



# INTERSEX RESEARCH STUDY

ALBANIA, BOSNIA AND HERZEGOVINA,

THE FORMER YUGOSLAV REPUBLIC OF MACEDONIA AND SERBIA

2017



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# I. ACRONYMS

**AIS** – Androgen Insensitivity Syndrome

**BLEE** – Being LGBT in Eastern Europe

**BD** – Brčko District of Bosnia and Herzegovina

**CAH** – Congenital Adrenal Hyperplasia

**CAT** – *UN* Committee Against Torture

**CAIS** – Complete Androgen Insensitivity Syndrome

**CCPR** – *UN* Human Rights Committee

**CEDAW** – Committee on the Elimination of Discrimination against Women

**CESCR** – *UN Committee on Economic, Social and Cultural Rights*

**CIPIPD** – Commissioner for Information of Public Importance and Personal Data Protection

**COE** – Council of Europe

**CPE** – Commissioner for Protection of Equality

**CRC** – *UN* Committee on the Rights of the Child

**CRCA** – Children’s Human Rights Centre of Albania

**CSO** – Civil Society Organization

**DHT** – Dihydrotestosterone

**DNA** – Deoxyribonucleic Acid

**DSD** – Disorder of Sex Development

**EU** – European Union

**FBiH** – Federation of Bosnia and Herzegovina

**ICAO** – International Civil Aviation Organization

**ICD** – International Statistical Classification of Diseases and Related Health Problems

**LGBT** – Lesbian, Gay, Bisexual and Transgender

**LH** – Luteinizing Hormone

**HRC** – Human Rights Council

**MOH** – Ministry of Health

**MRKH** – Mayer-Rokitansky-Küster-Hauser Syndrome

**NGO** – Non-Governmental Organization

**OHCHR** – Office of the United Nations High Commissioner for Human Rights

**OII Europe** – Organisation Intersex International Europe

**PAIS** – Partial Androgen Insensitivity Syndrome

**RS** – Republic of Serbia

**RS** – Republika Srpska

**SOC** – Sarajevo Open Centre

**SOGI** – Sexual Orientation and Gender Identity

**TLAS** – Tirana Legal Aid Society

**UN** – United Nations

**UNDP** – United Nations Development Programme

**UNFPA** – United Nations Population Fund

**UNICEF** – United Nations Children’s Fund

**UPR** – Universal Periodic Review

**WHO** – World Health Organization



## II. BACKGROUND: The BLEE project and the need to produce this report

UNDP is the multilateral institution with a convening role vis-à-vis both governments and civil society across three focus areas (eliminating poverty, accelerating sustainable development, and boosting resilience). UNDP works on the ground in 170 countries and territories, working with governments and people to find their own solutions to global and national development challenges to help empower lives and build resilient nations. Advancing lesbian, gay, bisexual, transgender, and intersex equality and inclusion is an integral part of UNDP's mandate for the promotion of rule of law and human rights in relation to the emphasis of "leaving no one behind" within the Sustainable Development Goals and the 2030 Agenda for Sustainable Development.

This report has been developed as part of the project "Being LGBTI in Eastern Europe: Reducing Inequalities & Exclusion, and Combating Homophobia & Transphobia Experienced by LGBTI people in Albania, Bosnia and Herzegovina, the former Yugoslav Republic of Macedonia, and Serbia" (BLEE). The project considered LGBTI issues in each of the countries from a human rights and development perspective, contextualizing these against the backdrop of civil society capacity development, community mobilization and government competence. This includes but is not limited to the right to health and well-being within the context of development. The intention of the national BLEE reports, developed during the project implementation, was to voice lesbian, gay, bisexual, transgender and intersex (LGBTI) communities' concerns; identify gaps in legislation and practice; and provide recommendations to relevant stakeholders.

Among many other learnings in the Western Balkans region, it appeared that there is very little information about the situation surrounding intersex people and issues they face in the selected project countries. That was the main reason why UNDP invested additional effort to investigate this situation around intersex issues in the four Western Balkans BLEE project implementation countries.

Across the Western Balkans region, people remain largely unaware of the painful personal stories of intersex people and the human rights violations they face. The social expectations for either a girl or a boy at birth, or a woman or a man in society, are the source of the problems intersex people face. Society does not usually recognize a person without reference to their sex. Meanwhile, intersex-chromosomal, anatomical or gonadal characteristics do not belong exclusively to either sex. This is why intersex persons encounter huge barriers to the enjoyment of their universal human rights. Stereotypes and norms grounded on the binary female–male classification have led to unnecessary medical and surgical interventions on intersex infants and a climate of incomprehension in society. Parents of intersex babies are often ill-informed and baffled. Medical professionals may be quick to propose 'corrective' surgeries and treatments aimed at 'normalizing' the sex of the child. Such surgeries, which are cosmetic rather than medically necessary, are often performed on intersex babies and toddlers. This can result in irreversible sex assignment and sterilization – performed without the full informed consent of the parents and, even more importantly, without the consent of intersex persons themselves. 'Corrective' operations and treatments are usually traumatizing and humiliating. They can take a long time and post-operative complications are common. There are long-term effects on intersex individuals' mental health and well-being. The sex assigned to children at an early age may not correspond with their identity and feelings later in their lives. Western Balkan

countries have been slow in recognizing and upholding the human rights of intersex people and the gender diversity they represent. The fundamental rights of intersex people are not respected as they remain largely unrecognized in societies.

### III. RESEARCH METHODOLOGY

The “Intersex research study in Albania, Bosnia and Herzegovina, the former Yugoslav Republic of Macedonia and Serbia” was commissioned by UNDP to stimulate the development of a framework of action and provide a possible way forward in advancing the human rights of intersex people. The objective for the study is to raise awareness on the situation of intersex persons and to inform governments, key stakeholders and practitioners in the Western Balkans about current ethical and human rights developments, including current global good practice to protect and empower intersex people.

The study was undertaken from February to June 2017 and the information contained in this report is based on a comprehensive desk and field research. Desk research included the review of international medical documents, internal medical protocols, declarations, international guidelines, publications, resolutions, administrative procedures, legislation and other relevant materials related to intersex persons in Albania, Bosnia and Herzegovina, the former Yugoslav Republic of Macedonia, and Serbia.

The field research involved interviews with medical specialists (1 each in Albania, Bosnia and Herzegovina, the former Yugoslav Republic of Macedonia, and 2 in Serbia), representatives of LGBTI organizations and other relevant human rights NGOs (3 in Albania, 1 in Bosnia and Herzegovina, 4 in the former Yugoslav Republic of Macedonia and 2 in Serbia), and lawyers and medical legal practitioners (3 in Albania, 1 in Bosnia and Herzegovina, 1 in the former Yugoslav Republic of Macedonia and 2 in Serbia) who are familiar with intersex issues and people and parents of intersex babies.

# IV. MAJOR FINDINGS

## 1. INTRODUCTION: Intersex phenomena

Intersex is an umbrella term for people born with variations of sex characteristics, chromosomes and/or hormones which may not correspond with societal and medical expectations. More precisely, intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies.<sup>1</sup> Sometimes when a baby is born, it can easily be identified as intersex by its bodily characteristics. Occasionally intersex babies have external (outside) genitalia that appear clearly female or male, but the internal genitalia can be different, malformed or absent. Therefore, in some cases, an intersex body can be discovered during childhood, at puberty or even in adulthood.

While there is no systematic data collection and estimates depend upon which intersex variations are included, according to experts between 0.05 and 1.7 percent of the population is born with intersex traits.<sup>2</sup> This gap in estimation (the higher estimate over 30 times more than the lower) is mainly due to lack of consensus on the diagnosis of intersex.<sup>3</sup> Being intersex relates to biological sex characteristics, and is distinct from a person's sexual orientation or gender identity. An intersex person may be straight, gay, lesbian, bisexual or asexual, and may identify as female, male, both or neither.<sup>4</sup> Some intersex people have an intersex gender identity.

Throughout history, intersex people and their bodies were first glorified, then stigmatized and discriminated against.<sup>5</sup> The terms 'hermaphrodite'<sup>6</sup> or 'pseudo hermaphrodite' were used until the beginning of the 20<sup>th</sup> century, when for the first time the term 'intersexuality' was mentioned in medicine.<sup>7</sup> The term 'hermaphrodite' as applied to plants and animals means having both female and male reproductive organs; when applied to people, this term is incorrect and misleading and can contribute to stigma and misunderstanding.

Treatment of intersexual persons until the 20<sup>th</sup> century did not include medical sex 'normalizing' procedures such as surgeries and hormonal therapy, which were later initiated by modern medicine.

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1 Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe Office of the Commissioner for Human Rights, Inter-American Commission on Human Rights, et al. (24 October 2016).

2 Free & Equal, United Nations campaign for LGBTI equality, Intersex factsheet, Available at: <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf>.

3 A community interpretation of statistics on how many humans are born intersex can be found here: <http://oii-usa.org/2563/how-common-is-intersex-in-humans/>.

4 Ibid.

5 Dreger, A.D. (1998). *Hermaphrodites and the Medical Invention of Sex*, Cambridge, Massachusetts, London, England: Harvard University Press.

6 The term used in biology for organisms who can perform both male and female functions and fertilize themselves. See more at: Goldschmidt, R. (1917). "Intersexuality and the endocrine aspect of sex". *Endocrinology* 1, pp. 433–456.

7 Ibid.

People lived with ambiguous genitalia and in a gender assigned at birth. In the 1950s, a team from the Johns Hopkins Hospital,<sup>8</sup> led by a clinical psychologist John William Money<sup>9</sup> started advocating for conducting early medical interventions, including genital surgery and hormonal treatment on children with sex variations. He believed treatments are necessary and represent the only efficient solution for a child's normal development. However, over time, it has been shown that imposing gender and sex can have negative, even fatal, consequences for children.<sup>10</sup>

In modern medicine, variations in the sex characteristics of intersex persons are medically classified and treated with surgeries and hormone therapy. These procedures are common practice in most countries in the world. The goal is to create a 'stable', 'normal' and 'adjusted' person with a standard sex and gender and a heterosexual orientation. These early interventions can cause physical and psychological trauma which affect intersex persons' lives, who often become ashamed and isolated from society. Society does not recognize intersex people in daily life as they are still very invisible, and in some cases have no available mechanisms and legal provisions to protect their rights.

The intersex community was organized for the first time in the USA in the early 1990s with the support of medical specialists. These groups were organized as support groups for people with the same diagnoses and were named DSD (Diverse Sex Development) or AIS (Androgen Insensitivity Syndrome) groups. They developed approaches that worked from the inside (by working with medical practitioners) and worked directly with those affected by medical practice (by providing support). As the intersex community were empowered, they grew into a human rights movement and joined the LGBT<sup>11</sup> community. This addition has potential advantages (visibility, solidarity, alliances, mainstreaming of intersex issues and inclusion) and disadvantages (potential or real backlash, appropriation, misrepresentation and exclusion).

What links the experiences of intersex people and LGBT people are that they are subject to discrimination based on homophobia and/or transphobia.<sup>12</sup> The LGBT community faces two grounds of discrimination, on the basis of sexual orientation and gender identity. Intersex is not a sexual orientation or a gender identity. Intersex people have all kind of sexual orientations, gender identities and gender expressions. Intersex people, just like trans people, are primarily discriminated against on the grounds of physical appearance and gender expression that arise from their ambiguous sex characteristics. In many cases, they are discriminated against from birth when they are subjected to invasive, irreversible treatment without their consent.

Intersex people do not necessarily see themselves as part of the LGBT community and do not see what is common between their life experiences and those experienced by LGBT people.<sup>13</sup> However, due to similarities around the obstacles they face – discrimination related to gender and medical

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8 Available at: [http://www.hopkinsmedicine.org/the\\_johns\\_hopkins\\_hospital/index.html](http://www.hopkinsmedicine.org/the_johns_hopkins_hospital/index.html).

9 John William Money (1921–2006) was a psychologist and sexologist who researched gender identity and sexual preferences and introduced the terms 'gender identity' and 'gender role'.

10 Colapinto, J. (2000). *As Nature Made Him: The Boy Who Was Raised as A Girl*. New York, Harper, p. 22 and further.

11 Gay, Lesbian, Bisexual and Trans people.

12 Council of Europe Commissioner for Human Rights (2015). *Human rights and intersex people*. Issue Paper. Available at: <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2933521&SecMode=1&DocId=2367288&Usage=2>.

13 <https://www.ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex>.

issues – the LGBT community accepts intersex people and their issues as a part of their movement. For example, ILGA-Europe<sup>14</sup> became an LGBTI<sup>15</sup> organization following the decision to include ‘intersex’ in ILGA World’s name and mandate at their 2008 Vienna Conference.

After establishment, different intersex community groups started to challenge the medical approaches to intersex issues. Now the intersex community is divided into two groups, one promoting a medical approach (labelled by diagnosis) and the other promoting demedicalization (a human rights approach).

## 2. MEDICAL APPROACHES TO INTERSEX

### 2.1 Medical definition of intersex

The official medical term for intersex conditions is known as Disorders of Sex Development (DSD), recommended at the Chicago Consensus held in 2005.<sup>16</sup> This term refers to congenital atypical chromosomes, genitals, and/or hormonal structure.<sup>17</sup>

Medical diagnosis can serve as an act or process of identifying or determining the nature and cause of a baby’s or an adult’s intersex condition and can guide doctors and parents in choosing which diagnostic analysis and tests to conduct for further follow-up and management.

### 2.2 Background information of sex and sex development

Intersex babies can be born with different sex variations, for example, partially or full developed male and female sex characteristics and/or genitalia. The medical term ‘genitalia’ is used to describe male or female reproductive organs. The genitalia include internal and external structures.<sup>18</sup> Intersex people may have different chromosomes or hormones than non-intersex people.

In the nucleus of each cell, the deoxyribonucleic acid (DNA) molecule is packaged into thread-like structures called chromosomes. Each chromosome is made up of DNA tightly coiled many times around proteins called histones that support its structure.<sup>19</sup> The biological system determines the development of sexual characteristics in an organism, and is therefore important for understanding the sex-determination system. Humans are born with 46 chromosomes in 23 pairs. The X and Y

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14 [www.ilga-europe.org](http://www.ilga-europe.org).

15 LGBTI is used as an umbrella acronym for these groups despite their differences. It has been adopted by international and European organizations such as the United Nations, the Council of Europe and the European Union.

16 Chicago Consensus recommendations from 2005, available at: <http://www.aissg.org/PDFs/Chicago-Agenda-Oct-05.pdf>.

17 Kun Suk Kim and Jongwon Kim (2012). Disorders of Sex Development, The Korean Urological Association, available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3272549/>.

18 See Annex 1 for a full list of male and female external and internal genitalia.

19 <https://ghr.nlm.nih.gov/primer/basics/chromosome>.

chromosomes determine a person's sex. Most women are 46XX and most men are 46XY.<sup>20</sup> Intersex people can have different chromosomes.

Hormones are special chemical messengers in the body that are created in the endocrine glands. These messengers control most major bodily functions, from simple basic needs like hunger to complex systems like reproduction and a person's emotions and mood. The hormones are created by glands, which are part of the endocrine system.<sup>21</sup> A gonad (sex gland or reproductive gland) is a gland that produces the gametes (sex cells). The male gonad is the testicle and it produces sperm (reproductive cells) in the form of spermatozoa. The female gonad is the ovary and produces egg cells.

*"My vagina was a size and shape of a pencil [miniature and thick without opening], which surgeons tried to correct since I was born. I was also born with an enlarged clitoris, which obviously bothered everybody around me. The surgeons convinced my mother that he had to reduce the size of the clitoris. They reduced the size once, but it continued to grow, because at that point of my life I didn't want to take medications. I was 17 years old when my clitoris was removed. That was 1987, when you would think that such barbaric surgeries would not happen..."*

– Anonymous intersex person with feminizing surgery<sup>22</sup>

The development of sex begins between weeks 7 and 10 when the fetus develops testicles which produce androgens (male hormones) or ovaries which produce estrogen (female hormones). The testes start producing testosterone and the anti-mullerian hormone (AMH) and the development of the male internal sex organs is initiated: epididymides, ducts deferens and seminal vesicles. AMH suppresses the development of female internal sex organs, i.e. the fallopian tubes, uterus and upper portion of the vagina. The development of the external genitals takes place between 9 and 14 weeks. The testosterone stimulates the growth of a penis and scrotum. If no testosterone is produced, the external genital organ develops into a vagina. The sex hormones testosterone and estrogen initiate the development of secondary sex characteristics during puberty. Intersex people can have one type of sex characteristics and hormones of another sex.

## 2.3 Intersex diagnosis

There are at least 40 types of intersex variations<sup>23</sup> with differences regarding genes, chromosomes, anatomy and hormones.<sup>24</sup> All these variations are grouped under the term 'intersex'. It is very important that intersex persons are not classified into a new collective category of sex such as 'other' or 'third sex' which exists in parallel with the categories of 'men' and 'women'. Such categorization

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20 <http://www.who.int/genomics/gender/en/index1.html>.

21 <http://www.hormone.org/hormones-and-health/what-do-hormones-do>.

22 An experience of an intersex person from Germany, in: Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter. Bulletin Texte Nr. 42. Available at: [https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloeppe-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen](https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloeppe-2016_zur-aktualitaet-kosmetischer-genitaloperationen).

23 The most common intersex diagnoses are listed in Annex 2.

24 World Health Organization (2015), Sexual health, human rights and the law, Geneva, p. 26.

would be wrong due to the large number of different intersex variants and the fact that some intersex persons are identified as men or women, some as one and the other, and some as none.<sup>25</sup>

A diagnosis of an intersex variation can be very stigmatizing and have a great impact on the emotional, sexual and cognitive well-being of intersex individuals. All United Nations member states including Albania, Bosnia and Herzegovina, the former Yugoslav Republic of Macedonia and Serbia use the International Statistical Classification of Diseases and Related Health Problems (ICD) to diagnose intersex conditions. The ICD is the international “standard diagnostic tool for epidemiology, health management and clinical purposes”. The ICD is maintained by the World Health Organization (WHO),<sup>26</sup> the directing and coordinating authority for health within the United Nations system. The ICD is the basis for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. It is the diagnostic classification standard for all clinical and research purposes. The ICD defines the universe of diseases, disorders, injuries and other related health conditions.<sup>27</sup>

Intersex-related diagnoses are listed in the following chapters of the ICD:

1. Chapter IV. Endocrine, nutritional and metabolic diseases (E20-E35)
2. Chapter XIV. Diseases of the genitourinary system (N46-N48)
3. Chapter XVII. Congenital malformations, deformations and chromosomal abnormalities (Q50-Q56, Q90-Q99)

This report does not include diagnoses from Chapter V of the ICD, Mental and behavioural disorders.

*The diagnostic categories, which are codes in the ICD, play a crucial role in expressing scientific understanding, establishing medical approaches, forming clinical protocols, and defining surgical, hormonal and other treatments. Those categories defining intersex bodies incorporate differences between stereotypical female and male bodies on one hand that are considered to be healthy and bodies that vary from female and male standards on the other hand considered to be “disordered”, “malformed” and “abnormal”. The current classification therefore contributes to stigma, discrimination and violence against intersex people and the ICD endorses medical attempts as appropriate to “fix” or “normalize” intersex bodies through surgery and hormones, which has a direct role in determining how intersex bodies are treated in society at large.*

*Those who work on intersex issues know very well that the words that define us are key and, at the same time, that those words are just the beginning. Precisely because of that, our purpose is consistent with human rights standards. We also need concrete medical protocols derived from that terminology to be fully compatible with those standards, and we need human rights violations against intersex people to be properly investigated, documented, reported, punished*

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25 Council of Europe Commissioner for Human Rights (2015), p. 15.

26 The World Health Organization is a specialized agency of the United Nations that is concerned with international public health. It was established on 7 April 1948 and is headquartered in Geneva, Switzerland.

27 <http://www.who.int/classifications/icd/en/>.

*and redressed. We need the World Health Organization to not only change the way in which doctors around the world study, analyse, write and speak about us, but to change radically the way in which they treat us"*

– Mauro Cabral Grinspan of Justicia Intersex, and co-director of Global Action for Trans Equality<sup>28</sup>

Intersex people were silent for a very long time, but as society gets more aware of their existence, they are more encouraged to come out with personal stories. The opinions and experiences shared by intersex persons are crucial for understanding how medical interventions have determined their mental and physical health.

*So, my case was ambiguous genitalia and, because of that, I had my first surgery when I was 3 months old, and I believe by now I have had 21 surgeries. They do not tell parents the whole truth when they claim that it is very easy to repair with one or two surgical interventions, and before [the] child figures out what happened, it is too late ... What they do not say is that your whole life will depend on surgeries. Surgeries are unsuccessful and one leads to another. I am very unhappy how I was mishandled all my life. When they ask me now why I had all those surgeries ... my response is that I didn't have any operations which were not medically necessary, but they became medically necessary because of what the doctors did to me when I was baby.* <sup>29</sup>

– Tiger, intersex person with masculinizing surgery<sup>30</sup>

Today, some authors claim that surgical interventions related to gender differentiation mutilate and damage patients, and should not be performed unless the patient has given consent to perform the surgical intervention.<sup>31</sup> Medical interventions may be described as 'normalization' surgeries, 'corrections', treatment for 'malformations' or 'disorders of sex development', genital 'enhancement', 'genital reconstruction', and 'sex assignment'. They take place during infancy, childhood and adolescence, but also include prenatal interventions. Procedures may include labiaplasties, vaginoplasties, clitoral 'recession' and other forms of clitoral cutting or removal, hysterectomies, gonadectomies (sterilization), hypospadias 'repairs', phalloplasties and other forms of penile augmentation surgeries, other forms of urogenital surgeries, and prenatal and post-natal hormone treatment. Associated practices include dilation, repeated genital exams, post-surgical sensitivity testing and medical photography. Rationales include social and cultural norms, gender stereotypes, parental distress, fear of discrimination and stigmatization, gender identity confusion, stigma associated with having genitalia that does not match the sex of rearing, and marriage prospects.

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28 From an interview given to The Guardian "I am transgender and being myself is not a disorder". Available at: <https://www.theguardian.com/global-development-professionals-network/2017/feb/24/im-transgender-why-does-the-who-say-i-have-a-mental-disorder>.

29 Klöppel, Ulrike (2016) "Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter". Bulletin Texte 42. Available at: [https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloep-pel-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen](https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloep-pel-2016_zur-aktualitaet-kosmetischer-genitaloperationen).

30 Surgeries of the urethral outlet to the tip of the penis (hypospadias).

31 Zoran Krstić, Interseksualna stanja ili poremećaji u diferencijaciji pola, Medicinska istraživanja, Vol. 47/Sveska 3/2013, str. 53. Časopis. Available at: <http://www.mfub.bg.ac.rs/dotAsset/68142.pdf>, 3 October 2017.



Some medical specialists openly talk about how treatment on intersex babies is harmful and traumatizing, for example paediatric surgeon Mika Venhola<sup>32</sup> from Finland. Three former United States Surgeon Generals published a paper “Re-Thinking Genital Surgeries on Intersex Infants”<sup>33</sup> which calls for a moratorium on performing medically unnecessary surgeries on intersex children. Consequences of medical interventions may often include: sterility; insensitivity; chronic pain; chronic bleeding; chronic infections; massive internal and external scarring; chronic metabolic imbalances; depression; post-traumatic stress; internalized shame; long periods of hospitalization and their negative impact on education and employment; serial interventions to treat the outcome of past interventions; lifelong dependence on the medical system; and isolation. There is also the question of whether fully informed consent for intervention is given by parents.

Moreover, in an UN interagency statement by OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO published in 2014, it is stated that although such operations may be justified from the point of view of health benefits, including the reduction of cancer risk, this does not exclude the possibility that they are proposed on the basis of insufficient evidence, without taking into account alternative solutions that could preserve the ability of intersex people to procreate.<sup>34</sup> Estimates are that the wrong gender is determined in 8.5 to 40 percent of cases of people who are intersex.<sup>35</sup>

## 2.4 Medical protocols on intersex conditions in Europe

Medical protocols for treating intersex children are not common. In Sweden, their National Board of Health and Welfare (Socialstyrelsen) created specialized protocols for treating intersex children. The protocol prescribes that between the ages of 2 and 12, so-called genital surgeries should not be conducted. However, in most cases genital surgeries are performed before an intersex child’s sixth month of age.

Austria, Germany and Switzerland take the Recommendations of the Pediatric Endocrine Society<sup>36</sup> from the United States and the recommendations of the European Society for Paediatric Endocrinology<sup>37</sup> as the bases for treating intersex children. The two societies released a statement on the management of intersex disorders, also known as the Chicago Consensus, but it was disapproved by intersex organizations’ representatives due to the ongoing exclusive, medical approach to the intersex condition.<sup>38</sup>

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32 Mika Venhola is Deputy Chief MD, PhD, Assistant Chief, Dept of Pediatric Surgery Oulu University Hospital. His statement is available here: <https://www.youtube.com/watch?v=riNtxjntqZE>.

33 Elders, M. Joycelyn and others (2017). Re-Thinking Genital Surgeries on Intersex Infants, Palm Centre. Available at: <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>.

34 OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014), Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement. [http://www.who.int/reproductivehealth/publications/gender\\_rights/eliminating-forced-sterilization/en/](http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/).

35 Furtado, P.S. et al. (2012). Gender dysphoria associated with disorders of sex development, Nat. Rev. Urol. 9 October 2012; doi:10.1038/nrurol.2012.182.

36 <https://www.pedsendo.org/home/>.

37 <https://www.eurospe.org/>.

38 Consensus statement on management of intersex disorders, Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>.

The United Kingdom has special protocols on the management of certain forms of atypical gender.<sup>39</sup> The website of the United Kingdom's National Health Service (NHS) features comprehensive information concerning medical and legal questions regarding intersex persons.<sup>40</sup> Spain has protocols formed by the Spanish Pediatric Society in cooperation with the European Association of Urology.<sup>41</sup>

It should be noted that, despite recommendations made by the Committee on the Rights of the Child, Denmark will continue subjecting intersex children to compulsory surgery.<sup>42</sup>

## 2.5 The role of parents

When a child is born, the first question in any culture or society is the same: is it a boy or a girl? This innocent question indicates a clear line that separates socially recognized sexes, male and female. This further indicates the limitations of the understanding of gender and sex. Social and cultural pressure and norms are strong when an intersex child is born. The parents are forced to make quick decisions about the future of their child. They are guided by medical professionals and there is no one outside the medical system they can ask, share concerns with and consult on this issue. Sometimes they are advised not to share information about the intersex condition with their child. Information is too medicalized and not comprehensive enough for the general public.

With the majority of intersex people, there is nothing physically wrong, but medical professionals often want to 'fix' the intersex body. In a process to understand what is 'wrong' with their child, a whole range of emotions (e.g. fear, anger and shame) can arise. Parents question if they have done something wrong to cause this condition or if could they have done something to prevent it. It is very important for parents to know about the health implications and risks of operations and to take time to research and exchange experiences with other parents where this is feasible.

The complexity of intersex conditions can be very frightening for parents, which can bring them to ask for a second opinion and reassess the treatment processes. A common finding in some of the targeted countries was that in some cases, parents prefer treatment abroad. At this point, they break contact with their doctors and the national health care system.

As part of this research, there were a few attempts to reach and interview parents of intersex children, although after first contact was established, the parents always withdrew. It was assumed that parents are afraid to expose themselves or may be embarrassed or are being cautious.

Parents should get basic information on intersex babies, starting with parenting schools. When an intersex baby is born, parents should be supported not just by medical specialists, but also by psychologists and/or social workers. The public should get information about the existence of intersex people through media and social campaigns, awareness and solidarity days, and through visible intersex people. Having a functional support system (psychosocial, psychological, medical, social and legal) for parents and intersex children will ensure better understanding and acceptance.

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39 Statement: <https://dsdtrn.genetics.ucla.edu/consensus>.

40 More info: <http://www.nhs.uk/conditions/disorders-sex-development/Pages/Introduction.aspx>.

41 The fundamental rights situations of intersex people, FRA, EU Agency for fundamental rights, 04/2015, <http://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf>.

42 Available at: <http://stop.genitalmutilation.org/>.

## 3. HUMAN RIGHTS APPROACH TO INTERSEX

### 3.1 Human rights and intersex

From a human rights and legal perspective, several issues around intersex are controversial, predominantly in the area of discrimination, access to justice and reparations, access to information, and legal recognition.<sup>43</sup> Bearing in mind the particular human rights of intersex people, the most often violated are: the right to life, the prohibition of torture and inhuman or degrading treatment, the right to respect for private and family life, and the right to freedom of expression.<sup>44</sup> Few countries so far protect intersex people from discrimination, or provide access to reparations for harmful practices. Likewise, there are few court cases challenging discrimination and forced treatment, although multiple cases exist where courts have approved medical intervention without adequate evidence, or approved coercive interventions.

The invisibility of intersex persons in society is another serious problem. A combination of individual and/or familial isolation, social and institutional stigma, discrimination and violence and the traumatic experiences associated with medicalization and their chronic consequences make intersex people vulnerable to be structurally excluded from access to health care, education, adequate accommodation, and employment. The great fear of stigmatization and social exclusion for most intersex people is a reason to “stay in the closet” even when they become aware of their gender. Society still knows very little about the existence of intersex people because there is very little information available to the public on this topic. Only recently, the awareness of their suffering has started growing, but the wider human rights community still does not recognize it as an urgent problem.<sup>45</sup>

Even though there are currently no specific provisions for intersex persons, rights contained in international human rights treaties apply to all people and thus to intersex persons.<sup>46</sup> Intersex issues in the international human rights system, so far, have been addressed by: the United Nations Human Rights Office of the High Commissioner (OHCHR), UN Special Procedures, UN Treaty Bodies, WHO, and other UN agencies, including the United Nations Development Programme (UNDP), UNICEF and the United Nations Population Fund (UNFPA). A number of treaty bodies – namely the Committee against Torture (CAT), the Human Rights Committee (CCPR), the Committee on the Elimination of Discrimination against Women (CEDAW), the Committee on Economic, Social and Cultural Rights (CESCR) and the Committee on the Rights of the Child (CRC) – have interpreted the rights of the intersex people as a part of the international human rights framework. They issued recommendations to Member States to secure guarantees of bodily integrity, autonomy and self-determination to intersex children, and ensure that no one is subjected to unnecessary medical or surgical treatment

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43 Council of Europe Commissioner for Human Rights (2015), pp. 30–35.

44 SOC (Sarajevski otvoreni centar) (2016). Recommendations for improvement of legal and medical access for intersex persons in B&H., Available at: [http://soc.ba/site/wp-content/uploads/2017/01/HRP\\_tijelo\\_01\\_18.01.2017\\_web.pdf](http://soc.ba/site/wp-content/uploads/2017/01/HRP_tijelo_01_18.01.2017_web.pdf).

45 Council of Europe Commissioner for Human Rights (2015), p. 14.

46 Such an interpretation was also confirmed by the UN Committee on Economic, Social and Cultural Rights (CESCR) in accordance with the International Pact on Economic Social and Cultural Rights. The Committee considers that “other status” also includes “gender identity ... among the prohibited grounds of discrimination”. CESCR (2009), General Comment No. 20, (E/C.12/GC/20).

during infancy or childhood (CAT, CEDAW, CRC and CRPD); ensure that no one is subjected to undocumented medical or surgical treatment during infancy or childhood (CRPD); adopt legislation to prohibit the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age at which they can provide their free, prior and informed consent (CEDAW); ensure adequate access to justice, including by amending the statute of limitations (CEDAW); ensuring that intersex people's personal integrity and sexual and reproductive health rights are respected (CESCR); ensure full, free and informed consent to medical and surgical treatment of intersex people (CAT and CRC); investigate incidents of surgical and other medical treatment of intersex people, and adopt legal provisions to provide redress to the victims, including adequate reparation or compensation (CAT, CRC and CEDAW); educate and train medical and psychological professionals on the range of sexual and related biological and physical diversity and/or the human rights of intersex people (CAT, CEDAW and CRC); and consult intersex people and related civil society organizations.

Another great contribution to support advocacy for intersex people's rights was made by the United Nations (UN) Free & Equal campaign for Intersex Awareness: "Intersex babies are perfect just as they are"<sup>47</sup> launched in 2016 and with the UNDP video "Being intersex in Western Balkans"<sup>48</sup> launched in 2017.

In 2012, the European Commission published the thematic report "Discrimination against trans and intersex people on the grounds of sex, gender identity and gender expression", which examined the situation of discrimination against intersex people in Europe for the first time.<sup>49</sup> The Parliamentary Assembly of the Council of Europe (PACE) made history in 2013 by passing a resolution on the bodily integrity of intersex children.<sup>50</sup> PACE Resolution 1952 is the first resolution of its kind by any European institution. The resolution urges national authorities to "undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support." In 2013, the European Union (EU) adopted Guidelines to Promote and Protect the Enjoyment of All Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons.<sup>51</sup> The Guidelines are the first ever EU policy document that explicitly refers to intersex people. The EU Agency for Fundamental Rights (FRA) issued the focus paper "The fundamental rights situation of intersex people".<sup>52</sup> These documents confirm that sex 'normalizing' treatments are still taking place without consent all over Europe.

In 2015, the Council of Europe Commissioner for Human Rights published an issue paper: "Human rights and intersex people". This issue paper traces the steps which have already been taken towards understanding and responding to the situation of intersex people from an ethical and human rights perspective. It urges governments to end medically unnecessary "normalizing" treatment of intersex people when it takes place without their free and fully informed consent. It also suggests ways forward in terms of protection against discrimination, adequate recognition of sex on official

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47 <https://www.unfe.org/>

48 Video available at: <http://www.eurasia.undp.org/content/rbec/en/home/blog/2017/4/7/Being-intersex-is-hard-our-silence-makes-it-harder.html>

49 [http://ec.europa.eu/justice/discrimination/files/trans\\_and\\_intersex\\_people\\_web3\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/trans_and_intersex_people_web3_en.pdf)

50 <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174>

51 <https://eeas.europa.eu/sites/eeas/files/137584.pdf>

52 Available at: <http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

documents, and access to justice.<sup>53</sup> Similarly, in 2015 the European Union Agency for Fundamental Rights (FRA) issued a paper on the fundamental rights of intersex people, examining the legal situation of intersex people. It draws on evidence from the FRA's updated legal analysis on homophobia, transphobia and discrimination on the grounds of sexual orientation and gender identity, which now includes a section on intersex issues.<sup>54</sup>

At the Third International Intersex Forum in Malta, in 2013, the first declaration of intersex activists was made: "Intersex people must be supported to be the drivers of social, political and legislative changes that concern them. We want to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination."<sup>55</sup> At the 1<sup>st</sup> European Intersex Community Event in Vienna on 31 March 2017, a new European statement was issued: "We affirm that intersex people are real, and we exist in all regions and all countries around the world. Nothing about us without us!"<sup>56</sup>

Against this backdrop, the intersex movement is consolidating and strengthening, and intersex people are rising up and fighting for their rights, raising their voices to tackle systematic, societal and cultural abuses against intersex people.

## 3.2 Sex assignment and sex markers in personal documents

From the outset, it is important to distinguish between sex and gender. 'Sex' refers to the biological and physical aspect of a person, whether someone is born male or female. It is what is listed on a person's identification card, certificates, passport and other means of identity, certification and credentials. 'Gender' corresponds to the social aspect of a person, who that particular person considers themselves to be.<sup>57</sup>

Administrative laws, such as birth registration, and legal gender and administrative processes can put pressure on parents and medical professionals to choose and assign the sex of an intersex child. The sex assigned at birth becomes a legal and social fact and can represent the identity of a person. While the importance of assigned sex does not present an issue for most people, it becomes a serious problem for those who cannot fit into one of the two categories 'male' or 'female'.

Parents are required to register their child in birth registers soon after the birth, where they need to provide information about the baby's name and sex, which is usually either male or female. This requirement comes from the belief that sex is one of the main human identities and that every person must be registered under one of the two sex categories.

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53 Council of Europe Commissioner for Human Rights (2015), pp. 30–35.

54 EU Agency for Fundamental Rights (FRA) focus paper "The fundamental rights situation of intersex people".

55 <https://www.ilga-europe.org/what-we-do/our-advocacy-work/trans-and-intersex/intersex/events/3rd-international-intersex-forum>.

56 <https://oii-europe.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/>.

57 Cristina Castagnoli, 'Transgender Persons' Rights in the EU Members States' (Policy Department C: Citizens' Rights and Constitutional Affairs, June 2010).

The obligation to assign a baby's sex puts pressure on parents and medical professionals in relation to an intersex baby, particularly as parents are often not adequately or not at all informed about their intersex baby's status and the process of treatment.

In Europe, there are different examples about provisions related to birth registration. In Belgium, sex is usually registered during the first week and a maximum period of three months from the birth of an intersex child, while in France a maximum period of three years is allowed in exceptional cases for intersex births, even though, in practice, it is reported that parents tend to "have their child assigned to one or the other sex/gender as quickly as possible".<sup>58</sup> Finland and Portugal seem to be the only two countries in Europe that do not impose a time limit on the registration of sex when it cannot clearly be defined.<sup>59</sup>

A majority of societies do not usually recognize a person who does not belong to one of the two sexes. In almost all European countries, the sex/gender marker in personal documents is limited to two categories "F" (female) or "M" (male). The sole exception is Germany, as it omits any reference to sex/gender on its identity cards. In 2013, Germany added a third category "Other" as a possibility to be marked in personal documents.

When it comes to passports, the International Civil Aviation Organization (ICAO) has allowed for sex to be registered as "F", "M" or "X" (i.e. "unspecified") since 1945. However, following EU harmonized rules regarding the passports' information page, the sex category included on the passports of all 28 EU member states has remained limited to "F" or "M" alone.<sup>60</sup> This contrasts at the global level with countries such as Australia, Malaysia, Nepal, New Zealand and South Africa that already allow "X" as another sex category on passports, while the Indian passport application form allows for three gender categories: "Female", "Male" and "Others". Of note, the Australian Passport Office has a policy for sex and gender diverse passport applicants that "provides flexibility as it makes it clear that birth or citizenship certificates do not need to be amended for sex and gender diverse applicants to be issued a passport in their preferred gender. A letter from a medical practitioner certifying that ... if they are intersex and do not identify with the sex assigned to them at birth is acceptable."<sup>61</sup>

Although the option of a neutral or a third sexual marker has already been accepted in some European countries,<sup>62</sup> from a legal angle, in the case of the Western Balkans countries<sup>63</sup> it might be less complicated and easier to implement the recommendations of some associations representing the rights of intersex people: it is not necessary or useful to introduce a third sex into sex labels, but is

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58 Belgian Civil Code, Articles 55, 56 and 57; Ministère de la Justice (French Ministry of Justice) (2011), *Circulaire Relative aux Règles Particulières à Divers Actes de l'État Civil Relatifs à la Naissance et à la Filiation* (Instruction about particular rules for various acts of civil status concerning birth and filiation); FRANET thematic legal studies on Finland and Portugal serving as background information for the FRA Report on Homophobia, Transphobia, and Discrimination on Grounds of Sexual Orientation, Gender Identity and Intersexuality – 2015 Update – Comparative Legal Analysis (information on Portugal provided by Instituto dos Registos e Notariado (Institute of Registration and Notary Affairs)).

59 Ibid.

60 ICAO (2006), *Machine Readable Travel Documents, Sixth Edition, Part 1, Section IV*, p. 11.

61 See more at: [www.passports.gov.au/web/sexgenderapplicants.aspx](http://www.passports.gov.au/web/sexgenderapplicants.aspx); Australian Government (2013), *Guidelines on the recognition of sex and gender*.

62 For example Germany.

63 SOC (Sarajevski otvoreni centar) (2016).

better to add the most appropriate sex for a child after appropriate medical tests and analyses, with timely and extensive support to parents and the child.<sup>64</sup>

### 3.3 Intersex in anti-discrimination legislation

Discrimination is treating another person less favourably than someone else on the basis of a personal characteristic such as gender, race and sexual orientation. Intersex people need to be protected against discrimination. Laws that include specific provisions to do so can help intersex people to be more visible in society and to protect them from harm and to encourage them to advocate against discrimination and violence.

When talking about discrimination, the notion of **sex characteristics** is considered the most adequate name for the basis on which intersex persons can be discriminated against. This was the conclusion adopted by activists and organizations that advocate for the rights of intersex people at the 2014 European Intersex Meeting.<sup>65</sup> Still, most European societies recognize people as either male or female. This does not account for all variations in sex characteristics. As a result, intersex people experience fundamental rights violations, ranging from discrimination to medical interventions without their consent.

Sex characteristics are a new ground on which someone could be subject to discriminatory behaviour and it is a rare to find it in existing anti-discrimination provisions around the globe. It is important to note that sex characteristics are different than sexual orientation and gender identity. If the grounds of “sex characteristics” is not mentioned explicitly, the rights of intersex people (with variations of sex characteristics) should be by default protected on the ground of “sex” or “other forms of discrimination” that is usually contained in anti-discrimination provisions. Thus, intersex discrimination will be better covered by sex discrimination rather than discrimination on the basis of sexual orientation and/or gender identity, as it concerns physical (sex) characteristics.

The first country in the world which includes intersex in its equality legislation is South Africa. With the Judicial Matters Amendment Act 2005,<sup>66</sup> the Promotion of Equality and Prevention of Unfair Discrimination Act 2000 was modified. It states that “Intersex” means “a congenital sexual differentiation which is atypical, to whatever degree” and that “sex includes intersex”. This law was truly ground-breaking, as apart from it being the first of such laws, it was formulated to cover all intersex people within its definition and leave no one out.

in Australia, intersex people were recognized fully and authentically in anti-discrimination legislation with the historic passing of the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013. The Act includes: new attributes protecting people on the grounds of intersex status, and gender identity and sexual orientation; protection for all intersex people, independent of characteristics such as sex, sexual orientation or gender identities; recognition that intersex has a biological basis; the intention of no substantive religious exemptions applicable to in

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64 Ibid.

65 <https://oii.europa.org/statement-of-the-european-intersex-meeting-in-riga-2014/>

66 Available at: <http://www.justice.gov.za/legislation/acts/2005-022.pdf>

tersex; the intention that sport exemptions will not be applied as a blanket rule, but include case-by-case assessment; and the removal of religious exemptions on gender identity and sexual orientation grounds from aged care.<sup>67</sup>

In Europe, Malta recently became the first (and only) country in Europe to explicitly provide protection against discrimination on the ground of “sex characteristics”. In 2015, Malta passed a Gender Identity, Gender Expression and Sex Characteristics Act,<sup>68</sup> which states that sex characteristics “refers to the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and, or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and, or structure.” The new policy recognizes the right to physical autonomy, bodily integrity and gender identity for all people.

The policy grants protections against discrimination across public services, requiring public services to eliminate unlawful discrimination and harassment on the ground of sex characteristics. It requires public services to promote equality of opportunity for all, irrespective of these characteristics. It regulates the process to legally change gender on documents such as passports, for both minors and adults. The bill also makes it illegal to perform any unnecessary medical treatment on the sex characteristics of a person without their consent, which can be deferred until the person to be treated can provide informed consent, and allows the parents of a “minor whose gender has not been declared at birth” to delay the gender marker on their child’s birth certificate. More specifically, the entry of a sex marker on the birth certification can be postponed until the gender identity of the child is determined. The bill also allows for changes to the sex/gender marker to align it with one’s gender identity at any point in one’s life following a simple administrative procedure.

Malta has also committed to recognize gender markers other than male or female, as well as the absence of such markers, from a competent foreign court, or responsible authority acting in accordance with the law of that country. The Act unequivocally prescribes that medical interventions stimulated by social factors, without a minor’s consent, are strictly forbidden (unless in exceptional circumstances). Agreement between an interdisciplinary team, appointed by the Equality Minister, and those with parental authority, or the child’s tutor, is also required.

Many other European countries still legally require births to be certified and registered as either male or female. In at least 21 EU Member States, sex ‘normalizing’ surgery is still carried out on intersex children. In 8 EU Member States, a legal representative can consent to sex ‘normalizing’ medical interventions independently of the child’s ability to decide.<sup>69</sup>

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67 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013. Available at: <https://www.legislation.gov.au/Details/C2013A00098>.

68 Malta (2015), Act for the recognition and registration of the gender of a person and to regulate the effects of such a change, as well as the recognition and protection of the sex characteristics of a person, 2 April 2015. Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>.

69 The fundamental rights situation of intersex people, European Union Agency for Fundamental Rights (FRA 04/2015). See also: Council of Europe Commissioner for Human Rights (2015).



### 3.4 Rights of the child

Most of the medical interventions related to intersex conditions are carried out immediately after birth or during earliest childhood, in order to define sexual organs in accordance with one of the two recognized sexes. As a consequence of such an approach, intersex children are subjected to sometimes unnecessary medical interventions that are accessed without analysing each individual patient and without considering alternative ways of accessing treatment. The consequences of such 'treatment' on children are numerous, both mental and physical.

Many human rights violations against intersex people are committed against babies, infants and children; most of them take place in medical settings. Bearing in mind that most of the violations of the basic human rights of intersex persons occurs at earliest childhood or adolescence, special attention must be given to respect of the rights of intersex children. After an intersex baby is born, recognition of its human rights should be immediate and effective. The rights of the child and the rights of the patient are many times at stake, and these are very useful normative frameworks to address intersex issues.

Children's human rights are most comprehensively regulated by the Convention on the Rights of the Child<sup>70</sup> that considers that all decisions affecting a child's life should be in the best interest of the child. The UN Committee on the Protection of the Rights of the Child in February 2015 expressed concern about unnecessary medical and surgical interventions on intersex children, which are being conducted without their consent, and which often produce irreversible consequences on their further physical and psychological development. Committee urged all Member States to ensure that intersex children do not undergo medical or surgical treatment without their own or the consent of their legal representatives; provide them the right to respect their body integrity, personal autonomy and the right to self-determination; and provide their families with adequate support and assistance<sup>71</sup>

All state institutions should protect the rights of children. However, there are some specialized state bodies with particular tasks to take care of and protect children and advocate for their human rights such as children's ombudspersons, child protection authorities and patients' ombudspersons. These institutions should be on the front line of recognition and protection of the rights of intersex children.

### 3.5 Genital mutilation

The intersex community calls the operations to 'normalize' sex "genital mutilation".<sup>72</sup> There is strong opposition to operations that are performed on children who are not sufficiently mature to understand the significance of such medical interventions and give their consent.<sup>73</sup> Operations carried

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70 <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>.

71 Council of Europe Commissioner for Human Rights (2015), pp. 30 and more.

72 Anne Tamar-Mattis, J.D. (2017) Medical treatment of people with intersex conditions as torture and cruel, inhuman, or degrading treatment or punishment, Advocates for Informed Choice, USA. Available at: <https://interact-advocates.org/wp-content/uploads/2017/03/interACT-Report-for-UNSRT-on-Intersex.pdf>.

73 van Lisdonk, J. (2014). Living with intersex /DSD, The Netherlands Institute for Social Research, 2014, pp. 20–25.

out on intersex children constitute a violation of the right to autonomy and physical integrity, and are often motivated by the inability of their parents or guardians to adequately deal with the atypical nature of their own child.<sup>74</sup>

Important agencies and organizations<sup>75</sup> have recognized the harmful treatment of intersex babies, children and adults. It is noted that these interventions can lead to a serious breach of human rights that falls into the scope of torture and ill treatment. Many human rights violations against intersex people are committed in medical settings and justified by psychological and medical rationales. However, regardless of whether they are performed in medical settings, they are harmful practices.

The UN Special Rapporteur on torture pointed out in 2013 that intersex children are often subject to irreversible sex assignment, involuntary sterilization and/or genital-normalizing surgery, performed without their informed consent or that of their parents “in an attempt to fix their sex” as they fail to conform to socially constructed gender expectations. This leaves some intersex children with permanent, irreversible infertility and causes severe mental suffering. He added that discrimination on the grounds of sexual orientation or gender identity may often contribute to the process of the dehumanization of the victim, which is often a necessary condition for torture and ill treatment to take place.<sup>76</sup>

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74 World Health Organization (2015), p. 26.

75 For example: United Nations and Amnesty International.

76 UNHRC (2013), Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez. Available at: [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf?utm\\_source=AIC+mailing+list&utm\\_campaign=0940e5a7fc-&utm\\_medium=email](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf?utm_source=AIC+mailing+list&utm_campaign=0940e5a7fc-&utm_medium=email).

# V. COUNTRY BRIEFS

## 1. ALBANIA

Albania has been a potential candidate to join the European Union since 2003 and was granted candidate status in 2014. In its annual report for 2015, the European Commission noted that while Albanian human rights laws are broadly in line with European standards, the implementation of existing laws is insufficient.<sup>77</sup> There are positive developments, such as the adoption of a National Action Plan for work on LGBTI issues in Albania; however, the overall public awareness of the rights of LGBTI people remains low and legal provisions that can prevent discrimination against intersex people are not in place.

### 1.1 Health care and intersex

The Ministry of Health oversees the centralized health care system and at the same time manages health care legislation and budgets and monitors health care needs and reforms. All citizens are entitled by law to equal access to health care, which is funded by the state. Private practice is limited to a small number of facilities. The health care system is divided into three levels of care: primary, secondary and tertiary care.

In Albania, when an intersex baby is born in a maternity hospital, it can be officially recognized only as a hermaphrodite. In practice, the intersex condition might be hidden for years. The registration of children in Albania is regulated through Law No. 10129, dated 11.05.2009, "On Civil Status", as amended. This law asserts that the parents bear primary responsibility for the registration of their children, and in case this procedure fails, it falls to the state institutions to carry out this procedure.<sup>78</sup> The law does not provide any time limits for registration of the name and sex of a newborn, but encourages early registration. Mothers who register their newborns within 60 days from the birth (births inside the territory of the Republic of Albania) or within 90 days (births from Albanian citizens outside Albania) receive a monetary reward.<sup>79</sup> If parents register their baby within a time period of 30 days from birth, it is legislated that they are offered a bonus of up to US\$40 by the state.

There are several risks that occur for registering sex from the moment of birth. When a baby is born, the two recognized options for registering the sex – traditionally and mostly recognized by the medical staff – are "male" and "female". So, based on the will and desire of the parents, the registration of the sex of an intersex baby is still based on the two recognized options. In some specific cases, the term "hermaphrodite" is also used, but this denies the further registration of the birth in the civil status office, since there are only the two recognized options for sex in the electronic register of

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77 [https://ec.europa.eu/neighbourhood-enlargement/sites/near/files/pdf/key\\_documents/2015/20151110\\_report\\_albania.pdf](https://ec.europa.eu/neighbourhood-enlargement/sites/near/files/pdf/key_documents/2015/20151110_report_albania.pdf).

78 TLAS (2015). Ending Childhood Statelessness, available at: <http://www.tlas.org.al/sites/default/files/ENS%20-%20TLAS.pdf>, 2015.

79 Article 41 of Law no. 10129, date 11.5.2009 "On Civil Status" amended.

births, without the possibility of a third or “undefined or unspecified” option for the “sex”. In practice, having the sex of a baby registered as hermaphrodite means that the birth will not be registered at all.

After the birth, parents and the baby are referred to the primary health care paediatric department called “Konsultore”. In this department, parents are consulted on their baby’s condition and referred to the University Hospital Centre “Mother Teresa” in Tirana for further testing. At the University hospital, medical specialists (e.g. endocrinologist, geneticist and paediatric surgeon) verbally agree on which tests and analysis to conduct for establishing an intersex diagnosis. When all results are collected, the parents are informed about the baby’s diagnosis and the proposed treatment.<sup>80</sup>

The Ministry of Health receives information and statistics from the maternity hospitals on the number of intersex babies born each year. According to available information, the numbers vary every year; for example, nine intersex babies were born in 2013, two in 2014 and five in 2015.<sup>81</sup> A few years ago, the Obstetric-Gynecologic University Hospital reported one case of birth of an intersex child which was turned into a media story.

*The journalists asked questions about this “abnormal” child. I got very irritated and I remember it was very difficult to explain to them that the baby was not abnormal; that the child was healthy and everything would be resolved in the future*

- Gynaecologist in Tirana, Albania<sup>82</sup>

In Albania, a medical multidisciplinary team working with intersex babies and children does not exist. Few specialists participate in the process of medical treatment and verbally agree on which tests and analysis to conduct. Written protocols for establishing intersex diagnosis do not exist.<sup>83</sup>

In an interview with a paediatric surgeon,<sup>84</sup> he explained that he performed numerous surgeries on hermaphrodite patients, but he does not consider those as an intervention on intersex children, as he was just “fixing the body”. He also commented that when parents bring their intersex baby or child to him at an early age, he can help them by performing the surgery. But in some cases, the parents bring their intersex child to the hospital at an advanced age, when he cannot treat them successfully. In his opinion, early consultation with a doctor is considered important for two reasons: to identify the sex of the child as soon as possible and thus lower the possibility of confusion during the gender development of the child and to avoid any health complications. The doctor also stated that in the last few years there are just a few surgeries performed on intersex babies. In Albania, hypospadias (a congenital disorder of the urethra where the urinary opening is not at the usual location on the head of the penis) is not considered as an intersex condition. There are around 200 babies per year born with hypospadias; in the doctor’s opinion, this number was bigger in the past and has reduced because of the approximately one-third of Albanians that have emigrated from the country. The hospital keeps a registry with information and number of babies born with hypospadias.

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80 Voko, K. (2013). Access to health services and quality of care for LGBT persons in Albania, p. 22.

81 This information is provided by a lawyer from the Children’s Human Rights Centre of Albania (CRCA).

82 Voko, K. (2013), p. 24.

83 Interview with paediatric surgeon D.A. from University Hospital “Mother Teresa” in Tirana.

84 Ibid.

Maternity hospitals in Albania send information to the Ministry of Health with the number of babies born per year (male, female and hermaphrodite). Information that the baby is born intersex (hermaphrodite) is included in the hospital discharge paper.<sup>85</sup>

## 1.2 Human rights protection

In Albania, intersex persons are not visible in society and existing legislation and its implementation may not be sufficient to protect them. Intersex or “sex characteristics” are not explicitly mentioned in laws.<sup>86</sup> On a positive note, an Action Plan 2016–2020 to help fight discrimination against LGBTI communities was adopted in 2016 by the government. The plan (which according to Albanian law is now legislation to be enforced) will focus on three main interventions:

1. Improvement of legislation and raising awareness on LGBTI issues
2. Elimination of all forms of discrimination towards LGBTI people
3. Improvement of access of LGBTI people to employment services, education, health care, housing and sports by guaranteeing them equal opportunities.<sup>87</sup>

The human rights organization Tirana Legal Aid Society (TLAS)<sup>88</sup> is in the process of engaging the legal system to legalize the status of two intersex children. One of the cases was referred by a civil status office with which TLAS collaborates:

*The child (A.B.) is three years old, born with variations in sex characteristics. Immediately after birth, the parents registered the baby as a “male”. The medical staff that assisted the birth of the child reported the sex as “male” based on their understanding. Subsequently, the child was registered in the civil status office as “male”. After some months, the parents began medical consultation and they were advised by the doctor to undergo surgery because the child was diagnosed with congenital adrenal hyperplasia (CAH). The surgery was performed when the child was two years old. After the intervention, the child was defined as female and prescribed to continuously take medication. The case will be decided in court, with a request to change the sex marker in the birth certificate from “male” to “female”.*

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85 This information is from an in-depth interview with Rubena Moisiu, director of Maternity in University Hospital “Koco Gliozheni” in Tirana.

86 As part of the research, some laws were reviewed (Law Nr. 10, 107 “For Healthcare in the Republic of Albania,” Law Nr. 10, 138, “For Public Health”; Law Nr. 9, 952 “For the Prevention and Control of HIV/AIDS and Law Nr. 10, 221 “For the Protection from Discrimination. Law on Civil Status”), but no reference was found in relation to intersex individuals.

87 More info in ILGA Enlargement Review Albania 2016. Available at: [https://www.ilgaeurope.org/sites/default/files/enlargement\\_review\\_albania\\_2016.pdf](https://www.ilgaeurope.org/sites/default/files/enlargement_review_albania_2016.pdf).

88 Tirana Legal Aid Society (TLAS) is a local organization based in Tirana with a mission to fulfill the social and legal needs of people in need; educate and increase awareness of the Albanian society on the rule of law and human rights; and promote improvements in Albanian legislation, the progress of the community and strengthening democracy in Albania.

*The child (A.J.) is nine years old and born as intersex. The child was unregistered and stateless from the time he was born. The child's sex was filed as "hermaphrodite" in the medical records. The baby was released from hospital immediately after birth. The parents kept his variations of sex characteristics as a secret and they did not register the child. They raised him as a boy and gave him a male name. Since the child was unregistered, he could not attend school and could not access health care. Albanian law does not provide any possibility to be registered other than as "male" or "female". The parents were advised to register the child based on a medical examination. The medical professionals performed several tests, one of them was karyotype,<sup>89</sup> after which a doctor concluded that the child is female. Based on the medical report, the child was registered as a "female" (the child was not involved in the decision-making; he was not asked about his/her identity). The parents want to change the sex marker in the birth certificate from "female" to "male", because the child has been raised as a boy and behaves like a boy. Counseling is being provided to the child and TLAS is litigating for the case.<sup>90</sup>*

### 1.3 Communities and organizations

The intersex community is not organized in Albania. Some civil society organizations are raising awareness on intersex issues. The Streha<sup>91</sup> centre started in December 2014, established by two LGBT organizations, Alliance against Discrimination LGBT and Pro LGBT. The Streha centre is a temporary transitional service for young LGBTI people, 18 to 25 years old, that have been evicted from their homes or are under threats of violence and need shelter. TLAS, described above, gives legal support to parents of intersex children.

### 1.4 Conclusions and suggested priorities

In terms of health care, there is much to be improved in Albania for intersex people, in particular to preserve bodily integrity and freedom from forced and coercive medical practices. When an intersex baby is born, the final diagnosis (codes from ICD are used) is established by a medical specialist at the university hospital in Tirana. The medical team is not multidisciplinary and they do not follow internal written protocols.

In Albania, there are no provisions that specifically address the human rights of intersex people. In anti-discrimination law, sex characteristics are not listed possible grounds of discrimination. The only current legal cases concerning intersex children are for changing the sex marker in documentation. However, the cases are strategically being used to aim at legal recognition of intersex people and to push for changes in legislation. State institutions and stakeholders still do not recognize intersex persons at any level in the system and there is a total lack of services for intersex people.

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89 <http://www.webmd.com/baby/karyotype-test#1>.

90 Information is from an interview with Anisa Metalla, TLAS, Albania.

91 <http://strehalgbt.al/sq/>.

Advocacy for the rights of intersex people by CSOs is at an early stage. There is much work to be done. Only some LGBTI CSOs collaborate with intersex children and their parents but need more education on intersex issues.

The following are recommendations to improve health care and the human rights situation of intersex people:

- 1) Form multidisciplinary medical teams (including currently active specialists) which will be able to establish intersex diagnoses, monitor the condition of intersex infants and children and help parents in the process.
- 2) Develop and adopt written protocols for treatment and for follow-up processes and medical care of intersex children.
- 3) Educate medical staff in relevant hospitals on intersex issues.
- 4) Collect and analyse data and report annually on intersex-related diagnoses and practices in all maternity and paediatric hospitals.
- 5) Establish adequate and sustainable psychological and social counselling and therapy for intersex people and their parents.
- 6) Include updated and appropriate information on intersex issues in curricula for medical schools and universities.
- 7) Include more sensitive vocabulary in curricula for continuous medical education for nurses and midwives to be able to help parents to understand a baby's intersex condition.
- 8) Recognize sex characteristics as grounds of discrimination in anti-discrimination law and other provisions that tackle discrimination.
- 9) Inform and train state authorities and state bodies responsible for the protection of human rights to be able to provide adequate protection of intersex persons.
- 10) Establish support systems (support groups, help lines and/or social media networks) for intersex people and their parents.
- 11) Increase knowledge and capacity of CSOs and support them to advocate for intersex peoples' rights.
- 12) Collect qualitative and quantitative data on the life situations of intersex individuals and their families.
- 13) Train the media on how to report on intersex issues and how to raise awareness in the general public on this topic.

## 2. BOSNIA AND HERZEGOVINA

Bosnia and Herzegovina (B&H) has been recognized as an independent state since 1992, becoming a UN member state in the same year. After adoption of the Dayton Peace Agreement in 1995, a state federal structure was been created. Since 2003, Bosnia and Herzegovina has been recognized by the EU as a potential candidate country to join the European Union. Bosnia and Herzegovina consists of two entities (Federation of Bosnia and Herzegovina and Republika Srpska) and one district (Brčko District). The Federation of Bosnia and Herzegovina (FBiH) is federal unit of state and is divided into 10 cantons. The FBiH Gender Centre has been coordinating work on LGBTI issues in FBiH. The Republika Srpska (RS) is a unitary federal unit, consisting of 63 municipalities and towns. The RS Gender Centre has been coordinating work on LGBTI issues in that part of the state. The Brčko District (BD) has a unique political structure. BD carries responsibilities in its territory for all areas important for the human rights situation of LGBTI people (e.g. criminal legislation, family law and health protection laws).

### 2.1 Health care and intersex

The health care system in Bosnia and Herzegovina is complex. It is divided into 13 subsystems. The Ministry of Civil Affairs of Bosnia and Herzegovina is a central-level public administration body with responsibilities related to health. Also of national importance is the Ministry of Human Rights and Refugees and the Agency for Gender Equality within the Ministry. The Federation of Bosnia and Herzegovina has a decentralized health care system and most jurisdictions (functions and responsibilities) are provided by the cantons. In Republika Srpska, the health care system is centralized and under supervision of the Ministry of Health and Social Welfare, Health Protection Agency and Health Insurance Fund. In the Brčko District, four medical institutions are operating: one hospital and three medical centres.

In Bosnia and Herzegovina, there are 27 gynaecological-obstetric hospitals, in which tests are inadequate for determining intersex diagnoses, and no operations are performed on intersex children. There is no multidisciplinary medical team and there are no internal medical protocols related to diagnostics and treatment of intersex persons. Intersex babies and children are not diagnosed in hospitals. They are referred to larger medical centres for further management.

According to information provided in an interview,<sup>92</sup> there were no cases of intersex babies at the University Clinical Centre in Sarajevo in recent years and there is no information on the number of previous cases. In the past, at the University Clinical Centre, after determining an intersex diagnosis, the parents and baby were referred for further treatment to the Institute for Mother and Child or the University Children's Hospital in Belgrade, Serbia. After the referral, the doctors did not receive further information about the baby's progress. Doctors in Bosnia and Herzegovina have inadequate information, knowledge and medical staff to work with intersex babies and their parents, and do not have an appropriate multidisciplinary medical team. In a few hospitals, intersex babies were born, but no surgery was performed and all intersex babies and children were referred to larger medical centres.<sup>93</sup>

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92 Statement of paediatric surgeon A.J. from University Clinical Centre of Sarajevo.

93 SOC (Sarajevski otvoreni centar) (2016).



## 2.2 Human rights protection

At the state level, there is no institution or organization that concerns itself with the human rights of LGBTI people (e.g. criminal legislation, family law and health protection laws). Instead, each state unit is responsible for protecting the rights of LGBTI people. Bosnia and Herzegovina has an advanced legal framework on anti-discrimination. In 2016 the House of People of the BiH's Parliamentary Assembly and by both chambers of the bicameral assembly adopted amendments to the anti-discrimination law to include sex characteristics. This is the first country in the South-East Europe region that has recognized sex characteristics as grounds for discrimination in its anti-discrimination legislation and thus provides protection for intersex people. However, the implementation of this provision is still to be proven in practice.

## 2.3 Communities and organizations

Intersex people are not visible and are hard to reach in Bosnia and Herzegovina. Civil society organizations are not in contact with intersex people. Only one CSO, Sarajevo Open Centre (SOC),<sup>94</sup> conducted research on the treatment of intersex babies and children, as found in their Recommendations for improving legal and medical access for intersex persons in B&H.<sup>95</sup> They contacted 27 medical institutions in Bosnia and Herzegovina with a questionnaire on the following issues: the number of newborn intersex babies, the existence of relevant internal protocols and procedures, type of surgeries, and decision-making procedures (by parents and doctors). Seven hospitals replied and four of them reported cases of intersex newborns. The gynaecological-obstetric hospital in Tuzla reported six intersex newborns in the last four years. Although this data represent just a fragment of the overall situation, it clearly shows that intersex babies exist and the phenomenon is not that rare. SOC also translated the Council of Europe publication "Human rights and intersex people".<sup>96</sup> The CSO Foundation CURE<sup>97</sup> suggested changes to the terminology used in gynaecology textbooks for medical high schools, using "intersex person" instead of "hermaphrodite".

## 2.4 Conclusions and suggested priorities

In terms of health care, there is a lack of information and protocols in Bosnia and Herzegovina relating to intersex children. There were cases of intersex children born in hospitals, but no surgical operations were performed.<sup>98</sup> There is no multidisciplinary medical team and they do not have internal and follow-up protocols for the treatment of intersex children.

In anti-discrimination law in Bosnia and Herzegovina, sex characteristics are included as grounds for discrimination; however, the implementation of this law is still to be proven. There are CSOs open to work on intersex issues, but have limitations in experience and knowledge.

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94 <http://soc.ba/en/>.

95 SOC (Sarajevski otvoreni centar) (2016).

96 Available at: <http://soc.ba/en/ljudska-prava-i-interspolne-osobe/>.

97 <http://www.fondacijacure.org/>.

98 SOC (Sarajevski otvoreni centar) (2016).

The following are recommendations to improve the human rights situation and health care for intersex people:

- 1) Form multidisciplinary medical teams (including currently active specialists) which will be able to establish intersex diagnoses, monitor the condition of intersex infants and children and help parents in the process.
- 2) Develop and adopt written protocols for treatment and for follow-up processes and medical care of intersex children.
- 3) Educate medical staff in relevant hospitals on intersex issues.
- 4) Collect and analyse data and report annually on intersex-related diagnoses and practices in all maternity and paediatric hospitals.
- 5) Establish adequate and sustainable psychological and social counselling and therapy for intersex people and their parents.
- 6) Include updated and appropriate information on intersex issues in curricula for medical schools and universities.
- 7) Include more sensitive vocabulary in curricula for continuous medical education for nurses and midwives to be able to help parents to understand a baby's intersex condition.
- 8) Recognize sex characteristics as grounds of discrimination in anti-discrimination law and other provisions that tackle discrimination.
- 9) Inform state authorities and state bodies responsible for the protection of human rights (including the B&H Ombudsman and Ombudsman for children from Republika Srpska) to be able to provide adequate protection of intersex persons.
- 10) Establish support systems (support groups, help lines and/or social media networks) for intersex people and their parents.
- 11) Increase knowledge and capacity of CSOs and support them to advocate for intersex peoples' rights.
- 12) Collect qualitative and quantitative data on the life situations of intersex individuals and their families.
- 13) Train the media on how to report on intersex issues and how to raise awareness in the general public on this topic.

## 3. THE FORMER YUGOSLAV REPUBLIC OF MACEDONIA

The former Yugoslav Republic of Macedonia formally applied to join the EU in 2004. In its annual report on progress made towards EU accession, published in November 2016, the European Commission pointed out that the LGBTI community continues to suffer hate speech in the media.<sup>99</sup> The Commission expressed disappointment at the government's failure to add the grounds of sexual orientation and gender identity to existing anti-discrimination legislation. Considerable efforts need to be made to promote acceptance and diversity, through public campaigns and trainings for law enforcement officials.

### 3.1 Health care and intersex

The former Yugoslav Republic of Macedonia has an improving standard of compulsory state-funded health care, which is available free of charge to all citizens (those who pay for state-owned medical insurance) and registered long-term residents. Private health care is also available in the country based on private insurance schemes. The Ministry of Health oversees the health service and the Health Insurance Fund (HIF) collects the contributions, allocates funds, and supervises and contracts health care providers. The health care system is divided into three levels of care: primary, secondary and tertiary care.

In the former Yugoslav Republic of Macedonia, medical specialists in local hospitals are able to diagnose an intersex condition, but they do not perform any medical interventions. They direct parents with an intersex baby or child to the major medical centres where they are treated or, in some cases, further referred to the Institute for Mother and Child in Belgrade, Serbia.<sup>100</sup> Referrals to the hospital in Serbia are not funded by the state (health insurance), they are private arrangements and families make their own efforts to get this treatment.

The existing medical institutions do not share information about the number of intersex babies and children. There is no multidisciplinary medical team and no internal medical protocols on intersex-related treatment.

In an interview,<sup>101</sup> a doctor shared information about three cases of intersex teenagers (all of them identified as girls) in her medical practice over a period of more than a decade. All girls had the same symptom (missing periods) when they presented themselves to the gynaecologist. They were referred for further tests and examination by endocrinologists after being diagnosed as intersex. Generally, there is a lack of information about the medical approach to intersex issues in the country.

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99 [https://ec.europa.eu/neighbourhood-enlargement/sites/near/files/pdf/key\\_documents/2016/20161109\\_report\\_the\\_former\\_yugoslav\\_republic\\_of\\_macedonia.pdf](https://ec.europa.eu/neighbourhood-enlargement/sites/near/files/pdf/key_documents/2016/20161109_report_the_former_yugoslav_republic_of_macedonia.pdf)

100 Interview with gynaecologist I.K. from University Clinical centre "Mother Teresa" in Skopje.

101 Interview with gynaecologist I.K. from University Clinical centre "Mother Teresa" in Skopje.

## 3.2 Human rights protection

State institutions and legislation do not recognize intersex people. In the former Yugoslav Republic of Macedonia, anti-discrimination law<sup>102</sup> identifies gender as grounds for discrimination but not sexual orientation, gender identity or sex characteristics. Thus, LGBTI people have not been recognized in the law and there is no direct protection for intersex persons.

## 3.3 Communities and organizations

Intersex people are not visible and they are not recognized in society. Several LGBT CSOs are not actively working on intersex issues, but are showing interest and willingness to learn about the subject. None of the existing human rights organizations in the former Yugoslav Republic of Macedonia is working on intersex cases.

## 3.4 Conclusions and suggested priorities

In terms of health care, there is a lack of knowledge in the former Yugoslav Republic of Macedonia relating to the treatment of intersex babies, but there is information about the treatment of intersex teenagers. Medical specialists are not organized in a multidisciplinary team. Written internal and follow-up protocols for the treatment of intersex children do not exist.

In terms of human rights, legislation and administrative procedures regarding intersex persons are not in place. The prohibition of discrimination in legislation is not sufficient to protect intersex people; the protection of intersex people should be more specific, based on their bodies' autonomy and integrity. LGBT CSOs are showing an interest to learn about intersex issues.

The following are recommendations to improve the human rights situation and health care for intersex people:

- 1) Form multidisciplinary medical teams (including currently active specialists) which will be able to establish intersex diagnoses, monitor the condition of intersex infants and children and help parents in the process.
- 2) Develop and adopt written protocols for treatment and for follow-up processes and medical care of intersex children.
- 3) Educate medical staff in relevant hospitals on intersex issues.
- 4) Collect and analyse data and report annually on intersex-related diagnoses and practices in all maternity and paediatric hospitals.
- 5) Establish adequate and sustainable psychological and social counselling and therapy for intersex people and their parents.

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102 Official Gazette of RM, no. 50 from 13 April 2010.

- 6) Include updated and appropriate information on intersex issues in curricula for medical schools and universities.
- 7) Include more sensitive vocabulary in curricula for continuous medical education for nurses and midwives to be able to help parents to understand a baby's intersex condition.
- 8) Inform and train state authorities and state bodies responsible for the protection of human rights to be able to provide adequate protection of intersex persons.
- 9) Establish support systems (support groups, help lines and/or social media networks) for intersex people and their parents.
- 10) Increase knowledge and capacity of CSOs and support them to advocate for intersex peoples' rights.
- 11) Collect qualitative and quantitative data on the life situations of intersex individuals and their families.
- 12) Train the media on how to report on intersex issues and how to raise the awareness of the general public on this topic.
- 13) Formalize and define a cooperation and referral system for intersex babies and children between medical institutions from the former Yugoslav Republic of Macedonia and Serbia.

## 4. REPUBLIC OF SERBIA

Serbia became a candidate country to join the European Union in 2012 and negotiations started in 2014. In its 2016 Report on Serbia, the European Commission assessment stated that the "legal and institutional framework for the respect of fundamental rights is in place ... but its consistent implementation across the country needs to be ensured."<sup>103</sup> The need to improve the position of groups that face discrimination was particularly emphasized. There is a high level of stigmatization and self-stigmatization of intersex people, particularly in rural areas and there is very little information about intersex people living in Serbia.<sup>104</sup> Available reports indicate widespread ignorance among representatives of institutions, including doctors and health workers, resulting in potential significant violations of human rights.<sup>105</sup>

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103 European Commission (2016), Serbia 2016 Report, Brussels, p. 5, available at: [http://ec.europa.eu/enlargement/pdf/key\\_documents/2016/20161109\\_report\\_serbia.pdf](http://ec.europa.eu/enlargement/pdf/key_documents/2016/20161109_report_serbia.pdf)

104 See <http://www.transserbia.org/interseks> and <http://www.asocijacijaaduga.org.rs/podrka-interseks-osobama/>

105 Vučković, D. Study on Homophobia, Transphobia and Discrimination on Grounds of Sexual Orientation and Gender Identity, Legal Report: Serbia, Danish Institute for Human Rights, p. 5, para. 21, available at: [http://www.coe.int/t/Commissioner/Source/LGBT/SerbiaLegal\\_E.pdf](http://www.coe.int/t/Commissioner/Source/LGBT/SerbiaLegal_E.pdf)

This is probably why there are no active intersex communities and services in Serbia where intersex people and parents of intersex children can access for support.<sup>106</sup> There is no official term for intersex in the Serbian language, and the English term is used without proper understanding. The Serbian public and media equate intersex with the term 'hermaphrodite', which strengthens social stigma relating to being intersex.<sup>107</sup>

## 4.1 Health care and intersex

Private and state-owned health care is available in Serbia. The state-owned health care system is divided into three levels of care: primary, secondary and tertiary care. Treatment for intersex babies and children is available only in medical institutions in the capital, Belgrade.

Institutions in Serbia do not recognize the term 'intersex' and still use the term 'hermaphrodite'. The University Children's Hospital and the Institute for Mother and Child "Dr Vukan Čupić" in Belgrade are the two main medical institutions for children in the country. Over a decade, a multidisciplinary team of nine medical specialists have been working with intersex babies and children. Information on existing practices and relevant diagnoses of intersex children were only found in these two institutions.

The Ministry of Health and the Statistical Office do not have information about the number of intersex newborns and treated babies in Serbia. Intersex babies and their parents from Bosnia and Herzegovina and the former Yugoslav Republic of Macedonia are in some cases referred to the Institute for Mother and Child in Belgrade based on a personal recommendation by their physician or a peer.<sup>108</sup> These referrals are not covered by health insurance and the families make their own arrangements to seek treatment in Serbia.

All intersex-related diagnoses have codes according to the ICD, which are used in Serbia's medical care. The number of intersex cases listed by code of diagnosis per year gives information on the intersex babies that have been treated in Serbia including the babies who are referred from Bosnia and Herzegovina and the former Yugoslav Republic of Macedonia. However, that information was not available to the authors of the report.

The Institute for Mother and Child is the leading institution at the national level for infants, and pre-school, school-aged and adolescent children. Within the Institute, there is a paediatrics clinic, a paediatric surgical clinic and a centre for science, research and educational activities.

There is a multidisciplinary team medical specialists (including four paediatric endocrinologists, three paediatric surgeons, and including a urologist, a geneticist and/or a gynaecologist) that work with intersex babies. Some specialists from the team are members of the global Disorder of Sex Development (DSD) network.<sup>109</sup> This team created a medical protocol which is used internally for establishing presumptive intersex diagnoses using tests and examinations. In the protocol, the doctors use the term 'hermaphrodite'.

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106 Belgrade-based CSO Gayten LGBT published a call for intersex people to join a support group three years ago, but no one has responded yet.

107 UNDP (2017). Being LGBTI in Eastern Europe: Serbia Country Report.

108 Information obtained from interview with gynaecologist I.K. from Mather Teresa hospital in Skopje.

109 <http://www.gla.ac.uk/schools/medicine/research/childhealth/researchinterests/i-dsdproject/>.

Although there is a multidisciplinary team working in the Institute, there is no practice of sharing information among colleagues, for example, lectures and scientific papers on intersex issues. Learning from existing practice and treatment of intersex children could be very helpful for other medical practitioners in Serbia and elsewhere in the subregion.

*When a girl in her later teenage years and her mother were sent to the Institute for Mother and Child with a presumptive diagnosis of being intersex, the paediatric gynaecologist did not refer the girl to the experienced medical team.*

#### - Intersex activists in Serbia<sup>110</sup>

Information that includes codes of diagnoses and codes from surgeries is collected and archived in the database of the Institute for Mother and Child. However, there is no disaggregated list of the number of intersex cases; therefore, there is no public information on that number.

The medical protocol contains guidelines for examination, clinical tests, laboratory tests, ultrasound examination, genitography and additional tests for intersex babies. The protocol also contains information on the head doctor, code of procedures, date, place and time. The protocol includes the list of the following procedures:

- **General examination** of the newborn: conducted for early detection of an intersex condition.
- **Clinical tests:** performed by a neonatologist, paediatric endocrinologist, paediatric surgeon urologist and a gynaecologist and include medical history, paediatric examination and examination of external genitalia. The clinical tests include laboratory tests which measure levels of hormones (luteinizing, follicle stimulating, testosterone, 17-alpha-OH, progesterone and cortisol), urine tests and the basic metabolic panel.
- **Ultrasound examination** of the inner genitals: performed by a radiologist and gynaecologist.
- **Genitography:** performed by a radiologist in cooperation with a paediatric gynaecologist and a paediatric surgeon.

When an intersex baby is born and referred to the Institute, the multidisciplinary team schedules a consulting meeting. According to the information received by the staff at the Institute, this happens eight to ten times per year, correlating to the number of intersex babies treated in the Institute.<sup>111</sup>

After all the medical results are collected, the team of specialists assembles to discuss the results and make conclusions. If it is necessary, the team consults additional experts (e.g. molecular biologists, radiologists, paediatric oncologists, clinical psychologists and social workers). The meeting minutes are recorded by a resident doctor. The minutes include information about the process, examination and treatment. The team also gives written conclusions on the intersex condition of the

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110 Interviewed by the author of the study, July 2017.

111 Statement of paediatric surgeon V.K. from the Institute for Mother and Child in Belgrade.

baby. If additional tests<sup>112</sup> are conducted, they provide more insight into the degree of development of external and internal genitalia; the existence, nature and structure of glands; and the reactivity of the external genitalia on androgen hormones. After receiving the results of the additional tests, the multidisciplinary team is called again to establish a diagnosis and recommend treatment for the intersex child.

The head of the medical team explains the cause and nature of the babies' condition to the parents; additional necessary diagnostic and therapeutic procedures; and presents information about possible sexual and reproductive problems in adulthood. The parents are informed about the possible consequences on the psychosexual development of the child. The medical specialist assists the parents in making a decision on which gender they will raise their child. As stated by the paediatric urologist,<sup>113</sup> psychologists who are sensitized and educated on intersex issues are not included in the team, although there is a necessity for professional psychological support to be provided to the parents in the process of decision-making. Suggested surgical operations are often cosmetic and are not necessary in the opinion of some interviewees. After surgery, some of the children are recommended to take hormones for the rest of their lives and have scars which can cause a lot of pain, especially during childhood. There is no guideline for monitoring the health status of intersex children after the medical and surgical interventions. Sometimes parents do not follow up with scheduled examinations of the baby and the contact with the doctors is lost.

*It is very important that someone talks with the parents; they are scared and pressured by their families to announce the gender of the child. In this process, we need in our team experienced and sensitized psychologists and counsellors to calm down the parents, help them understand and stop them from making impulsive decisions.*

- Paediatric surgeon urologist, Institute for Mother and Child in Belgrade

Some evidence shows that the surgery itself can cause severe and irreversible physical harm and emotional distress.<sup>114</sup> Although doctors strive to predict the likely gender identity of these infants, a significant percentage will develop a gender identity different from the one assigned at birth. Irreversible genital surgery, including removal of healthy genital tissue, can be traumatic if the gender assignment turns out to conflict with the individual's own gender identity.<sup>115</sup> Even if the gender prediction is correct, a number of complications associated with these surgical operations can arise, including loss of sexual sensation, pain during intercourse, incontinence, scarring, and the need for repeated surgical interventions. A gonadectomy can create a need for hormone replacement therapy, and may also prevent fertility that is gained through developments in assisted reproductive

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112 Such as stimulation tests with human chorionic gonadotropin (hCG), stimulation synacthen tests (ACTH test), urethra-cystovaginoscopies, laparoscopic examinations of the abdomen, biopsies of the gonads, and stimulation tests with testosterone injections.

113 Statement of paediatric surgeon urologist Vladimir Kojović, Institute for Mother and Child in Belgrade.

114 Human Rights Watch (2017). "I Want to Be Like Nature Made Me" Medically Unnecessary Surgeries on Intersex Children in the US, Available at: <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-un-necessary-surgeries-intersex-children-us>

115 Cohen-Kettenis, P.T. (2005) Gender change in 46, XY persons with 5alpha-reductase-2 deficiency and 17beta-hydroxysteroid dehydrogenase-3 deficiency. Arch Sexual Behav. 34(4), pp. 399–410.



technology.<sup>116</sup> Surgeries whose purpose is to ensure physical and psychological health too often lead to the opposite result.<sup>117</sup>

Medical professionals should be more informed, educated and sensitized about intersex issues. Exchange of knowledge and practices among colleagues and other relevant medical co-workers is important.

## 4.2 Human rights protection

There are no specific legal provisions relating to intersex people in Serbian legislation. However, the general Anti-Discrimination Law<sup>118</sup> recognizes sexual orientation and gender identity (SOGI) and health status as prohibited grounds for discrimination, but no sex characteristics are included. Prohibition of discrimination based on sexual orientation is also mentioned in some other laws,<sup>119</sup> but the majority of them still include SOGI under general clauses, as “other” grounds where discrimination is prohibited. In theory, this can be applied to cases of discrimination against intersex people but no such cases have been recorded as before the court. The 2013 Strategy for the Prevention and Protection from Discrimination for the period from 2013 to 2018, and the accompanying Action Plan adopted in 2014<sup>120</sup> both envisage inclusion of SOGI among the personal characteristics that should be included when creating new laws and amending existing laws that contain anti-discrimination provisions. It also forbids discrimination on the basis of health conditions.<sup>121</sup> So far, the implementation of the recommendation in the Action Plan has largely been lacking and sex characteristics are not considered in legislation amendments.<sup>122</sup>

Surveys only for intersex people have not been conducted. However, lessons can be taken from those done with the LGBTI population. LGBTI people in Serbia are not satisfied with how medical institutions respond to their physical and mental health needs.<sup>123</sup> Specific needs of LGBTI people are not recognized.<sup>124</sup> Currently, medical textbooks contain a limited amount of relevant information, and in some cases treat sexual orientation as a disease.<sup>125</sup> Intersex variations are still considered to be medical disorders.

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116 Hughes, I.A., C. Houk, S.F.Ahmed and P.A. Lee (2006). Consensus statement on management of intersex disorders. *Arch Dis Child*. 91, pp. 554–562.

117 <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>.

118 Official Gazette RS, 55/2013.

119 Dobrković, D., ed. (2007). *Human Rights in Serbia 2006*, Belgrade Centre for Human Rights, Belgrade, p. 109.

120 Official Gazette RS 107/2014.

121 See Strategy, p. 45, 4.4.4. para. 3 and 4 in connection with 2014 AP 3.2.10, 4.1.3., 4.4.1, 4.4.2, 4.5.1.

122 UNDP (2017). *Being LGBTI in Eastern Europe: Serbia Country Report*, p. 16.

123 NGO Safe Puls of Youth survey from 2012 indicated that only 1 in 10 LGBTI people feel that medical institutions are adequately responding to their physical and mental health needs.

124 B. Tepavčević, I. Fetoski, *Prekoputa homofobije, Analiza životnog iskustva LGBT osoba u Srbiji i preporuke za smanjenje diskriminacije, Siguran puls mladih*, Belgrade, 2014, available at: [http://korak-hapi-step.eu/wp-content/uploads/2014/12/Prekoputa-homofobije\\_Analiza-%C5%BEivotnog-iskustva-LGBT-osoba-u-Srbiji-i-preporuke-za-smanjenje-diskriminacije.pdf](http://korak-hapi-step.eu/wp-content/uploads/2014/12/Prekoputa-homofobije_Analiza-%C5%BEivotnog-iskustva-LGBT-osoba-u-Srbiji-i-preporuke-za-smanjenje-diskriminacije.pdf).

125 D. Todorović, J. Todorović, “LGBT zajednica živi u strahu, neizvesnosti i nevidljivosti”, 10/12/2014, available at: <http://arhiv2015sr.labris.org.rs/lgbt-zajednica-zivi-u-strahu-neizvesnosti-i-nevidljivosti/>.

Currently, Serbia uses two categories for sex markers in documents, “M” for male and “F” for female. There is a proposal of a third sex marker “O” (other) in a model gender identity law proposed by Gayten LGBT.<sup>126</sup> Serbia has no legal provisions or procedures for recognizing gender where this differs from the sex assigned at birth, even in cases of gender-affirming surgery.<sup>127</sup>

CSOs have made a great contribution by translating all major international declarations adopted on intersex people in the last seven years and have made these available to the community and the general public.<sup>128</sup>

### 4.3 Communities and organizations

In Serbia, intersex people are starting to be present in social life and in society in general. Intersex people are establishing contact with the LGBT community and with their support they are working on raising awareness about the issue.

Gayten-LGBT<sup>129</sup> translated several important documents and regularly publish translated articles, documents and news about and for intersex people.<sup>130</sup>

Lectures and workshops on this topic were organized for other LGBT CSOs in Serbia and Bosnia and Herzegovina. The Intersex Day of Solidarity and Intersex Awareness Day were announced and celebrated on social networks. Calls for intersex people to join the organization and to establish a support group are open.<sup>131</sup> Other human rights and LGBT CSOs have insufficient knowledge on intersex issues, but are interested in learning more. Capacity-building, lectures and knowledge-sharing are required by CSOs.

XY Spectrum was recently established as the first civil society organization in the region primarily working with intersex children and their parents. The organization is established in Belgrade and has working relationships with international intersex organizations. The work focuses on raising awareness, capacity-building and advocating for intersex people and their rights. XY Spectrum has representation on the board of directors of Intersex International Europe (OII Europe).<sup>132</sup>

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126 Model Law available in Serbian at: <http://transserbia.org/images/2015/dokumenti/Gender%20Identity%20Bill.pdf>.

127 UNDP (2017). Being LGBTI in Eastern Europe: Serbia Country Report, p. 8.

128 Translations are provided by NGO Gayten-LGBT and available at: <http://transserbia.org/resursi/biblioteka>.

129 <https://www.transserbia.org>.

130 <http://transserbia.org/resursi/biblioteka/1211-trans-interseks-kvir-osvrti-i-novi-horizonti>.

131 The call is available at: <http://transserbia.org/interseks/595-podrska-i-poziv-interseks-osobama>

132 <https://oiieurope.org>

## 4.4 Conclusions and suggested priorities

In terms of health care, there are challenges for intersex people, but there is more information and experience in Serbia than in the other countries reviewed. The Institute for Mother and Child in Belgrade has an experienced multidisciplinary team working with intersex babies and children. The team has an internal medical protocol for treatment. However, follow-up protocols are missing. Psychologists or/and social workers are not part of medical team. Diagnoses related to the intersex condition are collected and stored in the hospital database. Informed consent for surgical operations does exist and is obligatory; however, there are complaints in the community about the practice and there is no established system for monitoring intersex children's health status.

Legislation and administrative procedures regarding intersex persons are not in place. LGBT CSOs are working towards greater visibility and support for intersex persons and other human rights organizations are interested in intersex issues.

The following are recommendations to improve the human rights situation and health care for intersex people:

- 1) All medical interventions, tests and medications for the treatment of intersex conditions should be covered by the National Health Insurance.
- 2) Standardize information in order to make it accessible and readable from state medical centres and private hospitals about the number and treatment of intersex children.
- 3) Ensure that psychologists and social workers who are educated and sensitized on intersex issues are part of medical teams.
- 4) Educate medical staff in relevant hospitals on intersex issues.
- 5) Collect and analyse data and report annually on intersex-related diagnoses and practices in all maternity and paediatric hospitals.
- 6) Establish adequate and sustainable psychological and social counselling and therapy for intersex people and their parents.
- 7) Include updated and appropriate information on intersex issues in curricula for medical schools and universities.
- 8) Include more sensitive vocabulary in curricula for continuous medical education for nurses and midwives to be able to help parents to understand a baby's intersex condition.
- 9) Increase knowledge and capacity of CSOs and support them to advocate for intersex peoples' rights.
- 10) Establish support systems (support groups, help lines and/or social media networks) for intersex people and their parents.
- 11) Collect qualitative and quantitative data on the life situations of intersex individuals and their families.

- 12) Inform state authorities and state bodies responsible for the protection of human rights (including the Ombudsman from FB&H and the Ombudsman for children from Republika Srpska) to be able to provide adequate protection of intersex persons.
- 13) Train the media on how to report on intersex issues and how to raise the awareness of the general public on this topic.
- 14) Establish an Office of Children's ombudspersons to work on the protection of intersex children.
- 15) Recognize sex characteristics as grounds of discrimination in anti-discrimination law and other provisions (e.g. related to education, labour and health) that tackle discrimination.

# ANNEX 1

## Male and female external and internal genitalia

**Table 1:** Male and female external and internal genitalia\*

MALE		FEMALE	
Internal genitalia	External genitalia	Internal genitalia	External genitalia
Testes (organ that produces spermatozoa)	Penis (organ carrying the duct for the transfer of sperm and elimination of urine)	Ovaries (organ in which eggs are produced)	Vulva with labia minora (the smaller inner folds of the vulva) and labia majora (the larger outer folds of the vulva)
Epididymis (duct behind the testis, along which sperm passes to the vas deferens)	Scrotum (external sac of skin that encloses the testes)	Fallopian tubes (pair of tubes along which eggs travel from the ovaries to the uterus)	Clitoris (a small sensitive and erectile part of the female genitals at the anterior end of the vulva)
Vas deferens (duct that conveys sperm from the testicle to the urethra)		Uterus (womb)	
		Cervix (narrow neckline passage forming the lower end of the uterus)	
		Vagina (muscular tube leading from the external genitals to the cervix of the uterus)	

\*Definitions in the Table 1 are taken from MedicalNet.com<sup>133</sup>

# ANNEX 2

## The most common intersex diagnoses

The most common intersex diagnoses are:

**Androgen insensitivity syndrome (AIS).**<sup>134</sup> People with AIS have XY chromosomes and are partially or completely insensitive to androgen. They have no ovaries or uterus. They may have little or no underarm hair, acne or body odor, and they may have pale nipples. AIS occurs in different gradations, and a distinction is made between CAIS (complete) and PAIS (partial).

**Complete androgen insensitivity syndrome (CAIS).**<sup>135</sup> People with CAIS almost always feel themselves as women and their external genitals look female. Most often CAIS is detected in puberty when a girl misses her period, and in some cases when an inguinal hernia appears or because it is known to run in the family. People with CAIS have male internal sex organs (testes) that are undescended and located in the pelvis or abdomen. If they are not surgically removed, undescended testes have a small chance of becoming cancerous later in life.

**Partial Androgen Insensitivity Syndrome (PAIS).**<sup>136</sup> Partial androgen insensitivity typically results in “ambiguous genitalia.” The clitoris is large or, alternatively, the penis is small and with hypospadias. Partial androgen insensitivity may be quite common, and has been suggested as the cause of infertility in many men whose genitals are of typically male appearance. Hormonal tests in a newborn with a 46, XY karyotype and ambiguous genitalia will show normal to elevated testosterone and LH, and a normal ratio of testosterone to DHT. A family history of ambiguous genitalia in maternal relatives suggests PAIS. Partial forms of testosterone biosynthesis defects can also be 5alpha-RD2 and 17beta-HSD3.<sup>137</sup>

**Congenital adrenal hyperplasia (CAH).**<sup>138</sup> CAH occurs when there is a broken genetic ‘recipe’ for making cortisone in the adrenal glands (the glands on top of the kidneys that produce various hormones). When the recipe is broken, the adrenal glands, while trying to make cortisone, make an unusually high level of hormones that can cause virilization (masculinization). XX embryos can develop larger than average clitorises, or even a clitoris that looks rather like a penis, or labia that look like a scrotum. The Prader scale can be used to measure the degree of virilization of baby genitalia.<sup>139</sup> In later development, a girl can have characteristics associated with male hormones (androgens), such

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134 <https://ghr.nlm.nih.gov/condition/androgen-insensitivity-syndrome>.

135 Ibid.

136 Ibid.

137 <http://www.isna.org/faq/printable>.

138 <https://ghr.nlm.nih.gov/condition/congenital-adrenal-hyperplasia-due-to-11-beta-hydroxylase-deficiency>.

139 The Prader scale (named after Dr Andrea Prader) is a rating system for the measurement of the degree of virilization of the genitalia of the human body.

as muscle bulk, body hair and a deep voice. The metabolic effects of CAH can be counteracted with cortisone. However, the long-term use of cortisone itself produces significant dependence and other side effects. CAH also occurs in XY individuals, and requires medical attention as it has “significant impacts on health”, but it does not cause ambiguous genitalia.

**Klinefelter syndrome.**<sup>140</sup> This syndrome, also known as 47, XXY, only affects babies born as boys. They have an extra X chromosome in addition to the usual 46 chromosomes. The syndrome affects roughly 1 in 600 or 700 men, making it one of the most common types of intersex conditions. Males with this syndrome produce insufficient testosterone, leading to late onset of puberty and sometimes failure to complete puberty. The penis and testes are relatively small prior to puberty. Boys develop less muscle mass and have altered bodily distribution of fat and in some cases breast formation. The testes remain underdeveloped in adulthood. This syndrome may be accompanied by a list of symptoms, including problems with concentration, memory, coordination, fatigue, expression of emotions and social interaction. Testosterone in different forms (gel, injection or capsule) is prescribed to increase energy, to improve concentration, to increase libido, to develop muscle mass and to alter the fat distribution around their body. The syndrome also reduces the risk of osteoporosis and can cause problems with fertility.

**Turner syndrome.**<sup>141</sup> Turner syndrome is also known as 45, X or 45, XO, where the person affected has 45, X in some cells and, for example, 46, XX or 46, XY in others. This syndrome affects girls and women and the development of their ovaries, the production of sex hormones, height and physical sexual maturity. Those affected are almost always short in stature and have different combinations of symptoms including a wide and/or short neck and a low hairline at the back of the neck. Turner syndrome can also cause heart, kidney, thyroid gland and hearing problems; incidence of diabetes; high blood pressure; reduced motor development; and deficiencies in spatial awareness and short-term memory. No cure for Turner syndrome is known. Treatment can include human growth and estrogen replacement therapy.

**Mayer-Rokitansky-Küster-Hauser syndrome (MRKH).**<sup>142</sup> MRKH occurs only in females and is found in two types. MRKH syndrome type 1 affects reproductive organs and can cause skeletal abnormalities, particularly of the spinal bones. MRKH syndrome type 2 affects kidneys in formation or position, or one kidney may fail to develop (unilateral renal agenesis). Those affected can have hearing loss or heart defects. MRKH is usually discovered during puberty, because of a missing period or kidney problems.

**Swyer syndrome.**<sup>143</sup> Swyer syndrome is also known as XY gonadal dysgenesis. A person is born without functional gonads (sex glands). The gonads can have minimally developed tissue in place of testes or ovaries. A child born with Swyer syndrome looks like a typical female. In puberty, secondary sex characteristics will not develop. Hormone replacement therapy can be used to initiate the period, to develop female secondary sex characteristics and to reduce the risk of low bone density (osteopenia and osteoporosis).

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140 <https://ghr.nlm.nih.gov/condition/klinefelter-syndrome>.

141 <https://ghr.nlm.nih.gov/condition/turner-syndrome>.

142 <https://ghr.nlm.nih.gov/condition/mayer-rokitansky-kuster-hauser-syndrome>.

143 <https://ghr.nlm.nih.gov/condition/swyer-syndrome>.

**Ovo-testes.**<sup>144</sup> Ovotestes are gonads (sex glands) containing both ovarian and testicular tissue. A person may have both ovotestis, or they may have a combination of an ovary on one side and a testis or ovotestis on the other. Babies born with ovotestes have “ambiguous genitalia” and some can have labioscrotal fusion and/or hypospadias. If ovarian tissue is at least partially developed, a person can grow breasts and have a period. Sex hormone replacement therapy can be helpful for those with delayed puberty.

**Hypospadias.**<sup>145</sup> Hypospadias is a condition where the external opening of the urethra (urinary meatus) is not located at the tip of the penis. The urethral opening can be located anywhere along the length of the penis or in the scrotum, and the foreskin is usually split. There are a few types of hypospadias: distal or granular (when the opening is found near the head of the penis), midshaft (when the opening is found in the middle to the lower shaft of the penis), penoscrotal (when the opening is found where the penis and scrotum join) and perineal (when the opening is behind the scrotal sac). If the opening is closer to the scrotum, there is a greater chance of a curved penis. The position and shape of the urethral opening can make it difficult to urinate while standing and/or enable ejaculation. The function and appearance of the penis can be medically altered. Boys with hypospadias are fertile.

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144 <http://emedicine.medscape.com/article/256289-overview>.

145 <http://emedicine.medscape.com/article/1015227-overview>.





