Intersex Genital Mutilation

Human Rights Violations Of Children With Variations Of Reproductive Anatomy





NGO Report (for LOIPR)
to the 7th Report of Spain on the
Convention on the Rights of the Child (CRC)

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https://intersex.shadowreport.org/public/2021-CRC-Spain-LOIPR-NGO-Intersex-IGM.pdf





Executive Summary

Despite laws formally "prohibiting" IGM in currently 8 Autonomous Communities, all typical forms of Intersex Genital Mutilation are still practiced allover Spain, facilitated and paid for by the State party via the public health system, and perpetrated by public University Hospitals and private health-care providers alike. The categorical failure of the current laws to adequately protect intersex children from harmful practices becomes even more apparent in comparison with the State party's vastly superior, current anti-FGM legislation and policies.

Spain is thus in breach of its obligations under CRC to (a) take effective legislative, administrative, judicial or other measures to prevent harmful practices on intersex children causing severe mental and physical pain and suffering of the persons concerned, and (b) ensure access to redress and justice, including fair and adequate compensation and as full as possible rehabilitation for victims, as stipulated in CRC art. 24 para. 3 in conjunction with the CRC-CEDAW Joint general comment No. 18/31 "on harmful practices".

This Committee has consistently recognised IGM practices to constitute a harmful practice under the Convention in Concluding Observations.

In total, UN treaty bodies CRC, CEDAW, CAT, CCPR and CRPD have so far issued 72 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, (b) ensure redress and compensation and (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 NGO Report has been compiled by StopIGM.org / Zwischengeschlecht.org, an international intersex NGO. It contains Suggested Questions (see p. 15).

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A. Introduction

1. Spain: Intersex, IGM and Human Rights

Starting in 2015, so far **8 autonomous Communities** in Spain (out of 17) have enacted **laws to formally prohibit or at least restrict IGM practices** (*Madrid, Murcia, Extremadura, Navarra, Balearic Islands*, *Andalusia, Valencia, Canary Islands*); however, **none of them sanction IGM**, or address obstacles to access to justice, and **none of them are enforced**.

In 2018, this Committee (CRC/C/ESP/CO/5-6, para 24) already considered IGM in Spain as a **harmful practice**, and recommended the State party to "*prohibit unnecessary medical or surgical treatment* [...] on intersex children". Thereafter, on the **national level** a **Draft Law** was green-lit for discussion in Parliament, but in 2019 **expired** due to the change in the legislative period.

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Spain** – advocated, facilitated and **paid for by the State party**, and perpetrated both by public university hospitals and private health-care providers – constitute a **serious breach** of Spain's obligations under the Convention.

2. About the Rapporteurs

This NGO report has been prepared by the intersex NGOs Caminar Intersex and StopIGM.org / Zwischengeschlecht.org.

- Caminar Intersex (English translation: Walking Intersex) is a Spanish NGO based in the Canary Islands. It was founded in 2019, although it started its activism in 2015. Its main objective is training, education and awareness-raising for the respect of intersex bodies in our society. Caminar Intersex was substantially involved in the unanimous approval of the 2021 Law aimed at prohibiting genital mutilations of intersex babies in the Canary Islands. Currently, they are working with the Canary Islands Government Health Department on the Protocol for intersex people.
- 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!" According to its charter, StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to relevant UN treaty bodies, often in collaboration with local intersex persons and organisations, substantially contributing to the so far 72 Treaty body Concluding Observations recognising IGM as a serious human rights violation.

¹ https://Zwischengeschlecht.org/ English homepage: https://StopIGM.org

^{2 &}lt;a href="https://zwischengeschlecht.org/post/Statuten">https://zwischengeschlecht.org/post/Statuten

³ https://intersex.shadowreport.org

^{4 &}lt;u>https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations</u>

In addition, the Rapporteurs would like to acknowledge the work of **Brújula Intersexual.**⁵ And we would like to acknowledge the work of **Amets Suess Schwend** ⁶ and **Daniel J. García López**.⁷

3. Methodology

This thematic NGO report is a localised update to the **2019 CCPR Spain NGO Report** (for LOIPR)⁸ and the **2017 CRC Spain NGO Report** (for Session)⁹ by partly the same Rapporteurs.

^{5 &}lt;a href="https://brujulaintersexual.org/">https://brujulaintersexual.org/

⁶ https://academic.oup.com/eurpub/article/31/Supplement 3/ckab164.166/6405737

⁷ https://brujulaintersexual.files.wordpress.com/2017/10/intersex-manifesto-english.pdf

⁸ http://intersex.shadowreport.org/public/2019-CCPR-LOIPR-Spain-Intersex-Brujula-StopIGM.pdf

^{9 &}lt;u>http://intersex.shadowreport.org/public/2017-CRC-Spain-NGO-Brujula-Zwischengeschlecht-Intersex-IGM.pdf</u>

B. Precedents

1. 2018 CRC Concluding Observations on Intersex (CRC/C/ESP/CO/5-6, para 24)

 $\underline{http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC\%2fC\%2fESP\%2fCO\%2f5-6\&Lang=encount.pdf$

Harmful practices

24. The Committee recommends that the State party prohibit unnecessary medical or surgical treatment from being performed on intersex children, when those procedures entail a risk of harm and can be safely deferred until the child can actively participate in decision-making. It also recommends that the State party ensure that intersex children and their families receive adequate counselling and support.

2. 2019 CCPR List of Issues prior to Reporting (LOIPR) (CCPR/C/ESP/QPR/7, para 10)

 $\underline{https://tbinternet.ohchr.org/\ layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR\%2fC\%2fESP\%2fQPR\%2f7\&Lang=enrangentation.}$

Children with variations of sex characteristics (intersex) (arts. 7, 17 and 24)

10. Please report on the measures adopted to limit or prohibit the performance of medically unnecessary irreversible surgery and other unnecessary medical procedures on intersex newborns and children until they have reached an age at which they are able to give their free, prior and informed consent. Please also provide information on measures taken to facilitate effective access to justice and redress, including rehabilitation, for those who have been subjected to such surgical procedures or other medical treatment without their consent.

C. IGM in Spain: State-sponsored and pervasive, Gov fails to act

1. Overview: IGM practices in Spain: Pervasive and unchallenged

In **Spain** (CRC/C/ESP/CO/5-6, para 24), same as in the fellow European Union states of *Portugal* (CRC/C/PRT/CO/5-6, para 28(b); CCPR/C/PRT/CO/5, paras 16-17), *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 34-35; CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f), and *Germany* (CRC/C/DEU/CO/5-6, para 24(c); CAT/C/DEU/CO/5, para 20; CEDAW/C/DEU/CO/7-8, paras 23-24; CRPD/C/DEU/CO/1, paras 37-38), and in **many more State parties**, 9 there are

- no legal or other protections in place on the national level to ensure the prevention of IGM practices; and no effective legal or other protections in the Autonomous Communities of Madrid, Murcia, Extremadura, Navarra, Balearic Islands, Andalusia, Canary Islands, as stipulated in art. 24(3) and the Joint General Comment No. 18/31
- no legal or other protections in place on the national level to ensure the accountability of IGM perpetrators
- **no legal or other measures** in place to ensure **access to redress and justice** for survivors of childhood IGM practices
- **no legal or other measures** in place to ensure **data collection** and **monitoring** of IGM practices, except in the Autonomous Community of the Canary Islands
- no legal or other measures in place on the national level to ensure education and training of medical professionals on the consequences of IGM practices

Despite that the persistence of IGM practices in Spain is a **matter of public record**, same as the **criticism and appeals** by **intersex persons**, **experts and allies**, to this day the Spanish Government fails to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to "take effective legislative, administrative, judicial or other measures" to effectively protect intersex children from harmful practices.

What's worse, this situation persists despite that in 2018, this Committee already considered **IGM** in Spain as a harmful practice, and recommended the State party to "prohibit unnecessary medical or surgical treatment [...] on intersex children", and to "ensure that intersex children and their families receive adequate counselling and support" (CRC/C/ESP/CO/5-6, para 24).

2. Spain's commitment to "protect intersex children from violence and harmful practices", "investigate abuses", "ensure accountability" and "access to remedy"

a) UNHRC45 Statement, 01.10.2020

On occasion of the 45th Session of the Human Rights Council the State party supported a public statement calling to "protect [...] intersex adults and children [...] so that they live free from violence and harmful practices. Governments should investigate human rights violations and abuses against intersex people, ensure accountability, [...] and provide victims with access to remedy." ¹⁰

⁹ Currently we count **72 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see: https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

¹⁰ Statement supported by Spain (and 34 other States) during the 45th Session of the Human Rights Council on 1 October 2020, https://www.dfat.gov.au/international-relations/themes/human-rights/hrc-statements/45th-session-human-rights-council/joint-statement-led-austria-rights-intersex-persons

b) UNHRC48 Statement, 04.10.2021

On occasion of the 48th Session of the Human Rights Council the State party supported a public follow-up statement reiterating the call to end harmful practices and ensure access to justice:

"Intersex persons also need to be protected from violence and States must ensure accountability for these acts. [...]

Furthermore, there is also a need to take measures to protect the autonomy of intersex children and adults and their rights to health and to physical and mental integrity so that they live free from violence and harmful practices. Medically unnecessary surgeries, hormonal treatments and other invasive or irreversible non-vital medical procedures without their free, prior, full and informed consent are harmful to the full enjoyment of the human rights of intersex persons.

We call on all member states to take measures to combat violence and discrimination against intersex persons, develop policies in close consultations with those affected, ensure accountability, reverse discriminatory laws and provide victims with access to remedy." ¹¹

3. Existing Laws and Legislative Initiatives against IGM

Out of the 17 Autonomous Communities in Spain, so far 8 have enacted laws claiming to formally prohibiting or at least restricting IGM practices (Madrid, ¹² Murcia, ¹³ Extremadura, ¹⁴ Navarra, ¹⁵ Balearic Islands, ¹⁶ Andalusia, ¹⁷ Valencia, ¹⁸ Canary Islands ¹⁹), however, only 2 of these laws contain (minor) sanctions concerning intersex people at all (Valencia, Canary Islands), and none of them contain any sanctions for IGM practices, or address obstacles to access to justice, namely the statutes of limitations, or contain extraterritorial protections. In fact, concerning IGM none of them are enforced.

On the **national level**, in 2018 a Draft Law was filed in the Spanish Lower House gaining Commission support, however, the Original Draft and the watered-down Commission Draft both didn't contain any sanctions, or address obstacles to justice, or extraterritorial protections, and due to the change of the legislative period the **proposal expired** in 2019.

Statement supported by Spain (and 52 other States) during the 48th Session of the Human Rights Council on 4 October 2021, https://www.bmeia.gv.at/oev-genf/speeches/alle/2021/10/united-nations-human-rights-council-48th-session-joint-statement-on-the-human-rights-of-intersex-persons/

¹² Comunidad de Madrid: Ley 2/2016, 29.03.2016, art. 4, para 3 (prohibition); art. 53 (sanctions), https://www.boe.es/eli/es-md/l/2016/03/29/2/con

Comunidad Autónoma de la Región de Murcia: Ley 8/2016, 27.05.2016, art. 8, para 3 (prohibition); art. 52 (sanctions), https://www.boe.es/eli/es-mc/l/2016/05/27/8/con

¹⁴ Comunidad Autónoma de Extremadura: Ley 12/2015, 08.04.2015, art. 11, para 2, https://www.boe.es/eli/es-ex/l/2015/04/08/12/con

¹⁵ Comunidad Foral de Navarra: Ley Foral 8/201, 19.06.2017, art. 17, para 1, https://www.boe.es/eli/es-nc/lf/2017/06/19/8/con

¹⁶ Comunidad Autónoma de las Illes Balears: Ley 8/2016, 30.05.2016, art. 23, para 2, https://www.boe.es/eli/es-ib/l/2016/05/30/8/con

¹⁷ Junta de Andalucía: Ley 8/2017, 28.12.2018, art. 29, https://www.boe.es/eli/es-an/l/2017/12/28/8/con

¹⁸ Comunitat Valenciana: Ley 23/2018, 29.11.2018, arts. 46-50, https://www.boe.es/buscar/act.php?id=BOE-A-2019-281

Comunidad Autónoma de Canaria: Ley 2/2021, 07.06.2021, art. 4(3), 6(2), 8(1a), 20(2), 27(2), 27(3a), 27(3a,e), 31(1), https://www.boe.es/diario boe/txt.php?id=BOE-A-2021-11382

In contrast, FGM is explicitly forbidden in the Spanish Criminal Code, with sanctions including "imprisonment from six to twelve years" (Organic Act 11/2003, modified article 149.2). Also, extraterritorial protections are established (Organic Act 6/1985, article 23.4, modified by Organic Act 1/2014). Further, Article 158 of the Civil Code, modified by Organic Act 9/2000, allows judges to adopt preventive measures in the case of an imminent risk of genital mutilation. As FGM is considered a crime, professionals aware of an actual or impending incident are therefore subject to mandatory notification (article 450 of the Criminal Code; articles 262 + 355 of the Civil Procedure Act; Organic Act 1/1996).²⁰

4. Most Common IGM Forms advocated and perpetrated by Spain

Despite above mentioned commitments and regional laws to protect intersex children, to this day, in Spain all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated by state funded University and Public Children's Clinics, and paid for by the Spanish National Health System (SNS).

Currently practiced forms of IGM in Spain include:

a) IGM 3 – Sterilising Procedures:

Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones ²¹

The Spanish Association of Urology ("Asociación Española de Urología (AEU)") endorses the 2022 Guidelines of the European Association of Urology (EAU), 22 which include the current ESPU/EAU "Paediatric Urology" Guidelines 2022²³ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:²⁴

"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", 25 the Guidelines refer to the "ESPU/SPU standpoint on the surgical management of Disorders of Sex **Development** (DSD)", ²⁶ 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."

https://uefgm.org/index.php/legislative-framework-es/ 20

For general information, see 2016 CEDAW NGO Report France, p. 47. 21 $\underline{https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf}$

²² https://uroweb.org/guidelines/endorsement/

https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf 23

²⁴ Ibid., p. 89

Ibid., p. 88 25

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, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

Also, the **"2016 Global Disorders of Sex Development Consensus Statement"** 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)²⁸:

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy Self-examination Annual ultrasound (post-puberty) Post-pubertal biopsy Based on ultrasound and results of first biopsy If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	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) Post-pubertal biopsy Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – 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, the current **DSD Guidelines** by the "DSD Working Group" of the **Spanish Society of Paediatric Endocrinology** (**SEEP**)²⁹ unchangingly promote "prophylactic gonadectomy" (p. 44–46):

"In Complete Androgen Insensitivity (CAIS) without residual receptor activity, the rate of malignant tumors is low. [...] [T]he general recommendation is prophylactic gonadectomy in late puberty. [...] Having decided to perform a gonadectomy in these patients, the need for hormone replacement treatment should be discussed with the family and patient. In general, the doses of estrogen needed to maintain bone mass and prevent symptoms of estrogen deficiency are higher than those used in menopause, and should be adapted to each patient."

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation³⁰

The Spanish Association of Urology ("Asociación Española de Urología (AEU)") endorses the 2022 Guidelines of the European Association of Urology (EAU), ³¹ which include the current ESPU/EAU "Paediatric Urology" Guidelines 2022 ³² of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.17 "Disorders of sex development", ³³ despite admitting that "Surgery that alters appearance is not urgent" ³⁴ and that "adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to

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

²⁸ Ibid., at 180 (fn 111)

²⁹ available at https://www.seep.es/images/site/home/GUIA MANEJO ADS DSD SEEP.PDF

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

³¹ https://uroweb.org/guidelines/endorsement/

^{32 &}lt;a href="https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf">https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf

³³ Ibid., p. 86

³⁴ Ibid., p. 88

an age when the patient can give inform consent", 35 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, 36 referring to the 2018 ESPU Open Letter to the Council of Europe (COE), 37 which further invokes parents' "social, and cultural considerations" as justifications for early surgery (p. 2).

Accordingly, the **Madrid University Children's Hospital La Paz**'s current "*Formative Itinerary Paediatric Surgery*" ³⁸ lists under "PAEDIATRIC GYNAECOLOGY SURGERY" (p. 14, p. 15 in PDF):

"Procedures on female external genitalia

Treatment of: labial synechiae.

Clitoral hypertrophy. Correction of intersexual stages."

An April 2019 presentation by paediatric surgeons and urologists from the **Madrid University Children's Hospital La Paz**³⁹ about "*long-term surgical results*" of feminising procedures on 33 CAH patients operated on 1977-2012 came to the following

"CONCLUSIONS

Glans reduction in CAH patients cause a decrease in genital sensitivity. The surgical consequences for sexual and social development in this condition should lead us to a multidisciplinary, more conservative management."

In other words, the surgeons indirectly admit that a "more conservative management" regarding IGM 2 is **not the actual status** also at the Madrid University Children's Hospital La Paz – despite that IGM has been formally outlawed in Madrid since 2016 (see p. 9).

Also, the Barcelona Children's University Hospital Vall d'Hebron which self-describes its department of "Paediatric Urology" as "a pioneer in the treatment of sexual differentiation disorders at the paediatric age", offers on its homepage "Partial clitoridectomies", "Sigmoid vaginoplasty", "Perineal and abdominoperineal vulvovaginoplasty" and "Surgical treatment of sexual differentiation anomalies". ⁴⁰

Also, at the Murcia University Hospital "Virgen de la Arrixaca", the chief of paediatric surgery Dr Gerardo A. Zambudio publicly advocates "feminising surgical techniques", namely

³⁵ Ibid., p. 88

³⁶ Ibid., p. 89

³⁷ https://www.espu.org/images/documents/ESPU Open Letter to COE 2018-01-26.pdf

 $[\]underline{\text{https://www.comunidad.madrid/hospital/12octubre/file/5544/download?token=GqK9FrzO}$

^{39 30}th ESPU, 25.04.2019, Session 9: DSD. Javier SERRADILLA RODRIGUEZ, Alba BUENO JIMÉNEZ (Children's Hospital La Paz, Paediatric Surgery); Susana RIVAS VILA, María José MARTÍNEZ URRUTIA, Roberto LOBATO, Solon CASTILLO, Virginia AMESTY and Pedro LÓPEZ PEREIRA (Children's Hospital La Paz, Paediatric Urology): "LONG-TERM SURGICAL RESULTS IN CONGENITAL ADRENAL HYPERPLASIA"

^{40 &}lt;u>https://www.vallhebron.com/en/specialities/paediatric-urology</u>

partial clitoris amputation and "vaginoplasty" on "girls" diagnosed with Congenital Adrenal Hyperplasia (CAH), on his private homepage "Uropediatria.com".⁴¹

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair" 42

The Spanish Association of Urology ("Asociación Española de Urología (AEU)") endorses the 2022 Guidelines of the European Association of Urology (EAU), ⁴³ which include the current ESPU/EAU "Paediatric Urology" Guidelines 2022⁴⁴ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.6 "Hypospadias", ⁴⁵ 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." ⁴⁶ – despite admitting to the "risk of complications" ⁴⁷ and "aesthetic[...]" and "cosmetic" justifications. ⁴⁸

Accordingly, the **Madrid University Children's Hospital La Paz**'s current "*Formative Itinerary Paediatric Surgery*" ⁴⁹ lists under "PAEDIATRIC UROLOGY SURGERY" (p. 13, p. 14 in PDF):

"Treatment of diseases of the penis.

Congenital malformations of the penis. Curved penis. Hypospadias."

The Barcelona Children's University Hospital Vall d'Hebron self-describes its department of "Paediatric Urology" as "a pioneer in the treatment of sexual differentiation disorders at the paediatric age", and offers on its homepage "Hipospadias correction techniques: Mathieu, Snodgrass, Onlai, Duckett, oral or bladder mucous in interscrotals. Meatotomy. Nesbitt technique" and "Surgical treatment of sexual differentiation anomalies". ⁵⁰

The **2018 ECE Annual Meeting** (20th European Congress of Endocrinology) was held in **Barcelona**, with a "Symposium 30: Disorders of Sexual Development (DSD)" chaired by local paediatric endocrinologist Laura Audi, promoting early "[s]urgical repair" as the rule and the "late surgery and the no surgery alternatives [which] have been recently proposed" as a secondary "choice". ⁵¹

Also, at the Murcia University Hospital "Virgen de la Arrixaca", the chief of paediatric surgery Dr Gerardo A. Zambudio publicly advocates early, unnecessary "hypospadias repair" explicitly with psychological indications, on his private homepage "Uropediatria.com":⁵²

46 Ibid., p. 27

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^{41 &}lt;a href="http://www.uropediatria.com/uropediatria/tratamiento-genitales-ambiguos/">http://www.uropediatria.com/uropediatria/tratamiento-genitales-ambiguos/

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

⁴⁴ https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf

⁴⁵ Ibid., p. 26

⁴⁷ Ibid., p. 27

⁴⁸ Ibid., p. 27

^{49 &}lt;u>https://www.comunidad.madrid/hospital/12octubre/file/5544/download?token=</u>GqK9FrzO

^{50 &}lt;a href="https://www.vallhebron.com/en/specialities/paediatric-urology">https://www.vallhebron.com/en/specialities/paediatric-urology

⁵¹ ECE 2018, Symposium 30: Disorders of Sexual Development (DSD), presentation by Nicolas Kalfa, "Atypical Genital Development and Hypospadias: a Pediatric Urology perspective from Etiology to Surgery, for abstract see http://programme.bioscientifica.com/ece2018?q=Symposium+30&view=search

^{52 &}lt;u>http://www.uropediatria.com/uropediatria/tratamiento-moderno-del-hipospadias/</u>

"Classical treatment of hypospadias delayed treatment until 3-5 years of age. They usually use catheters for 7 days with bed rest for the child during this time.

Modern hypospadias treatment recommends an earlier age of operation, between 6-18 months because there are psychological advantages. Postoperative management in terms of dressings, bandages, catheterisation etc. is simpler at this early age. Surgery can now be performed on an outpatient basis without hospitalisation."

Also, the Sevilla University Hospital "Virgen Del Rocío" in Andalusia in its leaflet for parents publicly promotes early "hypospadias repair", despite admitting the surgery may be "unnecessary" and could be "postponed", and that there are significant complication rates:⁵³

"In at least 2 out of 10 children there are long-term problems that require further intervention (especially in the most severe cases of hypospadias)."

Also, the Badajoz Hospital "Quirónsalud Clideba" in Extremadura offers surgery for "hypospadias" on its homepage under "paediatric surgery". 54

Also, the "Paediatric Surgery Training Guide" of the Hospital Complex of Navarra obliges resident doctors to practice "hypospadias repair". 55 (Further, the guide obliges paediatric surgeons "at least have acquired a solid knowledge" also of "Intersex states" and "Abnormalities of the female external genitalia". 56)

Also, the private Andromedi clinic operating in Sevilla, Madrid and Tenerife (Canary **Islands**) offers "hypospadias" surgery on its homepage: ⁵⁷

"The optimal time for hypospadias repair should be in the first year (12-15 months) of the infant's life. It is recommended that in any case it should be carried out before the child is aware of its genitalia, to avoid the psychological implications that genital surgery could have on the child."

5. Obstacles to redress, fair and adequate compensation

Also in **Spain**, the **statutes of limitation** prohibit survivors of early childhood IGM practices to call a court, because persons concerned often do not find out about their medical history until much later in life, and severe trauma caused by IGM practices often prohibits them to act in time once they do.⁵⁸

Notably, the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 "on harmful practices" clearly and explicitly stipulates "that the perpetrators and those who aid or condone such practices are held accountable" (para 55 (o)), as well as "equal access to legal remedies and appropriate reparations in practice" (para 55 (q)). Conclusion, this situation is clearly not in line with Spain's obligations under the Convention.

https://www.hospitaluvrocio.es/wp-content/uploads/2019/06/hipospadias.pdf 53

https://www.quironsalud.es/clideba/es/cartera-servicios/cirugia-pediatrica-4560 54

See p. 9 in document (p. 11 in PDF) $\underline{https://www.navarra.es/NR/rdonlyres/FDB796ED-211E-4F85-8FFC-9CA909D287EF/304836/CIRUGIAPEDIATRICACHN.pdf}$

⁵⁶ Ibid., see p. 8 in document (p. 10 in PDF), No.s 75-77

https://www.andromedi.com/urologia-infantil/hipospadias/ 57

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.

D. Suggested Questions for the LOIPR

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

Harmful practices: Intersex children (art. 24(3))

- Please provide information on the measures taken to prevent the unnecessary medical or surgical treatment of intersex children, to provide families with intersex children with adequate counselling and support, and to guarantee access to effective remedies for victims subjected to such treatment during childhood, including the statute of limitations for raising a claim against such treatment.
- 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.