## DH-BIO Seminar: "Early intervention on intersex children – protecting the rights of the child"

I welcome the initiative of the Council of Europe Steering Committee for Human Rights in the fields of Biomedicine and Health to bring together today human rights experts, civil society representatives, academics, and members of the medical profession for this crucial discussion on early surgeries on intersex children.

My Office published <u>an issue paper</u> on the human rights of intersex people in 2015. Copies are available in the room today and on our website. Among the many issues discussed in the paper, I have been particularly touched by the stories of intersex children.

In most - if not all - member states, intersex children continue to be routinely subjected to a range of procedures that are not medically necessary, including so-called "sex-normalising" surgeries, without their informed consent. These medical procedures mostly aim at making them fit the societal expectations about male and female bodies, sometimes under the pressure of being able to tick a gender marker box on ID documents.

But the consequences of these procedures and treatments performed on intersex children are dire. They can include wrong sex-assignment and misgendering children, permanent infertility, incontinence, life-long need for medication, and loss of sexual sensations. For many, this results in lifelong physical pain and psychological suffering. Some intersex people report having experienced these medical procedures as nothing short of torture.

Human rights experts are universally united in finding that these early medical procedures without informed consent violate the human rights of intersex children, including the right to self-determination, to physical integrity, as well as the right to respect for private life, and the right to health, including mental health.

As children, intersex children have additional rights under the UN Convention on the Rights of the Child, some of which are so very relevant in relation to early surgeries. Fundamental principles that should guide all actions involving them include that their "best interests" should be a primary consideration, and that children have the right to express their views and that these be given due weight in all matters affecting them.

Unless it is a matter of medical emergency, intersex children should be the only ones to decide whether they want to modify their own bodies - when they are old and mature enough to make an informed decision. Intersex children and their parents should be provided with support and counselling, including by putting them in touch with other intersex persons.

I will continue to urge member states to prohibit non-vital or non-emergency surgeries conducted without the informed consent of intersex children. Four countries in Europe have already done so, to a certain extent: Malta, Iceland, Portugal, and Germany. The laws in these countries send the right signal to society that there is nothing to be fixed in intersex bodies.

I want to leave you with one powerful idea today: whether there is a legal ban or not, the role of medical professionals is immense and can change everything. Doctors are on the front lines to reassure parents and direct them to objective, non-discriminatory information. Doctors can advise to act in the best interests of the child and renounce or delay any procedure that is not medically necessary. In the United States, several clinics have publicly announced they would no longer conduct early surgeries on intersex children.

Let me end with this fundamental question by paediatric surgeon Mika Venhola which is cited in our issue paper:

## "Why operate on the child's body if the problem is in the minds of the adults?"

I wish you a successful seminar.