

“FIXING” THE BODY, ENDANGERING THE SOUL?

CHALLENGES OF INTERSEX CHILDREN UNDER THE FUNDAMENTAL RIGHTS



Team Portugal II

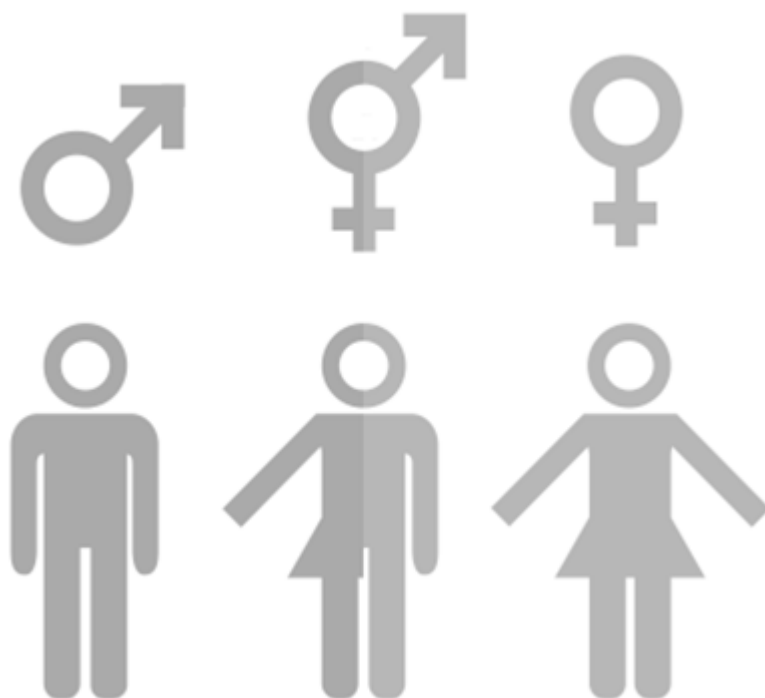
Ana Brandão | Elisabete Ferraz | Pedro Santos

Accompanying Teacher

Maria Perquilhas

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I. INTRODUCTION

“I tell ya, life ain’t easy for a boy named Sue.”

Shel Silverstein, sung by Johnny Cash, “A boy named Sue”, 1969

“*Is it a girl or a boy?*” How often do we hear this question when a newborn comes into this world? Although it may appear harmless to most of us, for some individuals who cannot be clearly classified as male or female at birth, the answer will define not only the way they see themselves but also how they will be socially and legally recognised. In fact, we are used to distinguishing human beings as male or female. Besides, society does not usually recognise a person without reference to their sex or gender¹. However, this binary classification no longer responds to the diversity that a person’s bodily features can assume².

According to experts, around 1.7% of the population is born with intersex conditions³. Intersex individuals cannot be classified according to the medical norms of male and female bodies regarding their chromosomal, gonadal or anatomical characteristics⁴. In these cases, when parents choose the sex of their new-born child they must be aware that the sex assigned at birth will subsequently become a legal and a social fact and will accompany them throughout the rest of their life.

Because of their invisibility to the majority, due to the fact that they do not fit the parameters of legal and social standards, intersex people suffer a great variety of challenges ranging from mere bureaucracy, to discrimination or medical interventions without informed and conscious consent.

Therefore, the present paper focuses on the impact that some practices, such as issuing birth certificates and medical treatments, can have on the fundamental rights of intersex children.

The best interests of intersex infants are often manipulated to support the lack of social, legal and medical knowledge, research and relevant legislation on the matter. The legal requirement for intersex children to be identified as either male or female leaves them vulnerable to surgical intervention, for cosmetic reasons and without informed consent, which is a real problem, not only because it is irreversible, but also because it may

¹ Sex and gender are distinct, with sex being a biological term and gender being a psychological and cultural term. Sex denotes biological characteristics that a person has with specific reference to genitalia and their reproductive system; gender traditionally denotes having either a male or female proscribed normative role in society.

² Anne Fausto-Sterling (*Sexing the Body*, page 78, available at <https://libcom.org/files/Fausto-Sterling%20-%20Sexing%20the%20Body.pdf>) proposes that, in addition to males and females, we should also accept the categories herms (named after “true” hermaphrodites), merms (named after male “pseudo-hermaphrodites”), and ferm (named after female “pseudo-hermaphrodites”).

³ It is estimated that the prevalence of babies born with ambiguous genitalia prompting medical investigation and a diagnosis is 1 in 2000 babies; see L. Liao, D. Wood and S. Creighton, *Parental Choice on Normalising Cosmetic Genital Surgery*, British Medical Journal 351 (2015), available at <https://pdfs.semanticscholar.org/57e4/d8d0e78eafd233e58d3169ccd19de1aa2731.pdf> and Anne Fausto-Sterling, *Sexing the Body*, pages 51-54, available at <https://libcom.org/files/Fausto-Sterling%20-%20Sexing%20the%20Body.pdf>.

⁴ Medical practice uses the term Disorders of Sex Development (DSD) to cover congenital conditions in which the development of chromosomal, anatomical or gonadal sex is atypical.

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potentially be detrimental, both physically (through pain or in relation to sexual function) and physiologically (many intersex people do not identify with the sex they were assigned to), to the child as they develop into a gender identity. Shame and secrecy have allowed the perpetuation of these practices for years, exposing these children to severe human rights breaches and revealing their particular vulnerability and the absence of effective measures to protect them.

Regarding all this, we will approach the subject of intersex children from a fundamental rights perspective, considering the positive legal and medical advances across many European countries and around the world. For those purposes, the rights of intersex children and their main challenges will be assessed according mostly to two international instruments: the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of the Child (UNCRC). We will also examine the recommendations of some institutions, agencies, activists and NGO's that by means of pioneering and remarkable work are drawing the public's attention to a reality that society can no longer pretend doesn't exist.

II. WHO ARE THE INTERSEX?

As referred before, intersex persons⁵ are born with sex characteristics that do not fit typical binary notions of male or female bodies. The variations of sex anatomy, can include⁶:

- a) ambiguous genitalia, such as, enlarged clitoris, fused labia (Congenital Adrenal Hyperplasia CAH), absence of vagina (vaginal agenesis, or Mayer-Rokitansky-Küster-Hauser syndrome MRKH), urethral opening not on the tip of the penis, but somewhere below on the underside of the penis (hypospadias), anomalous small penis or micropenis (e.g. Androgen Insensitivity Syndrome AIS), breast development in males (gynaecomastia), and/or
- b) irregular hormone producing organs or atypical hormonal response, for example, a mix of ovarian and testicular tissue in gonads (ovotestes, “True Hermaphroditism”), the adrenal gland of the kidneys (partly) producing testosterone instead of cortisol (Congenital Adrenal Hyperplasia CAH), low response to testosterone (Androgen Insensitivity Syndrome AIS), undescended testes (e.g. in Complete Androgen Insensitivity Syndrome CAIS), little active testosterone producing Leydig cells in testes (Leydig Cell Hypoplasia), undifferentiated streak gonads (Gonadal Dysgenesis GD if both gonads are affected, or Mixed Gonadal Dysgenesis MGD with only one streak gonad), and/or
- c) atypical genetic make-up, e.g. XXY (Klinefelter Syndrome), XO (Ullrich Turner Syndrome), different

⁵ Historically, people with intersex conditions were referred to as "hermaphrodites" but this word has been rejected as embodying many of the misperceptions and mistreatment of intersexed people.

⁶ See the NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC) regarding the *Intersex Genital Mutilations. Human Rights Violations Of Children. With Variations Of Sex Anatomy*, available at http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf.

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karyotypes in different cells of the same body (mosaicism and chimera).

While many intersex forms are normally detected at birth (or earlier during prenatal testing), others may only be revealed at puberty or later in life (e.g. due to the absence of menstruation or physical development that do not correspond with the assigned sex).

Due to the great diversity among the intersex, it's not correct to cluster them, biologically speaking, into only one category, in parallel to female and male categories. In addition, it's important to acknowledge that being intersex relates to biological sex characteristics and is fully distinct from a person's sexual orientation or gender identity, where the psychological component is more enhanced. Therefore, an intersex person may be straight, gay, lesbian, bisexual or asexual, and may identify as female, male, both or neither⁷.

III. INTERSEX CHILDREN AND THE ENJOYMENT OF HUMAN RIGHTS

a) Background and Awareness in European Union

In the European Union, intersex issues have gradually emerged as relevant to fundamental rights protection thanks to the work developed by some European and United Nations institutions⁸, agencies¹⁰ and ethics councils¹¹, activist movements and NGO's¹², which have contributed to a better understanding of the challenges intersex people are faced with, such as discriminatory behaviours and violations to their physical

⁷ The Office of the United Nations High Commissioner for Human Rights (OHCHR) *Free & Equal* campaign refers that “*Intersex people experience the same range of sexual orientations and gender identities as non-intersex people*”.

⁸ In 2013, the Council of the European Union launched some guidelines to promote and protect the enjoyment of all human rights by lesbian, gay bisexual, transgender and intersex (LGBTI) persons, aiming to provide officials of EU institutions and EU Member States, with guidance to be used in contacts with third countries and with international and civil society organisations, using a case-by-case approach, in order to promote and protect the human rights of LGBTI persons within its external action (see Council of the European Union *Guidelines to Promote and Protect the Enjoyment of all Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons*, Foreign Affairs Council meeting Luxembourg, 24 June 2013, available at <https://ec.europa.eu/europeaid/sites/devco/files/137584.pdf>). See, also, the European Parliament Resolution on the *EU Roadmap against homophobia and discrimination on grounds of sexual orientation and gender identity*, adopted in 2014, available at <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+REPORT+A7-2014-0009+0+DOC+XML+V0//EN>).

⁹ The UN High Commissioner for Human Rights and the UN Special Rapporteur on Torture pointed out that intersex people can suffer from discrimination which may lead to seriously ill treatment, especially during childhood (see United Nations (UN), High Commissioner for Human Rights (2011), *Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity*, Human Rights Council, Nineteenth session, Report No. A/HRC/19/41, 17 November 2011, available at http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/a.hrc.19.41_english.pdf, and United Nations (UN), Special Rapporteur on Torture (2013), *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Juan E. Méndez, Human Rights Council, Twenty-second session, Report No. A/HRC/22/53, 1 February 2013, available at http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

¹⁰ See FRA Focus Paper 04/2015 entitled *The Fundamental Rights Situation of intersex people*, available at <http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>.

¹¹ For example, the Italian Committee on Bioethics, the German Ethics Council and the Swiss National Advisory Commission on Biomedical Ethics published a set of recommendations to safeguard the rights of intersex people.

¹² Such as ILGA-Europe, Organisation Intersex International Europe and Zwischengeschlecht.org / StopIGM.org.

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and physiological integrity¹³. Hence, progress has been made in terms of recognising the need to specifically protect them in equal treatment legislation¹⁴.

Human rights are universal and indivisible, therefore applicable to everyone, including intersex children. The Universal Declaration of Human Rights (UDHR) states, in Articles 1 and 2, that “*All human beings are born free and equal in dignity and rights*” and that “*Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status*”. Also, the European Convention on Human Rights (ECHR) protects everybody and contains an open-ended list of prohibited grounds of discrimination in Article 14, including the ground of sex and gender¹⁵⁻¹⁶.

The Charter of Fundamental Rights of the European Union (CFREU) protects human dignity in Article 1 and the right to integrity in Article 3, prohibiting any discrimination based on any ground such as sex and genetic features (see Article 21). There’s no doubt that children are holders of human rights rather than only objects of protection.

The United Nations Convention on the Rights of the Child (UNCRC) establishes a set of rights that are extremely relevant concerning the protection of intersex children against discriminatory acts and offenses to their integrity. Indeed, Article 3 prescribes that the best interests of the child is a primary consideration regarding all issues that affects children. In Article 7, the UNCRC establishes the right of the child to be registered immediately after birth and to have the right, from birth, to a name and, in Article 8 the right to preserve their identity. Articles 12 and 13 enhance the child’s right to form and express their points of view freely in all matters affecting them and, the right to freedom of expression¹⁷.

¹³ Regarding childhood and as a result of the lack of knowledge of intersex issues, is important to note that intersex children have been treated as a taboo, suffering from bullying and exclusion in schools.

¹⁴ Regardless the national legislative progresses that we will look at, EU Directives related to equal treatment adopt the binary male/female norm.

¹⁵ Unequal treatment of intersex individuals has been frequently addressed in EU policies and advocacy as part of discrimination on the ground of sexual orientation and/or gender identity. Although, such treatment can better be addressed as discrimination on the ground of sex because it is linked to the sex assigned to a person at birth and its direct consequences. Intersex civil society organizations are advocating that a specific ground entitled “sex characteristics” or “intersex status” should be created in order to increase visibility and foster equality for the intersex.

¹⁶ South Africa was the first country in the world to include an express reference to intersex in its equality legislation, through the *Judicial Matters Amendment Act 2005* which altered the *Promotion of Equality and Prevention of Unfair Discrimination Act 2000*. The Australian federal law called *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* introduced an intersex specific ground of discrimination. In Europe, Malta’s *Gender Identity, Gender Expression and Sex Characteristics Act (2015)* explicitly provides protection against discrimination on the ground of “sex characteristics”. In Spain, the *Basque Country Act 14/2012 on non-discrimination based on gender identity* includes references to “intersex persons”. In the United Kingdom, the *Scottish Offences (Aggravation by Prejudice) Act 2009* includes intersex issues in its open wide definition of gender identity.

¹⁷ Article 24 of the CFREU establishes the rights of the child, prescribing that “*1. Children shall have the right to such protection and care as is necessary for their well-being. They may express their views freely. Such views shall be taken into consideration on matters which concern them in accordance with their age and maturity. 2. In all actions relating to children, whether taken by public authorities or private institutions, the child’s best interests must be a primary consideration. 3. Every child shall have the right to maintain on a regular basis a personal relationship and direct contact with both his or her parents, unless that is contrary to his or her interests.*”.

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Taking these rights into account¹⁸, and in relation to intersex children, non-urgent medical surgeries and the registration of a sex marker on birth certificates may be arbitrary and in breach of their enjoyment of human rights¹⁹.

b) Registration of sex at birth: lack of legal recognition

When a child is born, an official registration of their sex is demanded. For an intersex newborn, this is one of the first moments when their parents are confronted with the well-known binary pattern female/male, and consequently, when their rights are under imminent risk.

Some questions emerge at this point: do parents of intersex children have the obligation to register them as female or male after the birth? Does this obligation violate the full enjoyment of their human rights? Is this legal binary imposition a discriminatory act?

In countries that only have the female-male option, parents are forced to choose the baby’s sex, usually pressured by the medical standards and procedures that advise them that the child must fit into one of the existing categories. The lack of legal recognition, medical support and counselling in these cases originates serious violations to the child’s rights to physical and mental integrity and, later in their adolescence, to express their views freely.

As holders of human rights, intersex children are covered not only by the UDHR protection (especially Articles 2 and 6), but also by the protection conferred upon them by Articles 8 and 14 of the ECHR, which guarantees the right to freely develop a personal and a gender identity, without any discrimination based on grounds of sex.

UNCRC, in Articles 2, 3, 7 and 8, establishes the child’s right to be registered at birth, imposing on States Parties the obligation to respect and preserve their gender identity, taking into account the best interests of the child, ensuring that no discriminatory practices related to their sex are pursued.

Although the majority of EU Member States require that newborns must be promptly registered as male or female, in some European countries birth registration legislation allows other possibilities and flexible measures regarding the assignment of a sex to intersex babies. In effect, we can distinguish different legal approaches across Europe. Thus, in some EU Member States, a delay in the registration of a newborn is

¹⁸ And other key human rights, such as the right to life (established under Article 3 of the UDHR, Article 2 of the ECHR, Article 2 of the CFREU and Article 6 of the UNCRC), the prohibition of torture and inhuman or degrading treatment (enshrined in Article 5 of the UDHR, Article 3 of the ECHR, Article 4 of the CFREU), the right to respect for private life (prescribed in Article 12 of the UDHR, Article 8 of the ECHR, Article 7 of the CFREU and Article 16 of the UNCRC), the right to health (established under Article 25 of the UDHR, Article 35 of the CFREU and Article 17, 23 and 24 of the UNCRC).

¹⁹ In May 2014, the Commissioner for Human Rights published a paper (entitled *A boy or a girl or a person – intersex people lack recognition in Europe*, available at <https://www.coe.int/en/web/commissioner/-/a-boy-or-a-girl-or-a-person-intersex-people-lack-recognition-in-euro-1?desktop=true>) which exposed the human rights challenges faced by intersex individuals.

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allowed when their sex cannot be immediately defined.²⁰ Other EU Member States permit not only a sex neutral identification to be registered on birth certificates²¹, but also the possibility of not including the baby’s sex on the birth certificate²² or the statement that the sex could not be determined²³.

For their innovational approach to this subject, we will look at the birth registration legislation of three specific Member States (the Maltese, Portuguese and German legislation) which we consider better respond to the challenges posed by the social expectations and legal and medical requirements faced by intersex children.

In Malta, according to the *Gender Identity, Gender Expression and Sex Characteristics Act 2015*²⁴, the entry of a sex marker on the birth certificate can be deferred until the gender identity of the child is determined. Malta has also committed to legally recognise other gender markers in addition to male and female, as well as the absence of such markers on birth certificates.

In Portugal, a proposal presented by the Government regarding the right to self-determination of gender identity and expression of gender and the right to protection of sexual characteristics²⁵ is under discussion and is expected to be approved in April 2018, in order to reinforce legal recognition of transsexual²⁶ and intersex people²⁷. This proposal defines some plans of action concerning medical interventions on transsexual and intersex individuals and intends to clarify several concepts like gender identity, gender expression and sexual characteristics, inspired by the legislation of other countries and communities (like Chile, Malta and The Community of Madrid); at the same time, it promotes transsexual and intersex people’s rights and enhances

²⁰ Usually this delay intends to allow a medical identification to define the predominant sex, which leads to the legal imposition of choosing a male or female sex. In Belgium, for example, the sex is usually registered during the first week and in a maximum period of three months from the birth of an intersex child; in France, a maximum period of three years is permitted in cases of intersex births. Portugal and Finland do not impose a time limit on the registration of sex when it cannot be clearly defined.

²¹ Such as “unknown sex” in the United Kingdom.

²² In Latvia, for example. In Finland, the lack of sex certification implies that an intersex infant gets an incomplete personal identity code.

²³ It’s the case of Netherlands.

²⁴ The *Gender Identity, Gender Expression and Sex Characteristics Act* requires public services to eliminate any kind of discrimination and harassment on the ground of sex characteristics, promoting equality of opportunities for all. This Act can be accessed at <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>.

²⁵ This proposal can be consulted at <https://www.portugal.gov.pt/download-ficheiros/ficheiro.aspx?v=32f5cbdc-4e31-487b-9fd3-41a33bd7297e>.

²⁶ Transsexual people identify with the gender role opposite to the sex assigned to them at birth and seek to live permanently in the preferred gender role. This is often accompanied by strong rejection of their physical primary and secondary sex characteristics and a wish to align their body with their preferred gender. Transsexual people might intend to undergo, be undergoing or have undergone gender reassignment treatment.

²⁷ This proposal seeks to establish the right to self-determination of gender identity and gender expression, eliminating certain requirements of the legal recognition procedure of gender identity (presentation of a medical report). The initiative also promotes the right to the protection of the primary and secondary sexual characteristics of persons, making any medical intervention that implies changes in the body or sexual characteristics dependent on express and informed consent. Regarding children, except in situations of health risk, medical treatments should only be performed as soon as their gender identity is manifested. In order for this to be possible, is required that the child can produce express and informed consent through their legal representatives, taking into account the principle of progressive autonomy, guaranteeing their right to freely express their opinion and to be taken into account according to their age and maturity and with the principle of the best interests of the child. This proposal establishes the right to maintain sexual characteristics (Article 5), provides that no medical intervention should be performed until the person reveals their gender identity (Article 7, no 1) and, sets that any medical intervention performed after the expression of gender identity depends on child’s informed consent, expressed through legal representatives and respecting the principles of progressive autonomy and child’s best interests (Article 7, no 2).

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the right of self-determination of gender and children’s expression of gender.

In Germany, since the adoption of the *Act to Amend Civil Status Regulations 2013*, it is possible to fill birth certificates without a sex marker and no deadline to include such marker is imposed. Despite the fact that Germany confers a possibility that doesn’t exist in the majority of the EU Member States, a case related to this matter was brought to the German Constitutional Court (*Bundesverfassungsgericht*) that obligated the judges to decide if the *Civil Status Act* respected the general right of personality and protection of gender identity of the intersex individuals.

In summary, the case dealt with an individual that, at birth, was assigned and registered by their parents as a female. The complainant was born with an atypical set of chromosomes and was not identified with either the female or the male gender. According to the German law, the complainant could change the register, choosing between the male/female dichotomy or leaving the sex/gender marker field blank. The complainant filed a request with the competent registry office to correct the complainant’s birth registration by deleting the previous gender entry “female” and replacing it with “inter/diverse”, alternatively only with “diverse”. The registry office rejected the request and pointed out that under German civil status law a child needs to be assigned either the female or the male gender in the birth register and emphasised that – if this is impossible – no gender entry is made. The request for correction filed thereupon with the Local Court was rejected; the complaint filed against this decision was unsuccessful.

The complainant appealed to the German Constitutional Court claiming a violation of their general right of personality (which includes the protection of gender identity) under article 2(1) in conjunction with article 1(1) of the Basic Law (*Grundgesetz – GG*), discrimination based on gender under article 3(3) first sentence GG and, a violation of the principle of equal treatment under Art. 3(1) GG.

Taking the above arguments into account, the German Constitutional Court considered that the general right of personality also protects the gender identity of persons who cannot be assigned as either female nor male gender, and, that the current law, not allowing other gender entry besides female or male, interferes with their fundamental right. The *Bundesverfassungsgericht* stated, not only that gender identity is an important part of an individual identity, which determines, for instance, how people are addressed, what is expected of a person in terms of behavior, upbringing and appearance – besides the importance that is attributed in terms of law – but also that, the *Civil Status Act*, only allows two positive entries, which means that people who don’t recognize themselves either as female or male do not have the possibility to a positive entry.

In October 10, 2017²⁸, German’s Federal Constitutional Court concluded that the *Civil Status Act* threatened the self-determined development and protection of intersex persons’ personality and that the previous decisions taken by the Federal Court of Justice, the Celle Higher Regional Court and the Hanover Local Court

²⁸ The Federal Constitutional Court’s decision can be consulted at http://www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/EN/2017/10/rs20171010_1bvr201916en.html.

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were unconstitutional by denying a positive entry other than female or male on birth’s certifications. The decision mentioned that having as an alternative for the binary pattern “missing data” gives the impression that an alternative gender is ruled out, conveying the idea that the person’s gender hasn’t been clarified yet. The Court referred, considering the arguments presented by the third parties, that a third option allowing a positive entry in birth register wouldn’t affect the status of men and woman under civil status law; that the fact of the introduction of a third positive entry may be associated with bureaucratic and financial costs during a transitional period does not justify denying the option of a further gender entry; and the organizational interests of the State cannot justify the denial of a third standardized and positive entry either. The judges concluded that provisions that only allow two positive entries in birth registers are discriminatory, affirming that this disadvantage isn’t justified and that the protection against the discrimination based on gender also includes the protection of gender from people who don’t see themselves as female or male. Therefore, the *Bundesverfassungsgericht* legally recognized a third gender and set a deadline until the end of 2018 for the legislator to regulate the matter by means of law²⁹.

Here arrived, we can acknowledge that as long as the registration of an immutable, or hard to change, sex marker on the intersex child’s birth certificate is required, intersex children will remain vulnerable to discrimination and, their right to develop a personal gender identity will be in crisis due to the binary system instituted. Alternatives to gender markers in legal documents, such as the possibility of including a gender-neutral marker, should be considered by the public authorities in order to assure a full enjoyment of their human rights³⁰.

c) **Medical interventions on intersex children: the Gordion Knot**

It is common practice to submit intersex children to surgical and other medical procedures for the purpose of trying to make their appearance conform to binary sex stereotypes which may not be necessary to guarantee their healthy development.³¹ Until the 90’s, the prevailing medical opinion was that ambiguous sex could and should be fixed, and in fact, genital surgeries on intersex babies became routine in spite of the fact they were

²⁹ By a decision of 14 March 2018, delivered on 19 March 2018, the Austrian Constitutional Court opened proceedings for the repeal of state registration of sex (E 2918/2016). An intersex person, being neither male nor female, had asked the civil status office to correct the entry in the birth register from male to “inter”, “other”, “X” or a similar designation, or to delete the sex-entry as a whole. After the civil status office had refused and the Administrative Court confirmed, the Constitutional Court now preliminarily has found in favour of the intersex person. The decision is available at https://www.vfgh.gv.at/downloads/VfGH_Pruefungsbeschluss_E_2918-2016_unbest_Geschlecht_ano.pdf.

³⁰ However, it should not be overlooked that the registration of a child without a sex selection may in some jurisdictions lead to practical problems: consider, for example, the choice of a child’s name. In some systems, such as the Portuguese one, there are no general neutral names available, which leads to the imposition that the chosen name does not create any doubt concerning the child’s sex.

³¹ The predominant theory used to understand the relationship between sex and gender until the end of the 20th century was Professor John Money’s nurture theory. Money concluded that gonads, hormones and chromosomes did not automatically determine a child’s gender role, and that that “mix-sex children” could be assigned to the “proper gender” early in their childhood and be nurtured within that gender role provided the appropriate behavioural interventions ensued.

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rarely medically necessary. Nowadays, an emerging shift in the medical perspective is perceptible among a number of practitioners, with a consensual common ground regarding the medical management of intersex children³². Thus, the legal challenges that these practices imply remain the same.

These medical procedures, performed at an early age, are often irreversible and can cause permanent infertility, incontinence, pain, loss of sexual sensation and depression³³. Normally performed without full, free and informed consent, these practices may violate the child’s rights to physical integrity, to be free from torture and ill-treatment, and to live free from harmful practices³⁴. On this particular subject, Intersex Rights Organisations aims to end normalising surgeries and other cosmetic medical treatment, which they decry as “intersex genital mutilation” (IGM). Equally relevant on this topic are the Yogyakarta Principles, a set of principles elaborated by a group of experts in human rights law. Although they are not binding on states, they are considered as an interpretative parameter by the Council of Europe as human rights standards³⁵⁻³⁶. In this particular, and since 2006 this group regards as a basic state obligation to “*take all necessary legislative, administrative and other measures to ensure that no child’s body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration*” as well “*establish child protection mechanisms whereby no child is at risk of, or subjected to, medical abuse*” (Principle 18, b) and c)).

As regards to the legal framework with respect to genital-normalizing surgery in intersex children, the focus of the ECHR is Article 3 (the prohibition of torture), Article 8 (respect for private and family life) and Article 14 (the prohibition of discrimination). At the same time, there are numerous Articles of the UNCRC that are potentially breached in infant genital-normalizing surgery, including Article 2 (freedom from discrimination), Article 3 (the best interests of the child being paramount), Article 12 (respect for the views of the child), Article 16 (the child’s right to privacy), Article 24 (the child’s right to health and health services) and Article 37 (protection from torture or other cruel, inhumane or degrading treatment)³⁷⁻³⁸. The participation of children

³² The Lawson Wilkins Paediatric Endocrine Society (USA) and the European Society for Paediatric Endocrinology have published the so-called “*Consensus Statement on the management of intersex disorders*”, also known as “*the Chicago Consensus*”. See I. A. Hughes, C. Houk, S. F. Ahmed, P. A. Lee, *Consensus statement on management of intersex disorders*, LWPES/ESPE Consensus Group, Arch Dis Child 2006, 1–10, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/>.

³³ In fact, the psychological distress caused by the negative outcomes of surgery can result in self-harming and suicidal behaviour.

³⁴ UN Special Rapporteur on torture (2013) draws attention to the fact that intersex children are often submitted to irreversible sex assignment, involuntary sterilisation and genital-normalising surgery, performed without their informed consent or that of their parents.

³⁵ The Yogyakarta Principles, *Principles on the application of international human rights law in relation to sexual orientation and gender identity*, 2007, available at http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf.

³⁶ About the Yogyakarta Principles, see Piero Tozzi, *Six Problems with the 'Yogyakarta Principles'* (April 2, 2007). International Organizations Research Group Briefing Paper No. 1, available at SSRN: <https://ssrn.com/abstract=1551652>.

³⁷ See M. Bauer and D. Truffer, *NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC) (Zwischengeschlecht, 2014)*, available at www.intersex.shadowreport.org.

³⁸ Also some Articles of the CFREU are important in this matter, such as Article 3 (the right to integrity of the person), Article 7 (the respect for private and family life), Article 21 (the prohibition of discrimination) and Article 24 (the rights of the child, including the right of children to express their views freely and to have their views taken into consideration on matters which concern them in accordance with their age and maturity).

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in decisions that affect their body and their ability to self-determination is essential. The UNCRC promotes parental decision-making under Articles 3 and 18, in that the best interests of the child are paramount, which would allow for parental consent to cover therapeutic interventions that would benefit the child’s health. However, in the case of non-therapeutic interventions, the UNCRC aims to protect the child from harm and promotes a supportive approach to autonomous decision-making. On the other hand, Article 24 (3) of the UNCRC affirms that States Parties shall take all effective and appropriate measures to abolish traditional practices that are prejudicial to health. Health care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide an informed consent. Genital-normalizing surgery is considered as harmful when the child does not make the decision and states should take legislative measures promoting advocacy to prevent harmful practices against intersex children in breach of the child’s human rights. States Parties should guarantee that no child is subjected to unnecessary medical or surgical treatment, protecting bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support.

Central to this position is that Article 8 of the ECHR requires safeguarding measures to protect a person’s physical integrity, which is not currently provided in the context of medical and parental decision-making in infant genital-normalizing surgery.

As referred above, in 2015 Malta adopted the *Gender Identity, Gender Expression and Sex Characteristics Act*, which was the first law to prohibit surgery and treatment on the sex characteristics of minors without an informed consent, stating, in Article 14, that “*it shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and, or surgical intervention on the sex characteristics of a minor which treatment and, or intervention can be deferred until the person to be treated can provide informed consent*”.

At this point we are obliged to critically appraise the way in which the subject has been dealt with, especially in relation with the medical approach and in confrontation with the essential core of human dignity.

As asked by Melanie Newbould³⁹, why is early genital surgery considered in the child's best interests?

Obviously, we are not addressing situations where there is a life-threatening risk that imposes the intervention to safeguard a child’s right to life (Article 6 of the UNCRC) which is peacefully recognized as prevailing.

Taking into account the foregoing legal framework, it is clear that when a situation of this kind arises, the rights of the child are put in tension, in particular the right to preserve the child’s identity (Article 8 of the UNCRC), the right of the child to intervene in decisions of particular importance in relation to their life, when there is sufficient capability for it (Article 12 of the UNCRC), as well as the child’s right to physical integrity

³⁹ Melanie Newbould, *When Parents Choose Gender: Intersex, Children, and the Law* - Med Law Rev (2016) 24 (4): 474, available at <https://doi.org/10.1093/medlaw/fww014>.

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and sexual identity, protected under article 8 of the ECHR. Crossing the referred framework, it is the child’s best interest principle, granted in article 3 of the UNCRC.

All medical interventions on newborns, due to their natural incapability of expressing an opinion and of deciding, are performed without their personal consent. It is settled in European legal systems within the states that, since children who are faced with medical interventions do not have natural competency to make their own decisions, the legal representatives have the faculty/obligation to decide and express, with their best interests in mind, their desire to perform the surgery⁴⁰.

In theory, the legal representatives of the child are those who are entitled to determine what the child’s will is and, if provided consent is given to the intervention in a fully informed manner⁴¹, there would be no problem in this particular.

At this point, we must ask ourselves: it is legitimate, in light of the child’s abovementioned fundamental rights and on the assumption that the child is unable to express their will, to exclusively give the legal representatives the power to take decisions on the performance of a highly-intrusive and likely definitive surgical intervention? It is not within the core of child’s personality the decision on the eventual ablation of part or totally of their genitals? Doesn’t that choice to intervene limit the child’s development? Do the states have the obligation, under international instruments, to protect intersexual children from early surgical interventions, assuring that their right to choose sex and gender (or not to choose at all) remains within their reach, when their natural capability arrives?

In an attempt to answer these questions, some guidelines can be taken into account. When a clinical manifestation of intersexuality does not provoke a situation that seriously undermines life or development that demands an urgent intervention, it is our belief, due to the current international framework that was surveyed, that is duty of the states to promote an effective system of protection of minors by opposing intervention based on the sole decision of the legal representatives, with the purpose of, with it, effectively ensuring children’s rights provided in Articles 3, 8 and 14 of the ECHR and 12, 16, 24 and 37 of the UNCRC.

⁴⁰ Regarding to the legal recognition of autonomy to consent (civil capacity), the national frameworks have particular importance in determining where the minority status ends and the person assumes full capability. Apart from some national peculiarities, in most European countries the age of legal majority begins at 18. However, there are some acts where the age criterion is removed and it is given to the child the ability to decide if it is found that regardless of age, the child has the natural capability to perceive and decide their will, in an enlightened way. In this regard, there are well known orientations intended to investigate the capability such as the “*Gillick competence*” or the *mature minor doctrine*. Those orientations have been introduced as normative parameters that tend to reduce the amplitude of the effects of legal majority by establishing open clauses that allow the decision maker to verify casuistically the child’s natural capacity and not to be subject to a formal clause. See Robert Wheeler, *Gillick or Fraser? A plea for consistency over competence in children*, BMJ 2006, 332, available at <https://doi.org/10.1136/bmj.332.7545.807> and Melinda T. Derish, *Mature Minors Should Have the Right to Refuse Life-Sustaining Medical Treatment*, 28 JLMedEthics 109 (2000), available at <https://scholarship.law.berkeley.edu/cgi/viewcontent.cgi?article=3178&context=facpubs>.

⁴¹ We must not forget the particular position of parents, who are often not fully informed about the consequences of their decision and, in particular, may not even have freely formed their will in so far as they are simultaneously influenced by social pressure and the desire to have a child that is part of the norm.

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It is imperative, in our opinion, to ensure that any decision on urgent, necessary and irreversible surgery or other intervention has to be taken by a multidisciplinary group that truly ensures, as far as possible, the child's best interest and intervenes only if absolutely necessary for the child's growth and until the child is able to decide. In this context, when a intervention is necessary, and in the light of existing studies, there is no real guarantee that the parents, as legal representatives, are in a position to correctly form their resolution given their personal and emotional connection. For this reason, the establishment of the compulsory intervention of a professional medical group with special qualifications in this area can be an important step in preventing unreasonable surgeries. Simultaneously, we consider it essential that there should be a procedure in place for the formation of qualified, persistent informed consent, together with the express elimination of the possibility for the parents to make such choice by themselves. Such a procedure should also ensure that no decision is taken without full demonstration of the impossibility to wait for the development of the child until their have sufficient capacity to decide, bearing in mind the actual danger that may result from such delay, especially regarding social and educational factors⁴².

Lastly, with regard to the non-urgent medical surgeries and treatments, the child's role in the decision-making process is fundamental, as the child is the one who can legitimately take that decision. Thus, due to the rights and interests in conflict, we believe that only the child is in the position to decide who it wants to be, ultimately, to define who they are. To guarantee the complete formation of the child's will, a procedure must be adopted that ensures the professional supervision of the child, determines the child's actual maturity, the ability to formulate their decision with full awareness of the consequences for their health, body and development, as well as in order to ascertain, in light of what has been established, the safeguarding of their actual superior interest. To this extent, if we place ourselves in the core of personality, the decision, once verified its presuppositions, must be adopted exclusively by the child.

The child's ability to decide, regardless of their age and under the best existing knowledge at the time of the decision, should be measured casuistically, allowing a period of reflection that secures, as far as possible, that the decision that the child adopts is the one that suits them best. Solely through the full respect of the child's will is possible to preserve their right to self-determination.

⁴² In this regard, it is interesting to note the decision adopted by the Constitutional Court of Colombia in 1999. Confronted with the tension of the various vectors, the Court concluded, at the same time, that prohibiting surgeries would imply human experimentalism which is not conform to the dignity of the human person, and that its performance should follow a protocol which would effectively ensure the best interests of the child and the protection of their fundamental rights. See Julie A. Greenberg, *Legal Aspects of Gender Assignment*, *The Endocrinologist*, Vol. 13, No. 3, 279, 2003, available at <https://ssrn.com/abstract=459810>.

d) Empowerment of Intersex Children Human Rights

As we have been saying, there is a junction between legal requirements, medical pressure and social expectations following the birth of an intersex baby. Hence, legal and medical professionals should be better aware of the challenges faced by intersex children to ensure the full respect of their human rights.

In view of the foregoing, the lack of legal and social recognition associated with non-necessary medical interventions, threatens, not only their right to freely develop their personality, but also their right to an equal treatment, without any discrimination based on their sexual characteristics and, to preserve their physical and mental integrity – ultimately, their human dignity⁴³.

We cannot forget that Article 8 of the ECHR protects individuals against arbitrary interference by the public authorities in their private life⁴⁴. In addition to this negative obligation, public authorities also have the duty to undertake positive measures to assure the respect of this right. In fact, Article 8 entails a positive obligation on the part of the state to protect the physical integrity of people within their jurisdiction. Though Article 8 does not contain an express reference to the right to self-determination, the notion of personal autonomy is an important principle subjacent to the interpretation of its guarantees. In this sequence, the European Court of Human Rights has pointed out that elements such as gender identification and name fall within the protection of Article 8.⁴⁵ The European Court holds that gender identity and self-determination belong to one of the most intimate aspects of private life and that registration of a person’s sex in the state’s birth register (and the display of sex in certificates and identity documents) thus has identity building effects. In 2013, the Parliamentary Assembly of the Council of Europe (PACE) called on its Member States to “*ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than a 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*”.⁴⁶

The rights consecrated in the UNCRC can be read to mean that all non-medically necessary normalisation or gender related treatment leading to irreversible alterations to the body must be expressly consented by the

⁴³ Principle 31 of the Yogyakarta Principles states that “*Everyone has the right to legal recognition without reference to, or requiring assignment or disclosure of, sex, gender, sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to obtain identity documents, including birth certificates, regardless of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to change gendered information in such documents while gendered information is included in them*”. Principle 32 refers that “*Everyone has the right to bodily and mental integrity, autonomy and self-determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person*”.

⁴⁴ Moreover, Article 16 of the UNCRC stressed that children shall not be subjected to arbitrary or unlawful interference with their privacy.

⁴⁵ See *Van Kück v. Germany*, Application No. 35968/97, judgment of 12 June 2003, available at <https://www.unionedirittohumani.it/wp-content/uploads/2012/07/CASE-OF-VAN-KUCK-v.-GERMANY.pdf>.

⁴⁶ See PACE’s Resolution 1952 (2013) *Children’s right to physical integrity*, available at <http://assembly.coe.int/nw/xml/xref/xref.xml2html-en.asp?fileid=20174&lang=en>.

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child in line with their best interests and their ability to form and express their views regarding their body and identity. As well, the registration of an unchangeable sex marker on the intersex child’s birth certificate without regard to their gender identity may be wanton and in breach of the child’s right to personal identity and to express their personality.

Thereby, states must recognize that there is an implicit obligation to protect intersex children from genital-normalization surgery and that one mechanism by which to do so is to allow a child to be registered without assigning a sex. Allowing a child to be registered without an assigned sex could encourage the child to identify their sex and gender congruence and better enable any decisions on genital surgery to be lawfully considered. Thus, respecting and reinforcing their right to freely develop their personality, attending to their points of view and best interests, through a supported-decision-making approach to support the welfare of the child, which, at its core, places the child as the primary decision maker⁴⁷.

IV. CONCLUSIONS

Although public awareness of this reality is increasing, intersex children remain subject to violations to their human rights as long as birth and other registries do not ensure a proper record of their sex identity, and as long as they are medically treated as children with health disorders. Hence, we advocate that states’ public policies must facilitate the recognition of intersex individuals before the law through the adoption of a new provision or marker on birth certificates and other legal documents, or, at least by providing the possibility of not choosing a specified male or female sex/gender marker, thereby respecting their right to self-

⁴⁷Yogyakarta Principles 31 recommends that states should “A. Ensure that official identity documents only include personal information that is relevant, reasonable and necessary as required by the law for a legitimate purpose, and thereby end the registration of the sex and gender of the person in identity documents such as birth certificates, identification cards, passports and driver licences, and as part of their legal personality; B. Ensure access to a quick, transparent and accessible mechanism to change names, including to gender-neutral names, based on the self-determination of the person; C. While sex or gender continues to be registered: i. Ensure a quick, transparent, and accessible mechanism that legally recognises and affirms each person’s self-defined gender identity; ii. Make available a multiplicity of gender marker options; iii. Ensure that no eligibility criteria, such as medical or psychological interventions, a psycho-medical diagnosis, minimum or maximum age, economic status, health, marital or parental status, or any other third party opinion, shall be a prerequisite to change one’s name, legal sex or gender; iv. Ensure that a person’s criminal record, immigration status or other status is not used to prevent a change of name, legal sex or gender”. Principle 32 stresses that states shall “A. Guarantee and protect the rights of everyone, including all children, to bodily and mental integrity, autonomy and self-determination; B. Ensure that legislation protects everyone, including all children, from all forms of forced, coercive or otherwise involuntary modification of their sex characteristics; C. Take measures to address stigma, discrimination and stereotypes based on sex and gender, and combat the use of such stereotypes, as well as marriage prospects and other social, religious and cultural rationales, to justify modifications to sex characteristics, including of children; D. Bearing in mind the child’s right to life, non-discrimination, the best interests of the child, and respect for the child’s views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child’s evolving capacity; E. Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child’s right to bodily integrity; F. Provide adequate, independent counselling and support to victims of violations, their families and communities, to enable victims to exercise and affirm rights to bodily and mental integrity, autonomy and self-determination; G. Prohibit the use of anal and genital examinations in legal and administrative proceedings and criminal prosecutions unless required by law, as relevant, reasonable, and necessary for a legitimate purpose”.

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determination. Also, we defend that EU and national equal treatment and non-discrimination legislation should include a specific ground based on sex characteristics providing them with greater visibility.

In relation to medical treatments, in our opinion states have the obligation to intervene in order to prevent all unnecessary, non-emergency, invasive and irreversible surgery or treatment on intersex babies, postponing an eventual decision on this matter, until the child is able to meaningfully express their will in a supported-decision-making process and to give their informed consent, once verified their ability to clearly understand the consequences that their decision can entail. Only this way, can states guarantee full enjoyment of intersex children’s right to their bodily integrity, autonomy and self-determination, and their right to pursue happiness.



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