Prepared by: Péter Stánicz, Senior Legal Advisor

Department for Equal Opportunities and Children’s Rights

**Questionnaire on bioethics and disability**

1. **Legislative and policy framework vis-a-vis:**
   1. **Prenatal diagnosis**

The ombudsman’s office has no relevant information or practice regarding prenatal diagnosis. Analysis of the clinical practice of the procedures followed in case of a prenatal death or miscarriage, including the right to grieve and to human dignity is underway.

* 1. **Disability-related abortion**

Abortion is regulated by the Fundamental Law of Hungary (enshrining the state’s positive obligation to protect the right to life, nonetheless, the foetus may not have human rights, as fundamental rights may only be attained by persons upon birth), and more specifically by Act LXXIX of 1992 on the protection of foetal life and Decree 32 of 1992 (XII. 23.) on the execution of Act LXXIX of 1992.

Act LXXIX of 1992 prescribes that abortion can be made on two different grounds: should the pregnant woman’s life be endangered by the pregnancy or in case of severe crisis of the pregnant woman. The severe crisis is described as a crisis that may cause physical or mental damage or result in the social alienation of the woman. The Constitutional Court states in it’s decision 48/1998. (XI. 23.) that the severe crisis may not be subject to investigation, it is validated by the pregnant woman’s request (that she claims she is in fact in a situation of severe crisis) per se. Nevertheless, the state has the obligation to promote the right to life, including the obligation to operate a functioning and effective advisory system on pregnancy and to support the woman in crisis. The regulation on abortion has no specific provisions vis-a-vis disability other than specifically proclaiming it as a possible reason for the woman to apply for abortion before the 12. week of pregnancy (the severe crisis itself, may include a likely disability of the born-to-be child, therefore, the provision does not effectively distinguish).

* 1. **Informed consent to medical treatment and scientific research**

Large-scale ex officio examination of the refusal of life-saving or life-sustaining medical treatment as well as a separate investigation on consent to medical research vis-a-vis children are undergoing, therefore, no conclusions are available yet.

* 1. **Protection of persons with disabilities undergoing research**

The aspects of persons with disabilities shall be examined in the above mentioned process.

* 1. **Euthanasia and assisted suicide**

An ex officio investigation on the right to self-determination and personal autonomy vis-a-vis end of life decision-making is underway, mapping the practice of healthcare institutions and the limitations and possible implications of the relevant legislation. Active euthanasia and assisted suicide is legally forbidden in Hungary, while the passive form of euthanasia is regulated with severe limitations and restrictions (noting that the use of the term euthanasia may be advised to be reconsidered, given the possible negative associations and links to abuse cases and the liability and responsibility of medical professionals). Refusal of medical treatment is regulated by Act CLIV of 1997 on healthcare, prescribing that the person may refuse life-saving or life-sustaining treatment in case he/she is suffering from a terminal illness that – despite all medical efforts and possible treatments – is incurable and would shortly lead to the death of the person. The refusal may be made in an advance directive (or continuing power of attorney) or on the spot by the person. The advance directive shall come into effect if the person loses complete mental and legal capacity (including de facto restricted mental capacity). If the person refuses the life-saving or life-sustaining treatment on the spot, he/she has to be examined by a medical committee of 3 (including the physician responsible for the treatment of the person, another physician of the relevant medical field of the illness and a psychiatrist). The committee has to unanimously declare the illness to be fulfilling the legal requirements and the person to be bearing full mental capacity. Then the person has to renew the refusal of treatment on the third day of the examination to show that his or her determination is final. In case of patients with hindered mental or legal capacity, the healthcare provider is to turn to the courts for a decision on the right to refuse life-saving or life-sustaining treatment. In an advance directive the person may preemptively – while bearing full mental/legal capacity - refuse selected forms of medical treatment in case of a future loss of legal capacity. The advance directive may also nominate a continuing power of attorney for the person or exclude specific persons from becoming a substitute decision-maker for the person.

1. **Statistical Data**

The ombudsman’s office has no official data or statistics available in the relevant fields. An inquiry made to the leading clinics of universities of healthcare education revealed that refusal of life-saving or life-sustaining treatment, as well as the presence of advance directives or continuing power of attorneys in healthcare settings is scarce, with no concrete numbers given whatsoever.

1. **Discrimination against persons with disabilities on research involving humans**

The ombudsman’s office has no official knowledge in the field.

1. **– 5. National ethics committees**

The ombudsman’s office has no official knowledge on the working of ethics committees.

1. **Promotion of the rights of persons with disabilities in bioethical discussions**

Non-governmental organisation such as the [Hungarian Civil Liberties Union (TASZ)](https://hclu.hu/en) or the [Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ)](http://efoesz.hu/who-we-are/) have related practice, with the ÉFOÉSZ including the participation of persons with disabilities in it’s advocacy.