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## CHILD AND YOUTHS HEALTH PRIORITIES IN GEORGIA

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### INTRODUCTION

Every year, more than 10 million children die totally preventable deaths. The world knows what it takes to improve child health and survival but millions still die because they lack access to these basic services. Most child deaths occur in the developing countries. Pneumonia, diarrhoea, malaria, measles, HIV/AIDS and malnutrition are the primary killers of children in the world. "In 2002, as part of the millennium development goals for health, nations pledged to ensure a two-thirds reduction in child mortality by 2015, from the base year 1990" (1). Many countries made substantial progress in reducing child and maternal mortality but it is a still huge problem for developing counties.

Georgia is one of the counties in the Caucasian region. The country has the strategic position at the crossroads of Europe and Asia. Georgia's location at a major commercial junction and among several powerful neighbours has provided both advantages and disadvantages through some twenty-

five centuries of history. Georgia was part of Soviet Union during 70 years and it achieved independence in 1991. In spite of centralized economic and political control imposed during seventy years of Soviet rule, Georgian cultural and social institutions survived.

Nowadays country has lot of difficulties. It has been caused by the distractions of continuing military crises and by the chronic indecision of policy makers about the country's proper long-term goals and the strategy to reach them. Also, like the other Tran Caucasus states, Georgia lacks experience with the democratic institutions.

The demographic features of Georgia are quite difficult to determine, since the total population is known only approximately. The main reasons for this are the large-scale migration of unrecorded numbers of people and the under-registration of births and deaths. Furthermore, since 1993-1994 some regions in Georgia (Abkhazia and Tskhinvali) do not submit data to the Georgian State Statistics Department. The Abkhazian war occurred in 1992 and the government lost control of this region of Georgia.

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### THE MAIN RESULTS (SOCIO-DEMOGRAPHIC DATA)

According to the UNICEF (2) statistics the total population of Georgia is 5 126 000 in 2003. Average life expectancy at birth male/female is 68.4/75.0. Annual no of birth is 52 000. GNI per capita is 830\$. School enrolment is 99%, total adult literacy 100%. (Male 100% female 99%) Total fertility rate is 1.4; Percent of population urbanized 52%; Access to safe water urban 90% rural 61%. Nowadays based on UNDP data maternal mortality is 32/100 000. Under-5 mortality rate is 29/1000; infant mortality rate is 24/1000(3). Low birth weight rate is 6% (1998-2003 years) Moderate and severe underweight 3%, stunting moderate and severe is 12%; Children who are exclusively breastfed under 6 months is 18% (2).

Georgia is in the midst of a painful economic and social transformation to a market economy following the break-up of the Soviet Union. Children and women continue to experience the negative impact of the transition to a democratic system and a market-oriented economy. "Nowadays the country spends under US\$ 20 per person per year on health (equivalent to 3.9 percent of GDP in 2000), 73 percent of which is private and 27 percent public. Public expenditures on health in Georgia are one of the lowest in the region. Continuous under funding of the health sector for the last number of years is exacerbated by the gap between budgeted and actual expenditures, as well as by

misallocation of scarce resources. As a result, the poor in Georgia suffer disproportionately. Although the public share of health care expenditures remains poor, per capita allocation has increased from US\$ 1 to US\$ 7 since introduction of reforms several years ago."(4)

Generally health status of the population is declining. Georgia has universal access health care system during the soviet period. That time health care available for all as a free public service. Under the communist regimes after 1945, in Central-and East Europe and the Soviet Union health care was declared a public responsibility. The goal was to attain universal access to care with broad coverage in terms of services and that was achieved in most countries by the mid '70s. Health systems in socialist countries also provided strong public health measures, such as compulsory childhood immunization. This helped them to achieve better health outcomes than other countries with similar levels of income. The Soviet system placed special emphasis on treatment of women and children; many specialized treatment, diagnostic, and advanced-study centres offered paediatric, obstetric, and gynaecological care. Maternity services and prenatal care were readily accessible. According to most standard indicators, in 1991 the health and medical care of the Georgian population were among the best in the Soviet Union. The rate at which tuberculosis was diagnosed, 28.9 cases per 100,000

populations in 1990, was third lowest, and Georgia's 140.9 cancer diagnoses per 100,000 populations in 1990 was the lowest rate among the Soviet republics. Infant mortality rate was 15.9 per 1,000 live births in 1990 (5).

In the years immediately following independence of Georgia the health system suffered severe financial shortages. These resulted in delayed or non-payment of staff salaries, informal user fees being levied on patients, a virtual cessation of investment in equipment or buildings for health facilities, the development of a black market in pharmaceuticals and a near collapse in the national preventive programmes, including the national immunization programme (6). All these affected on child health.

### **CHILD HEALTH PRIORITIES IN GEORGIA**

Child health is an international priority. As indicated by UNICEF, Georgia focuses on the following child health priorities: education, integrated childhood development, immunization 'plus', fighting HIV/AIDS, protecting children from violence, exploitation, abuse and discrimination.

Deputy Minister of Georgia Ministry of Labor, Health and Social affairs also determines the strategic priorities for the county are: Maternal and Child Health, Primary Health Care, Education, Child Protection (7).

In 2000 the Georgian government adopted a State programme for a

national health policy. The same year saw the adoption of a Strategic plan for health care development in Georgia. One of the goals of this programme is to improve maternal and child health services in the country (8).

### **EFFECTIVE AND EQUITABLE CHILD HEALTH SERVICE:**

Cost effective intervention is very important for poor countries or even for industrialised countries. Equity in health care is based on the principle of making high quality health care accessible to all. Accessible and affordable health services have a vital role to play in reduction burden of disease in less developed countries (9).

Not every child receives high-quality safe and effective care. Poor children are more likely than their better-off peers to be exposed to health risks and they have less resistance to disease because of under nutrition and other hazards typical in poor communities. The inequalities are compounded by reduced access to preventive and curative interventions (10).

Health care system reform strategies in developing countries have emphasized new methods for generating resources for health care and rational approaches, such as those based on disease burden and cost-effectiveness, for the allocation of resources in public programmes. Immunization programmes save millions of lives every year worldwide. Vaccination is heralded

as one of the most cost effective medical interventions (11).

The Expanded Program on Immunization (EPI) has made considerable progress towards immunizing the world's women and children, preventing 3.2 million child death episodes per year from measles, neonatal tetanus, and pertussis, as well as 440,000 cases of paralytic poliomyelitis. Vaccinations provided through the EPI are believed to be one of the most cost-effective child survival interventions at a cost between \$5 and \$10 per child (12).

Children suffer disproportionately from infectious diseases in developing countries. It is estimated here that the death of 4 million children can be prevented each year by reaching a 100% child immunisation rate, reaching 100% of the populations with potable water supply safe sanitation, and eradicating female illiteracy. The potential benefit of improved hygiene for reducing child mortality was analysed in the article "Hygiene and health in the developing countries: defining priorities through cots benefit assessment". A cost-effectiveness analysis revealed that hygiene improvements can prevent the death of child at only a fraction of the cost of water supply and sanitation in the developing regions of the world. A hygiene education programme that reaches households with children under the age of 5 years, with illiterate mothers, and without safe sanitation, i.e., at least

30 million households worldwide, is estimated to prevent about 0.6 - 1 million deaths per year (13).

Varley et al. (1998) present estimates of the health benefits of improved hygiene based on a review of 65 studies. They cite a range of 10 -30% reduction in diarrhoeal incidence/morbidity. Similarly, Esrey et al. (1991) cite a range of 20 - 40%, and Curtis (2002) reports a mean reduction of 44% in cases of severe diarrhoea from good hand washing practices." (13)

Furthermore Vitamin A supplements are associated with a significant reduction in mortality when given periodically to children at the community level. The reviewers suggest that the Vitamin A supplements should be given to all measles patients in developing countries whether or not they have symptoms of vitamin A deficiency (14).

"The evidence is also presented to suggest that, subject to cost-effectiveness examination, two other strategies-vitamin A supplementation and the prevention of low birth weight-should be promoted to the first category of interventions, as classified by Feachem, i.e. those which are considered to have high effectiveness and strong feasibility." (15)

Also the article from Lancet (16) presents child survival interventions with sufficient or limited evidence (1 and 2) of effect in reducing mortality from the major causes of under 5

death. Zinc and Vitamin A are effective (level 1 and 2 evidence) both as preventive and therapeutic intervention to reduce pneumonia and diarrhoea. Also breastfeeding, water sanitation, hygiene are successful preventive intervention (level 1 and 2 evidence).

### HOW ABOVE MENTIONED INTERVENTIONS APPLY TO GEORGIA?

Donor organizations provided Expanded Programme on Immunization (EPI) for Georgia. Only 19% is routine EPI vaccines financed by government in 2003 (2). Several programs for the training and education on breast-feeding are already in Georgia and mainly UNICEF sponsors them. The World Bank sponsors safe motherhood programmes

Since 1999, a five-year intersectoral State programme, *Promotion of healthy lifestyles*, has been in operation. This programme is coordinated by a State Commission under the chairmanship of the President of Georgia. Children and adolescents are priority targets for the programme (8).

There is no study to present evidence how effective are these interventions in Georgia.

### STRUCTURE

The primary health care units are expected to provide the population with health education, maternal and child health care, immunization, prevention, treatment of diseases and injuries, and to ensure patients access

to essential drugs. The primary health care (PHC) structure currently in place in Georgia is essentially that inherited from the Soviet era. Although it was generally hospital-oriented, it did create a large network of primary care units in rural and urban areas. However, sub-specialists generally staffed these units, and an integrated model of family medicine did not exist. The primary care system currently faces financial constraints and is poorly attended. As part of the health reforms, the Ministry of Health Care is trying to strengthen primary care provision. A number of pilot programs to develop family medicine have been started recently with the support of international organizations.

“Children’s polyclinics are part of the primary care units and they provide basic and some specialized services to children up to the age of 15 years. They are located in both rural and urban areas and have outpatient facilities. Services include immunization and home visiting of new-born. When the clinics were built, they were intended to cover a catchments of 10,000 children under 15 years of age. The clinics mainly employ pediatricians but, depending on the size of the catchments and funds available, may also have a minimum of nine part- or full-time specialists (17)”.

The public pediatric hospitals provide all pediatric services to children. But because of high level of informal payments mostly in the

hospitals, the pediatric services are not accessible for children from low social class. According to Socio-Demographic Surveys, only 46% of those who were sick sought professional treatment, and 20% of those that self-treated themselves did so because they could not afford professional treatment (17).

### **ROLE OF EDUCATION, TRANSPORT AND OTHER AGENCIES**

Interest in health education has been rising because there is increasing evidence that many of the most serious problems of health are associated with specific behaviour and lifestyles.

The article "Potential interventions for preventing pneumonia among young children in developing countries: promoting maternal education" discussed the role of education in improving the health and survival of young children in developing countries. It suggests that women's education has some potential as a child health intervention. It is concluded that improvement in women's education will lead to reductions in pneumonia mortality in children ranging from 2 to 11% over a period of 10-15 years. Reviewers could not find a consistent association between maternal education and ARI morbidity (18).

John Ehiri and Jullia Prowse demonstrate very interesting results in the review article. They argue that food safety education is one of the main factors to control childhood

diarrhoea. And there is evidence that mother's education is universally associated with the development of diarrhoea a children. Food hygiene education programme should be designed and integrated with water and sanitation programmes in the developing countries (19).

There is more evidence about women's education for child health, especially child survival in the third World. More educated women are more likely to have initiated immunization and even more likely to have ensured that their children are fully vaccinated. More educated women are also more likely to have received prenatal care, to have been immunized with tetanus toxoid during pregnancy, and to have their deliveries attended by trained personnel. More-educated women also marry and enter motherhood later and have fewer children. As a consequence of their greater likelihood of using health services, of avoiding high-risk pregnancies and of experiencing fewer pregnancies, they are considerably less likely to die in childbirth and thereby orphan their children with deleterious consequences. More-educated women also have fewer stunted children, who will be disadvantaged in later life through their adaptation to low-nutritional inputs, for example through producing lower-birth weight children of their own (20).

### **PROBLEMS AND BARRIERS:**

The one of the main problems was vaccine preventable diseases and

immunization in Georgia. According to World Bank, 1999, in 1998 in Georgia only 63% of children were immunized against measles, and none in 1994-95, because of lack of vaccines.

It is very interesting article about diphtheria epidemic in Georgia 1993-97 years. Epidemic diphtheria reemerged in Georgia in 1993. 1405 cases were reported during these years. 53% of the diphtheria cases occurred among persons  $\geq 15$  years of age. Improvements in routine childhood vaccination coverage and implementation of mass adult vaccination campaigns have been critical to bringing the epidemic under control. By mid-1998, the overall diphtheria situation in Georgia appeared to have been controlled (21).

Nowadays vaccine Preventable Disease incidence has been reduced, the country received polio free certification in 2002 (zero reporting for Polio and maternal and neonatal tetanus was maintained, diphtheria incidence was reduced from 5.5/100,000 children in 1997 to 0.6 in 2002). Immunization coverage shows high results (around 90% nationally for all basic antigens). Yet, immunization coverage of remote areas, timely immunization as well as the monitoring and reporting system need improvement (7).

Based on socio demographic data there are several problems due to child health in the country. The main problem is under-5 mortality which

is higher than other newly independent states (Belarus 17, Ukraine 20, and Latvia 12). Depute Minister of Georgia specified that Infant Mortality Rate (IMR) 23.8 per 1,000 live births in 2002 is mainly caused by the high neonatal mortality (16.2). The main causes of IMR are the inadequacy of parental service quality, low awareness of existing health benefit packages and their utilization (7). According to data supplied by the State Statistics Department, infant mortality in Georgia is below the average for the NIS and close to the figures for neighbouring countries. However, it should be pointed out that because of under-registration the actual infant mortality rate is considerably higher, what is confirmed by the data of the Ministry of Health. This is also a problem with other rates based on data from the registries of births of the State Statistics Department (8). Furthermore recent data show maternal mortality to be one of the highest not only among the NIS but also in the European Region as a whole.

Exclusively breastfed under 6 months is 18% in Georgia. "Infants aged 0-5 months who are not breastfed have seven fold and five fold increased risks of death from diarrhoea and pneumonia, respectively compared with infants who are exclusively breastfed" (22). According to the National Center for Disease Control of Georgia ARI rate in Children till 14years old is 8050.27 per 100 000 in 2003. 4102 diarrhoea

cases were reported in 2003 among children till 14 years old (23).

Although in the more developed parts of the region stunting and wasting are rare, micro-nutrient deficiencies are a region-wide issue. Iodine, for example, is vital to the development of the brain in very young and unborn children; serious deficits can lead to mental retardation. "In many parts of the region—all the Central Asian countries, Russia, Ukraine, and Georgia, for example—the level of iodine deficiency disorders (IDD) is considered as mostly moderate and severe." (24)

#### **OVERCOME THE BARRIERS:**

A realistic picture of the country's epidemiological profile and the capabilities of its health system are needed before appropriate public health interventions can be developed and implemented.<sup>1</sup> Usually child survival interventions are not reaching the children who need them most. Poor coverage is clearly a result of weakness in both the provision of and demand for services, and a consequence of malfunctioning health system. Equity must be a priority in the design of child survival interventions and delivery strategies and mechanism to ensure accountability at national levels must be developed. The potential impact of relatively inexpensive health interventions in this area is immense. Most of the deaths could easily be avoided by simple measures, such as better information and better hygiene in the

operating theatres and education, information campaigns.

Most of diseases are preventable by highly cost-effective interventions promoting healthy lifestyles. For example to combat IDD which is problem for Georgia are well-known and applicable, as demonstrated by other countries in the region that succeeded in. Nowadays American health Alliance provides technical assistance to the Ministry of Health of Georgia in assessing the extent and magnitude of iodine deficiency in Georgia and in designing programs to decrease this condition in the population.

As Deputy Minister declares the following actions must be taken: effective coordination of multilateral and bi-lateral development partner assistance; government and non government collaboration; improve government capacity in order to effectively utilize donor assistance (7).

According to the statistics (2) there are problems with neonatal mortality, chronic undernutrition (stunting) and low breast feeding rates in Georgia. Government should start to cope with this problem at first in local settings. The success of promotional programs depends not only on the interventions themselves but on the acceptance and acquisition of the desired knowledge, skills and behaviours. As research suggests there are several efforts about breastfeeding:

(1) modifying hospital policies;

- (2) using social supports;
- (3) providing incentives;
- (4) educating mothers and health workers; and
- (5) initiating legislation and political action to create policies aimed toward healthier infant feeding practices (25).

Effective child health programme should be implemented in Georgia.

Actions should be undertaken based on best evidence and western experience of successful child health interventions. However, the factors which influence child health in developing countries are more significantly influenced by social equity, political stability and improvement in household and community environmental health then specific medical intervention (19).

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## ბავშვებისა და ახალგაზრდების ჯანმრთელობის პრიორიტეტები საქართველოში

ნინო მირზიკაშვილი, თთარ გერზმაგა

ყოველ წელიწადს 10 მილიონ ბავშვზე მეტი იღუპება იმ დაავადებებისაგან, რომელთა პრევენციაც შესაძლებელია. მსოფლიოსათვის ცნობილია, თუ რა არის საჭირო ბავშვთა ჯანმრთელობის გაუმჯობესებისათვის, მაგრამ მილიონობით ბავშვი კვლავ იღუპება ასეთი სამსახურებისადმი არახელმისაწვდომობის გამო. ბავშვთა სიკვდილიანობის ყველაზე მაღალი მაჩვენებლები განვითარებად ქვეყნებშია. მსოფლიოში ბავშვთა სიკვდილიანობის უპირველესი მიზეზებია პნევმონია, ფალარია, მალარია, წითელა, აივ/შიდსი და ცუდი კვება. “ათასწლეულის განვითარების მიზნებით” - 2015 წლისათვის ბავშვთა სიკვდილიანობა უნდა შემცირდეს ორი მესამედით. ბევრმა ქვეყანამ მნიშვნელოვან წარმატებებს მიაღწია დედათა და ბავშვთა სიკვდილიანობის შემცირების საკითხში, მაგრამ ეს კვლავ უდიდეს პრობლემად რჩება განვითარებადი ქვეყნებისათვის.

# THE ISSUE OF BULLYING IN CHILDREN AND YOUTH IN DEPENDENCE ON THEIR RELATION TO SCHOOL AND FAMILY ENVIRONMENT

Michaela Šimková<sup>1</sup>

## ABSTRACT

In the actual society, the occurrence of socially pathological phenomena in children and youth is increasing constantly. The issue of bullying takes a prominent rank among these phenomena. The author dealt with mapping of this relevant topic by using valid information sources and implementing research of occurrence of bullying in children and youth at elementary schools and more-year grammar schools. The following selected results of the research demonstrate the issue of bullying in children and youth in dependence on their relation to school and family environment.

## Key words:

*Child – minor – bullying – social pathology – family – school*

## 1. INTRODUCTION

How Наконеинэ (1999), the period of adolescence represents *seeking of self-identity*. The minor tries different masks, seeks ways of entertainment that will be recognize by the reference group. He also rebels and generation conflicts arise. The individual makes himself a more and more differentiated object of self-reflection and asks himself the question of sense of life (17). How Шниан, Р., Крејиншповџ, D. (1997) state, things typical to a large degree for adolescence are *the tendency to test limits, to exaggerate, to risk*. This influences the character of problems in this developmental period (19). How Janata (1999) stated, recently *the necessity of prevention of aggression and bullying among young people increases*.

The pedagogical effort to find efficient methods and measures is not proportional to complaints. Pedagogical possibilities enabling emotional education and training of skills how to learn to master aggressive impulses and how to create satisfactory relations towards others are not exploited. Pedagogues often react to aggressive behaviour with punishment and social rejection, which is felt as further threat by aggressively behaving individuals, thus not leading to decrease of the level of anger and aggression (5).

### 1.1. Current situation of selected issue

#### 1.1.1. Risk group of children and youth

How Матовљек (2003) stated, the term *child/minor* represents, according to some legal norms (e.g. Law 140/1961) valid in the Czech

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Republic, a person under 15 years of age. According to other norms and conventions of international organizations (UNO, UNESCO), it is a person under 18 years of age. According to the Civil Code (Law 40/1964), the capability of a physical person to have rights and duties originates by birth. Even a conceived child has this capability, as far as it is born alive (16). How Vögnerovč (2002) stated, the child should develop not only communication with the parents, but also *social interaction at parallel level* in order to master successfully the socialization development. At the level of middle school age, the child group (school class etc.) differentiates more and more. The *norms of the coeval group* start to gain gradually more significance than generally proclaimed norms of adults (21). How Hayesovč (1998) stated, the *theory of social identification* asserts significantly, stressing that the membership in a social group constitutes a significant part of self-conception and is able to determine reactions to other persons or events; so that people react in the first instance as group members, and only then as individuals (3). How Matmjnek (1999) stated, the term *adolescence* is derived from the Latin verb *adolescere* (grow, mature, strengthen). The term *adolescents* (typical for psychology) is interchanged freely with the designation *minors* or *juniors* (typical for medical sciences) and also with a broader designation *youth* (more characteristic for

sociology and pedagogy) (14). *Adolescence, minor age*, is formally defined by reaching majority according to law. But psychological limits are less definite. In the atmosphere of collective life of minors, inappropriate, dangerous habits are easily created. Older school age, approximately from 11 to 15, is often designated as the period of adolescence. Mature intellect abilities are controlled by a still immature and undeveloped personality. Emotional ambivalence is characteristic for this developmental period (2).

#### 1.1.2. Selected risk behaviour in psycho-social sphere

*Social pathology* (from the Greek *pathos* = suffering; *logos* = word, science, speech) is a summarizing concept for unhealthy, abnormal, generally undesirable social phenomena, i.e. socially dangerous, negatively sanctioned forms of deviant behaviour, but particularly for the study of the causes of their origin and existence (6). The frequented term *social* is derived from the Latin word "*socius*", literally "companion", the other, or "friend", comrade. Man is born as an individual, but practically as a member of a small group – family. This blood-related small group can include not only the child and the parents, as in the so-called social mini-family, but also a broader circle of relatives (siblings, grandparents, relatives etc.). This community of other persons, bound in a certain way, creates the so-called *social net*.

This social net can be not only the family, the class, the collective of teachers at a certain school, the work or sports team, but also the community of neighbours, friends from an interest group (cultural, religious) (10). How Macek (2003) stated, conflicts, convulsions and crises are not the basic characteristics of adolescence, but the fact is that it is a *very delicate period for the development of the so-called risk and problem behaviour*. This behaviour has two types in essence. Partly it relates to damaging of health (physical or mental), and in the other significance, this behaviour is related to danger to the society, i.e. negative influence and damage to other people. Most frequently, the following behaviours of present adolescents are classified as spheres of problem behaviour: *pre-delinquent behaviour and commission of crime, aggression, violence, bullying and hazing (including racial intolerance and discrimination of some groups); drug abuse (including alcohol and smoking); sexual risk behaviour (including premature motherhood and parenthood); alimentary disturbances; attempted and completed suicides*. These spheres or forms of risk behaviour include further newly also *risk sports and risk behaviour of adolescents in driving vehicles*. The problems mingle and facilitate each other mutually. There are different pictures in individual phases of adolescence as well. For these reasons it is important to concentrate on typical psychological characteristics related to problem behaviour. A more general social-psychological development model of

relations between problem behaviour and its determinants was designed by R. and S. Jessor (1975). It comprises four blocs of mutually related factors that influence behaviour:

- demographic characteristics and characteristics of social structure,
- socialization influences,
- perceived characteristics of the environment,
- personality characteristics of the adolescents.

*It is confirmed that the family is the most important structure for prediction of problem behaviour*. The following points are significant: education and profession of both parents, as well as their incorporation into other social structures or reference value groups (religious communities etc.). School does not appear as an independent factor in Jessors' model. *Nevertheless, in our present conditions, we have to consider school as a possible risk factor* (13). How Нељпор (2001) stated, *alcohol ranks among the most important risk factors in relation to a series of problems in early adolescence*. In the age of 23, the drunkards took hard drugs 2-3x more often, they had multiple drug problems or underwent treatment because of alcohol and drug problems, they were imprisoned 3x more often because of driving under alcohol influence and committed 2x more often violent behaviour or crime. One of possible explanations is that alcohol interferes with the development of social and other skills that are necessary for success in further life (18).

### 1.1.3. Problems of aggression and bullying

How Langmeier, J., Крејишиновб, D. (2000) stated, *violence in the media - violence in television, in videomovies, in magazines, in computer plays and in the technology of virtual reality is not - contrary to violence experienced in families and other social groups - real; it is only imagined, represented, possible. In spite of it, many people call it the most dangerous culprit, because nowadays it can become the most frequent and the most accessible. Today there are already hundreds of works, laboratory and clinical researches with different methodological and theoretical base about its influence on psychical development of children, adults and the whole society. Most studies agree on the conclusion that "long watching of television violence can have permanent influence on the character and personality of the children and it can lead to serious criminal behaviour and to anti-social violence of all types." Uncaringness towards violence committed by other people in the environment, unwillingness to help and "primitivization" of emotional relations in and outside the family is considered as a serious consequence of long-term watching of television violence. Television violence watched by an immature individual, or violence that he can even "produce" himself by pressing a computer key gets through the screen very impressively into the mental and emotional world of the*

*individual, breaking also into the private life of the family and of the whole culture. But television can influence the development indirectly as well - for example by limiting the emotional contact within the family. The most endangered individuals are children and minors whose parents neglect the education role in this regard or cannot meet it fully (11). How Колбш (2001) stated, we speak about bullying, when ugly or embarrassing things are told to the child by an individual or a group; when the child is subjected to physical violence; when he/she is menaced; closed in rooms, etc. These incidents can repeat and it is difficult for the child to defend against them. We can see degenerated, perverse form of traditional pressure to masculinity in the bullying among boys (7).*

How Hirigoyen (2002) stated, *during the phase of domination, both protagonists take retreating attitude at first, to avoid open conflict. The aggressor attacks only in small and indirect hints and tries to disconcert the other at first, without provoking open conflict. As soon as domination begins, the victims do not dare or do not know how to complain. The victims lose their value in their own eyes, but also in the eyes of the aggressor. As soon as violence shows itself openly and without restraint, it represents a breach into the psyche of the victim that was not prepared for it because he has become insensitive in the subjection of the aggressor till the moment. It is a*

process hard to understand. *The feeling of wrongdoing of the victim is often boosted by the environment that is also confused, being only rarely able to support the victim without judging him.* The victims have tendency to be more and more kind and conciliatory, only to escape aggressor's violence. The victim feels alone, guilty, and gets into *social isolation* (4).

## 2. MATERIAL AND METHODS

The main aim of the research was to map the occurrence of socially pathologic phenomena in children and youth in South Bohemian Region. The examined sphere of the whole research was represented by the most widespread socially pathologic phenomena: bullying, alcohol and smoking, non-alcohol addiction, sex risks (time of first sex, voluntary – involuntary, under influence of alcohol, under influence of drugs, protected – non-protected), but also subjective feeling at school, relation to family environment, etc. In the scope of the quantitative research, questionnaire inquiry was carried out in children and youth of classes VII, VIII and IX of elementary schools and of the same age classes of more-year grammar schools in South Bohemian Region. Representation of socially pathologic phenomena was discovered in 1018 respondents with the help of this research method. Thanks to a standardized questionnaire, the respondent's anonymity was observed and the respondents could select one or more possible answers.

The following selected results of the research demonstrate the issue of bullying in children and youth in dependence on their relation to school and family environment. On the base of qualitative methods, the following research hypotheses were stated:

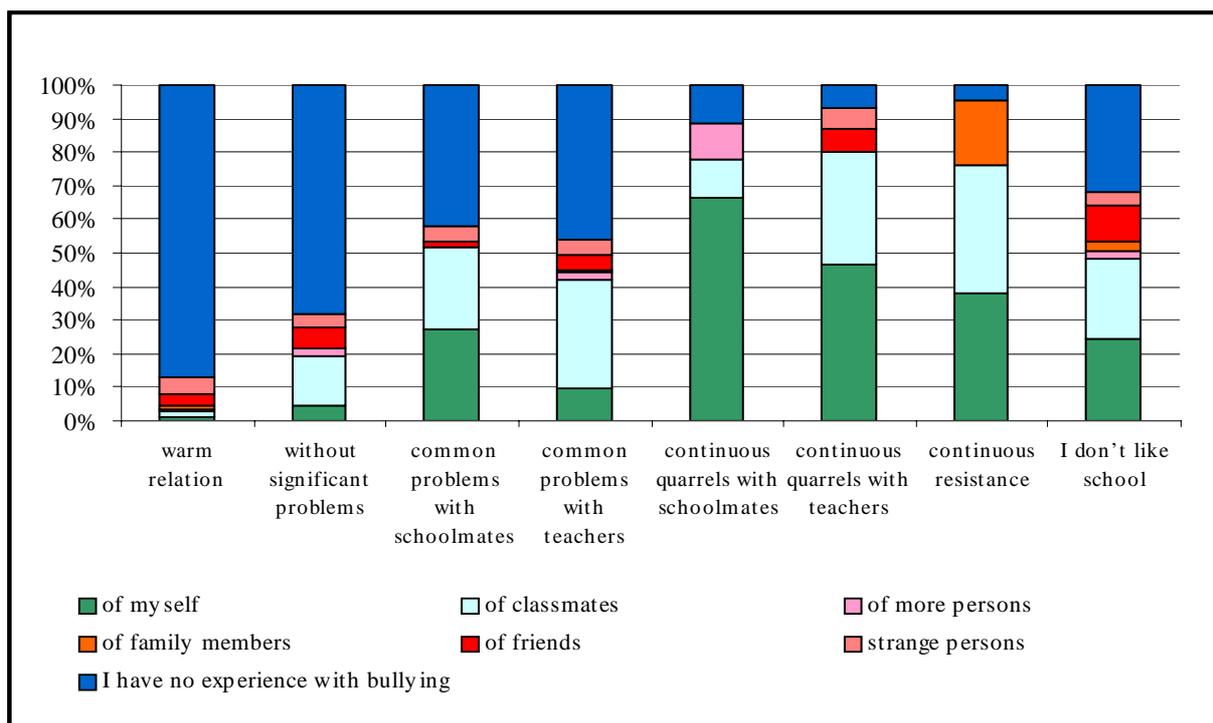
- The more negative the relation of the child and minor to the family environment, the higher the risk of experience with the issue of bullying.
- The more negatively the child and the minor feel in the school environment, the higher the risk of experience with the issue of bullying.

## 3. RESULTS AND DISCUSSION

It was discovered from the processed data obtained from the answers of 1018 respondents that 41,8% of children and youth have met bullying. Pupils of classes VII, VII and IX of elementary schools met this phenomenon in 38,1% and pupils of more-year grammar schools in 44,5%. The charts show that the most children and youth have experience with bullying in school environment, further in class environment, in the crowd, and the less in the domestic environment. The most children and youth have experience with bullying classmates, further with being bullied.

Chart 1 (Dependence of experience with bullying on subjective feeling of child and minor in school environment) shows distribution of the answers of the respondents, the

**Chart. 1. Dependence of experience with bullying on subjective feeling of child and minor in school environment. (in %)**



type of their experience with bullying, and what person was involved in dependence on subjective feeling in school environment. It is obvious that respondents who have warm relation to school feel very well there and like to go there, do not have experience with bullying. Particularly those respondents who feel very badly at school because of constant quarrels with schoolmates stated themselves as victims; subsequently those who feel very badly at school because of constant quarrels with teachers. Respondents who answered that they mostly meet bullying of schoolmates have noticeable problems with teachers; as well as those who stated to feel constant resistance towards school. The chart shows also that experience with bullying was stated by those respondents in which problems in

coeval group prevail over problems with teacher authority. How Kolom (1997) stated, dealt with the presence of bullying at all types of Czech schools. The first cases of bullying in school age children started to appear at the beginning of the Nineties. Since then they have been increasing in geometric progression. It is mostly very traumatic for the bullied child to tell the parents who he loves and cares about, how humiliated he is, how he is not able to assert himself and how nobody respects him. Nevertheless, there is a series of warning signals that should tell the parents that something is wrong with their child. One of the suspicious displays is for example the fact that no schoolmate visits the child at home – he seems to have no friends. Further, the child can be sad to depressive, not speaking about what happens at school. The school

results can worsen markedly, the child is poorly concentrated and disinterested. He often visits the doctor and suddenly unjustified absences can occur. The author distinguishes *three types of bullying individuals*. *The first type of bullying individual* is a rude, primitive person with discipline persons and disturbed relation to authority. Sometimes he is incorporated into gangs committing criminal activity. He bullies hardly and heartlessly, requires absolute obedience, uses violence to intimidate others. The most frequent cause of this behaviour are frequent and brutal punishments from the parents. The children cannot endure the suffering and vent the accumulated aggression on their victims. *The second type of bullying individual* is very polite, even narcissistically cultivated, excessively anxious, sometimes with sadistic or sexual tendencies. He bullies trickily, pointedly and often without presence of witnesses. His parents usually apply very strict and consequent education in military style. The parents are intellectuals who do not listen to their children, putting only immensely high demands on them. Their children miss tenderness, understanding and love and caress. *The third type of bullying individual* is optimistic, adventurous, with high self-confidence, often popular and powerful. He bullies to amuse himself and others. In his family, there often lack adequate emotional education, spiritual and moral values. *The victims of bullying*, contrary to the aggressors, often lose their nerve, they are overcome by panic, horror, despondency, remorse and

exaggerated self-criticism (8). How Antier (2004) stated, *the adolescent attacks his environment in order to explore their reactions and to find out on the base of these relations who he actually is*. The reaction of the parents and teachers doesn't lie in flight from the adolescent's aggression, because this only escalates this phenomenon (1). How Kolb (1997) stated, potential victims of bullying are children of a different ethnical group, children from poor conditions, mother's pet children and very sensitive children suffering from inferiority complexes. It can generally be said that the victim can be predicted. Children from families where father is missing or where hyper-protective upbringing prevails, are mostly more endangered and more at risk. But in certain circumstances, everyone can become a victim, possibly only because he is somehow different. Bullying is a disorder of the whole group. Among the aggressors' parents, the group of those who do not bear the truth prevails. They are not able to accept the fact that their child could be cruel, that he could maltreat weaker children. They sometimes even agree with their child, openly or latently. Ironically, the aggressors' mothers often cry and are worried about the life of their child. They did not notice that he was the one who endangered the life of the victim. They argue also that their child had to defend himself somehow. *The victims' parents often hold back the retrieval of bullying as well*. Quite often, they are anxious, fearful persons, afraid from solutions. In advanced stage of bullying, even the teacher can hold back the investigation, because he is not

prepared for such a situation, or is dragged in the game without knowing it (8).

Chart 2 (Dependence of experience with bullying on relation to family environment) shows distribution of the answers of the respondents, the type of their experience with bullying, and what person was involved, in dependence on the relation to family environment. It is obvious that respondents who have warm or good relation to their family have no noticeable experience with bullying. Particularly those respondents who have markedly negative relation to their family because of continuous family crisis stated themselves as victims. Only those respondents who have negative relation to their family characterized by continuous problems and quarrels met experience of bullying in family members. How Lanyadovb, Horneyovb (2005) stated, *aggressive behaviour of children represents an effort to defend themselves against negative experience originated mainly in the family and to express dissatisfactions*. Children and adolescents find a way to get rid of tension through different projection mechanisms, exposing the others to the same feelings of anger and fear they feel as unbearable themselves (12). How Vannikovb (2004) stated, *in some families, the problems of the children and adolescents originate particularly in blocked communication between the parents or between the children and the parents*. Further, the problems of children and adolescents escalate in families in which emotional coolness reigns; in which the child is

underestimated or overestimated; where the child is not accepted unconditionally; where upbringing rules are not clearly formulated etc. (22). How Krejiiovb (2003) stated, *the necessity of cooperation of the school and the family is very important. The families have the biggest impact on the upbringing and the development of the children and they have right to decide jointly about the contents of the education. The parents and the teachers are equivalent partners* (9).

Chart 3 (Dependence of bullying environment on relation to family environment) shows that respondents who have markedly negative relation to their family because of continuous family crisis meet bullying in domestic environment. On the contrary, respondents with warm relation to family environment stated bullying in domestic environment in the least number of cases, stating bullying in school environment in most cases. We can conclude from the chart that children and youth having negative relation to family background characterized by continuous problems and quarrels can vent these problems outside the family - in class, at school, in crowd, and they can distinguish bullying better. How Lbpatenkovb (2004) stated, *the firing device for most social and health problems in children and adolescents is not mastering of the parents' demands, but also maltreatment, sexual abuse or neglect, alcohol or drug abuse etc.* (20). How Matovb (1997) stated, *in last decades the researchers discover with surprise that minor delinquents come from well situated and at first sight well functioning families in*

much more cases than in the past. The *influence of the family* on adolescents and children gets generally weaker and the *coeval group* following a deviant norm has *primary influence* on the origin of socially pathological behaviour. Nevertheless, it keeps holding true that most families of children and minors with occurrence of socially pathological phenomena are less cohesive and the atmosphere in them is more conflicting than in families with normally developing children. Only recently we could notice a change in the attitude towards families of young delinquents. Experts stop being fascinated by imperfections of these families and signs of their dysfunction; they rather concentrate on usable sources of support that can be mobilized to the benefit of the child and the minor. A positive change is also considering the *social net of the family* - it is based on the premise that the ability of the family to influence the children is related to a broader social connection of the family (15).

#### 4. CONCLUSION

The research was carried out with regard to principles of social-environmental approach putting stress on the child who is to be helped, and we see him at the same time the most consequently possible in interaction particularly with his social environment - family, school, coeval group. Interpersonal and broader social relations in which the child and the minor is integrated were taken into consideration. A significant precondition for solving the problems of bullying is determination of the measure of experience with this phenomenon in

children and youth. The research discovered in what environment children and minors meet the problems of bullying the most and in what mutual relation it is with their subjective feeling in family and school background. It was discovered from the processed data obtained from the answers of 1018 respondents that 41,8% of children and youth have met bullying. Pupils of classes VII, VII and IX of elementary schools met this phenomenon in 38,1% and pupils of more-year grammar schools in 44,5%. The charts show that the most children and youth have experience with the problems of bullying in school environment, further in class environment, in the crowd, and in the domestic environment. The most children and youth have experience with bullying classmates, further with being bullied. The number of respondents who have met these problems personally or in their environment is relatively high. Thus it is necessary to increase continuously the knowledge of individual forms of bullying both in children and youth, and in parents and teachers. A non-omissible task is carried out by the media in this case, because thanks to them, the researched issue becomes more transparent. The implemented research confirmed the research hypotheses. It showed that the more negative the relation of the child and the minor to family environment, the higher the risk of experience with problems of bullying; and the more negatively the child and the minor feels in the school environment, the higher the risk of experience with the problems of bullying.

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## ბავშვების დაზინების პრობლემა სკოლასა და ოჯახთან მათი დამოკიდებულების კავშირში

### მისაელა შიმკოვა

რეალურ სამოგადობაში განუხრელად იზრდება ბავშვებსა და ახალგაზრდებს შორის სოციალურად პათოლოგიური მოვლენა. ამ მოვლენებს შორის დაზინების საკითხი სულ უფრო მზარდ პრობლემას წარმოადგენს. ავტორი შეეცადა სათანადო ინფორმაციის გამოყენებით ამ საკითხის შესწავლას და ჩააგარა კვლევა, რომელიც უკავშირდება დაწყებით და საშუალო სკოლებში ბავშვების დაზინების პრობლემას. ნაჩვენები შედეგები ასახავს ბავშვების დაზინების პრობლემას სკოლასა და ოჯახთან მათი დამოკიდებულების კავშირში.

# PSYCHO-SOCIAL CONNECTIONS OF ONCOLOGY DISEASE IN CHILDREN AND YOUTH AND THEIR FAMILIES

Hana Burkertová<sup>1</sup>

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## ABSTRACT

Childhood disease is a family disease, since it affects everyone in the family system. Children and families must confront many new stressors and challenges. The physical and emotional demands of childhood cancer vary according to the stage of the family development, and degrees of family support. Understanding what children and families experience through the course of childhood cancer is necessary for the providing of the comprehensive care. Family-based interventions appear to be an essential aspect of good psychosocial care for pediatric oncology patients.

## KEYWORDS:

*Pediatric oncology patients – family – psychosocial – effects*

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## 1. INTRODUCTION

The diagnose of tumorous disease is a very strong psychical commotion for all concerned persons (excluding the smallest children) (14, 34, 20, 18, 1). It concerns the ill child, the members of his/her family, particularly parents, siblings, grandparents, other individuals from the surroundings of the patient, but also health care workers. The study A substantive theory of keeping the spirit alive: The spirit within children with cancer and their families (38) confirms the preceding pieces of research that point out the impact and the consequences that the oncology

disease of children and youth has for their life and for the life of their families (2, 5, 6, 23, 30, 31, 32, 35, 39). The oncology treatment of the child is related to a series of other problems in the family, as for example psychical burden, problems with upbringing of healthy siblings, problems in partner coexistence of the parents of ill children, loss of social contacts, financial problems (8). A lot of the concerned persons keep the experience, although in case of successful treatment, as a negative trace during the whole remaining life. When the child dies, the survivors are marked with his/her death forever (16).

Great attention is to be given to the measure and the way of passing the

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information to the patient and his/her family, reducing the fear and uncertainty of the patient and his/her family, overcoming the communication barriers between the ill child and his/her doctor, estimating the general quality of the patient's family, mastering the relation of the family members to the siblings of the ill child, to the changes in the previous life of the family, securing the active role of the adults in the surroundings of the ill child, advising the parents on non-violation of the upbringing principles (14).

## **2. PSYCHO-SOCIAL CONNECTIONS IN ONCOLOGY/MALIGNANT DISEASE**

### **2.1. Passing of information**

The psychologically most serious tasks that have to be mastered include: to observe the measure and the way of information, both the primary, and the subsequent pieces of information that should be regular and comprehensive. The pediatrician is bound to inform the parents truthfully, while observing delicacy and not destructing the last hopes. Absolute necessity is the individual attitude during which the doctor communicates the bitter truth to the parents gradually (33). It is optimal to inform both parents at the same time (14). The most frequent error is often disagreement of the health care workers, passing different and incomplete information and using excessive scientific terminology (36). The principle should apply that the

parents should know about their child more than anyone of their relatives, friends etc. who will ask them questions later (24).

We do not hide the illness from the child, the kind of information is always discussed with the parents. A small child is given the information in a playful way, he/she should be prepared to the surgical procedure awaiting him/her. In case of bigger children and teenagers, the doctors do not avoid the name of the disease and try to explain the essence of the disease (25). From studies carried out in lethally ill 6 to 10 years old children follows that despite of the effort of the parents and the nursing staff to hide the serious character of the illness and the unfavourable prognosis from the child, the child perceives in some way that his/her disease is not a common disease (37).

### **2.2. Psycho-social consequences of the disease and its impact on the child and his/her family**

The encounter with an oncology disease represents a huge burden particularly for the parents and the child.

Some parents will remember for all their life the moment of the diagnose notification. Thus the diagnose notification depends among other things also on other circumstances, e.g. who tells the truth, how he tells it, whom he tells it to, where and

when he tells it (9). It is always suitable to pass the diagnose to both parents at the same time and not to put one of them at stress from having to inform his/her partner himself/herself (9, 14).

The notification of a serious diagnose or its suspicion, including the cases when the disease has developed gradually, provokes shock, sadness and anxiety in the parents. The attention is narrowed on stating the disease and the parents think that nobody has explained them the situation, that nobody has spoken to them altogether. The shock subsides gradually and the parent feels non-informed and alone in the difficult situation. Each of the family members copes with the fact of the disease in his/her unique way, but most parents pass through a series of stages of coping with an incurable disease, as Elisabeth K bler-Ross (1955) described them:

1. **Shock**, when irrational thinking and feeling prevails, the parents experience feelings of impersonalization and confusion and they can react inadequately.
2. **Denial**, or possibly **displacing**, when the parent seeks magical solutions and fights against accepting the diagnose ("it is not true", "a miraculous medicine must exist", "the doctors have not told me anything"). They start to seek all evidences that the information of the disease is not true.
3. **Sadness, anger, anxiety, guilt** – possible displays of anger and wrath against the health care staff

and against the partner ("anger against the whole world") and seeking guilt in others. A frequent reaction in this period is further profound sadness, self-pity and particularly guilt.

4. In the stage of **bargaining**, the parents set themselves aims, mostly time-limited, that have great value for them. They try to "bargain" with the parents, ask whether the children will live to enter school, to pass graduation etc.
5. **Reorganization**, the last stage when the situation is accepted by the parents, the parents cope with the fact of the illness, accepting the child as he/she is and seeking optimal ways for the future.

However, by far not all the parents reach the last stage mentioned. Remaining sadness and guilt of fear for the life of the child usually condition the ambiguous relations of the parents towards the child (oscillation from anger to exaggerated family love) that can remain in a long term. But when the original unintentional reactions are not overcome, the balance of the whole family system is disturbed and the child does not get the care and support he/she needs (19).

### 2.3. Family of child with oncology disease

Good relations in the family are a precondition of healing. Observing and long-term monitoring of families with chronically ill children show

that not only the upbringing attitude of the parents, but also the relations of all family members and an undisturbed home atmosphere are very important for further development of the child's disease. The mother is the most important person for the child, having the most difficult task at the same time, because she spends the most time with the ill child. Mothers also suffer the most during the above described phases of adaptation to the chronic disease of the child, and a series of neurotic problems as sleeplessness, headaches, anxiety and fear has been observed in them. The significance of providing help intervention to families (mothers) through another experienced instructed mother and the so-called child-life specialist (individual who generally takes part in health care with orientation on emotional and developmental needs of children and families) is dealt with by Ireys and collective in their study Maternal outcomes of a randomized controlled trial of a community-based support program for families of children with chronic illness. The mother who as the accompanying person has experienced her personal suffering, but also the fear from the possible loss of her child, is evidently the most competent person, because she is able not only to understand best the worried mother, but also to provide her recent information of all available services and social assistance (26). Less known and described are attitudes and reactions of fathers towards the ill child. The bond between them is not so firm as

between the mother and the child. The fathers often drown their problems in excessive diligence, they become workaholics who work many hours overtime, feeling that the child prefers to be with the mother who certainly will know what to do in case of symptoms of the disease. Thus the influence of the fathers on the ill child is actually indirect, mostly through the relation with the mother (11).

Ideal adaptation of the family implies the organization of the family life so that it not only meets the needs of the ill child, but also of all other family members. The most frequent deviations from ideal adaptation are hyperprotectivity, rejection of the child, continuing anger towards the other parent. Accepting the fact of the disease and coping with the disease in the family system are conditioned by a series of factors as e.g. the type of the disease, etiology, individual characteristics of the ill child, individual characteristics of other family members, the structure and organization of the family system and the quality of the family relations, the development phase of the family (unmarried mother, divorced parents, first child, communication level in the family), the environment (social isolation, lack of social support).

However, in case of a long-term disease or permanent affection of the child, the adaptation of the family is never quite finished and each deterioration during the disease represents a new shock for the family

- often even more striking than the notification of the first diagnose (19, 20).

Each oncologically ill child and the family of each of them suffers in other way - with despair, anger, fear, anxiety, shame, change of life style of the family and change of personal role in the family and in the society and particularly with fear of death. The attitude taken by the parents is important for the way how the child experiences the disease (children under ten perceive their disease through feedback of their environment, mainly from their parents and closest relatives (36).

The experiencing of the disease by the child is influenced by the upbringing attitudes in the family as well (11). From the developmental point of view, the age when the child got ill is significant. From the psychological point of view, maximal meeting of specific developmental needs that can be interfered by the disease is decisive in individual developmental phases, so that the development of the child is not generally slowed down or seriously disturbed in some areas (19, 20).

The chronic disease troubles the child particularly when he/she is not informed of his/her disease, he/she cannot imagine how it originated, whether he/she is in some way responsible for it, what its course and prognosis will be like. It is completely natural that the youngest chronically ill children experience

their disease with all its consequences as a punishment. On the basis of this, feelings of shame, guilt, anxiety can arise in children who are not informed about their disease and they can endure till adulthood. A lot of children express with their behaviour or indirect questions the wish to know the truth about their disease. The doctor and the parents must go to meet this wish the most they can, but with caution. A non-implemented or insufficient dialogue, disappointment from not being allowed to ask any questions, not only encourages uncertainty, but causes distrust as well (33). Children under seven often react to the disease with defiance, aggression or apparent misbehaviour, while in older children we can already see real depression (11).

#### **2.4. Reaction of the child and the family to disease and treatment**

During individual periods of the treatment the children and their families must withstand considerable stress. The disease is a threat for children and youth regardless from their age, having impact on their development. Coping with chronic disease in a bad way is professionally called maladaptation. It can show itself just with bad-temper, anger, sorrow, anxiety or fear emerging during the whole course of the chronic disease. These internal conditions of the children follow from reducing activities, from medical examinations, from

recognizing their own difference etc. One of the forms of maladaptation is "active offensive defence". The child is aggressive against him/herself and others, he/she is rude to siblings or even to parents, doctors, schoolmates, or attacks verbally. Passive escape defence in disease means apathetic accepting of all what happens to the ill child, without own active contribution to healing (11).

## 2.5. Siblings

They are one of the most ignored groups in connection with the impact of the disease on the environment of the ill child.

Oncology disease can have a considerable emotional impact on the siblings of the ill child (27, 28, 29). To help these siblings to cope and to accept the disease of their siblings, supportive sibling groups work at a lot of clinics in the world. One of the aims of these supportive groups is to reduce anxiety.

Houtzager, Grootenhuis, Last, (2001) evaluate in their work called *Supportive groups for siblings of pediatric oncology patients: impact on anxiety* the influence of participation in a sibling group on the anxiety of these children.

Symptoms and antagonistic feelings of siblings of children with oncology diseases could be mitigated by timely and pointed information about the disease and with possible group discussion and activities shortly after the confirmation and

notification of the oncology diagnose of their ill sibling (22).

## 2.6. Return to school environment and resocialization

Social contacts of the child during the treatment must be maximally supported (14, 1). Schoolmates can be a great support for the child during the lengthy and demanding treatment (letters, videocassettes).

When the therapeutic regime of the child allows it, it is suggested to keep the most possible contacts with the school and the schoolmates. It is very important that the child is accepted into the school environment without exaggerated attention (14). The schoolmates of the ill child should be informed in a appropriate way before his/her return to school, so as to prevent different misunderstandings.

This is the task of teachers and other educators who should be informed primarily by the parents of the child (about the disease, treatment, side-effects of the treatment and the disease, special needs, possible changes in physical appearance etc.).

## 3. DISCUSSION AND CONCLUSION

Oncology disease of the child has an impact on the whole family and environment, for this reason it is indispensable to fix attention and care on all components of the life of the child and his/her family as

needed. Oncology disease in children often represents an existential threat for all family members, changing their habitual ways of life. It was found that the healthy family members are affected as well and suffer from a double burden - they must cope simultaneously with their own problems and support the ill child (3).

The disease of the child makes big demands on the family. The parents can get into economical problems (25). It happens that mothers caring for their long-term ill children lose their jobs during this period, a part of the families do not stand the huge burden that the disease and the indispensable treatment carry, and disintegrates (34). Due to the job loss, the monthly income of the family is reduced, while the costs related to the treatment increase (8). The contact

with a social worker and provision of social assistance to the family of the ill child is a necessary component of the complex care for the child with malign tumour (25).

The character of the psychological burden differs in the individual phases of the course of the disease and the treatment, or in the period after its ending. They can be five in essence: the initial phase of the diagnose and the initiated treatment, the phase of long-term treatment, the after-care phase (with differently long periods of surviving, curing, but also with the possibility of recurrence or relapse of the disease), sometimes the phase of dying (in case of failed treatment), followed by the phase of the death of the child and the phase after it, that represents a period emotionally demanding and indefinitely long (14).

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### ბავშვებში, ახალგაზრდებში და მათ ოჯახებში ონკოლოგიური დაავადებების ფსიქო-სოციალური კავშირები

#### ჰანა ბურკერტოვა

ბავშვის ავადმყოფობა ოჯახის ავადმყოფობაა, რამდენადაც იგი ოჯახის ყველა წევრს ეხება. ბავშვები და მათი ოჯახები აწყდებიან უამრავ სტრესს და პრობლემას. ბავშვის კიბოთი ავადობისას ფიზიკური და ემოციური მოთხოვნილებები იცვლება ოჯახის განვითარების და მისი მხრიდან მხარდაჭერის გამოხატულების დონის მიხედვით. ყოველისმომცველი დახმარების უზრუნველყოფისათვის დიდი მნიშვნელობა აქვს იმ ასპექტების გათვალისწინებას, რასაც კიბოთი დაავადებული ბავშვის ოჯახი აწყდება. ოჯახზე დაფუძნებული ინტერვენციები საკმაოდ ეფექტურია ონკოლოგიური პაციენტებისათვის სათანადო ფსიქოლოგიური მხარდაჭერის უზრუნველყოფაში.

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## POLICY ON ABUSED AND NEGLECTED CHILDREN

Medea Kakachia<sup>1</sup>

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### ABSTRACT

The goal of the current paper is to review policy formulation stages and observe current policy. Federal legislation implements the facilitation framework of the fostering the abused children and their consequent adoption by new families. Research argues that focus of a current policy is pro-adoption and it represents in itself the recent shift from pro-separation to pro-adoption. The paper discusses advantages and shortcomings of the current policy on adoption. The forthcoming paper will discuss outcomes of a policy and its shortfalls and makes comparative analysis with the current situation in Georgia.

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### INTRODUCTION

The actual policy of USA on adoption of children in foster care is represented by the Adoption and Safe Family Act of 1997 (AFSA). Providing a clear mandate on adoption of abused and neglected children, the policy lacks in protecting the children from abuse in foster care.

The goal of the current paper is to review policy formulation stages and observe current policy. Federal legislation implements the facilitation framework of the fostering the abused children and their consequent adoption by new families. Research argues that focus of a current policy is pro-adoption and it represents in itself the recent shift from pro-separation to pro-adoption. The paper discusses advantages and shortcomings of the current policy on adoption. The forthcoming paper will discuss outcomes of a policy and its shortfalls and makes comparative analysis with the current situation in Georgia.

### POLICY ON ADOPTION AND SAFE FAMILY

Parents have the primary authority and responsibility for their children, but society bears the cost of raising neglected and abused children. The complexity of child abuse issues encompasses those related to the physical, mental and sexual abuse of children by an adult responsible for their care. Importance of the current policy is demonstrated in recorded data in a permanently growing number of abused or abandoned children. The 1994 investigations by Child Protective Services (CPS) Agencies all over country confirmed that over 1 million children were subjected to neglect or abuse. This is 27 percent increase compare to the same indicator of 1990. Nearly half of children abused or neglected were 6 years old or younger, while more than one fourth was 3 years old or younger. Furthermore, it is assumed that an impressive number of unrecorded abuse cases exist due to the delicacy of the subject and difficulty in discovering cases when they first happen. There is a clear evidence that the number of abused and neglected children stays higher

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than what is reported through official CPS statistics. A study released by the Department of Health and Human Services in September 1994 estimated that the total number of abused and neglected children grew from 1.4 million in 1986 to over 2.8 million in 1993. During the same period, the study estimated that the number of children who were seriously injured quadrupled from about 143,000 to nearly 570,000.

Solution to the problem has been seen in different domains of child protection. For the observable period of time the policy has shifted from promoting the in-house rehabilitation and protection to the placement in foster care to the quick adoption from foster care facilities. Some weighty factors determined the policy change.

In recent years, number of children settled in foster care has significantly increased and reached little over 450 000. This increase reflects the progressive number of separated abused and neglected children, but also unveils the waning number of children leaving foster care facilities for reuniting or adoption.

Important factor in shifting the policy towards pro-adoption is an impressive number of potential foster parents. Many strong organizations in non-profit sector are protecting rights of foster parents. Catholic Charity USA and Hear My Voice is just couple of such an examples. Furthermore, many organizations with the same mission evolved in for-profit sector over the last decades. Sometimes these are nationwide organizations, for instance: Adoptive Families of America, Adopt A Special Kid (AASK) etc.

The current Policy, represented by ASFA gives a privilege to the eventual adoption of

neglected children to maintain their safety. The ASFA mandates that "if reasonable efforts to keep a family together failed, a permanent family for the abused should be found quickly, probably through adoption". The Act de-emphasizes the role of foster care institutions because it is costly and temporary. The ASFA committed the Nation to adoption as the best solution to the problem of abused children.

The policy was adopted in the House of Representatives through Bill 867 in November 1997. The Law was adopted in the first session of the 105th Congress of the U.S. on November 19, 1997 and passed as Public Law No. 105-89. The Act was signed by President Clinton.

Senate Committee on Health, Education, Labor, and Pensions (established in 1999) plays a lead role in the policy oversight, while the Department of Health and Human Services (DHHS) through its subordinate Administration of Children, Youth, and Families is responsible for its implementation. Below are some conditions that the latter have to meet, as it is mandated by the Policy:

- Provide training to caseworkers and other staff members
- Develop Assessment Plan and Plan of Individual Treatment for each child
- The individual assessment and Treatment Plans review in not less than every six months
- Initiate termination within 90 days of the child adoption plan development
- If the child is in conversion home, contract placement agreement with the foster parents within 60 days of child's setting freed for adoption.
- If the child is not in conversion home, within 30 days of Adoption Plan development,

- identify three potential families for adoption. If the family is not found, assign the case to adoption recruitment specialist
- Complete background checking of prospective adoptive parents within 150 days of the date of their application.
- Require a third party contractors to comply with the above provisions
- Maintain a computerized record system for the information specified.

### **POLICY INITIATION AND DEVELOPMENT**

The history of abused child care in the U.S. goes as far back as the late 19th century with the invention of orphanages for poor and unattended children. The first prominent attempt to focus public interest on the issue was undertaken by President Franklin D. Roosevelt in the 1930s. He hosted a conference on child welfare. The conference resulted in increased involvement of States in abused child care. Sharing the President's vision, many states developed and adopted a preliminary social welfare policy. The core of the policy relied with measures to preserve natural families and support them in overcoming social difficulties, while enjoying a satisfactory home life. The income supplements ("mothers pensions") were given to single and widowed mothers. Simultaneously, small communities of orphans, called "cottage homes," were established for children who could not live with the abusing family. States' child welfare agencies were the main implementers of the policy.

Child abuse grew into a major issue in the 1950s. Many professionals found a sound link between the drastic increase of juvenile

delinquency and the problem of abused children. This exploration translated into empowerment and delegation of unprecedented authority to child care agencies. A self-evident example of such an authority is the appropriations of making intervention in families. As a result, unsolicited and unneeded interventions became overwhelming.

Later on, two explicitly different approaches have been developed in American society. Advocates of one direction stand for preservation of natural families focusing on at home services, while the advocates for the opposite view focused on separation of natural families and short-term treatment of abused child.

In 1955, Vincent De Francis, leading the Children's Division in American Human Association, advocated for this approach. He called a conference of child care professionals. The United States Children's Bureau followed De Francis' recommendations and in 1961, after a four-year study and planning, issued a list of available child protection services. The policy also focused of strategic and organizational changes and incorporated child abuse/neglect departments into the existing child welfare agencies of states. The cornerstone of the policy was envisioning the social caseworkers as family-helpers, not family separators. Caseworkers studied living conditions of the problematic family, its neighborhood, moral and spiritual attributes of the family. Based on the study they developed individual strategy for each family to preserve it. The at home services were augmented. In general, the emphasis of the policy was in improved treatment of the neglectful parents, thus strengthening the natural families of abused children.

The advocacy of the opposite view of child abuse treatment started evolving almost simultaneously. This perspective relied on separation of natural families and short-term treatment of abused children in temporary foster facilities. A leading pediatrician, Dr. N. Henry Kempe, was first to articulate the term “inadequate parents” and envisioned a system of temporary foster care in parallel with the rehabilitation of violent parents. The Child Abuse Prevention and Treatment Act of 1973 reflected the first measurable achievement of this wing of advocates. In fact, this was the first federal policy on the issue. Previous policies acted only on the states’ level. The Act was originated in Dr. Kempe’s suppositions to remove abused children from family and place them in foster care while their parents were given a home remedy. Within this policy, National Center on Child Abuse and Neglect was founded under the Secretary of Health, Education, and Welfare. The Center, as a federal agency, was coordinating the implementation of child care services’ provisions. In addition, it conducted research and training on the subject and created an advisory board of members of different federal agencies.

This wing of policy advocacy gradually developed into a completely new approach to the issue, even though the policy implementation demonstrated tangible results. The policy was challenged in 1978, by a movement of following professionals: Anna Freud—a child psychologist, Albert Sotlin—a Yale professor of pediatrics, and Joseph Goldstein—a lawyer. In their book “Beyond the Best Interests of the Child”, they recommended termination of parental rights in severe cases and consequent adoption of the child. This was a “new notion” in treatment of abused child. Different interest groups, including lobbyists

of foster parents (such as Family Preservation Services), have joined their campaign.

The new movement resulted into a new shift in policy, reflected in Adoption Assistance and Welfare Act of 1980. The new policy discouraged long-term placement of abused children in foster care and encouraged measures to place a child into new permanent families. Thus, the policy of abused child care for the first time in its history supported adoption.

In 1983, the Committee of Children, Youth and Families was established in the House of Representatives. The committee was overseeing the implementation of the Adoption Assistance and Welfare Act of 1980 before the federal and state agencies. “Congress did not want to sink funds into a foster care system where the average placement was greater than two years because the system was not seen as a permanent solution”.

In the 1990s, it became obvious that the government still was making too many efforts for maintaining foster care. It was providing foster care services to excess number of abused children for four and more years (instead of the two years ruled). The policy image became insufficient. The House Committee of Children, Youth and Families was dismantled in 1993. Meanwhile the message of “adoption as the best solution for abused children” was dispersed to the public by lobbyists for adoptive parents and private adoption organizations. The House Ways and Means Committee and later the Senate started to hold hearings on the issue, inviting adoptive families, lobbyists of adoption, representatives of the state foster care agencies, and other organizations. Just as at

previous stages of this policy development, the current policy formulation was accompanied with the clash of views of two opposite approaches to the issue. The pro-preservers of biological families, using the traditional values of public management, stood for improving the process of abused child treatment. This included better services for family rehabilitation and reunification. The pro-terminators, valued the “new”, “market” approach in public administration. They invisioned children and foster parents as ‘clients’ and offered the more results-oriented policy to serve to the best interests of “clients”. However, their approach lacked in terms of values; their solutions did not consider traditions and ideals. Indeed, they saw new and safe families for children as à permanent and timely solution. In the Congressional testimonies both sides, respectively, represented data in support of their positions.

The prominent advocacy for ‘Adoption as the best solution’ resulted into the new policy, adopted in 1997 and fully inforced in 2000. The Policy is represented bó ASFA. It gives à privilege to the quick and eventual adoption of neglected children to maintain their safety. The ASFÀ committed the Nation to adoption as the best solution to the problem of abused children. The policy “triangle” alos have undergone to transformations: Senate Committee on Health, Education, Labor, and Pensions (established in 1999) plays à lead role in the policy oversight, while the Department of Health and Human Services (DHHS) through its subordinate Administration of Children, Youth, and Families is responsible for its implementation.

## SUMMARY AND RECOMMENDATIONS

Summarizing the current policy it is to be stated that with its adoption the Congress has put sound emphases on the adoption of abused and neglected children rather than on their fostering in public facilities or their re-unification with the biological families. The Congress also makes the States responsible for defining different standard provisions for the ASFÀ, enforcing them to increase the number of adoptions. At the same time, the Policy largely overlooks family preservation, support and reunification services. The current policy is à clear example of à new public management approach to the social problem. It reflects 1) deregulation of the “reasonable efforts” provision, 2) the new “market” approach to the safety of abused children, and 3) à new “market” approach to the needs of the vocal group of potential foster parents.

The policy on abused and neglected children has significantly shifted from its original goal of reuniting and strengthening biological families to the termination of parental rights and quick adoption of abused children. The ASFÀ of 1997 re-emphasizes child safety, seeing solutions of this issue laid with the permanent adoption; it has been vastly focused on decreasing number of children in state custody.

The brief studies conducted by law clerk Hilary Baldwin in Saint Joseph County, Indiana unveiled that soon after adoption of the ASFÀ there was à drastic rise in adoption, às well as in voluntary termination of parental rights in the county. Biological parents do give èð their basic human rights of parenthood in exchange for the right of post-adoption visits to their children. With these findings, Baldwin concludes that the

new policy implicates incentives for parents to terminate their rights, thus contributes to the separation of biological families even stringer than it can be seen at a first glance.

In order to maintain an equal treatment of natural families, it is necessary to develop a new public management approach, where the neglectful parents would be provided an efficient care by governmental or private organizations. The envisioned methods of

work of these organizations should be based in the “at home” treatment approach.

It is to be mentioned, that the new policy of 1997 was fully enforced only in 2000. It has been so far followed with few studies to determine its real impact and whether or not it is a proper solution to the problem. The real impact of the policy will come in less than a decade since its enforcement.

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## ძალადობის მსხვერპლ და უარყოფილ ბავშვებთან დაკავშირებული პოლიტიკა

### მედეა კაკაჩია

მოცემული ნაშრომის მიზანია პოლიტიკის ფორმულირების ეგაპებისა და არსებული პოლიტიკის მიმოხილვა. ფედერალური კანონმდებლობა გეგმავს ისეთი სამუშაო ჩარჩოების დანერგვას, რომელთა მიზანია ძალადობის მსხვერპლი ბავშვების დახმარება და ახალი ოჯახების მიერ მათი შვილად აყვანის ხელშეწყობა. კვლევა არ ეთანხმება იმ აზრს, რომ არსებული პოლიტიკა ფოკუსირებულია შვილად აყვანაზე და არა განცალკევებაზე. შრომაში განხილულია შვილად აყვანის არსებული პოლიტიკის დადებითი და უარყოფითი მხარეები. მომავალ ნაშრომში განხილული იქნება პოლიტიკის შედეგები და მოცემული იქნება შედარებითი ანალიზი საქართველოში ამჟამად არსებულ სიგუაციასთან.

## HEALTH AND SOCIAL ASPECTS OF CARE FOR CHILDREN AND YOUTH WITH TUMOROUS DISEASES IN THE CZECH REPUBLIC

Hana Burkertová<sup>1</sup>

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### ABSTRACT

Tumorous diseases in children represent less than 1% of 55 000 new cases of malign diseases diagnosed in the Czech Republic every year, but they are the 2nd most frequent cause of death after injuries, being actually the most frequent cause of death in children among diseases. Complex care for children and youth with tumorous diseases must be carried out exclusively in specialized departments of pediatric oncology. Comprehensive care is the term used for care oriented on the whole patient and his/her needs, not only on the needs related to his/her health condition (on physiological needs). The team providing comprehensive care should include experts from a series of disciplines who will constitute a team able to help both the patient and his/her family.

### Keywords:

*Pediatric oncology patients – comprehensive care – social – health*

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### 1. INTRODUCTION

Each year more than 55 000 new cases of malignant diseases are diagnosed in the Czech Republic. Tumorous diseases represent less than 1% of this number. But in developed countries including the Czech Republic, the tumours are the 2<sup>nd</sup> most frequent cause of death in children among diseases (16). Interdisciplinary care for pediatric oncology patients is at a high level in the Czech Republic, a level that can be compared to the level of top world centres (7).

### 2. DIFFERENCE OF MALIGNANT TUMOURS IN CHILDREN FROM MALIGN TUMOURS IN ADULTS

#### 2.1. Malignant tumours in children

- The representation of individual types of tumours in children and in adults is different. The most frequent tumours of the adult age practically do not occur in children, and vice versa. The so called epithelial tumours (e.g. breast, intestine, lung carcinoma) are absolutely exceptional in children.
- Biologically, the tumours in children are quick-growing. Infantile tumours metastasize (constitute daughter foci) far sooner, endangering the life of the patient very often. On the other hand, thanks to these

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characteristics, the tumours in children are much more responsive to chemotherapy and radiotherapy than tumours occurring typically in adult age (breast or colorectum carcinoma).

- Other differences are organization of the care and therapy results. In last 3 decades, pediatric oncology has singled itself out as an independent discipline situated outside oncology of adults and classical pediatrics. With regard to relative rarity of infantile tumours and the necessity of highly specialized diagnostic and therapeutic care, infantile tumours are very strictly centralized at the national and international level in developed countries. It is proved that patients treated in specialized centres have better therapy results than children treated elsewhere. Under the condition of treatment in a regular pediatric oncology centre, the children infantile malign tumours reach a survival rate without signs of disease of 5 years from diagnose in more than 75 % of cases.

## 2.2. Complex care for children and youth

Complex care for children and youth with tumorous diseases must be carried out exclusively in specialized departments of pediatric oncology from the beginning. Only there it is possible to ensure quick, full and right diagnostics, complex care including treatment of complications

and lifelong monitoring of the cured patient (9).

Children and youth with oncological disease under the finished 18<sup>th</sup> year of age, i.e. up to the 19<sup>th</sup> birthday belong to a pediatric oncology centre without exception (7).

For professional and economic reasons, the existence of one pediatric oncology centre for an area with 4-5 millions of inhabitants is considered as optimal in Europe and North America.

In the conditions of the Czech Republic it represents one centre for the area of Bohemia and one for the area of Moravia and Silesia.

## 2.3. Concept of complex pediatric-oncology care (10)

- Secondary prevention – health education, preventive oncological examinations
- Complex diagnostics – primary – at general practitioner's, subsequently team diagnostics in a specialized centre
- Complex treatment
  1. Somatic rehabilitation – general, special
  2. Psychological rehabilitation and subsequent care
  3. Social rehabilitation and care
  4. Dispensary care – at general practitioner's and in a specialized centre
  5. Care for patients in terminal condition

6. Care for dying patients
  7. Care for the family of the dying and dead patient
- The reasons for the centralization of the therapy are:
1. Difficult complex diagnostics of tumorous diseases of children, demanding complex treatment with risk of acute or even life threatening complications, risk of occurrence of late after-treatment complications.
  2. Each patient is monitored after having finished the active anti-tumorous treatment. At the beginning, the dispensary controls are oriented mainly on the condition of the basic disease (confirmation of the reached remission) according to specific monitoring plans for individual tumour types and clinical stages (from the point of therapy finishing to the point of reaching of plateau on specific survival rate curves). After having reached about 2 years since finishing the anti-tumorous treatment, the doctors concentrate on detecting possible late consequences of chemotherapy and/or radiotherapy (6).
  3. The cured child should be continually monitored by a pediatric oncologist in adult age as well. The significance of psychological and social components of complex care for individuals treated in childhood on tumorous disease increased particularly after the percentage of long-term surviving and cured children had markedly increased (8). Modern multimodal treatment leads at present to long-term remission of the disease in up to 80% of children with malign disease (6)
  4. The actual concept of the care in pediatric oncology has essentially three levels, the first of them representing the actual treatment process, i.e. the effort to control the disturbed biological situation in order to suppress the disease permanently. The second level is psychological care, while the third component is social care. Its task is to integrate the cured children into the society without any negative impact by the "tumour past". The individual components should follow up one another smoothly (11).
  5. Comprehensive care is the term used for care oriented on the whole patient and his/her needs, not only on the needs related to his/her health condition (on physiological needs).
- Comprehensive care should take advantage of the services of a lot of specialists together – it should be the standard care of big hospitals.

## 2. 4. Key elements of well organized comprehensive care

1. Professional team of health care workers specialized on the problems of pediatric oncology

- pediatric oncologists
- pediatric haemato-oncologists
- nurses (nurses with specialization on pediatric oncology at all levels and grades)

Pediatric oncologists cooperate with a whole range of other specialists from diagnostic and therapeutic disciplines, as e.g. biochemistry, haematology, display methods, pathologic anatomy, immunology, microbiology, molecular biochemistry, cytogenetics, surgery, orthopedics, urology, neurosurgery, otorhinolaryngology, stomatology, ophthalmology, gynecology, radiotherapy, nuclear medicine, anesthesiology and resuscitation, neurology, rehabilitation and other superspecialization in pediatrics (7).

2. Available broad range of services for patients and their families: as e.g. social consultancy, psycho-social support, educational programs, school teaching for hospitalized children (including the offer of cooperation with school and teachers at place of residence), support groups both for patients and for their families, special programs to improve the life quality of the patients and their family, provision of contact with health care workers at place of residence, special

programs intended for patients and their family with the aim to help them master efficiently different examinations, therapeutic interventions, other services as e.g. alimentation, accommodation, transport of the patients.

The team providing comprehensive care should include experts from a series of disciplines who will constitute a team able to help both the patient and his/her family. Doctors, nurses, social workers, rehabilitation workers, psychologists or psychiatrists, teachers, spiritual pedagogues, play therapists or therapists (music-therapist, ergo-therapist) for leisure time activities of the child, rest etc. should cooperate in this team. They should be included in this team from the point of the notification of the diagnosis, accompanying the patient and his/her family till the end of the treatment. The team should offer a series of services and programs. The study *Social work in pediatric oncology: A family needs assessment* - evaluates the perception of psycho-social needs in 77 families having a child with oncology diagnosis. Preliminary results suggest for the sphere of social work interventions in specific spheres as creation of an informal support network, improvement of communication among families concentrated on the disease, the need of adequate information in different stages of the disease and subsequent support services for families (14).

Thanks to clearly specified techniques and psycho-social

interventions, the ill children and their families can be prepared to master the disease.

Providing psycho-social interventions and services plays a role in prevention of psycho-social problems, being able to contribute significantly to improve life quality of the ill child and his/her family (4, 12). Each family has individual needs that can change variedly during the course of the disease. The team should work together so that the patient and his/her family can master the disease and its treatment as efficiently as possible. During the hospitalization, the patient will meet some members of the team every day, others can be invited to participate actively only in case of need. The same team, or the team supplemented as needed, should be at disposition during the visits to the clinic as well. Very important is the good communication among the patient, his/her family and all members of the health care team. The intensity, complexity and duration of the treatment requires that all involved participants trust one another and strive to participate together in the care.

The experience from the hospital can be very hurting for the child. It is important that the child gets a certain feeling of control, so that this experience from the hospital environment could be positive. Medical examinations are an integral part accompanying the oncological treatment, demanding on time. To win the child to participate in the

treatment it is very important that he/she understands what will happen to him/her, how it will happen and why. Understanding must be always individually adapted to the age and development level of the child.

For that reason, the cooperation of the parents with the members of the nursing and therapeutic team is very important, in optimal case they should be a part of the team.

## **2. 5. Optimal components of care for children and youth with oncology disease and their families**

Oncology disease of the child has an impact on the whole family and environment, for this reason it is indispensable to fix attention and care on all components of the life of the child and his/her family as needed.

**Education** - should help the parents to understand possible social and emotional impacts of the disease and the treatment on the ill child and his/her family, help the parents to cope with and master the treatment of their child - stress management, other supporting techniques.

**Psycho-social support** - Psycho-social support should include both the actual patients and their families and it should be provided both during the whole process of treatment, and after the treatment as needed.

**Psychotherapeutic and behavioral interventions** - their aim is to help the patients and their parents to master the feelings of anxiety, fear, anger, guilt, depression, further to help the patients to master unpleasant physiological displays related to oncological treatment, as e.g. nausea, loss of appetite, help in mastering the therapeutic interventions.

**Help in ensuring further services** - their aim is to help to get a grasp of the environment and the operation of the hospital, help in ensuring accommodation, boarding, parking, transport to the hospital and from the hospital to the place of residence.

**Financial and social consultancy** - help provided to the parents in the process of applying for and arranging social benefits and social care from the state.

**Support groups** - these can be intended both for the parents of the ill children, for the sibling of the ill children and for the children with oncology disease; for these, the groups can be further divided into groups for younger children and groups for teenagers or into groups of children with brain tumours etc. The groups for parents can be both lead by the clinic employees (professionals - doctors, social workers, psychologists, psychiatrists, psychiatric or oncological nurses, priests), by individual parents, and organized by non-profit organizations in the place of the hospital or the clinic, but they can be

also organized by non-profit organizations in individual cities (regions), localities or directly at home. The groups can be open or closed. The groups intended for ill children should be lead by professionals (psychologist, social worker concentrated on the problems of pediatric oncology, teacher, musico-therapist).

**Leisure time and rest activities** - summer camps, winter camps, weekend actions.

**Activities of volunteers** - coordinated by volunteer centres at hospitals.

Individual special actions - fundraising activities, lectures.

### 3. DISCUSSION AND CONCLUSION

**For parents of oncologically ill children it is important** to have a high-quality family background, personal contact with the doctor, repeated and with sufficient time. The best is the possibility to have their doctor to whom they can turn with trust. They need to have the possibility to speak about the illness and the treatment of their children, e.g. with the psychologist, other parents, they need financial provision of the family. The treatment of oncological diseases is a team issue.

In providing care to children and youth with oncological diseases, the Czech Republic is at the level of world centres, while the sphere of

psycho-social help has a vast space for improvement. There is not sufficient scientific research that would map this important area. The survey focused to determine the interconnection of health and social care at workplaces specializing on the treatment of infantile oncological and oncohaematological diseases in the Czech Republic, carried out by the author of the article in 2004, brought the following conclusions. There is no high-quality integrity and interconnection of health, social and psychological care. It is important to improve mutual communication and information sharing among the parents, the psychologist, the nursing staff related to the psychical condition of the child. There are reserves in the subsequent psychological, therapeutically supporting, rehabilitation, social care; it would be optimal if it worked in the same way as the oncologists cooperate with general practitioners in the place of residence. The parents who want to cooperate more intensely during the treatment often have to travel to a specialized clinic outside the hospitalization period, or they must postpone their problems to the hospitalization period.

When the treatment finishes and the child returns to his/her everyday life, he/she would need support to cope with a lot of difficulties that come up, and he/she often depends on the central clinic.

It would be necessary to improve the availability of information of the problems of oncological diseases in children and of its treatment.

The social worker helps the parents to get grasp of the unusual situation - to learn which are all the possibilities of social support, where and how they should lay these claims, they sometimes help to settle the situation of families who are not able to care for the child during the disease. The social worker does not work in the department but only in the scope of the whole hospital, and is not in contact with the nurses. Her involvement is not self-evident in each case, the needs of the children and the parents are settled only on request, even general information is not automatic, this being caused by a great number of cases on one social worker who provides her services in the hospital to several departments.

Another chapter is the problems of children whose disease does not respond to the treatment or whose definite curative treatment is not possible. Domestic hospice care specialized on children would lighten markedly the care for terminally ill patients for the doctors and the parents. For the time being, we miss a systematically provided psycho-social care for the family after the death of the child in the Czech Republic.

However, perfect working of complex care for children and youth with oncology disease and their families in the Czech Republic is conditioned by huge financial expensiveness of the treatment, massive work load of the staff and other related factors as well.

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**სიმსივნური დაავადებების მქონე ბავშვებისა და  
ახალგაზრდებზე ზრუნვის სამედიცინო და სოციალური  
ასპექტები**

**ჰანა ბურკერტოვა**

ყოველწლიურად ჩეხეთის რესპუბლიკაში რეგისტრირებული ავთვისებიანი დაავადებების 55 000 ახალი შემთხვევიდან ბავშვთა სიმსივნური დაავადებები 1%-ზე ნაკლებს შეადგენს, მაგრამ ის მეორე ადგილზეა ბავშვთა სიკვდილიანობის გამომწვევ მიზეზებს შორის. სიმსივნური დაავადებების მქონე ბავშვების და ახალგაზრდების კომპლექსური მკურნალობა უნდა ჩაგარდეს მხოლოდ ბავშვთა ონკოლოგიის სპეციალიზირებულ განყოფილებებში. გერმინი ყოვლისმომცველი მკურნალობა გულისხმობს ადამიანის საერთო, და არა მხოლოდ მის სამედიცინო პრობლემებთან დაკავშირებულ საჭიროებებზე ორიენტირებას. ყოვლისმომცველი მკურნალობის უზრუნველყოფის გუნდი უნდა მოიცავდეს სხვადასხვა დისციპლინების ექსპერტებს, რომლებიც შექნიან ისეთ გუნდს, რომელსაც შეეძლება როგორც პაციენტის, ისე მისი ოჯახის დახმარება.

## TERMINOLOGY OF INFECTIONS OF FETUS AND NEWBORN

Miloš Velemínský<sup>1</sup>, Miloš Velemínský Jr.<sup>2</sup>, Petr Sák<sup>2</sup>, Milan Hanzl<sup>2</sup>

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### ABSTRACT

The authors described precisely terminology of infections of foetus and newborn and presented their experiences with this topic. They presented that pregnant women not only are exposed to the infections prevalent in the community but also likely to reside with young children, who represent a significant additional factor in exposure to infectious disease. However, the infecting organism may invade the blood stream and infect the placenta and uterus. Pregnancy induces an immunologic bias in the mother toward humoral immunity and away from cell mediated immunity. The latter is most important against many intracellular pathogens. Transplacental spread after maternal infection and invasion of the bloodstream is the usual route by which the foetus becomes infected.

### Key words:

Classification of infections -foetus - newborn - mother - intraovular infection - bloodstream infection - FIRS - SIRS- PROM - syndrom of infected amnion - amniotic inflammation - cytokines

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### 1. INTRODUCTION

Major advances in biology and medicine made during the past four decades have contributed greatly to our understanding of infections that affect the foetus and newborn. As the medical, social, and economic impact of these infections becomes more fully appreciated, the time is again appropriate for an intensive summation of existing information on this subject. The scope of the present article encompasses infections of the foetus and newborn, including those acquired in utero, during the delivery process, and in the early months of life. Infection acquired in utero may result in resorption of the embryo,

abortion, stillbirth, malformation, intrauterine growth retardation, prematurity, and the untoward sequelae of chronic postnatal infection. Infection acquired during the birth process or soon after birth may result in severe systemic disease that leads to death or persistent postnatal infection. Both in utero infection and infection acquired during the birth process may lead to late-onset disease. The immediate as well as the long-term effects of these infections are a major problem throughout the world.

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## 2. CLASSIFICATION OF INFECTIONS OF FOETUS AND NEWBORN

### 2.1. Intraovular infection

#### 2.1.1. Hematogenic

- a) early (embryo and foetopathy, intrauterine growth retardation)
- b) late (parenchymatous placenta inflammation, intrauterine growth retardation, premature birth, clinical symptoms of afterbirth infection).

#### 2.1.2 Ascending

Maternal and foetal syndrome of infected amnion (sepsis of mother, premature birth, sepsis of foetus and newborn) – inflammation of amnionic type.

#### 2.1.3 Other descending infections spreading per continuitatem (premature birth, clinical symptoms of afterbirth infection)

*Syndrome of infected amnion (1, 2, 5, 10, 21, 27, 32, 53, 60, 61, 64, 65, 66)*

The syndrome of infected amnion (65, 66) is one of the forms of infection of foetus and newborn caused by bacteria colonizing the vagina. Thus it is endogenous infection passing through ascending way to the foetus and infecting it thereafter. However, the damage of foetal membranes is not an indispensable condition for it.

We distinguish the so called *risk of maternal syndrome of infected amnion (RMSIA)*, where we suppose its development (e.g. premature discharge of amniotic fluid, positive finding on the cervix without clinical

symptoms) and the factual *maternal syndrome (MSIA)* of infected amnion showing itself in increased temperature of the mother over 37,5°C, increased number of leucocytes over 15 000/mm<sup>3</sup>, higher level of CRP > 2,0 mg/dl in the mother and tachycardia of the foetus.

Further we distinguish the *risk of foetal syndrome of infected amnion (FSIA)* where infectious complications can be supposed which can show themselves in intrauterine and postnatal way, but without presence of clinical or laboratory signs (e.g. amniotic fluid discharged long ago, temperature of the mother, premature birth). The *factual foetal syndrome of infected amnion* can occur as the so called *Foetal Inflammatory Response Syndrome (FIRS)* (19).

The *Foetal Inflammatory Response Syndrome FIRS* is defined as elevation of plasmatic IL-6 in foetuses in case of premature birth or PROM (amniocentesis, cordocentesis – IL-6 in amniotic fluid and in foetal plasma) (19). It shows itself in the tendency to “expel” the foetus prematurely from the unfavourable environment of the uterus, in the increased level of IL-6 in foetuses. Clinically, after birth, it shows mostly in early beginning sepsis with breathing disorder, perinatal hypoxia etc. It has a relation with serious neonatal morbidity (RDS, sepsis, BPD, IVH, cPVL, NEC). Newborns with higher concentration of IL-6 in foetal plasma had significantly higher morbidity. The system inflammation response of the

foetus, defined as elevation of foetal IL-6, is an independent predictive factor of serious newborn morbidity, being dependent on the gestation age of the foetus. The leading cause of the development of FIRS is intraamniotic infection, but there are probably other potential causes of the development of this condition as well (3, 10, 16, 25).

## 2.2. Inflammation of placenta and foetal membranes

### 2.2.1. Inflammation of amniotic type

The term inflammation of placenta includes changes in the placenta itself, in foetal membranes or in the umbilical cord as a consequence of infection or action of chemical substances. It can occur anytime during pregnancy. Possible reactions depend on the pregnancy stage. They concern necrosis of cells and tissues and also exsudation and proliferation of fibrous tissue. Necrosis and proliferation are equivalents of inflammation prevailing in the picture, particularly in embryonic and early foetal stage, while the inflammation with cellular exudate is detected in the 2<sup>nd</sup> and 3<sup>rd</sup> trimesters. It is an acute and partially necrotizing inflammation of foetal membranes, chorion plate or umbilical cord. It is necessary to define a rare form of course with accumulation of macrophages and lymphocytes and repletion of the actual cells of fibrous tissue in the stroma of the foetal membrane. The inflammation can affect different

parts of the wall of amnion cavity, the so-called amnion, chorion plate or umbilical cord.

There are a lot of synonyms for this disease in literature: *Amniotic sac infection syndrome, chorioamnionitis* (5, 6,13, 16, 18, 22, 23, 24, 26), *intraamniotic infection* or *ascending infection* (17,36). As the process does not always cover equally all sections of the wall of foetus cavity (*amnion cavity*) of the *ovum*, other terms are used as well:

- *Amnionitis*: inflammation in the stroma of the free foetal membrane (synonym: *membranitis*).
- *Chorion placentitis*: inflammation of fibrous tissue of chorion plate (synonym: *chorionitis*).
- *Vasculitis* of chorion plate: inflammation of rami of alantoid blood vessels (synonym: *foetal plate fasculitis*).
- *Omfalovasculitis*: inflammation of blood vessels of umbilical cord, the vein is usually affected sooner and more than the artery (*umbilical cord vasculitis*).
- *Funiculitis*, or *funisitis*: inflammation of Wharton jelly.

The disease proceeds according to localization (*staging*) and intensity (*grading*) of the inflammation. In dependence on the staging of the process, we distinguish: *minimal picture* of the inflammation of amnion, in which only one section of the wall of amnion cavity is affected, *partial picture* with affection of two sections and *full picture* with cell infiltrates in all three sections of the wall of amnion cavity. That means

that in the full picture, the foetal granulocytes regularly pass also the wall of blood vessels of umbilical cord and infiltrate partially Wharton jelly (31, 65, 66, 67).

The intensity (grading) of the inflammation of amnionic type can be defined in different ways. Three grades of intensity are distinguished:

- *Weak*: Individual granulocytes (more than 5) in at least five separately situated visual fields with HPF (High Power Field).
- *Middle*: More granulocytes in more neighbouring visual fields.
- *Strong*: Diffuse cell infiltrates in a lot of visual fields.

Altshuler (4) distinguishes three grades in the area of chorion plate and free foetal membrane as well. However, he does not consider the density of cell infiltrate, but he stresses the tissue layer infiltrated by inflammation cells on one hand and the presence of tissue necroses on the other hand. He distinguishes three grades:

- *Grade 1*: granulocytes limited to basal sections of chorion plate.
- *Grade 2*: granulocytes in all sections of chorion plate and foetal membrane.
- *Grade 3*: necrotizing chorio-amniitis.

The changes in umbilical cord are evaluated separately:

- *Grade 1*: focus infiltrates.
- *Grade 2*: diffuse distribution.
- *Grade 3*: necrotizing inflammation (26, 29, 36).

*Chronic form of course*. The chronic course of inflammation, or recession of its activity for example after antibiotic treatment, can be recognized by a marked reduction, or possibly absence of mother granulocytes in basal sections of the chorion plate and free foetal membrane and foetal granulocytes in the wall of blood vessels of the chorion plate or of the umbilical cord. The transition to chronic inflammation of amnion is characterized by an increased occurrence of fibroblasts, mononuclear cells and macrophages. These can contain iron or lipofuscin. There is increased content of collagen fibres particularly in the foetal membrane. A very rarely occurring final stage is a more or less marked fibrosis in the area of free foetal membrane.

Literature has described only few cases of chronic chorioamniitis (19, 30, 33, 34, 35). The clinical significance is unclear yet.

A specific form of chronic inflammation in the area of umbilical cord is chronic necrotizing funiculitis (6,7). From the histological point of view, ringlike perivascular necrosis of Wharton jelly is produced, which is pervaded in different densities by granulocytes, lymphocytes, plasmatic cells and macrophages. Particularly granulocytes can be proved in blood vessel walls as well. In advanced stage, cell infiltrates can be fully absent.

From *differential diagnostic point of view*, granulocytic infiltrates of non-infectious genesis must be considered: with foetal acidosis, after meconium passage, as a consequence of prestasis and stasis in subchorion space as a consequence of disorder of circulation in blood vessels of the umbilical cord. These infiltrates, unlike inflammation responses conditioned by infection, don't show any amniotropism. They usually affect only one area, for example the subchorion fibrin layer or the circular infiltrate around the umbilical cord vein. To the contrary, amniitis is missing. There was a statistically significant connection between the extent of the inflammation process and the intensity grade in case of the intensity grade III, particularly in full picture of amnion inflammation, while a weaker intensity of response of inflammation cells correlated with minimal or partial picture. In immature, prematurely born newborns we found the full picture more often than in mature newborns: in about 1/3 mature newborns and in 47% of prematurely born ones with pregnancy duration over 28 weeks. To the contrary, we found this picture in 75% of very immature prematurely born babies (< 28 pregnancy weeks). A similar distribution concerned the intensity of inflammation process. The intensity grade III occurred in less than 10% of mature newborns, but in almost 30% of prematurely born ones (67).

### 3. PATHOGENESIS FROM THE POINT OF VIEW OF A PATHOLOGIST

#### 3.1. Pathogenesis of amnionic inflammation

The most important infectious ways are:

- ascension of infectious agent from vagina and cervix,
- infection through hematogenous way as a consequence of dissemination of germs from mother on one hand, as a consequence of foetal parasitemia on the other hand,
- direct dissemination of germs coming from endometritis,
- descension of infectious agent through Fallopian tube,
- iatrogenous infection caused by amniocentesis, puncture of umbilical cord, intrauterine transfusion etc. (43, 46, 58, 62, 66, 67, 68).

By a long way the most frequent infectious way is ascension of germs. Less frequently, the germs are disseminated through maternal hematogenous or foetal hematogenous way. Other ways are exceptional. Dissemination of endometritis to the placenta is possible, but probably very rare. It is known that chronic or recurrent inflammation of endometrium is an unfavourable condition for blastocyst implantation. We consider, in accordance with other authors, that in most cases and independently from the pregnancy stage, maternal cell inflammation response occurs sooner and it is

usually much more marked than foetal response (33, 34, 35, 38, 48, 55). Frequent germs are grampositive streptococci, staphylococci, anaerobic cocci and lactobacilli, as well as gramnegative bars, e.g. colibacteria, hemophilus and aerobacter. Pseudomonadae, listeriae and candidae are more rare. Difficultly detectable germs are anaerobs and germs of bacterial vaginosis: mycoplasmas, chlamydiae and gardenerellas. Besides, herpes viruses come forward as germs of amniotic inflammation. In a lot of cases, we find discrepancy between the proof of germs and morphology. There is no statistically significant connection between the proof of germs from cervical scraping and occurrence of clinical syndrome of amnionic infection (27, 55, 66, 68). To the contrary Gibbs (20) found a positive proof of the germ in amniotic fluid in almost 70% of women with the syndrome of amnionic infection, but only in 7,7% of women without inflammation of amnion. But the negative bacterial culture from the scraping of amnion or chorion plate does not exclude infectious origin of the inflammation, particularly in cases where no special cultivation methods were used. The full picture of amnionic inflammation can exist although the proof of the germ is missing. In these cases, it is necessary to research for the germ in the baby exceptionally intensively. On the other hand, morphologic substrate of inflammation of amnion is fully missing, or it is produced only very discretely in about two thirds of cases

of infection with streptococci B and fundroyantly occurring sepsis "Early Onset".

In approximately 70% of cases, the ascension of germs occurs with ruptured membrane sac, in about 30% of cases with closed cervix. The most frequent cause of open birth canal is the premature rupture of foetal membranes. Another cause can be instrumental rupture of membrane sac or extended delivery. The risk of infection increases particularly in the case of extended rupture of membrane sac. In the delivery canal with amniotic fluid draining away during less than 6 hours we observed the amnion inflammation in 11%, while in the delivery canal with amniotic fluid draining away during more than 12 hours it was in 75% of cases.

The link between infection, histologically proven inflammation and clinical picture are the inflammatory cytokines (7). The histologic proof of acute inflammation of amnionic type correlates with increased concentration of interleucine 1-beta, interleucine-6 and 8, G-CSF (Granulocyte-Colony Stimulating Factor) and TNF (Tumor Necrosis Factor) in umbilical blood or in amniotic fluid (11, 12, 20). Increased concentrations of cytokines were measured in women with premature rupture of the foetal membrane sac and with premature delivery activity. The highest concentrations accompanied the clinical picture of syndrome of amnionic infection

(15,51). Ascending germs were phagocytosed by macrophages and the monocytic neurophile system was activated. The cells showing the antigen are in these cases either macrophages or the B cells, or dendritic cells. The T cells are activated only when other stimulating factors are present besides the specific antigen as well. What is important is the individual functions concerning selective "destruction" of infected cells by CD-8-positive, cytotoxic T-cells, the activation of macrophages by TH1-cells and the activation of B cells by TH1 and TH2 cells. These produce different types of antibodies for humoral immunity response. That's why foetal lymphocytes and monocytes are able, in the point of the delivery, to produce relevant concentrations of inflammatory cytokines. Cytokines as chemotactical factors cause migration of granulocytes into cervical fibrous tissue and discharge metalloproteinases. The activated granulocytes secrete elastinase (PNM-E), lysosomal proteolysis with depolymerizing effect on the collagen of fibrous tissue in the area of foetal membrane, chorion plate and Wharton jelly. Some authors (37) found significantly increased values of PNM-E in maternal and umbilical venous blood with histological proof of amnion inflammation in comparison with pregnancy without presence of chorioamnionitis.

Enzymatic decomposition of collagen supports fast dissemination of inflammatory process inside the

wall of amnion cavity. The dissemination and intensity of the inflammation depend on the type of germs and on local conditions in the tissue. For example simultaneous storage of meconium conditions the increase of intensity of the inflammation. Typical is the course of the inflammation of foetal membrane, placenta and umbilical cord taking place in stages, where we distinguish an early response from the mother, followed by a later response from the foetus (9). First, maternal granulocytes in the decidua and later in foetal membrane can be observed (amniitis, or membranitis). They come from the blood vessels of decidua parietalis and they pass gradually through the decidual and amnionic fibrous tissue of the free foetal membrane. They pass the subchorion fibrin intraplacentally and they get into the immediately neighbouring fibrous tissue of basal parts of the chorion plate. Up to this point of infection, it is exclusively the cell response of the mother. From the differentially diagnostic point of view it is important that it is possible to prove this reaction in a foetus already dead. In these specific cases, the inflammatory process need not be conditioned by infection each time. To the contrary, the cellular co-response of the foetus shows itself in migration of foetal granulocytes from the blood vessels of the chorion plate and the umbilical cord and – regardless of some exceptions – it is always conditioned by infection. From the 14-15<sup>th</sup> pregnancy week, the foetus is able to react on infection with production of granulocytic

exudate. In case of inflammation of amnionic type, the granulocytosis in the liver of the foetus is multiplied. It is possible that this is caused by interleukin-8 from the liver of the foetus, circulating in foetal circulation. The monocytes of newborns are also able to produce and to discharge interleukin-8. Byscher (11,12) proved in clinical symptoms of the syndrome of amnionic infection a significantly increased discharge of IL-6 and IL-8 through CD3-positive cells of the newborn. The cytokines activate the production of phospholipases in their own cells and bacterial. This stimulates metabolism of arachidonic acid in amnion and decidual cells and prostaglandins are produced. Besides, interleukines induce the synthesis of prostaglandins by leukocytes. Intrauterine concentration of prostaglandins increases significantly. E2 stimulates cervix maturation and dilatation and F2 induces myometrium contraction. This explains the close connection of ascending infection and premature birth (39, 40, 48, 50).

At the beginning of the amnion inflammation, infiltrates of granulocytes and necroses can be often proved only in focus form. This applies particularly for the infection of foetus cavity with an intact membrane sac. The germs are not equally distributed among different sections of the wall of amnion cavity, and the proof of inflammatory cell response is analogically irregular. The inflammatory cell response can

be found, according to our experience, at first on the free wall of the foetal membrane, in the neighbourhood of the pole of the foetal membrane. The period of time between the beginning of the inflammation on the internal cervix and the creation of the full picture of the amnion inflammation amounts to some 12 to 24 hours. Morphological examination of the placenta must regard this circumstance with the help of an analogically standardized method (66). Independently from the age of the pregnancy, we find in accordance with other authors that the maternal cell inflammatory response occurs as a matter of principle sooner, being usually much more marked than the foetal response (11,48) of microfibrine. We have not proved the relation between intrauterine retardation of the foetus growth and immaturity.

#### **4. PATHOGENESIS FROM THE POINT OF VIEW OF THE OBSTETRICIAN**

##### **4.1. Infection of foetus and newborn**

A whole series of factors, as e.g. virulence of infection agent, point of infestation, general immune condition of the mother and the foetus or the newborn, decide whether the infection in the foetus and the newborn manifest itself. Very specific is particularly the immune condition of the foetus and the newborn that is the basic factor of the defence of the macro-organism, however very limited in

this period. More immunity components show themselves as deficient. They are particularly opsonization, chemotaxis and the ability of lysis in connection with low level of complement and other serum factors. The IgG levels depend on the level of their passage from the mother and on the gestation age. The ability of synthesis of the individual immunoglobulin classes differ markedly from the conditions in further life stages. Significant deviations are proved in the function of T lymphocytes, NK cells (Natural Killers) and in the sphere of mediators of cell immunity. But at the same time, there are a lot of immunological deviations, and at present we don't know exactly their clinical significance in most of them. The defence against infection is negatively influenced by different pathologic conditions as hypoxia, hypoglycemia, hyperbilirubinemia, hypotrophy of the foetus and other demanding situations for the foetus and the newborn. All this is very significant from the point of view of a relatively high incidence of infections and their high risk in this age.

#### 4.1.1. Significance of premature birth

Premature birth causes 8-10% of perinatal morbidity and mortality. In the pathogenesis of premature birth, the following factors can be observed:

1. Activation of maternal or foetal hypothalamic-hypophysial-adrenal axis (stress)

2. Decidual chorioamnionitic inflammation (hematogenous, ascending)
3. Decidual hemorrhage (hypertension, smoking, cocaine addiction, blood vessel lesion of placenta)
4. Pathological distension of uterus (multiple pregnancy, polyhydramnion, uterine anomaly).

The final markers of these pathogenetic factors leading to degradation of extracellular matrix in foetal membranes and in the cervix and further to activation of myometrium are the matrix of metalloproteinases MMP-1 and MMP-9, foetal fibronectin, ultrasound proof of cervix reduction and its funnelling.

There is a wide range of literature data about the relation of premature birth and infection. We state the most important ones (8, 11, 12, 15, 19, 25, 28, 32, 41, 42, 47, 48, 49, 62, 66). At present a lot of authors think that the production of cytokine plays a significant role in pathogenesis of intraamniotic infection. After the invasion of the micro-organism into the tissues, the organism of the foetus reacts by initiating of defence mechanisms. The main initiator of activation of cytokines is the foetus that strives to get from the "stress space". But the prostaglandin level is influenced also by the production of corticotropine-releasing-hormone that stimulates the production of

cortisol, thus increasing the prostaglandin production.

*The processes in course during premature birth can be summarized as follows:*

- Monocytes and macrophages are activated.
- Cells in decidua are stimulated to production of IL-1 and TNF.
- By influence of these cytokines, toxic effect on endothelium cells, musculature and tissues occurs.
- In this period IL-6 and IL-8 are produced.
- Inhibition cytokines, i.e. TGF beta, IL-4 and IL-10 begin to assert themselves.
- Interleukin-4 inhibits the production of prostaglandins. Cytokine network is stabilized.
- Cytokines IL-1,6 etc. stimulate synthesis of prostaglandins. Prostaglandins play a significant role in the birth start.
- PGE accelerate "cervix maturation", forming of Gap junctions, and they increase the calcium level in myocytes.
- Arachidonic acid (precursor of prostaglandins) is discharged. Arachidonic acid takes part in supression of inhibitor cytokines.
- *Cytokine Rantes* discharges histamine from basophile substances.
- PG and the cytokine granulocytic elastasis activate matrix metaloproteinases that destruct membranes and collagen.
- IL-1 ra inhibits the effects of IL-1.
- Metaloproteinases play a significant role in premature birth.

## 5. FACTORS OF THE MOTHER, PLAYING A ROLE IN THE ORIGIN OF INFECTION

There is a series of risk factors both from mother's side and from baby's side. They can be divided into medical and non-medical predisposing factors. The risk of the origin of infection is increased also by a lower social level related to hygienic habits of the woman, way of nutrition, abuse of psychotropic substances etc. Sexual life of the woman, particularly promiscuity, prostitution etc. plays a markedly negative role. Sometimes the parity and the age of the woman are stressed as well. From medical points of view, factors as prematurely discharged amniotic fluid, premature rupture of foetal membranes, any insufficiency of the cervix play a significant pathogenetic role. Positive bacteriological finding in the sampling from cervix or from the back third of the vagina are dangerous for the origin of infection as well. It is important to stress that for example in case of long-term hospitalization, nosocomial incidence of intra-amnial infections of the mother can be observed as well. As pathological background, the presence of vulvovaginitis, urinary tract infection (both cystitis and pyelonephritis), foci of tooth origin or from Waldeyer's ring etc. must be reminded. One of important pathogenetic factors in the origin of infection of the foetus (60) is vaginosis. At the point of birth, important factors of the origin of infections are premature birth,

prolonged birth, asphyxia of the foetus and long-term activity of uterine contractions. It must be stressed that there is a close relation between premature birth and prenatal and perinatal infection. So called barrier mechanisms play a significant role for reduction of the risk of the origin of infection. The foetus develops in a sterile environment. As soon as the protective walls are infected, the foetus is infected as well. *The foetus activates itself and reacts to the stress environment of the uterus with production of cytokines in the sense of FIRS (19, 25).* The foetus is protected against penetration of infection by vaginal microflora, immune factors of the cervix and the mechanical barrier consisting of membranes. Under physiological conditions, vaginal microflora is protected against invasion of pathologic microorganisms by lactobacillus Döderlein (LD), bacterial flora that produces hydrogen dioxide, neuraminase phospholipase etc. The vagina is covered by pavement epithelium containing glycogen that is a source of energy for LD. The discharged lactic acid influences pH 3,8-4,5 (60). During colonization, cytokines are produced and their effects mobilize macrophages. When this defence mechanism fails for any reasons, vulvovaginitis or vaginosis originates. In the cervix, the secretion IgA and bactericidal factors (lactoferrin, proteases), lymphocytes (CD4, CD8) are present, mediating immune response. A significant mechanical obstacle is the mucous plug. The significance of innervation

of the cervix is discussed in connection with its dilatation. The amniotic fluid contains lysosome, transferrin, immunoglobulines, zinc etc. that have bacteriostatic actions. Considerable significance in protection of the foetus against infection is attributed to the placenta. The defence function is closely related to the functionality of the capillary blood stream. The villus epithelium has bactericide effect, synzicium is rich in proteolytic enzymes. Infarctions of placenta are dangerous. The rule applies that the younger the placenta, the more marked are the defence mechanisms. The villus epithelium acts in a bactericidal way, the villi contain proteolytic enzymes. Trophoblast produces receptors for the bond of transferrine, which reduces the storage possibility of iron that is important for the life of the bacteria.

The syndrome of infected amnion progresses pathogenetically in four stages (32, 66, 67, 68). The *first* is the origin of bacterial vaginosis and penetration of the micro-organism into the cervix. In the *second* stage, the cervix is colonized and pathogens pass into decidua and chorion. In the *third* stage, the infection disseminates to foetal membranes and in amniotic fluid. In the next, *fourth* stage, the infection passes from the infected amniotic fluid into the foetus through aspiration, swallowing and vascular way.

Bacterial vaginosis origins through outbreak of normal vaginal micro-

flora. It is actually disturbance of the environment of the vagina, that shows in replacement of LD by opportunistic infection from the external environment. It shows in discharge from the genitalia – but the process can be fully asymptomatic. The pH of the environment increases to more than 4,5. Typical is the presence of gram-negative cocci, but mostly *Gardnerella vaginalis*, anaerobic infection, mycoplasmas occur. In the origin of infection, premature rupture of foetal membranes and premature discharge of amniotic fluid play an important role. But different authors evaluate these phenomena in different ways. The causes of pathogenesis of prematurely discharged amniotic fluid have multifactor character; it is a combination of the effect of fibronectin, metalloproteinases and cytokines and elastase of granulocytes, foetal membranes are destructed and synthesis of prostaglandins increases, thus provoking premature birth.

From pathogenetic point of view, three most important risks are to be stressed:

- prematurity; the higher the prematurity, the greater the danger of origin of infection, primarily because the immune condition of the foetus is not mature, but also secondarily as a consequence of intense complex care that the baby often experiences after birth;
- chorioamnionitis; premature discharge of amniotic fluid longer than 18 hours;

- maternal colonization with GBS.

Transudated neurophiles produce free oxygen radicals. In simplified terms, it is probable that ischemia provokes inflammatory reaction that destructs the brain mass with its consequences.

Ischemia provokes primarily imbalance between energetic demands of nervous elements and the possibility of their creation (ATP). At the same time, the internal environment is markedly disturbed (through disturbed distribution of ions Na, K and Ca because of affection of the relevant transport mechanisms, pumps, and because of disturbed permeability of gradually destructing membranes of nervous cells). Then responses occur, the consequence of which is destruction of brain mass.

## 6.ASCENDING INFECTION

### 6.1. Syndrome of infected amnion (SIA), definition and etiology

The histologic background is amnionic inflammation of placenta (51, 52, 56, 57, 54,55). The syndrome of infected amnion has a marked negative impact on perinatal morbidity and mortality. It is closely related to premature birth and premature discharge of amniotic fluid (PROM). The infection originates through ascension of micro-organisms into the amniotic sac. In case of intact amniotic sac, the amniotic fluid is sterile. But it can be infected also without premature

rupture of foetal membranes (*Streptococcus agalactiae*). A range of these micro-organisms that were found in birth canals are probably related to PROM (Table 2.).

In relation to premature birth and premature discharge of amniotic fluid (PROM), the role of mycoplasmatic, ureoplasmatic and chlamydia strains is stressed. A range of these micro-organisms is stated in table 1 and 2.

Some authors indicate findings of micro-organisms in amniotic fluid in case of births with PROM. It is understandable that the results can be influenced by contamination with mucous membranes of birth canals, when the amniotic fluid is not obtained by amniocentesis (27).

Any micro-organism from the above mentioned range can take part in the development of FIRS, of early and late infection of newborn. This relation is recorded in the tables 1. and 2.

### **6.1.1 Maternal syndrome of infected amnion - clinical picture and diagnostics**

6.1.1.1 Clinical picture of maternal syndrome of infected amnion (SMIA)  
The syndrome of infected amnion in the woman can be diagnosed on the base of clinical, laboratory and apparatus examinations (Table 2 an 3). It is necessary to distinguish the risk of origin of SIA from its actual

clinical displays (19, 20, 23, 26, 28, 53, 54, 55, 57).

#### *6.1.1.1.1 Clinical displays of SIA*

- temperature over 37,5°C
- pathologic cardiograph particularly with tachycardia of the foetus
- discharge of turbid amniotic fluid
- oligohydramnion
- painful palpation of uterus
- low ultrasound biophysical profile of the foetus.

#### *6.1.1.1.2 Laboratory examination*

- leucocytosis > 15000/mm<sup>3</sup>
- positive CRP with ascending trend
- cytokines (particularly IL-6)
- positive result of microbial examination of vagina and cervix.

#### *6.1.1.1.3 Etiology of early and late infections of newborns*

Demonstrated on Table 2.

#### *6.1.1.1.4 Predisposition factors for origin of syndrome of infected amnion from mother's side*

(1, 6, 8, 11, 16, 18, 19, 23, 24, 25, 27, 28, 29, 30, 33, 34, 35, 37, 40, 41, 44, 45, 47, 50, 52, 54, 55, 57, 60, 61, 62, 69, 70, 71)

#### *Development of pregnancy*

- multiple pregnancy
- developmental defects of uterus
- incompetence of cervix
- vulvovaginitis
- non-specific vaginosis - bacterial vaginosis
- infection of urinary tract (particularly cystitis)
- asymptomatic bacteriuria

**Table 1. Ways of perinatal infection (Freely adapted after 62, 68)**

WAYS OF INFECTION	umbilical cord	CHAIN OF INFECTION
cavity of ovum		amnion chorion
intervillous spaces	villi	intervillous spaces  basal decidua
1 – ascending way 2 – hematogenous way – maternal 3 – hematogenous way – foetal 4 – way per continuitatem 5 – descending way		a – transamniotic way b – transmembranous way c – transdecidual way d – displacentar way e – umbilical way f – transvillous way

**Table 2 Etiology of early and late infections of newborns  
Freely adapted after Gibbs & Blanco (20).**

Infections	Early	Late
Frequent	Escherichia coli	Staphylococcus CONS
	Streptococcus agalactiae	Escherichia coli
Less frequent	Staphylococcus aureus	Enterobacter, MRSA
	Streptococcus pneumoniae	(meticillin resistant S. aureus)
	Staphylococcus CONS	Streptococcus agalactiae
	Neisseria meningitis	
	Klebsiella pneumoniae	

**Table 3. Most significant markers of the syndrome of infected amnion  
Freely adapted after Gibbs & Blanco (20).**

Test	PPV %	NPV %
Leucocytosis of mother	40-50	89-90
CRP	10-45	80-97
Microbiological finding in amniotic fluid	67	85-95
Oligohydramnion	33	86-93
Low biophysical profile	31-60	96-97

PPV – positive predictive value

NPV – negative predictive value (27)

- parasitic disease (oxyuriasis)
- bartholinitis
- PROM with risk increase after 12 hours after amniotic fluid discharge (with negative cultivation)
- premature and excessive uterine activity
- STD infection
- anaemia of mother
- premature birth in anamnesis
- traumatic coitus
- bad socio-economic situation of the woman
- risk life style, i.e. drug abuse, smoking, irregular sleep.

*Iatrogenic factors*

- cervix conization
- cerclage
- perinatal corticoid administration
- transvaginal monitoring during birth (measuring of intrauterine pressure, IFPO, scalp electrode) - exceptional
- repeated vaginal examination during birth
- relation between epidural application of analgesia and infection occurrence is also described.

*6.1.1.1.5 Possible consequences of amnion infection for the mother*

- puerperal endometritis
- rarely sepsis in the woman originates.

*6.1.1.1.6 Possible consequences of amnion infection for the foetus*

- development of FIRS (13) and subsequently miscarriage
- foetus infection
- birth of dead child
- premature birth.

*6.1.1.1.7 Possible consequences of amnion infection for the newborn*

- relatively often, the foetus has no clinical signs of disease
- FIRS
- early or late sepsis.

## 7. DANGER OF PROM

It consists in a markedly negative influencing of perinatal mortality and morbidity. There is a whole range of consequences following from premature rupture of membranes.

The most frequent complications of PROM were studied by JAUNIAUX et al. (29) and GOMEZ et al. (19).

## 8. DISCUSSION AND CONCLUSION

The syndrom of infected amnion (65,66) is one of the forms on infection of feotus and newborn cause by bakteria colonizing the vagina. Thus it is endogenous infection passing through ascending way to the feotus and infecting it thereafter. However, the damane of foetal membranes is not an indispensablecodnitono for it. The FIRS is defined as elevation of plasmatic IL-6 in foetuses in case of premature birth or PROM(19). Newborns with higher concentration of IL-6 in foetal plasma had significantly higher morbidity. The system inflammation response of the foetus, defined as elevation of foetal IL-6, is an independent predictive factor of serious newborn morbidity, being dependent on the gestation age of the foetus.

The term inflammation of placenta includes changes in the placenta itself, in foetal membranes or in the umbilical cord as a consequence of infection or action of chemical substances. It can occur anytime during pregnancy. The disease proceeds according to localisation (staging) and intensity (grading) of the inflammation.

Chronic course of inflammation, or recession of its activity for example after antibiotic treatment, can be recognized by a marked reduction, or possibly absence of mother granulocytes in basal section of the chorion plate and free foetal granulocytes in the wall of blood vessels of the chorion plate or of the umbilical cord. A specific form of chronic inflammation in the area of umbilical cord is chronic necrotizing funiculitis (6,7).

From differential diagnostic point of view, granulocytic infiltrates of non-infectious genesis must be considered: with foetal acidosis, after meconium passage, as a

consequence of prestasis and stasis in subchorion space as a consequence of disorder of circulation in blood vessels of the umbilical cord.

The most important infectious ways of amniotic inflammation are: ascending infectious agent, hematogenous way as a consequence of dissemination, endometritis - direct dissemination, infection through Fallopian tube, iatrogenic infection (amniocentesis, puncture of umbilical cord, intrauterine transfusion, etc.). The most frequent infectious way is ascension of germs. There is a series of risk factors both from mother's side and from baby's side. They can be divided into medical and non-medical predisposing factors. The risk of the origin of infection is increased also by a lower social level related to hygienic habits of the woman, way of nutrition, abuse of psychotropic substance, etc. Sexual life of the woman, particularly promiscuity, prostitution, etc. plays a markedly negative role.

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## ნაყოფთან და ახალშობილებთან დაკავშირებული ინფექციების ტერმინოლოგია

მილოშ ველემინსკი, მილოშ ველემინსკი უმცროსი,  
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ავტორები მუსტად აღწერენ ნაყოფთან და ახალშობილებთან დაკავშირებული ინფექციების ტერმინოლოგიას და საკუთარ გამოცდილებას აღნიშნულ საკითხთან დაკავშირებით. მათ წარმოადგინეს არა მხოლოდ ის ორსულები, რომლებიც დაინფიცირებული არიან სამოუგალოებაში გავრცელებული ინფექციებით, არამედ ისინიც, ვინც ცხოვრობენ იმ ბავშვებთან ერთად, რომლებსაც ინფექციური დაავადებებით დასნებოვნების დიდი რისკი გააჩნიათ. დაინფიცირებულმა ორგანიზმმა შეიძლება ჩაითრიოს სისხლიც და, აქედან გამომდინარე, შემოქმედება იქონიოს პლაცენტასა და საშვილოსნოზე. ორსულობა იწვევს დედის იმუნოლოგიურ და უჯრედოვან ცვლილებებს. ეს უკანასკნელი ძალიან მნიშვნელოვანია უკრედშიდა პათოგენებზე შემოქმედების თვალსაზრისით. დედის დაინფიცირების შედეგად მისი გრანსპლაცენტარული გავრცელება, ჩვეულებრივ, იწვევს ნაყოფის დაინფიცირებას.

## TOXOPLASMOSIS IN GRAVIDITY – A PROBLEM STILL TOPICAL

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### ABSTRACT

The authors present a case of toxoplasmosis occurred in gravidity with consequent infaust damage. The described case remains of the convenience of examinations aimed at the diagnostics, therapeutics and prevention of toxoplasmosis in pregnant women, although this examination is included only in recommended examinations in the scope of general one-off screening in pregnancy.

### Key words:

*Toxoplasmosis in pregnancy – case history – diagnostics - therapy – prevention – general one-off screening in pregnancy*

### 1. INTRODUCTION

Toxoplasmosis is an endemic zoonosis caused by a parasitic protozoon *Toxoplasma gondii*. The life cycle of the parasite is characterized by the change of final host (cat or another felid) and temporary host (warm-blooded vertebrate including man). The aim of the present study is to demonstrate a case of toxoplasmosis occurred on gravidity with consequent infaust damage of the foetus.

### 2. CASE HISTORY (33-year-old patient)

#### Family History

- mental retardation in a cousin, otherwise insignificant

#### Personal History

- smoker
- waitress

#### Gynecological History:

- primigravida
- menarche in the age of 13, cycles completely irregular up to 60/5

#### Present gravidity

- smoker, 10-15 cigarettes till the 2<sup>nd</sup> month of gravidity
- in 18<sup>th</sup> week amniocentesis (risk of m.Down 1:250) – 46 XY, normal
- KS and Rh negative – after AC Partobulin applied
- in 23<sup>rd</sup> week of gravidity in examination in a private OLG ultrasound diagnosis of dilatation of lateral brain ventricles (up to 13 mm)
- in 29<sup>th</sup> week in examination in a private OLG progression of the ultrasound CNS finding with infaust prognosis for the foetus with diagnosis of obstruction hydrocephalus with serious

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- dilatation of lateral brain ventricles (confirmed by superconsultation examination)
- premature termination of gravidity indicated and the patient sent to our centre
- In 31<sup>st</sup> week of gravidity induction of delivery of dead foetus, rectum position, boy 1480 g / 35 cm
- After birth blood sampling of the mother for examination of anthroozoonoses  
KFR Toxoplasmosis: 1:4096  
IgG ELISA: positive  
IgG in UI/ml: 198  
IgM ELISA: positive  
IgA ELISA: positive  
Concluded as toxoplasmosis occurred in gravidity.  
Other examinations negative.

### 3. DISCUSSION

#### Epidemiology:

- In its asymptomatic form, toxoplasmosis affects minimally 1/3 of world population
- The incidence and primary infection in gravidity is estimated at 2-8/1000, from which infection of the foetus occurs in about 50%
- The presence of antibodies IgG in the mother before gravidity protects against intrauterine infection of the foetus (50% adults have toxoplasmosis antibodies)

#### Ways of infection:

##### 1) *Orally-alimentary way:*

- through zoitocysts (a form of tissue cyst containing slowly reproducing forms)

- \* kitchen processing of meat
- \* consumption of insufficiently heat-treated meat
- \* tasting of garnish, raw forcemeat
- through oocysts (sexual phase of biological cycle) excreted by cat excrements into the external environment where they can exist in the long term
  - \* by contaminated food or potable water
  - \* through the way hand-mouth from the soil and sand contaminated by cat excrements

##### 2) *Less frequent ways of infection:*

- droplet infection
- through conjunctival sac
- skin erosions during manipulation of infectious material
- in transplantations

##### 3) *Transplacentally*

- in parasitemia in case of primoinfection of the mother
- the risk of communication from mother to foetus increases with the duration of gestation

#### Clinical picture of acquired toxoplasmosis in mothers:

- 2/3 are asymptomatic
- ganglion syndrome particularly in the area of throat and neck, axillary and inguinally ganglions
- subfebrilia
- excessive tiredness
- chorioentinitis
- meningoencefalitis
- affection of the peripheral nervous system

**Clinical symptoms of congenital toxoplasmosis:**

**1) antenatally:**

- hydrocephalus or dilatation of ventricles in prenatal ultrasound examination
- IUGR
- premature birth

**2) postnatally:**

- at the most 10% of the infected newborns are seriously affected
- often asymptomatic course
- affection of CNS (hydrocephalus, intracranial calcification, encephalomyelitis, microcephalus)
- mental retardation
- sight affection, chorioetinitis, blindness
- neurological symptoms (spasms, nystagmus, pulsating fontanelle, retarded psychomotor development, cerebellum symptoms, epilepsy)
- hearing affection, deafness
- low birth weight
- hepatosplenomegalia, icterus, anemia, hydrops foetus
- late consequences in adulthood

**Diagnostics of toxoplasmosis:**

**1) examination of pregnant woman**

**2) examination of foetus or newborn**

- isolation of the parasite from blood or body fluids, placenta, fatal tissues
- histological diagnostics

- immunological methods
- PCR
- serological methods

**Diagnostic criteria of active infection in pregnant woman:**

- seroconversion in any test
- significant increase of antibodies (IgG together with IgM and IgA) in an interval of at least 3 weeks (quadruple increase of IgG accompanied by IgM positivity) (8)
- titres over 1:512 are a sign of recent or running infection (1)

Congenital toxoplasmosis, postencephalitic phase with extensive calcifications in the area of cortex and marrow, basal ganglia and in ventricle wall.

Toxoplasma - terminal colony. Immunohistological proof, APAAP.

Lymphocyto-histiocytic vilitis, congenital toxoplasmosis.

Toxoplasmatic encephalitis with disseminated cortex foci and ependymitis necroticans.

Initial focus in encephalitis toxoplasmotica.

**Prevention:**

- in gravidity, the examination of toxoplasmosis is included in

Titer (=Serumverdünnung)	Titer (thinned serum)
Wochen	weeks
Monate	months
Jahre	years
Diagnostika toxoplazmózy u matky.	Diagnostics of toxoplasmosis in mother.

- recommended (not compulsory) examinations in the scope of a general one-off screening
- the screening should identify women who are not immune at the beginning of gravidity
  - education of women:
    - \* non-ingesting of raw and half-raw meat, particularly pork and liver
    - \* personal hygienic regime
    - \* prevent contact with cats and their excrements

**Treatment:**

- 1<sup>st</sup> trimester Spiramycin (Rovamycin)
- after 14<sup>th</sup> week of gestation – combination of sulphonamides and Pyrimethamin (Daraprim)

**4. CONCLUSION**

Congenital toxoplasmosis originates as a consequence of acute infection of the mother during pregnancy or shortly before impregnation. The probability of infection of the foetus and the extension of its affection depends on the time when the infection occurred. A case of toxoplasmosis occurred in gravidity with consequent infaust damage of the foetus is presented. The described case reminds of the convenience of examinations aimed at the diagnostics of toxoplasmosis in pregnant women, although this examination is included only in recommended examinations in the scope of a general one-off screening in pregnancy.

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**ტოქსოპლაზმოზის ორსულობის პერიოდში – აქტუალური პრობლემა**

**მილოშ ველემინსკი, პიტერ საკი, ნ. მაღატოვა**

ავტორებმა წარმოადგინეს ტოქსოპლაზმოზის შემთხვევა, რომელიც დაკავშირებული იყო ნაყოფის დაზიანებასთან. აღწერილი შემთხვევა აღნიშნავს იმ გასინჯვების აუცილებლობას, რომელთა მიზანია ორსულებში ტოქსოპლაზმოზის დიაგნოსტიკა, მკურნალობა და პრევენცია, თუმცა ეს გასინჯვები შეტანილია მხოლოდ ორსულობისას რეკომენდებული ზოგადი გასინჯვების ჩამონათვალიში.

## INVESTIGATION OF ATHLETES' BLOOD PRESSURE WITH DIFFERENT SPHYGMOMANOMETERS DURING PHYSICAL LOADING

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It is known, that blood pressure (BP) supervision has a great importance for the study of cardiovascular system's functional condition of healthy and nonhealthy persons, as well as of athletes, especially when determination of this hemodynamic parameter is conducted during physical loading.

Nowadays standard, semi-automatic and automatic sphygmomanometers are used for the measurement of BP. Automatic sphygmomanometers have special importance for monitorial supervision of patients' BP. Research, conducted by automatic sphygmomanometer (AM-5600) and intra-arterial catheter (invasive method) among the same persons at rest, has established that BP numbers measured by automatic sphygmomanometer are lower, than BP numbers measured by invasive method. During physical activity BP numbers obtained by automatic sphygmomanometer were higher than BP numbers obtained by intra-arterial catheter. It is notable, that during BP determination by invasive method and by standard sphygmomanometer at rest among the same persons, BP numbers were

higher during BP measurement by standard sphygmomanometer, although during the use of all above-mentioned methods, there was not big difference between BP numbers (3).

For the purpose of dynamic supervision on BP changes among humans, the investigations were conducted using automatic and standard sphygmomanometers. There was not any marked difference between BP indices in this case, too (2).

Several authors (1) have noted that BP monitorial supervision during 24 hours by automatic sphygmomanometer among patients has practical importance for assessment of their cardiovascular system's functional condition. The information about studying BP changes among athletes by automatic sphygmomanometer was not available in the existing literature.

The aim of our research was to study BP dynamic changes with physical loading among athletes.

### MATERIAL AND METHODS

The study was conducted on 15 systematically trained male athletes (football players and runners), 20-24 years old. Automatic (MOBIL O

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**Table 1. Changes of certain hemodynamic parameters by automatic, standard and semi-automatic sphygmomanometers during physical loading (M±m)**

Hemo dynamic parameters	Data of automatic sphygmomanometer n=10														Data of standard sphygmomanometer n=10					Data of semi-automatic sphygmomanometer n=10					
	before loading	I loading	P %	II loading	P %	III loading	P %	IV loading	P %	V loading	P %	Recovery 2 min	P %	Recovery 4 min	P %	before loading	Recovery 2 min	P %	before loading	Recovery 2 min	P %	Recovery 4 min	P %		
SBP	127 ± 2.9	138 ± 5.2	>0.001 +9	136 ± 4.1	>0.001 +7	143 ± 3.2	<0.001 +13	145 ± 4.6	<0.001 +14	147 ± 4.2	<0.001 +16	132 ± 3.6	>0.001 +4	126 ± 4.8	>0.001 -0.8	115 ± 4.3	129 ± 3.2	<0.02 +12	110 ± 2.6	>0.001 -4	123 ± 4.4	128 ± 3.4	>0.001 +4	117 ± 3	>0.001 -5
DBP	77 ± 3.2	83 ± 3.8	>0.001 +8	81 ± 4.1	>0.001 +5	78 ± 4	>0.001 +1	77 ± 1.7	>0.001 0	79 ± 4.4	>0.001 +3	78 ± 2.5	>0.001 +1	73 ± 3.7	>0.001 -6	69 ± 4.3	68 ± 3.2	>0.001 -1	71 ± 5.2	>0.001 +3	77 ± 2.8	72 ± 1.9	>0.001 -6	75 ± 3.3	>0.001 -3
HR	87 ± 3	98 ± 1.9	<0.001 +13	104 ± 4.5	<0.001 +20	111 ± 3.8	<0.001 +28	116 ± 4.3	<0.001 +33	118 ± 4.6	<0.001 +36	96 ± 3.7	>0.001 +10	89 ± 3.1	>0.001 +2	76 ± 2.1	97 ± 3.2	>0.001 +4	75 ± 1.9	>0.001 -1	79 ± 2.6	89 ± 2	<0.001 +13	84 ± 2.9	>0.001 +6

**Table 2. Determination of certain hemodynamic parameters by automatic and standard sphygmomanometers during cycle ergometer loading (M±m)**

Hemo-dynamic parameters	Data of automatic sphygmomanometer n=5					Data of standard sphygmomanometer n=5				
	Before loading	during loading	P %	recovery 5 min	P %	before loading	during loading	P %	recovery 5 min	P %
SBP	120 ± 6.4	151 ± 2.5	<0.001 +26	127 ± 6	>0.001 +6	112 ± 8.6	145 ± 5.4	<0.001 +29	117 ± 7.5	>0.001 +5
DBP	66 ± 3.2	59 ± 5.1	>0.001 -11	69 ± 3.4	>0.001 -4	72 ± 4	60 ± 4.3	>0.001 -11	71 ± 4.3	>0.001 -1
HR	74 ± 2	123 ± 2.5	<0.001 +66	80 ± 3.4	>0.001 +8	76 ± 2.5	120 ± 2.5	<0.001 +58	80 ± 3.8	>0.001 +6

GRAPH S/N:B04947, IEM, GmbH), semi-automatic (Mediwatch, ISO 9002/EN46002) and standard sphygmomanometers were used for the study. BP and heart rate (HR) were registered in automatic and semi-automatic sphygmomanometers before and after physical loading, but in case of standard sphygmomanometer HR was determined by palpation of the radial artery. Running on place for 2 minutes, 180 steps per minute was used as a dosed physical loading. This loading was performed 5 times with 20-30 second intervals (during these intervals BP was measured). Besides, athletes performed physical loading on cycle ergometer for 5 minutes by 500 kgm/min intensity.

## RESULTS

As it is demonstrated on Table 1, systolic blood pressure (SBP), as well as HR are increased after each 2 minutes of running and this increase is statistically significant ( $P < 0.001$ ). In case of diastolic blood pressure (DBP), this parameter does not increase or decrease significantly during physical loading. In regards with running for 2-2 minutes we determined BP and heart rate as by automatic, as well as by semi-automatic and standard sphygmomanometers.

It was revealed, that in comparison with standard and semi-automatic sphygmomanometers, automatic sphygmomanometer showed higher numbers of BP and HR, although

from the point of view of practical importance, any diagnostic meaning should not be given to this difference.

As for the physical loading on cycle ergometer, higher numbers of SBP are noted on automatic sphygmomanometer, than on standard sphygmomanometer, although in these studies any marked changes of SBP were not obtained (Table 2)

It was demonstrated that SBP registered on automatic sphygmomanometer during physical loading

is relatively higher compared to SBP measured by standard method.

From above-mentioned we can conclude that automatic and semi-automatic sphygmomanometers have practical importance for the study of patient's cardiovascular system's condition, but for the functional investigation of athletes, especially during mass screening, these devices should not be given any advantage in comparison with generally used BP measuring standard devices.

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**სხვადასხვა საზომი ხელსაწყოებით სპორტსმენთა  
არტერიული წნევის დინამიკის შესწავლა ფიზიკურ  
დატვირთვისთან დაკავშირებით**

**თამარ სვანიშვილი, ნ. გამცემლიძე**

არტერიული წნევის (აწ) გაზომვას ფიზიკურ დატვირთვისთან დაკავშირებით განსაკუთრებული მნიშვნელობა აქვს სპორტულ მედიცინაში როგორც კლინიკური, ისე პრაქტიკული მუშაობისთვის.

ჩვენი გამოკვლევის მიზანს წარმოადგენდა აწ-ის ცვლილებების შესწავლა სხვადასხვა დომირებული ფიზიკური დატვირთვის შესრულების დროს. სპორტსმენები ასრულებდნენ დატვირთვის ადგილზე სირბილის სახით და ველოერგომეტრზე მუშაობით. აწ-ის გაზომვა ხდებოდა ავტომატური, ნახევრად-ავტომატური და სტანდარტული სფიგმომანომეტრებით.

გამოკვლევებით დადგენილი იქნა, რომ ავტომატური სფიგმომანომეტრით ფიქსირდებოდა აწ-ის და გულის შეკუმშვათა სიხშირის შედარებით უფრო მაღალი ციფრები, განსხვავებით ნახევრადავტომატური და სტანდარტული სფიგმომანომეტრებით მიღებული მონაცემებისა, მაგრამ სპორტსმენთა გამოკვლევებისას ამ სხვაობას არ უნდა ენიჭებოდეს პრაქტიკული და დიაგნოსტიკური მნიშვნელობა.

## SYSTEM OF INTEGRATION IN THE CZECH REPUBLIC, IN THE DENMARK AND IN THE NETHERLANDS

Jitka Dvořáková<sup>1</sup>

Motto

*National and racial minorities have existed since the beginning of human development. De facto each European nation its linguistic minorities; small states and nations are minorities among bigger states and even the biggest states and nations are at least a minority in comparison to the whole human world. Therefore the best solution of the minority policy is a presumption of better and universal organisation of the world.*

Tomáš Garrigue Masaryk,  
the first Czechoslovakian president

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### ABSTRACT

Migration was not solved after the Second World War with UN Convention Relating to the Status of Refugees (admitted in 1959). This phenomenon is still very delicate for each European state and also for the whole world. Thus endeavour to solve migration issues became a national and also international task. This article introduces three systems of integration in three European countries – in the Czech Republic, in the Denmark and in the Netherlands and tries to show, how different could be situation in post-communist state (who did not have experiences with immigration and integration) and in states, who are considered as the most experienced in the Europe.

### Key words

Migration - integration - the Czech Republic - the Denmark – the Netherlands

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### 1. INTRODUCTION

Migration as a thorny theme of most states in the whole world shows, that this problemacy is still very delicate for everybody – not only for migrants but as well for native people. The biggest migration wave arose during and after the World War II and it caused the genesis of human rights concerning this theme. The first convention (United Nations

Convention relating to the Status of Refugees) was established in 1951 as a reaction to the world migration arising from horrors of the war. But after some time it came to light that this is not a problem relating only to wars also that people move different reasons and because of various situations and experience. Sometimes it can be because of army conflicts, persecutions, intentional violence committed by one group to another group; sometimes it can be because of economic situation

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(especially because of poverty), natural catastrophes, etc. Migration does not only mean that one moves from one state to another; it can also be resettlement from one part of some country to another part (so-called internal resettlement). So we can find different migration's victims, culprits and reasons.

Nowadays there has been rising tension between the natives and migrants, who want to settle down in foreign countries. This tension very often arises from mutual misunderstanding and from increasing amount of people leaving their native land. Multicultural society is becoming a fact, which is necessary to grasp, and which has to be introduced to both sides (to migrants as well as to the majority population). There is only one way of coexistence of the majority and minorities – integration. Integration is a two-way process shows how we can handle migration. That creates environment open to different habits and opinions together with keeping democratic values and principles.

Even though many immigrants, refugees and their children find satisfying living conditions in the Europe, regardless they stay out of the main “social stream”. One of the main questions remains: *“How can we deal with value differences among various groups of population and how can we make lower the tension, which is necessarily brought by these differences?”* Another question is: *“What are our possibilities in providing successful integration of immigrants, refugees and*

*their children?”* These questions led me to the intention to find and compare existing integration systems in three European countries – in the Czech Republic, in the Denmark and in the Netherlands.

## 2. TERMINOLOGY

At first it is necessary to define previous and following terms, which are relevant to this issue. When somebody comes to the border of some state without visas and asks for asylum then we can speak about “**asylum seeker**”. This person can be recognized as a **refugee** if he/she fits to the conditions defined in the UN Convention Relating to the Status of Refugees (admitted in 1959). Such person is owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it (Convention and Protocol relating to the Status of Refugees, 1996). People who originally came from another state, and become citizens of the new country are called **immigrants**.

An **alien** – this official term used in Danish legal system which means immigrant and refugee together. Against Dutch terminology operates with term **newcomer** (which means

someone who originally came from another country, and came to the Netherlands after October 1998) and **oldcomer** (which means someone who originally came from another country, and came to the Netherlands before October 1998).

The process of mutual adaptation (= integration) enables probably the best way of coexistence between majority and their minorities. **Integration**, which means both-sides managing incorporation into society, is qualitatively higher degree of adaptation respecting the right to preserve dissimilarities (17).

### 3. CURRENT SITUATION AND SYSTEM OF INTEGRATION IN THE CZECH REPUBLIC

#### 3.1 Current situation in the Czech Republic

The Czech Republic was acquainted with refugee issues and migration very shortly after the Velvet Revolution in 1989. In 1990 were coming the first immigrants and asylum seekers. At the end of June 2004 there were about 252120 foreigners with permanent and long term residence in the Czech Republic (2). The most frequent nationalities of these immigrants were following (in the round brackets there is number of foreigners): Ukrainian (70 496); Slovak (61 681); Vietnamese (31 501); Polish (17 102); Russian (13 899); German (5359); Bulgarian (4298); Moldavian (3737); Chinese (3170); American (3116); Byelorussian (2794); Rumanian (2469), Kazachstanian (1989);

Austrian (1935) and others (25 890). Foreigners with permanent and long term residence represent about 2.3% of inhabitants in the Czech Republic (CR). The above mentioned nationalities show how multifarious the composition of inhabitants in this post-communist state is. Integration as the only one way of coexistence of the majority and minorities is still at the beginning. We did not have any professionals or legislation for this issue because of no experiences with this phenomenon during communism (we had only the Romany minority as a really different ethnic group; I do not take into account other ethnic groups like e. g. the Moravian, Silesian who belong to the Czech nationality). Nowadays we can find several centres specialized for help to refugees and immigrants (e. g. Counselling Centre for Refugees, Organization for the First Aid to Refugees, Center for Questions of Migration, Charity's Multicultural Centres, etc.), but they still do not have any special methodology of working with this vulnerable group intended to their integration and participation in the democratic society in the new country (they use, of course, basic methodology of social work but this is not sufficient).

#### 3.2 Legislation in the Czech Republic

The Constitution of the Czech Republic guarantees primary human rights and freedoms in spirit of democratic values. So citizens of the CR (where citizenship don't need to be identical to nationality) have -

right to freedom of thought, conscience and religion; rights of national and ethnic minorities (especially right to education in their own language, right to use their language in official contacts, right to participate on decision-making about their minority) and other primary rights (rights to judicial protection; economic, cultural and social rights; political rights).

Legal status of refugee is in the Czech Republic based on the Asylum Act No. 325/1999 Coll. as amended (Rozumek, 2003). This act substituted the Refugee Act No. 498/1990 Coll. as amended and adjusts problems of asylum regulation in the CR (adjusts status of asylum seekers, their rights and duties; adjusts problems of asylum facilities, etc.). The main basis for this act is the United Nations Convention relating to the Status of Refugees.

The Act on stay of foreigners in the territory of the CR, No. 326/1999 Coll. as amended, specifies the conditions of foreigner's entrance to the territory of the CR (further more only "territory"); his/her stay there and travelling from this territory and delimits force of CR's police (further more only "police"), Ministry of Interior (further more only "ministry") and Ministry of foreign affairs in the area of state administration (18).

Other national regulations of refugee and immigrant problemacy are following: Act on obtaining and loosing the citizenship No. 40/1993 Coll. as amended; Act on

administrative proceedings No.71/1967 Coll., (administrative rules) – based on its character, the asylum proceedings show some deviations from the general settings, so they contain special settings and the administrative rules apply only as a support. Instruction No. 18 062/96-21 on education of foreigners at basic schools, secondary schools and colleges including special schools in the CR, published in the Bulletin of the Ministry of Education, Youth and Physical education No. 7/1996. Instruction No. 13 821/1995-21 on arrangement of Czech language courses for persons with status of a refugee in the territory of the CR, published in the Bulletin of the Ministry of Education, Youth and Physical education No. 6/1995.

### *3.3 History and statistics of asylum seekers*

In the years 1990 – 2002 asked for asylum 60 467 persons approximately from 60 countries of the world. Until the 31. of October 2003 was given an asylum to 2 382 persons from 59 countries.

From the 1. January until 31. of December 2004 there were 5459 asylum seekers in the CR. In comparison to the year 2003 (when we had 11 400 asylum applications) we can see that there was going down the number of asylum seekers (by 52%, see table 1). This fact has several reasons, among others – the admission to the European Union and application of Dublin enactment (n. 343/2003), which stopped seeking of asylum in different states all at once. Another reason are migration

**Table 1. Progression of number of asylum-seekers from the 1 of July 1990 until 31 of December 2004**

	Count of applications	Change according years ( %)
1990	1602	
1991	2226	
1992	841	
1993	2207	
1994	1187	-46,2
1995	1417	19,4
1996	2211	56,0
1997	2109	-4,6
1998	4085	93,7
1999	7220	76,7
2000	8788	21,7
2001	18094	105,9
2002	8484	-53,1
2003	11400	34,4
2004	5459	-52,1
Total	77330	

(Source: <http://www.mvcr.cz/dokument/2005/rocnka04/index.html#amp>)

changes – concretely decrease of asylum seekers from Slovakia (because Slovakia also entered European Union) and from Russia. The most frequent nationality of asylum seekers in 2004 was Ukraine (29% from the whole amount of asylum seekers), when Ukraine is the primary country of origin for asylum seekers coming to the Czech Republic, numbers of such seekers are more than 100 hundred persons per month (MVCR, 2005). The second most numerous group of asylum seekers becomes from Russia (27% of asylum seekers), the third becomes from Vietnam (7% from whole number of asylum seekers), and from China (6%) and Belarus (4%).

In the year 2004 there was given asylum to 142 persons, when most of them were refugees from the Russia

(45%), Belarus (29%), Kazakhstan (10%), Armenia (9%), Afghanistan (7%), Ukraine (5%), Kyrgyzstan (4%) and Iraq (4%).

From the first moment, when the asylum-seekers came, we'll need to take care of their integration – it is necessary to find asylum facilities, create appropriate legislation relates to refugees and ensure accomodation for asylum seekers, etc.

An asylum is given to them, who are persecuted from the political reasons, who have well founded fear from being persecuted for reasons of race, nationality, religion and membership of a particular social group in their country of origin, and in individual cases from another, humanitarian reasons (7). People

haven't been granted asylum, when reasons for migration are economic. The CR represents target country of economic migration mostly for citizens from the Ukraine, Slovak Republic, Georgia, Moldavia, Vietnam and partially also from Belarus (12).

### 3.4 Integration system in the Czech Republic

The Refugee Facilities Administration of the Ministry of Interior (abbr. SUZ, RFA) administrates 3 types of asylum facilities: reception centres, residential centres and integration asylum centres (look at anexe 1). Total capacity of asylum facilities is almost 2 500 beds and the number can be increased to 3 000 in the event of an emergency (SUZ, 2005).

#### 3.4.1 Reception centres

Reception centers are determined to provide accommodation and basic living conditions for new asylum seekers. Each asylum seeker have to pass admission procedure, what means: identification carried out by the Foreigner's Police, initiation of asylum grant proceedings by an administrative body and comprehensive medical examination. After finishing the admission procedures can asylum seeker move to his/her private housing or can stay in some of residential centers.

In the Czech Republic there we can find two reception centres: Вульни Lhoty reception centre and Praha-Ruzyně Airport reception centre.

#### 3.4.2 Residential centres

These centers offer similar services like a reception centres. In comparison to reception centres, there is possibility to leave residential centres with any limitations even for a long period of time.

Our country has following residential centres (names are according to villages or towns, where are the centres located): Zastávka u Brna, Вмб-Је•овб, Иервенэ Ђjezd, Навншов, Kostelec nad Orlicí (these centres are owned by the state and operated by the RFA), Сеи, Strб• pod Ralskem, Bruntál, Zбэљов and Каљава (which are operated by other legal entities, under contracts concluded with RFA and for a fee).

Asylum seekers in residential centres can be divided how Uherek (2002) mentions to the three following categories: people, who have the CR as a station for further journey to another states of EU; people, who want to work at the territory of the CR; people who are refugees according the UN Convention relating to the Status of Refugees.

#### 3.4.3 Integration asylum centres

These centres are intended to them who have been granted asylum. "Recognized refugees" have access to labour market, to the social security and health system - they have the same rights and duties as Czech citizens. Their stay is governed by a contract of lease and they have to pay

for it. This accommodation is finished, when person finds a permanent residence, offered under the state integration programme.

In the Czech Republic there we can find these integration asylum centres: Předměstí, Jaroměř, Zastávka u Brna and Hořava.

#### *3.4.4 State integration program (the main priorities of integration)*

This program is intended to persons who have been granted asylum and contains following:

- Provision of Czech language lessons (gratis) until 30 days after the juridical power of positive decision about granting of asylum. They'll need to make a final exam from Czech language (they'll gain certificate about graduation).
- This certificate is requirement for provision of habitation. The Asylum Act makes it possible to give a financial contribution to municipalities so they can pay for part of expenses related to the establishment of an asylum facility within their territory (14). For 2001 the government specified that the amount of the contribution would be CZK 7 (0.20 EUR) per capita per day (14).
- Help finding accommodation. (Re-qualifications, responsible for it are work offices.)

#### *3.4.5 Vulnerable groups in the Czech Republic*

**Children.** For pre-school children are Children's centres, which are in all

asylum facilities (similar as nurseries). Program in these centres is focused on learning of basic hygienic habits; working in collective as a way how to understand to the conditions in new country; overcoming the language barrier. Children can also develop their creativity in graphics and plastic art courses. Artistic activities are very important as well for the therapy of high mental burden (migration and living in asylum facility presents highly stressful situation).

School age children attend elementary school, where are similar conditions as in normal Czech classes. Before school is necessary to learn Czech language (children have Czech language lessons).

**Unaccompanied minors and adolescents.** Unaccompanied minor is an alien under 18 years of age who found himself or herself on the Czech Republic territory with no company of parents or other legal representatives (8).

The unaccompanied minors are placed in children's diagnostic homes, Ministry of Education opened a special diagnostic institution "Orphanage for alien minors", which offers protective and institutional education. For unaccompanied adolescents are specialised two asylum facilities: Zastávka u Brna and Kostelec nad Orlicí residential centres.

For unaccompanied minors is prepared a special psychological and educational counselling intended to help them to handle with this very difficult situation.

**Single women and mothers.** It's necessary to protect women and mothers as a vulnerable group and provide them stay in dignified manner. There is offered special psychological and social counselling, health care and individual material support - especially during pregnancy and motherhood.

#### 4. SYSTEM OF INTEGRATION IN THE DENMARK

##### 4.1 Legislation in the Denmark

Denmark has a special Ministry for Refugee, Immigration and Integration Affairs. Danish politicians, thus, created the 1998 integration law to achieve the following political objectives: "secure that foreigners are able to participate in the political, economic, working, social, religious and cultural life of society on equal terms with other citizens", "secure that foreigners become selfsupporting as quickly as possible" and "give every foreigner an understanding of the fundamental values and norms of Danish society (4). So the Act on Integration of Aliens in Denmark (the Integration Act) was adopted in 1999. This Act is supplemented with a law on education in Danish language and society and is intended to the

aliens legally residing in the Denmark (alien is a word for refugees and immigrants together) and it's general effort is to integrate aliens. The Act included two very controversial initiatives: firstly, restrictions were made so that refugees could not freely choose where to live in Denmark; and secondly, unemployed refugees and immigrants would receive a lower social benefit relative to unemployed Danes (6). So the above mentioned comments show an avert side of otherwise positive effort of this Integration Act to integrate Danish refugees and immigrants.

##### 4.2 System of integration in the Denmark

It is the government's goal that foreigners living in Denmark become integrated in the Danish society and the government believes it is best accomplished through employment (5). Thus the Danish integration goes through the general policy, which says, that - all citizens in Denmark should have access to the working life and to the social life of society. It means, that all danish citizens (including refugees and immigrants) are equal in access to the all state resources (housing, etc.).

###### 4.2.1 Asylum-Seeking Phase

The main aim of this phase is to prepare asylum seekers for entering the labour market and the educational system. Asylum seekers have to participate in tuition and activation schemes (which are made and assess by Office for Alien

Affairs), where the main purposes are following:

- for them, who are granted residence permit, is necessary to establish the foundation for successful integration process
- for them, who are denied residence permit, make returning to the home country easier
- create an active and meaningful everyday environment for all asylum seekers
- expand the asylum seeker's professional competences
- increase the asylum seeker's sense of responsibility of their own lives and for the community (in the place of their accommodation)

Asylum seekers (adults and children) have to participate in leisure-time activities, social and cultural activities, sports, projects, and courses. They can also participate in voluntary humanitarian work or in other volunteer work. Tuition and activation schemes must be settled in contract between the leader of asylum facility and the asylum seeker (ans also must be drawn). In the contract there have to be establish an extent and content according to each asylum seeker's skills and competences or personal circumstances (including health conditions) of:

- the area of asylum seeker's participation
- introduction course, which will be visited by asylum seekers

- tuition, in which must asylum seeker participate
- activation schemes agreed by asylum seeker

Contract has to be drawn up for period of time, which can't be longer than six months. The organisations, which are responsible of asylum seeking phase are following: - Danish Immigration Service (covers all alien's expense), - Danish Red Cross or the Danish Emergency management Agency are authorised to run the places of accommodation.

#### *4.2.2 Integration Phase*

When has asylum seeker been granted asylum, than he/she is involved to the introduction programme and transferred to the municipality, which is responsible for drawing up an individual contract and handling introduction benefit payments. Social worker as a central person in this process manages contact to and conducts interviews with the alien. Social worker have to make a decision about the content and extent of introduction programme and use contract as a method for achievement of goals agreed by both sides (social worker and immigrant or refugee). Social workers also inform aliens about their rights and legal duties and be able to give one-on-one help and psychological counselling.

The introduction programme is based on the alien's wishes, background and as well on the needs of labour market and includes:

- Danish education
- guidance and further qualification
- practice placement in companies and others business organizations
- employment with payment subsidy

Individual contract, which is the way of achievement immigrant and refugee goals, have to content – refugee and immigrant objectives for employment and education; content of activities, which ensure the goals for employment and education and definition of scope and level of Danish education. Every three months there have to be supervision of goal's attainment. The aim of making an individual contract is to prepare immigrants and refugees for the labour market (see Annexe 2 – Danish Individual Contract).

Aliens can get the subsidy to provide training and retraining of professional, linguistic, or social skills.

### **4.3 Special methodology for integration in the Denmark**

#### ***4.3.1 Working Capacity Method***

This programme was introduced in 2003 and is intended to the citizens in Denmark, who can't find job and feel to be outside of the labour market (pertinently have limited working capacity). Method has to help citizens to be self-supporting (rehabilitation of people, who have physical, psychological or social

limitations, which influence the working capacity).

Social workers have to apply a resource profile, which consists of the twelve following elements: - *education; employment experiences; interests; social competences (including state of conflict-solving skills); capacity for accepting change; capacity for learning (including intelligence); requests that are relevant for work; expectations of performance; working identity; housing and finances; social network; health.* Each element has to be assess in terms of resources, barriers and client's potentials. Social workers have to make decision according to this assessment about priorities and deal with employment's possibilities on the labour market.

#### ***4.3.2 The South Funen Integration Model***

In Denmark there was established cooperation among several municipalities (cities – Broby, Ryslinge, Ringe and Faarborg) with main purpose, which is integration of immigrants and refugees. They have tried to create unity and presence in dealing with refugees and immigrants by way of following aims:

- flexibility in integration working processes
- swift and constructive solutions
- long-term visions and objectives
- exchange of knowledge and experiences

Refugees and immigrants have to participate in language education

which is combined with work-preparatory programs - these activities take 37 hours every week (see table 2 - Danish Integration Model (the South Funen) .

## 5. SYSTEM OF INTEGRATION IN THE NETHERLANDS

### 5.1 Legislation in the Netherlands

The most important act relevant to this term is - the **Newcomers Integration Act** (WIN, *Wet Inburgering Nieuwkomers*), which has to promote the independence of newcomers by means of an integration and build their new life as effectively as possible. There is established a close cooperation (pertinently consultation) with different Ministries - Education, Interior, Welfare and Sports and also with Association of Dutch Municipalities. You can see the number of immigrants who have been granted residence permit in table 3 and as well the prognosis of this number up to year 2020 (see table 4).

Another relevant act is the **Aliens Act 2000**, which came into force on April 2001. This act regulates applying for a residence permit (the regular procedure, the asylum procedure - see annexe 3), checks and deportation. Clearer rules and shorter procedures speed up decision on application for residence permits while maintaining high standards (15). All applicants have rights to be heard (they must have chance to tell his/her own story); and those, who are turned down, must know that their application has been carefully considered.

For monitoring link between alien's right of residence and the services provided by the government was **Linkage Act** established. Government provides various services such as social security benefits, family allowance and housing subsidies which are collectively known as public services (9).

**Table 2. Danish Integration Model (the South Funen)**

Phase 1	Phase 2	Phase 3	Phase 4
1 month (2-3 month in extraordinary cases)	2+ month 30 hours a week	Average 6 month 37 hours a week	1 - 2½ year
Receival/reception	Preparation for work	''Work''	Work
Receival, organise a home, acclimatisation/ adjustment.  Visitation for and start of the Danish education.	The Danish education, including Danish language and education in social conditions. Preparation and planning for individual work placement.	Employment in local companies on special conditions or activation in a municipality scheme. Combined with Danish education.	Ordinary employment in a local company. Combined with individually organised Danish education following an agreement between the employee and the employer.

(Developed in 1999 and since then further developed by Anette Jensen, Svend Skipper, Merete Clausen and colleagues

**Table 3. Number of immigrants granted a residence permit**

NUMBER OF IMMIGRANTS GRANTED* A RESIDENCE PERMIT			
Period	Traditional immigrants	Asylumseekers	Total
2003 (1 <sup>st</sup> half)	13 223	4 832	18 055
2002	26 658	4 800	31 458
2001	23 193	8 240	31 433
2000	20 412	9 730	30 142

Source: Immigration and Naturalisation Department (IND) and Central Bureau for Statistics (CBS)

\* A granted residence permit could be related to the current or a previous year

**Table 4 . Immigrants as of 1st January 2003 and prognosis up to 2020**

IMMIGRANTS AS OF 1ST JANUARY 2003 AND PROGNOSIS UP TO 2020			
Period	Non-Western	Western	Total
2003 (1st half)	1 622 716	1 418 694	3 041 419
2005	1 7 32 428	1 433 754	3 166 198
2010	1 974 268	1 502 021	3 476 294
2020	2 425 016	1 727 399	4 152 406

Source: Central Bureau for Statistics (CBS)

**Table 5. Migration motives of non-Dutch Immigrants, 1998 ('000)**

Country of birth	Total	Family reunion	Accompanying family member	Family formation	Asylum	Labour	Study	Other
<b>European Union of which:</b>	18,0	1,9	2,0	1,3	0,0	9,7	2,1	2,2
<i>Belgium</i>	1,8	0,2	0,1	0,1	0,0	0,8	0,1	0,4
<i>Germany</i>	4,7	0,2	0,1	0,1	0,0	0,8	0,1	0,4
<i>United Kingdom</i>	4,1	0,5	0,6	0,2	0,0	2,5	0,1	0,2
<i>Other EU countries</i>	7,5	0,7	0,7	0,5	0,0	3,9	1,2	0,4
<b>Turkey</b>	5,1	1,6	0,1	2,7	0,3	0,3	0,1	0,1
<b>Morocco</b>	5,3	1,6	0,0	2,8	0,3	0,2	0,3	0,1
<b>Suriname</b>	3,2	0,7	0,2	1,8	0,1	0,1	0,1	0,1
<b>Afghanistan</b>	3,9	0,6	0,0	0,0	3,3	0,0	0,0	0,0
<b>Iraq</b>	7,4	1,6	0,0	0,0	5,7	0,0	0,0	0,0
<b>United States</b>	3,1	0,5	0,6	0,4	0,0	1,1	0,2	0,3
<b>Former Soviet Union</b>	2,6	0,4	0,2	0,6	0,7	0,3	0,3	0,1
<b>Other countries</b>	32,8	5,1	2,1	8,4	6,8	4,6	3,3	2,5
<b>Total (in thousand)</b>	81,6	14,0	5,2	18,0	17,3	15,3	6,4	5,4

Source: Nicolass, H., Sprangers, A. Migratino motives of non-Dutch Immigrants in the Netherlands. Research report. Voorburg: Statistics Netherlands, 2005. Available from:

<http://www.cbs.nl/nl/publicaties/publicaties/maatschappij/bevolking/papers/migrationmotives.pdf>

When we'd like to look at the groups of migrants coming to the Netherlands and the purpose of it, than: "The most numerous groups of foreign immigrants in the Netherlands arrive for the purpose of asylum, for the purpose of labour, as family reunionists or as family forming migrants" (11, see table 5).

### 5.2 System of integration in the Netherlands

Integration program is composed by Dutch language, Social Orientation and Vocational Orientation (this as well connect with social counselling and general coaching programme).

The integration system is following - municipality (working under the WIN) admits the newcomer and takes the primary responsibility of implementation of integration policy. Newcomer has to apply for and participate in the integration program (this has to be agreed with him/her by the Local Government).

Integration process contains following aims:

- newcomer participates effectively in the society
- newcomer participates actively in the made-to-measure integration program
- municipality has to provide a made-to-measure program (with referral to further training for the labour market

When has newcomer been granted asylum, than the municipality starts with integration inquiry. The aims of this inquiry are: 1. assess the application form; 2. initial interview; 3. test of knowledge and skills (also of Dutch language and society); 4. the final interview with establishment of final objectives, rights and duties for individual newcomer. This procedure (see table 6 - Integration procedure in brief) has to continue with training of skills necessary for the labour market. General coaching programme is essential for

**Table 6. Integration procedure in brief**

<b>INTEGRATION PROCEDURE IN BRIEF</b>	
1. Registration with Citizens Affairs (GBA) or issue of residence document ↓	
2 Submission of application ⇒	2. Exemption (temporary or permanent)
↓	
3. Integration inquiry ⇒	3. Waiver
↓	
4. Integration programme ↓	
5. Conclusion with a certificate	

achievement of newcomer's goals. Normal duration of the integration programme is one year and finish with the test of Dutch language (NT 2) and Dutch society (MO). This test measures only level of knowledge (newcomer doesn't need to pass or fail it).

Municipality is funded by government and has to develop an apportionment system – how to finance all required parts of integration programme.

### 5. 3 Special methodology for integration in the Netherlands

In the Netherlands there is possible to find several methodologies appointed for work with refugees and immigrants, the principal methods are nantheless – The Tree Model (Het boommodel), The Entire Neighbourhood (Heel de wijk) and The District is Everybody's (De wijk is van ons allemaal). Other methods are following – Tailor-made filing cabinet (Archiefkast voor maatwerk); Thinking of Holland (Denkend aan Holland); Out-of-school learning (Buitenschools leren); Awareness course.nl (Bewuste koers.nl); Networking for integration of refugees (Netwerken voor integratie van vluchtelingen); Intensive traject for illiterate persons (Intensief traject voor analfabeten); Program for restoring the social independence of refugees (Herstelprogramma maatschappelijke zelfredzaamheid van vluchtelingen). When I'd like to introduce all programmes, it'll probably take so many space, so I'll will introduce the three main

methods – The Tree Model, The Entire Neighbourhood and The District is Everybody's.

#### 5.3.1 *The Tree Model*

This special method was developed by Cootje Logger (Dutch organisation – Loggerconsult) and Jeichien Martens (Dutch organisation – Humanitas) in the year 2000. It's base on dialogue between newcomer and coach, when the coach starts with questions about newcomer's competencies and skills (the roots of the tree); follow with goals, which have to be achieved by immigrants and refugees in their new country (the branches of the tree). The close contact between coach and newcomer can enable to find more detailed description of client's needs – e.g. building the client's network (necessary contacts, the trunk of the tree). In fact – learning of Dutch values is not one of the aim, but this relationship presupposes common value exchange.

This method can be intended to the different clients and used internationally.

#### 5.3.2 *The Entire Neighbourhood*

This type of method would like to improve the liveability of a neighbourhood, based on the requirements of people living there. The aim is to fight against individual and collective disadvantage and promote citizen's participation. There are followed two strategies: - depth strategy (promoting and realisation of a social infrastructure); - width strategy (exchange of

experiences between national projects and national expertise).

This process has several phases:

1. district has to be analysed
2. exploration of residents's needs
3. cooperation between institutions, municipality and residents
4. exchange between individuals and institutions

The results of this method is better cooperation between institutions and residents, active participation.

### **5.3.3 The District is Everybodys**

This integral methodology is intended to the linkage of individuals, social groups, the district as a whole, municipality and other institutions. The aim is to tie people solving similar problems together. This way diminishes the religious and cultural differences and goes from the underneath (from clients and local partners themselves).

## **6. DISCUSSION**

The meaning of integration in these three European countries is quite different as well as their history of migration. Different are also the state intentions concerning this issue and as well the the public preparedness for this phenomenon.

### **6.1 The Czech Republic**

The Czech Republic represents country with system of integration intended to the first help to "recognized refugees", immigrants and their children. There is very poor method for helping with finding

accomodation (state offers only one integrative flat, which isn't usually in very good locality with good occupational opportunities), so for "recognized refugees" and their children is necessary to take care of themselves in finding work and accomodation (if they refused state proposal). Immigrants (as an another category) have to help themselves from the beginning of entrance the CR (so, there is any methodology used for immigrants in social work).

In the CR, there are organizations working with these groups of clients, but they are usually intended to the legal issues (e.g. helping with errand of asylum applications - especially in cases of negative decisions on asylum application; helping with family reunification, etc.), they are able of course to help clients with finding job or accomodation, but this is usually on the level of counselling (for immigrants as well).

Methodologies used for decreasing of intercultural tensis are mostly provided by Multicultural Centres and other organizations. These activities are mostly oriented to the multicultural activities as e.g. - Concerts, Exhibitions, Films, Vespertine discussions and other activities, which have to decrease xenophobia and racism in the society (these activities are mostly oriented to closeness of another cultures to the Czech people - this is important, but in fact - this is still starting point of real integrative process). So there is no methodology, how to involve an

individual clients to the society, which creates their social environment (in fact – how to help them with finding friends, with learning of Czech traditions, habits and values). We don't have as well any methodologies how to empower clients to the finding their own possibilities and sources for successful integration.

In case of children – there is methodology for working with refugee children (with them, who are accommodated in Residential and Integration asylum centres or with them, who are unaccompanied placed in children's diagnostic homes). This methodology is usually oriented to the free-time activities (graphics, plastic art courses) and Art-therapy. There is as well paid attention to the psychic problems of children (psychotherapy). Category of immigrant children is marginalized as well as category of immigrant adults. Thus there is any methodology intended to the immigrant children and adults. Methodology, which could be used for successful integration, isn't specialized and children are mostly alone in their endeavour of being integrated.

## 6.2 The Denmark

In the Denmark there government believes that integration is best accomplished through an employment. So already all asylum seekers have to sign contract with asylum facility about increasing of each asylum seeker's skills, professional competences and sense

of responsibility for their own lives and community. "Recognized refugees" are involved to the "introduction programme" and have to sign up the *individual contract* with concrete municipality, to which they are transferred. All aliens get subsidy to provide training and retraining of professional, linguistic, or social skills. Thus Danish way of integration is practically intended to the real involvement of aliens to the society through employment. But in fact, aliens have to be involved in labour market and if not, they won't get any allowance. So this system is quite strict and authoritative to the all immigrants and refugees.

In the Denmark there is also possible to find several special methods used with immigrants and refugees (as e.g. Working Capacity Method - see chapters 4.3.1 and 4.3.2 South Funen Integration Model). But in fact, we can't find also any methodology oriented to the integration of refugee or immigrant children.

## 6.3 The Netherlands

The Dutch integration program is composed by Language, Social Orientation and Vocational Orientation. Municipality have the primary responsibility of integration policy and newcomers have participate in the made-to-measure programme, which have to prepare them to the labour market. This participation isn't conditioned like in the Denmark. So this integration system respect more the will of client

with regard to the democratic principles.

Multifarious composition of social work methodology oriented to refugees and immigrants (see chapter 5.3) shows that this country pay quite big attention to the successful integration. But also in the NL, there is no special methods used for children's integration.

## 7. CONCLUSION

Comparison of these three systems shows how different is situation in states with different historical experiences of migration problems. Especially the Dutch integration system represents country with

many methodologies oriented to immigrants and refugees in spirit of having respect to the democratic values. Over against the Danish way of integration is more practically intended to the strict requirement of learning Danish language and being involved to the labour market (because "work is the key to successful integration"). The Czech Republic represents eastern country, which started to solve these migration problems and which is at the beginning of successful integration. In fact, in all three countries, there is no special methodology oriented to integration of refugee and immigrant children.

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## ინტეგრაციის სისტემები ჩხეთის რესპუბლიკაში, დანიასა და ნიდერლანდებში

### ჯიტკა დგორაკოვა

გაეროს კონვენციით (რომელიც დამტკიცდა 1959 წელს) ლგოლვილთა სტატუსის შესახებ მიგრაციის პრობლემა მეორე მსოფლიო ომის შემდეგ არ გადაჭრილა. ეს მოვლენა კვლავ დელიკატური საკითხია ყოველი ევროპული ქვეყნისათვის და მთელი მსოფლიოსათვის. ამდენად, მიგრაციის პრობლემის გადაჭრა ეროვნული და საერთაშორისო ამოცანაა. მოცემულ სტატიაში განხილულია სამი ევროპული ქვეყნის – ჩხეთის, დანიის და ნიდერლანდების, ასევე იმ ქვეყნების ინტეგრაციის სისტემები, რომლებსაც ყველაზე დიდი გამოცდილება აქვთ ამ საკითხებში. ავტორი შეეცადა ეჩვენებინა, თუ როგორი რთულია სიგუაცია პოსტ-კომუნისტურ ქვეყნებში (სადაც არ არსებობს იმიგრაციის და ინტეგრაციის გამოცდილება).



**ANNEXE 2**

**Danish Individual Contract**

Name:	Civil Registration Number:
-------	----------------------------

Goals for employment and education:

Danish education according to paragraph 21 and 22 in the Danish Integration Act:

Offers according to paragraph 23 in the Danish Integration Act:

Need for clarification of competences:

Date for follow-up:

Follow-ups must take place at least every 3 months.

I have been informed that I may file a complaint against the municipal council, to the Danish Board of Social Affairs, should the council fail to fulfil the contract (cf. Par. 53, Article 2 in the Danish Integration Act).

I have been informed that the municipal council – in case I am a recipient of introduction benefits – may reduce or discontinue my benefits, if I do not fulfil the contract by partially or completely rejecting or failing to turn up for offers set up in the contract, without any valid excuse (cf. Par. 31 in the Danish Integration Act).

[Contracts in which the individual is offered Danish education only:

I have been informed that I may be excluded from participation in tuition, if I fail to appear at lessons without any valid excuse.]

I have been informed that failure to turn up for the introduction programme without any valid excuse may imply that I will not be granted permanent residence permit (cf. Par. 11, Article 6 in the Danish Alien Act).

Date:

The municipal council hereby places itself under obligation to provide introduction programme out in the contract.

I hereby place myself under an obligation to participate in the introduction programme offered set to me by the municipal council.

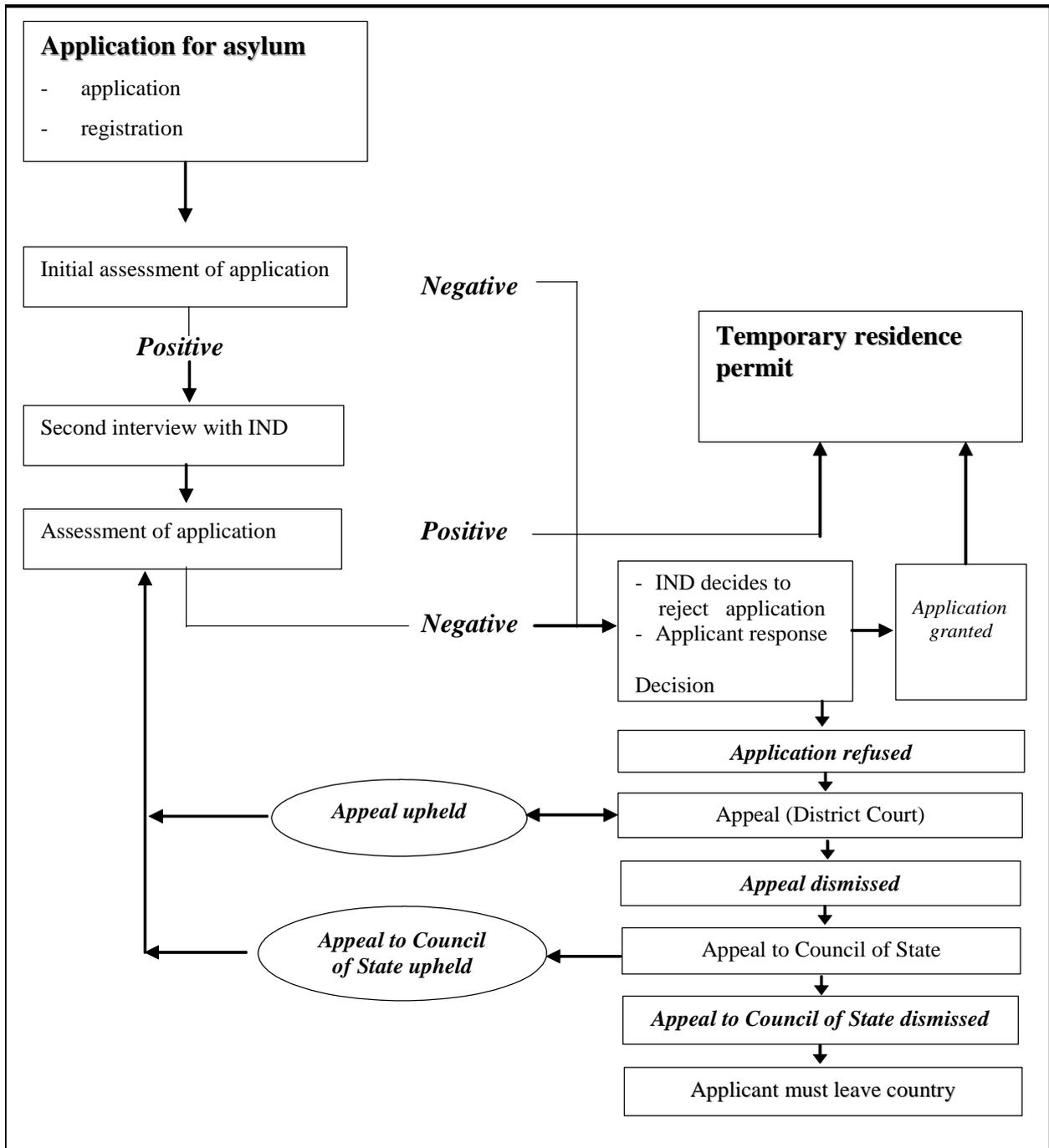
On behalf of the municipal council?

.....  
(Signature)

.....  
(Signature)

ANNEXE 3

Diagram of Asylum Procedure in the Netherlands



# THE QUALITY OF LIFE OF PERSONS WITH MENTAL HANDICAPES IN CASE OF THEIR SPECIAL NEEDS

Markéta Dundálková<sup>1</sup>

## ABSTRACT

The quality of life of persons with intellectual disability is in great extent influenced by the attitudes and values shared by society in general. Despite the financial difficulties, the general health care system and the early services for children with intellectual disabilities maintain relatively good standards. The purpose of rehabilitation is to minimise the immediate consequences of lasting or long-term disability. The aim of modern social services is to enable and support persons with intellectual disability to live as far as possible at home or in the least restrictive environment. The successful process of integration of persons with intellectual disabilities into mainstream life depends on breaking various barriers. Every citizen of the Czech republic is entitled to education. The Czech Government regards the employment of persons with disability as one of the most serious human rights problem in the country. The government claims that the purpose of social security is not to increase the number of occupationally unplaceable persons with disability entirely dependent on unemployment and social care benefits. The state supports families who care for a family member with disability with benefits for the care of a relative or another person with the aim of preventing the person in question being sent to an institution. The current legislative framework of social services does not provide instruments which are necessary for starting de-institutionalisation process.

## Key words:

*Quality of life - persons with mental handicapes - special needs*

## 1. INTRODUCTION

Maximum support needs to be given to all forms of secondary and university institutions training personnel working with persons with intellectual disability (in mainstream and specialised services likewise). Awareness Raising keeps the public well informed about intellectual disability and these gradually change their attitudes towards persons with intellectual disability and other categories of disability. It implements intellectual

disability topics into schools of medicine and inservice training for medical personnel (6, 7).

## 2. DIFFERENT SERVICES, NATIONAL AWARDS, COOPERATION OF GOVERNMENTAL BODIES

Some examples of National Awards are:

- The Government Board's award prize for the best work publicising the problems of disability;
- The Minister of Health's Annual Award to recognise the work done for the benefit of persons with disability;

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- The annual Olga Havlová Prize;
- The NGO – Rytmus annual award for teachers, who successfully integrate pupils with disability into mainstream education (4);
- The competition “The Architecture of Humanity” announced in the spring of 2001 by the Ministry of Labour and Social Affairs (MOLSA), with the aim of celebrating good examples on designing building for social care purposes (3); and
- Sport events such as the Special Olympics and Abyolympics, which take place at a national level.

Medical Care helps to improve the quality, accessibility and funding system of early medical care services. In conjunction with health insurance companies, to resolve the problem of payment for the medical rehabilitation provided at special schools, institutions and special educational centres (9, 4, 26).

Rehabilitation achieves a closer cooperation between the Ministry of Labour and Social Affairs (and its subordinate Czech Social Security Administration offices), the Ministry of Health, the Ministry of Education, Youth and Physical Education, civic associations and health insurance companies in what concerns rehabilitation services. (5, 48)

Community-based support services ensure personal assistance, home and respite care services when needed. These services systema-

tically help to develop and improve community and home care services with respect to the needs of the users; to ensure that adults and children are protected against low levels of care (9); to enable clients and their families to have a choice, which would be in harmony with their individual needs and circumstances, and to maximise the use of services by the clients through a sufficiently wide and reasonable offer; to protect the communities and to prevent social exclusion of individual families and/or their members, through the timely recognition and flexible ensuring of needs of the communities, towns and regions concerning the desirable support of families and children in difficult life situations; to reduce the number of children placed in institutions and through the system of interconnected and comprehensive services, to support the life of children in their natural environment, where their needs will be professionally evaluated, adequately satisfied and further examined. If the latter is not possible, to promote the development of a substitute family care system; ensure that children with disability living in institutions and foster families have the best possible conditions of education, health and social care (2, 12, 13, 29).

The main weaknesses of the present social services system can be pointed out as the following:

- The net of social services is deficient in terms of range, types and capacity, and the regional

- proportion of the services is unbalanced;
- Institutional services highly outweigh community services;
  - De-institutionalisation is not taking place;
  - The legislative framework is out-of-date;
  - The personnel in the public utility sphere is not sufficiently educated and trained;
  - The system of financing services – governmental and non-governmental - is unequal;
  - The system for monitoring quality and efficiency of services does not exist;
  - The complex data base/information system about service providers is not available; and
  - Clients have limited opportunities to participate on the decision-making process of these issues. Interviewed parents, who care after children with intellectual disability at home made several statements during the roundtables expressing various examples of difficulties and problems, which they are facing:
    - “The financial support for families allows us only to survive”;
    - “Better to have a grown-up child in an institution than under a bridge” (parent in Brno);
    - In view of some financial benefits being only provided to the family member with intellectual disability until he/she is 26 years old, one parent said: “Do they [state authorities] think mental disability lasts only 26 years?”;
  - Aware of the alarming lack of day centres, respite care services, personal assistance and the nonexistence of living places such as supported living schemes, one father said: “What will happen to our child when we die? Will he go to live under a bridge?” Another parent also said: “I am quite happy with the agency [provides sheltered living], but such a weak financial mechanism [state system of financing NGOs] forces me to put my daughter on the waiting list of an institution. Just in case...” (46).
  - Some services are too far away from the users and their families placing them in a certain geographical isolation;
  - Local governments do not warrant social services for their citizens;
  - Legislation does not fully regard a member of family providing home care as an employed person;
  - There is no link between different services, which are focused on the age of clients. Therefore during the child development course, it is difficult for families to find an appropriate place for a family member according to her/his needs. There should be a transition of programmes from school to the employment field; and
  - There is a lack of facilities for elderly persons with intellectual disability (39, 15, 18).

*Accessibility helps to promote the use of guidelines for making various information material accessible to persons with intellectual disability; to create comparable conditions for the governmental and non-governmental sectors in the provision of services, by means of uniform criteria of payment for the current system (not according to the number of beds in a institution) (19); to develop a system for the accreditation and funding of counselling centres operating outside the department of education. NGOs and civic associations should inform their members about changes in the social services.*

The information providers following this system include:

- Local and regional authorities;
- Early care centres (17);
- Institutions of educational-psychological counselling (e.g., state-run as well as private special educational centres, educational-psychological counselling centres, etc.);
- Medical rehabilitation centres; and
- NGOs (51).

Education helps to recognise the child rights to inclusive education. By means of new legislation in the education sector, to strengthen the parents' right of choice as regards to the line of education for their children with disability (28); to define the number of teaching instruments and the compensatory and rehabilitation tools (paid from the school budget), as well as the state contribution to these instruments helping in the education of children with special

needs; to ensure the reimbursement for transport costs, personal assistance and guides for integrating pupils and students with disability in mainstream schools; to promote lifelong learning activities for the youth and adults with intellectual disability (47, 14, 41).

The integration process barriers lie on the organising and financing of support services such as:

- Personal/teacher assistance;
- Transport to schools;
- Teaching instruments for special needs; and
- Unsatisfactory cooperation of governmental bodies (education, health and social affairs departments) (23, 24, 27).

Employment is necessary to develop and legitimise a supported employment model, in which personal assistants help a person with intellectual disability to understand and cope with required operations, and attain the expected degree of performance (49, 50). In the process of amending the Employment Act, help to revise the disability pension system and the wording of the concept of "person with reduced working ability"; to continue the reimbursement of social security payments and furthermore, to support employers giving jobs predominantly to persons with disability whilst doing business in a normal competitive environment; to change the system for rating the degree of fitness reduction of insured persons with disability for

sustained gainful activities, and change also the classification of disability into positive recommendations; to provide a legal framework granting the right to persons with disability or his/her legal representative to choose his/her real provider of care, regardless of whether this is a close person, a personal assistant, a sheltered living service, or a governmental or non-governmental institution of social care (43, 42).

This obligation can be fulfilled in three ways separately or in a combined form:

- Employment of persons with disability;
- Purchase of products originating from those companies with more than 55% of employees with disability; and
- Payments to the State (30).

The Government Policy and Practice in the System of Health Assessment - In terms of evaluating health services - Income Maintenance and Social Security, the Ministry of Labour and Social Affairs has developed two state systems of health assessment, and the consequences resulting therefore are (25, Government Resolution 2000):

- One system determines the rate of disability reduction of persons with disability in regards to sustained wage-earning activities for purposes of pensions insurance (33); and
- The other system establishes a disability classification for

purposes of state social support benefits (11).

Family life and personal integrity help to prepare a methodology and conception for the citizen advocacy; to create a network of NGOs who are willing to work on the field of guardianship and to prepare information for legal cases; to prepare a methodology for prevention the bullying of persons with intellectual disability (20, 22, 34, 35).

During interviews, judges highlighted two serious difficulties they face during the juridical process:

- The difficulty to decide who is an appropriate judicial expert (psychologist or psychiatrist) for a certain person; and
- The difficulty to find and appoint a public guardian (21).

Large Residential Institutions help to establish a programme of de-institutionalisation; to support persons with intellectual disability who live in institutions to develop the capability to speak for themselves and express their needs and wishes (as other persons in mainstream life do); to promote the establishment of self-advocacy groups by providing training to self-advocacy members; to create guidelines for individual programme plans and their assessment; to enable persons with intellectual disability to contribute to their communities and therefore to enhance their valuable social status; and to introduce a new policy on the

funding of services for persons with disability, which will prevent discrimination on the provision of social services between the private and non-governmental sector (8, 16, 37).

It is partly result of insufficient political support of the reform in social services. Living conditions in many institutions stay in many ways pure mainly due to lack of financial resources. Complaints and Control Procedures:

- Legislation: Concerning complaints and in general, each single complain coming to an authority, such as the MOLSA, is subject to investigation. According to MOLSA officers, complainers are usually not sufficiently informed about their rights. Neither do they know where to turn to with their claims.
- Controls and Inspections: As regards to control and inspection procedures, the present out-dated legislation allows only inspections in the financial, health, social insurance and hygiene spheres. There is neither a legislative tool nor a methodology for controlling the quality of services. Hence, the control of services is focused only in complying with edicts, instructions and standards in terms of hygiene and boarding. The quality control system shall be a part of the new act on social services, which is expected to be implemented in 2003 (40).

There is no official evidence about the discrimination of persons with intellectual disability in terms of culture (36).

There are recreation and sport activities for persons with intellectual disability provided by NGOs or residential service providers as part of their daily or weekly programmes (45).

One of result of political changes in the beginning of nineties was de-monopolisation of the social services. Non-governmental sector took up its traditional role and started to provide modern and missing services in Organisations of Persons with Disabilities (38).

### 3. DISCUSSION AND CONCLUSION

The perception of the social role of persons with intellectual disability can be changed by various means, such as the attribution of awards, the media, awareness-raising campaigns amongst professionals, etc. Parents see difficulties in communicating with the medical personnel and in their attitudes towards their children with intellectual disability. Parents from rural areas also highlighted the limited access to specialised services, such as early care centres.

Main components of rehabilitation, early care, medical rehabilitation, vocational rehabilitation, etc., are provided in the Czech Republic. However, all the components are

separated from each other. Therefore, a comprehensive rehabilitation system needs to be set up and legislatively codified. However, the current legislative framework does not provide room for a modern form of social services.

Although general statistics do not contain data concerning where or with whom people with intellectual disability live, it can be estimated that the majority of persons with intellectual disability still lives in approximately 200 institutions. Although legislation in terms of architecture has been significantly improved, there are other barriers, which discriminate persons with intellectual disabilities and their families. Parents and self-advocates highlighted mainly human barriers such as arrogance, which they face when communicating with public servants.

A basic system of counselling for citizens with disability and their parents has been developed in the Czech Republic with the aim of improving information accessibility. However, conditions for educating children with severe or profound intellectual disabilities are far from satisfactory. There are problems, which must be addressed such as teacher assistance, transport to schools, and organising education for

children with intellectual disabilities inside or outside institutions.

Despite introducing several measures for supporting the employment of persons with disability, the latter still belong to the most disadvantaged group of employees. The pension system also plays a negative role and the system of evaluation of reduced working ability, which focuses dominantly on negative diagnosis, as well. The purpose is to provide a respectful support to those who, for objective reasons, cannot regularly work.

However, according to NGOs the system of health assessment does not fulfil this declaration. In reality the system in many ways works against the employment of persons with intellectual disability. However, the benefits for parents caring for a child with disability at home is much lower than the financial amount allocated to the care of a person in an institution. However, parents expressed their dissatisfaction at the lack of funding for cultural and sport activities for their children. The funding of such activities run by NGOs is not equal compared to the financial provisions in institutions. However, the governmental bodies has been unable to "tune" legislation according to new situation which appeared in the terrain.

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## ფსიქიკური დარღვევების მქონე პირთა ცხოვრების ხარისხი და მათი სპეციფიკური საჭიროებები

### მარკეტა დუნდალკოვა

ინტელექტუალური დარღვევების მქონე პირების ცხოვრების ხარისხზე დიდ გავლენას ახდენს საზოგადოების საერთო დამოკიდებულება და ღირებულებები. ფინანსური სიძნელების მიუხედავად, ჯანდაცვის სისტემა ზოგადად და ინტელექტუალური დარღვევების მქონე ბავშვების დახმარების სამსახურები საკმაოდ კარგ სტანდარტებს ინარჩუნებენ. რეაბილიტაციის მიზანია ხანგრძლივი უნარშემღლულობის მყისიერი შედეგების მინიმუმამდე დაყვანა. თანამედროვე სოციალური სამსახურების ამოცანაა ინტელექტუალური დარღვევების მქონე პირების შეძლებისდაგვარად დახმარება ბინამზე ან შემზღულ გარემოში, რათა მათ იცხოვრონ უკეთესი ცხოვრებით. საერთო ცხოვრებაში ინტელექტუალური დარღვევების მქონე პირების ინტეგრირების პროცესის წარმატება დამოკიდებულია სხვადასხვა ბარიერების ნგრევაზე. ჩეხეთის ყველა მოქალაქეს აქვს განათლების უფლება. სოციალური სფეროს არსებული საკანონმდებლო ჩარჩოები არ უზრუნველყოფს იმ მექანიზმებს, რომლებიც აუცილებელია დეინსტიტუციონალიზაციის პროცესის დასაწყებად.