Do children have adequate health care?

*Health care is secured by regulations, but in practice, much of it remains just on paper*

The Convention on the Rights of the Child, adopted in November 1989 at the United Nations, which is ratified by 192 countries, among other things provides for legal protection of the child before and after birth and defines up to what age a person is considered a child, says for "Politika" professor dr Radovan Bogdanović, president of the Association of Paediatricians of Serbia.

"Politika", in partnership with UNICEF, publishes a page dedicated to child rights once a month. This time, the topic is the right to health care, which is addressed in Articles 6 and 24 of the Convention on the Rights of the Child.

A child must have the right to the highest attainable standard of health care that one country can offer, highlights doctor Bogdanović, but also explains that in practice, availability of health care is not equal everywhere: poor children and children from marginalized social groups, including the Roma population, children with disabilities, as well as children from remote rural areas are at a disadvantage in this respect, although the situation is better than it was 10-15 years ago.

Parents of seriously ill children know best whether a child really has adequate health care. Marija Joldić, president of the National Organization for Rare Diseases says that problems occur already at diagnosing: these diseases are difficult to diagnose.

– There are few experts for these diseases, so it is hard to get help for those who need it and live in the provinces. Some diseases are not recognized in National Health Insurance Fund’s (NHIF) rulebook at all, parents have to pay themselves for most of the therapy, there is no palliative care of children, and no registry

...
of patients with rare diseases – says Marija Joldić.

Precisely because of this absence of a register, it is not known exactly how many people are suffering from rare diseases. It is known that there are between 6000 and 8000 rare diseases, and children suffer from those diseases in as much as 75 percent of cases, while 30 percent of ill children die before the age of five.

Although children should have access to healthcare by law, in the practice, the burden of treatment usually falls on the parents. One example of what does not work is home care – says Ms Joldić.

– Patients who are forced to lie in bed and have the right to home care, do not receive it. With diseases that cause skin lesions, the parents are trained on how to dress their child’s lesions, although that should be a job for a professional. When the patient loses their parents, there is nobody to dress their lesions – says Marija Joldić.

She notes that the rare diseases that affect children – are diseases of the whole family. Many parents have to quit their jobs to care for a child, medications and therapies are too expensive, and families have to pay for genetic analyses in the national laboratories out of their own pockets.

To make the paradox even bigger, for children who are not diagnosed the Fund for Medical Treatment Abroad will soon start paying for sending the samples for DNA analysis to laboratories abroad, while the analyses in the national laboratories are paid by the parents themselves.

– Medications are a huge problem – there are very few researches and they are done one adults, not on children. It is also a torment when a child is becoming a teenager, because there are doctors for certain diseases who treat only children – says Ms Joldić.

Dejana Ivanović
A referral from paediatrician needed for a visit to a child psychiatrist

At the Clinic for Children and Youth of the Mental Health Institute in Belgrade, each year there are around 2000 first exams and around 9000 follow-up exams of children from the territory of the entire Serbia, and occasionally, children from Montenegro and Republika Srpska also come for treatment. Docent dr Milica Pejović-Milovančević, child psychiatrist and head of the Clinic for Children and Youth, says that there are no waiting lists in this institution, but that there is a list of appointments for the organization of work, and the average length of treatment at the Clinical Department for Children and Youth is 17 days. In the Day Hospital for Children and Day Hospital for Adolescents, the little patients are treated from 30 to 35 days.

"All children and young people generally come for treatment to a specialized psychiatric institution with an appropriate referral issued by a paediatrician or selected physician. Considering that those children belong to the population that is exposed to an increased risk of getting ill, parents can easily come with a child to a psychiatrist in specialized health care institutions. The competent paediatrician in the health centre is the one who determines the need for provision of additional health care in specialized institutions dealing with the mental health of children and young people. The state has recognized the need for a larger number of experts dealing with mental health of children and young people and has approved new specializations in child psychiatry, and we're hoping that it will soon open new jobs for child psychiatrists", explains Dr Milica Pejović-Milovančević.

If the medical condition of the child requires mandatory provision of psychiatric services in specialized health institutions, the parents can get those services, but generally not in the place where they live. Serbia has a relatively small number of specialized psychiatric institutions where health care services can be provided to children and all are mainly located in the university centres.

Katarina Đorđević
Child's right to vaccination

– Immunization is one of the most effective preventive measures, it protects the individual and the community. Protection against infectious diseases by immunization is a basic right of a child, and this is again one of the components of the strategy for reducing inequalities in access to health care and part of the strategy for poverty reduction. The opponents of immunization refer to allegedly dubious quality of vaccines, claiming that they cause diseases – but all that can easily be refuted in a professional debate – explains doctor Bogdanović.

On the other hand, the state is obliged to provide regular and continuous supply of vaccines. Sanctions for parents who do not vaccinate their children, in his opinion, are not the right solution: it would be better to make those who refuse vaccination pay extra insurance until the child's coming of age, because of the increased risk of illness and endangering the health of other children.

The Association of Paediatricians, with the support of the Ministry of Health and with the help of UNICEF, is implementing a project in 10 health centres to increase the capacity of paediatric services for stimulation of development of children in the early years and early detection of developmental problems and disorders.
"Don't panic, your child is totally fine, just a little slower, but there is no need to worry", "don't bother your child by taking her to doctors all the time, she is a good baby and advancing fine, but she is just a bit lazy", "slowly but surely he will catch up with his peers"... parents get these and similar answers from paediatricians when they panic because their baby aged seven or eight months is crying often and for long periods of time, because they are not sitting up the way they should or because they are falling behind with development compared to other children. And that is the first stumbling block in early detection of disease, according to many parents of children with special needs.

Paediatricians often do not recognize the occurrence of a problem at the earliest age of children. But even when they do recognize it, there is nowhere to send the child to.

– We have a variety of counselling services, for divorce, for addictions, foster parents undergo trainings, they have assistance, there is a 24-hour hotline, and for us, the parents of children with autism, the family support does not exist – says Vesna Trajković, president of the Association of Parents of Children with Autism.

The biggest problem, says a mother of a fourteen-year-old boy diagnosed with autism based on her own experience and experiences of parents in the association, is that there is no cooperation between the ministries of education, social care and health.

– For 14 years, none of the competent authorities have come to my family's house to see the conditions in which the child lives, what we do and how we act. They didn't come to our house or other people's houses. There are no professional, licensed therapists to work with children – says Trajković, noting that if a child with autism has a toothache during the weekend, he or she would have to wait for Monday because the intervention is only possible at the Faculty of Dental Medicine.

– We do not have anyone to call during the night to get expert advice if a problem occurs, the same goes for weekends, holidays... For the past ten years, practically nothing in our country has changed – notes Trajković.

There are no precise data on exactly how many autistic people live in Serbia, and there are no studies on where the children with autism are. When the education of children with special needs is concerned, Trajković believes that inclusion is positive, but that the manner of its implementation is negative. This type of education requires expert assistants for children, training of teachers, special program and textbooks, continuity of work, and not having parents themselves choose assistants. Many have to pay for them too. So far, 140 children in Belgrade got their personal assistants, and around 400 need one.
Parents are a part of all activities, which means that one of them can not be employed. There are day-care centres for children and young people with special needs and without them, life in the family would be impossible. Children are taken care of there, they socialize, study and work. But there is one more problem, says Trajković, and that is that our law recognizes autism only until the age of 26, and after that...

Julijana Simić-Tenšić
Important role of a visiting-nurse

Each visiting-nurse in Serbia is obliged to provide proper health care and support to the parents in order for the early growth and development of children from birth to five years of age to be better and of higher quality. While working with the youngest family members, they have so far relied on the so-called rough assessment of the situation in the family. With the project "Support for early childhood development and social inclusion of children through strengthening the capacity of visiting-nurse services" started by UNICEF and the Ministry of Health, the nurses have been given a new tool to make a more accurate assessment of each child's situation.

Based on such lists, each nurse can make a valid assessment of the family situation and help parents improve the growth and development of the child – explains Andelka Kotević, coordinator for the visiting-nurse services of Serbia, reminding us that 10 health centres from the country and 90 nurses are part of the project, which doesn't mean that all others will not be trained for this work. She also notes that out of 1260 visiting-nurses in Serbia, the largest number work in the capital – 240 of them.

– Those who are not included in the project will receive a shorter version of all tools, so we will equip them with the necessary skills in a timely manner so they can continue with assessments of early childhood development – Ms Kotević assures us.

So far, the visiting-nurses have only somewhat worked on creating an "ID card" for each family, adds the coordinator.

Everything was coming down to assessing the health risks that could otherwise be read from the medical record. With the new approach to work, the new "ID card" can also contain psychosocial risks, such as child neglect, unemployment, hygiene levels or the presence of alcoholism in the family...

The experience of the Initiative for inclusion "Veliki mali" ("Big Small") in cooperation with the families of children with developmental difficulties shows that health care services are not available to them in sufficient extent and that they encounter various obstacles.

– Children with disabilities who have flat feet or abnormal curvature of the spine do not have access to services the way others do, and instead, they are referred exclusively to specialized institutions in bigger cities or the parents get instructions and go through trainings in order to work with their child themselves. Several years ago, a mother of a girl with Down syndrome came to us when she wasn't able to get a referral for regular physiotherapy exercises, although the condition of the spine indicated that a surgery was imminent unless something was done about it. She was not able to get access to this service even within the day-care – people from the "Veliki mali" initiative recall.

90 nurses from Serbia participate in the seminars, and get the necessary knowledge on early childhood development. Tools they use are in the form of tests, the so-called check-lists that contain certain questions for specific ages of children.

There's no more rough assessment of the situation in the family

Matija Brakočević