Bratislava, 16 September 2019

**INPUT OF THE SLOVAK NATIONAL CENTRE FOR HUMAN RIGHTS TO THE REQUEST OF THE SPECIAL RAPPORTEUR ON RIGHTS OF PERSONS WITH DISABILTIES**

*Slovak National Centre for Human Rights (the “Centre”) is a national human rights institution established in the Slovak Republic, accredited with status B by the Global Association of National Human Rights Institutions. As an NHRI, the Centre is a member of the European Network of NHRIs (ENNHRI). The Centre was established by the Act of the Slovak National Council No. 308/1993 Coll. on the Establishment of the Slovak National Centre for Human Rights. Pursuant to Act No. 365/2004 Coll. on Equal Treatment in Some Areas and on Protection from Discrimination, and on amendments and supplements of certain acts, as amended (the Anti-discrimination Act), the Centre also acts as the only Slovak equality body. As an NHRI and Equality Body, the Centre performs a wide range of tasks in the area of human rights and fundamental freedoms including the observance of the principle of equal treatment.*

*The Centre among other powers:*

*1) monitors and evaluates the observance of human rights and the observance of the equal treatment principle;*

*2) conducts research and surveys to provide data in the area of human rights; gathers and distributes information in this area;*

*3) prepares educational activities and participating in information campaigns aimed at increasing tolerance of the society;*

*4) provides legal assistance to victims of discrimination and manifestations of intolerance;*

*5) issues expert opinions on matters of the observance of the equal treatment principle;*

*6) performs independent inquiries related to discrimination;*

*7) prepares and publishes reports and recommendations on issues related to discrimination; and*

*8) provides library services and services in the area of human rights.*

**The Centre submits following answers to the request concerning the report on bioethics and disability for the 43rd session of the Human Rights Council on the bioethics and disability:**

1. **Please provide information on the legislative and policy framework in place in your country in relation to:**

 **a) *Prenatal diagnosis***

The overall prenatal diagnosis and a medical care for pregnant women is mainly regulated in the following acts:

* Act No. 576/2004 Coll. on Healthcare and Services Related to the Provision of Healthcare, as amended – this act regulates the rights and obligation of medical facilities and healthcare professionals as well as the patients' rights.
* Act No. 577/2004 Coll. on the Scope of Healthcare Covered by the Public Health Insurance and on Fees Payable in Respect to the Provision of Healthcare, as amended – this act stipulates the scope of all screenings, examinations and interventions provided as a part of the preventive medical care for pregnant women.
* Expert Regulation of the Ministry of Healthcare of the Slovak Republic No. 14631 – 3/2006 of 19 October 2006 on Prenatal Screening of Congenital Development Defects – the regulation includes standards of the prenatal screening of congenital development defects in relation to biochemical markers of pregnancy.
* National Conception of Healthcare in the Field of Gynaecology and Obstetrics – the conception determines the scope of the healthcare provided in the field of gynaecology and obstetrics as well as its development in upcoming years.

**b) *Disability-related abortion***

The following laws and documents regulate abortion, including disability-related abortion:

* Act No. 73/1986 Coll. on Abortion, as amended. This act regulates the basic conditions and the procedure of abortion.
* Decree of the Ministry of Health of the Slovak Republic No. 73/1986 Coll. on Abortion, as amended. The decree represents an implementation regulation of the Act No. 73/1986 Coll. on Abortion, as amended.

Accordingly, abortion is allowed upon request or consent of a woman by 12 week of pregnancy, Anytime after 12 weeks of pregnancy, abortion is allowed if life or health of woman is in danger or if healthy development of the foetus is endangered or if genetic development of the foetus is defective. This includes situations when foetus is not viable or is seriously defective. In general, biochemical screening is conducted in the 16week of pregnancy and can uncover certain genetic defects, including possible Down Syndrome or Spina Bifida.

* Act No. 300/2005 Coll. the Criminal Code, as amended – the criminal code prohibits unauthorised abortions.
* Charter of the Patients' Rights – a policy document based on the Act No. 577/2004 Coll. on the Scope of Healthcare Covered by the Public Health Insurance and on Fees Payable in Respect to the Provision of Healthcare, as amended that includes the set of rights of patients in the Slovak Republic.

**c) *Informed consent to medical treatment and scientific research***

The informed consent to a medical treatment and scientific research is regulated by the Act No. 576/2004 Coll. on Healthcare and Services Related to Provision of Healthcare, as amended. This act recognises three different types of a consent – (i) a general consent to the medical treatment, (ii) consent to an abortion and (iii) consent to a scientific research.

**d) *Protection of persons with disabilities undergoing research***

* Act No. 576/2004 Coll. on Healthcare and Services Related to the Provision of Healthcare, as amended – this act regulates the bio scientific medical research carried out in the Slovak Republic, including issues of ethical acceptability of the biomedical research and its assesment, informed consent to biomedical research and cases when a person is not in the position to give the informed consent.
* Act 362/2011 Coll. on Medicaments and Medical Devices, as amended – this act regulates usage of medicaments and medical devices during the scientific research and clinical trials.
* Act 462/1992 Coll. the Constitution of the Slovak Republic, as amended – the constitution includes basic human rights guarantees applicable to medical research and clinical trials on humans.
* Act No. 300/2005 Coll. the Criminal Code, as amended – the criminal code prohibits unauthorised harvesting human organs and tissues, unauthorised experiments and cloning of human being.

**e) *Euthanasia and assisted suicide***

* Act 462/1992 Coll. the Constitution of the Slovak Republic, as amended – the constitution provides basic human rights guarantees in respect to right to life and protection of human dignity.
* Act No. 300/2005 Coll. the Criminal Code, as amended – the criminal code prohibits any form of assisted suicide.
1. **Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) in relation to:**

**a) *Prenatal diagnosis***

The vast majority of prenatal diagnosis examinations and screening is available to all pregnant women free of charge, based on the mandatory public health insurance. If it comes to prevention, there are approx. 51 types of medical examination, interventions or screenings concerning pregnant woman or a foetus depending on health indications. As a part of the prenatal screening of congenital development defects, women have access to approx. four screening tests depending on the trimester of pregnancy (combined, double/triple, integrated and biochemical integrated screening). Pregnant women can receive prenatal diagnosis and care in facilities that have licenced gynaecology and obstetrics departments or ambulance, usually in the facility or ambulance located in the place of their residence.

According to the National Centre of Health Information, there was 883 gynaecology and obstetrics ambulances serving 1 878 605 women out of which 66 791 were pregnant in 2017[[1]](#footnote-1). In the same year, the number of medical visits of pregnant women was 604 670. Pregnant women underwent USG examination 305 655 times. In 2015[[2]](#footnote-2), 1 512 women out of 1 976 women underwent prenatal diagnosis. Out of 290 children (foetuses) with positive results, 213 children (73.4 %) were diagnosed with congenital development defects. Despite negative findings, 171 pregnant women underwent additional screenings due to various risk factors such age, family anamnesis etc.).

 **b)** ***Disability-related abortion***

In general, pregnant women can undergo abortion due to life and health threating health conditions or based on request of a woman. Upon the request or due to the health condition, pregnancy can be terminated up to 12 week of pregnancy. If the life of a woman is engendered or the foetus is damaged or non-viable, the abortion can be carried out at any point of the pregnancy. In the past, the abortion of foetus with genetic mutation could be carried out until 24 week of the pregnancy. Legal provision regulating this option was written-off after the 2007 decision of the Constitutional Court of the Slovak Republic. The Constitutional Court ruled that abortion of a foetus with genetic mutation is an abortion due to the health condition, and therefore it should be carried out by the 12 week of the pregnancy. However, it is still a regular medical practice to carry out abortion of a foetus with genetic mutation until 24 week of the pregnancy, bearing in mind that majority of the screening uncovering genetic defects of the foetus is conducted in further stages of pregnancy.

Women face two major obstacles in relation to the access to abortion in Slovakia in general. Firstly, unlike prenatal diagnosis and general medical care for pregnant women, abortion cost is not generally covered by the mandatory public health insurance. Currently, the cost of abortion in Slovakia (excluding abortions due to health reasons) is 250 - 390 EUR, which makes abortion inaccessible for women from socially disadvantaged background. Secondly, the medical personnel can rise a conscientious objection, and therefore refuse to carry out abortion requested by a women or indicated by her health condition. In such case, women must seek other licensed medical professional what can be difficult in some areas of Slovakia where the healthcare infrastructure is weak.

In 2017[[3]](#footnote-3), there was 6 102 legally induced abortions in Slovakia. Out of 100 legally induced abortions, approx. 15 abortions were carried out due to the health conditions.

 **c) *Informed consent to medical treatment and scientific research***

Attending medical professional is obliged to inform the patient about purposes, consequences and risks of the recommended health care, including all available treatment options and risks of refusal to undertake the proposed treatment. The abovementioned information are provided to the person who is going to receive the proposed healthcare or to her/his legal guardian. The attending medical professional is obliged to provide all information in a manner that is easy to understand, respectfully, without pressuring the patient taking into account the intellectual maturity of the patient. The patient should have enough time to decide whether to give the informed consent or not. The written informed consent is required in respect to abortion, bio scientific research, sterilisation, invasive interventions under anaesthesia, in case of the change of prescribed healthcare, harvesting human organs and tissues, transplantation of human organs and tissues. Anyone who is entitled to give an informed consent has also a right to withdraw the consent already given.

In some cases, the informed consent is not required. It usually when the treatment is ordered by the court, a person is infected by highly transmittable disease and he/she is dangerous to public health or when a person is not capable to make an informed consent due to the state of mental health.

If it comes to the scientific research, there are no special protection concerning persons with disabilities. According to Act No. 576/2004 Coll. on Healthcare and Services Related to the Provision of Healthcare, as amended, there is a special protection granted to pregnant women and breastfeeding mothers, persons who do not have capacity to grant an informed consent as well as persons requiring the immediate medical intervention. There are several human rights guarantees regulated in respect to bio medical scientific research, however, these are applicable to all persons participating in the research. For instance, when conducting the bio medical research, it is required that the human dignity of a person, including physical and psychological dignity as well as protected interest and security of a participant is respected

 **d) *The existence of measurements of quality of life which affect both clinical decision-making and health policy***

The quality of life is measured through a set of indicators determined by the Statistical Office of the Slovak Republic. Indicators are produced and disseminated by the Statistical Office of the Slovak Republic and are based on a concept generally accepted within the European Statistical System. The data source for the indicators are mainly sample statistical surveys (e.g. Labour Force Survey, EU SILC, EHIS, HBS), which correspond to statistical requirements on the quality, especially robustness, timeliness and comparability within the EU. The indicators cover both, objective and subjective aspects of the quality of life in nine different dimensions.

While the indicators are used when forming the national policies on health (e.g. Strategic Framework for Health Care for the Years 2013 – 2030), it is unknown to what extent are these indicators and data used in the clinical decision making.

**e) *The practice of experimental, controversial and/or irreversible treatments***

No data available.

 **f) *The practice of euthanasia and assisted suicide on persons with disabilities***

**There is a general prohibition of** euthanasia in the Slovak Republic. It is considered a crime under the Criminal Code, as a crime of participation in a suicide punished generally by 6 month to 3 years in prison.

1. **Please provide information on discrimination against persons with disabilities on research involving humans.**

No data available.

1. **Please describe how national ethics committees address the rights of persons with disabilities. Please provide information on protocols, guidelines, decisions, investigations or publications in relation to persons with disabilities.**

The Centre is not aware of any guidelines, protocols, publications or investigations specifically in relation to the persons with disabilities.

1. **Please describe to what extent and how persons with disabilities are involved in the work of national ethics committees.**

Ethic commission is composed of professionals appointed by the Minister of Health of the Slovak Republic. It has 5 to 15 members and governs its operation by the statute. According to the Statute of the Ethic Commission of the Ministry of Health of the Slovak Republic, all members of the commission should be appointed with ensuring the plurality of aspects of ethics in mind. The only requirements concerning the plurality of the membership of the commission is that one member must appointed by the chambers – professional organisations in healthcare and that no more than half of the members can have no medical background. Unfortunately, there are no requirements to include representatives of persons with disabilities and therefore, there are no such members. Majority of the members are representatives of healthcare professions, academia or law.

1. **Please refer to any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of persons with disabilities in bioethical discussions.**

No data available.

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1. The most recent information on gynaecology and obstetrics available. [↑](#footnote-ref-1)
2. The most recent information on congenital development defects available. [↑](#footnote-ref-2)
3. The most recent information on abortions available. [↑](#footnote-ref-3)