



## IS MY RIGHT TO HEALTH BEING ACCOMPLISHED?

Coalition of NGOs for Child Protection in Kosovo - KOMF in partnership with UNICEF



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As part of continues capacity development and empowerment of KOMF, in 2017 KOMF with UNICEF support has commissioned the Needs Assessment Report which documented KOMF needs, challenges, lessons learned and potential for further development. This process resulted with establishment of several Thematic Working Groups within KOMF.

The publication has been drafted in frame of the Thematic Group for Child Rights in Health from Arbnora Kllokoqi and Donjeta Kelmendi from the Coalition of NGOs for Child Protection - KOMF in cooperation with Zana Shabani – Save the Children, Mrika Aliu – Action for Mothers and Children and Dr. Vlora Ismaili - Jaha. An important contribution was provided by the UNICEF office in Kosovo, in particular Dr. Agron Gashi and Dren Rexha.

The document outlines children's rights to health, it provides an overview of some of the key areas which should be considered in the frame of policy development and implementation, by providing recommendations on how to address them.

Coalition of NGOs for Child Protection in Kosovo – KOMF, established in June 2011, is a coalition composed of 27 local and international NGOs working in the child protection field, with the joint mission to advocate and protect the rights of children in Kosovo.

This publication does not necessarily reflect views of KOMF donors.

### **KOMF Members are:**

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# I. EXECUTIVE SUMMARY

## Key issues on the development and implementation of Policies on the Child Rights in Health Care

The child rights to health care are guaranteed from the International Convention on the Rights of the Child as well as by Kosovo legislation.

The International Convention on the Rights of the Child provides to a child the right to enjoy a better health condition and to benefit from the services related to the treatment of disease and health recovery<sup>1</sup>. The right to protection and necessary care of children is guaranteed also by the Constitution of Kosovo<sup>2</sup> and the Law on Health<sup>3</sup>.

Despite this, children continue to have limited access to healthcare. Services provided at the level of the Primary Health Centers are not focused on addressing the needs of vulnerable groups, there is also a limited experience in how to promote social inclusion and provide access to basic services for vulnerable groups<sup>4</sup>.

Patients, with special emphasis on children, are not always aware of their rights to receive special services at a particular place, and they have no knowledge of assessing the quality and no confidence in expressing dissatisfaction.

Access is limited due to financial barriers, but other challenges or barriers such as perceptions about the quality of healthcare and the lack of trust in health sector staff, low capacities, poor staff communication and discrimination should be also addressed. It is worth mentioning that very few services are provided to persons who are unable to physically access health institutions<sup>5</sup>.

Lack of a broad spectrum of guidelines and protocols as well as insufficient compliance with existing ones

results in suboptimal provision of services. There are missing clear indications and clear referral mechanisms to patients among health care levels.

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The family medicine system is not yet fully functional in some municipalities, therefore it is recommended that it shall become functional in fulfilling tasks within reproductive health, mother health, child and adolescent health. It is also recommended to review performance indicators at each level of health care as well as consultation indicators.

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Family Medicine Centers are recommended to focus on meeting the needs of vulnerable groups, increase social inclusion and ensure access to basic services. Based on their mandate, the Family Medicine Centers should perform home visits (as needed). This would help to reach vulnerable groups, promote social inclusion and ensure access to basic health services for marginalized groups.

Kosovo is characterized by a high average birthrate. On the other hand, although the infant mortality rate has fallen, Kosovo continues to be the country with the highest infant mortality rates in Europe. Also, many mothers in Kosovo do not commence with breastfeeding sufficiently early due to lack of awareness, causing potential stagnation in growth and development during the first 2 years of child life.

In Kosovo 95% of children are vaccinated with DTP3, 79% are completely vaccinated while only 1/3 of children are completely vaccinated among Roma, Ashkali and Egyptian communities.

Personnel providing child health care should inform and discuss with parents about breastfeeding, nutrition and immunization for a better health of children.

Many children seeking health care, especially when it comes to more serious diseases as malignant diseases such as leukemia or others, in absence of capacity and confidence in the health system in Kosovo, seek recovery abroad. The Ministry of Health should increase local capacities for the treatment of serious diseases by allocating specializations in the field of Pediatrics Oncology and to train, in the short term, the nursing midwifery staff on Children's Oncology.

There is a lack of medicines from the essential list, parents are forced to pay for themselves, which implies huge expenses from their income. Often, due to difficult financial conditions, parents can not afford it and consequently the lack of medicines needed for them can have major consequences on their health, often fatal consequences.

In Kosovo, investments in health sector are extremely low, among the lowest in the region<sup>6</sup>.

Insufficient funding for health sector hampers the ability to meet basic needs for child health, public health and nutrition. This hampers implementation of health sector reforms and policies. Public health expenditures are mainly focused on capital and hospital investment. Expenditures on primary care and goods and services should increase<sup>7</sup>. The Ministry of Health should establish a sustainable fund and increase the budget for health with a special emphasis on children. The law on health insurance should be implemented and a health insurance fund should be established.

Also, the Ministry of Health should undertake actions for a long-term and sustainable supply of medicines, anesthetics, infusions and other expendable materials in UCCK to ensure that medicines from the essential list will never be missing. It shall increase the budget for oncological medicines because, according to experts and health workers, 90% of cytostatics are provided by different donors, while only 10% is provided by the Ministry of Health. Urgent budget increase is required for cytostatics for all diseases.

## II. THE ORGANIZATION OF THE HEALTH SYSTEM IN KOSOVO

The Health Law envisages provision of inclusive and non-discriminatory health services with equal standards of healthcare for all citizens by providing standards in meeting the requirements at all levels of health care.

*The health care services, which are guaranteed under Article 27 of the Law on Health in the Republic of Kosovo, contain the following services:*

- a) Primary
- b) Secondary and
- c) Tertiary

Primary health care is a priority in the health system reform processes. The operational plan for development of primary health care is approved by the Ministry based on the proposal of the Municipal Assembly in accordance with the medium-term plan approved by the Government. The Primary Health Care Activities include health promotion, prevention, early detection, diagnosis, treatment and rehabilitation related to diseases, disorders and injuries, including dental care and minor surgical interventions based on the concept of family medicine.

Primary Health Care Institutions are: Main Family Medicine Center with the constituent units defined by the secondary legislation adopted by the Ministry<sup>8</sup>.

Secondary and tertiary health care is provided through institutions designated under the Law on Health, including hospital, outpatient, diagnostic, therapeutic, rehabilitation, emergency transport, dental care and regional public health services<sup>9</sup>. Secondary health care institutions are: General and Special Hospital with the constituent units defined by secondary legislation act rendered by the Ministry; Specialist Polyclinics; Specialistic Ambulance; Dental Clinics; Mental Health Center with the House for Community Integration; Blood Transfusion Center; Physical and Climatic Rehabilitation Center; Sports Medicine Center; Work Medicine Center; Regional Public Health Centers; Center for the Rehabilitation of Listening and Speaking.

Tertiary health care includes advanced healthcare, hospital care, outpatient care and public health care. Tertiary healthcare institutions are: University Clinical Center; University Clinical Dental Center; National Institute of Public Health; National Medical Laboratory Center; National Sports Medicine Center; National Blood Transfusion Center; National Telemedicine Center.



## III. VITAL DATA OF CHILDREN

### 3.1 Birthrate

Kosovo is characterized with a high average birthrate. According to the Kosovo Agency of Statistics (KAS), Kosovo's birth statistics for 2015 are 24,716 births, of which live births are 24,594, which means 122 are dead births. Whereas, births registered outside Kosovo are 6,717, of which 6,715 are live births and 2 dead births. The vitality coefficient is 2.9 (total ratio between live births and deaths). The masculinity coefficient is 110.1. The dead birth rate - fetal deaths in 1000 births was 4.9%. In medical institutions were born 99.8% while the rest occurred in other countries. The largest numbers of mothers who have given birth are 25-29 years old with 35.0%, age groups 30-34

years old with 24.5%, age groups 20-24 years with 23.4% and other age groups constitute 17.0% of the total number of births.

The average age of women who gave birth in 2015 is 28.2 years. The first child was born by 37.3% of mothers; the second child was born by 32.8% of mothers and the third child by 19.3% mothers. According to the weight of a child born in health institutions, the largest number of babies is with 3,000 to 3,499 gr. or 37.6%; 3 500 to 3 999 gr, or 30.7%; 2 500-2 999 gr. or 13.3% etc. Infants born alive with weight less than 1000 gr account for only 0.2%.



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### 3.2 Death Rate

Although the infant mortality rate has declined, Kosovo continues to be the country with the highest infant mortality rates in Europe. The perinatal mortality rate for 2015 is 12.1 per 1000 (for newborns weighing  $\geq 500$  g or  $\geq 22$  weeks of gestation), thus showing a significant decline compared to year 2000 when the perinatal mortality rate was 29.1% in 2012 it was 11.04%<sup>10</sup>, in 2013 it was 16.26%, in 2014 it was 11.99%.

Neonatal mortality rate of children and newborns is almost twice as high for the poor (9.13 and 19 per 1000 live births) than for the rich (4, 7 and 9 per 1000 live births). The rate of child mortality among Roma, Ashkali and Egyptian communities according to MICS data, 41 per 1,000 live births and for children under five years the mortality rate is 49 per 1,000 live births, which together represent three times more than the average child mortality rate in Kosovo.<sup>11</sup>

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Prematurity continues to be the most common cause of premature neonatal deaths with 56%, followed by congenital abnormalities with 15% and asphyxia with 13%, while infections are responsible for 7% of early neonatal deaths.<sup>12</sup>

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Prematurity means the prematurely born babies, especially those born before the 30th week of gestation. Some of the major causes of premature birth are stress, health problems or various infections, depression, a very short time between two pregnancies with less than 6-9 months between the birth of a child and the onset of another child's pregnancy. Also, the causes of premature births relate to lifestyle and environmental factors such as tobacco, alcohol, drug use, exposure to chemical substances and lack of any sport activity, sexual, physical or psychological abuse. Prematurity can cause lung disease, child's growing backwardness and development stagnations such as cerebral paralysis, mental retardation, speech disorders, behavioral attention disorders and learning abilities.

**Inborn or Congenital Abnormalities.** Lack of iodine, folate insufficiency, obesity and diabetes are related to some congenital anomalies, therefore early detection offers better results and allows parents to be aware of treatment options<sup>13</sup>. It is estimated that about 94% of severe congenital abnormalities occur in countries with low and moderate income where women often do not have access to adequate nutrition, may have increased exposure to infections that incite or increase the developmental incidence of premature birth anomalies. Moreover, the advanced age of mothers increases the risk of chromosomal abnormalities, including Down syndrome, while the younger maternal age increases the risk of some other congenital anomalies. The blood connection (when the two parents are blood related) increases the prevalence of rare congenital abnormalities and nearly doubles the risk of death for children, intellectual disabilities and other anomalies in the circle of first rank cousins. Certain ethnic communities have a relatively high prevalence of rare genetic mutations, which lead to a higher risk for congenital anomalies. Another reason that has been introduced into the risk factor for congenital anomalies is the lack of folic acid. Each pregnant woman is recommended to take a minimum dose of 0.4 mg of folic acid per day, 3 months before the pregnancy and the first 3 months of pregnancy. Lack of folic acid is seen as a risk factor for spinal abnormalities.

**Asphyxia and Infections.** Asphyxia is the result of a lack of oxygen supply to the body before, during or shortly after birth. Initial treatment presents an effective recovery. The situation should be discussed sensibly with parents, throughout the child's stay at the hospital. Infections can often be easily managed, with simple treatments, but there are also more severe infections that may not cause symptoms to the mother and can not be diagnosed until they cause serious complications such as premature birth or dead childbirth. Infections are caused due to lack of good basic hygiene and cleanliness during childbirth, lack of clean and safe injecting practices. Women who have been subject to hunger from socio-economic conditions may have parasitic infections or a poor nutritional condition.<sup>14</sup>

Many early infections of a newborn can be prevented by good basic hygiene and purity during baby's birth, with particular attention to umbilicus

care. Many recent infections of the newborn can be gained in hospitals. These can be prevented through exclusive breastfeeding, strict hand washing procedures for all staff and family members before and after the child's touch, failure to use water for air humidification at the incubator and by performing all procedures under sterile conditions.

Furthermore, the 3<sup>rd</sup> objective of the United Nations Sustainable Development Goals is to ensure healthy

life and promote well-being for all at all ages. This goal envisages that by 2030, prevention of deaths of newborns and children under the age of 5 in all countries aiming at reducing neonatal mortality will be reduced to at least 12 per 1,000 live births and mortality below 5 years of age to at least up to 25 per 1,000 live births.

## IV. UNDERWEIGHT BIRTHS

The newborn weight presents a good indicator of health and nutrition status of the mother, but also the potential for newborn to survive, grow, for long-term health and for psychological development. According to the Kosovo Agency of Statistics, 99 percent of births are weighed upon birth and approximately 5 percent of babies are assessed with weigh less than 2,500 grams at birth.

The low birth weight (defined as less than 2,500 grams) carries a significant number of risks to children's health. Children who do not nourish enough in the womb carry the risk of dying from the early days, months or early years of their life. But, even those who survive may have limited immune function and consequently bear the risk of being affected by the disease, are more likely to remain underdeveloped with limited muscle strength during their lifetime and have the highest probability of suffering diabetes and heart disease later in their life. Another challenge for children born under weight is the risk that some children may have lower levels of intelligence (IQ) and cognitive impairment disorders that affect their entire life such as school attendance and opportunities for employment as an adult.

The birth of the child with an underweight is a consequence of the mother's health and malnutrition. The following are the most influential

factors: inadequate nutrition of the mother before pregnancy, malnutrition during pregnancy, short stature (height). Smoking during pregnancy is also one of the major causes of underweight births.

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Also, inadequate weight gain during pregnancy is a particular importance to the fact that there is a greater chance of stalling fetal development. Teenage women who give birth when their body has not yet been developed yet are exposed to the higher risk to give birth of underweight babies.

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Mother's milk is ideal for infants born prematurely. The milk produced by a mother who has given prematurely birth of a child has different composition from the mother's milk that gave mature birth of the baby. This milk corresponds to food requirements that the prematurely born baby needs. The prematurely born children are much more vulnerable to infections and maternal milk enriched with protective bodies helps them better protect themselves from environmental microbes. They do not digest artificial milk well while they digest and absorb the mother's milk well.

## V. BREASTFEEDING AND NUTRITION SITUATION OF INFANTS

Proper child nutrition can increase their survival opportunities, as well as promote optimal growth and development, especially during their critical period from birth until the age of 2 years. According to the Kosovo Agency of Statistics, 45% of newborns are fed with breast milk within the first hour after birth and while more than four fifths (86%) are fed with breast within the first day after birth; breastfeeding is prevalent for only 40% of children under the age of 6 which contributes to the adequate breastfeeding rate for less than half of children aged 0-23 months (46%). The average of any breastfeeding form is 14.1 months for children under 3 years of age and 2.0 months for breastfeeding alone.

While majority of children (90%) are fed with at least the minimum number of meals, only two-thirds (63%) are fed with the minimum number of foods or minimum food diversity, so less than half (49%) of children aged 6-23 months and only one third (35%) of the poorest households are fed with the minimum acceptable quantity of food.<sup>15</sup>

However, many mothers in Kosovo do not commence breastfeeding sufficiently early or do not feed their children (exclusively) by breastfeeding for the recommended 6 months or stop breastfeeding too early. Due to improper information, mothers tend to switch to formula milk which may cause restrictios in growth and malnutrition with micro nutritional elements which may also be uncertain if hygiene conditions, including drinking water, are not present. Studies have

shown that except continuation with breastfeeding, consumption of proper and adequate solid, semi solid and soft food from age of 6 months onwards leads to better health and improved growth with opportunity in reduction of growth stagnation and development during the first 2 years of their life. UNICEF and WHO recommend that infants should be provided with breastfeeding within the first hour after their birth and to be provided only with breastfeeding during the first 6 months of their life.

In order to calmly cope with breastfeeding, mother needs more energy, proteins, vitamins and some mineral salts such as calcium, phosphorus, copper and zinc. It is estimated that in order to produce 700 to 800 ml of milk per day, the mother's diet should be increased by 500 cal.<sup>16</sup>

Malnutrition occurs when the body does not receive necessary amount of energy (calories), proteins, carbohydrates, fats, vitamins, minerals and other substances needed to keep the organism healthy for its good functioning. The main reasons for undernutrition, especially for children, are: poverty, food shortages, recurrent diseases, inadequate care and poor hygiene. When a family is unable to secure necessary quantities of food and lives in poor conditions that make the most common occurrence of diarrheal diseases and other diseases, their children are more likely to be under-nutritioned. When children become ill, they quickly lose their energies and nutrients which endanger more their lives than lives of adults.<sup>17</sup>

Also, during maternal milk feeding, there are objective difficulties such as pain and tingling of nipples, flat and inside nipples, breast inflammation which discourages young mothers and terminate breastfeeding for their babies. Also, many mothers give up breastfeeding because of missinformation that feeding their babies with formula milk gets more weight. If mother begins to supplement the baby's diet giving to the baby several times a day formula milk bottle, then the baby's interest in sucking the breasts decreases. The baby begins to lesser suck the breast which sends to them signal to produce less milk and thus interrupts the breastfeeding process.

The amendment of the Law on Breastfeeding is in progress in order to empower actions in this area. The Ministry of Health, along with other line ministries and other partners are recommended to apply and monitor legislation and policies, ensure sustainability of breastfeeding promotion, including compliance with the International Code and to fortify the flour with iron and folic acid.

## 5.1 Nutrition situation

When children are offered better food, they are likely to be less exposed to recurrent diseases and have good care, they reach their potential level of growth and are considered as well nourished. Malnutrition is associated with more than half of all children's deaths in the world. Weight ratio to the age presents a measuring unit of acute and chronic malnutrition while the ratio to the age presents the linear growth metering unit.

One in twenty five children (4%) under the age of 5 have moderate stagnation or are too short for their age, reflecting chronic malnutrition as a result of not receiving adequate nutrition for a long period of time and as a consequence of frequent and chronic diseases. Although, almost no children under the age of 5 in Kosovo have been classified with under weight of severe form, approximately 2% are moderately or severely underweight and 4% overweight or too heavy for their height.<sup>18</sup>

According to a research conducted by UNICEF and the Kosovo National Institute of Public Health (NIPH) on the nutritional status of school age children in Kosovo, 15.7% of school age children have been identified suffering from light anemia. Anemia was also present in 23% of pregnant women, thus reflecting a significant public health problem. To assess the nutritional status of children, the survey measured the height of each child by comparing them with World Health Organization (WHO) standards and concluded that 15.5% of children were weak and 4.7% were poorly developed.<sup>19</sup>

The main reasons for malnutrition, especially for children, are: poverty, lack of food, inadequate care, poor hygiene, and poor quality of food, improper nutrition and children care practices. Precisely, the causes of malnutrition are a combination of the lack of healthy and sufficient food for family. In Kosovo there is no proper mechanism for food quality registration.

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The high rate of poverty causes insufficient food consumption and the children are those who are suffering more. In the immediate period before and after childbirth and during early childhood, poverty and lack of healthy and sufficient foods are factors of serious diseases and sometimes of irreparable health consequences. In 2014, the Ministry of Health has established a working group that has prepared the Nutrition Action Plan 2014-2020 with the aim of improving the nutrition status of the population with special emphasis on vulnerable groups. The plan has not been approved. The plan was reviewed for the period 2017 - 2021.

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In order to improve the public health, the Law on the Fortification of Flour with Iron and Folic Acid was approved by the Assembly of Kosovo. According to the laboratories results, from the control over the implementation of this law in 2016 and 2017 show that only half of the flour sold in Kosovo is fortified with these two materials. According to UNICEF, at the global level, many people, especially children and mothers suffer from essential minerals and vitamins deficiency such as iron, vitamin E, iodine and zinc. The Ministry of Agriculture, Forestry and Rural Development, together with the National Institute of Public Health and the private sector, with the support of UNICEF, is committed in fortifying the flour with iron and folic acid in order to prevent anomalies of birth and anemia and affect the better development of children health.

Fortification of the flour with iron and folic acid will have impact on prevention of many diseases, as the results of application of this law are already visible in many countries of the world. Local producers are legally obliged to fortify flour with iron and folic acid.





## VI. VACCINATION

In Kosovo 95% of children are vaccinated with DTP3, 79% are completely vaccinated while only 1/3 of children are completely vaccinated among Roma, Ashkali and Egyptian communities.

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One of the reasons for the low coverage of immunization in Kosovo is the lack of knowledge and awareness of the parents on the health

consequences of non-vaccinated children. It is more than necessary that primary health care institutions (Family Medicine Centers) conduct home visits to identify unvaccinated children and detect child diseases that may often have fatal consequences for the child's health.

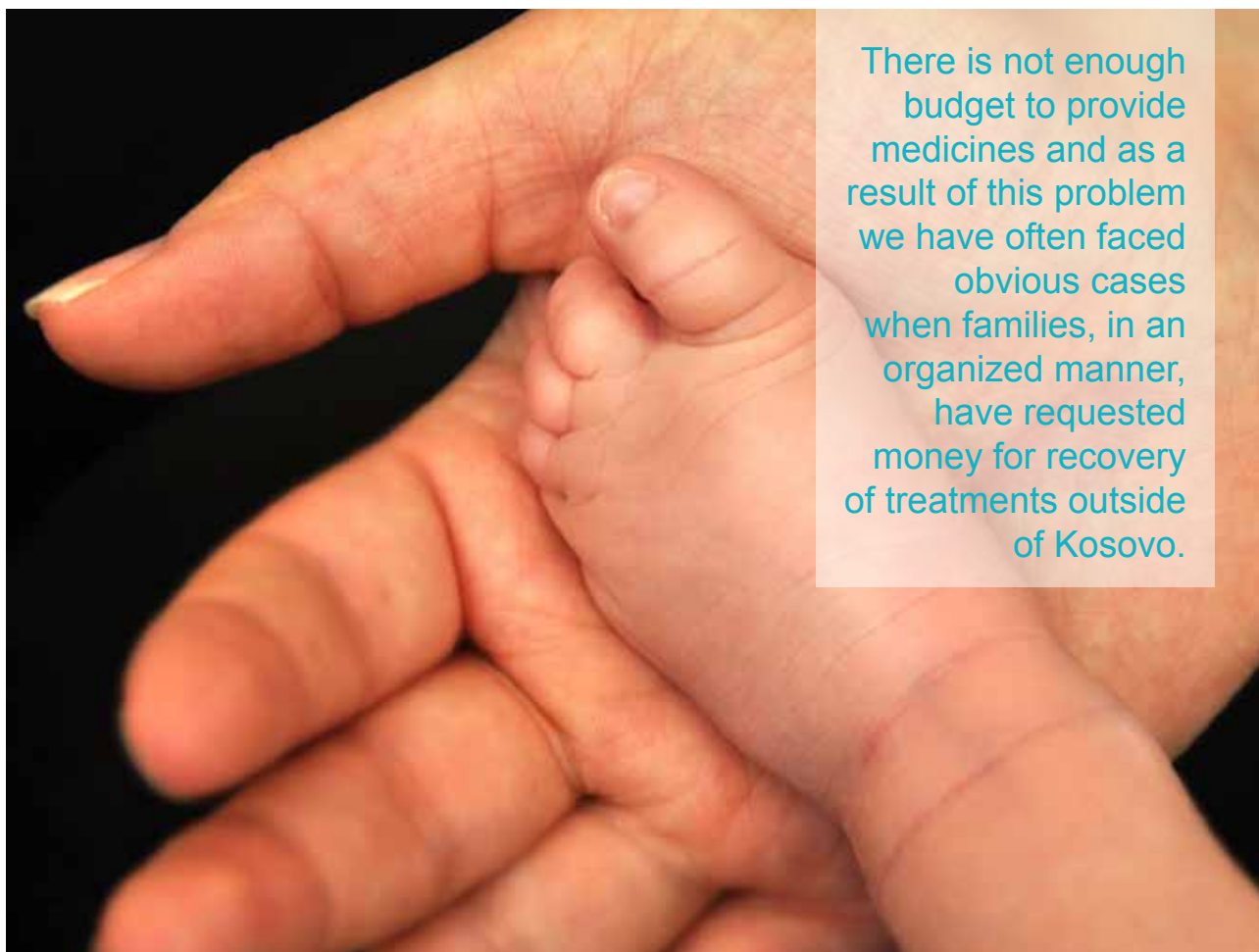
This would help to reach vulnerable groups, promote social inclusion and ensure access to basic health services for marginalized groups, which often because of low awareness, are failing to realize their children's immunization.



## VII. THE TREATMENT OF CHILDREN WITH SEVERE DISEASES

Malignant diseases are serious diseases which children are not spared from and require extremely costly treatment. Given the number of cases of affected children in Kosovo, unfortunately, these diseases are emerging as a challenge for Kosovar society<sup>20</sup>. According to health professionals, acute leukemia is the most common malignant disease in children. In Kosovo, during 2016, were diagnosed 49 cases of children affected by malignant diseases and lymphoma, of which 29 are diagnosed with leukemia.<sup>21</sup>

The biggest issues which directly affect children with leukemia relate to late stages of diagnosis, which is not only due to delays in/and poor management of cases in primary and secondary health care, but also due to lack of diagnostic equipment, lack of functionalization for years of equipment donated to hospital for children suspected in having malignant disease, lack of space in UCCK for diagnostic equipment and dilemmas for laboratory equipment and limited funds for abroad medical treatment.



There is not enough budget to provide medicines and as a result of this problem we have often faced obvious cases when families, in an organized manner, have requested money for recovery of treatments outside of Kosovo.

The Oncology Pediatric Clinic at UCCK continues lacking a benchmark to what extent it can handle the disease of leukemia and other carcinogenic diseases in children. Due to this situation, this clinic does not enjoy sufficient trust in parents whose children are treated for leukemia which causes that a significant number of them seek medication outside of Kosovo. This is also confirmed by the fact that doctors work under great pressure to provide family members with certificates for treatment outside of Kosovo.

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**Budget decentralization issue for the University Clinical Hospital Service remains a challenge in Kosovo. As a solution to this, the possibility of increasing the current budget**

**for medicines as well as putting oncology medicines under their own responsibility of the clinics is considered.**

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There are still gaps in legal infrastructure because the right of children to health services and free services will be denied until this matter is fully regulated by such laws, which is essential and indispensable. Failure to apply the Law on Health Insurance continues to be a problem that further adds on the gap.

In absence of the budget offered to treat diseases they are faced with and which require recovery abroad, there are cases that are forced to seek help from citizens by raising money in the street, schools, various institutions, etc.

Despite the considerable number of children identified with malignant disease, the budget allocated for treatment as well as the follow-up procedures required for the disease is insufficient.

## VIII. LACK OF MEDICINES FROM THE ESSENTIAL LIST

During the recent years, there was lack of medicines, infusions, anesthetic drugs and other materials at the University Clinical Center of Kosovo - UCCK, especially the lack of medicines in the Pediatric Unit, Intensive Pediatric and Hematology. It is considered that 86% of patients are paying for medicines.<sup>22</sup> Lack of necessary therapy for children in need for appropriate therapy may have fatal consequences for children. Regarding lack of medicines, the patients are stating about that they are also obliged to buy on their own costs the most essential things from test tubes for blood tests, dressings and physiological solutions. Most of laboratory test they are doing privately, too.

Lack of medicines and consumables was also with the Children's Hemodialysis Unit at the Pediatric Clinic, when during 2016, children in need of hemodialysis have traveled together with their family members three times a week in the direction of Tirana to perform dialysis, as in Kosovo, due to

lack of respective consumable materials, provision of dialysis services for children was not possible.

In 2016, the Children's Hemodialysis Service within the Pediatric Clinic has benefited from a donation of consumable material from Meditech L.L.C Company through the Coalition of NGOs for Child Protection in Kosovo.

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Despite continuous increase in the planned budget for medicines and consumables from €16,100,000 in 2009 to €21,183,118 in 2013 to €21,670,496 in 2015, in public health institutions is consistently ascertained lack of medicines and consumables and this fact is causing a great dissatisfaction among patients.<sup>23</sup>

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## IX. MANAGING THE BUDGET

The allocated budget for the health sector in Kosovo for 2016 by health experts, citizens and trade union representatives is considered to be insufficient to improve the situation in this area, which would affect the quality of health services.

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The Ministry of Health for 2016 has used 49.92% of the budget for wages, 29.67% for goods and services, 8.30% for subsidies and transfers, 9.14% for capital investments and 2.98% for municipal utilities.<sup>24</sup>

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According to the Health Sector Strategy, functional budget allocation indicates that only 32% of the budget allocated to goods and services can be spent directly for the patient (Rtg, RM, CT, laboratory tests and medicines). The rest of the budget, 68% is a fixed cost that will remain the same regardless of the number of patients treated. This means that out of the overall public budget, only 28% can be a patient-related direct budget with only 23 € per year available for diagnosis and treatment per capita. The health sector in Kosovo is mainly financed by income tax, taxes and co-payment while out of pocket pay of citizen's are very high and includes about 40% of health care expenses.

Challenge for insufficient financial resources for health in Kosovo is not related just to the fact that the Government does not allocate enough money for direct patient services but it relates to that the relative share of these funds is used to pay fixed costs such as buildings, energy, maintenance and wages, thus leaving the smallest share of direct costs for the patient related to diagnosis, treatment, prevention and promotion.

It is considered that 86% of patients are paying for medicines, 59.5% for co-payment, 33.4% have paid for medical supplies, 31.9% for consultations (including private sector), 17.3% for other issues 10% have paid for food. In total, 88.4% of all patients requiring care in health institutions have paid out of their pocket.<sup>25</sup> A significant proportion of citizens do not have sufficient access to health care due to high medication costs to be paid from their pocket. Simulations using household data show that poverty rate is higher due to spending in health and the middle class is becoming more vulnerable to health spending. Some health services to which poorer groups are more likely to access are not funded.

Public health spending is largely funded by taxes, but there is also additional donor support that is not reflected in the overall budget. About 5 percent of budget funding is financed by own source revenues of health institutions (e.g. healthcare user fees and medication payments). The rest is funded by local and foreign donations. Donor contributions not presented in the total budget for 2013, amounts to about € 5.5 million in cash and € 4.5 million in kind. Support of donors outside of the budget for period 2014-2016 is estimated to reach EUR12.3 million (including Luxembourg Government support for health information system development, Global Fund support for the TB/HIV prevention and treatment project and supply of medicines through "Hope" project).<sup>26</sup>

The budget spending on treating patients abroad amounts to over 8 million euros. The amount spent on treating these cases of all ages and diseases which it was applied for, amounts to about 8,130,000 Euros. According to the Office for Medical Treatment Outside of Public Health Institutions, during 2016 were filed 1958 applications for receiving healthcare. Applications of 1,100 cases

were granted, some cases were carried over in 2017. Number of requests over the years is roughly the same, while the number of beneficiaries has tripled due to the increase in the budget for abroad treatment. The budget for treatment outside of public health institutions for 2014 was EUR 3 million.

According to Administrative Instruction no. 03/2016 for Medical Treatment outside the Public Health Institutions, patients up to the age of 18 are covered with 100% of the value noted in treatment preinvoice regardless of whether they are urgent or non-urgent cases.

## X. FINDINGS AND RECOMMENDATIONS

The following findings present major health sector constraints and recommendations provide steps to address key challenges in improving child health development in Kosovo.

■ **Provision of childcare services** - Children continue to having limited access to healthcare. Services provided at the level of primary health care centers (Family Medicine Centers) are not focused on meeting the needs of vulnerable groups; there is also limited experience in how to promote social inclusion and providing access for basic services to vulnerable groups.

Access is limited by financial barriers, but other challenges or barriers such as perceptions about quality of care and lack of trust in health sector staff, low capacity, poor staff communication and discrimination shall be also addressed. It is worth mentioning that few services are provided to persons who are unable to physically participate at health institutions.

Lack of broad spectrum of roadmaps and protocols as well as insufficient compliance with existing ones results in suboptimal provision of services. There are missing clear indications and clear consultation mechanisms to patients among health care levels.

**RECOMMENDATION:** Based on their mandate, the Family Medicine Centers are recommended to carry out home visits in order to meet the needs of vulnerable groups (mothers and children), increase social inclusion and provide access to basic services. The home visits program should be expanded and implemented by MoH in cooperation with municipal authorities and donors.

The family medicine system is not yet fully functional in some municipalities; therefore it is recommended that it shall become functional in fulfilling tasks within reproductive health, mother health, child and adolescent health. It is also recommended to review performance indicators at each level of health care as well as consultation indicators.

The University Clinical Center of Kosovo as well as the Hospital Services, should work in increasing the number of specialized staff, in order that the childcare and adequate treatment of children is at the right level, in order to improve communication between child patients and medical staff, thus to gain trust of family members to local health institutions. To work on a 3 year plan with mid-staff and specialists for better communication with parents.

The Health Inspectorate should continuously monitor, inspect, advise, recommend and take legal action against all health institutions in order to improve the quality of health services to children, increase patient confidence and increase public responsibility and accountability of health service providers. Medical and social disciplines about this issue. Provide a financial support to establish the care according to international standards of palliative care for children with end stage cancer.

■ **Infant Mortality** - Kosovo continues to be the country with the highest infants' mortality rates in Europe. The perinatal mortality rate for 2015 is 12.1 per 1000. Prematurity continues to be the most common cause of early neonatal deaths in 56%, followed by congenital abnormalities with 15% and asphyxia 13%, while infections account for 7% of early neonatal deaths.

**RECOMMENDATION:** The Ministry of Health, UCCK, Family Medicine Centers should work on raising citizens' awareness to prevent the main causes of infant mortality, such as health problems or various infections, depression, short period between 2 consecutive pregnancies, living style and environmental factors such as smoking, alcohol, drug use, stress, exposure to chemical substances and sexual, physical or psychological abuse.

The Ministry of Health, UCCK and hospital centers should ensure quality in provided care, continuous professional education, better supply of the Clinic with medical equipment and consumable materials, continuous supply of Surfactant which has contributed to increased survival of prematurely born babies.

■ **Breastfeeding** - Only 40% of children under the age of 6 months which contributes to the adequate breastfeeding rate for less than half of children with age 0-23 months (46%).

**RECOMMENDATION:** UCCK and the Ministry of Health according to the Law on Breastfeeding, shall promote breastfeeding and raise mothers' awareness that breastfeeding, above all, affects better health and reduces the childrens' death rates. Proper nutrition of babies protects children from infections and provides the ideal source of nutrients.<sup>27</sup>

■ **Malnutrition:** is one of problems faced by a considerable number of children in Kosovo. One in twenty five children (4%) under the age of five have moderate stagnation or are too short for their age, reflecting chronic malnutrition as a result of not receiving adequate nutrition for a long period of time and as a result of frequent and chronic diseases. The main reasons for malnutrition, especially for children, are: poverty, lack of food, inadequate care, poor hygiene, poor quality of food, poor nutrition and baby care and inadequate access to quality health services.

**RECOMMENDATION:** UCCK shall promote the healthiest nutrition for pregnant mothers because birth of under-weight babies is mainly consequence of the mothers' health and malnutrition. Personnel providing child health care should inform advice and discuss with parents about child nutrition in order to prevent anemia and other diseases in children. Develop a special follow-up program for child nutrition.

■ **Immunization of children** - In Kosovo 95% of children are vaccinated with DTP3, 79% are completely vaccinated while only 1/3 of children are completely vaccinated among Roma, Ashkali and Egyptian communities. The main reason remains the lack of parents' knowledge and awareness of the health consequences of children who are not vaccinated.

**RECOMMENDATION:** Family Medicine Centers shall carry out home medical check-ups to identify unvaccinated children and detect childhood diseases that may often have fatal consequences.

■ **Treatment of children with severe illness** - There are problems with diagnosis of children with malignant disease and leukemia because; the UCCK - The Pediatric Hospital has never been able to perform all and sufficient diagnostic tests. At the same time, there is a lack of investment in adequate diagnostic equipment for leukemia disease in children.

Hospitals are lacking specialized human resources for treatment of malignant diseases and leukemia, despite continuing vocational training at all levels of healthcare as it is foreseen by the Health Law. In hospital centers, there is a lack of psychological and social support to the children and parents of children affected by severe diseases in order to alleviate challenges they are faced with.

**RECOMMENDATION:** The Ministry of Health should set parameters or standards showing the extent of treatment or management of serious diseases such as leukemia in children. Development of an orientation and education program for children with cancer, for families or caregivers of children who are facing this disease in order to provide them with all information and access to easy consultation on how to act in such cases, shall be taken into consideration.

In its medium term, the Ministry of Health should allocate specializations in the field of Pediatrics Oncology as well as train, in the short term, the nursing midwifery staff for childrens' oncology. Urgent budget increase for cytostatics is required.

MoH and UCCK should create appropriate child friendly facilities in hospitals as well as increase the number of psychologists and social workers in hospital centers who should work and support children affected by severe diseases as well as their families.

■ **Lack of medicines from the essential list** - It is considered that 86% of patients are paying for medicines, as a result of allocated insufficient budget for supply of medicines from the essential list. In absence of drugs from the essential list, parents are forced to pay from their own pocket and often, because of difficult financial conditions they can not afford it. Consequently, lack of medicines needed for them can have major consequences to the health of children, often fatal consequences.

**RECOMMENDATION:** The Ministry of Health should undertake actions for a long-term and sustainable supply with medicines, anesthetics, infusions and other consumable materials to UCCK, thus ensuring that medicines from the essential list will never be missing.

■ **Budget Management** - Investments in the health sector in Kosovo are extremely low, among the lowest in the region. The budget allocated to the Kosovo health sector for recent years is considered to be insufficient for improving situation in this sector; this was confirmed by health experts, representatives of relevant institutions and citizens. 86% of patients are paying for medicines, 59.5% for co-payment, 33.4% have paid for medical supplies, 31.9% for consultations (including the private sector), 17.3% for other issues and 10% have paid for food. In total, 88.4% of all patients requiring care in health institutions have paid from their own pocket.

Although the Law on Health Insurance has been approved, the right of children to health services will be denied until the budget for the implementation of this law is allocated.<sup>28</sup>

**RECOMMENDATION:** The Government of Kosovo and the Assembly should increase the budget and health investments with special emphasis on children.

Also, based on the summary of findings from the Multiple Indicator Cluster Survey published by KAS, supported by UNICEF, the health sector funding needs to be gradually improved within public sector spending. The rational utilization of existing resources needs to be followed by accurate analysis of health sector spending, giving priority to programs and investments that are of interest to and bring great benefits to the population. Cost/benefit profiles for prestigious investments in tertiary care should be carefully evaluated and priority



should be given to funding areas addressing the greatest burden of disease, including primary health care. Insurance schemes should include basic package services for all ante, peri and postnatal interventions for all mothers and children.<sup>29</sup>

The 2020 Health Strategy emphasizes the lack of resources and calls for greater efficiency of development and coordination mechanisms as well as synergy among the partners involved in providing health services. In order that children enjoy their rights to health, all steps recommended by KOMF should be taken into account and implemented by relevant institutions responsible for the child's health.

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