



THE SITUATION AND POSSIBILITIES OF ROMA WOMEN IN MATERNITY CARE



‘Where there's a child, there's blessing too.’

Anita from István-akna, mother of two children

Ez a kiadvány a Születésház Egyesület *Tedd meg az első lépést! Együtt a nőikkel a tiszteletteljes szülészeti ellátásért* (Norvég Civil Támogatási Alap), illetve a *Szülési jogok és esélyegyenlőség* (Nyílt Társadalom Alapítvány Budapest) című projektjeinek keretében, roma nők körében felvett mélyinterjúk tapasztalatait foglalja össze. Az interjúk célja az volt, hogy mélyebben megismerjük és megértsük a megkérdezett roma közösségek nőtagjainak tapasztalatait, szükségleteit és igényeit a szülészeti ellátással kapcsolatban.

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I. INTRODUCTION

Entering the maternity care system every woman needs the same: personal attention, personalized care¹, real support and the respect of her dignity. The Hungarian maternity care system is not able to grant all of these to women due to systematic problems and the approach taken. Most women feel vulnerable in the paternalistic healthcare system. **If someone belongs to a disadvantaged group (like Roma, disabled, etc.), it makes them even more vulnerable and multiply disadvantaged.**

BirthHouse Association held five professional days in 2014 with the title '*Diversity and access to maternity care in Hungary*'². In the course of this we committed ourselves to map the special situation of certain groups of disadvantaged women in maternity care and to reveal possibilities for improving the current system involving professionals, managers of institutions and the women concerned³.

Preliminary to the professional forums, our basic assumption had been that women regarded as disadvantaged in any respect, as well as women belonging to the so-called majority, face the very same problems in maternity care, 'only' the extent of the problem differs: **women belonging to various disadvantaged groups are affected by the negative effects of the system multiply, which is even further aggravated by their poor possibilities of advocacy.**

Continuing our previous work, this year we paid special attention to the situation of women living in extreme poverty, including Roma women in maternity care. Roma women are multiply disadvantaged in many areas of life, since they are discriminated both as women and as being Roma.

As part of another project⁴ we conducted 20 in-depth interviews with women from four segregated Roma communities in the towns of Told, Szakácsi, as well as in two suburbs of the city of Pécs: Györgytelep and István-akna. The informal interviews gave us the opportunity to understand their situation and preferences in maternity care and to identify the problems and their causes.

In the present study we primarily investigate the interviews conducted with women along the following topics: family planning, prenatal care, access to care and information, personalized care model, obstetric interventions, communication with and treatment of women, discrimination, and community-building. We use verbatim quotes from the interviews, but changed the names of women in all instances. In addition to the interviews, we also consider it important to share the experience of the discussions and round-table talks with health professionals and NGO representatives, which took place in the course of the above-mentioned programme series.

II. SELECTED ROMA COMMUNITIES, CONSIDERATIONS

While selecting the settlements, our primary consideration was to meet Roma women living in communities in extreme poverty and segregated places. We had access to these communities and women through NGOs working in the same settlement or region. The common traits of the three settlements are that families live in extreme poverty, are mainly unemployed and Roma, however, these communities differ from each other in terms of structure and organization.

1. Szakácsi

Szakácsi is a small village located at a dead-end road in Borsod-Abaúj-Zemplén County, in Edelény subregion. According to official data the population is 155 inhabitants⁵, primarily Roma people. There is a lack of job opportunities, mobile phone coverage is minimal, except for mobile network code '30' which is used to call ambulance or other assistance. The *Bódva-völgyi Közéleti Roma Nők Egyesülete*⁶ ('Roma Women in Public Life of Bódva Valley Association') works in this region seated in Edelény, 30 km from Szakácsi. The village is virtually untouched in the sense that social work is not present in the village and NGO activities or projects do not reach here either. **Six interviews were conducted with women there.**

2. István-akna, György-telep

István-akna and György-telep are two segregated settlements belonging to the southern Hungarian city of Pécs. The fate of the two settlements was heavily affected by the layoffs carried out in the industrial plants after the fall of communism. The problems deriving from segregation are further exacerbated by the fact that the spatial segregation of different local social groups is not only based on financial aspects but it is also determined by ethnicity. About 100-150 people live in the two areas, mostly Roma people, job opportunities are also very limited here. However, in contrast to Szakácsi, NGO and municipal efforts are taken to abolish the slums.⁷ We contacted the women living in the settlements with the help of *Kethanipe Egyesület*⁸ ('Kethanipe Association'). **We carried out seven in-depth interviews with women there.**

3. Told

This village lies in Hajdú-Bihar County, in Berettyóújfalu subregion, eastern Hungary. This is also a small village at the end of a dead-end road and has 387 inhabitants. Most inhabitants are Roma people, who can find jobs through the projects of *Igazgyöngy Alapítvány* ('Pearl

Foundation') operating in this area.⁹ A community-building activity is present in several areas thanks to the Foundation, including a mother and baby club, where we could meet women in person. **We conducted seven in-depth interviews with women in this settlement.**

III. CONDUCTING INTERVIEWS, METHODOLOGY

We met and spoke with nearly 30 women in the three settlements and carried out interviews with 20 of them.¹⁰ During the interviews we were mainly curious about what women themselves find important to say about having children, first of all about topics regarding childbirth: pregnancy, delivery, healthcare and the assistance granted to them, as well as their own needs.

Planned method: narrative interview

Taking all these topics into consideration, we chose a **narrative unstructured interview** as the method of interviewing. In case of narrative interview the researcher has an initial topic without particular questions and lets the interviewee talk freely about the given topic. It is essential how the interviewee wishes to be seen, what stories they reconstruct, what they emphasize and what they leave out.¹¹ During the interviews we are interested in the other's personal, confidential, inner feelings and thoughts, therefore it is crucial to maintain a trusting relationship between the interviewer and interviewee.

Establishing trust – motherhood as link

There were several levels to gaining their trust. We got in contact with the local NGOs which served as a gateway to the community. Before conducting the interviews we had travelled to all three settlements several times to meet the communities and women – with the help of the organizations –, so that when we came for the interviews they had known us and seen us in the village before. We brought our own children every time and joined the current community events, the mother and baby club, cooking together, apple peeling (Told, István-akna). **In fact, the latter opened the door to women and created the basis of confidential atmosphere between us: a situation where we are related to each other as women and mothers.** In line with this, we had to dismantle the formalities of relationship between researcher and interviewee. We carried out the interviews mainly with children around, eating, having coffee, smoking together.

Challenges, difficulties, solutions

However we could not implement the classical form of narrative interview completely as we had originally planned. This was partly because most women found the situation difficult that they were given the opportunity to talk about themselves at length without interruption and that what they say is important and matters. **It turned out to be the greatest challenge for us: to make women understand that there isn't any right or wrong answer, it is important what they say and think about a particular topic.**

In order to dismantle the barriers we had to change the original 'unstructured' form of interviewing and we facilitated the flow of talk by asking the following questions, among others: what did they know about pregnancy and childbearing beforehand? What barriers were there in the access to maternity care? What kind of problems did they face during care? Who did they get help from? What else could have helped?

Although the questions helped the flow of discussion, it often occurred that we had to rephrase a simple question because it was not comprehensible for the interviewee. We experienced that a language barrier was a main factor in communication, which may have several causes: low level of education, different attitude to healthcare issues, distinct cultural norms of the local Roma community, existing taboos and their effect on the women of the community, etc.

IV. ROMA WOMEN IN MATERNITY CARE

In the following, we summarize the findings and conclusions of the interviews with Roma women and the two professional round-table discussions.¹²

1. Family planning

In order to improve the situation of women and families living in extreme poverty, the key areas are family planning, and conscious preparation for family life as well as creating employment.

Sexual education, and contraception: the Committee on the Elimination of Discrimination against Women (CEDAW) in its 2013 report drew the attention to the fact that disadvantaged women (disabled, Roma, HIV-infected and migrant women) in Hungary are especially afflicted by healthcare problems in connection with abortion, early pregnancy and preterm birth, which can be related to the lack of access to appropriate family planning methods.¹³

The participants of the round-table agreed that the most essential point during family planning is sexual education, especially providing information about the possibilities of

contraception. According to the experience of health professionals, couples are extremely uninformed about contraception, they lack the basic anatomical knowledge whereas the responsibility lies disproportionately on women. The number of competent professionals is insufficient. Meanwhile, there is little opportunity to prepare young people for sexual life appropriately (i.e. public education and lack of programmes).

It is still common and accepted to start sexual life at an early age in the closed, traditional, mainly Roma communities: young people 'marry' already at the age of 15, they keep the early-conceived baby and raise them up with the help of the large family. Childbearing, parenting and the motherhood of young women are family affairs, and above all women's affairs.

The problem of giving birth as a young adult was raised mostly in the interviews conducted with the community of István-akna. Three of the interviewees gave birth at 15 and 16 for the first time and it was obvious in all cases for the mothers and their families to keep the child and raise them with the help of the grandmothers. According to an influential figure of the community in István-akna, who had been the Roma municipal president earlier, it is not the youth who should be addressed but their parents, particularly the mothers.

'They aren't prepared at all. They just find it funny that they are dating a boy, then are so proud to get pregnant. But they don't know what pregnancy is all about. Moreover, they aren't in a relationship... The girls livin' here nearly nobody is in relationship... they just... you know... they have another baby, even if they aren't in a relationship and this is so funny that they become mums. And when I sat down to talk with them I told them that they started irresponsibly and they are offended: "but we are in love!" They don't take note that they could use protection. It isn't the young mothers that should be addressed first but the older mothers. They should be prepared... it is no point in talking with a 14-year old girl, they let it go by, it is funny for them to have a baby, she wants to grab the boy because the girls today do that. The older mothers should be addressed so that they'll be able to prepare their own daughters because the problem is with them. Because the mothers are either prudish, or started early themselves – so if I did it, you should do it too.' Nóra, István-akna

'I was 15 at that time. But it wasn't good like that. We knew that there'd be a baby and then came this question of course whether we keep her or not. I was at school that time and it shouldn't have been then and I didn't know what responsibility it is. I just accepted that I'd have a baby then but it was bad that I could've had my young life and I had to put up with it...' Anita, István-akna

Roma people and a high number of children: the assumption is still alive in society that Roma families have a higher number of children. This assumption was partly supported by

a research finished in 2011 conducted in the two multiply distressed and ethnically mixed regions investigated by us (Borsod and south of Baranya).¹⁴ The research showed that lower education correlates with having more children than average but it also depends on which ethnic group and which region is investigated. Based on the findings of the research, the ethnic composition (i.e. the higher than the national average rate of Roma population) contributes to the rate of fertility which exceeds the national average. *'It is not only the worse structural position specific to this ethnicity to blame, but there are other factors implicated as well. In order to understand the nature of these factors and the meaning of ethnicity, and thus conclude whether the factors are really linked to the cultural characteristics of the Roma people, further research is needed.'*¹⁵

Regarding the topic, participants of the round-table reported that according to their experience birth rates have been decreasing among Roma families recently. While earlier even 6 or 8 children were not uncommon, today it seems that they do not plan further children after the 3rd or 4th child is born. The decrease of birth rate also implies that there is a change in the role of women in Roma community: it is becoming more significant for Roma women to have a career as an alternative to motherhood as well as to have an opportunity for conscious family planning and contraception.

In our study, 3 out of the 20 interviewees had 8, 6 and 5 children, the others gave birth to 2 or 3 children. It is also important to note that 11 interviewees gave birth to their first child over the age of 20, 6 women at the age of 17-19, while 3 women gave birth at the age of 15-17 for the first time.

'– And how many children do you want? – Two. For the time being, then we'll see. I don't dare to have 5 children. That's for sure. Sometimes even Lili is too much.' Emese, Szakácsi

'My daughter is now 16, finishing the eighth grade, she and her boyfriend are in love with each other, but will it last... You know the father is not stable himself, financially. And he'd had a long relationship which he quit. We have a good relationship, (but) somehow he hasn't developed pride about family and children. And also I don't want (her) to live this life of parenting and then there is this man beside her, who, I don't know, will either raise her or push her under. And now she hasn't even gone out really and a man dictates what to do.' Léna, István-akna

Economical position, financial reasons: Participants of the round-table agreed that the lack of family planning among families living in extreme poverty in disadvantaged settlements is partly due to financial reasons. Contraceptive drugs and condoms are too expensive for families, in their financial situation: they are often unable to afford them .

According to ÁNTSZ (National Public Health and Medical Officer Service), 45% of people appearing at Családvédelmi Szolgálat ('Family Services') did not protect against unwanted pregnancy, that is, did not use any form of contraception (e.g. natural method, condom, contraceptive pills). **Many of them explained the lack of protection with the high price of contraceptive devices, pills but they did not use any other method or device either.** In 2010, 12% of women applying for abortion asked for another abortion again within 1 year.¹⁶

'There is no money for the pills here. So you have to deliver the child because abortion is not the custom. You can buy a condom but that's also expensive (a packet costs 1000 Ft, there are 3 pieces in it). And a young couple wants it more than three times. Even us, old people do it more than three times...' Tamara, Szakácsi

Based on the experience of health visitors and other participants, **conscious family planning comes into view when a family manages to improve their social status achieving better financial circumstances.** In those families where the mother and/or the father is employed, much more attention is paid to contraception.

2. Access to care

According to a research report conducted in 2012, regional disparities in healthcare is one of the greatest problems with respect to social exclusion in the Hungarian healthcare system¹⁷. Disadvantaged regions are characterized by a lack of professionals and hard-to-reach services. This is supported by a research report carried out in 2010 on the behalf of *Egészségbiztosítási Felügyelet* (Health Insurance Supervision), which showed that regional disparities in healthcare service do not derive from the variation in demands of the service.¹⁸

Based on the round-table discussions and the interviews we concluded that one of the biggest problems of mothers living in situations of extreme poverty – and often in isolation – is that they are less likely to attend prenatal care, especially care by an obstetrician. Most frequently, this is because of major obstacles to (physical) access to obstetrical care, i.e. the hospital or clinic may be located 20 or 30 km from their home.¹⁹ Meanwhile, the opening hours of obstetrical clinics do not take into account public transport schedules, meaning that it is virtually impossible to arrive at the obstetrician's appointment on time and return home the same day travelling by public transport. **Thus, it is usually not a personal decision by women living in extreme poverty and in isolated villages not to see the doctor – it is rather an unsolvable problem.**

All the women living in the settlements who were selected for interviews mentioned the difficulties related to access to care. Women living in Szakácsi have to travel 30 km to Edelény for obstetric care. Women in Told have to travel 23 km to Berettyóújfalu, while those living in István-akna and Györgytelep have to go to the clinic in Pécs 13 km away.

'A round-trip bus ticket is 1,000 forints, and that's just the bus. Sometimes I had to choose between buying bread for my child or going...' Ildikó, Szakácsi

'It is often a problem to manage travelling. Just going a few stops, that's already one ticket, then the health visitor sees them. Then they have to go to the doctor, at the other end of the city and that's another bus ticket. It takes hours, from morning until afternoon.' Anett, György-telep

The municipalities try to solve this problem by taking women to doctors' appointments with the village car, however, it usually happens that the municipality does not provide this service as originally intended.

'... I've just talked with the mayor, sayin' 'give me the village car', he nodded, he will, but that I should refuel the village car. But then when they took someone else, they didn't have to refuel. And then he even took that guy at night, but not this one. Here they really show favors.' Olga, Szakácsi

Access to care and its barriers was a main topic at the round-table. Regarding this, Dr. Zsolt Zákány emphasized that most of the specialized mobile medical units were discontinued, although they have numerous advantages in the care of women living in extreme poverty and in small villages: mothers can have complete access to specialized care, if there is a chance to get to know their circumstances and to establish personal contact and successful communication with them at the right time.

3. Maternity care

Hungarian maternity care has two pillars: basic care is provided by the local family health nurse and the GP, while specialized care is available at the local obstetric health center. According to the experience of women, the least important point of maternity care proved to be the visit to the obstetrician. Women can rarely expect personal attention and proper information from the care provider obstetricians beyond the compulsory examinations (blood collection, ultrasonography, physical examination, etc.).

'And when you ask, you want to know something about pregnancy, if everything is OK, they just don't say; don't answer clearly; just want to finish the examination quickly, so they can go to the next woman.' Margó, Told

'Private doctor? No. Useless. You feel the same pain. He can't help the birth anyway. And the advice he's givin, ney, couldn't use anyway. And then the birth, now, that goes on its own.' Margó, Told

'My experience is that care is like on an assembly-line here in Pécs. And they don't say anything. They make the woman lie or sit down on the examination table, they put on the sensors, give her the button and tell her to push it when she feels movement – but what this is important or good for, such things are not mentioned. Therefore, if she doesn't know what it is for, irrespective of her education, she won't find it important. In people's minds radical examinations seem to be important, when they cut, drill, carve, wow, that's surely important. But when there is such a simple, painless thing, they think it can be neglected. It does not even provide some visual experience, like sonography— although it is not common here to show the child during sonography, doctors usually don't turn the monitor at any point of the examination, saying here's your child. Even though it would be important.' Anett, György-telep

In the current maternity care system women have most contact with the family health nurse during pregnancy. The family health nurse visits all three settlements once a week, usually on a specific day. However, the effectiveness of the local family health nurse service is significantly hindered by the high number of job vacancies in disadvantaged areas, resulting in a significantly higher number of clients per family health nurse.²⁰

The interviewees gave different opinions on the role of family health nurse. At one extreme, they regard her only as a representative of authority and embodiment of rules, whereas on the other hand, which is less common, they regard her as a source of information and personal care.

'Well, I had a very nice family health nurse, I love her to this day. I went to obstetric clinic, she came with me, prepared me and everything.' Helga, Szakácsi

'She was a very kind person, she was so nice, I could talk to her about anything. She sent me to examinations, I went everywhere, I went to Barcika (the city) for sonography. She did everything, there was no problem, I would go.' Emese, Szakácsi

The birth outcome depends largely on the physical and mental course of the pregnancy for both the mother and the baby. 'Pregnancy is best controlled by the mother' – said Dr. Zsolt Zákány, who claims that it is essential to support the mother's inner strength and effort in this. Women should be informed and helped based on their needs and demands from the beginning of the pregnancy. The interviews made with women support and confirm this to a great extent. Women claimed, however, that they do not get the most important and most appropriate support from health professionals (doctors, local health visitors, etc.) but from their mother, mother-in-law, elder sisters, mother and baby club leaders or from each other.

'We usually discuss it together in two. She knows more than a doctor.' Margó, Told, who discusses pregnancy-related issues with her sister-in-law with four children.

'It was great for me that mum was around, I expected her to be there. She was there beside me, helping me in everything.' Anita, István-akna

'I firmly believe in personal contact. It is worth starting with 'I understand you but let's try to discuss'. It works in most cases. They acknowledge me because I'm local and they've known me since I was a child, also I'm Roma, I have positive experiences. They often bring me half of a lab report, I'd tell them the other half, then they trust me and come back next time. Style is important: I don't speak down. Knowledge is not only what I've learnt, but also what she's experienced.' Anett, György-telep

4. Obstetric care: birth, interventions, neonatal care

According to Dr. Zákány's experience we cannot disregard the fact that the primary task of the obstetricians is the care of complicated cases, and this is what they receive thorough surgical training for. The technical tools and innovations that have become available in recent decades have also contributed to the demand on external control of medical devices, which has been increasing even in the assistance of normal births.

Due to the spread of medicalization to such an extent, the profession has become alienated from the nature of birth, and interventions are used increasingly in a routine manner. In 1999 the World Health Organization (WHO) drew attention to the spread of medicalization at maternity wards among others when it investigated the **evidence for and against the most commonly and routinely used birth interventions** and, based on these findings, published their recommendations in relation to normal childbirth.²¹

Given the above, it is not surprising that during our research all the 20 interviewees (except for rapid labour and non-intended homebirth) underwent some sort of medical

intervention in the hospital, i.e. contraction-amplifying oxytocin, episiotomy, amniotomy, Kristeller maneuver (pressing the uterus from the outside through the mother's abdominal wall to accelerate the birth), caesarean section, analgesia (oxygen mask).

Women perceive all interventions without exception as bad experiences and thus consider childbirth an event that one should get over and survive:

'When I was delivering Annamari, they elbowed into me, really... ney, they didn't care nothin, and wouldn't help, like a doctor should, but elbowed me in the stomach... it hurt, even after that, my bones here would hurt.' Olga, Szakácsi

'Well, it didn't hurt, just my stomach. Giving birth didn't [hurt]. A lot of infusion relieved the pain. They even gave a mask.' Norina, Told

'They given me a lot of gas during contractions. It been better if they didn't, cuz my little girl ain't suckle then. Cuz they say, that, I read in a book, that a child you get this gas with, sleeps more and you see, the baby need suckle the first 3-4 days and the first days matter most for the milk.' Tiffani, Told

'I wasn't put asleep, but this... (epidural). I was very scared, even though it was the third because with Nikoletta I was forced... well, not forced, I had to get it because she was stuck in the birth canal and would have lasted longer if I didn't, and then the doctor suggested it and I got a half, so I could relax and with normal childbirth. They didn't have to do vacuum, as is so fashionable nowadays.' Léna, István-akna

Since there were interviewees on all three settlements that received oxygen mask for pain relief, it can be assumed that this method of pain relief is widespread in rural hospitals. None of the women reported that it would have helped them during labor, on the contrary.

'Well, I saw two of everything, imagine, I opened my eyes, I saw two doctors, all of them double. I was dizzy. Oh, as if I been drunk. And just cuz they gave me the gas. It hurt the same, it just makes you high. Well I still screamed, coz they gave it to me to shut my mouth. The midwife brought it. She thought, you won't scream when you inhale it, at least you'll be silent then.' Mari, Told

Caesarean section: 5 of the 20 women interviewed gave birth by Caesarean section.

'There are a lot of caesareans, it's around 60-40%. 40% is caesarean. (It's like) Someone comes, opens the door and you come out. I told it even to the doctor, of course if it's justified it's understandable, but if it's not really justified, they steal you childbirth experience. My experience is that the women around are afraid, what if there is another caesarean... This is also a fact that in most cases a young resident doctor is on duty. He doesn't dare to take such a risk, to wait for another two hours to see if the head comes through. But he knows then, if it's caesarean, a 'big doctor' will come beside him and the burden is divided proportionately. The problem is that we're talking about responsibility and not psychological burden. Thus, partly because of inexperience, partly because they aren't prepared, they don't really dare to go into a situation – not even a risk, just a situation to wait for another two hours.' Anett, György-telep

'My belly is a little insensitive there, cos I guess they had to cut a lot of muscles, and it's a little itchy in bad weather. It healed very quickly, but I can pull the pants only to below my tits, because under that I didn't feel anything but pain. They had to go well deep to make room, to be able to take them out.' Léna, István-akna

Newborn, breastfeeding: The interviewed women emphasized two things regarding the topic after birth. Firstly, that the baby is put on the mother after delivery and this is the best experience of their childbirth, however, shortly afterwards the newborn is taken from them and given tea and formula in their absence which affects their future chance of breastfeeding.

Helga (from EdeLény) reported that she lost her milk after two and a half weeks although she wanted to breastfeed: *'They didn't say nothing. They just took her, gave her something, took her back, that's all...'*

Tiffani from Told did not manage to breastfeed either. *'When they took the baby, he just latched and fell asleep. I was quarrelling with them, don't give him neither tea, nor formula but take him to me. I'm sure he got something, cos' when he arrived, he was just sleeping. They messed it up, cos' I always had this dream, that he is born and I nurse him and he suckles.'*

Gratitude money,²² financial situation: According to women's report money determines their quality of hospital care. If they give money to doctors, they get more attention and better care, and if not, the woman in labour gets less attention. Whereas, Roma people have a good chance to be put in a separate ward. (The question of physical segregation of Roma is detailed in the chapter about discrimination.)

'Well, I think I should have given money to the doctors. You see, I'm poor, I couldn't give them it. That's the truth. They didn't care about me, they ignored me.' Emese, Szakácsi

'If you have money you get to the VIP room. Those who are better situated get to the twin-room, poor people get a less quiet room.' Anett, György-telep

Only few of the women interviewed said that they had a private obstetrician at the hospital. Two of them reported that they gave gratitude money to the obstetrician at the birth of their first child but later they didn't. An interviewee from Szakácsi gave even exact numbers about the 'tariffs' of one of the obstetricians working in Kazincbarcika: C-section is 150,000 Ft, normal birth is 80,000 Ft, while prenatal care costs 10,000 Ft per visit.

'A private doctor? I never had one, it was always the doctor on duty. What for? They don't pay more attention. With some of my friends it turned out at the last minute that their private doctor was abroad. I felt then it's useless. It was a different doctor every time and I was always satisfied.' Léna, István-akna

5. Treatment, communication

In 2014, the WHO published a statement standing out for the fundamental human right of women to receive the highest level of care possible in pregnancy and birth, and to be treated in a manner commensurate with the principle of human dignity.²³

The present healthcare service, the disrespectful treatment of ignoring women's autonomy violates women's rights and has a negative effect on the physical and mental health of women and their children and the well-being of families and society.

The treatment and communication in hospitals was a recurring theme in our study. However, interview subjects did not emphasize inappropriate treatment or insufficient information as a problem 'worth mentioning' in itself, but spoke of it just as part of their experiences.

Treatment: The expression 'I was left alone' came up frequently during our discussions. Annamária from Szakácsi mentioned it 11 times while narrating her own experiences that she was left alone in the hospital.

'The doctors left me in the delivery room. I gave birth alone. Even her leg got stuck. Oh, it was terrible. My baby nearly died, I shouted in vain for the nurses that the baby is out, they did not come in. They came 10 minutes later when I was really screaming for them to come.' Annamária, Szakácsi

'I had a dead fetus and I had to deliver him too. See, that wasn't nice. They pull it with weights. And they leave you alone. I was lying there from 8 in the morning until 10 in the evening. Noone bothers. So there are bad experiences too.' Betti, György-telep

Treatment and communication are inseparable concepts. Ill-treatment is usually accompanied with a humiliating communication or the lack of communication.

'The consultant asked me, why I didn't have sex with my husband so that I would open and deliver. Now, how can he say something like that?' Annamária, Szakácsi

'I sayin', doctor, I can feel you stitchin' me, I say, this hurts so much. She was speaking with a nurse, turned a deaf ear, didn't listen that I feel that she is pulling the thread, that hurt so much. But I forced myself and said to myself, oh my Lord, I don't mind, I can bear this. I don't care what she's doin', I'll bear it for the child. I got over it and that's all.' Emese, Szakácsi

'But this second, Paul, this, this was cruel. They ain't treat me right. I given birth in Miskolc. Both of them, but I regret I gone there with the second, cos' they ain't treat me right... I guess cos' I'm Roma, that's why. But ain't everyone the same. Now, there are filthy, smelly ones! Ya see, I don't belong to them! I ain't like that. But they lump together everyone. Well, I don't know.' Gizi, Szakácsi

'I went home for the stuff, I ran into my doctor on the way back. I told him, doctor, we gonna give birth today. But I saw on his face that his day is screwed up from then. Meanwhile we waited two hours for me to open, the doctor examined, it is still 1 cm. He says, 'it'll be cesarean'. I say, what, after two hours? But I felt I giving up. It is so humiliating, so unpleasant that they are pushing me into the operating room and I get to know from the assistant that I'm operated because the doc's child is having a party.' Anett, György-telep

Communication barriers and possibilities: Every woman has the right to gain service in their mother tongue and in a manner that they can understand. An accepting and non-judgmental manner of communication is a prerequisite to establishing a trustful relationship. Women living in extreme poverty are typically not highly educated, they have difficulty or are unable to interpret technical terms used throughout the care process. Since they are insecure in an institutional environment, they rarely ask questions or ask for help. Participants of the professional round-table discussion agreed that it is extremely important to provide the mothers with instructions that they can understand and follow, throughout the care. In addition, in the

case of the Roma women coming from more traditional, typically closed Roma communities it is essential to know and respect the cultural differences: the Roma concept of disease was mentioned as an example, which is different from that of the majority population, as well as family hierarchy and its role in the communication of patients and professionals. Round-table participants also agreed that it would provide significant help if there was a supporting person available for Roma (and non-Roma) women who are unfamiliar with technical terms and care processes and have difficulty finding their way in healthcare institutions. Someone who would explain to them in a comprehensible manner what would happen and how during the examination, what the lab report says, what is further to be done, etc. Professionals agreed that it would be necessary for both sides to disclose the information appropriately and raise awareness. It was also unanimously agreed that the primary goal of a mediator should be to support women in making use of their own abilities, but opinions were divided whether it is important and necessary for the mediator to be Roma.

Roma culture and identity: It was a recurring question during the round-table discussions if it would be possible and necessary to establish maternity care sensitive to Roma culture. Can we speak about Roma culture and identity at all in general, while there are at least three large Roma communities different in language and traditions, and in addition, the inner rules of Roma communities may often differ within one village? Professionals emphasized that Roma culture and identity are not community-building forces any more. It was explained by the professionals and supported in interviews with women that one generation earlier traditions had been much stronger and had meant real organizing force, whereas they have disappeared from most places by now. Traditions have been replaced by a multitude of local rules typical to segregated communities living in hopeless situations. These systems of rules bear traits of earlier traditions and have features deriving from poverty and segregation, as well as features coming from local conditions. Therefore it is essential to know the conditions of the community and to take it into account during the healthcare of mothers. Considering this, it would be not only impossible but even dangerous to develop a protocol regulating the care of Roma women in general; in present circumstances it would probably strengthen and justify the exclusionary attitudes.

CASE OF ANNAMÁRIA – SZAKÁCSI

Annamária was transported by ambulance to the hospital in Kazincbarcika, where she had a privately paid doctor. When she was taken to hospital she had not been fully dilated and she had to stay in hospital for 10 days until the birth.

'The consultant asked me, why I don't have sex with my husband so that I would open and deliver. Now, how can he say something like that?'

When she went into labor, the hospital staff did not notice since she had been 'just left' alone. Annamária gave birth alone, literally, without professional help. It was a complicated birth, the baby's leg got caught during delivery. Even the umbilical cord had to be taken off the newborn's neck by the mother. Later on, it turned out that the privately paid doctor had been absent from the hospital, he had gone on vacation, but the mother hadn't been informed about that.

'The doctors left me in the delivery room. I gave birth alone. Even her leg got stuck. Oh, it was terrible. My baby nearly died, I shouted in vain for the nurses that the baby is out, they did not come in. They came 10 minutes later when I was really screaming for them to come.'

After the baby was born, it was taken away to be examined. One of the nurses came back and told the mother that her baby died.

'One nurse came in, when I was taken from delivery room, sayin, ma'am, your child has died. I became depressed after that.'

As the mother was crying desperately, the head obstetrician of the department came into the room. Then he informed the mother that the child of another mother died that day, and not Annamária's. The child was taken to Miskolc after the birth but the mother was not informed of the reasons and details, she was only told that the child's life is in danger. She went over to Miskolc as soon as she was able to. There another child was taken and presented to her:

'We went to Miskolc to visit, then the nurse would take another child to me. I told her, you see nurse, I sayin, this ain't my child. Then she starts quarrelling with me, this is your child, how can you throw her away.'

Annamária suffered from post-traumatic stress syndrome after birth, she was having treatment for a long time, and according to her the family health nurse, her mother and her sister-in-law helped a lot in her crisis. She does not want to have more children. She mentioned to have been left alone 11 times, during the interview. The case did not have any consequences, there wasn't any complaint made and the case was not investigated.

6. Personalized care

International best practices which aim to improve the statistics for socially disadvantaged mothers in maternity care (and thus helping the mother and child to a higher level of physical and mental health), are built basically around three concepts.

Access: equal, barrier-free access to appropriate quality of healthcare.

Contact: establishing and strengthening the relationship with the unborn child. Establishing a trustful relationship with a person who accompanies the mother possibly throughout pregnancy, childbirth and early postnatal period, and is present at childbirth (i.e. midwife, doula, supporting co-parent, or obstetrician). Sufficient communication and contact with the mother.

Support: Strengthening and supporting the mother's own power, skills and capabilities, while considering the mother's personal situation realistically.

The importance of personal attention and support was emphasized by all interviewees without exception:

'What I liked most was that I didn't give birth alone. There was always someone with me. My mum was there when I was without a partner. Or else the fathers. I felt I was safe this way. They couldn't help me but still they were there holdin' my hand.' Léna, István-akna

'And it was also good that there were students. Imagine, about ten boys and five girls. One askin', can they come in, I don't care, I'm in great pains, of course they can come. But I was lucky then, that I agreed, cos' there was this girl, who was there really holdin' my hand, sayin' you are clever Juli, keep it up, listen to the voice. She'd bring wet towel and keep goin' to the tap. That help, she'd given me, it meant so much. I told her, then I started cry, I don't know what would have been if you weren't there, tears are still comin' to my eyes.' Tiffany, Told

'Well it surely would've meant a lot if Pisti had been there. Good, cos' they say why there a man, and ya' see the blood, and all, but we are covered there. And if he's just standin' at my head and just holdin' my hand, talkin' to me, that means so much in my mind. It's better than that mask. I'd choose this instead.' Tiffany, Told

The professional round-table participants also put an emphasis on the personal support of mothers. Pregnancy is best controlled by the mother, thus it is essential to support the mother's inner strength and effort in this – said Dr. Zsolt Zákány. But how can we establish an inner control where it's absent? How can we teach it? According to the experience of Nóra L. Ritók and the *Igazgyöngy Alapítvány* the basis of the supporting work to establish this kind of inner control is to establish a personal and trustful relationship between mothers and supporting persons. In the development of trust, however, one of the main obstacles is when the care provider treats mothers with an approach and communication reflecting authority. The expert also pointed out that it is those families which drop out of care who are in greatest need of support. For instance, the system avoids those troubled families, where just the achievement of cooperation would take plenty of time, attention and effort, and often waits until the last moment when the involvement of authorities becomes inevitable. **Very few professionals undertake to visit families due to the lack of preparedness, resource, and often intent.** Professionals agreed that one cannot provide these families with appropriate and efficient care without proper local knowledge. This local knowledge includes being familiar with the conditions of the settlement, municipality and the local service providers, as well as having accurate and real knowledge of the mother's living conditions, and the internal rules, the relations, problems and cultural preferences (how much they preserve e.g. traditions, or religious affiliations) of the community.

The centralization of care, protocol-controlled service and the lack of honest feedback by the staff ('just as long as the paperwork is in order') all result in the aggravation of existing problems.

In Dr. Zákány's view, it is really important for the woman to build a deep and trustful relationship with a supportive person who will be present at birth, but the role of the doctor is overrated in this regard. **The task of the doctor is to avoid complications and the doctor on duty is perfectly suited for this role.** Besides, a doctor on duty cannot be accused of representing a false role with false promises: they are the medical staff on duty, providing treatment to the best of their knowledge and conscience. The primary task of the profession is to ensure that women get the highest quality, evidence-based maternity care from all doctors on duty.

7. Community building

Igazgyöngy Alapítvány organizes a baby and mother club in Told, attended by women, families, including children on a weekly basis. According to their experience it is easier to address and involve women through their children. The women successfully involve their peers in the initiated activities and they are effective mediators towards men in the community.

'It's good, cos' aunt Ivett knows, and she works in healthcare, we've learnt a lot. I also came with Gáborka's papers, final reports and lab reports, that c'mon and help me understand what it means, cos' what the health visitor explains, we ain't understand any of it. In the hospital they talk in English, we don't understand a word, and aunt Iboly explains it so nicely. So much, I learn a lot here too. Well, and in life too. Cos' this aunt Iboly, she's so good.' Jolán, Told

Also participating in the round-table discussions, the colleagues of *Holdam Egyesület*²⁴ ('Holdam Association') operate a women's circle in two hamlets, which is designed for women to share their experiences of womanhood and to support each other through attentive listening, joining common activities and selfless intercourse. **In their experience, informal get-togethers in confidential atmosphere provide the best opportunity for women to talk about the questions and problems that profoundly shape their personality and to reflect on their experience, draw strength, and ask for help if necessary.** The values, stories and beliefs preserved by the community can be observed during these get-togethers. We can understand through birth stories how the community relates to childbirth, maternity care system, and what kind of values and expectations they pass on to their daughters about motherhood.

One participant of the round-table, Klara Farkas (health visitor), confirmed that it is often particularly difficult to involve mothers in programmes which are organized at a venue or in a manner that is alien to their living space. It is necessary for the care provider to visit the mothers in their own environment as many times as possible and to provide them with comprehensible advice adequate to the specific situation. Long-term, far-reaching changes can only

be achieved through personal involvement and empowerment. Personalized care would not only yield immediate benefits for the women and their family living in extreme poverty but it would necessarily lead to the strengthening of the community as well.

'Maybe we won't make a difference but we are here and we are talking and she can take me aside with any kind of problem and we can discuss. I cannot just come and talk at them. It cannot be like that. I just cannot force my will on them. My ears have to be there, so that I hear what their problem is and then we can just talk about it. And then, next time, she'll come, sayin', you know what aunt Ivett told us... I know. They share with each other what they know, for sure. What I would say to them is that we learn from each other's experience, because they tell me, and then it often happens that I'm surprised, that there's something like that, that this exists because I've never gone through that. And then we discuss that. Or Mr Zákány, the consultant would come over here and give a presentation, moreover, he does the examinations. He comes over and the mothers just have to walk up here. So this also happens in the village.' Ivett, healthcare nurse, leader of mother and baby club from Told

8. Discrimination

The European Roma Rights Centre (ERRC) conducted a study among Roma people if they have experienced discrimination during healthcare service. The overwhelming majority of the interviewed answered 'yes'. According to a 2009 research of the Agency for Fundamental Rights (FRA) 18% of Hungarian Roma people experienced some discrimination in healthcare.²⁵

Round-table participants and interviewees confirmed these findings, claiming that Roma women often encounter negative statements, and discrimination regarding their origin during maternity care. Women reported that a secluded, separate room was provided for gypsy mothers in the hospital in two settlements out of three (Miskolc, Berettyóújfalu).

György-telep: *'Women are often mistreated because they are gypsies. You go to give birth as a gypsy woman, you may be well-groomed, but if your pocket is not full with money, you remain a gypsy woman. I had a privately paid doctor at the birth of both children, they saw that I'm approaching their norms, but I felt I couldn't meet them completely. Especially at the postnatal ward. They are nice to the not-Roma even if they are brought in from beside the trash can. But 'gypsy women give birth several times for family allowance', that's what I felt in the hospital.'* Anett

Szakácsi: *'I was separated. They done it here [in Miskolc] every time. To the six beds. You are thrown to the six beds.'* Emese

'When I was 45 weeks pregnant, I was put in a room in Miskolc where the walls were moldy. And there were only gypsies. At the end of the corridor. They would never come, askin' 'are you OK?', so the doctor wouldn't come to us like he did with the others. When I gave them the money, they put me over to the Hungarians and they gave an appointment for 07:00 the next morning. I'd always say that it is a curse to be a gypsy, I don't know why but somehow we are mistreated much because of that.' Ildikó

Told: *'They don't like gypsies. It is not present in the delivery room, but rather in the hospital, at the postnatal ward.'* Jolán

'Here in Újfalú, room five and six are the gypsy rooms, at the end of the corridor. I liked to be there, I don't deny that I'm a gypsy, but I talk both with gypsies and Hungarians. I'm open to talk with everyone.' Jolán

Complaint, legal remedy: Women extremely rarely file a complaint if they are mistreated during maternity care - except in cases of medical malpractice -. Birth House Association has been operating a legal aid service for several years with the experience that women rather wish to forget the grievance experienced, instead of taking any kind of steps. It obviously has complex reasons (lack of supporting environment, vulnerability, the foreseen unsuccessfulness of the process, socialization, etc.), thus it is not surprising that Roma women living in extreme poverty do not make a complaint about the experienced mistreatment or incidental discrimination – similarly to women belonging to the middle-class majority.

FINDINGS

- ▶ Families are underinformed regarding the possibilities of contraception, they lack the basic anatomical knowledge, and the responsibility lies disproportionately on women. The number of competent professionals is insufficient. Meanwhile, there is little opportunity to prepare young people for sexual life properly (public education, lack of programmes).
- ▶ The lack of family planning among families living in extreme poverty in disadvantaged settlements is partly due to financial reasons. Contraceptive drugs and condoms are too expensive for families in their financial situation: they are often unable to afford them.
- ▶ In case of mothers living in extreme poverty and often in isolation, one of the major problems is that they participate in maternity care at lower proportions, especially in specialized care. The main reason is that there are serious (physical) obstacles to their access to care.
- ▶ In the present maternity care women have the most contact with the health visitor. The interviewees gave different opinions on the role of health visitors. At one extreme, they regard the health visitor only as a representative of authority and embodiment of rules, whereas on the other hand, which is less common, they regard her as a source of information and personal care.
- ▶ Women claimed that they don't get the most important and most appropriate support from health professionals (doctors, health visitors, etc.) but rather from a confidential person (mother, mother-in-law, elder sister, mother and baby club leaders or from each other).
- ▶ In hospitals the following birth interventions are routinely used (with rare exceptions) during birth: contraction-amplifying oxytocin, episiotomy, amniotomy, Kristeller maneuver (pressing the uterus from outside through the mother's abdominal wall to 'press out' the child), caesarean section, analgesia (oxygen mask).
- ▶ Women perceive all interventions, without exception, as bad experiences and thus consider childbirth an event that one should get over and survive.
- ▶ Money determines the quality of hospital care. If families give money to the doctor, they get more attention and better care. If they don't, mothers get less attention and Roma

people have a good chance to be taken to a separate ward.

- ▶ Treatment and communication are inseparable concepts. Ill-treatment is usually accompanied with humiliating communication or the lack of communication.
- ▶ Women living in extreme poverty are typically not highly educated. They have difficulty or are unable to interpret technical terms used throughout the care process. It would be essential to know and respect the cultural differences of women coming from more traditional, closed Roma communities.
- ▶ It would provide significant help if there was a supporting person available for Roma (and non-Roma) women who are unfamiliar with technical terms and care processes and have difficulty finding their way in healthcare institutions. Someone who would explain in a comprehensible manner what will happen and how during the examination, what the lab report says, what is further to be done, etc. This could ease the work of professional staff and it could improve the efficiency of communication.
- ▶ The basic condition of support work is the establishment of a personal and trustful relationship between the mother and support person. In addition, the main obstacle of establishing such a relationship is when a care provider treats the mother with an approach and communication reflecting authority. **However, very few professionals undertake to visit families due to the lack of preparedness, resource, and often intent.**
- ▶ Local knowledge includes being familiar with the conditions of the settlement, municipality and the local service providers, as well as having accurate and real knowledge of the mother's living conditions, and the internal rules, relations, problems and cultural preferences (how much they preserve e.g. traditions, religious affiliations) of the community.
- ▶ **Informal get-togethers in confidential atmosphere provide the best opportunity for women to talk about the questions and problems that profoundly shape their personality and to reflect on their experience, draw strength, and ask for help if necessary.**
- ▶ It is necessary for the care provider to visit mothers in their own environment as many times as possible and provide them with comprehensible advice adequate to the specific situation. Long-term, far-reaching changes can only be achieved through personal

involvement and empowerment. Personalized care would not only yield immediate benefits for the women and their family living in extreme poverty but it would lead to the strengthening of the community as well.

- ▶ Roma women often encounter negative statements, and discrimination regarding their origin during maternity care. Women reported that a separate room was secluded for gypsy mothers in the hospital in two settlements out of three (Miskolc, Berettyúújfalú)
- ▶ Women extremely rarely file a complaint, or they do not file at all, if they are mistreated during maternity care – except in cases of medical malpractice.

NOTES

- ¹ Személyközpontú gondozás alatt azt értjük, amikor a nő fizikai és lelki állapotára, egyéni szükségleteire és szociális körülményeire való tekintettel részesül ellátásban.
- ² <http://www.szuletes haz.hu/a-projekt-osszefoglalasa/>
- ³ Tudnak-e szülni a magyar nők? Császármetszés és következő szülés szakmai és betegjogi szempontokból (2013. november 29.), 2. Értsük meg egymást! Roma nők a szülészeti ellátórendszerben (2014. január 31.), 3. Elfeledett szülés – Anyaság és szülés a reprodukciós diskurzusban (2014. április 29.), 4. Távol Budapesttől – A szülészeti ellátáshoz való hozzáférés a szülő nő lakóhelyével és gazdasági helyzetével összefüggésben. (2014. július 11.), 5. Akadálymentes? Fogyatékkal élő nők a szülészeti rendszerben. (2014. szeptember 05.)
- ⁴ A kutatást és az interjúkat az alábbi projektek keretében végeztük: „Tedd meg az első lépést – Együtt a nőekkel a hozzáférhető, tiszteletteljes szülészeti ellátásért” – Norvég Civil Támogatási alap, valamint a „Szülési jogok és esélyegyenlőség” 2014-2015, a Nyíl Társadalom Intézet által támogatott program.
- ⁵ <http://foldhivatalok.geod.hu/telepules.php?page=32258>
- ⁶ <http://romanok-edeleny.hu/>
- ⁷ <http://www.gyorgytelep.hu/>, TÁMOP-5.3.6-11/1-2012-0001 „Benned a Létra” - Komplex humán kapacitás fejlesztés és társadalmi részvétel feltételeinek biztosítása Pécs – György-telep szegregációs krízisterületén, és környezetében. István-aknán hasonló jellegű munka most kezdődött.
- ⁸ <http://www.khetanipe.hu/>
- ⁹ <http://igazgyongy-alapitvany.hu/en/>
- ¹⁰ Az interjúkat a Születésház Egyesület két munkatársa, Fazakas Pálma és Schmidt Erika készítette.
- ¹¹ Earl Babbie, A társadalomtudományi kutatás gyakorlata, Balassa Kiadó.
- ¹² Értsük meg egymást! Roma nők a szülészeti ellátórendszerben (2014. január 31.), Távol Budapesttől – A szülészeti ellátáshoz való hozzáférés a szülő nő lakóhelyével és gazdasági helyzetével összefüggésben. (2014. július 11.)
- ¹³ CEDAW/C/HUN/CO/7-8, <http://www2.ohchr.org/english/bodies/cedaw/docs/54/CEDAW-C-HUN-7-8.pdf>
- ¹⁴ Husz Ildikó – Zárójelentés az Alacsony végzettségű roma és nem roma nők gyermekvállalása a hátrányos helyzetű térségekben (OTKA PD78513) c. kutatási pályázat teljesítéséről (2011.07.30.).
- ¹⁵ Ua.

- ¹⁶ Nemzeti Társadalmi Felzárkóztatási Stratégia – Mélyszegénység, Gyermekszegénység, Romák – (2011–2020), Helyzetelemzés, 1. számú melléklet, 45. old.
- ¹⁷ Civil Társadalmi Jelentés a Nemzeti Társadalmi Felzárkóztatási Stratégia megvalósításáról Magyarországon 2012-ben, http://www.romadecade.org/cms/upload/file/9270_file9_hu_civil-society-monitoring-report_hu.pdf
- ¹⁸ Dr. Vitray, J et al., Szükségletre korrigált egészségügyi ellátás igénybevételének egyenlőtlenségei Magyarországon (2010), http://www.egeszsegmonitor.hu/dok/lgenybeveteli%20egyenlotlensegek_2010.pdf
- ¹⁹ A hazai várandósgondozás két pilléren nyugszik: az alapellátást a védőnő és a házi orvos nyújtják, míg a szakellátás a területileg illetékes szülészeti szakrendelésen érhető el.
- ²⁰ dr. Zákány Zsolt, szülész-nőgyógyász, osztályvezető főorvos, Berettyóújfalu
- ²¹ Nemzeti Társadalmi Felzárkóztatási Stratégia – Mélyszegénység, Gyermekszegénység, Romák – (2011–2020), Helyzetelemzés, 1. számú melléklet, 48. old.
- ²² https://hu.wikipedia.org/wiki/Sz%C3%BCI%C3%A9s#WHO_aj.C3.A1nl.C3.A1sa_a_norm.C3.A1lis_sz.C3.BC.C3.A9sre_vonatkoz.C3.B3an
- ²³ http://apps.who.int/iris/bitstream/10665/134588/38/WHO_RHR_14.23_hun.pdf
- ²⁴ <http://www.holdam.hu/>
- ²⁵ EU Fundamental Rights Agency, European Union minorities and discrimination. Main results, European Union minorities and discrimination survey (2009)

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