

Committee on Civil Liberties, Justice and Home Affairs

Hearing on "The situation of fundamental rights in the European Union in 2015"

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I want to thank LIBE for inviting OII Europe to inform you about the challenges intersex people face in the EU. It is the first time OII Europe is officially invited to speak at the European Parliament and we hope that this is the first step to opening a dialogue.

Intersex people are born with primary and secondary sex characteristics – such as inner and outer genitals, chromosomes, gonads, hormonal structure, muscle mass, hair distribution and stature – that do not belong strictly to male or female categories, or that belong to both at the same time. Individuals with variations of sex characteristics are medically labeled as having a “disorder or sex development” (DSD). A DSD diagnose most often is accompanied by the notion that that person needs to be “fixed” by medical means. To “fix” an intersex person means to subject their body to a treatment that aims to alter their sex characteristics by surgical intervention and/or hormonal treatment towards a more female or male appearance. It also aims to enable these bodies to fulfill the societal expectations of what is considered by medical professionals to be the intersex person’s “real” sex. A 2014 study issued by the Dutch Institute for Sociological Research compared medical data and found the total prevalence of intersex people to be 1 in 200 – that is, 1 in 200 is the number of intersex people which, according to the medical norm allegedly “needs” medical attention.

Common practices to make bodies conform to the male or female category include – but are not limited to – clitoris amputation, reduction or recession; hypospadias ‘repair’ – in order to move the opening of the urethra from its original place on the shaft of bottom of the penis, to its tip; vaginoplasty and construction of an artificial vagina; forced vaginal dilation; removal of gonadal tissue – basically a castration – or imposition of hormones in order to alter the sex characteristics of the child. These interventions can cause psychological trauma as well as severe physical impairments, ranging from painful scar-tissue or lack of sensation to osteoporosis and urethral issues.

According to the 2015 FRA focus paper on the fundamental rights situation of intersex people in the European Union, so-called ‘normalising’ surgery is carried out on children with

variations of sex characteristics in at least 21 Member States. 18 Member States do require patient consent provided the child has the ability to decide; but as the current medical guidelines still recommend surgery at a very early age – and most often the first interventions are performed in the first 2 years of life – the majority of intersex individuals will not be able to take their own decisions in this matter. In 8 Member States a legal representative can consent to such intervention *independently* of the child’s ability to decide. These findings show very clearly that the right to self-determination and bodily autonomy of people with variations of sex characteristics is violated within the EU.

“Everyone has the right to respect for his or her physical and mental integrity”. Performing medical treatment that is not life-saving without the free, personal and fully informed consent of the person themselves is clearly violating their right to physical and psychological integrity, which is included in the Right to the integrity of the person, as enshrined in Article 3 of the EU Charter of Fundamental Rights and which is also included in the Right to respect for private and family life, as enshrined in Article 7 of the EU Charter of Fundamental Rights and Article 8 of the European Convention on Human Rights. These interventions have also been declared to be a form of inhuman and degrading treatment, among others by the UN Special Rapporteur on Torture and the UN Committee against Torture, thus violating the Right to prohibition of Torture enshrined in Article 4 of EU Charter of Fundamental Rights and Article 3 of the European Convention on Human Rights

The effect of the current pathologization of intersex bodies begins in childhood. But it doesn’t end there. Let me now speak of intersex adults, the majority of which have been subjected to medical and psychological intervention in the past five decades. Intersex people in the EU face stigma, structural and verbal discrimination, harassment, lack of adequate medical care, lack of access to needed medication, lack of legal recognition, and the invisibility of their bodies in our society. There is a reported risk of poverty due to lack of education as a result of dropping out of school and/or physical and psychological impairments due to treatments, or a lack of self-esteem caused by social stigma. Intersex youth do not find themselves positively represented anywhere, as variations of sex characteristics are not included in school or university curricula, unless as a disorder or disease. When growing older, just like anyone else, intersex people need to rely on the health sector much more. Access to general healthcare is often impaired by prejudices of healthcare professionals and the refund policies

of health insurance companies, thus violating intersex people's Right to health as enshrined in Article 35 of the EU Charter of Fundamental Rights. This is particularly true where accessibility to particular services (e.g. availability of preventive check-ups for certain conditions or general health services) is related to the sex/gender of the individual seeking the service.

Other common issues faced by intersex people in the EU are a lack of access to hormone substitution or a hormone substitution which does not fit the real needs of the person's body and again instead aims to enforce the assigned sex of female or male.

Since 2008 EU Member States have been repeatedly called on by different UN bodies, including the CEDAW, CAT, CRPD and CRC to take the necessary legislative, administrative and other measures to guarantee the respect for the physical integrity and autonomy of intersex persons and ensure that no one is subjected during infancy or childhood to unnecessary medical or surgical procedures. In 2015 the Commissioner for Human Rights of the Council of Europe published an issue paper on "Human Rights and Intersex People". The UN bodies as well as the Commissioner for Human Rights urge the Member States to guarantee counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary surgery and other medical treatment; to ensure that full, free and informed consent is respected in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give full, free and informed consent; and to provide adequate redress for the physical and psychological suffering caused by such practices to intersex persons and guarantee intersex people's access to justice.

But until now Malta is the only EU Member State to have banned unconsented medical intervention and to have provided, joined by Greece in December 2015, an anti-discrimination framework on the explicit ground of sex characteristics. This is highly unfortunate to say the least. OII Europe would like to urge the Committee on Civil Liberties, Justice and Home Affairs to use the momentum and raise awareness on intersex issues.

The key priorities are to prohibit medical treatments on intersex people, without their personal, free and fully informed consent; this includes prohibiting medical treatment on intersex children that is not life-saving but merely cosmetic. Anti-discrimination legislation that explicitly includes individuals with variations of sex characteristics is important to



guarantee intersex peoples access to justice and the enjoyments of their rights. On a European level a comparative study on how the current EU legislation on sex and gender equality can also cover sex characteristics would be key. An initiative report issued by the European Parliament providing a first official European Parliament position on intersex would be very welcome too. We urge you to take the responsibility in your hands and to actively work for the betterment of intersex people's lives within the European Union.

THANK YOU