\*\*\* Please note that Ukraine is an agricultural country, with more than 31% of the population living in rural areas. There are currently medical, administrative, territorial, social and educational reforms underway in Ukraine. In this regard, the secondary medical care network is practically not developed in rural areas, although the primary care network is well developed. In Ukraine, the system of preventive and preventive measures is poorly developed. There is a lack of media outreach on bioethics among the population.

**Questionnaire on bioethics and disability**

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

Prenatal diagnostics is carried out through various methods upon the request of the woman and in case of relevant medical indications. The issue of invasive diagnostic methods is solved on a case-by-case basis. Non-invasive techniques are offered to all pregnant women at risk. Screening techniques are available to identify major genetic pathologies. All examinations are conducted only with the consent of the woman.

In particular, according to a unified clinical protocol approved by the Ministry of Health in 2015, all women are advised to undergo a screening test to identify is a fetus has a Down syndrome.

* 1. Disability-related abortion

According to the law, abortions for persons with disabilities are carried out in case of relevant medical indications and with the consent of the disabled person or her guardian. In some statutory cases, abortions are performed without the consent of the person or her legal representatives by court order. We do not exclude the possibility of abortions for persons with intellectual and mental disabilities without their informed consent, but we cannot provide such information

* 1. Informed consent to medical treatment and scientific research

According to the law, any treatment and research is carried out solely with the informed consent of the person to be treated or participating in the research, or with the informed consent of the guardian or trustee, in cases of incapacity or inability to provide such consent. In some cases specified by law, treatment is carried out without the consent of the person or his or her legal representatives by court order. We do not exclude the possibility of treatment or research without informed consent, but we cannot confirm this information

* 1. Protection of persons with disabilities undergoing research

According the law, people with disabilities are screened at their own informed consent or with the guardian's consent. We do not exclude the possibility of conducting research without such consent, but we cannot confirm this information.

* 1. Euthanasia and assisted suicide

According to the law, euthanasia is forbidden in Ukraine

1. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) in relation to:
   1. The availability, accessibility and use of prenatal diagnosis

Prenatal diagnosis is available and accessible, some doctors recommend examination in case of relevant medical indications.

According to the site https://ukurier.gov.ua/en/articles/rozvitok-programi-prenatalnoyi-diagnostiki-vryatuy/, the Center for Pediatric Cardiology and Cardiac Surgery annually examines more than 1000 women with suspected fetal heart disease, diagnosed with 18 weeks of pregnancy, from 2004 to 2017, diagnosed with more than 3000 complex heart defects.

* 1. The availability, accessibility and use of disability-related abortion

Non-governmental organizations are approached by persons with disabilities and their guardians, with questions about whether or not to have an abortion. NGOs provide, where possible, legal or psychological support, and provide psychological and social support for such persons. Abortion statistics are not maintained by the parent NGOs; these statistics are medical records and are not accessible to the parent NGOs. For the last 5 years the All-Ukrainian Non-Governmental Organization "Coalition for the Protection of the Rights of Persons with Disabilities as a result of Intellectual Disorders" has developed and implemented a training course on sexual and reproductive health.

* 1. The practice of informed consent to medical treatment and scientific research

In all cases of need for medical treatment, the informed consent of the person or his/her legal representative is given. In legally regulated statutory cases, such consent may be given by the board of trustees, or by a court decision. For persons with intellectual and mental disabilities, these standards are often observed, especially in institutional settings. Information on such cases is periodically appears in the media. Our organization also receives this information during monitoring visits to boarding institutions.

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

In Ukraine today there are 21 state standards for social services exist. Before receiving the service, the needs of persons with disabilities are determined according to specially designed scales. This process has recently begun in Ukraine, so we cannot provide a specific assessment of the impact of this measurement on clinical decision making and health policy.

* 1. The practice of experimental, controversial and/or irreversible treatments

Experimental therapies are conducted only with the informed consent of the person or his/her legal representative. Parent NGOs do not have information on conflicting and irreversible treatments. Parents have no access to statistics.

Often the parents of children with disabilities in age of the early development resort to the use of controversial treatments due to their own ignorance and incompetence, lack of confidence to official medicine.

* 1. The practice of euthanasia and assisted suicide on persons with disabilities

Introduction of a network of palliative and hospice facilities in Ukraine at the state level is only beginning. Parent NGOs study the experience of overseas colleagues in palliative care services.

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

We do not have such information, but do not exclude the fact of discrimination.

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.

We were surprised to learn that there are bioethics committees in Ukraine and that the 7th National Bioethics Congress is starting its work on September 30, 2019. Analyzing the Working program of the congress, we see that the issues of bioethics and people with disabilities are not considered.

And also we were surprised to learn that the Bioethics Committee exists at Pirogov Vinnitsa National Medical University, created by order of the rector (№ 158 of 27.06.2003 and works in accordance with the order # 395 of 10.11.2005 and on the basis of the "Regulations on the Ethics and Bioethics Committee" approved by the rector of Pirogov VNMU on October 15, 2008)

Our suggestion is that they operate as closed clubs on interest, not open to public involvement.

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

Thanks to the information received from the UN Committee, we intend to step up our work on cooperation with both local and national bioethics committees.

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.

Thanks to the participation of the Ukrainian delegation in the 22 session of the UN Committee on the Rights of People with Disabilities and the meeting with a representative of the Office of the Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas-Aguilar, we will study and disseminate expertise concerning bioethics and disability among public organizations of Ukraine.