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## UNESCO, bioethics and child

### ABSTRACT

UNESCO has adopted three principal international bioethics declarations with the purpose to protect »the inherent dignity of the equal and inalienable rights of all members of the human family«. Children are a particularly sensitive category of the »human family« whose rights were attempted to be protected through declarations, directly or indirectly, starting with the Universal Declarations on Human Rights. It has been twenty years since adopting the »Convention on the Rights of the Child« by the UN (20 November 1989). This paper shall look into the basic rights of the child in accordance with UNESCO's documents.

**Key words:** bioethics, child, law, UNESCO

According to the Convention on the rights of the Child, »... a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier«(1).

UNESCO has adopted three principal international bioethics declarations with the purpose to protect »the inherent dignity of the equal and inalienable rights of all members of the human family«(2). Children are a particularly sensitive category of the »human family« whose rights were attempted to be protected through declarations, directly or indirectly. In Croatia the translation of the bioethics declarations adopted by UNESCO was published in 2008: Universal Declaration on the Human Genome and Human Rights, International Declaration on Human Genetic Data and Universal Declaration on Bioethics and Human Rights(2). The aim of this paper is to research the extent to which children's rights are protected by these docu-

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ments as well as the extent to which principles based on these documents are implanted in our practice.

*Universal Declaration on the Human Genome and Human Rights* was adopted on 11 November 1997. Human genome is defined as a fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity(2). Prior to research, treatment or diagnosis affecting an individual's genome, assessment of the potential risks and benefits is necessary. In all cases, the prior, free and informed consent of the person concerned shall be obtained. If the latter is not in a position to consent, consent shall be obtained in the manner prescribed by law, guided by the person's best interest. If a person does not have the capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law. Should the person be exposed to any risk or burden, the research is intended to contribute to the health benefit of other persons in the same age category or with the same genetic condition(2).

Universal Declaration on Human Genome and Human Rights does not directly mention protection of children's rights. The importance of free consent is stated generally and without detailed instructions for persons who do not have the capacity to consent. The Declaration does not provide instructions concerning manners in which children can participate in consenting for individual medical procedures, but it refers to legal regulations in force for all persons without the capacity to give valid consent(2). According to the Croatian law, a child may not give valid consent; instead, a parent or a legal guardian consents on behalf of a child(3).

*International Declaration on Human Genetic Data* was adopted on 16 October 2003 with the aim to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data, human proteomic data and of the biological samples. Article 2, among other, provides a definition of genetic screening as »large-scale systematic genetic testing offered to a population or subsection thereof intended to detect genetic characteristics in asymptomatic people«(2). Prior to carrying out procedures involved in collecting human genetic data, proteomic data and biological samples, it is necessary to obtain free and informed consent. When a person is incapable of giving valid consent, in accordance with domestic laws, authorization should be obtained from the legal representative, who should have regard to the best interest of the person concerned. Emphasis of taking into consideration the opinion of a minor in Article 8 of the International Declaration on Human Genetic Data should be pointed out as a positive example and a great step. It is significant that this Declaration speaks of

a child directly, emphasizing the importance of obtaining and taking into consideration his or her opinion in proportion to age and degree of maturity(2).

Genetic screening shall be ethically acceptable only when having significant consequences on health of a person, taking into consideration his or her best interest.

Newborn screening is the procedure within the field of protective medicine with the aim to detect diseases in newborns where timely diagnosis and treatment shall lead to a significant reduction in mortality, morbidity and invalidity(4). Screening for phenylketonuria and congenital hypothyroidism is widely accepted, including in our country. Phenylketonuria is an autosomal recessive disorder of phenylalanine hydroxylase in tyrosine and if it is not treated it leads to accumulation of phenylalanine and its metabolites in bodily fluids and result in heavy mental retardation, epilepsy and other neurological disorders. In our country screening for congenital hypothyroidism was introduced in 1985 through TSH RIA measuring method. Apart from screening for phenylketonuria and congenital hypothyroidism, Croatian maternity wards also a screen for congenital deafness(4). Given examples show that newborn screening for Phenylketonuria and hypothyroidism is carried out for the benefit of the newborns, which is in accordance with the principles of the International Declaration on Human Genetic Data(2).

*Universal Declaration on Bioethics and Human Rights* was adopted on 19 October 2005. This Declaration looks into the ethical issues concerning medicine, bioanthropological sciences and accompanying technology(2). The declaration emphasizes the importance of respect for human dignity, human rights and fundamental freedoms. In accordance with this, the interests and welfare of the individual should have priority over the sole interest of science or society, as well as the importance of respect for the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, without mentioning the autonomy of minors. Further text of this Declaration states the importance of protecting rights and interests of persons who do not have the capacity to consent. The Declaration explains the meaning and expresses the importance of consent concerning preventive, diagnostic and therapeutic medical interventions. It emphasizes in the same manner the importance of consent concerning engagement in scientific research, which should take place after receiving adequate information. Authorization for research and medical practice concerning persons who do not have the capacity to consent should be obtained in accordance with law. This Declaration points out the importance of involving the person concerned to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent. This section is particularly important in health care of children, as well as

in involving children in research, because it implies active participation of children in decision-making related to their health(2).

It is necessary to respect the privacy and confidentiality of data obtained from patients. The Declaration does not explain how and to which extent it is possible to ensure privacy and confidentiality obtained from children during medical practice.

*Convention on the Rights of the Child* was adopted by a UN General Assembly on 20 November 1989 (1). It contains the responsibilities of adults towards a child, the responsibilities of different social factors concerning child's protection. Convention on the Rights of the Child is the first document that considers a child as a subject with his or her rights. It is a legally binding instrument and it includes the right of monitoring its implementation in countries that have adopted and ratified it. Croatia ratified the Convention on 8 October 1991. It ensures civil, political, economic, social and cultural children's rights. It requires governments to unconditionally pursue activities concerning protection of children's rights. It has a holistic viewpoint that all rights are fundamental, inseparable and inter-dependant and equally important. There are four principles on which all rights contained in a Convention are based:

1. The principle of non-discrimination according to which children should be protected from discrimination.
2. The right to life and development in all areas of life.
3. Welfare of the child is the most important factor affecting decision-making or medical procedures concerning child.
4. Children are active participants in resolving all issues affecting their life and must have freedom to express their opinion.

According to the Convention there is no hierarchy of children's rights, they are responsibilities towards children which must be met by states parties to the Convention. Everyone involved must be active and engaged when it comes to contributing of implementing rights of the child(1).

On the day of its independence, 8 October 1991, Croatia became a state party to the Convention on the Rights of the Child. By becoming a state party, our country has obliged to modify and adopt its laws and articles in accordance with the Convention. State parties have the obligation to acquaint both children and adults with the principles and provisions related to the rights of the child. These rights must be known and unconditionally respected by persons living and working with children, persons in daily contact with children, as well as persons creating the environment in which the child grows and develops. Children must be acquainted with their rights in order to be aware of both rights and possible solutions should their rights

be threatened. The purpose of all factors stated in the Convention is child's optimal development and teaching the child how to protect his or her own rights, as well as the rights of others(1).

When discussing health care rights of minors, many authors base their arguments on Articles 12 and 13 of the Convention on the Rights of the Child, which are cited hereafter.

Article 12 - »States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child«. The child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body«(1). Article 13 - »The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kind«(1).

In the same manner, the *Ethics Working Group of the Confederation of European Specialists in Paediatrics-CESP*) issued their statement on the informed consent of a child in *Pediatrics* journal in 2003(5). They base their viewpoints on the abovementioned Article 12 of the Convention on the Rights of the Child. Although the text of the document does not state that the right to child's own views and the right to express those views freely refer to health care, the authors believe that the Article is applicable to health care as well. They define child's consent as his or her agreement to the medical procedure when it is not allowed by law or his or her cognitive functions are not adequately developed to give an informed consent. Every child, whether competent or not, has the right to information concerning his or her health explained in an adequate manner and based on such information the child can express consent or disagreement with all aspects of medical care (preventive, diagnostic, therapeutic and research). The purpose of both is partnership, providing information as basis for patient's choice of the course of action that fits him or her most appropriately. Children may refuse a medical intervention or a treatment which is not essential for saving their life. When a procedure is essential to save a life or prevent serious damage, physicians have the obligation to act in the best interest of a child. The authors emphasize that children own rights despite the fact that sometimes they are not able to express them(5).

All of us who work with children have the obligation to promote their rights, give the child the right to express him or herself and act as his or her true representative. We must provide the child with the information in a manner which he or she is able to understand. Physicians should listen carefully to child's opinion, estimate child's

competence, protect his or her dignity and privacy and attempt to obtain child's consent necessary in preventive, diagnostic and therapeutic procedures, as well as in research(5). The report of UNESCO's International Bioethics Committee on patient's consent emphasizes the importance of acting in accordance with the Convention on the Rights of the Child, pointing out that one must be aware that the competence to make a decision develops with child's growth and development. But the question of when exactly that occurs still remains(6).

According to the Convention (Article 24) the child has the right to the enjoyment of the highest attainable standard of health, to be provided information, education and support concerning basic knowledge regarding his or her health(1).

The Universal Declaration on Bioethics and Human Rights emphasizes that every person is entitled to all rights and freedoms stated in it and that children are entitled to special care. It is important to state that Article 22 of the above-mentioned Declaration emphasizes the role of the state, who should institute appropriate measures to follow Declaration's principles. It also mentions that states should encourage information dissemination of scientific information on bioethics. In accordance with that, this paper reminds of documents concerning child's rights in receiving health care, the importance of active involvement of children in giving or refusing consent, as emphasized in the above-mentioned declarations and the Convention on the Rights of the Child. It is important to mention that countries, including Croatia, are invited to apply those principles in everyday life. The necessity to harmonize legal regulations concerning health care and research involving children should be particularly emphasized. For instance, the Act on Patients' Rights is not harmonized with the Convention on the Rights of the Child. This act has neglected to include the possibility and necessity of minors to play an active role in decision-making regarding their health(3).

Physicians should actively involve a child in decision-making process regarding his or her health. It implies change in our views regarding the moral status of a child, as well as requirements of society who must keep up with these changes by modifying legal regulations and, most importantly, changes must be implemented in practice.

We may conclude that it is absolutely necessary for persons who work with children to have a perfect knowledge of the content of the Convention on the Rights of the Child and UNESCO's bioethics declarations. The child must become an active SUBJECT in health system, with all his or her rights. The child has the right to free expression, seeking, receiving and dissemination of information. The state has the obligation in accordance with this Convention and declarations to foster education and training in bioethics on all levels, encourage information and programs and harmonize legal regulations.

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