IN THE EUROPEAN COURT OF HUMAN RIGHTS

M v. France

(Application no. 42821/18)

WRITTEN COMMENTS

Submitted jointly by

OII Europe
ILGA-Europe
C.I.A.

Introduction

These written comments are submitted on behalf of OII Europe (Organisation Intersex International Europe e.V.), ILGA-Europe (European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association), and C.I.A. (Collectif intersexes et allié-e-s) pursuant to leave granted by the President of the Fifth Section. The present case concerns the breach of bodily integrity through sex-assignement procedures on intersex children and the obstacles faced when seeking reparation before the Courts. The third-party interveners analyse the operations imposed on intersex persons in the light of broader trends at the national, regional and international levels that favour recognizing operations on intersex children as breaching the prohibition of inhuman and degrading treatment and torture. It further provides contextual information and comparative law in relation to the obstacles faced by intersex persons in accessing justice. In doing so, the present submission places the Court's jurisprudence in a wider legal and policy context, drawing from regional and international comparative law. The submission provides information about "intersex" as a variation of sex characteristics which does not require medical intervention (I). It analyses the severe suffering caused by sex-assignement procedures in the light of Article 3 of the Convention and broader international developments (II). It further reviews the current obstacles faced by intersex people seeking access to justice, documenting lack of information and secrecy around their situation (III). Last, the submission brings into light the emerging trend towards recognition of the need for a flexible approach to statutes of limitation, placing recent national, regional and international law developments in the context of Article 6 of the Convention (IV). The Annexes support the arguments through testimonies of intersex persons and medical professionals.

I. Who are intersex people

1. The term "intersex" is an umbrella term for the physical spectrum of variations of sex characteristics that naturally occur within the human species. Intersex individuals are born with sex characteristics - sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns - that do not fit the typical definition of male or female. The term intersex acknowledges the fact that people with variations of sex characteristics other than male or female exist.[1] According to the United Nations up to 1.7% of the population, or, globally speaking, as of 2019, 131 million people have been born with intersex traits.[2] The French *Haute Autorité de Santé* (High Authority on Healthcare (HAS)) considers that the frequency of intersex new-borns may reach 2% of births in France.[3]

2. Intersex Genital Mutilation (IGM) is an intervention on a healthy intersex body. It is performed when, according to societal and medical notions, a person's external genitals do not look "normal" enough to pass as "male" or "female".[4] Studies published in the Netherlands in 2014 reveal at least 1 in 200 people are at risk of being subjected to invasive surgeries and other medical interventions, e.g. hormonal treatment, based on being diagnosed by medical professionals as having a "Disorder of Sex Development" (DSD) or an "unspecified" diagnosis, such as "unspecified malformation of the male/female genitalia".[5] "Disorder of Sex Development (DSD)" is a medical umbrella term, which was introduced in 2006 by a Clinician Consensus Statement. Together with new categories of "syndromes", it replaced the older medical terms. Some clinicians use DSD to stand for "differences of" or "diverse" sex development. However, in all its forms the term pathologizes **healthy variations of sex characteristics** and refers to intersex sex characteristics as characteristics that are "deviant" from the norm of male and female bodies and thus need to be "disambiguated" or "fixed". The term "DSD" does not align with human rights standards.[6]

3. Surgeries and medical interventions on intersex infants and children are still common. According to a 2015 survey published by the EU Fundamental Rights Agency, so-called sex-"normalising" surgeries on intersex infants and children are carried out in at least 21 EU Member States. Until recently, only Malta and, with certain nuances, Portugal prohibited these harmful medical interventions. On 26 January 2021, the Belgian Parliament unanimously approved a resolution to recognize the right to physical integrity of intersex minors. The resolution calls on the government "to establish, in collaboration with the representative associations, a legislative framework that protects the physical integrity of intersex minors by guaranteeing, except in cases of serious medical necessity, the prohibition of any decision to modify the sexual characteristics of a minor without their informed consent".[7] Several empirical studies conducted in Germany found that, by 2013, 96% of all intersex persons across different categories had received hormonal therapy; 64% of persons concerned had received a gonadectomy, 38% a reduction of their clitoris, 33% vaginal operations and 13% corrections of their urinary tract. Many had been submitted to a series of operations and were confronted with post-operative complications.[8] In 2016 and 2019, two German studies showed that surgical interventions performed on intersex children

[1] Dan Christian Ghattas (2019): Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist. Ed. by ILGA-Europe and OII Europe. Brussels/Berlin, p.9.
[2] United Nations Office of the High Commissioner for Human Rights (2015): Fact Sheet. Intersex.https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf
[3] Haute autorité de santé, Situation actuelle et perspectives d'évolution de la prise en charge médicale du transsexualisme en France, novembre 2009, p. 23
[4] Dan Christian Ghattas (2019): Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist. Ed. by ILGA-Europe and OII Europe. Brussels/Berlin, p.11.
[5] The Netherlands Institute for Sociological Research (2014): Living with intersex/DSD. An exploratory study of the social situation of persons with intersex/DSD. Written by Jantine van Lisdonk. Appendix B Prevalence table for intersex/dsd. https://www.scp.nl/english/Publications/Publications_by_year/Publications_2014/Living_with_intersex_DSD
[6] Dan Christian Ghattas (2019): Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist. Ed. by ILGA-Europe and OII Europe. Brussels/Berlin, p.9.
[7] Médias de Bruxelles, BX1, "Le droit à l'intégrité physique des mineurs intersexes approuvé en commission de l'Égalité des chances", 26 janvier 2021, https://bx1.be/depeches/le-droit-a-lintegrite-physique-des-mineurs-intersexes-approuve-en-commission-de-legalite-des-chances/.
[8] Rupprecht (2013), "Children's right to physical integrity", report, Committee on Social Affairs, Health and Sustainable Development, PACE (Doc. 13297).

from age 0-10, despite claims of medical specialist, had not gone down between 2005 and 2016 and was still high,[9] despite a lack of evidence that these operations have a positive effect.

4. Since 2009, United Nations Treaty Bodies have made 59 calls on Member States to stop human rights violations against intersex people.[10] Of these, 17 Council of Europe Member States have received 39 UN Treaty Bodies recommendations - three concerning France - 15 of which in the past two years alone[11].

II. The practice of intersex genital mutilation and other sex-assignement operations read in the light of Article 3 of the European Convention on Human Rights

A. The demonstration of the severity of the suffering inflicted on intersex minors

5. The applicability of Article 3 to a given situation requires demonstration that the treatments in question reach a "minimum level of severity" and the Court has identified several general, non-exclusive factors (1). In specific cases, concerning the medical environment, the Court has also developed specific criteria for identifying the minimum level of severity (2).

1) Surgeries and other medical treatments on intersex people read in the light of the general criteria identified by Article 3 case-law.

6. According to the Court, relevant circumstances for Article 3 applicability assessment include "the duration of the treatment and its physical or mental effects" and sometimes the “sex, age, state of health of the victim, etc."[12].

7. The treatments on intersex persons, which are of **long and indefinite duration**, take place at an early age. Operations sometimes begin a few weeks after birth, and generally as soon as possible.[13] In the 1980s, the average age of intervention was 15 months, as "results before 12 months were considered better".[14] Treatments can last a lifetime, as hormone intake is followed by surgery, then operations necessary to counter the side effects of the first operations.[15] The suffering begins quickly, is revived with each operation, and is permanently inscribed in the body of the child who has become an adult.[16] They therefore have a **permanent** character and effect. This is all the more problematic considering intersex children are initially in good health, the organs being viable, and the operations therefore lead to a deterioration of health, both physical and mental.[17]

8. Moreover, the operations are carried out on the bodies of children, who are often incapable of expressing their consent. **Age is a factor of vulnerability** according to the Court, which has held it to be a **decisive criterion for finding a violation of Article 3**.[18] The "victim", who is a minor and unable to consent, must therefore enjoy enhanced protection, having regard to the need to protect its best interests. This situation of vulnerability is recognised by the Commissioner for Human Rights, who considers that intersex persons are "particularly vulnerable" to the risk of "infringements [of] their fundamental rights".[19] This particular vulnerability of intersex children allows for a more flexible appreciation of the requirements of the applicability of Article 3 and reinforces the absolute nature of the prohibition.[20]

2) The specificity of the act performed by medical staff on minor children.

9. In the medical context, according to the Court, there is no interference with Article 3 if the measure is "dictated by a therapeutic necessity ".[21] The Court has specified that the medical necessity must be "convincingly demonstrated".[22]

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[9] U. Klöppel (2016): Zur Aktualität kosmetischer Operationen ‚un-eindeutiger' Genitalien im Kindesalter. Hg. von der Geschäftsstelle des Zentrums für transdisziplinäre Geschlechterstudien der Humboldt-Universität zu Berlin. Berlin. https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/bulletin-texte/texte-42/kloeppel-2016_zur-aktualitaet-kosmetischer-genitaloperationen; Josch Hoenes, Eugen Januschke, Ulrike Klöppel (2019): Häufigkeit normangleichender Operationen „uneindeutiger" Genitalien im Kindesalter. Follow Up-Studie.https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-4

[10] The United Nations Committee on the Rights of the Child (CRC); The United Nations Committee against Torture (CAT); The United Nations Committee on the Elimination of Discrimination against Women (CEDAW); The United Nations Committee on the Rights of the People with Disabilities (CRPD). See OII Europe, Intersex Resources, February 2021, https://oiieurope.org/wp-content/uploads/2018/05/International-intersex-human-rights-movement_Links-to-human-rights-documents-adressing-intersex-and-important-events_February-2021-1.pdf.

[11] Country (Number of recommendations): Austria (2); Belgium (2);Denmark (2); France (3); Germany (4); Ireland (2); Italy (3); Liechtenstein; Luxembourg; Malta; Netherlands (2); Portugal; Slovakia; Spain; Switzerland (4); UK (3). See OII Europe, Intersex Resources, June 2020,

[12] ECHR, Irlande v. UK, 18 January 1978, app. n°5310/71, §162.

[13] GUILLOT, Vincent, op. cit, p.53. See also Amnesty International (2017), “First, Do Not Harm”, p.20.

[14] CATTO, Marie-Xavière, « Le principe d'indisponibilité du corps humain, limite de l'usage économique du corps. », sous la direction de CHAMPEIL-DESPLATS, Véronique, Ecole doctorale de droit et de sciences politiques, Centre de Théorie et analyse du droit, Droit public Université Paris Nanterre, 2014, 432.

[15] GUILLOT, Vincent, op. cit, p. 36; Amnesty International (2017), *op. cit.,* p. 34; Committee Against Torture, Concluding Observations on Intersex people, Germany, CAT/C/DEU/CO/5, para.20.

[16] DERAVE, Charly, op. cit., p.46.

[17] J. Woweries (2012): Deutscher Ethikrat. Stellungnahme zur Situation von Menschen mit Intersexualität in Deutschland. Berlin. https://www.ethikrat.org/fileadmin/PDF-Dateien/Stellungnahmen_Sachverstaendige_Intersexualitaet/Woweries_-_Expertenbefragung.pdf

[18] ECHR, Mubilanzila Mayeka and Kaniki Mitunga v. Belgium, 12 Octobre 2006, app. 13178/03, § 69.

[19]Commissioner for Human Rights, Council of Europe, Human Rights and Intersex people, Issue paper, 2015, p 7. https://rm.coe.int/human-rights-and-intersex-people-issue-paper-published-by-the-council-/16806da5d4. [Hereinafter Commissioner for Human Rights, COE, 2015].

[20] PASTRE-BELDA, Béatrice, « La protection à géométrie variable de l'article 3 de la Convention européenne des droits de l'Homme», op. cit. pp. 595.

[21] ECHR, Herczegfalvy v. Austria, 24 April 1992, app n° 10533/83, §82.

[22] ECHR, Jalloh v. Germany, 11 July 2006, app. n°54810/00, §69.

10. In 2018, the French *Conseil d'Etat* recalled that for "medical necessity" to be established, a medical act must have a therapeutic purpose - that is diagnosing, preventing, or curing a pathology - and be necessary to reach such a purpose[23]. In most cases, when performing surgeries on intersex children doctors don't invoke therapeutic but **psychological motives**, to "ensure the mental and social development of the children".[24] However, the *Conseil d'Etat* observed that to establish the therapeutic purpose, **suffering must indeed be experienced and expressed by the person**.[25] Accordingly, when the child is not able to express its will, only a "very serious medical motive", that is, only interventions which are necessary to prevent life-threatening situations or physical suffering, can justify that, without waiting that the child is old enough to participate in the decision, a medical act which infringed the physical integrity be performed. Similar conclusions were drawn from the *French National Consultative Ethics Committee* in 2019. It recommended that the decision on interventions that are irreversible and remove or substantially alter a sexual organ should be taken only by the persons concerned, once they are in a position to make an informed choice[26].

11. The lack of medical necessity also results from the **absence of scientific evidence as to the benefits** of the interventions, as confirmed by a 2017 study commissioned by the Council of Europe[27]. It was observed that "quality of life" studies on patients into adulthood are "poorly researched"[28]. At the same time all evidence-based reviews acknowledge that harms have occurred and may continue to occur for patients, including pain, dysfunction, error in gender assignment, and have detrimental impacts to their quality of life. Except for a few rare life-saving procedures[29], no scientific review has identified any other procedure as medically necessary or confirmed to have a balance of long-term benefits from gender-"normalizing" interventions in infancy[30]. It concluded that "**freedom from experimentation** is breached "as children continue to undergo **unproven treatments without proof of their therapeutic character".**[31] Medical treatment of an experimental character without the consent of the person involved may amount to a violation to Article 3 ECHR, as established by the European Commission of Human Rights[32].

12. Moreover, the cosmetic purpose is acknowledged by the medical community.[33] Experts consider these interventions a response to "**socio-cultural needs that are medically unjustified**".[34] According to the French Urology Association, "[a]part from metabolic and endocrine disorders that require specific paediatric care from birth, children suffering from congenital adrenal hyperplasia must be rapidly referred to a paediatric surgeon in order to **improve the aesthetic appearance of the external genitalia and to create the anatomical conditions for sexual function during adult life**."[35] This line of argument is especially common in regards to, but not limited to children diagnosed with congenital adrenal hyperplasia (CAH). It is also particularly the case for hypospadias, when the opening of the urethra is not at the end of the penis. It is not a disease in itself, and the justification for early intervention is to allow for "sex-typical manner for urination" and to make "the penis look normal".[36] Some medical guidelines explicitly refer to "aesthetic and psychological reasons".[37]

13. Thus treatments that are non-vital and are not performed to prevent actual physical harm but are conducted for cosmetic purposes or socio-cultural needs do not qualify as medical necessities and therefore fall under Article 3.

B. The qualification of the interference with regard to the intensity of the harm inflicted

14. The Court's case-law provides for a gradation of the treatments prohibited by Article 3, and the severity of the suffering inflicted is the main criterion for making the distinction.[38] Furthermore, an act may be contrary to Article 3 by reason of the mental suffering it causes, even if the physical acts taken separately do not reach the required threshold of severity.[39] The most common operations on intersex persons (1) give rise to physical and mental suffering that may be characterised as degrading and inhuman treatment and even torture (2).

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[23] Conseil d'Etat, Section du rapport et des études, Étude à la demande du Premier ministre, Révision de la loi de bioéthique: quelles options pour demain? Étude adoptée en assemblée générale le 28 juin 2018, p. 133. [Hereinafter Conseil d'Etat, Etude, 2018].
[24] Conseil d'Etat, Etude, 2018, P.134.
[25] Conseil d'Etat, Etude, 2018, p. 135.
[26] Comité Consultatif National d'Ethique [CCNE], Avis 13, Questions éthiques soulevées par la situation des personnes ayant des variations du développement sexuel, adopté le 19 september 2019 à l'unanimité des membres présents. https://www.ccne-ethique.fr/sites/default/files/avis_132_1.pdf. Recommandation n°3, p. 21.
[27] K. Zillén, J. Garland, S. Slokenberga, The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties, 2017 (Commissioned by the Committee on Bioethics for the Council of Europe), available at <https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016806d8e2f>
[28] *Ibid.* p. 43.
[29] Namely: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion. *Ibid.* p. 43
[30] *Ibid.*
[31] *Ibid, p. 44.*
[32] EHRR (dec.) 2 March 1983, X. v. Denmark, no. 9974/82, DR 1983, 283.
[33] CREIGHTON, Sarah, CHERNAUSEK, Steven, ROMAO, Rodrigo, RANSLEY, Philip, SALLE, Joao, « Timing and nature of reconstructive surgery for disorders of sex development – Introduction », Journal of Pediatric Urology, 2012, p. 603.
[34] SCHNEIDER, Érik, « Les droits des enfants intersexes et trans sont-ils respectés en Europe ? Une Perspective », Rapport d'expert, Conseil de l'Europe, 2013, §§144-145.
[35] Association française d'urologie, "Prise en charge chirurgicale de l'hyperplasie congénitale des surrénales (HCS) chez la fille », 16 mars 2004, https://www.urofrance.org/base-bibliographique/prise-en-charge-chirurgicale-de-lhyperplasie-congenitale-des-surrenales-hcs. The position was reaffirmed in 2017 by Antoine Faix, in charge of the andrology and sexual medicine committee at the French Urology Association. See https://www.20minutes.fr/societe/2172971-20171126-personne-intersexe-depose-plainte-contre-medecins-operee-devenir-homme
[36] GUILLOT, Vincent, « Intersex Genital Mutilations », NGO Report to the 5th Periodic Report of France on the Committee on the Right of the Child, 2015,p.41.
[37] *Ibid*.
[38] ECHR, Ireland v. UK, 18 January 1978, app. n°5310/71, §167.
[39] ECHR, Z. and others v. UK, 10 May 2001, app. n° 29392/95, §§ 72 et 74.

1) Severe physical and mental suffering caused by sex-assignment operations.

15. The suffering endured by children undergoing sex-assignment interventions is well documented.
Intersex people and organisations from across the Council of Europe region have submitted more than 86 shadow reports to UN treaty bodies addressing the long-term health consequences of these breaches of their bodily integrity.[40]

16. Those reports highlight, among other forms of intervention, feminising procedures (including amputation or reduction of the clitoris, vaginoplasty and vaginal dilatation) which have a high risk of complications and reportedly lead to long-term health issues, such as loss of sexual sensation, painful scars, vaginal stenosis.

17. In addition, to prevent vaginal narrowing and stenosis, the neo-vagina formed in young children is often continuously dilated by the insertion of solid objects by doctors or parents. Children experience this as a **form of rape or sexual abuse**, also reported by parents. Masculinising surgeries include the "repair" of hypospadia, with complication rates over 50%, including urethral stenosis leading to kidney failure requiring dialysis treatment. They also lead to a loss of sexual sensitivity.

18. The reports also describe sterilisation procedures, used for both “feminising" and "masculinising" purposes (castrations, gonadectomies, hysterectomies)[41]; which cause **permanent injury, irreversible infertility and severe mental suffering**. They are usually accompanied by lifelong metabolic problems. They take place at an extremely early age, with one witness reporting the child was castrated at two and a half months, and that his healthy testicles were "thrown in the garbage". For more testimonials about these operations and their consequences, see Annex 1.1.

19. The intensity of the suffering is recognised by UN Committees. They consider the operations cause “severe physical and psychological suffering”[42] which persists in the "long-term",[43] in a context of "violence in the medical environment".[44]

20. The European Parliament refers to these interventions as "genital mutilation" with consequences for "physical, psychological, sexual and reproductive health"[45]. The European Commission has confirmed that “non-vital surgery and medical intervention on intersex infants and adolescents without their personal and fully informed consent” are to be considered “intersex genital mutilation”.[46]

2) Interventions on intersex children amount to degrading and inhuman treatment and even torture.

21. This Court has established that **inhuman treatment** causes "severe physical and mental suffering".[47] It may result from a series of cumulative acts.[48] In the case of intersex children, it is clear from the testimonies and reports that the cumulative operations of sex-assignment cause severe physical and moral suffering. **Degrading treatment** creates "feelings of fear, anguish and inferiority in the victims that humiliate, degrade and possibly break their physical or moral resistance".[49] ‘Fear’, ‘intimidation’ and anxiety are recurrent feelings, strongly documented and supported by numerous testimonies of intersex people.[50] Humiliation is reflected in the terms used by doctors, per example describing the child as a 'failed boy' and even a 'monster'.[51] Physical and mental resistance is often broken, as evidenced by the long list of side effects and suicide attempts.[52] Mental resistance is also shattered by the constant lies surrounding the child's allegedly rare disease. One testimony reveals that the doctors made the child believe there was no one else like him and he was the only one on the planet. The child suffered from anxiety very early on, requiring the use of tranquilisers.[53] The treatment to which intersex children are subjected is therefore degrading.

22. Torture is defined by the Court as "deliberate inhuman treatment causing very serious and cruel suffering".[54] Whereas there is no unique approach adopted by the Court to identify torture, it is usually inferred from a combination of factors. It relies on the criteria[55] adopted in the United Nations Convention against Torture and Other Cruel, Inhuman or Degrading

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[40] *For a full list please visit https://oiieurope.org/wp-content/uploads/2018/09/List-of-intersex-specific-shadow-reports-to-UN-committees-OII-Europe-February_2021.pdf For additional testimonies also see the OII Europe (2019): #MyIntersex Story. Personal accounts of intersex people living in Europe https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf*
[41] *GUILLOT, Vincent, op. cit., p.36.* See also Amnesty International (2017), “First, Do Not Harm”, https://www.amnesty.org/download/Documents/EUR0160862017ENGLISH.PDF.
[42] *Committee on the Rights of the Child, « Observations finales concernant les deuxième à quatrième rapports périodiques de la Suisse », 2015, CRC/C/CHE/CO/2-4, p.10.*
[43] *Committee on the Elimination of Discrimination against Women, «Concluding observations on the combined seventh and eighth periodic reports of Germany », 2017, CEDAW/C/DEU/CO/7-8, p.8.*
[44] *United Nations entities, Joint Statement, “Ending violence and discrimination against LGBTI people”, p. 1. https://www.who.int/hiv/pub/msm/Joint_LGBTI_Statement_ENG.pdf?ua=1*
[45] *European Parliament, Resolution on promoting gender equality in mental health and clinical research, 2016/2096(INI), 2017, §BC.*
[46] *European Comission, #UnionOfEquality. LGBTI Equality Strategy 2020-2025, p.15.*
[47] ECHR, Ireland v. UK,, 18 janvier 1978, req. n° 5310/71, §167.
[48] ECHR, Irlande v. UK, 18 janvier 1978, req. n° 5310/71, §167.
[49]ECHR, Irlande v. UK, 18 janvier 1978, req. n° 5310/71, §167.
[50] GUILLOT, Vincent, op. cit., p. 15; see also: Amnesty International (2017), “First, Do Not Harm”, https://www.amnesty.org/download/Documents/EUR0160862017ENGLISH.PDF; OII Europe (2019): #MyIntersex Story. Personal accounts of intersex people living in Europe https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf; and many testimonies to be found in intersex NGO shadow reports, see footnote 40.
[51] Ibid., p. 14 et 18.
[52] Commissioner for Human Rights, Council of Europe, Human Rights and Intersex people, Issue paper, 2015. p.22.
[53] *Ibid*, p.15.
[54] ECHR, Irlande v. UK, op. cit. § 167.
[55] ECHR, Selmouni v. France, 28 July 1999, app. n° 25803/94, §97

Treatment or Punishment.[56] In the case of Jalloh v. Germany, Judge ZUPANČIČ considered that, to reach the threshold of torture the treatment must cause "severe pain or suffering" and be administered by State agents in a context of intimidation or discrimination.[57]

23. It is clear from the Court's case law that medical personnel are assimilated to State agents when they work in structures placed under the authority of the Ministry of Health,[58] *i.e.* when the State is involved in the conduct of operations. In France, the State is involved in several respects. First, the 2011 civil status circular calls for "appropriate treatment "[59] - including sex-conforming operations - which the public prosecutor's office is therefore aware of. Moreover, the health establishments which carry out the operations and the health insurance organisations which finance them are under the supervision of the Ministry of Health and Social Affairs[60]. In addition, many renowned French public universities and private clinics employ doctors who "promote, prescribe and perform" sex-conforming operations.[61] Finally, the Common Classification of Medical Acts (CCAM) includes a section entitled "Correction of Sexual Ambiguities", which brings together six sex-assignment operations.[62] Sexual conformation operations are therefore attributable to the French State.[63]

24. The requirement of the intentional element is clarified by the Court by reference to the Convention against Torture.[64] According to the Committee against Torture, **intention must be assessed objectively and not subjectively.**[65] The ECtHR recalls that the prohibition applies irrespective of the motivation of the authors. Thus, the "philosophical basis underpinning the absolute nature of the right under Article 3 does not allow for any exceptions or justifying factors or balancing of interests".[66] Moreover, **intention may also derive from the undeniably high degree of intensity of the experienced suffering.**[67] Whereas doctors do not intend to cause the suffering, they are acting with a view to assigning a sex, with knowledge of the risks and suffering caused by their interventions on the bodies of intersex children, which have been extensively documented through various sources.[68] They nevertheless act with full knowledge of the facts, without the infliction of pain being the primary motivation.

25. Furthermore, in its General Comment No. 2, the Committee against Torture considers that "**discriminatory use** of mental or physical violence or abuse is an important factor in determining whether an act constitutes torture".[69] The interventions are indeed the result of discriminatory treatment of intersex children: Healthy intersex new-borns are undergoing operations, whereas healthy non-intersex new-borns are not. Intersex children are undergoing sex-assignment treatments only because of their sex-characteristic, which is a key element to their biological identity.[70]

26. Discrimination on the ground of gender identity contributes to the process of dehumanisation of the victim, which is often a necessary condition for torture and ill-treatment to take place.[71] The rational for subjecting intersex children to sex-conforming surgery, includes prevention of "transgenderism" and "homosexuality". It is accompanied by the attempt to forcefully establish a gender expression and behaviour in the child, which is considered adequate for the assigned sex.[72] This practice therefore deprives intersex children from developing their own personal gender identity. It also discriminates against diverse gender expression and gender behaviour in all children, including non-intersex children.

27. The severity of the suffering is a key factor to the identification of torture. The "severe" nature of the pain is relative in essence: "it depends on all the circumstances of the case, such as the duration of the treatment, its physical or mental effects and, in some cases, the sex, age and state of health of the victim, etc. "[73]. The circumstances of the operations (cf.

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[56] Convention contre la torture et autres peines ou traitements cruels, inhumains ou dégradants, adoptée dans sa résolution 39/26 du 10 décembre 1984, entrée en vigueur le 26 juin 1987, R.T.N.U., vol. 1465, p. 85, Article 1.
[57] ECHR, Jalloh v. Germany, 11 July 2006, n° 54810/00, Concurring opinion of Judge ZUPANČIČ .
[58] ECHR, V.C. v. Slovakia, op. cit., interpretation resulting from the combination of §§9, 102 & §109.
[59] Circulaire du 28 octobre 2011 relative aux règles particulières à divers actes de l'état civil relatifs à la naissance et à la filiation, BO Ministère de la Justice et des Libertés, n° 2011-11 du 30 novembre 2011, p.27. NOR : JUSC1119808C.
[60] MORON-PUECH, Benjamin, « Le droit des personnes intersexuées – Chantiers à venir – 1re partie », Socio – La nouvelle revue des sciences sociales, 2017, p. 28.
[61] GUILLOT, Vincent, op. cit., p.9.
[62] XAVIERE, Marie-Catto, op. cit., p.432. The six operations are JMEA001 - Transposition of the clitoris; JMEA002 - Pedicled neurovascular flap of the clitoris; JMMA001 - Vestibuloplasty with burial or resection of the clitoris, for feminising; JMMA004 - Reduction clitoridoplasty ; JZMA002 - Uretroplasty, vaginoplasty and vestibuloplasty with burial or reduction of the clitoris, for feminisation; JZMA003 - Uretroplasty and vestibuloplasty with burial or reduction of the clitoris, for feminisation
[63] *See* YZERMANS Manon, "La pratique de la conformation sexuée des mineurs intersexués au regard des obligations incombant à la France en vertu de la Convention européenne des droits de l'homme", Mémoire sous la direction de Madame Marina EUDES, Université Paris-Nanterre, 2019, p.34.
[64] ECHR, Ilhan v. Turkey, op. cit., §85.
[65] Committee against Torture, General Comment n°2, «Implementation of article 2 by States parties», 2008, CAT/C/GC/2, §9.
[66] ECHR, Gäfgen v. Germany, 1 June 2010, app. 22978/05, §107.
[67] ECHR, Aydin v. Turkey, 25 Septembre 1997, req. n°23178/94, §§80-88.
[68] See Annex 1.1 and Annex 2.
[69] Comité contre la Torture, « Observation générale n°2 – Application de l'article 2 par les États parties », 2008, CAT/C/GC/2, §20.
[70] For more on the discriminatory aspects of the interventions, see YZERMANS Manon, "La pratique de la conformation sexuée des mineurs intersexués au regard des obligations incombant à la France en vertu de la Convention européenne des droits de l'homme", Mémoire sous la direction de Madame Marina EUDES, Université Paris-Nanterre, 2019, Section 2.
[71] UN General Assembly (2001), 56th session, Question of torture and other cruel, inhuman or degrading treatment or punishment, A56/156, para. 19. https://documents-dds-ny.un.org/doc/UNDOC/GEN/N01/445/79/PDF/N0144579.pdf?OpenElement.
[72] See e.g.CARPENTER, Morgan: The human rights of intersex people: addressing harmful practices and rhetoric of change, Reprod Health Matters. 2016 May 24(47), p. 75; DREGER, Alice; FEDER, E.K., TAMAR-MATTIS, A.: Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine. J Bioeth Inq. 2012; 9(3): p. 277; WHITE, Perrin C.; SPEISER, Phyllis W.: Congenital Adrenal Hyperplasia due to 21-Hydroxylase Deficiency, Endocrine Reviews, Volume 21, Issue 3, 1 June 2000, p. 262; MEYER-BAHLBURG, H. F. L.: What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?, The Journal of Clinical Endocrinology & Metabolism, Volume 84, Issue 6, 1 June 1999, p. 1844–1846; MEYER-BAHLBURG, H. F. L. (1990): Will Prenatal Hormone Treatment Prevent Homosexuality? Journal of Child and Adolescent Psychopharmacology, 1(4), p. 280; DORNER, G. (1968): Hormonal Induction and prevention of female homosexuality. Journal of Endocrinology, 42(1), Page 163
[73] ECHR, Selmouni v. France, op. cit., §100.

Supra, II.A.) reveal a high degree of suffering, both physical and moral. Intersex persons who have undergone the operations also consider them as torture.[74] Furthermore, the Special Rapporteur on Torture himself issued a strongly worded statement condemning non-consensual surgical **intervention on intersex people as a form of torture** which **"**causes severe mental suffering"**.**[75] The position expressed by other UN Committees, the Council of Europe and the European Commission is also along these lines; and it reflects broader national, regional and international developments.

C. National, regional and international developments supporting the finding of a violation of Article 3.

28. The characterisation of the acts as inhuman and degrading treatment, and *a fortiori* as acts of torture, is in line with the Court's logic of analysing the situations in the light of today's conditions as identified in the *Selmouni v. France* judgment. This evolving factor is the "increasingly high standard being required in the area of the protection of human rights and fundamental liberties [which] correspondingly and inevitably requires greater firmness in assessing breaches of the fundamental values of democratic societies."[76] Thus, this evolving criterion must be analysed in the light of recent developments regarding the enhanced protection of the fundamental rights of intersex persons in law and in case law, at national and international levels.

1) A finding of a violation of Article 3 in accordance with the position of the Council of Europe

29. Already in 2013, the Parliamentary Assembly of Council of Europe was particularly worried about early childhood medical interventions on intersex children, which are a "violation of the[ir] physical integrity", and "which supporters of the procedures tend to present as beneficial to the children themselves despite clear evidence to the contrary."[77] In 2017, the Assembly recalled the issue of consent given the lack of evidence of the long-term success of treatments, which moreover have no "real therapeutic purpose", but rather a "social" one.[78] The qualification of torture is not explicitly retained, as within the Council of Europe, such a qualification falls within the Court's jurisdiction. On the other hand, the Assembly explicitly points out that these practices raise important questions in the light of Articles 3 of the Convention.[79]

30. Similarly, in 2015, the Commissioner for Human Rights published an issue paper entitled "Human Rights and Intersex Persons"[80]. It referred to the damage to "physical" and "psychological" well-being and the "negative consequences throughout life", including "sterilisation, severe scarring, infections in the urinary tract, reduced or complete loss of sexual sensation, removal of natural hormones, dependency on medication, and a deep feeling of violation of their person." In the same vein, the report by Marlene Rupprecht described the treatment suffered by children as "**traumatising**" due to "humiliating procedures".[81] Some operations are experienced as **sexual violence**, in particular the "feminising" procedure consisting in keeping the neovagina "open using a dilator" which is usually inserted regularly by the child's mother.[82] The parents themselves sometimes "have had the impression of committing **rape** on their child. "[83] The intensity of the pain is also revealed by "self-harming and suicidal behaviour", which, according to one study, is "twice as high as in a community-based comparison group of non-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse".[84] Although the notion of torture is not explicitly included in these reports, they all nevertheless indicate a context that is conducive to such a qualification. Besides, the Commissioner for Human Rights notes the emergence of a common position among regional and international bodies for the protection of fundamental rights on the need to intervene against these operations which cause "lifelong harm".[85]

2) The existence of an international consensus condemning the practice of sex-assignement

31. The condemnations of States by United Nations (UN) committees are indicative of the existence of an international consensus recognizing sex-assignement operations as a violation of bodily integrity (See Annex 2). They also illustrate the insufficient pressure that such condemnations represent, as the practice continues worldwide. The Committee on the Rights of the Child considers that the operations, which are "medically unnecessary" [86] and "irreversible" cause "severe physical and psychological suffering" and undermine the physical and mental integrity, autonomy and self-determination of intersex children. It recalls the need for free and informed consent prior to any surgical procedure performed on an intersex child.[87] So does the Committee on the Rights of Persons with Disabilities which denounce their "invasive nature" with "irreversible effects".[88] The Committee on the Elimination of Discrimination against Women and the Human Rights Committee[89] also underline the inadequacy of irreversible practices, which cause "long-term physical and psychological

[74] GUILLOT, Vincent, op. cit. p. 6 ; LORRIAUX, Aude, op. cit.
[75] MENDEZ, Juan, « Rapport du Rapporteur spécial sur la torture et autres peines ou traitements cruels, inhumains ou dégradants », Conseil des droits de l'homme, A/HRC/22/53, 2013, §77.
[76] Selmouni v. France, op. cit., §101.
[77] Council of Europe, Parliamentary Assembly, « Children's right to physical integrity », Resolution 1952, 2013, §2.
[78] Council of Europe, Parliamentary Assembly, « Promoting the human rights of and eliminating discrimination against intersex people », Resolution 2191, 2017, §2.
[79] *Ibid*., §6.
[80] Commissioner for Human Rights, Council of Europe, Human Rights and Intersex people, Issue paper, 2015. https://rm.coe.int/human-rights-and-intersex-people-issue-paper-published-by-the-council-/16806da5d4
[81] RUPPRECHT, Marlene, «Children's right to physical integrity », Report, Committee on Social Affairs, Health and Sustainable Development, Doc. 13297, PACE, 2013, §54.
[82] Commissioner for Human Rights, COE, 2015, p.21.
[83] *Ibid*.
[84] *Ibid*.
[85] PILLAY, Navi, Haut-Commissaire des Nations Unies aux droits de l'homme, Déclaration à l'occasion de la remise du prix « LGBTI Friend of the Year » de l'ILGA et de la présentation du rapport 2014 Homophobie d'État et du Panel de l'ILGA sur l'orientation sexuelle et la législation internationale en matière de droits de l'homme, 30 mai 2014.
[86]Committee on the Rights of the Child, «Concluding observations on the combined second to fourth periodic reports of Switzerland », 2015, CRC/C/CHE/CO/2-4.
[87]Committee on the Rights of the Child, « Concluding observations on the combined fourth and fifth periodic reports of Chile », 2015, CRC/C/CHL/CO/4-5
[88] Committee on the Rights of Persons with Disabilities, « Concluding observations on the initial report of Uruguay », 2016, CRPD/C/URY/CO/1, §44.
[89] Human Rights Committee, « Concluding observations on the fourth periodic report of Switzerland », 2017, CCPR/C/CHE/CO/4, §24.

suffering".[90] In a joint statement, United Nations entities report "abuse in medical settings" through these surgical interventions, which continue to be carried out in the face of "widespread impunity".[91] In 2015, the Office of the High Commissioner for Human Rights explicitly stated that these acts - which are "typically irreversible and cause severe, long-term physical and psychological suffering" - can, **when forced or otherwise involuntary, breach "the prohibition of torture and ill-treatment**".[92] This issue is of particular concern to Special procedures mandate-holders on the right to health and torture.[93]

32. In 2019, the European Parliament confirmed the "high prevalence of surgeries and medical treatments carried out on intersex infants, although in most cases these treatments are not medically necessary"[94]. It deplored that many intersex children face **"human rights violations and genital mutilation"** when undergoing sex-normalising treatments.[95] It strongly condemned these treatments and surgery and encouraged Member States to adopt legislation prohibiting them.[96] In its 2020-2025 LGBTIQ Strategy, the European Commission condemned medical intervention on intersex infants and adolescents as being "[h]armful practices" or "intersex genital mutilation" which may have "serious bodily and mental health repercussions".[97]

33. National human rights bodies follow the same approach towards condemning IGM and other treatments. Testimonies, found amongst others in reports of the New Zealand and San Francisco human rights commissions and the documentary *Intersexion*, confirm the **traumatic experiences** of intersex people's suffering following medical interventions without consent.[98] The Swiss Ethics Committee considers that the medical practice is motivated by cultural and social value judgements that are no longer compatible with fundamental human rights, in particular with respect for the rights of the individual physical and psychological integrity and the right to self-determination.[99]

34. Case-law from national Courts also prohibit the practices. In 1999, the **Colombian Constitutional Court** delivered two decisions which **significantly restricted the possibility of doctors and parents to perform surgery on intersex children**, because such surgery could infringe the rights of the child and its best interests.[100] In 2008, it reinforced its position, in a case where the complainant was a father who wished to opt for surgery for his five-year-old intersex child, which was refused by the social services.[101] The Court decided that "in intersex cases involving surgery, **the decision of the child was paramount**, while the right of the parent to make decisions was secondary"[102]. In Germany, Christiane Völling sued the surgeon who removed her uterus, tube and ovaries without her consent 30 years previously. The Cologne District Court found that **the doctor had "culpably violated her health and self-determination" and** ordered the surgeon to pay her €100 000 in damages.[103] Importantly, this case established two key principles: i) the continued effect of surgeries suffered in the past and ii) compensation beyond a mere token gesture or apology.

35. Oppositions are voiced also within the medical community. Dr. Venhola, a paediatric surgeon, denounced the interventions and confessed that "when [he] was doing [his] first intersex surgery due to cosmetic reasons [he] **felt it was such a huge human rights violation**, and especially a violation of children's rights"[104] (see Annex 1.3).

III. Systematic lack of information and secrecy around the situation of intersex children and their families supporting the need for a flexible approach to statutes of limitation

36. International and national bodies recognise the right of intersex children to compensation for the damages suffered. The International Intersex Forum's Public Statement called for the provision of "**adequate redress, reparation, access to justice and the right to truth**". It stressed that frequent unavailability of medical records hinders intersex people's access to judicial remedies.[105] The Committee on the Rights of the Child recommended that States promptly "investigate incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation"[106] However, in practice, this right is hindered by the lack of flexibility of statutes of limitation.

[90] Committee on the Elimination of Discrimination against Women, « Concluding observations on the combined seventh and eighth periodic reports of Germany », 2017, CEDAW/C/DEU/CO/7-8, §23 (e).
[91]United Nations entities, Joint Statement, "Ending violence and discrimination against LGBTI people", p. 1. https://www.who.int/hiv/pub/msm/Joint_LGBTI_Statement_ENG.pdf?ua=1
[92] Human Rights Council, « Discrimination and violence against individuals based on their sexual orientation and gender identity », 2015, A/HRC/29/23, §38. https://undocs.org/A/HRC/29/23
[93]Ibid, §81.
[94] European Parliament [EP], 2019, Resolution on the rights of intersex people (2018/2878 (RSP)), §C. https://www.europarl.europa.eu/doceo/document/TA-8-2019-0128_EN.html. [Hereinafter European Parliament Resolution, 2019]
[95] European Parliament Resolution, 2019, op. cit. §L.
[96] European Parliament Resolution 2019, §2.
[97] European Commission, LGBTIQ Equality Strategy 2020-2025, COM/2020/698 p.15. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52020DC0698
[98] New Zealand Human Rights Commission (2010), "To be who I am" – intersex material from report of the inquiry into discrimination experienced by transgender people; San Francisco Human Rights Commission (2005), "A human rights investigation into the medical 'normalization' of intersex people"; Ponsonby Productions Ltd. (2012), "Intersexion".
[99] Commission nationale suisse d'éthique pour la médecine humaine (NEK-CNE), Attitude à adopter face aux variations du développement sexuel. Questions éthiques sur l'intersexualité, prise de position n°20/2012, novembre 2012, p. 20.
[100] Corte Constitucional de Colombia (Constitutional Court of Colombia), Sentencia SU-337/99, 12.05.1999, and Sentencia T-551/99, 02.08.1999.
[101] Corte Constitucional de Colombia (Constitutional Court of Colombia), Sentencia T-912/08, 18.12.2008.
[102] ICJ (2011), Sexual orientation, gender identity and justice: A comparative law casebook, p. 151.
[103] See Section 2.1 for her own personal testimony; Kölner Landgericht (Cologne District Court), 25 O 179/07, 6 February 2008.
[104] Bonobo3D (2013), Mika Venhola on intersex, http://youtu.be/riNtxjntqZE; M. Venhola (2012), "Intersex: Ambiguous genitals or ambiguous medicine?", 12th International Symposium on Law, Genital Autonomy, and Human Rights: Programme and Syllabus of Abstracts.
[105] Public statement by the Third International Intersex Forum (2013) at: www.ilga-europe.org/home/news/latest/ intersex_forum_2013
[106] Committee on the Rights of the Child, Concluding observations on the fifth periodic report of New Zealand, 2016, CRC/C/NZL/CO/5, §25, c.

37. In many legal systems across the Council of Europe region, informed consent is required prior to medical intervention[107]. According to French law, the patient must give an "informed consent" before the medical act is performed.[108] Prior to the consent,[109] medical staff must deliver exhaustive information concerning "the different investigations, preventive treatments or actions that are proposed, their utility, their urgency, their consequences, the frequent or serious risks that are normally foreseeable and other solutions possible and the foreseeable consequences in case of refusal [to undergo the medical acts]".[110] In practice, however, information is usually unclear, and the consent is therefore vitiated.

38. Ethics Bodies from Council of Europe Countries have recognised the issues resulting from lack of complete information.**[111]** The lack of information is also acknowledged by French bodies. The *Conseil d'Etat* [112] and the *Défenseurs des Droits*[113] note that the medical staff usually fails to deliver exhaustive information regarding the utility and the risks of the medicals acts to parents of intersex children. Several testimonies in France and abroad suggest that parents and intersex children were not correctly informed before, during and after the sex-assignment procedures,[114] as highlighted in cases brought before the Courts in Germany[115]. According to the testimonies, "intersex" was presented as a pathology to the parents, without accurate and complete information on the situation of the child, the extent of the interventions that would be performed during childhood and their physical, sexual, reproductive and psychological consequences. Thus, consent given by the parents were not free and informed and the interventions were therefore illegal and subjected to compensation for the damages resulting from them.[116]

39. The Council of Europe Commissioner for Human Rights also notes that **parents are often ill-informed and impressionable and are not given adequate time or options necessary to provide fully informed consent.** [117] One mother explained how parents can be swayed, as doctors led her to question herself "because of how adamant they were".[118] Another mother confessed she felt "manipulated" by the medical professionals she trusted.[119] For its part, the European Parliament noted that "cosmetic surgeries and urgent surgeries" are often "proposed as a package, preventing parents and intersex people from having full information on the impact of each".[120] Besides, parents are strongly pressured to make decisions "without being fully informed of the lifelong consequences for their child".[121] Doctors use terms such as "disorders" to refer to the sexual variations they associate with a disease.[122] Some openly admit that early surgery is intended to facilitate the consent - inevitably vitiated - when the child "is still in the cradle".[123] Besides, parents often only have access to psychological support if they consent to corrective surgery.[124] The Council of Europe itself recognises the pressure on parents to make decisions in an emergency, with devastating consequences for the future life of their child, "without a real understanding of the long-term consequences of [these] decisions".[125]

40. In addition, **the reality of the situation is hidden to intersex persons** as they grow older. The French *Conseil d'Etat* acknowledged that the reality behind the surgeries, which are mutilating and can have dramatic and irreversible consequences, is often hidden from intersex persons.[126] The *Défenseur des droits* refers to a study[127] which reveals that many participants were made to believe they had no choice but to engage in various treatments and that there exists an

[107] See PRE-MAX Consortium (2016), Patients' rights in the European Union. Mapping eXercise: final report (for the European Commission), p. 30 https://op.europa.eu/en/publication-detail/-/publication/8f187ea5-024b-11e8-b8f5-01aa75ed71a1/language-en. The Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention) states as a general rule that an intervention in this field «may only be carried out after the person concerned has given free and informed consent to it» (Article 5). Article 6 adds that «an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit».
[108] L.1111-4 of the French Public Health Code
[109] *ECtHR, 2 June 2009, Codarcea v. Romania, n° 31675/04*.
[110] Article L.1111-2 of the French Public Health code
[111] Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) (2012), "On the management of differences of sex development: ethical issues relating to 'intersexuality'" Opinion No. 20/2012; German Ethics Council (2012), "Intersexuality opinion"; NEK-CNE (2012) https://www.ethikrat.org/pressekonferenzen/veroeffentlichung-der-stellungnahme-intersexualitaet/?cookieLevel=not-set&cHash=f1ef156feb53148773d0a3c45c3df624; Denmark, Board of Equal Treatment (Ligebehandlingsnævnet) (2013), Decision No. 249/2013, 27 November 2013.
[112] Conseil d'Etat, Etude, 2018, p.141.
[113] Défenseur des Droits, Avis 17-04, 2017, p.2.
[114] Défenseur des Droits, Avis 17-04 du 20 Février 2017 relatif au respect des droits des personnes intersexes, https://juridique.defenseurdesdroits.fr/doc_num.php?explnum_id=18576, p.2. [Hereinafter Défenseur des Droits, Avis 17-04, 2017].
[115] OLG Cologne, 3 sept. 2008, no 5 U 51/18 ; LG Nuremberg-Fürth, 17 déc. 2015, no 4 O 7000/11.
[116] Défenseur des Droits, Avis 17-04, 2017, p.4.
[117]Commissioner for Human Rights, COE, 2015, p.23.; State of Victoria Department of Health (2013), Decision-making principles for the care of infants, children and adolescents with intersex conditions, p. 2 ; J. C. Streuli, E. Vayena, Y. Cavicchia-Balmer and J. Huber (2013), "Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development", Journal of Sexual Medicine, Vol. 8 No. 3, pp. 1953-1960; C. Greenfield (8/7/2014), "Should we 'fix' intersex children?", The Atlantic.
[118] State of Victoria Department of Health (2013), Decision-making principles for the care of infants, children and adolescents with intersex conditions, p. 2 ; J. C. Streuli, E. Vayena, Y. Cavicchia-Balmer and J. Huber (2013), "Shaping parents: Impact of contrasting professional counseling on parents' decision making for children with disorders of sex development", Journal of Sexual Medicine, Vol. 8 No. 3, pp. 1953-1960; C. Greenfield (8/7/2014), "Should we 'fix' intersex children?", The Atlantic.
[119] LORRIAUX, Aude, « L'histoire de M., première personne intersexe au monde à porter plainte pour mutilations », Slate, 10 avril 2019.
[120] European Parliament Resolution 2019, §C.
[121] European Parliament Resolution 2019, §G.
[122] GUILLOT, Vincent, *op. cit.*, p. 22; Amnesty International (2017), "First, Do Not Harm", p.14.
[123] Ibid., p. 71-72.
[124] Ibid.
[125] Conseil de l'Europe, Assemblée parlementaire, « Promouvoir les droits humains et éliminer les discriminations à l'égard des personnes intersexes », Résolution 2191, 2017.
[126] Conseil d'Etat, Section du rapport et des études, Étude à la demande du Premier ministre, Révision de la loi de bioéthique: quelles options pour demain? Étude adoptée en assemblée générale le 28 juin 2018, p. 132. [Hereinafter Conseil d'Etat, Etude, 2018].
[127] Défenseur des Droits, Avis 17-04, 2017, p.4.

institutionalised disregard for the bodily autonomy of people with intersex variations. It recommended the creation of a compensation fund to ensure an adequate reparation of the damages.[128] This collective procedure of reparation was also recommended by the German Ethics Council.[129]

41. The Commissioner for Human Rights of the Council of Europe deplored that "**secrecy and shame around intersex bodies have permitted the perpetuation of these practices for decades, while the human rights issues at stake have remained for the most part unaddressed.**"[130] It notes that intersex persons are frequently "unaware of the surgeries or treatments that were performed on them early on in their life.[131] Therefore, States have a "**duty to end the secrecy around intersex issues**". It added "truth, and accountability for past malpractice and human rights violations, should be the cornerstones of any process towards reparation. "[132]

42. For its part, the European Parliament noted that "many intersex people **do not have full access to their medical records and therefore do not know that they are intersex or are not aware of the medical treatments they have been subjected to**".[133] It therefore recommended that Member States improve access for intersex people to their medical records [134].

43. Testimonies confirm that intersex people often do not have access to their medical records.[135] Operations of sexual conformation are also disguised, the removal of genital organs being sometimes described as an intervention to prevent the development of a tumour.[136] One testimony mentions an incomplete file, with the first six years of life missing, and some pages belonging "obviously to another boy's file".[137] Without access to their medical records, intersex persons are unable to establish the details of their identity. Not only do the persons not know that they have undergone sex-assignment surgery, but also that they were born with a variation in sexual characteristics. In addition, the lack of access to one's medical records can lead to severe health repercussions once the intersex person gets older and is in need to seek medical health care for long-term impairments resulting from these interventions.

IV. Comparative national, regional and international law approaches on statutes of limitation in cases involving breach of bodily integrity.

44. The *Stubbings and Others v. United Kingdom* judgment establishes the link between the right to access a court and statutes of limitations, analysing the former as a limitation on this right, and thus an interference with Article 6§1 ECHR.[138] The Court considers limitation rules must not "restrict or reduce the access left to the individual in such a way or to such an extent that the very essence of the right is impaired".[139] They comply with Article 6 only when they pursue a legitimate aim, with a reasonable relationship of proportionality between the means and the aim.[140] Regarding violations of physical integrity, victims cannot reasonably be expected to take legal action before they become aware of the damage suffered.[141] Similarly, when it is scientifically proven that a person is unable to know that he or she is suffering from a certain disease, such a circumstance should be taken into account in calculating the limitation period.[142] This applies all the more to cases where a person does not know that they do not suffer from a disease, because they were made to believe that they did.[143]

45. To identify the principles applicable to statutes of limitations in case of ill-treatment, the Court, in *Mocanu and others v. Romania*,[144] used the requirements of the UN Committee against Torture on the application of Article 14 of the Convention against Torture. The latter obliges States Parties to ensure an effective right to reparation, which may be impeded by the statute of limitations.[145] The Committee emphasized the importance of ensuring "de jure and de facto access to timely and effective redress mechanisms for members of groups marginalized and/or made vulnerable" and of addressing "formal or informal obstacles that they may face in obtaining redress".[146] In identifying vulnerable groups, the Committee emphasizes that "gender" is often a determining factor. Specifically with regard to torture, the Committee considered that **the statute of limitations should be abolished**, in view of the "continuous nature" of its effects.[147] Accordingly, States must provide reparation to all victims of torture "regardless of when the violation occurred".[148] In 2003, the Committee expressly recommended Turkey to "[r]epeal the statute of limitations for crimes involving torture".[149] Interpreting the Convention in the light of these considerations, the Court held that "where a State agent has been charged with crimes involving torture or ill-treatment, it is of the utmost importance for the purposes of an "effective remedy" that

[128] Défenseur des Droits, Avis 17-04, 2017, p.5.
[129] Conseil d'éthique Allemand, Intersexualité, 23 février 2012. http://www.ethikrat.org/dateien/pdf/stellungnahme-intersexualitaet.pdf
[130] Commissioner for Human Rights, COE, 2015, p 7.
[131] Commissioner for Human Rights, COE, 2015, p.14.
[132] Commissioner for Human Rights, COE, 2015, p.51.
[133] European Parliament Resolution 2019, §H.
[134] European Parliament Resolution 2019, §6.
[135] For more testimonies on secrecy and lack of information, see Annex 1.2.
[136] GUILLOT, Vincent, *op.cit,* p.55.
[137] Ibid, p.16.
[138] ECtHR, Stubbings and others v. UK, 22 October 1996, app. n° 22083/93, §§50-51. http://hudoc.echr.coe.int/fre?i=001-58079
[139] *Ibid.,* §50.
[140] Ibid.
[141] ECtHR, Eşim v. Turkey, 17 September 2013, app. n° 59601/09, §25.
[142] ECtHR, Howald Moore v. Switzerland, 11 March 2014, app.. nos 52067/10 and 41072/11, § 78.
[143] YZERMANS Manon, *op. cit*, p. 55.
[144] ECtHR, Mocanu and others v. Romania, 17 September 2014, app. nos 10865/09 45886/07 32431/08, §190.
[145] UN Committee Against Torture (CAT), General comment no. 3, 2012 : Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment : implementation of article 14 by States parties, https://www.refworld.org/docid/5437cc274.html §38.
[146] Ibid, § 39.
[147] Ibid, §40.
[148] Ibid.
[149] Conclusions and Recommendations of the UN Committee against Torture: Turkey, 27 May 2003, CAT/C/CR/30/5, D. (c).

criminal proceedings and sentencing are not time-barred."[150] In any event, the rules of prescription must be compatible with the Convention, and it is therefore "difficult to accept inflexible limitation periods admitting of no exceptions".[151]

46. As regards the proportionality of the limitation rules, it is strictly controlled by the Court. The margin of appreciation of States Parties is restricted when the case affects the physical integrity of an individual. Moreover, the margin has recently been reduced, as revealed in the *Mocanu and Others v. Romania* judgment (2014), which was much more favourable to victims than the judgment in *Stubbings et al. v. the United Kingdom* (1996). While in 1996 the emphasis was on legal certainty, in 2014 the Court insisted on the **necessary flexibility of the limitation period**. In 1996, the margin of appreciation left to the State led to finding non-violation of article 6§1; in 2014, however, the restriction of this margin led to finding a violation. Such an approach could be foreseeable in the 1996 judgment, which warned that, due to "developing awareness in recent years of the range of problems caused by child abuse and its psychological effects on victims [...] it is possible that the rules on limitation of actions applying in member States of the Council of Europe may have to be amended to make special provision for this group of claimants in the near future."[152] Since the Convention is a living instrument to be read in the light of today's living conditions, it is reasonable to consider that in 2021, the situation of intersex persons, a particularly vulnerable group of plaintiffs, requires greater flexibility in limitation rules.

47. Council of Europe Countries have also adopted flexible approaches to statutes of limitations centred on the victim's knowledge. Concerning the starting point of the limitation period, it begins to run at the time when the claimant becomes aware of the person who caused the damage and of the damage itself in Austria[153], in the Netherland[154], in Norway[155], in Poland[156] and in Switzerland[157].In the Netherlands, it is determined by reasonableness and fairness. For health complaints, the required knowledge is only assumed to exist when there is a sufficient degree of certainty to the cause of the health complaints.[158] In a case of medical error where a child had suffered brain damage, the Supreme Court ruled that the limitation period did not start to run at birth, but when the parents became aware that the brain damage was partly caused by the doctor's wrongdoing.[159] In Poland, for damage related to a health disorder or bodily injury, the starting date is when the injured person learns about the existence of the injury and becomes aware of its consequences "from authoritative and competent sources".[160] In Switzerland, the injured party will have sufficient knowledge of the damage if it is aware of its existence and nature in all its essential characteristics.[161] Besides, the prescription period does not commence and – if it has begun – is suspended "for as long as the claim cannot be brought before a court for objective reasons".[162]

48. Under exceptional circumstances, **limitation periods are set aside** in some States. In Azerbaijan, there is no limitation period for claims concerning compensation of damages to the life or health of a person (e.g., including as a result of torture, violence, sexual assault, etc.).[163] In Belgium, acts of indecent assault and rape as well as **female genital mutilation** have no limitation period.[164] In Norway, limitation period does not apply when "the damage is caused … while the injured party was less than 18 years old" or when "the responsible party, or any person that the responsible party is responsible for, before the cessation of the injuring circumstances knew or ought to have known that it could cause risk of loss of life or serious damage to the health."[165] Under extraordinary circumstances, Article 5 of the Polish Civil Code provides a measure to combat statute of limitations. It is often raised in medical cases, **where lack of full and comprehensive information about the effects of an infectious disease may justify exceeding the limitation period of claims for compensation.[166]** In 1999 The District Court decided that "the fact that the hospital has kept the injured person for thirteen years in the belief that there are no negative effects of the surgery and that any possible ailments of the surgery are not a consequence of it justifies not taking into account the statute of limitations as obviously contrary to the principles of social coexistence".[167] In Switzerland, limitation period does not apply to sexual assault committed against minors under sixteen years.[168]

49. To conclude, all these individual issues - encompassing being lied to from birth and constantly hindered from discovering the truth and accessing legal reparation for the psychological and physical harm suffered - are combined in the case of intersex people suffering from being subjected to non-vital surgeries. Thus, intersex people suffer from systematic violation of their rights enshrined in Article 3 and Article 6 of the European Convention on Human Rights.

[150] ECtHR, Abdülsamet Yaman v. Turkey, 2 novembre 2004, app. n° 32446/96, § 55
[151] ECtHR, Mocanu and others v. Romania, 17 September 2014, app. nos 10865/09 45886/07 32431/08, §326.
[152] ECtHR, Stubbings and others v. UK, 22 October 1996, app. n° 22083/93, §56.
[153] Austrian Civil Code, Section 1489 ("*Allgemeines bürgerliches Gesetzbuch*") Text No. 52.
[154] Supreme Court, 26 November 2004, ECLI:NL:HR:2004:AR1739 (Bosman/G).
[155]Limitation Act 1979, Statute on Limitation Section 9 §1.
[156] Article 442 §1 of the Civil Code as amended on 27 June 2017.
[157] Loi fédérale complétant le Code civil suisse (Livre cinquième : Droit des obligations), Article 60 CO.
[158] Supreme Court, 24 January 2003, ECLI:NL:HR:2003:AF0694 (BASF/Rensink).
[159] Supreme Court 31 October 2003, ECLI:NL:HR:2003:AL8168 (*Saelman*)
[160] Supreme Court, 12 May 2011, III CSK 236/10.
[161] BGE 136 III 322, E. 4.1.
[162] Article 134 para. 1 No 6 CO.
[163] Civil Code, Article 384.0.3.
[164] Preliminary Title of the Code of Criminal Procedure, Articles 21bis.
[165] Statute on Limitation Section 9 §2, litra a) and b).
[166] Judgement of the Supreme Court, 8 November 2002, III CKN 1115/00.
[167] Judgement of the District Court in Wroclaw, 20 September 1999, I C 708/96.
[168] Article 187 No. 1 Civil Code.

ANNEX

1. Testimonies

1.1. Testimonies on the suffering and the consequences of the operations

- **Christiane Völling**

Amongst testimonies of trauma and pain is the experience of Christiane Völling, who was born in 1960 in Germany with "indeterminate external genitalia" and was raised as a boy. Ms Völling only discovered what had happened to her following an unrelated incident during which a questionnaire on intersex issues was passed on to her in 2006, almost 30 years after the intervention. In her autobiography, Völling stated:

"The castration [removal of internal testes] that I suffered and the paradoxical administration of high-dose testosterone considered as necessary resulted in **physical and psychological damage** such as hot flashes, depression, sleeping disorders, early osteoporosis, the disappearance of my sexuality and my reproductive capacity, trauma linked to the castration, lesion of the thyroid glands, change in my brain's metabolism and my bone structure as well as many other secondary effects and lesions. The taking of testosterone has caused the development of a typical male hair pattern, a masculine beard, the loss of all my hair linked to the impact of the androgens, a masculinisation of my previously feminine voice, the masculinisation of my facial features and the production of a male anatomy despite female predispositions. The **male genitalia surgically constructed have caused irreversible damage** such as chronic urinary infections, disorders of urination, strictures and scarring. **These interventions have made me lose all my innate feeling of belonging to a sex and all sexual behaviour**."[169]

- **Tiger Howard Devore**

Similarly, Tiger Howard Devore complains about the "masculinising" treatment that he received regarding hypospadias, stating his childhood was filled with pain, surgery, skin grafts, and isolation, adding: "And I still have to sit to pee." For him, "[i]t would have been just fine to have a penis that peed out of the bottom instead of the top and didn't have the feeling damaged".[170]

- **#MyIntersexStory; Testimony from France (age 30-35)**

"I was mutilated in October 1999, in his private clinic. I remember everything, from the shameful shaving of my sex to the gloomy awakening with a nurse shaking my stretcher to wake me sooner. Then I spend weeks and months cleaning my wounds – my mother did it at first, and it was so embarrassing. It was in the same months that I was wearing my corset and cleaning the wounds on my skin every night. I lose my sex life, of course, then my girlfriend. I started anorexia.
The mutilation was a dirty work. I still have folded scars, and parts of a "normal vulva" missing (I read, 16 years later in my medical records, that they talked about retraction). I went to several surgeons years after, to ask for something better. I'll never forget what one of them told me: "Well...fact is, there is not enough left to do anything better…". Back to my 16, and back to the hospital. Remember when I told you I had my period? I had it. Once. Then it disappeared. The doctors said it was because of the trauma of the corset (nothing about the mutilation, nothing about anorexia). They ran other tests. I had new period, once, 10 months after the first. Back to echographies and blood tests, back to pills. My medical records stated than my levels of delta 4 androstenedione and of testosterone were too high — they didn't tell me. They gave me a progestogen, without telling me anything except that "it would help me

[169] C. Völling (2010), Ich war Mann und Frau: Mein Leben als Intersexuelle (I was a man and a woman: my intersex life), Fackelträger, p. 94.
[170] M. Bauer and Zwischengeschlecht.org (2013), "Stop intersex genital mutilations!".

having my period" and then, be a normal 17 yo girl. I read, later, that my medical record said "Stein-Leventhal" (which means PCOS) but they never told me."[171]

- **#MyIntersexStory, Testimony from Belgium (age 40-45)**

"Society is binary and everyone thinks it's always been that way! This ignorance is still present because it is maintained by medical and government authorities. I always thought I wasn't wanted as I was because **I was transformed with surgeries and hormone injections.** And then when I wasn't doing well because of all this, well, I was **sent to psychiatry**! Everyone has missed the real cause of my suffering. My parents did not understand what the doctors told them, but they were convinced that treatments were needed to correct the problem. So, the problem was me! It is not easy to live when you feel that in your heart, when you are afraid of not being loved by your own parents and family, when you are mocked and rejected.
(…)
I felt all my life invisible and unworthy to exist as I was. I have been an object for science and above all a very big problem for my whole family! When my parents talked about me, it was always to complain. My needs, my emotions, my opinion were not taken into account. I had to do as they wanted. I felt manipulated by everyone and everyone lied. **I was abused because I was a vulnerable child** and so were my parents. I still have nightmares about all this. Just as I told the United Nations to testify and explain the feelings of a child who, every morning, receives a visit from the surgeon surrounded by a group of students and everyone talks about his genitals aloud as if he were just a doll in a bed. Someone was lifting the sheets, someone else was taking pictures. I was very embarrassed, I had to be wise and I was told that I was there to be cared for so that everything would be all right.
This way of suffering everything leaves its mark. I was lied to about who I was. I was told how to behave. I was lied to about the effects of the hormones injected and their consequences. The negative and irreversible effects have been deliberately overlooked. **My body couldn't stand all that** and that's normal! I was made sick and now I have to go through all this alone! **These are all complications and my life has been put in unnecessary danger**. My physical and mental well-being has been seriously affected by all this.
I received "with love" everything the doctors had said to do to make me a "normal man". The reproaches I have since received have forced me to bow my back. For years I tried to express my distress and make my family understand it, but in vain. My parents still feed their denial at 80. Every time I try to come back to this subject that obsesses me, they feel aggrieved and struggle, they prefer to relativize and marginalize me. Simply because nothing has healed at home either. After the XXY diagnosis and infertility, my parents' behaviour changed dramatically. My father was totally desolate because his only son was not going to be able to give him natural offspring. And my mother was hit on the head when the doctor told her she was guilty of the problem because the extra x chromosome came from her! To the pain of the treatments was added the guilt of relationships that had become tense at home and the fear of no longer being loved! **At 14, I had my chest removed** by total mastectomy without the torsoplasty that we do today for trans people. **The effects have been terrible**, I keep this area lifeless and nipples insensitive.
I keep the **complications** such as **periodically painful glandular masses on the flanks and under the arms**. I suffered from **muscle tears and joint pain**. I had little stamina and I was always very tired. My father said I was lazy and told my mother they wouldn't do anything good with me! My mother did the best she could despite the fact that my academic and learning difficulties were never recognized. The classmates laughed at me openly and often made me fall down the stairs. Twice I had **broken bones.** I was afraid to go to school. I still hear my father telling me that if I was bored, I should fight "like a man". I experienced all this as **deeply unfair**. The truth is, I wasn't allowed to be myself. I am still always afraid of what people think of me and afraid of how others look at me. When I have to go to the pool with my children, I often have to take an **anxiolytic**. In conclusion, it is mainly my parents who should have been supported and the environment informed. The good job of being a parent is to love, support and defend your child and not to obey inhuman social obligations defended by medicine. Instead, parents learn to be intrusive and control everything in their child, as if to give them the illusion

[171] OII Europe, 2019, Personal accounts by intersex people living in Europe, p.35-37.

that this is the only way to erase everything. Thank you to all the intersex people and allies who have helped me and continue to support me today."[172]

1.2. Testimonies revealing secrecy and shame

- **Testimony of an intersex man**

Eric Schneider refers to the following testimony that he received from an intersex man whose mother was specifically asked by medical practitioners to raise him as a girl:

"I was assigned female at birth but very quickly, it was clear that my behaviour tended to be that of a male. Alongside the surgery, my parents were strongly advised to bring me up in a manner which was geared more to femininity. This began with the toys and the clothes they chose for me and continued with moving me from a mixed school to a school for girls, carefully monitoring my recreational activities with the boys in the neighbourhood (no football or so-called boy's games) and registering me for so-called girl's extra-curricular activities (such as knitting and sewing). Despite all this, my male identity remained. During this period, my Mum was accused by medical professionals of not being strict enough. When I was ten or eleven, my Mum saw that I was unhappy and above all lonely because I did not have any friends, and slackened the reins a little, which allowed me to make new contacts. Except for school, she gradually respected my choices more and more but it was a long road. I've forgiven her now as I know she was only following the practices of the time and it was impossible to find any other information (through the Internet, books or the media). Our relationship was sorely tested when I learnt the truth about my intersexuality. **The fact that I was intersex did not shock me as much as finding out that I had been lied to all my life,** and although I have forgiven my mother our relationship was knocked back by this.[173]

- **Sarah Graham**

In 2006, Sarah Graham, an intersex woman, wrote the following testimony about her experience: "When I was eight, a gynaecologist told my parents this devastating news: that I had a very rare genetic condition and that if my ovaries weren't removed I would develop cancer when I reached puberty and die. **Nearly 20 years later I discovered that my doctors had lied to my parents and me. And this wasn't a one-off – it was standard policy (until the mid-1990s) to hide the truth about all conditions like mine. I was 25 when I found out the extent of the cover-up, and the shock of suddenly being told the true nature of my diagnosis – with no support and after being systematically lied to for so many years – nearly killed me.** I went into an emotional meltdown."[174] Her testimony indicates that irreversible sex assignment surgery and sterilisation are often performed without the fully informed consent of the parents, let alone the consent of intersex persons themselves.

- **#MyIntersexStory; Testimony from Belgium (age 60-65)**

"My Intersex adventure started in 1958 right after I was born when doctors noticed a genital ambiguity but for the sake of convenience very quickly decided to assign me female without even consulting my parents. Diagnosis: PAIS. From that moment, the first interventions and treatments were scheduled and went on for all of my childhood and adolescence. As doctors had very little experience with this kind of cases at the time and some gender theories were emerging, they **took the opportunity to turn me into a case study.** They never thought it necessary to explain my situation to me and they **forbade my parents to reveal it**. (...)The most shocking to me were medical examinations as I was naked in front

[172] OII Europe, 2019, Personal accounts by intersex people living in Europe, p.13-17
[173] E. Schneider (2013), "An insight into respect for the rights of trans and intersex children in Europe", Council of Europe, pp. 30-31.
[174] S. Graham (08/08/2006), "The secret of my sex", The Independent.

of the assistants/students and the pictures they would take at such occasions as if I were a "freak" in a circus. All of this without ever having been sick"[175]

- **#MyIntersexStory; Testimony from the UK (age 40)**

"I was born in 1981, and when I was three weeks old the doctors noticed that there was something "wrong" with me, since I was not urinating in the right place. I had some tests, and they discovered an intersex "condition". Apparently they gave my parents the option of performing a surgery, but there would be certain complications either way, however, **they didn't tell them it was an intersex condition.** (...) They told my parents that I was a boy that needed to be "perfected", this is something my parents accepted, because there was no internet back then, and they were never introduced to any other parents whose children were going through the same thing, they were never told that I didn't need fixing, that I would grow up to be just fine. **So the doctors basically took away my childhood.** (...) Everything that happened around me in my environment was telling me that I was not normal, that I had no place, that **I had to hide this secret,** I even had to hide that I danced! (...) When I was 15 years old, I had a checkup, the first time my father had waited outside. He had always been present while the doctor and often students came to poke me and measure me, telling me how I look or don't look, whether I'm becoming a real boy or not, checking to see if I was growing feminine characteristics, breasts, if I had body hair or not, to see if my voice was breaking etc etc. The man who had been my surgeon since I was three months old decided to check if I could produce sperm this time. **I had no idea that he didn't need to do this**, that a simple test could be done, but this doctor decided to do it manually. I had no idea that it was inappropriate, or that it was sexually motivated, as an intersex male **I was used to having no privacy** over the part of my body that everyone calls our "private parts", they had never been private in my life, at the hospital it was a show for everyone to see, **in my daily life it was a secret, my whole body was a shameful secret"**[176]

- **#MyIntersexStory; Testimony from Russia, Age 26**

"**Not knowing the truth about my body and treatment I received impacted me heavily over the years**, with me developing lots of shame and self-hatred caused by me feeling "not female enough" and me not understanding why my body's different. I still have to deal with a lot of issues I developed during those years, and I always will. Over the years I was never given an explanation on why my breasts didn't grow even after years of taking estrogen, the only advice I was given was to "eat more".
(...)
When I finally discovered that my father purposefully kept the truth about my body from me for 7 years, he said that he was following advice given to him by two different child psychologists, who both told him not to tell me the truth.
Discovering the truth about my body was the best thing in my life, the most empowering thing. For the first time in my life I knew I wasn't alone, I finally felt normal, I finally felt confident. But still I'll never be the person that I could've been if I would've known the truth from the very beginning".[177]

- **#MyIntersexStory; Testimony from a parent of an intersex children born in 2009**

"This is our family story. At 2008, while five months pregnant, I was asked to do an amniotic karyotype testing, due to our age (I was 43 and my husband was 40). The test revealed that everything was normal, except that the baby had an extra X in the sex chromosome, that is a 47,XXY (intersex) karyotype. As this was something new to us, we went online and gathered every possible, updated information about it, so we would be prepared properly. We also met through the internet with many XXY people around the globe, happy to share their personal XXY stories with us and very willing to support us psychologically. Unfortunately my first obstetric doctors in the local hospital were not that

[175] OII Europe, 2019, Personal accounts by intersex people living in Europe, p.19. https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf
[176] OII Europe, 2019, Personal accounts by intersex people living in Europe, p.43.
[177] OII Europe, 2019, Personal accounts by intersex people living in Europe, p.53-55.

well-informed: they call us on a hospital counselling meeting (two of them) and insisted that **the "standard procedure" was to terminate ANY XXY foetus, cause they will be "A freak! A monster! A nature's fault! Someone like with Down syndrome, a dump person incapable of living on its own! A boy with a so small phallus, so better not to be at all"** (these were their exact words…) Since we were informed that all these was false and outdated, we insisted on keeping the baby and they refuse to deliver it, so they made us sign papers that we continue on our own responsibility and they send me to an Athens central hospital to find new doctors to carry on. So, even before T was born, we had to struggle with medical ignorance for his safety and his profound right to be born. As I am hearing from other local hospitals, this "standard procedure" (to terminate healthy intersex foetuses) is still valid… So we can't say how many XXY's have already been "terminated" before being even born. This is an ignorant and racist genocide that has to be stopped, in Greece and globally."

1.3. Testimonies within the medical community

- **Mika Venhola**

The paediatric surgeon Mika Venhola has denounced surgical interventions of intersex people during childhood:

"When I was training to become a paediatric surgeon I was taught how to do these, 'corrective' cosmetic surgeries ... but when I was doing my first intersex surgery due to cosmetic reasons **I felt it was such a huge human rights violation**, **and especially a violation of children's rights**, that I swore I would never do this when I became independent and could decide for myself. And I have never done it, since then". Besides ""the gender of the [intersex] child is an educated guess and entails a great risk of error. The atypical genitals of babies with intersex conditions are not a health risk, but early genital surgery is performed for aesthetic or social purposes…Why operate on the child's body if the problem is in the minds of the adults?"[178]

- **Jörg Woweries**

During his career, the paediatrician Jörg Woweries referred many intersex newborns to paediatric surgeons, but turned around after he started doing follow-up research. In an interview with the journal *Beobachter* he describes this process:

"***Beobachter:*** Why did you advise parents to carry out sex-assigning operations [on their intersex children] for 25 years? ***Woweries:*** I learned during my training that these children should be operated on as early as possible. All renown medical textbooks supported this thesis. As a result of my advice 90% of these children were operated on. Most of them were made into girls. ***Beobachter:*** Why didn't you question this practice? ***Woweries***: because the respective surgeons always claimed that the children were doing fine. ***Beobachter:*** And you believed them? ***Woweries:*** Yes, back than I did. But I was surprised that there were no reports anywhere on the long-term effects. If a child has a heart defect, there are dozens of statistics on the consequences of surgery. There was nothing about sex-determining operations. When I retired I wanted to know more. ***Bobachter:*** What did you find out? ***Woweries:*** I found out that **apparently for 50 years operations were performed without anyone caring about the consequences of the surgery**. **If anything, there were short-term results, nothing more.** It was not until 2004 that the first congress on intersex took place in Lübeck. The first long-term results followed in 2008. They were shocking. ***Beboachter:*** Why? ***Woweries:*** The studies show how high the risk of surgery is and how many patients are harmed by the operations [...] I was horrified by what I had done. It was difficult for me to realise that what I thought was best had harmed many patients. [...] **The harm rates are so significant that I find this intervention without patient consent absolutely wrong. Parents should not be allowed to consent to such surgical**

[178] Bonobo3D (2013), Mika Venhola on intersex, http://youtu.be/riNtxjntqZE; M. Venhola (2012), "Intersex: Ambiguous genitals or ambiguous medicine?", 12th International Symposium on Law, Genital Autonomy, and Human Rights: Programme and Syllabus of Abstracts.

procedures on behalf of their children. If a patient with capacity nevertheless wishes an operation, it is his or her right to have it. [...] Legal measures are needed. This is the only way to put an end to this outdated procedure."[179]

2. United Nations and Council of Europe Bodies condemning human rights violations against intersex persons [180]

2.1. UNITED NATIONS

2014: OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO: Eliminating forced, coercive and otherwise involuntary sterilization: An interagency statement
http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/
2014: United Nations: Intersex People and Human Rights: Violations, Voices and Visions. (Side event at the UN prior to the 25th Session of the Human Rights Council in March 2014) http://youtu.be/hhTYYqCv7gE
2014: Statement by Navi Pillay United Nations High Commissioner for Human Rights on the occasion of the presentation of the ILGA "LGBTI Friend of the Year" award and 2014 State-Sponsored Homophobia report and the Panel on International Human Rights Law and Sexual Orientation
http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=14654&LangID=E
2015: United Nations (2015): Human Rights of Intersex Persons (Side event at the 30th Session of the Human Rights Council in September 2015) https://www.youtube.com/watch?v=uPGOnBSYbOc#t=20
2015: United Nations High Commissioners for Human Rights Zeid Ra'ad Al Hussein Opening Speech for the 30th Session of the Human Rights Council https://ihra.org.au/29966/statement-hrc30-intersex/
2015: Opening remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons
http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E#sthash.AxF1cw1j.dpu

United Nations General Assembly

2009: United Nations General Assembly: Right of everyone to the enjoyment of the highest attainable standard of physical and mental health (A/64/272, par. 49, foot. 67) http://www.refworld.org/pdfid/4aa762e30.pdf

2011: United Nations General Assembly: Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity (A/HRC/19/41, par. 57)
http://www.ohchr.org/Documents/Issues/Discrimination/A.HRC.19.41_English.pdf
2013: United Nations General Assembly: Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez (A/HRC/22/53)
http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
2015: United Nations General Assembly: Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (A/70/213)
http://www.un.org/en/ga/search/view_doc.asp?symbol=A/70/213
2019: United Nations General Assembly: Human Rights Council Fortieth session. Elimination of discrimination against women and girls in sport (A/HRC/40/L.10/Rev.1)
http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/40/L.10/Rev.1

The United Nations Committee on the Rights of the Child (CRC)

1989: United Nations: Convention on the Rights of the Child
http://www.ohchr.org/en/professionalinterest/pages/crc.aspx
2015: The United Nations Committee on the Rights of the Child concluding observations on Switzerland (CRC/C/CHE/CO/2-4)
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En
2015: The United Nations Committee on the Rights of the Child concluding observations on the combined fourth and fifth periodic reports of Chile (CRC/C/CHL/CO/4-5)
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fCHL%2fCO%2f4-5&Lang=en

[179] Jörg Woweries (2012): "Entsetzt über das, was ich tat". Titelthema: Intersexualität. Beobachter 20/2012.
[180] https://oiieurope.org/wp-content/uploads/2018/05/International-intersex-human-rights-movement_Links-to-human-rights-documents-adressing-intersex-and-important-events_February-2021-1.pdf

2016: The United Nations Committee on the Rights of the Child concluding observations on France (CRC/C/FRA/CO/5)
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/FRA/CO/5&Lang=En
2016: The United Nations Committee on the Rights of the Child concluding observations on Ireland (CRC/C/IRL/CO3-4)
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/IRL/CO/3-4&Lang=En
2016: The United Nations Committee on the Rights of the Child concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland (CRC/C/GBR/CO/5) https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/149/88/PDF/G1614988.pdf?OpenElement
2016: The United Nations Committee on the Rights of the Child concluding observations on the second periodic report of South Africa (CRC/C/ZAF/CO/2)
http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ZAF/CRC_C_ZAF_CO_2_25463_E.pdf
2016: The United Nations Committee on the Rights of the Child concluding observations on the fifth periodic report of New Zealand (CRC/C/NZL/CO/5)
http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/NZL/INT_CRC_COC_NZL_25459_E.pdf
2016: The United Nations Committee on the Rights of the Child concluding observations on the combined third to fifth periodic reports of Nepal (CRC/C/NPL/CO/3-5)
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3. Recommendations

3.1. Protecting intersex people against violations of their right to bodily integrity

See Dan Christian Ghattas (2019): Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist. Ed. by ILGA-Europe and OII Europe. Brussels/Berlin, p.15-18.

CURRENT BEST PRACTICES: The Maltese Gender Identity, Gender Expression and Sex Characteristics Act[181]:

- Povides clear and human rights-based definitions of terminology (e.g. sex characteristics).
- Makes a distinction between treatments that address an actual health need of a person, and surgeries and other medical interventions that are cosmetic, deferrable and performed for social reasons.

[181] 7 ACT XI of 2015, as amended by Acts XX of 2015 and LVI of 2016 and XIII of 2018 http://justiceservices.gov.mt/DownloadDocument. aspx?app=lom&itemid=12312&l=1

- Prohibits any sex-"normalising", sex-"assigning" or sex-altering treatment and/or surgical intervention on the sex characteristics of a minor that could be deferred until a time when the minor is able to make their own decision and provide informed consent.
- Allows for surgery and other medical treatment on an infant's or child's sex characteristics in cases where the infant's or child's life is at immediate risk, provided that any medical intervention which is driven by social factors without the consent of the minor is a violation of the law.
- Provides for legal consequences in case the law is breached.
- Allows a mature minor to seek a treatment aiming to alter their sex characteristics, which shall be conducted if the minor gives informed consent.
- Establishes the right to expert-sensitive and individually tailored, life-long psychological and psychosocial support for intersex individuals, their parents and their families

PERSONAL, PRIOR, FREE AND FULLY INFORMED CONSENT: In regard to intersex individuals, we often speak of the necessity of personal, prior, free and fully informed consent.

- **"Personal"** emphasises that only the intersex individual themself is able to consent to such an intervention and that parent or care-taker or medical porfessional cannot substitute for the intersex person's consent.
- **"Prior"** refers to the timing of the consent, such that specific consent must take place before the intervention for which it is sought. For example, there is a common experience such that although parental or individual consent was given for a specific intervention, additional surgeries or interventions were simultaneously performed without consent, then followed by an attempt to gather consent after the fact for the additional interventions.
- **"Free"** refers to the impact of power dynamics that may diminish a person's autonomy and pressure that may impact the individual's ability to consent. For example,reportedly pressure from healthcare providers has lead intersex adults to consent to an intervention that they did not want just to finally have that pressure cease.
- **"Fully informed"** emphasises the need for the provision of the full variety of information and opinions on an intervention, including de-medicalised information.

CONCRETE RECOMMENDATIONS TO STATES

In order to ensure intersex people's right to health, self-determination and bodily integrity, States should create laws that explicitly:

- **prohibit** medical practitioners and other professionals from conducting any irreversible, nonemergency sex-"normalising", sex-"assigning" or sexaltering surgical or other interventions on a person's sex characteristics unless the intersex person has provided personal, free and fully informed consent;
- **establish adequate legal sanctions** conducting any irreversible, non-emergency sex-"normalising", sex- "assigning" or sex-altering surgical or other interventions which can be deferred until the intersex person is mature enough to provide informed consent;
- **establish an independent working group**, composed in equal parts of human rights experts, intersex peer experts, psycho-social professionals and medical experts, to review and revise current treatment protocols to bring them in line with current medical best practice and human rights standards within a limited period of time laid down in the law.
- establish the right to expert-sensitive and individually tailored psycho-social **counselling** and support for all concerned individuals and their families, from the time of diagnosis or self-referral, for as long as necessary;
- allow for surgical and/or other reversible and irreversible interventions to be conducted on a **mature minor**'s sex characteristics, if explicitly wished for by the mature minor and provided the mature minor gives personal and fully informed consent.
- establish the **legal obligation** for medical professionals in regards to all surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or any hormonal set-up:
    - to inform the mature individual comprehensively about the treatment, including other possible medical options and details about risks and possible long-term consequences and effects, based on up-to-date medical information;
    - to provide detailed minutes of the consultation, including all of the above information, which is provided to the patient and in addition, in case of a minor, to their parent(s) or legal guardian(s).

3.2. Ensuring reparation for intersex persons who underwent sex-assignment operations

See Dan Christian Ghattas (2019): Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist. Ed. by ILGA-Europe and OII Europe. Brussels/Berlin, p.39-40.

RECOMMENDATIONS TO STATES:

In order to allow intersex people to access justice, States should:

- extend the **retention period for medical records** of surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or hormonal set-up, including consultation minutes, to a minimum of 40 years in order to allow intersex people access to their medical records at a mature age;
- extend the **statutes of limitations** for surgical and/or other interventions that aim to alter the genitals, gonads, reproductive organs or hormonal set-up of a person to at least 20 years, and suspend them until the minimum age of 21 of the person concerned;
- establish adequate **legal sanctions** for medical and other professionals who conduct any sex-"normalising", sex-"assigning" or sex-altering surgical or other interventions which can be deferred until the person to be treated is mature enough to provide informed consent;

3.3. Addressing research gaps through data collection

See Dan Christian Ghattas (2019): Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist. Ed. by ILGA-Europe and OII Europe. Brussels/Berlin, p.41.

There has been a promising increase in sociological, non-medicalised studies regarding the situation of intersex people over the past few years, most of them conducted in collaboration with intersex organisations and intersex people, acknowledging and remunerating their expertise. However, there is still a substantial lack of data and surveys regarding the living situation of intersex individuals.[182]

RECOMMENDATIONS TO STATES:

There are some parameters, which, when taken into account, have proven to increase the usefulness of research findings on intersex people and foster the development of targeted research approaches:

- Research on the situation of intersex people must ask about experiences, not about identity.
- Intersex people should not be researched only as a subgroup of LGBTI but as an independent part of the population; data disaggregation is key.
- Working together with intersex-led organisations and intersex-led peer support groups is vital for increasing the reach of studies on intersex people.
- Consulting with intersex activists and organisations is important
    - when creating questionnaires to avoid pitfalls that lead to inaccurate data;
    - when analysing and contextualising the data to increase the accuracy of the analysis.

[182] See: PACE (2017): Resolution 2191 (2017), Article 7.5., 7.5.1 and 7.5.2; see also: PACE (2013): Resolution 1952 (2013), Article 7.5.3.