# **Intersex Genital Mutilation** Human Rights Violations Of Children With Variations Of Reproductive Anatomy



Atthe Compro



NGO Report (for LOIPR) to the 6<sup>th</sup> Periodic Report of France on the International Covenant on Civil and Political Rights (CCPR)

# Compiled by:

# GISS | Alter Corpus (Intersex Human Rights NGO)

Mathieu le Mentec, Benjamin Moron-Puech

Association GISS / Alter Corpus Association française Loi 1901 32 Boulevard Saint-Germain 75005 Paris (France)

giss.info\_at\_protonmail.com Facebook: <u>https://fr-fr.facebook.com/gissaltercorpus/</u>

# StopIGM.org / Zwischengeschlecht.org (International Intersex Human Rights NGO)

Markus Bauer, Daniela Truffer

Zwischengeschlecht.org P.O.Box 1318 CH-8031 Zurich

info\_at\_zwischengeschlecht.org https://Zwischengeschlecht.org/ https://StopIGM.org/

# Vincent Guillot (Intersex Person and Advocate, France)

vincentguillot608\_at\_gmail.com

Nadine Coquet (Intersex Person and Advocate, France)

May 2021

This NGO Report online: https://intersex.shadowreport.org/public/2021-CCPR-France-LOIPR-NGO-Intersex-IGM.pdf





# **Executive Summary**

All typical forms of Intersex Genital Mutilation are still practised in France, facilitated and paid for by the State party via the public health system (*Sécurité Sociale – Assurance Maladie*). Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. The Government refuses to take action, upholding the impunity of IGM practitioners, while IGM survivors are denied access to justice and redress.

This Committee has consistently recognised IGM practices to constitute inhuman treatment in Concluding Observations, invoking Articles 2, 3, 7, 9, 17, 24 and 26.

**France** is thus in breach of its **obligations** under the Covenant to (a) take effective legislative, administrative, judicial or other measures to **prevent inhuman treatment and involuntary experimentation on intersex children** causing severe mental and physical pain and suffering of the persons concerned, and (b) **ensure equal access to justice and redress**, including fair and adequate **compensation** and as full as possible **rehabilitation** for victims, as stipulated in the CCPR in conjunction with the **General comment No. 20**.

In total, UN treaty bodies CRC, CEDAW, CAT, CCPR and CRPD have so far issued 52 Concluding Observations recognising IGM as a serious violation of non-derogable human rights, typically obliging State parties to enact legislation to (a) end the practice and (b) ensure redress and compensation, plus (c) access to free counselling. Also, the UN Special Rapporteurs on Torture (SRT) and on Health (SRH), the UN High Commissioner for Human Rights (UNHCHR), the World Health Organisation (WHO), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples' Rights (ACHPR) and the Council of Europe (COE) recognise IGM as a serious violation of non-derogable human rights.

**Intersex people** are born with **Variations of Reproductive Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations.

**IGM practices** include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures** that would not be considered for "normal" children, without evidence of benefit for the children concerned. **Typical forms of IGM** include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, involuntary human experimentation and denial of needed health care.

IGM practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, and less sexual activity.

For more than **25 years**, intersex people have denounced IGM as **harmful** and **traumatising**, as western **genital mutilation**, as **child sexual abuse** and **torture**, and called for **remedies**.

This Thematic NGO Report has been compiled by GISS | Alter Corpus, Vincent Guillot, Nadine Coquet, and StopIGM.org / Zwischengeschlecht.org.

It contains **Suggested Questions** (see p. 23).

# NGO Report for LOIPR to the 6<sup>th</sup> Report of France on the International Covenant on Civil and Political Rights (CCPR)

# Table of Contents

# **IGM Practices in France (p. 9-23)**

Executive Summary	3
Introduction	
Intersex, IGM and Human Rights in France	
About the Rapporteurs	
Methodology	
A. Precedents: Concluding Observations	7
1. Harmful Practices and CRC-CEDAW Joint General Comment No. 18/31	
a) CRC 2016 Concl Obs: CRC/C/FRA/CO/5, paras 47-48	
b) CEDAW 2016 Concl Obs: CEDAW/C/FRA/CO/7-8, paras 34-35	
2. Cruel, Inhuman or Degrading Treatment (CAT art. 16)	
a) CAT 2016 Concl Obs: CAT/C/FRA/CO/7, paras 34-35	
B. IGM practices in France: State-sponsored and pervasive	9
1. IGM in France: Still no protections, Government fails to act	
<ol> <li>IGM in France: Still pervasive, advocated and paid for by State party</li> </ol>	
a) French Reference and Competence Centres practising IGM	
b) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy	
c) IGM 2 - "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty".	
d) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"	15
e) IGM 4 – Prenatal "Therapy"	
3. French doctors and Government consciously dismissing human rights	
a) French agencies recognising intersex human rights	
b) French doctors and Government refusing to act	
4. Lack of Independent Data Collection and Monitoring	
5. Obstacles to access to justice, redress, and compensation	
C. Suggested Questions for the LOIPR	23
Annexe 1 – IGM Practices in France as a Violation of CCPR	
1. The Treatment of Intersex Children in Frace as Inhuman Treatment	
Art. 2: Non-Discrimination, Legal Implementation, Remedies and Reparations	
Art. 3: Equal Right of Men and Women	
Art. 7: Cruel, Inhuman or Degrading Treatment, and Involuntary Experimentation	
Art. 9: Liberty and Security of the Person	
Art. 17: Arbitrary or Unlawful Interference with Privacy	
Art. 24: Child Protection	
Art. 26: Equal Protection of the Law	
2. Lack of Independent Data Collection and Monitoring	26
Annexe 2 – Intersex, IGM and Non-Derogable Human Rights	27

# Introduction

# Intersex, IGM and Human Rights in France

IGM practices in France are known to cause severe, lifelong physical and psychological pain and suffering,<sup>1</sup> and have already been **recognised by UN treaty bodies CAT, CRC and CEDAW** to constitute **inhuman treatment** and a harmful practice.

This NGO Report demonstrates that the ongoing harmful medical practice on intersex persons in France – advocated, facilitated and paid for by the State party – persists in spite of previous Concluding observations by CRC, CAT and CEDAW,<sup>2</sup> and constitutes a serious breach of France's obligations under the Covenant. It further substantiates that, despite some agencies calling for action to protect intersex children, the Government refuses to take action, upholding the impunity of IGM practitioners, while IGM survivors are denied access to justice and redress.

# About the Rapporteurs

This NGO report has been prepared by the French intersex NGO GISS / Alter Corpus and the intersex persons and advocates *Nadine Coquet* and *Vincent Guillot* in collaboration with the international intersex NGO Zwischengeschlecht.org / StopIGM.org.

- The French Association **GISS** | **Alter Corpus**,<sup>3</sup> composed of persons concerned, lawyers and scholars, aims to protect and promote, legally and through their advocacy, the rights of intersexed persons and persons belonging to sex and gender minorities. It is regularly consulted in France and internationally by various human rights and ethics bodies. It participates in the drafting of legal texts for the recognition of the rights of intersex persons.
- Nadine Coquet is a French intersex person, survivor of IGM practices, intersex human rights defender and a member of OII Francophonie. Nadine has testified to IGM practices at a hearing of the French Senate.<sup>4</sup>
- Vincent Guillot is a French intersex person, survivor of IGM practices and an intersex human rights defender for more than a decade. Vincent is a co-founder of Organisation Intersex International (OII).<sup>5</sup>
- **StopIGM.org / Zwischengeschlecht.org** is an international intersex human rights NGO based in Switzerland, working to end IGM practices and other human rights violations perpetrated on intersex people, according to its motto, *"Human Rights for Hermaphrodites, too!"* <sup>6</sup> According to its charter,<sup>7</sup> StopIGM.org works to support persons concerned seeking

<sup>1</sup> CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", <u>http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E</u>

<sup>2</sup> CAT/C/FRA/CO/7, paras 34-35; CRC/C/FRA/CO/5, paras 47-48; CEDAW/C/FRA/CO/7-8, paras 18e-f + 19e-f

<sup>3</sup> Groupement d'information et de soutien sur les questions sexuées et sexuelles (Information and support group on gender and sexual issues), <u>https://hal.archives-ouvertes.fr/hal-01627306/document</u>

<sup>4 &</sup>lt;u>http://www.liberation.fr/debats/2016/05/31/stop-aux-mutilations-des-personnes-intersexuees\_1456398</u>

<sup>5 &</sup>lt;u>http://www.histoiresordinaires.fr/Intersexe-Vincent-Guillot-sort-de-la-nuit\_a1330.html</u> <u>http://www.lefigaro.fr/international/2013/11/01/01003-20131101ARTFIG00204-l-allemagne-devient-le-premier-pays-europeen-a-reconnaitre-un-troisieme-sexe.php</u>

<sup>6 &</sup>lt;u>https://Zwischengeschlecht.org/</u> English pages: <u>https://StopIGM.org/</u>

redress and justice, and regularly reports to UN treaty bodies, mostly in collaboration with local intersex advocates and organisations.<sup>8</sup> In 2015 StopIGM.org in collaboration with French intersex advocates Vincent Guillot and Nadine Coquet first reported the on-going practice in France to CRC,<sup>9</sup> CAT<sup>10</sup> and CEDAW.<sup>11</sup> In 2016 in Paris StopIGM.org facilitated non-violent protests and an Open Letter with 239 signatures denouncing French IGM clinics and universities and their complicity in international medical networks promoting and practicing IGM.<sup>12</sup>

# Methodology

This thematic NGO report is a localised update to the 2021 CCPR Finland NGO Report (for **Session**)<sup>13</sup> by partly the same Rapporteurs.

<sup>7</sup> https://zwischengeschlecht.org/post/Statuten

https://intersex.shadowreport.org/ 8

https://intersex.shadowreport.org/public/2015-CRC-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf 9

https://intersex.shadowreport.org/public/2016-CAT-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf 10

https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf 11

<sup>12</sup> Open Letter of Concern to 55th ESPE 2016 and French DSD Universities and Clinics by Persons Concerned, Partners, Families, Friends and Allies, September 2016, https://zwischengeschlecht.org/public/Open Letter ESPE 2016.pdf

https://intersex.shadowreport.org/public/2021-CCPR-Finland-NGO-Zwischengeschlecht-Intersex-IGM.pdf 13

# A. Precedents: Concluding Observations

1. Harmful Practices and CRC-CEDAW Joint General Comment No. 18/31 a) CRC 2016 Concl Obs: CRC/C/FRA/CO/5, paras 47-48

D. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39)

[...]

# Harmful practices

47. While noting with appreciation the progress made by the State party in eradicating female genital mutilation, the Committee is nevertheless concerned by the many young girls still at risk and the possible resurgence of the phenomenon. The Committee is also concerned that medically unnecessary and irreversible surgery and other treatment are routinely performed on intersex children.

48. Recalling the joint general recommendation/general comment No. 31 of the Committee on the Elimination of Discrimination against Women and No. 18 of the Committee on the Rights of the Child on harmful practices, the Committee recommends that the State party gather data with a view to understanding the extent of these harmful practices so that children at risk can be more easily identified and their abuse prevented. It recommends that the State party:

[...]

(b) Develop and implement a rights-based health-care protocol for intersex children, ensuring that children and their parents are appropriately informed of all options; that children are involved, to the greatest extent possible, in decision-making about their treatment and care; and that no child is subjected to unnecessary surgery or treatment.

# b) CEDAW 2016 Concl Obs: CEDAW/C/FRA/CO/7-8, paras 34-35

# Stereotypes and harmful practices

18. The Committee welcomes the State party's efforts to combat discriminatory gender stereotypes, including by promoting the sharing of household duties and parenting responsibilities, and to address the stereotyped portrayal of women in the media, including by regulating broadcasting licences and strengthening the role of the Higher Council for the Audiovisual Sector. The Committee also welcomes the legislative and other measures taken to combat harmful practices, including child and forced marriage, female genital mutilation and crimes in the name of so-called honour. The Committee is, however, concerned:

[...]

(f) That medically unnecessary and irreversible surgery and other treatment are routinely performed on intersex children, as noted by the Committee on the Rights of the Child and the Committee against Torture.

#### *19. The Committee recommends that the State party:*

[...]

(f) Develop and implement a rights-based health-care protocol for intersex children, ensuring that children and their parents are appropriately informed of all options; that children are involved, to the greatest extent possible, in decision-making about medical interventions and that their choices are respected; and that no child is subjected to unnecessary surgery or treatment, as recommended recently by the Committee against Torture (see <u>CAT/C/FRA/CO/7</u>, para. 35) and the Committee on the Rights of the Child (see <u>CRC/C/FRA/CO/5</u>, para. 48).

# 2. Cruel, Inhuman or Degrading Treatment (CAT art. 16)a) CAT 2016 Concl Obs: CAT/C/FRA/CO/7, paras 34-35

#### Intersex persons

34. The Committee is concerned about reports of unnecessary and sometimes irreversible surgical procedures performed on intersex children without their informed consent or that of their relatives and without their having all possible options always explained to them. It is also concerned that these procedures, which are purported to cause physical and psychological suffering, have not as yet been the object of any inquiry, sanction or reparation. The Committee regrets that no information was provided on specific legislative and administrative measures establishing the status of intersex persons (arts. 2, 12, 14 and 16).

#### 35. The Committee recommends that the State party:

(a) Take the necessary legislative, administrative and other measures to guarantee respect for the physical integrity of intersex individuals, so that no one is subjected during childhood to non-urgent medical or surgical procedures intended to establish one's sex;

(b) Ensure that the persons concerned and their parents or close relatives receive impartial counselling services and psychological and social support free of charge;

(c) Ensure that no surgical procedure or medical treatment is carried out without the person's full, free and informed consent and without the person, their parents or close relatives being informed of the available options, including the possibility of deferring any decision on unnecessary treatment until they can decide for themselves;

(d) Arrange for the investigation of cases of surgical or other medical treatment reportedly carried out on intersex individuals without their informed consent and take steps to provide redress, including adequate compensation, to all victims;

(e) Conduct studies into this issue in order to better understand and deal with it.

# **B. IGM practices in France: State-sponsored and pervasive**

# **1. IGM in France: Still no protections, Government fails to act**

Allover France, all forms of IGM practices remain widespread and ongoing, persistently advocated by the official public medical body "Haute Autorité de Santé (HAS)", including in "National Guidelines", prescribed and perpetrated by French public University or Regional Children's Clinics (including, but not limited to the 27 government-appointed "Reference and Competence Centres for Genital Development DEV-GEN"),<sup>14</sup> and paid for by the public Health System ("Sécurité Sociale – l'Assurance Maladie") – as the actors themselves publicly admit, as well as to the psycho-social justification of the surgeries, and to knowledge of the human rights criticism:

"Such a child is not born with just a variation of the normal, it is born with a part of its body that did not work. So, it is not... we must not discriminate it... same as if it had a serious abnormality... no. It is simply necessary to recognise that it was born with chromosomes that didn't work, with hormones that didn't work, and if there are medical means to help such children with hormones, it must be done; if there are surgical means to help this child to adapt to society, to current social life, we must not hesitate either."

#### - Alaa El-Ghoneimi, Hôpital Universitaire Robert-Debré, Paris, 11.05.2018<sup>15</sup>

"Let me be honest: the medical profession needs help. From time to time, as at the moment, we are faced with virulent, even aggressive comments. I hope you [the French Senate] heard the medical profession's message today."

#### - Pierre Mouriquand, Centre Hospitalier Universitaire de Lyon, 25.05.2016<sup>16</sup>

In contrast, **on the side of protections**, in **France** (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33; CEDAW/C/FRA/CO/7-8, paras 17e-f+18e-f) – same as in the neighbouring States of *Belgium* (see CCPR/C/BEL/CO/6, paras 21-22; CRC/C/BEL/CO/5-6, paras 25(b)+26(e)), *Switzerland* (see CCPR/C/CHE/CO/4, paras 24-25; CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20; CEDAW/C/CHE/CO/4-5, paras 38-39), *Italy* (see CRC/C/ITA/CO/5-6, para 23; CRPD/C/ITA/CO/1, paras 45-46), *Spain* (see CRC/C/ESP/CO/5-6, para 24), and the *United Kingdom* (see CAT/C/GBR/CO/6, paras 64-65; CRC/C/GBR/CO/5, paras 46-47; CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41), and in many more State parties,<sup>17</sup> there are

- **no legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM practices**
- **no measures** in place to ensure **data collection and monitoring** of IGM practices
- **no legal or other measures** in place to ensure the **accountability** of IGM perpetrators
- **no legal or other measures** in place to ensure **access to redress and justice** for adult IGM survivors

<sup>14 &</sup>lt;u>https://www.developpement-genital.org</u>

<sup>15</sup> Interview in segment "« Intersexualité : première plainte pour mutilation », Le magazine de la Santé, TV France 5, 11.05.2018, see <u>https://sexandlaw.hypotheses.org/388</u>

<sup>16</sup> Sénat, Session Ordinaire de 2016-2017, Maryvonne Blondin, Corinne Bouchoux, Rapport d'Information fait au nom de la délégation aux droits des femmes et à l'égalité des chances entre les hommes et les femmes sur les variations du développement sexuel : lever un tabou, lutter contre la stigmatisation et les exclusions, statement of Pierre Mouriquand, p. 194, <u>https://www.senat.fr/rap/r16-4411r16-4411.pdf</u>

<sup>17</sup> See https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

In contrast, **in France all types of Female Genital Mutilation (FGM) are prohibited** in the general provisions of the **French Penal Code**, in particular Articles 221–2, 222–3 and 222–5, referring to acts of **torture** and barbarity, and also Articles 222–9 and 222–10, which refer to intended bodily harm causing permanent infirmity or **mutilation**. Committing the **offence against a minor is considered an aggravating circumstance** that increases the penalty. The **principle of extraterritoriality is applicable**, making FGM punishable even if it is committed outside the country.<sup>18</sup>

# 2. IGM in France: Still pervasive, advocated and paid for by State party

All forms of IGM practices remain widespread and ongoing, facilitated and paid for by the State party via the public Health System ("Sécurité Sociale – l'Assurance Maladie") according to the relevant procedures codes classified in the "CCAM Classification Commune des Actes Médicaux" and advocated by the official public medical body "Haute Autorité de Santé (HAS)", including in both persisting and new "National Guidelines" ("Protocole National de Diagnostic et de Soins PNDS").

# a) French Reference and Competence Centres practising IGM

In France, many university hospitals practising IGM are organised within the "**Reference Centres for Rare Diseases of Genital Development: From the Foetus to the Adult**" ("*Centre de référence maladies rares du développement genital: du foetus à l'adulte – CRMR DEV GEN*"), which also coordinated the "National Androgen Insensitivity Guidelines" 2018 prescribing IGM practices (see below, p. 12, 14, 15, 18):



Source: "Haute Autorité de Santé (HAS)", "National Androgen Insensitivity Guidelines" 2018, p. 2219

<sup>18</sup> European Institute for Gender Equality (EIGE) (2013), Current situation and trends of female genital mutilation in France, https://eige.europa.eu/sites/default/files/documents/current\_situation\_and\_trends\_of\_female\_genital\_mutilation\_in\_france\_en.pdf

<sup>19</sup> Haute Autorité de Santé (HAS) (2017), Protocole National de Diagnostic et de Soins (PNDS). Insensibilités aux androgènes. Centre de référence du développement génital: du fœtus à l'adulte, https://www.has-sante.fr/portail/upload/docs/application/pdf/2018-01/pnds ais version finale.pdf

**Other university hospitals** practising IGM, and also participating in relevant National guidelines but which currently are not members of CRMR DEV GEN include

- Hôpital Universitaire Robert-Debré, Paris
- Hôpital Necker-Enfants Malades, Paris
- Hôpital Armand-Trousseau, Paris
- Hôpital Saint-Antoine, Paris
- Hôpital la Pitié Salpêtrière, Paris

In addition, also the CRMR "Reference Centres for Rare Malformations of the Urinary Tract" ("Centres de Référence des Malformations rares des voies urinaires – MARVU")<sup>20</sup> practice IGM on some children with intersex condition, namely epispadias and persisting urogenital sinus.

For a list of **41 French university hospitals practicing IGM**, see the "Open Letter of Concern to 55th ESPE 2016 and French DSD Universities and Clinics".<sup>21</sup>

# **Currently practiced forms of IGM in France include:**

# b) IGM 3 – Sterilising Procedures:

Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones <sup>22</sup>

The French Association of Urology ("Association Française d'Urologie") endorses the 2021 Guidelines of the European Association of Urology (EAU),<sup>23</sup> which include the current ESPU/EAU "*Paediatric Urology*" Guidelines<sup>24</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:<sup>25</sup>

"Individuals with DSD have an increased risk of developing cancers of the germ cell lineage, malignant germ cell tumours or germ cell cancer in comparison with to the general population."

Further, regarding "whether and when to pursue gonadal or genital surgery",<sup>26</sup> the Guidelines refer to the "*ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)*",<sup>27</sup> co-authored by paediatric surgeon Pierre Mouriquand (Reference Centre for Rare Diseases of Sex Development CHU Lyon) which advocates "gonadectomies":

"Testes are either brought down in boys or removed if dysgenetic with tumour risk or in complete androgen insensitivity syndrome or 5 alpha reductase deficiency. Testicular prostheses can be inserted at puberty at the patient's request."

 $<sup>20 \</sup>quad \underline{http://robertdebre.aphp.fr/centre-reference-maladie-rare/crmarvu/}$ 

<sup>21 &</sup>lt;u>https://zwischengeschlecht.org/public/Open\_Letter\_ESPE\_2016.pdf</u>

<sup>22</sup> For general information, see 2016 CEDAW NGO Report France, p. 47, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

<sup>23</sup> https://uroweb.org/guidelines/endorsement/

<sup>24 &</sup>lt;u>https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf</u>

<sup>25</sup> Ibid., p. 90

<sup>26</sup> Ibid., p. 89

P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, <u>http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf</u>

Also, the **"2016 Global Disorders of Sex Development Consensus Statement"**,<sup>28</sup> which is coauthored by paediatric surgeon Pierre Mouriquand (Reference Centre for Rare Diseases of Sex Development CHU Lyon) and refers to the "*ESPU/SPU standpoint*", advocates "*gonadectomy*" – even when admitting "*low*" cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)<sup>29</sup>:

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty)	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia
	Post-pubertal biopsy – Based on ultrasound and results of first biopsy – If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia		If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty)	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy	Partial AIS and testosterone synthesis disorders – Bilateral biopsy
	Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	- Low threshold for gonadectom Intensive psychological counseling and follow-up

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174

Accordingly, **IGM 3: Sterilising Procedures** plus arbitrary imposition of hormones as advocated by the official public medical body "*Haute Autorité de Santé (HAS)*" in the **new 2018** "*National Androgen Insensitivity Guidelines*" <sup>30</sup> for "*adolescents*" with Partial Androgen Insensitivity Syndrome (PAIS):

"Gonadectomy should be performed in the prepubertal period to avoid virilization at puberty. After the gonads have been removed, puberty inducing treatment will then be necessary (see chapter 4.3.2). The surgical procedures for gonadectomy and vaginoplasty are identical to those for CAIS patients." (p. 13)

"3.5.2 Tumor risk [...]

The prophylactic removal of gonads and the age at which it should be performed are currently under debate. The main reasons reported by the patients are the refusal of surgery, the wish not to have to take substitution treatment but also the psychological impact of the operation. The recommended attitude is to perform prophylactic gonadectomy after puberty, thus allowing optimal spontaneous pubertal development and the possibility of involving the adolescent in the decision.

Despite a low risk of tumour transformation, the family may want the procedure to be performed before puberty. In this case, it is desirable to discuss with the family the value of waiting until puberty and involving the adolescent in the decision. When the gesture is nevertheless envisaged, its realization must be discussed in multidisciplinary team RCP." (p. 10)

<sup>28</sup> Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, <u>https://www.karger.com/Article/Pdf/442975</u>

<sup>29</sup> Ibid., at 180 (fn 111)

<sup>30</sup> Haute Autorité de Santé (HAS) (2017), Protocole National de Diagnostic et de Soins (PNDS). Insensibilités aux androgènes. Centre de référence du développement génital: du fœtus à l'adulte, https://www.has-sante.fr/portail/upload/docs/application/pdf/2018-01/pnds ais version finale.pdf

To this day, IGM 3 procedures are paid for by the **public Health System** ("Sécurité Sociale – *l'Assurance Maladie*") according to the relevant procedures codes contained in the "CCAM Classification Commune des Actes Médicaux", chapter "8.3.2.11. Correction des anomalies de position du testicule", including codes "JHFA003 - Orchidectomie pour cryptorchidie abdominale, par laparotomie" and "JHFC001 - Orchidectomie pour cryptorchidie abdominale, par coelioscopie".<sup>31</sup>

# c) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation<sup>32</sup>

The French Association of Urology ("Association Française d'Urologie") endorses the 2021 Guidelines of the European Association of Urology (EAU),<sup>33</sup> which include the current ESPU/EAU "Paediatric Urology" Guidelines<sup>34</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.17 "Disorders of sex development",<sup>35</sup> despite admitting that "Surgery that alters appearance is not urgent" <sup>36</sup> and that "adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent",<sup>37</sup> the ESPU/EAU Guidelines nonetheless explicitly refuse to postpone non-emergency surgery, but in contrary insist to continue with non-emergency genital surgery (including partial clitoris amputation) on young children based on "social and emotional conditions" and substituted decision-making by "parents and caregivers implicitly act[ing] in the best interest of their children" and making "well-informed decisions [...] on their behalf", and further explicitly refusing "prohibition regulations" of unnecessary early surgery,<sup>38</sup> referring to the 2018 ESPU Open Letter to the Council of Europe (COE),<sup>39</sup> which further invokes parents' "social, and cultural considerations" as justifications for early surgery (p. 2).

Accordingly, **IGM 2: "Feminising" Genital Surgeries**: The "*National CAH Guidelines*" <sup>40</sup> promoting early surgery "*in the first months of life*" in order to "*minimis[e] psychological consequences for the child and the parents*" **remain in force unchanged:** 

#### *"4.4 Surgical Therapy*

#### *"4.4.1 Environment*

"[...] The surgical treatment is prescribed by the paediatric surgeon according to surgery for anomalies of sex development.

33 https://uroweb.org/guidelines/endorsement/

<sup>31 &</sup>lt;u>https://www.ameli.fr/accueil-de-la-ccam/trouver-un-acte/consultation-par-</u> chapitre.php?chap=a%3A1%3A%7Bi%3A0%3Bs%3A5%3A%228.3.2%22%3B%7D&add=8.3.2.11#chapitre\_8.3.2.11

<sup>32</sup> For general information, see 2016 CEDAW NGO Report France, p. 48. https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

<sup>34 &</sup>lt;u>https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf</u>

<sup>35</sup> Ibid., p. 86

<sup>36</sup> Ibid., p. 89

<sup>37</sup> Ibid., p. 89

<sup>38</sup> Ibid., p. 90

<sup>39 &</sup>lt;u>https://www.espu.org/images/documents/ESPU\_Open\_Letter\_to\_COE\_2018-01-26.pdf</u>

<sup>40</sup> Haute Autorité de Santé (HAS) (eds.), Protocole National de Diagnostic et de Soins (PNDS). Hyperplasie congénitale des surrénales par déficit en 21-hydroxylase. Protocole national de diagnostic et de soins pour les maladies rares (p. 50), online: <u>https://www.has-sante.fr/portail/upload/docs/application/pdf/2011-05/ald hors liste - pnds sur lhyperplasie congenitale des surrenales.pdf</u>

#### "4.4.2 Surgical Schedule

"French surgeons operate on the little girls when the metabolical and endocrine situation is stable, earliest **in the first months of life.** The essential reasons for choosing this age is the responsiveness of genital tissues when the repair is done early, and the **minimisation of psychological consequences for the child and the parents.**"

#### *"4.4.5 Surgical Procedure*

"The surgical procedure during the first months of life includes three principal stages:

• opening of the vaginal cavity at the pelvic floor (vaginoplasty), which represents the most difficult part, in particular in cases of high confluence

• if necessary, the reduction in size of the clitoris while preserving the vascularisation and the nerves

• the perineoplasty, which, if possible, consists of the reconstruction of the small labia, the margins of the vaginal introitus, and the **reduction of the labia majora** which are often enlarged." (p. 16) [own translation]

Also, the **new 2018** "*National Androgen Insensitivity Guidelines*" <sup>41</sup> prescribe for "*girls*" with Partial Androgen Insensitivity Syndrome (PAIS):

"Where sex selection at birth has been female, the appropriateness of surgery (clitoris, vulva, vagina) should be discussed in the [Pluridisciplinary Consultation Meeting] RCP. It can sometimes [!] be postponed until the child reaches the age where he or she can participate in questions and decisions concerning his or her body." (p. 13)

"Post-operative complications of genital surgeries are frequent: [...], vaginal stenosis in girls." (p. 13)

"Clitoral reduction surgery may be considered when clitoral hypertrophy generates aesthetic but also functional discomfort in the event of painful erections. The main risks of this surgery are the loss of sensitivity or on the contrary the occurrence of painful scars. Patients should be well informed of these risks before any procedure." (p. 13)

To this day, IGM 2 procedures are paid for by the **public Health System** ("Sécurité Sociale – l'Assurance Maladie") according to the relevant procedures codes contained in the "CCAM Classification Commune des Actes Médicaux", chapter "8.7.1. Correction des ambigüités sexuelles", including codes "JMEA001 - Transposition du clitoris", "JMMA001 - Vestibuloplastie avec enfouissement ou résection du clitoris, pour féminisation", "JMMA004 - Clitoridoplastie de réduction", "JZMA002 - Urétroplastie, vaginoplastie et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "JZMA003 - Urétroplastie et vestibuloplastie et vestibuloplastie et vestibuloplastie et vestibuloplastie et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "JZMA003 - Urétroplastie et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "Securite et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "Securite et vestibuloplastie et vestibuloplastie et vestibuloplastie et vestibuloplastie et vestibuloplastie et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "Securite et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "Securite et vestibuloplastie et vestibulopla

<sup>41</sup> Haute Autorité de Santé (HAS) (2017), Protocole National de Diagnostic et de Soins (PNDS). Insensibilités aux androgènes. Centre de référence du développement génital: du fœtus à l'adulte, https://www.has-sante.fr/portail/upload/docs/application/pdf/2018-01/pnds ais version finale.pdf

<sup>42 &</sup>lt;u>https://www.ameli.fr/accueil-de-la-ccam/trouver-un-acte/consultation-par-</u> chapitre.php?chap=a%3A2%3A%7Bi%3A0%3Bs%3A5%3A%228.3.2%22%3Bi%3A1%3Bs%3A3%3A%228. 7%22%3B%7D&add=8.7.1#chapitre\_8.7.1

*dilatation vaginale par bougies*<sup>43</sup>, as well as additional codes in **chapter** "8.4.4.5. Correction *des malformations congénitales du vagin*".<sup>44</sup>

# d) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"<sup>45</sup>

The French Association of Urology ("Association Française d'Urologie") endorses the 2021 Guidelines of the European Association of Urology (EAU),<sup>46</sup> which include the current ESPU/EAU "*Paediatric Urology*" Guidelines<sup>47</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.6 "*Hypospadias*",<sup>48</sup> the ESPU/EAU Guidelines' section 3.6.5.3 "Age at surgery" nonetheless explicitly promotes, "*The age at surgery for primary hypospadias repair is usually 6-18 (24) months.*" <sup>49</sup> – despite admitting to the "*risk of complications*" <sup>50</sup> and "*aesthetic[...]*" and "*cosmetic*" justifications.<sup>51</sup>

Accordingly, for **IGM 1: Masculinising**" **Genital Surgeries** the **new 2018** "*National Androgen Insensitivity Guidelines*" <sup>52</sup> prescribe for "*boys*" with Partial Androgen Insensitivity Syndrome (PAIS):

"Surgery of patients with PAIS raised in the male sex (correction of hypospadias, testicular lowering) is most often performed in the 2nd year of life. The surgery is based on the principles of hypospadias surgery. [...] Correction of anomaly(s) of testicular migration, peno-scrotal transposition or correction of the bifid aspect of the scrotum may be necessary. Reduction of gynecomastia is sometimes necessary in the peripubertal period[.]" (p. 13)

"Post-operative complications of genital surgeries are frequent: unsatisfactory cosmetic results, urethral failures (fistula, dehiscence), urinary difficulties (stenosis, urethrocele), sexual difficulties (persistent curvature of the penis, erectile dysfunction) in boys [...]." (p. 13)

To this day, IGM 1 procedures are paid for by the **public Health System** ("Sécurité Sociale – l'Assurance Maladie") according to the relevant procedures codes contained in the "CCAM Classification Commune des Actes Médicaux", chapter "8.2.4.14. Correction des malformations congénitales de l'urètre", including codes "JEMA006 - Urétroplastie pour hypospadias périnéoscrotal avec redressement du pénis", "JEMA014 - Urétroplastie pour hypospadias balanique ou pénien antérieur, avec reconstruction du prépuce", "JEMA019 -Urétroplastie pour hypospadias pénien postérieur ou moyen avec redressement du pénis",

 $<sup>\</sup>begin{array}{l} \mbox{43} & \mbox{https://www.ameli.fr/accueil-de-la-ccam/trouver-un-acte/consultation-par-} \\ & \mbox{chapitre.php?chap=a%3A4%3A%7Bi%3A0%3Bs%3A3%3A"8.1"%3Bi%3A1%3Bs%3A5%3A"8.3.2"%3Bi%3A3%3As%3A3%3A"8.1"%3Bi%3A1%3Bs%3A5%3A"8.3.2"%3Bi%3A3%3Bs%3A3%3A"8.7"%3B%7D&add=8.4.4.7 - chapitre\_8.4.4.7 \\ & \mbox{A2\%3Bs} \mbox{Massar} \mbox{A2\%3Bs} \mbox{Massar} \mbox{A3} \mbox{Massar} \mbox{Massar} \mbox{Massar} \mbox{A3} \mbox{Massar} \mbox{A3} \mbox{Massar} \mbox{A3} \mbox{Massar} \mbox{A3} \mbox{Massar} \mbox{A3} \mbox{Massar} \mbox{A4} \mbox{A4} \mbox{Massar} \mbox{A4} \mbox{Massar} \mbox{A4} \$ 

<sup>44 &</sup>lt;u>https://www.ameli.fr/accueil-de-la-ccam/trouver-un-acte/consultation-par-</u> chapitre.php?chap=a%3A5%3A%7Bi%3A0%3Bs%3A3%3A%228.1%22%3Bi%3A1%3Bs%3A5%3A%228.2.3%22%3Bi%3A2%3Bs%3A5%3A%228.3.2% 22%3Bi%3A3%3Bs%3A5%3A%228.4.4%22%3Bi%3A4%3Bs%3A3%3A%228.7%22%3B%7D&add=8.4.4.5#chapitre\_8.4.4.5

<sup>45</sup> For general information, see 2016 CEDAW NGO Report France, p. 48-49, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

<sup>46 &</sup>lt;u>https://uroweb.org/guidelines/endorsement/</u>

<sup>47 &</sup>lt;u>https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf</u>

<sup>48</sup> Ibid., p. 26

<sup>49</sup> Ibid., p. 28

<sup>50</sup> Ibid., p. 27

<sup>51</sup> Ibid., p. 27-28

<sup>52</sup> Haute Autorité de Santé (HAS) (2017), Protocole National de Diagnostic et de Soins (PNDS). Insensibilités aux androgènes. Centre de référence du développement génital: du fœtus à l'adulte, <u>https://www.has-sante.fr/portail/upload/docs/application/pdf/2018-01/pnds\_ais\_version\_finale.pdf</u>

**"JEMA020** - Urétroplastie pour hypospadias pénien postérieur ou moyen sans redressement du pénis", **"JEMA021** - Urétroplastie pour hypospadias balanique ou pénien antérieur, sans reconstruction du prépuce",<sup>53</sup> as well as additional codes in chapter "8.3.3.9. Correction des malformations du pénis".<sup>54</sup>

# e) IGM 4 – Prenatal "Therapy" 55

French doctors and clinics have been leading in introducing and defending prenatal "therapy" since at least 1984<sup>56</sup> and continue to practice it despite the **known serious risks** both for the intersex foetuses and the pregnant mothers (which led to the "therapy" being discontinued<sup>57</sup> in Sweden since 2010).

For example, a **2014 publication** by doctors from the **University Hospitals Lyon and Limoges**, despite acknowledging "*potential adverse effects on the fetus and the mother*" and that the procedure "*remains very controversial*" leading to "*several scientific societies to state that PreDex is an 'experimental therapy, which should only be done in prospective trials approved by ethical review boards*" continues to promote the "therapy" as an "*alternative, non-surgical treatment[...]*" to "cure" "genital virilization" in "46,XX patients" diagnosed with Congenital Adrenal Hyperplasia (CAH), reporting a "*French cohort (258 cases) of prenatally treated CAH*".<sup>58</sup>

Accordingly, at a **2016 Senate hearing** paediatric surgeon Pierre Mouriquand (Reference Centre for Rare Diseases of Sex Development CHU Lyon) confirmed:

"Dr Pierre Mouriquand. - [...] To avoid surgery, when hormonal treatment is prescribed during pregnancy to a woman who has a baby girl with CAH, the virilisation of the child can be significantly reduced. This treatment is very controversial because the side effects can be serious, not only in the mother - hypertension, stretch marks, diabetes - but also in the child who can present very important cognitive problems. These are the reasons why some countries - Sweden or the United States - have abandoned these hormone treatments.

Maryvonne Blondin, co-rapporteur. - What is the situation in France? Dr Pierre Mouriquand. - We continue to prescribe them." <sup>59</sup>

<sup>53 &</sup>lt;u>https://www.ameli.fr/accueil-de-la-ccam/trouver-un-acte/consultation-par-</u> chapitre.php?chap=a%3A3%3A%7Bi%3A0%3Bs%3A5%3A%228.2.4%22%3Bi%3A1%3Bs%3A5%3A%228. 3.2%22%3Bi%3A2%3Bs%3A3%3A%228.7%22%3B%7D&add=8.2.4.14#chapitre\_8.2.4.14

<sup>54 &</sup>lt;u>https://www.ameli.fr/accueil-de-la-ccam/trouver-un-acte/consultation-par-</u> chapitre.php?chap=a%3A3%3A%7Bi%3A0%3Bs%3A5%3A%228.2.4%22%3Bi%3A1%3Bs%3A5%3A%228. 3.3%22%3Bi%3A2%3Bs%3A3%3A%228.7%22%3B%7D&add=8.3.3.9#chapitre\_8.3.3.9

<sup>55</sup> See 2016 CEDAW NGO Report France, p. 50, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

<sup>56 &</sup>lt;u>https://clinicaltrials.gov/ct2/show/NCT02795871</u>

<sup>57</sup> https://academic.oup.com/jcem/article/97/6/1881/2536577

<sup>58</sup> Daniela Gorduza, Véronique Tardy-Guidollet, Elsa Robert, Claire-Lise Gay, Pierre Chatelain, Michel David, Patricia Bretones, Anne Lienhardt-Roussie, Aude Brac de la Perriere, Yves Morel, Pierre Mouriquand, "Late prenatal dexamethasone and phenotype variations in 46,XX CAH: Concerns about current protocols and benefits for surgical procedures", Journal of Pediatric Urology, Volume 10, Issue 5, Pages 941–947, October 2014, https://pubmed.ncbi.nlm.nih.gov/24679821/

<sup>59</sup> Sénat, Session Ordinaire de 2016-2017, Maryvonne Blondin, Corinne Bouchoux, Rapport d'Information fait au nom de la délégation aux droits des femmes et à l'égalité des chances entre les hommes et les femmes sur les

# 3. French doctors and Government consciously dismissing human rights

It must be duly noted that **French paediatric surgeons and endocrinologists** are particularly **adamant advocates** of IGM practices, **consciously dismissing** to consider any human rights concerns, despite **openly acknowledging** knowledge of relevant criticisms by human rights and ethics bodies. What's more, in spite of some French agencies calling for action to protect intersex children, the **French Government openly backs those doctors**, allowing them to **continue IGM practices with impunity.** 

### a) French agencies recognising intersex human rights

Since the CRC, CAT and CEDAW Concluding Observations to France, **several French Government agencies** have **recognised** the ongoing IGM practices on intersex children in France to constitute "*mutilations*", "*harmful practices*" and "*inhuman and degrading treatment*", and have **called for legislation** to explicitly prohibit IGM practices:

In December 2016, the French "Interministerial delegation on combatting racism, antisemitism and anti-LGBT hatred (DILCRAH)", referring to the CAT, CRC and CEDAW Concluding Observations, declared, "Stopping the surgeries and mutilations of intersex children [...] Unless they are not imperative for medical reasons, these surgeries are mutilations and must stop."<sup>60</sup>

On 17 March 2017, the **outgoing President François Hollande** said in a public statement, "*I'm* also thinking of the prohibition of surgical operations that intersex children are submitted to today, and which around the world are largely **considered as mutilations.**"<sup>61</sup>

A 2018 study by the **Council of State (Conseil d'État)** on a new **Draft Law on Bioethics** (see below), commissioned by the Prime Minister and approved by the General Assembly, notes, referring to the CAT and CRC Concluding Recommendations and the European Parliament Resolution 2016/2096(INI), "Some denounce the mutilating nature of these practices [276], which are likely to have irreversible and dramatic consequences both physically (urinary infections, neurological lesions, loss of sensitivity, pain, etc.) and psychologically, and which are often concealed from those who are subjected to them [277]" (p. 132). Regarding the right of the holders of parental authority to "consent" to such practices, the study concludes, "Ultimately, a medical procedure whose sole purpose is to conform the aesthetic appearance of the genitalia to representations of masculinity and femininity in order to promote the psychological and social development of the child should not be carried out as long as the person concerned is not in a position to express his or her will and to participate in the decision-making process" (p. 140).<sup>62</sup>

variations du développement sexuel : lever un tabou, lutter contre la stigmatisation et les exclusions, statement of Pierre Mouriquand, p. 188-189, <u>https://www.senat.fr/rap/r16-441/r16-4411.pdf</u>

<sup>60</sup> DILCRAH (2016), Plan de mobilisation contre la haine et les discriminations anti-LGBT, p. 25, <u>https://www.gouvernement.fr/sites/default/files/contenu/piece-</u> jointe/2017/01/plan de mobilisation contre la haine et les discriminations anti-lgbt dilcrah.pdf

<sup>61</sup> See full video at 12:09, <u>https://www.dailymotion.com/video/x5f1wll</u> See also Libération, 17.03.2017, <u>https://www.liberation.fr/sexe/2017/03/17/hollande-prone-l-interdiction-des-chirurgies-sur-les-enfants-intersexes\_1556444/</u>

<sup>62</sup> Conseil d'État, section du rapport et des études (2018), "Révision de la loi de bioéthique : quelles options pour demain?", Étude à la demande du Premier ministre. Étude adoptée en assemblée générale le 28 juin 2018, https://www.conseil-etat.fr/Media/actualites/documents/reprise-\_contenus/etudes/conseil-d-etat\_sre\_etude-pm-bioethique.pdf

In May 2018, the National Consultative Commission on Human Rights CNCDH stated in its report "Taking action against abuse in the health system: a necessity to respect fundamental rights" (p. 17), "The CNCDH also considers that certain treatments inflicted on intersex persons are inhuman and degrading treatment. Indeed, in their national [Androgen Insensitivity] guidelines dated 2018[52], the [Haute Autorité de Santé] HAS takes an ambiguous position on the practice of sexual mutilation surgeries on intersex newborns. These surgeries, performed to bring the appearance of their genitals into line with the sex in which the child will be raised, without medical necessity, have serious lifelong consequences for patients and numerous complications.[53] Such surgeries are carried out in disregard of the person's consent, parents being forced to decide immediately, and without taking into account international standards of child protection, respect for the child's physical integrity, and the recommendations of the United Nations (Committee on the Rights of the Child, Committee against Torture, Committee on the Elimination of Discrimination against Women, 2016) and the Parliamentary Assembly of the Council of Europe (resolution 2191, 2017[54])." <sup>63</sup></sup>

# b) French doctors and Government refusing to act

However, in spite of above strong statements, **nothing has changed in practice**. On the contrary, on several occasions French doctors and authorities have demonstrated their continued and active **refusal to comply** with the CRC, CAT and CEDAW Concluding Observations:

In 2018, the **Ministry of Health** refused to take measures to ensure that the hospitals under its supervision comply with the CRC, CAT and CEDAW Concluding Observations and the PACE Resolution 2191 (2017), and in 2019 this refusal was backed by the **Council of State (Conseil d'État)**, the Supreme Court for Administrative Justice.<sup>64</sup>

In 2018, the **"Haute Autorité de Santé (HAS)"** refused to withdraw the new 2018 **"National Androgen Insensitivity Guidelines"**<sup>65</sup> (see above, p. 12, 14, 15) advocating IGM practices, and in 2019 this refusal was backed by the **Council of State (Conseil d'État)**, the Supreme Court for Administrative Justice.<sup>66</sup>

The 2019 "Opinion 132: Ethical Questions raised by the Situation of People with Differences of Sex Development" of the **National Consultative Ethics Committee for health and life sciences CCNE**<sup>67</sup> completely ignored the CRC, CAT and CEDAW Concluding Observations to France,

 64 Conseil d'État, 2 oct. 2018, Groupement d'information et de soutien sur les questions sexuées et sexuelles c. Ministère de la santé, n° 420542, <u>https://www.legifrance.gouv.fr/affichJuriAdmin.do?idTexte=CETATEXT000039168436</u>
 For a summary of the proceedings, see 2020 CRC France NGO Report (INT/CRC/NGO/FRA/44537), p. 15, <u>https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf</u>

65 Haute Autorité de Santé (HAS) (2017), Protocole National de Diagnostic et de Soins (PNDS). Insensibilités aux androgènes. Centre de référence du développement génital: du fœtus à l'adulte, https://www.has-sante.fr/portail/upload/docs/application/pdf/2018-01/pnds ais version finale.pdf

<sup>63</sup> Commission nationale consultative des droits de l'homme (CNCDH), "Agir contre les maltraitances dans le système de santé : une nécessité pour respecter les droits fondamentaux", http://www.cncdh.fr/sites/default/files/180522 avis maltraitances systeme de sante.pdf

<sup>66</sup> Conseil d'État, 2 oct. 2018, Groupement d'information et de soutien sur les questions sexuées et sexuelles c. HAS, n° 422197, <u>https://www.legifrance.gouv.fr/affichJuriAdmin.do?idTexte=CETATEXT000039168438</u> For a summary of the proceedings, see 2020 CRC France NGO Report (INT/CRC/NGO/FRA/44537), p. 15

<sup>67 &</sup>lt;u>https://www.ccne-ethique.fr/sites/default/files/publications/avis\_132\_en\_anglais.pdf</u>

despite briefly mentioning "*basic rights*" (p. 16) and art. 3.1 CRC (p. 19), and despite repeatedly having been alerted to the Concluding Observations, including by the Referral letter of the **Ministry of Health and Solidarity** in 2019 (see p. 35, fn 6-7) and in a 2016 letter and annexe by legal experts (acknowledged by CCNE, p. 8, fn 3). Accordingly, the Opinion claims IGM to be strictly a thing of the past ("*Some previous practices inflicted on people with differences of sex development resulted in sequelae that were irreversible both physically and psychologically*," p. 16), and a "*medical practice*" (e.g. p. 5, 8), not a violation.

The French Parliament is currently discussing a new **Draft Law on Bioethics**.<sup>68</sup> **Article 21bis** of this Draft Law as passed on 2<sup>nd</sup> reading by the National Assembly and the Senate,<sup>69</sup> despite adding some caveats, ultimately further invalidates the current ineffective and unenforced legal provisions by **explicitly legalising early surgery** on intersex children, based on the medical opinion of the "*specialised multidisciplinary teams at the Reference Centres for Rare Diseases of Sex Development*" (i.e. the current IGM practitioners) and the "consent" of the "*holders of parental authority*". In addition, Article 21bis **increases the pressure on parents** to quickly "consent" to non-urgent procedures: The time limit for reporting the sex of the child will be reduced to three months, whereas today the law offers a time limit of one or two years.<sup>70</sup>

In its 2020 State report to the Committee against torture (CAT/C/FRA/8), the **French Government** claims "*the legislative framework in force is sufficient to prohibit them* [*i.e. IGM practices*]" (para 212) – despite that IGM continues and IGM survivors are denied access to justice and redress, including in the case at hand.

Faced by increasing calls for human rights and access to justice by IGM survivors and human rights bodies, **French paediatric surgeons** not only refuse to end IGM practices, but **publicly dismiss statements of human rights experts** as unsubstantiated and unfair:

For example **Prof. Alaa El-Ghoneimi** (Hôpital Universitaire Robert-Debré, Paris) simply dismissed the **2013 Report by the Special Rapporteur on Torture** as *"unjust"*.<sup>71</sup>

In the same vein, **Prof. Pierre Mouriquand** (Reference Centre for Rare Diseases of Sex Development CHU Lyon) dismissed both the **2013 Report by the Special Rapporteur on Torture** and the 2012 Recommendations by the Swiss National Advisory Commission on Biomedical Ethics blanketly as *"inappropriate and biased statements"* and *"biased and counterproductive reports"*, while insisting on continuing with IGM practices.<sup>72</sup>

At the same time, these doctors and other clinicians continue to publicly promote IGM practices as a "cure" to help "deformed" intersex children and to relieve "parental distress".

For example **Prof. Alaa El-Ghoneimi** (Hôpital Universitaire Robert-Debré, Paris) openly describes intersex children as "not normal" and in need of surgery for psychosocial reasons,

<sup>68 &</sup>lt;u>https://www.assemblee-nationale.fr/dyn/15/dossiers/bioethique\_2</u>

<sup>69 &</sup>lt;u>https://www.assemblee-nationale.fr/15/rapports/r3891.asp</u>

<sup>70</sup> For more information, see 2020 CRC France NGO Report, p. 17, https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf

<sup>71 &</sup>lt;u>http://www.lefigaro.fr/international/2013/11/01/01003-20131101ARTFIG00204-l-allemagne-devient-le-premier-pays-europeen-a-reconnaitre-un-troisieme-sexe.php</u>

P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, <u>http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf</u>

"Such a child is not born with just a variation of the normal, it is born with **a part of its body that did not work.** So, it is not... we must not discriminate it... same as if it had a serious **abnormality**... no. It is simply necessary to recognise that it was born with chromosomes that didn't work, with hormones that didn't work, and if there are medical means to help such children with hormones, it must be done; if there are **surgical means to help this child to adapt to society**, **to current social life**, we must not hesitate either."<sup>73</sup>

And paediatric psychiatrist **François Medjkane** (Reference Centre for Rare Diseases of Sex Development CHU Lille) advocates early surgery for the benefit of the parents so that they can better accept their "abnormal" intersex child, "surgery has a real restorative function, a normalisation that can boost parental investment".<sup>74</sup>

What's more, French IGM doctors openly admit that they **rely on the support of the French authorities** to be able to continue practicing involuntary, non-urgent surgery on intersex children with **impunity**, for example **Prof Pierre Mouriquand** (Reference Centre for Rare Diseases of Sex Development CHU Lyon) at a **2016 Senate hearing**, further framing legitimate human rights criticism and calls for judicial oversight as "*aggressive*", "*I'll be honest: the medical profession needs help. From time to time, as is the case at the moment, we have to deal with strong and even aggressive language. I hope you have heard the message from the medical profession today."<sup>75</sup> And as demonstrated above, the French Government is indeed willing to shield IGM practitioners from legal consequences of their actions, thus allowing them to continue with IGM with impunity.* 

# 4. Lack of Independent Data Collection and Monitoring

With **no statistics available** on intersex births, let alone surgeries and costs, and **perpetrators**, **governments and health departments colluding to keep it that way as long as anyhow possible**, persons concerned as well as civil society **lack possibilities to effectively highlight and monitor** the ongoing mutilations. What's more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists "on record".

To this day, the **French Government refuses to collect and disclose disaggregated data** on intersex persons and IGM practices.

For example, in a **2016 Answer to a Parliamentary Question**, the **Health Minister** Laurence Rossignol gave the obviously **false figure** of merely **160 births of intersex children** in France per year, without indicating any figures for IGM practices.

However, partial data was obtained as part of the research study "Mutilations génitales

<sup>73</sup> Alaa El-Ghoneimi (2018), interview in segment "Intersexualité : première plainte pour mutilation", Le magazine de la Santé, TV France 5, 11.05.2018, see <u>https://sexandlaw.hypotheses.org/388</u>

<sup>74</sup> François Medjkane at the Symposium "Dialogue sur les Prises en Charge du Développement Sexuel Atypique : une Table Ronde France-Suisse" at EHESS Paris, 11.07.2016, see Compte-rendu de la journée (2016-07-18 – version longue), p. 11

<sup>75</sup> Prof Pierre Mouriquand, in: Maryvonne Blondin, Corinne Bouchoux (2017), "Rapport d'Information fait au nom de la délégation aux droits des femmes et à l'égalité des chances entre les hommes et les femmes sur les variations du développement sexuel : lever un tabou, lutter contre la stigmatisation et les exclusions", Sénat, Session Ordinaire de 2016-2017, p. 194, <u>https://www.senat.fr/rap/r16-4411/r16-4411.pdf</u>

*intersexuées*" at the University Panthéon-Assas, Paris II.<sup>76</sup> The research team was able to access data of the National Health Data System SNDS ("*Système national des données de santé*") governed by the Public Health System ("*Assurance maladie*") revealing that in **2017**, **at least 4678 relevant procedures were performed on intersex children aged 0-12 years** – an increase in procedures compared to previous years.<sup>77</sup> This shockingly high number was also **acknowledged** by the majority of the members of the Senate.<sup>78</sup>

Further, also this number still represents only a fraction of the total relevant procedures on intersex children, as some of the most frequent intersex diagnoses are not included, namely Congenital Adrenal Hyperplasia (CAH), Androgen Insufficiency Syndrome (AIS) and Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), and apparently procedures performed in the biggest IGM clinics, namely the so called "*Reference Centres for Rare Diseases of Sex Development*", <sup>79</sup> are not included.

Nonetheless, the data includes a wide range of relevant IGM procedures, namely IGM 1: "Masculinising" Genital Surgeries ("JEMA006 - Urétroplastie pour hypospadias périnéoscrotal avec redressement du pénis", "JEMA019 - Urétroplastie pour hypospadias pénien postérieur ou moyen avec redressement du pénis", "JEMA020 - Urétroplastie pour hypospadias pénien postérieur ou moyen sans redressement du pénis", as well as additional procedures from CCAM chapter "8.3.3.9. Correction des malformations du pénis"), IGM 2: "Feminising" Procedures ("JMEA001 - Transposition du clitoris", "JMMA001 - Vestibuloplastie avec enfouissement ou résection du clitoris, pour féminisation", "JZMA002 - Urétroplastie, vaginoplastie et vestibuloplastie avec enfouissement ou réduction du clitoris, pour féminisation", "JLAD001 - Séance de dilatation vaginale par bougies") and IGM 3: Sterilising Procedures ("JHFA003 - Orchidectomie pour cryptorchidie abdominale, par laparotomie" and "JHFC001 -Orchidectomie pour cryptorchidie abdominale, par coelioscopie") (see also above, p. 11-13).

Notably, the **vast majority** of these procedures were performed in public University Clinics and **on children under 4 years of age (>86%)**.

A future **data collection exercise** is part of the above-mentioned **Bioethics Draft Law** (art. 21a, para. 12). However, it's a **one-off project**, the scope is **limited** and its independence **in question**.

Conclusion, reliable data collection on intersex births and IGM procedures would need to be independent, ongoing, comprehensive and disaggregated by diagnosis, procedure, age at intervention and clinic where the intervention took place.

# 5. Obstacles to access to justice, redress, and compensation

To this day, also in **France** the **statutes of limitation** prevent survivors of IGM practices to call a court because persons concerned often **do not find out** about their medical history until much

<sup>76</sup> Mutilations génitales intersexuées / Gis Genre, APR Axe 6 « Sexualités, LGBTI »-laboratoire LISE UMR 3320 CNAM – Laboratoire de sociologie juridique Univ. Panthéon-Assas, Paris II, lead investigator: Dr Benjamin Moron-Puech, <u>https://www.lp3c.fr/projets-finances/</u>

Full data set available on request. See also Benjamin Moron-Puech, notes for Senate hearing, p. 9, <u>https://f.hypotheses.org/wp-content/blogs.dir/3033/files/2020/01/2019-12-16-Mise-en-forme-notes-audition-au-Se%CC%81nat.pdf</u> The full data set is available at request from the Rapporteurs.

<sup>78</sup> See the explanatory memorandum to amendment 779 tabled by these deputies before the Special Committee responsible for examining the draft law on the bioethics law, http://www.assemblee-nationale.fr/dyn/15/amendements/2658/CSBIOETH/779

<sup>79</sup> See Open Letter of Concern to 55th ESPE 2016 and French DSD Universities and Clinics by Persons Concerned, September 2016, p.1, <u>https://zwischengeschlecht.org/public/Open\_Letter\_ESPE\_2016.pdf</u>

later in life, which in combination with severe trauma caused by IGM practices often proves to amount to a severe obstacle,<sup>80</sup> and effectively **prohibit survivors of early childhood IGM practices to call a court** – despite that in 2016 CAT explicitly recommended France to "[a]rrange for the investigation of cases of surgical or other medical treatment reportedly carried out on intersex individuals without their informed consent and take steps to provide redress, including adequate compensation, to all victims" (CAT/C/FRA/CO/7, para 35(d)).

This is evidenced by a **final court decision of the Highest Court (**"*Court de Cassation*") **dated 6 March 2018**,<sup>81</sup> **rejecting** the case of an IGM survivor wanting to lodge a complaint on the basis of article 222-10 of the Penal Code (aggravated violence resulting in mutilation or permanent disability) for having been submitted to non-consensual castration and "feminising" genital surgery as a child, with the court referring to **expired statutes of limitation**.<sup>82</sup> This case is now **pending** at the **European Court of Human Rights (ECHR)**.<sup>83 84 85 86</sup>

A second case of an IGM survivor born in 1979 who filed a complaint in 2016 before the criminal judge for mutilation intentional violence against a minor under 15 years of age, denouncing 7 non-consensual "masculinsing" genital surgeries between the age of 3 and 8, leaving the claimant with severe pain and suffering:

"«I've come to calculate everything I drink because every time I have to go to the bathroom, I feel like I'm peeing razor blades,» he says. «Sex is the same. I'm enjoying myself while having extreme pain!»" <sup>87</sup>

Since the complaint has been filed in 2016, a criminal investigation was opened in 2017. However, to this day, no public statement has been made concerning the progress of the investigation and the possibility of a trial. This kind of delay in dealing with such a case is highly unusual given the serious criminal offences at stake. This investigation therefore has only been made public via media interviews with the claimant.<sup>88</sup>

# This situation is clearly not in line with France's obligations under the Covenant.

Application no. 42821/18, M. v. France, <u>https://hudoc.echr.coe.int/fre#{%22itemid%22:[%22001-205290%22]}</u>
See also Third Party Intervention by StopIGM.org,

https://intersex.shadowreport.org/public/ECHR-42821\_18-M-v-France-Written-Comments-StopIGM.pdf See also Third Party Intervention by FIDH, LDH, Alter Corpus

<sup>80</sup> Globally, no survivor of early surgeries **ever** managed to have their case successfully heard in court. All relevant court cases resulting in damages or settlement (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

<sup>81</sup> An anonymised version of this decision is available from the Rapporteurs on request.

<sup>82</sup> B. Moron-Puech, "Rejet de l'action d'une personne intersexuée pour violences mutilantes. Une nouvelle 'mutilation juridique' par la Cour de cassation?", La Revue des Juristes de Sciences Po, juin 2018, p. 71-104, <u>https://sexandlaw.hypotheses.org/412/bmp-commentaire-6-mars-2018</u>

<sup>86</sup> See also A. Lorriaux, "L'histoire de M., première personne intersexe au monde à porter plainte pour mutilations", Slate, 10 Apr. 2019, <u>http://www.slate.fr/story/175530/histoire-m-premiere-personne-intersexe-plainte-mutilations</u>

<sup>87</sup> Vincent Vantighem (26.11.2017), "Une personne intersexe dépose plainte contre les médecins qui l'ont opérée pour 'devenir' homme", 20minutes, <u>https://www.20minutes.fr/societe/2172971-20171126-personne-intersexe-depose-plainte-contre-medecins-operee-devenir-homme</u>

<sup>88</sup> Ibid., and: Iris Peron (27.11.2017), "'J'ai été mutilé dans un souci de normalisation', témoigne une personne intersexe", l'Express, <u>https://www.lexpress.fr/actualite/societe/justice/j-ai-ete-mutile-dans-un-souci-de-normalisation-temoigne-une-personne-intersexe\_1964084.html</u>, Allodocteurs.fr, "Intersexualité: une personne dépose plainte pour mutilation", <u>https://www.francetvinfo.fr/sante/affaires/intersexualite-une-personne-depose-plainte-pour-mutilation\_2753545.html</u>, Interview in segment "Intersexualité : première plainte pour mutilation", Le magazine de la Santé, TV France 5, 11.05.2018, see <u>https://sexandlaw.hypotheses.org/388</u>

# **C. Suggested Questions for the LOIPR**

The Rapporteurs respectfully suggest that in the LOIPR the Committee asks the French State party the following questions with respect to the treatment of intersex children:

**Intersex genital mutilation (arts. 2, 3, 7, 9, 17, 24, 26)** 

- Please provide information on the measures taken to prevent the unnecessary medical or surgical treatment of intersex children and to provide adequate counselling, support and access to effective remedies for victims subjected to such treatment during childhood, including the statute of limitations.
- Please provide information on whether unnecessary medical or surgical treatment for intersex children is still covered by the public Health System (Sécurité Sociale Assurance Maladie).
- Please provide data, disaggregated by type of intervention, age at intervention, and hospital, on the number of intersex children subjected to non-urgent and irreversible surgical and other procedures, concerning the following CCAM codes: JHFA003, JHFC001, JMEA001, JMMA001, JMMA004, JZMA002, JZMA003, JLAD001, JEMA006, JEMA014, JEMA019, JEMA020, JEMA021

# Annexe 1 – IGM Practices in France as a Violation of CCPR

# **1.** The Treatment of Intersex Children in France as Inhuman Treatment

This Committee has repeatedly recognised IGM practices as a serious violation of Covenant, <sup>89</sup> and arts. 2, 3, 7, 9, 17, 24, 26 as applicable.

#### Art. 2: Non-Discrimination, Legal Implementation, Remedies and Reparations

**On the basis of being born with intersex traits,** intersex children are singled out for experimental harmful treatments, including surgical "genital corrections" and potentially sterilising procedures, that would be "considered inhumane" on "normal" children,<sup>90</sup> e.g. "normal" boys and girls, while on intersex children, according to a specialised surgeon, "any cutting, no matter how incompetently executed, is a kindness."<sup>91</sup> While similar inhuman treatment of other children is criminalised in the French Penal Law and perpetrators are persecuted, intersex children have no such legal protections and no access to justice, redress, rehabilitation and reparation. Clearly, IGM practices therefore violate Article 2.

#### Art. 3: Equal Right of Men and Women

**On the basis of their "indeterminate sex,"** intersex children are singled out for inhuman treatment, namely IGM practices. Generally, medical justifications for IGM are often rooted in **gender-based stereotypes**. Further, while **Female Genital Mutilation (FGM) is criminalised** in the French Penal Law, with also extraterritorial protections in force, IGM practices remain legally permitted. Clearly, IGM practices therefore also violate Article 3.

#### Art. 7: Cruel, Inhuman or Degrading Treatment, and Involuntary Medical or Scientific Experimentation

Like this Committee, the **Committee against Torture**<sup>92</sup> has repeatedly **considered IGM to constitute inhuman treatment** falling under the non-derogable prohibition of torture (same as FGM and gender-based violence). Intersex advocates consider harmful practices and inhuman treatment as the **most important human rights frameworks** to effectively combat IGM. <sup>93</sup>

Concerning **involuntary medical or scientific experimentation**, as generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental**. While due to the general avoidance of follow-up by doctors, IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition.

<sup>89</sup> See CCPR/C/CHE/CO/4, paras 24-25; CCPR/C/AUS/CO/6, paras 25-26; CCPR/C/DEU/QPR/7, para 13; CCPR/C/BEL/CO/6, paras 21-22; CCPR/C/MEX/CO/6, paras 12-13, CCPR/C/PRT/CO/5, paras 16-17, CCPR/C/FIN/CO/7, paras 20+21(c); CCPR/C/KEN/CO/4, paras 12(e)+13(e)

<sup>90</sup> Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75

<sup>91</sup> Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), Intersex in the Age of Ethics:148–159, at 150

<sup>92</sup> See CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; CAT/C/AUT/CO/6, paras 44-45; CAT/C/CHN-HKG/CO/4-5, paras 28-29; CAT/C/DNK/CO/6-7, paras 42-43; CAT/C/FRA/CO/7, paras 34-35; CAT/C/NLD/CO/7, paras 52-53; CAT/C/GBR/CO/6, paras 64-65

<sup>&</sup>lt;sup>93</sup> Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: "Ending the Impunity of the Perpetrators!" Input at "Ending Human Rights Violations Against Intersex Persons." OHCHR Expert Meeting, Geneva 16– 17.09.2015, online: <u>https://stopigm.org/public/S3\_Zwischengeschlecht\_UN-Expert-Meeting-2015\_web.pdf</u>

However, internationally there are **many examples proving also a strict definition to apply**.<sup>94</sup> For decades, intersex children have been regularly described and exploited by scientists as an *"experiment of nature"*.<sup>95 96 97</sup> Often **twins, siblings, mothers or other family members or relatives** of intersex children are used as controls.<sup>98 99</sup> Generally, intersex children, while being submitted to IGM practices or thereafter, are often used as **subjects in scientific research**, particularly in the field of genetics, also in **France** and internationally with the contribution of **French IGM doctors**.<sup>100 101</sup>

Thus, intersex children surely also fall under "*persons not capable of giving valid consent*" deserving "*special protection in regard to such experiments*" according to **General comment No. 20** (para 7), and involuntary experimental intersex treatments in France surely also constitute **involuntary medical or scientific experimentation in breach of article 7**.

What's more, regarding legislative and other measures, General comment No. 20 explicitly obliges State parties to

- "afford everyone protection through legislative and other measures as may be necessary against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity." (para 2)
- "inform the Committee of the legislative, administrative, judicial and other measures they take to prevent and punish acts of torture and cruel, inhuman and degrading treatment in any territory under their jurisdiction." (para 8)

<sup>94</sup> See e.g. Case Study No. 1 in 2015 CAT Austria NGO Report (p. 13-15), explaining how of two intersex cousins, one was castrated at age 5 or 6 and the other only at age 10 "to document the difference", https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf

<sup>95</sup> See e.g. Kang H-J, Imperato-McGinley J, Zhu Y-S, Rosenwaks Z. 5alpha-reductase-2 Deficiency's Effect on Human Fertility. *Fertility and sterility*. 2014;101(2):310-316, at p. 5, <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4031759/pdf/nihms578345.pdf</u>

<sup>96</sup> Clarnette, T.D; Sugita, Y.; Hutson, J.M.: Genital anomalies in human and animal models reveal the mechanisms and hormones governing testicular descent, *British Journal of Urology* (1997), 79, 99–112, at 99, http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf

<sup>97</sup> U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied zwischen M\u00e4dchen und Jungen, M\u00e4nnern und Frauen?, Monatsschr Kinderheilkd 2003 · 151:586–593, at 591, see also: Lang C.; Kuhnle U.: Intersexuality and Alternative Gender Categories in Non-Western Cultures, Horm Res 2008;69:240–250

<sup>98</sup> See e.g. Dittmann, R. W., Kappes, M. H., Kappes, M. E., Borger, D., Stegner, H., Willig, R. H., Wallis, H. (1990). "Congenital adrenal hyperplasia. I: Gender-related behavior and attitudes in female patients and sisters." Psychoneuroendocrinology 15(5-6): 401-420, see also: Ralf W. Dittmann, "Pränatal wirksame Hormone und Verhaltensmerkmale von Patientinnen mit den beiden klassischen Varianten des 21-Hydroxylase-Defektes. Ein Beitrag zur Psychoendokrinologie des Adrenogenitalen Syndroms", European University Studies, Bern: 1989

<sup>99</sup> For an example of studies on intersex twins by German gynaecologist Ernst Philipp in collaboration with Swiss endocrinologist Andrea Prader, see Marion Hulverscheidt (2016), Begriffsdefinitionen "Intersexualität" VII: Eine einheitliche Betrachtung des Zwittertums – der Kieler Gynäkologe Ernst, <u>http://intersex.hypotheses.org/3976</u>

<sup>100</sup> McElreavey K, Jorgensen A, Eozenou C, Merel T, Bignon-Topalovic J, Tan DS, Houzelstein D, Buonocore F, Warr N, Kay RGG, Peycelon M, Siffroi JP, Mazen I, Achermann JC, Shcherbak Y, Leger J, Sallai A, Carel JC, Martinerie L, Le Ru R, Conway GS, Mignot B, Van Maldergem L, Bertalan R, Globa E, Brauner R, Jauch R, Nef S, Greenfield A, Bashamboo A (2019), "Pathogenic variants in the DEAH-box RNA helicase DHX37 are a frequent cause of 46,XY gonadal dysgenesis and 46,XY testicular regression syndrome", Genet Med. 2020; 22(1): 150–159, <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6944638/</u>

<sup>101</sup> Bashamboo A, Ledig S, Wieacker P, Achermann J, McElreavey K. New Technologies for the Identification of Novel Genetic Markers of Disorders of Sex Development (DSD). Sex Dev. 2010;15(4):213-224

- "indicate how their legal system effectively guarantees the immediate termination of all the acts prohibited by article 7 as well as appropriate redress. The right to lodge complaints against maltreatment prohibited by article 7 must be recognized in the domestic law. Complaints must be investigated promptly and impartially by competent authorities so as to make the remedy effective. The reports of States parties should provide specific information on the remedies available to victims of maltreatment and the procedure that complainants must follow, and statistics on the number of complaints and how they have been dealt with." (para 14)
- "guarantee freedom from such acts within their jurisdiction; and to ensure that they do not occur in the future. States may not deprive individuals of the right to an effective remedy, including compensation and such full rehabilitation as may be possible." (para 15)

# Art. 9: Liberty and Security of the Person

As IGM practices cause known, severe physical and mental **pain and suffering** and are often practices with impunity in **public institutions**, including under **direct tutelage of the State** in case of intersex orphans under guardianship of Social services, where they are often submitted to IGM before they're given up for adoption, this surely also violates article 9.

#### Art. 17: Arbitrary or Unlawful Interference with Privacy

While intersex children are regularly **lied to about diagnosis and treatment**, and often even the fact that have an intersex condition is **concealed** from them, on the other hand **doctors regularly share and publish private details** about them in medical publications and text books. Often intersex persons and their parents are also **blackmailed by threatening to expose their intersex status**, if they don't do this or comply with that, notably but not limited to sports. This clearly violates article 17.

# Art. 24: Child Protection

As IGM practices are **mostly performed on very young children**, they surely constitute a violation of the right to protection of the intersex children concerned, and therefore of article 24.

# Art. 26: Equal Protection of the Law

Intersex children have the **same rights to effective protections** from IGM as for example girls against Female Genital Mutilation (FGM). However, while **FGM is criminalised** in the French Penal Law, with also extraterritorial protections in force, **IGM practices remain legally permitted**. This is clearly not in line with article 26.

#### 2. Lack of Independent Data Collection and Monitoring

With **no statistics available** on intersex births, let alone surgeries and costs, and **perpetrators**, **governments and health departments colluding to keep it that way as long as anyhow possible**, persons concerned as well as civil society **lack possibilities to effectively highlight and monitor** the ongoing mutilations. What's more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists "on record".

# Also in France, there are no official statistics on intersex births and on IGM practices available.

# Annexe 2 – Intersex, IGM and Non-Derogable Human Rights

# 1. Intersex = variations of reproductive anatomy

**Intersex persons**, in the vernacular also known as hermaphrodites, or medically as persons with "*Disorders*" or "*Differences of Sex Development (DSD)*", <sup>102</sup> are people born with variations of reproductive anatomy, or "atypical" reproductive organs, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at birth or earlier during prenatal testing, others may only become apparent at puberty or later in life.

While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations, with **1 to 2 in 1000 newborns** at risk of being submitted to non-consensual "genital correction surgery".

For more information and references, see 2014 CRC Switzerland NGO Report, p. 7-12.<sup>103</sup>

# 2. IGM = Involuntary, unnecessary and harmful interventions

In "developed countries" with universal access to paediatric health care 1 to 2 in 1000 newborns are at risk of being submitted to medical IGM practices, i.e. non-consensual, unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments that would not be considered for "normal" children, practiced without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs, and often directly financed by the state via the public health system.<sup>104</sup>

In regions without universal access to paediatric health care, there are reports of infanticide<sup>105</sup> of intersex children, of abandonment,<sup>106</sup> of expulsion,<sup>107</sup> of massive bullying preventing the

103 https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\_v2.pdf

<sup>102</sup> The currently still official medical terminology **"Disorders of Sex Development" is strongly refused by persons concerned**. See 2014 CRC NGO Report, p. 12 "Terminology".

<sup>104</sup> For references and general information, see 2015 CAT NGO Report Austria, p. 30-35, https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf

 <sup>105</sup> For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, https://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf
 For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12, https://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf
 For South Africa, see also https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens
 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda ; for Uganda, see also 2015 CRC Briefing, slide 46, https://intersex.shadowreport.org/public/Zwischengeschlecht\_2015-CRC-Briefing\_Intersex-IGM\_web.pdf
 For Kenya, see also http://www.bbc.com/news/world-africa-39780214
 For Mexico, see 2018 CEDAW NGO Joint Statement, https://stopigm.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018

<sup>106</sup> For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda For example in China, see 2015 Hong Kong, China NGO Report, p. 15, https://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf

<sup>107</sup> For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),<sup>108</sup> and of **murder**.<sup>109</sup>

Governing State bodies, public and private healthcare providers, national and international medical bodies and individual doctors have traditionally been **framing and "treating"** healthy intersex children as **suffering from a form of disability in the medical definition**, and in need to be **"cured" surgically**, often **with openly racist, eugenic and suprematist implications**.<sup>110 111 112 113</sup>

Both in "developed" and "developing" countries, **harmful stereotypes and prejudice** framing intersex as **"inferior"**, **"deformed"**, **"disordered"**, **"degenerated" or a "bad omen"** remain widespread, and to this day inform the current harmful **western medical practice**, as well as other practices including **infanticide** and **child abandonment**.

**Typical forms of medical IGM** include "feminising" or "masculinising", "corrective" genital surgery, sterilising procedures, imposition of hormones (including prenatal "therapy"), forced genital exams, vaginal dilations, medical display, human experimentation, selective (late term) abortions and denial of needed health care.

Medical IGM practices are known to cause **lifelong severe physical and mental pain and suffering**,<sup>114</sup> including loss or impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, incontinence, problems with passing urine (e.g. due to urethral stenosis after surgery), increased sexual anxieties, problems with desire, less sexual activity, dissatisfaction with functional and aesthetic results, lifelong trauma and mental suffering, elevated rates of self-harming behaviour and suicidal tendencies comparable to those among women who have experienced physical or (child) sexual abuse, impairment or loss of reproductive capabilities, lifelong dependency on daily doses of artificial hormones.

UN Treaty bodies and other human rights experts have consistently recognised IGM practices as a serious violation of non-derogable human rights.<sup>115</sup> UN Treaty bodies have so far issued 52 Concluding Observations condemning IGM practices accordingly.<sup>116</sup>

<sup>108</sup> For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see https://stopigm.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3

<sup>109</sup> For example in Kenya, see <u>https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/</u>

<sup>110 2014</sup> CRC NGO Report, p. 52, 69, 84, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\_v2.pdf

<sup>111</sup> In the WHO "World Atlas of Birth Defects (2nd Edition)", many intersex diagnoses are listed, including *"indeterminate sex"* and *"hypospadias":* 

http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf 112 "The Racist Roots of Intersex Genital Mutilations"

 <sup>&</sup>lt;u>https://stopigm.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM</u>
 For 500 years of "scientific" prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7, <u>https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

<sup>114</sup> See "IGM Practices – Non-Consensual, Unnecessary Medical Interventions", ibid., p. 38–47

<sup>115</sup> CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", <u>http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E</u>

<sup>116</sup> https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

# 3. Intersex is NOT THE SAME as LGBT or Transgender

Unfortunately, there are also other, often interrelated **harmful misconceptions and stereotypes about intersex** still prevailing in public, notably if intersex is counterfactually described as being the same as or a subset of LGBT or SOGI, e.g. if intersex is misrepresented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality, or as a form of sexual orientation.

The underlying reasons for such harmful misrepresentations include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**<sup>117</sup> <sup>118</sup> for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

Intersex persons and their organisations have spoken out clearly against instrumentalising or misrepresenting intersex issues,<sup>119</sup> maintaining that IGM practices present a distinct and unique issue constituting significant human rights violations, which are different from those faced by the LGBT community, and thus need to be **adequately addressed in a separate section** as **specific intersex issues**.

Also, **human rights experts** are increasingly warning of the **harmful conflation** of intersex and LGBT.<sup>120 121</sup>

Regrettably, **these harmful misrepresentations seem to be on the rise also at the UN**, for example in recent **UN press releases** and **Summary records** misrepresenting IGM as "*sex alignment surgeries*" (i.e. voluntary procedures on transsexual or transgender persons), IGM survivors as "*transsexual children*", and intersex NGOs as "*a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination*",<sup>122</sup> and again IGM survivors as "*transgender children*", and IGM as a form of "*discrimination against transgender and intersex children*" <sup>124</sup> and as "*sex assignment surgery*" while referring to "*access to gender reassignment-related treatments*".<sup>125</sup>

Particularly **State parties** are constantly **misrepresenting intersex and IGM as sexual orientation or gender identity issues** in an attempt to **deflect from criticism** of the serious human rights violations resulting from IGM practices, instead referring to e.g. "gender reassignment surgery" (i.e. voluntary procedures on transsexual or transgender persons) and "gender assignment surgery for children",<sup>126</sup> "a special provision on sexual orientation and

<sup>117</sup> CRC67 Denmark, <u>https://stopigm.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark</u>

<sup>118</sup> CEDAW66 Ukraine, https://stopigm.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics

<sup>119</sup> For references, see 2016 CEDAW France NGO Report, p. 45 https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

<sup>120</sup> For example ACHPR Commissioner Lawrence Murugu Mute, see https://stopigm.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT

<sup>121 2018</sup> Report of the Kenya National Commission on Human Rights (KNCHR), p. 15, <u>https://www.knchr.org/Portals/0/GroupRightsReports/Equal%20In%20Dignity%20and%20Rights\_Promoting%</u> <u>20The%20Rights%20Of%20Intersex%20Persons%20In%20Kenya.pdf?ver=2018-06-06-161118-323</u>

<sup>122</sup> CAT60 Argentina, <u>https://stopigm.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60</u>

<sup>123</sup> CRC77 Spain, https://stopigm.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children

<sup>124</sup> CRC76 Denmark, https://stopigm.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67

<sup>125</sup> CAT/C/DNK/QPR/8, para 32

<sup>126</sup> CRC73 New Zealand, <u>https://stopigm.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child</u>

gender identity", "civil registry" and "sexual reassignment surgery" <sup>127</sup>, transgender guidelines<sup>128</sup> or "Gender Identity" <sup>129</sup> <sup>130</sup> when asked about IGM by e.g. Treaty bodies.

What's more, **LGBT organisations** (including "LGBTI" organisations without actual intersex representation or advocacy) are frequently using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus **depriving actual intersex organisations** (which mostly have no significant funding, if any) of much needed **resources** <sup>131</sup> and public **representation**.<sup>132</sup>

# 4. IGM is NOT a "Discrimination" Issue

An interrelated diversionary tactic is the increasing misrepresentation by State parties of IGM as "discrimination issue" instead of a serious violation of non-derogable human rights, namely inhuman treatment and a harmful practice, often in combination with the misrepresentation of intersex human rights defenders as "fringe elements", and their legitimate demands and criticism of such downgrading and trivialising of IGM as "extreme views".

# 5. IGM is NOT a "Health" Issue

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as** *"health-care issue"* instead of a serious violation of non-derogable human rights, and the **promotion of** *"self-regulation"* **of IGM by the current perpetrators**<sup>133</sup> <sup>134</sup> <sup>135</sup> <sup>136</sup> – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health Ministries** construe UN Concluding observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse for "self-regulation" promoting state-sponsored IGM practices to continue with impunity.**<sup>137 138 139</sup>

129 CAT60 Argentina, <u>https://stopigm.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture</u>

<sup>127</sup> CCPR120 Switzerland, https://stopigm.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120

<sup>128</sup> CAT56 Austria, https://stopigm.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations

<sup>130</sup> CRPD18 UK, <u>https://stopigm.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD</u>

<sup>131</sup> For example in Scotland (UK), LGBT organisations have so far collected at least £ 135,000.– public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, <u>https://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf</u> Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as "supporting intersex people", but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), <u>https://stopigm.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD</u>

<sup>132</sup> See e.g. "Instrumentalizing intersex: 'The fact that LGBTs in particular embrace intersex is due to an excess of projection' - Georg Klauda (2002)", <u>https://stopigm.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002</u>

<sup>133</sup> For example Amnesty (2017), see https://stopigm.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors

<sup>134</sup> For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, https://stopigm.org/public/S3 Zwischengeschlecht UN-Expert-Meeting-2015 web.pdf

<sup>135</sup> For example CEDAW Italy (2017), see <u>https://stopigm.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN</u>

<sup>136</sup> For example CEDAW Austria (2019): CEDAW/C/AUT/CO/9, paras 34(h), 35(h)

<sup>137</sup> For example Ministry of Health Chile (2016), see <u>https://stopigm.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile</u>

<sup>138</sup> For example Ministry of Health France (2018), see 2020 CRC Intersex NGO Report (for LOIPR), p. 19, https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf

<sup>139</sup> For example Ministry of Health Austria (2019), see 2019 CRC Intersex NGO Report (for Session), p. 4-5, https://intersex.shadowreport.org/public/2019-CRC-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf