“Roma access to quality, inclusive and affordable health and long-term care in Hungary”

Introduction

The Autonómia Foundation is an independent, private foundation established in 1990 to strengthen civil society, support excluded groups and, above all, promote Roma integration. Its aim is to promote the development of civil society in Hungary, including Roma integration. It does this primarily by supporting civil initiatives in which people mobilize local resources to achieve their goals. Since its establishment, the Foundation has supported and implemented hundreds of Roma inclusion programs, participated in numerous research projects and has an extensive network of contacts. Detailed information on the Foundation's activities is available at www.autonomia.hu. The case study was drafted by Tibor Béres and Miklós Kórodi.

This research relies on two main types of sources. For each of the case study topics, the results and experiences of previous research and surveys in the field have been taken into account. We have also sought to illustrate the data and findings with real stories and cases. In order to do this, we conducted interviews with Roma people living in settlements at one of the Foundation's current program sites (Gyöngyös, mid-town, and Gyöngyösoroszi, a village with 1800 inhabitants). It is important to emphasize that the Roma communities in Hungary cannot be considered a homogeneous group from a cultural, linguistic, residential, and spatial point of view. A smaller part of the Roma population is mixed with the non-Roma population of the country, while the other, larger part lives mostly in small settlements, colonies, and metropolitan ghettos, in segregated conditions. The data collected in the latter can only be interpreted with limitations for the Roma communities in Hungary as a whole.

The Roma population, which accounts for around 6-8% of the Hungarian population, is the poorest, most excluded and most vulnerable group in society. The gap between the Roma and the majority of society has been growing since the change of regime, mainly due to residential segregation and segregation in other segments of society, especially in education. Moreover, the educational and labour market position of Roma remains weak, leading to a persistent and deepening poverty. This is often coupled with a negative, often hostile, climate surrounding Roma, which is reflected in prejudice and discrimination from the majority of society (Bernáth, 2014). A significant proportion of the Roma population in Hungary live in segregated settlements, where housing and living conditions are significantly worse than the national average and than those of non-Roma living in the immediate neighbourhood.

According to the results of the EU-MIDIS II survey (European Union Agency for Fundamental Rights, 2017), 75% of Roma in Hungary live below the poverty line. At the time of the survey, the share of early school leavers among young people aged 18-24 was 68%, and a quarter of Roma aged 45 and over had not completed any level of formal education. Income poverty rates were closely correlated with the concentration of Roma in settlements: the proportion of Roma living below the poverty line was highest in areas where respondents perceived that Roma residents lived 'exclusively' or 'predominantly' in segregated conditions.

- ✓ **Social determinants of Roma health**

Various studies consistently show that the health status of the Roma population is significantly worse than that of the general population, regardless of the country in which they live. However, it is important to note that the Roma communities in Hungary do not form a homogeneous group in terms of health status either. When we examine issues related to health, we cannot ignore this stratification and the issue cannot be simplified to poverty only. The age composition of the Roma population in Hungary is characterised by a higher number of children than their parents, relatively high fertility, and extended reproduction. At the same time the number and proportion of elderly people is strikingly low, due to higher mortality and lower life expectancy compared to the non-Roma population (KSH, 2016). Direct mortality data are not available due to the lack of ethnic-based data collection, but the age profile of the Roma population and several studies clearly indicate that the high mortality rate among the Roma population is significantly higher than in the general Hungarian population. These data also suggest that the leading causes of death in the Hungarian population (cardiovascular diseases, cancers, metabolic diseases) are significantly higher in the Roma population in the form of early death.

The research conducted by FRA-UNDP shows that the coverage of childhood vaccinations (age 6) is also essentially congruous among Roma, with some preventive health services or essential medicines being less accessible to Roma than to non-Roma, according to their own perception. A quarter of Roma aged 16 and over (24%) had a dental check-up in the year before the survey, compared to almost a third of non-Roma in their neighbourhood (31%), with a slightly larger difference in terms of incidence in cholesterol tests (23% and 37%) and cardiological screening (27% and 39%), and the largest difference between Roma and non-Roma in terms of X-rays, ultrasound or other similar tests (38% and 54%).

Among the social and psychosocial factors that influence health status, education, financial situation, economic activity, living environment and housing conditions play a prominent role. In the absence of all these, the emergence and persistence of both physical and mental illnesses is inevitable. The situation of Roma in Hungary is fundamentally determined by low educational attainment and the resulting low employment rate. Based on 2020 data, 66% of the Roma population is at risk of poverty or social exclusion. And the proportion of people living in severe material deprivation exceeds 46%. Regarding Roma housing and housing conditions, there are currently around 300,000 people living in segregated settlements in Hungary, typically with poor infrastructure.

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

In Hungary, social insurance is based upon a risk-sharing scheme and participation is compulsory for everyone. The insurance relationship resulting from the obligation to participate is the basis for entitlement to certain benefits. You are entitled to basic health care even if you are uninsured. Anyone whose social security number is invalid for any reason can only receive health care services for a fee, except for emergency and epidemic care.

Persons without insurance (e.g. pensioners, child beneficiaries) are entitled under social security rules only to health care benefits in kind (e.g. general practitioner, on-call care; health care for mothers, children and young people; emergency dental care; medication) on the basis of social solidarity. As ethnicity is a sensitive indicator in Hungary, there is no reliable data on the proportion of insured persons among members of the Roma community in Hungary. According to data from a 2012 survey (UNDP/World Bank/EC-FRA 2012), the vast majority of Roma aged 16 and over have health insurance (94%), just below the non-Roma in their neighbourhood (97%).

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

The Roma Civil Monitoring Report highlights the following points on Roma's access to health care. Primary health care in Hungary has a significant human resource deficit, characterised by the ageing of general practitioners and the spatial distribution of GPs' districts that are permanently vacant. The average age of general practitioners is rising, there is a very low replacement rate, and the number of vacant practices is increasing, leaving more and more patients without a general practitioner. GPs' practices remain permanently vacant mainly in the most disadvantaged regions where Roma communities are concentrated in Hungary. Generally speaking, access to primary care (health) services is also unfairly difficult for the majority of Roma communities in Hungary.

Despite improvements in recent years, there are still many areas with a high Roma population density where outpatient care is only available within a 20-minute drive. It is clear that for the majority of poor people without cars, access to specialist health care is even more difficult. A health care system closely linked to general practice plays a key role in caring for expectant mothers and supporting children from new-born to school age. However, this network also faces significant human resource shortages, most notably in areas with a high Roma population density.

Members of lower socio-economic status groups, including Roma communities, also face a serious burden due to the widespread presence of parasolvency, which is an informal payment or „under the table payment". Public healthcare is free, but you can get better care for money. Parasolvency is money paid illegally to a doctor working in the public health sector. At the initiative of the Medical Chamber, parasolvency became a punishable act. This results in its decrease.

Our interviewees visit the doctor with varying frequency. None reported visits for screening or preventive purposes. Primary care (GP) is only used for acute problems, while specialist care is only used for established illnesses. For example, women do not go for gynaecological screening, they only go when they have a problem. No one goes to the dentist for regular check-ups. In the case of villagers, this is also made more difficult by the fact that there is no care in the village anymore - it stopped a few years ago. They only go to the dentist when they are in pain. Only one woman has had a tooth replacement (only the so-called 'tooth-retaining treatments' are free of charge on a health care insurance basis.

It is important that the interviewees are not clear what is free - with health insurance - and what is not, and why they have to pay. Thus, the only family interviewed that uses the dental service more or less regularly also uses the free service in private practice, even though it is a very heavy financial burden.

There are no health mediators in Hungary.

- ✓ **Roma with disabilities**

Recent data and analyses on the situation of Roma people with disabilities are not available. A 2004 study based on 2001 census data found that the highest proportion of disabled people among ethnic minorities in Hungary are the Roma, whose learning opportunities are worse than those of non-Roma. Almost two-thirds of them did not even finish primary school, and only 4.5 percent had the opportunity to continue their education. Women are more disadvantaged than men: nearly three-quarters of them did not finish primary school. When comparing disabled people of Roma and non-Roma ethnicity by type of disability, two significant differences can be observed: the former have a much lower proportion of people with disabilities and a higher proportion of people with mental disabilities. The age structure of the Roma with disabilities follows that of the non-disabled population, but due to their poor health and lower life expectancy, Roma with disabilities are less likely to live beyond the age of 60 (Tausz-Lakatos, 204.)

We were unable to locate any relevant research data regarding Roma access to disability benefits. The Roma are not excluded from these benefits, but for example transport or administrative difficulties can make it difficult to access the disability benefits.

On this topic, it is worth noting that in Hungary it has been common practice in recent decades to classify Roma children as disabled. The Special Pedagogical Service, which examines the school readiness of Roma children, sent them *en masse* to special schools, claiming that they were mentally handicapped. The children who are classified as disabled are taught in segregated classes with a reduced curriculum, leaving them with no chance of going on to higher quality secondary education. This practice of segregation has been opposed by several rights groups.

- ✓ **Roma mental health**

In the current health care system, the Roma in poor health do not have access to higher quality specialist care. Early detection and treatment of mental illness can be achieved through a well-functioning signalling system with the help of trained professionals. However, in the periphery of the country, there is a lack of such professionals, and people living in the periphery of the country can only get access to a psychologist, for example, at a high financial cost. The distrust of psychiatrists on the part of some Roma towards health care institutions is particularly salient, and there is a strong stigma attached to consulting such professionals.

The health status of Roma is not determined by their ethnicity, but by socio-economic factors such as education, subjective financial situation and labour market situation. In these, Roma are systematically disadvantaged. Several studies show that people with the lowest levels of education are the most at risk of pathological stress and chronic depression.

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

There are around 1.8 million people aged 65 and over in Hungary, of whom around 1.3 million live with some form of disability (Gyarmati, 2019). Only 7% of this age group receive home care, while 3% have access to specialised care in nursing homes. The number of people waiting for nursing home care exceeds half of the current residents. The provision of basic services for the elderly (meals, home help) is a compulsory task for all municipalities, but capacity is unevenly distributed. There is also a lack of information among older people, most of whom do not know what they are entitled to.

These anomalies particularly affect Roma elderly people. As has been repeatedly pointed out in the study, a significant proportion of the Roma population live in regions with a lack of services, and there are significant barriers to accessing the various specialised services (if they are available nearby at all). The lack of information is particularly acute for Roma living in more isolated and closed communities. In addition, it is important to mention the financial implications of care for the elderly, especially care in nursing homes. There is a heavy financial cost to entering care homes, which neither older people living in extreme poverty and with low pensions, nor their families, are able to afford. This is true for both non-Roma and Roma members of society in Hungary.

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

Research in disadvantaged settlements, segregated settlements and among people living in extreme poverty shows that a significant proportion of families are fundamentally under-informed about contraception and lack basic anatomical knowledge. In many cases, the financial situation of families does not allow for informed contraception. The lack of adequately trained professionals and programmes for sexual education of young people is a problem. Mothers living in isolation have lower rates of participation in antenatal care and face significant barriers to accessing specialist care. For Romani women, prohibitions and taboos about sexuality and physicality in general also have a major impact on their access to health care. The fear of the doctor - of any medical intervention or examination - is compounded by their reluctance to undress in front of a doctor, especially if it is a strange man.

The women and girls we interviewed all think that having children early is wrong, but there is no uniformity in what they consider to be premature. The women (and mothers of the girls interviewed) had already given birth at the age of 16-17. In hindsight, women consider it premature to have given birth at that age, but they would not have considered it significantly later (age 18-25) to be ideal. Their main argument was that they could not existentially give the child what would have been ideal at the time.

Our interviews confirmed previous research findings. The lack of organised and professional education for the girls we interviewed was compounded by additional factors. Neither physicality nor sexuality is discussed in the family, mainly due to the taboo that is typical of the Roma community. Not only does this affect early childbearing, but girls are also left to their own experience in the process of physical maturation, which they have to cope with by constantly feeling ashamed of becoming a woman. This also affects their relationship with medical care, as not only is their sense of comfort affected by the examination, but there is also a sense of shame and fear attached to seeking medical care itself. This also makes it impossible for them to receive professional care for their health problems and illnesses.

In Hungary, there have been no mass forced sterilizations of Roma women. (The two interviewees who have been sterilized initiated the operation by themselves.) After the regime change, there have been a few cases of suspected sterilizations of Roma women against their will or with incomplete information. In one case in 2001, the UN Committee on the Elimination of Discrimination against Women (CEDAW) ruled that the sterilisation had been carried out without the patient's full and informed consent and had permanently deprived her of her reproductive capacity, thus violating her right to choose freely how many children she wished to have and at what intervals. The UN Committee called on the government to pay damages commensurate with the violations and to repeal the provision that allowed doctors to 'perform sterilisation without the need for an informed consent procedure if circumstances so warrant'.

- ✓ **Roma and Covid-19**

We do not have specific data on the trends in COVID morbidity and mortality among the Roma population. A significant proportion of Roma living in Hungary live in small villages, isolated and segregated areas, with limited access to services, including health care, and poorer overall health than non-Roma. A significant proportion of families live in extreme poverty and were therefore more vulnerable to the pandemic. More closed communities were also more easily exposed to scare stories and misinformation about the pandemic because they lacked access to reliable sources of information, lacked experience in selecting these sources, and many were only informed by unverified news circulating on social media. Experience has shown that in communities where there have been more serious illnesses or deaths, there has been a greater uptake of vaccination. (However, there has also been experience of deaths being attributed to the effects of the vaccine, even though the death was not caused by a COVID-related disease.)

Vaccines were only available after a state registration procedure. Electronic registration required a working email address, which proved to be an insurmountable obstacle for many families, especially the elderly. In disadvantaged regions, several NGOs and church organisations have launched a campaign to support vaccination uptake. This involved Roma activists visiting settlements and helping people to register for vaccination and hand over information.

An important trend, which has been growing since COVID, is that we have seen more and more cases where children are no longer examined by the medical doctor. In these cases, parents inform the doctor about their child's problem by phone, the doctor uploads the prescription to the online data cloud, and the parent goes to the doctor to get a certificate (for the school) for the child for up to two weeks. However, this seemingly flexible and user-friendly system is open to abuse, as families who are unable to judge the severity of the illness and-or are not under strong pressure to send their child to school, are effectively exempted from going to school without any substantial illness.

- ✓ **Discrimination and antigypsyism**

There is no comprehensive data available in Hungary on cases of discrimination against Roma in health care, but some previous research reports clearly confirm the existence of this phenomenon. According to a 2009 survey by the European Agency for Fundamental Rights, 18% of Hungarian Roma experienced discrimination in healthcare in the previous year.

The results of a survey among health care workers (PTE, 2018) also confirmed the presence of prejudice against Roma in patient care. The findings of the research showed that it most often took the form of unjustified waiting, altered tone of voice or communication elements (e.g. grimaces). In some hospitals, the use of so-called 'Roma wards' is common practice, which is perceived by Roma patients as overt discrimination, while health workers believe that this is in the interest of both Roma and non-Roma patients due to cultural differences (e.g. large numbers of loud relatives visiting Roma patients).

According to health care workers, cooperation between Roma and the health care system is hampered by the health care system's lack of knowledge about the specificities of Roma culture: for example, practitioners do not know the reasons for and the importance of social support and family presence together at the doctor's, do not understand this phenomenon and therefore do not like it.

Prejudice in the care system does not necessarily lead directly to poorer care or poorer health, but it can contribute to a patient's subsequent failure to seek medical attention in a timely manner because of a negative experience, whether lived or perceived. Other research (Babusik, 2007) also shows that perceived or real discrimination can affect the willingness of Roma to participate in screening.

Discrimination may lead to mistrust of the care system and doctors, and may even result in Roma patients being reluctant to seek care when they urgently need it. Several sources refer to the late access to doctors and the high prevalence of neglected and untreated diseases in the Roma population.

Our interviewees did not encounter any manifest prejudice or discrimination, but they did perceive that there are differences in the treatment of Roma. For this, they blame the Roma at least as much. 'I am a Roma, but I don't get on with them. I tell them that.' Another interviewee has a similar view: 'Roma talk to the doctor in a phlegmatic, insulting way. For me it's a shame. Their behaviour also affects my image.'

In one case, ethnic discrimination was mentioned, curiously in the case of a hospital specialist of Arab origin: ‘There is no respect for patients as doctors used to have. They are not thorough. And he looks at you like a monster. And he's blacker than I am. I don't know where he came from, but he's not like the old ones. Everyone calls him boss. He expected it.’ She thinks he's explicitly anti-Gypsy. She asked what he had against her, but he just gave her a dirty look.

Conclusion and Recommendations

Based on our experience and our current interviews, it is difficult to draw a specific picture of the health situation of Roma, as the problems they face or factors that significantly affect their health are common to the majority society, as well. The difference can be found in the extent of the impact of the problems and perhaps in the reactions and ways of coping ('coping strategies').

However, even in comparison to the Hungarian society as a whole, which is already in poor health, the Roma society does not apply prevention, their health awareness is not mature, and their lifestyle is inherently high risk.

A typical response to long waiting lists for check-ups and treatment is to turn to private health care, which is not the case here. In one case, we heard that treatment (surgery) had taken place by ‘seeing a doctor in Budapest’, but the meaning of this was not treatment in private health care, but the use of medical gratuities to avoid the waiting list. The question is whether the Roma people in the settlement have any knowledge of private care. (We also asked questions about the use of dental care: only one woman has used private care. Only one woman has only used dental services. Nevertheless, they do not use even the state-run dentist service.)

In cases where care is linked to a waiting list, it tends not to be used, leading to serious further deterioration in health.

The usual answer to the shortage of doctors (which is partly responsible for the waiting lists) is to look for a solution in Budapest. However, in many cases, the reason behind the use of Budapest is a lack of confidence in the quality of care provided in the smalltown hospital, where there is indeed a serious shortage of doctors.

The fact that the health problems of Roma are not or not sufficiently addressed by the health care system can be explained by many interrelated factors:
- In cases where those on the waiting list are not using prevention, their health awareness is ill-informed or incomprehensive and their lifestyle is inherently high risk;
- They do not understand health communication (but of course this is also true for non-Roma patients!), which makes them avoid interactions;
- Communication problems, frustration with waiting lists, conflict management problems in many cases and sometimes patronising treatment can lead some to aggressive behaviour that cannot be managed by health staff. This is compounded by an overall prejudiced expectation of Roma by the care system, which is a source of shame for Roma as a whole - and again, a disincentive to seek care;

- Instead of the immanent promise of fair health care, the parasolvency approach is being replaced by private health care that is truly higher quality but Roma patients have neither information nor experience of this. What is even more problematic is that most of them will not even be able to afford it (as we have seen in recent years with the virtual privatisation of dental care).

Today's Hungarian state health care system, as mentioned in the material, provides very low quality care for all Hungarian citizens. It is even lower if you live far from the big cities. In addition, however, with the sometimes explicit and sometimes implicit support of the government, a system of private care institutions (hospitals) has been built up and is gaining strength, whereby appropriate services can be obtained, of course for a fee.

The use of this service is of course shared by the whole of Hungarian society, depending on the resources available to each individual, but if we look at the financial situation of the Roma, it can be said that this parallel care is completely inaccessible to them. Those who could afford to use private care do not have adequate information on how to do so.

Thus, Roma are left with either state care that is barely suitable for treatment, if it is available at all near their place of residence, or higher care that can be obtained for a parasolvency fee (illegal payments) under the state health system. Thus, it is not only the previously known anti-gypsyism bias and prejudice, but also the fundamental transformation of the health care system that is an obstacle to the adequate health-care of Roma. It could be argued that by emptying out and neglecting the health (or social) care system, the state is also failing to provide adequate care for the most financially deprived.

- ✓ **National Roma Strategic Framework**

As indicated earlier in the case study, the residential distribution of members of Roma communities in Hungary is not uniform, and data collected in different areas cannot be interpreted for the whole of the Roma community in Hungary. A major weakness of the health chapter of the strategy is that it does not envisage coordinated policy interventions to balance territorial disparities.

Complex socio-economic and cultural factors play a role in maintaining and improving health. Together, these shape the sources and preconditions of health in multiple interactions. All sectors, ministries and institutions of society are therefore equally responsible for health, and health promotion is a cross-sectoral, cross-societal task.

The strategy's partial focus on the preconditions and resources of health foreshadows a failure of effectiveness.

The scope of targeted programmes is generally very limited, both in relation to the size of the problem and the target population, and they are not well suited to addressing the inequalities created by problems of the primary care system.

- ✓ **Positive solutions, good practices, and recommendations (bullet points)**

A positive practice is Vaccinate to Live - a civic information campaign in slums to support registration for the covid vaccine and to share useful information about the disease.

Also worth mentioning are the screening tests carried out by several NGOs (Maltese Charity, New Start Foundation) in remote settlements without health care services.

EMMA Association: Community based 'doula' (midwife without formal health care education) program.

Recommendations

- Designing educational formats that break the intergenerational patterns that inevitably lead to unplanned adolescent pregnancies, untreated internal medicine, gynaecological diseases or problems with self-acceptance. To do this, it is not enough to target girls (children), but women (mothers) must also be involved.

- The development of health care that takes into account the specific needs, sensitivities and fears of Roma girls, and the introduction of intimate, personalised forms of education in public education.

- Campaigns on health issues that identify common health problems in a clear and concise way, and provide guidance on where to go (while at the same time fighting against harmful forms of self-medication), should be conducted on the (social) media platforms favoured by Roma.

- Like the 'doula system', a programme should be considered in which Roma women who are willing and able to do so can act as informal counsellors for girls and women, helping them navigate in the health system, mediating and bridging the gap. This might also help to combat taboos about sexuality and physicality. (As one interviewee acts now in her community.)

- As we experienced making interviews, Roma women, mainly girls are reluctant to undergo, or even refuse, medical examination when it is done by a man. These situations could be avoided by a sensitive and culturally informed patient management system.

- It is important that more Roma professionals work in the health care system. This could be achieved through targeted support programmes and scholarships.

- Sensitising the health care system, improving the knowledge and attitudes of practising and future doctors and nurses towards Roma, for example through basic and continuing training courses.

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