccination or the available personal doctors simply refused to receive and administer the vaccines against Covid-19. Vaccination clinics were only available in the district and some municipal centres, which required transportation to reach.

In early 2022, the country's government held a meeting with a wide range of Roma organizations and mediators, seeking a solution on how to attract Roma to get vaccinated. A proposal by Integro Association and the NC Intellect network of organisations to organise mobile teams of health professionals to visit remote Roma neighbourhoods where people do not have private doctors and offer people a medical examination to establish their health status before vaccination was not accepted. In our opinion, this would increase people's confidence in the whole process many times over and facilitate the vaccine administration.

- ✓ **Discrimination and antigypsyism**

In many places, relations between medical staff and the Roma community are problematic. Many of them do not know and do not respect the cultural differences and traditions of Roma. They demonstrate discriminatory attitudes, behave rudely and are openly hostile. In the course of the research, a Roma woman from Sliven told us that Roma women who come to the hospital in Sliven to give birth to a child are isolated in the isolation ward, thus separating them from other women.

"In order for a woman from the Nadezhda district to give birth in the normal rooms of the maternity ward and not go to the isolation ward, as soon as she became pregnant she and her family looked for an address outside the district to register. This is the only way she has a chance to give birth in the normal maternity wards." (mother, 31, Sliven)

According to the health mediators, subtle racism is also manifested in other hospitals in the country by separating Roma in separate rooms on the grounds that this makes them feel better because they can safely communicate in their own language. Poorer and marginalised Roma are more often discriminated against, while the better-off can pay and thus get the attention and care they need.

Health mediators, who often witness racism and discrimination against Roma patients, usually remain silent and do not intervene, so as not to worsen their relationship with the skilled professionals they have to work with and because they are worried about losing their jobs. In practice, the work of health mediators is ultimately more about facilitating the work of health professionals with Roma patients and less about protecting the rights of Roma patients.

It is necessary to fundamentally change the institutions' understanding of the role of the health mediator in this respect. In addition to the tasks to facilitate the access of vulnerable people to health and social services and to facilitate the work of health professionals in providing services to such people, the health mediator should first of all be empowered to look after the rights of patients from vulnerable ethnic groups, as well as for non-discrimination against them.

In general, the sensitivity of Roma to discrimination by medical staff is low, because of internalised stigma, over-exposure to antigypsyism also in other areas of life, and lack of knowledge of their rights. There is a need for campaigns to raise awareness among Roma of the manifestations of antigypsyism towards them in accessing and receiving health, social and long-term care.

Conclusion and Recommendations (1-2 pages)

Access to health and long-term care for many Roma is difficult. A high rate of working-age Roma are without health insurance. The reason for this is both long-term unemployment and work without an employment contract in the grey sector, as well as the high distrust of the Roma towards the health care system. Many Roma feel that they would receive better care and more attention from medical staff if they paid cash for the medical services.

The requirement to pay the health insurance dues for the last 5 years, in order to be able to return to the health insurance system, is an insurmountable barrier for some sick and poor Roma, who often give up seeking health and social services. The presence of a high share of direct payments in the health system, despite mandatory health insurance, limits many of the poor and marginalized, and especially the elderly Roma, from effective examinations and treatment. Their diseases often take a chronic course, lead to various complications and often to earlier disability, which in most cases remains uncertified by specialized bodies, due to a lack of funds for conducting the needed examinations, failure to prepare the necessary documentation, the remoteness of services for examination of the ability to work, etc. This, in turn, deprives these Roma of the opportunity to receive the relevant social payments, social assistance, funds and various benefits provided upon the law for the people with disabilities.

The population, including the Roma, from rural areas and small settlements, where there is a shortage or a complete absence of doctors and nurses, is in a particularly difficult situation. Access for people from these settlements is difficult both to primary medical care and to specialized outpatient and hospital care, due to the uneven distribution of medics on the territory of the country. This challenge needs to be addressed as a priority in the coming years, bearing in mind the deepening poverty and social exclusion of the rural population, among which the majority are elderly people from the Bulgarian ethnic group and young people with low education from the Roma ethnic community.

Roma access to emergency medical care is often compromised by poor road infrastructure in Roma neighbourhoods, hampering ambulance access, and by poor communication between Roma and emergency medical centre staff, which is due, on the one hand, to a lack of cultural sensitivity to Roma on the part of the medical staff, and on the other - the lack of awareness among the Roma about the scope of medical conditions covered by emergency medical care in Bulgaria.

The social determinants have a particular role for the deteriorating health condition of the Roma community, among which the poor housing conditions and poor infrastructure in the Roma neighbourhoods take a leading place. Thousands of Roma still do not have access to clean drinking water and sanitation and live among piles of garbage and waste, due to a lack of organized garbage collection.

A particular challenge is overcoming the manifestations of racism and discrimination against Roma by the medical staff, as well as putting the observance of the human rights of Roma patients first.

- ✓ **Roma health in the National Roma Strategic Framework**

The National Strategy for Roma Equality, Inclusion and Participation 2021-2030 somewhat adequately analyses the main health challenges facing the Roma population, emphasizing premature mortality among Roma and high infant mortality in the community. It is positive that the Strategy prioritizes the improvement of child health, in particular through interventions for early childhood development, but in general the goals set in the strategy can be defined as unambitious, some - specific, others - too general and vague, with unmeasurable results and with too inadequately planned activities in the first action plan.

Healthcare is one of the priorities of the new National Roma Strategy but there is nothing about long-term care. The healthcare priority envisages one operational and 5 general objectives as follows:

- Operational objective: Equality in access to quality public health care and improvement of the health status of the population in the identified vulnerable ethnic communities, with a concentration of poverty.

General objectives:

1. Improving maternal and child health care in designated vulnerable ethnic communities with a concentration of poverty. Systematic implementation of activities ensuring the health aspects of early childhood development.
2. Improving access to quality public health care for persons in a situation of poverty and social vulnerability.
3. Reducing stigma and discrimination of people from vulnerable groups and raising awareness in the field of public health.
4. Development of the concept of health mediation.
5. Ensuring sustainable implementation of the policy regarding the implementation of vaccination prevention and expanding the scope of vaccinated persons with a view to implementing the immunization calendar, national vaccination programs and maintaining a high immunization coverage.

In the National Strategy Implementation Plan, the most specific measures with clear base and target indicators are planned under Goal 1: Improving maternal and child health care in identified vulnerable communities, with a concentration of poverty. For example, for the period 2022 - 2023, 1,000 gynaecological examinations are planned to be carried out with mobile units in settlements with a compact Roma population as well as 1,000 preventive examinations of children with mobile paediatric units and 1,000 screening examinations with a mobile mammogram for the prevention of breast cancer (although the latter is more a measure to combat socially significant diseases). Measures are planned to increase the coverage of children without general practitioners found by the health mediators, as well as conducting immunizations with mobile teams according to the National Immunization Calendar for persons up to 18 years of age, without a selected general practitioner and for persons from remote and hard-to-reach areas, as well as for persons with difficulty in mobility, through mobile groups for vaccination.

Under this objective it is also planned to introduce a program for nutritional support of pregnant women and children 0-3 years old, including identification of families in food insecurity, counselling, direct support for children up to 3 years old through food products/vouchers; support by purchasing packages of necessary basic products for new-born children from poor and at-risk families identified by the social assistance authorities. But this support will apparently reach only 100 women and 1,000 new-borns from 30 municipalities, which is a small number against the background of the high percentage of Roma children living in poverty - over 70%.

Access to quality healthcare for Roma living in poverty is mainly planned to be achieved through:

- HIV prevention and control activities, which include anonymous and free counselling and testing for HIV and sexually transmitted infections; it is not clear why these measures are planned within the Roma strategy as the Roma are by far not identified as main vulnerable group to HIV.
- Activities to improve the control of tuberculosis among the Roma community by conducting risk screening, accompanying and testing for tuberculosis; support in the treatment process of tuberculosis patients.
- Ensuring the functioning of mobile medical offices for low-threshold services, conducting examinations for socially significant diseases with mobile units - fluorographs, echographs and clinical laboratories.

There is also a measure that is not a measure, but a general goal, which is defined as follows: Increasing years of life in good health and prevention of early disability.

The most irrelevant and inadequate are the planned measures under objective 3: Reducing stigma and discrimination of people from vulnerable groups:

- Implementation of information campaigns and campaigns for the provision of low-threshold and mobile prevention services for HIV/AIDS, viral hepatitis and tuberculosis.
- Implementation of information campaigns for the provision of low-threshold services with 21 mobile offices
- Implementation of harm reduction programs for people who use psychoactive substances.
- Implementation of selective prevention programs for children and families from the Roma community.

It is clear that these measures could in no way address the negative attitudes of medical staff towards Roma in Bulgaria.

The National plan also includes training for new health mediators, measures for professional development of already working mediators; training to increase the qualification of employees from the municipal administrations and from the Health inspectorates to confirm the model of the health mediator.

It is planned to involve health mediators in municipal and state hospitals on a pilot basis, as well as to create a pilot system for monitoring the activities and analysis of the health mediation policy.

It is good that the focus of the strategy is placed on child and maternal health care and early childhood development, as well as that a goal is set to reduce stigma and discrimination of people from vulnerable groups. There are no specific goals for: reducing the chronicity of diseases and early disability in the Roma community; for the prevention of socially significant diseases, which are the most common cause of premature death; to ensure access of elderly Roma and Roma with various disabilities to disability certification and long-term care services. In the National Implementation Plan of the National Strategy for Equality, Inclusion and Participation of the Roma, no activities are foreseen to deal with the manifestations of discrimination and anti-Gypsyism, which are common among the medical staff in relation to the Roma.

- ✓ **Positive solutions, good practices, and recommendations**

In order to guarantee equal access to health services and long-term care for Roma with health problems, elderly Roma and Roma with disabilities, the following recommendations should be taken into account:

- Health rights to be restored after payment of contributions for 3 years back, instead of 5, providing for the possibility of deferred payment and not only lump sum payment;
- Creation of incentives, including by providing good pay, social benefits, office equipment, etc. to attract doctors and medical personnel to remote rural areas;
- Development of telemedicine in remote rural areas, including in Roma neighbourhoods;
- Development of national screening programs with national and European funding for prevention and early diagnosis and treatment of socially significant diseases in marginalized, poor communities from remote areas with difficult access to modern health services;
- Launch and expansion of scholarship programs to support Roma medical students with funding from the national budget and European programs;
- Expanding the mandate of health mediators with the right to intervene in cases of discrimination against Roma patients, informing them of the discrimination committed against them and giving them guidance on where and how to seek their rights;
- Expanding the scope of health mediation by enabling the appointment of health mediators within a delegated state budget not only from municipalities, but also from hospitals, emergency centres, non-governmental organizations and others;
- Guaranteeing funding for the activity of health mediators;
- Reduction of direct payments in the health care system;
- Provision of free medicines for children;
- Provision of targeted social assistance to pay for medicines/treatment of poor people, while reducing the bureaucratic approach and expanding supportive social work with needy individuals and families;
- Provide targeted funding for poor chronically ill patients to access disability assessment services (for transport, examinations, document preparation);
- Improving coordination and communication and establishing a partnership approach between different services from the health, social, administrative systems in order to facilitate patient access to these services;

- Conducting ongoing information campaigns among the Roma to explain the benefits of paying health insurance;
- Conducting an active policy with integrated measures to improve the housing conditions of extremely poor and marginalized persons and groups, guaranteeing access to clean drinking water, sewage and sanitation in their settlements. Ensuring access to European funding to improve housing conditions and infrastructure in Roma neighbourhoods that are outside the city regulation, including funding under European programs for the development of cadastral plans, detailed development plans, etc.

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