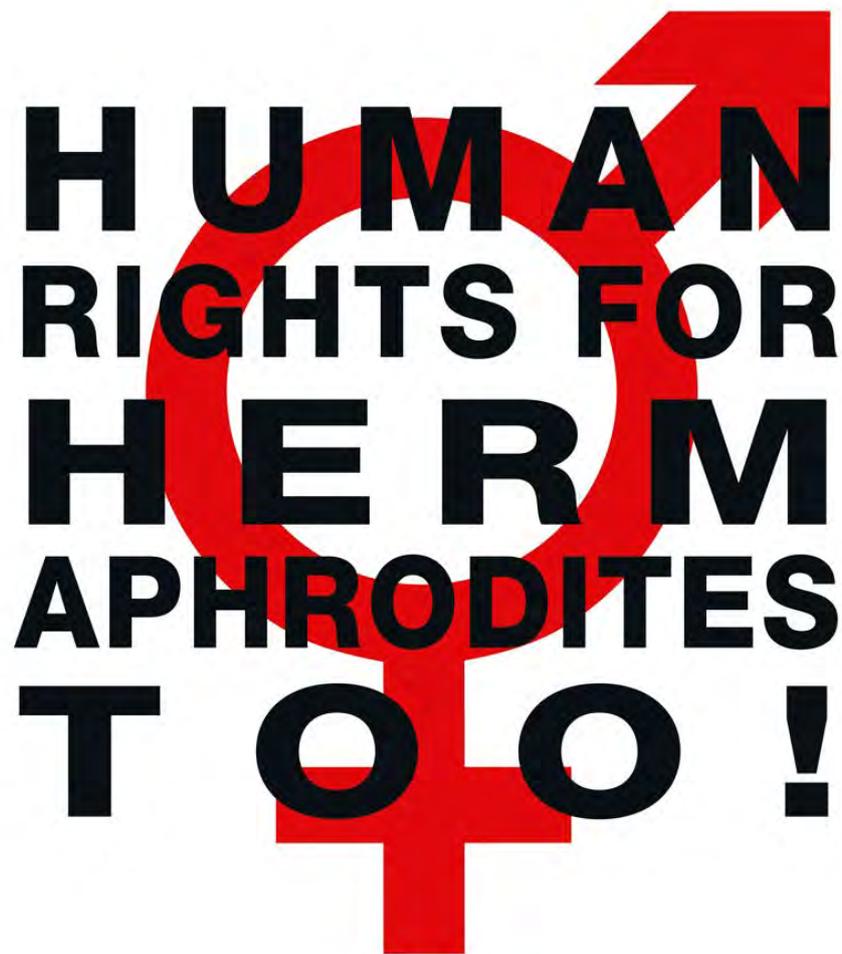


# Intersex Genital Mutilations

## Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for Session)  
to the 5th and 6th Report of Czechia on the  
Convention on the Rights of the Child (CRC)

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## Executive Summary

**All typical forms of Intersex Genital Mutilation are still practised in Czechia in University Hospitals under the direct control of the Ministry of Health, facilitated and paid for by the State party via the mandatory public health system. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. Despite criticism by Civil Society, Czechia fails to act.**

**Czechia 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 **50 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 **NGO Report** has been compiled by **StopIGM.org / Zwischengeschlecht.org**, an international intersex NGO. It contains **Suggested Recommendations** (see p. 18).

**NGO Report (for Session)  
to the 5<sup>th</sup> and 6<sup>th</sup> Report of Czechia  
on the Convention on the Rights of the Child (CRC)**

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## A. Introduction

### 1. Czechia: Intersex, IGM, Human Rights and State Report

IGM practices are known to cause **severe, lifelong physical and psychological pain and suffering**, and have been repeatedly **recognised by multiple UN treaty bodies<sup>1</sup>** including CRC as constituting a **harmful practice**, violence, and cruel, inhuman or degrading treatment.

The current practice in Czechia has been **criticised** NGOs, academics and doctors. However, intersex and IGM were **not mentioned in the 5th and 6th Czech State Report** of 2018.

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Czechia** – advocated and facilitated in **University Hospitals** under the **direct control** of the **Ministry of Health** and **paid for by the State party** via the mandatory **public health system** – constitute a **serious breach** of Czechia’s obligations under the Convention.

### 2. About the Rapporteurs

This NGO report has been prepared by the international intersex NGO *StopIGM.org*:

- **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>2</sup> According to its charter,<sup>3</sup> 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,<sup>4</sup> substantially contributing to the so far 50 Treaty body Concluding Observations recognising IGM as a serious human rights violation.<sup>5</sup>

### 3. Methodology

This thematic NGO report is a localised update to the **2019 CRC Portugal NGO Report (for Session)<sup>6</sup>** by the same Rapporteurs.

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1 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”,  
<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

2 <http://Zwischengeschlecht.org/> English homepage: <http://stop.genitalmutilation.org>

3 <http://zwischeneschlecht.org/post/Statuten>

4 <http://intersex.shadowreport.org>

5 <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

6 <http://intersex.shadowreport.org/public/2019-CRC-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

## B. IGM in Czechia: State-sponsored and pervasive, Gov fails to act

### 1. Overview: IGM practices in Czechia: Pervasive and unchallenged

In **Czechia**, same as in the neighbouring states of *Austria* (CRC/C/AUT/CO/5-6, para 27(a)-(b); CAT/C/AUT/CO/6, paras 44-45) and *Germany* (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 the fellow European states of *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 *Switzerland* (CRC/C/CHE/CO/2-4, paras 42-43; CEDAW/C/CHE/CO/4-5, paras 38-39; CAT/C/CHE/CO/7, para 20; CCPR/C/CHE/CO/4, paras 24-25), and in **many more State parties**,<sup>7</sup> there are

- **no legal or other protections** in place to **prevent all IGM practices** as stipulated in art. 24(3) and the CRC-CEDAW Joint General Comment No. 18/31,
- **no legal measures** in place to ensure **access to redress and justice** for adult IGM survivors,
- **no legal measures** in place to ensure the **accountability** of all IGM perpetrators and accessories,
- **no measures** in place to ensure **data collection and monitoring** of IGM practices.

Despite that the persistence of IGM practices in Czechia is a **matter of public record**, same as the **longstanding criticism and appeals** by **intersex persons, NGOs, academics and individual doctors** (see below, p. 17), to this day the Czech 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 **protect intersex children from harmful practices**.

### 2. Most Common IGM Forms advocated and perpetrated by Czechia

**To this day, in Czechia all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated by state-funded University Hospitals under the direct control of the Ministry of Health, and paid for by the State via the mandatory public health system.**

There are **at least 9 Czech University Hospitals** with paediatric departments **that practice IGM**, all of them under the direct control of the **Czech Ministry of Health**:

- The **General University Hospital in Prague** (Všeobecná fakultní nemocnice v Praze, VFN) of the 1<sup>st</sup> Faculty of Medicine of the **Charles University in Prague** (1. lékařská fakulta Univerzity Karlovy)
- The **Motol University Hospital in Prague** (Fakultní nemocnice v Motole, FN Motol) of the 2<sup>nd</sup> Faculty of Medicine of the **Charles University in Prague** (2. lékařská fakulta Univerzity Karlovy)

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<sup>7</sup> Currently we count **50 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see: <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

- The **Vinohrady University Hospital in Prague** (Fakultní nemocnice Královské Vinohrady) of the 3<sup>rd</sup> Faculty of Medicine of the **Charles University in Prague** (3. lékařská fakulta Univerzity Karlovy)
- The **Pilsen University Hospital** (Fakultní nemocnice Plzeň) of the 4<sup>th</sup> Faculty of Medicine of the **Charles University in Pilsen** (4. lékařská fakulta Univerzity Karlovy)
- The **Hradec Králové University Hospital** (Fakultní nemocnice Hradec Králové) of the 5<sup>th</sup> Faculty of Medicine of the **Charles University in Hradec Králové** (5. lékařská fakulta Univerzity Karlovy)
- The **St. Anne's University Hospital Brno** (Fakultní nemocnice u sv. Anny v Brně) and the **Brno University Hospital** (Fakultní nemocnice Brno) of the **Masaryk University in Brno** (Masarykova univerzita MUNI)
- The **Olomouc University Hospital** (Fakultní nemocnice Olomouc) of the **Palacký University in Olomouc** (Univerzita Palackého v Olomouci)
- The **Ostrava University Hospital** (Fakultní nemocnice Ostrava) of the **University of Ostrava** (Ostravská Univerzita)

**Currently practiced forms of IGM in Czechia include:**

**a) IGM 3 – Sterilising Procedures:**

**Castration / “Gonadectomy” / Hysterectomy /**

**Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation**

**Plus arbitrary imposition of hormones**<sup>8</sup>

Notably, the ground-breaking 2010 medical publication of international renown **rebutting the allegedly “high cancer risk”** often used as a justification for early “prophylactic” gonadectomies on intersex children diagnosed with Complete Androgen Insufficiency Syndrome (CAIS) by documenting that **the actual cancer risk is only 0,8%** (see below p. 31) was **co-authored by a Czech paediatrician**, Jana Kaprová-Pleskačová, working at the **Charles University in Prague** (Paediatric Department, 2nd Faculty of Medicine) and the **Motol University Hospital in Prague**. In 2013, Kaprová-Pleskačová **reinforced her criticism of unnecessary gonadectomies** in her **dissertation** “*Pathogenesis of germ cell tumor development: Application of current knowledge in early diagnostics in patients with disorders of sex development*” at the **Charles University in Prague**.<sup>9</sup>

Nonetheless, to this day the **Czech Urological Society (Česká urologická společnost ČLS JEP)** is associated with the European Association of Urology (EAU)<sup>10</sup> which in turn is affiliated with the European Society for Paediatric Urology (ESPU),<sup>11</sup> whose “*ESPU/SPU standpoint on the*

8 For general information, see 2016 CEDAW NGO Report France, p. 47.

<http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

9 Jana Kaprová (2013), “Pathogenesis of germ cell tumor development: Application of current knowledge in early diagnostics in patients with disorders of sex development.”, Dissertation, Charles University Prague, 2nd Faculty of Medicine, <https://is.cuni.cz/webapps/zzp/download/140041152>

10 The Czech Urological Society also endorses all EAU Guidelines, see current 2019 EAU Guidelines, p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>

11 The Czech Urological Society also endorses the ESPU/EAU “Paediatric Urology” Guidelines included in the EAU Guidelines, see *ibid.*, p. 5

*surgical management of Disorders of Sex Development (DSD)*<sup>12</sup> 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.”*

Also, the “2016 Global Disorders of Sex Development Consensus Statement”,<sup>13</sup> which 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>14</sup>.

**Table 2.** GCC risk: clinical management

	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 <b>Low threshold for gonadectomy</b> if ambiguous genitalia	<b>Bilateral gonadectomy</b> at diagnosis	<b>Low threshold for gonadectomy</b> 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 <b>gonadectomy</b> to avoid gynecomastia or if on testosterone supplementation	<b>Partial AIS</b> and testosterone synthesis disorders – <b>Prepubertal gonadectomy</b>  <b>Complete AIS – Postpubertal gonadectomy</b> or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy  – <b>Low threshold for gonadectomy</b> Intensive psychological counseling and follow-up
No data are available on the value of cryopreservation or safety if a precursor lesion for GCC is present.			

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

Accordingly, a **2019 medical publication** by doctors from the Department of Paediatrics at the **University of Pilsen**, the **Pilsen University Hospital**, the **Charles University in Prague** and the **Motol University Hospital in Prague**, published by the **Palacký University of Olomouc**, describes persisting unnecessary gonadectomies over generations:<sup>15</sup>

*“Our patients [diagnosed with CAIS] underwent **bilateral laparoscopic gonadectomy at the age of 9 and 6 years** [immediately after diagnosis]. No germ cell neoplasia was found. We started oestrogen replacement therapy in the older sister at the age of 11 years.”* (p. 381)

*“The family history was remarkable previously unreported **33-year-old aunt** with CAIS who underwent **removal of the gonads at the age of 13 years**.”* (p. 380)

12 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebcke, “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.jpuro.com/article/S1477-5131\(13\)00313-6/pdf](http://www.jpuro.com/article/S1477-5131(13)00313-6/pdf)

13 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>

14 Ibid., at 180 (fn 111)

15 Renata Pomahacova, Jana Zamboryova, Petra Paterova, Anna Krepelova, Ivan Subrt, Radka Jaklova, Petra Vohradská, Eliska Hrdonkova, Josef Sykora (2019), “Late diagnosis of complete androgen insensitivity syndrome and transmission/ carriers of the condition in a family with mutation c.2495G> T p.(Arg832Leu) in exon 7 of the androgen receptor gene: genetic, clinical and ethical aspects”, *Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub.* 2019 Dec; 163(4):379-382, <https://biomed.papers.upol.cz/pdfs/bio/2019/04/15.pdf>

And the Urological Clinic of the **General University Hospital in Prague** offers:<sup>16</sup>

*“Specialised Centre of Paediatric Urology*

*Basic focus:*

*The centre provides outpatient and inpatient care for patients with urological diseases aged 0 to 18 years.*

*Focuses on:*

- *diagnosis and treatment of congenital malformations of the urogenital tract ([...] hypospadias, epispadias and bladder exstrophy, [...]*
- *laparoscopic urogenital tract surgery in children and adolescents (cryptorchid laparoscopy, intersex, [...]) [...]*

*The Centre for Paediatric Urology is a training centre for students of the Charles University - 1st Medical Faculty, as well as doctors involved in urology specializations and a certified paediatric urology course.”*

And the Paediatric Clinic of the Department of Urology of the **General University Hospital in Prague** of the **Charles University Prague** (1<sup>st</sup> Faculty of Medicine) offers on its homepage:

*“The department provides facilities for surgical and diagnostic procedures in children from the earliest age up to 18 years. It is an exceptional workplace that provides comprehensive urological care for paediatric patients, including so-called super-consecutive care for patients from the Czech Republic, but also from Slovakia.*

*[...]*

*Spectrum of treatment in the children's department of the Urology Clinic of the General Teaching Hospital:*

*[...]*

*Methods of minimally invasive surgery:*

- *laparoscopic ablation and reconstruction operations of [...] upper urinary tract [e.g. “discordant reproductive structures”], cryptorchism [i.e. abdominal testes]”*

Further, a **2019 medical publication** out of the **Olomouc University Hospital** of the **Palacký University in Olomouc** states:<sup>17</sup>

*“In the case of post-pubertal males with cryptorchidism, an orchiectomy is recommended.”*

Also, the Urologic Clinic of the **Pilsen University Hospital** of the **Charles University** (4<sup>th</sup> Faculty of Medicine) prescribes:<sup>18</sup>

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16 Department of Urology, General University Hospital in Prague and 1<sup>st</sup> Faculty of Medicine, Charles University (2015), “Festive conference on the occasion of the 40th anniversary of the founding of the Urological Clinic of the General Teaching Hospital in Prague at the 1<sup>st</sup> Medical Faculty of the Charles University”, p. 40-41, <http://lib.congressprague.cz/40urolk2015/40urolk2015-programovy-sbornik.pdf>

17 Jan Šarapatka, Romana Šarapatková, Jan Vrána, Oldřich Šmakal (2019), “Kryptorchismus v dětství a dospělosti” (“Cryptorchidism in childhood and adulthood”), Urol. praxi 2019; 20(2): 70–74, p. 70, <https://www.urologiepropraxi.cz/pdfs/uro/2019/02/06.pdf>

18 <https://urol.fnplzen.cz/cs/node/464>

*“If a small [undescended] testis is found to be several millimetres in size, it is **removed**. The **normal-looking, undescended testis** at the pre-pubescent age is also **removed** as it no longer contains germ cells and is most susceptible to cancer.”*

(**Note:** “normal-looking, undescended” testes are known to not only produce vital hormones, but also sperm viable for assisted reproduction: “**CONCLUSIONS:** *In contrast to prevailing knowledge, we found that the **majority of the abnormally placed testes in our patients were endocrinologically efficient**. Some even showed **complete spermatogenesis**, providing these patients with what was previously considered impossible, the **chance of fatherhood**.”<sup>19</sup>*

Regarding the exaggerated “**high cancer risk**”, see above p. 7.)

And a **2018 presentation** of a survey on the prevalence of “*Gonadectomy for Adults With DSD Conditions In The International Disorders of Sex Development Registry*” co-authored by Lidka Lisá, a doctor from the **Institute of Endocrinology Prague** and the **Motol University Hospital in Prague** (both under direct control of the Czech Ministry of Health) noted that **out of 154 intersex patients diagnosed with CAIS, 123 were submitted to gonadectomy, i.e. 79.8%**.<sup>20</sup>

#### **b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilation<sup>21</sup>**

The Czech Urological Society (Česká urologická společnost ČLS JEP) endorses the current **2019 Guidelines of the European Association of Urology (EAU)**,<sup>22</sup> which (see p. 14) include the current **2019 ESPU/EAU “Paediatric Urology” Guidelines<sup>23</sup>** of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.16 “Disorders of sex development”**,<sup>24</sup> despite admitting that “*Surgery that alters appearance is not urgent*”<sup>25</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>26</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>27</sup> referring to the 2018 ESPU Open Letter to the Council of Europe (COE),<sup>28</sup> which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).

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- 19 K. Czeloth et al., “Function of Uncorrected Cryptorchid Testes”, 25th ESPU 2014, <http://stop.genitalmutilation.org/post/Undescended-Testes-Provide-Vital-Hormones-And-Often-Complete-Spermatogenesis>
- 20 A Lucas-Herald, A Kyriakou, J Bryce, M Rodie, [Glasgow], L Lisa [Prague], et al., “Gonadectomy for Adults With DSD Conditions In The International Disorders of Sex Development Registry”, poster presentation 232-P1, at ESPE 2018, [http://abstracts.eurospe.org/hrp/0089/eposters/hrp0089p1-p232\\_eposter.pdf](http://abstracts.eurospe.org/hrp/0089/eposters/hrp0089p1-p232_eposter.pdf)
- 21 For general information, see 2016 CEDAW NGO Report France, p. 48. <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>
- 22 See p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>
- 23 <https://uroweb.org/guideline/paediatric-urology/>
- 24 [https://uroweb.org/guideline/paediatric-urology/#3\\_16](https://uroweb.org/guideline/paediatric-urology/#3_16)
- 25 [https://uroweb.org/guideline/paediatric-urology/#3\\_16\\_4](https://uroweb.org/guideline/paediatric-urology/#3_16_4)
- 26 Ibid.
- 27 Ibid.
- 28 [https://www.espu.org/images/documents/ESPU\\_Open\\_Letter\\_to\\_COE\\_2018-01-26.pdf](https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf)

In Czechia, the intersex diagnosis Congenital Adrenal Hyperplasia (CAH) is included in the **neonatal screening programme** for newborn babies, which is medically necessary to detect and hormonally treat lack of cortisol and in some cases related potentially life-threatening salt-loss associated with CAH. However, the **Czech neonatal screening further explicitly prescribes unnecessary, cosmetic genital surgery** for “*external genital malformation*” (i.e. partial clitoris amputation and/or “vaginoplasty” for “enlarged” clitoris and/or “insufficient” vagina):

*“a minor degree of external genital malformation is often corrected for replacement therapy that blocks the production of male sex hormones without the need for surgery. The higher degree is solved surgically.”*<sup>29</sup>

*“Course of the disease with treatment: normal quality of life, in girls, surgery to normalise the appearance and function of the genital, fertility maintained.”*<sup>30</sup>

And a **2013 dissertation** “*Pathophysiological mechanisms and optimization of diagnosing congenital adrenal hyperplasia*” out of the **Paediatric Clinic** of the **Charles University Prague** (2<sup>nd</sup> Faculty of Medicine) and **Motol University Hospital Prague** also **advocates early, unnecessary surgery**:<sup>31</sup>

*“The treatment consists of administering glucocorticoids and correcting the external genital by surgery in girls.”*

*“Virilisation of the external genitalia in girls is corrected by surgery in two stages (during toddler age and before commencement of sexual life).”*

Accordingly, the Paediatric Clinic of the Department of Urology of the **General University Hospital in Prague** of the **Charles University Prague** (1<sup>st</sup> Faculty of Medicine) offers on its homepage:

*“The department provides facilities for surgical and diagnostic procedures in children from the earliest age up to 18 years. It is an exceptional workplace that provides comprehensive urological care for paediatric patients, including so-called super-consecutive care for patients from the Czech Republic, but also from Slovakia. [...]*

*Spectrum of treatment in the children's department of the Urology Clinic of the General Teaching Hospital: [...]*

**Female genital disorders:**

[...]

- **reconstruction of the female genital – genitoplasty, clitoridoplasty”**

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29 “Kongenitální adrenální hyperplazie (CAH)”

<https://www.novorozeneckyscreening.cz/kongenitalni-adrenalni-hyperplazie-cah>

30 “Péče o dítě s kongenitální adrenální hyperplazií” (“Care for a child with congenital adrenal hyperplasia”)

<https://www.novorozeneckyscreening.cz/pece-o-dite-s-kongenitalni-adrenalni-hyperplazii>

31 Jana Malíková (2013), “Patofyziologické mechanismy a optimalizace diagnostiky vrozené adrenální hyperplazie” (“Pathophysiological mechanisms and optimization of diagnosing congenital adrenal hyperplasia”), Dissertation, Paediatric Clinic, 2nd Faculty of Medicine, Charles University in Prague and Motol University Hospital, p. 32, <https://is.cuni.cz/webapps/zzp/download/140031024>

Accordingly, a **2018 joint presentation**<sup>32</sup> “*Quality of life after feminising genitoplasty*” by doctors from the Paediatric Surgery Clinic of the **Motol University Hospital Prague** of the **Charles University Prague** (2<sup>nd</sup> Faculty of Medicine) and the Great Ormond Street Hospital (London UK)<sup>33</sup> presented at the “29th Annual Meeting of Paediatric Urologists”, organised by the Urology Clinic of the **Ostrava University Hospital**, contains graphic photos (slides 5-7) of the following named IGM 2 procedures (slide 5):

**“Partial resection of hypertrophic clitoris**

***Sculpture of labia***

***Opening the vaginal entrance”***

What’s more, the presentation gives the following **numbers for IGM 2 procedures** at the Paediatric Surgery Clinic of the **Motol University Hospital Prague** (slide 9):

*“Patient group Paediatric Surgery Clinic, Motol University Hospital*

*1996-2018 / 1*

***FGP [= Feminising Genitoplasty] was performed on 104 patients with DSD***

*Age of patients at the time of surgery 13m-22yr*

- *46XX CAH (salt-wasting 87, non-salt wasting 3) 90*
- *46XY CAIS 7*
- *45X0 / 46XY MGD 6*
- *47XX Ovotesticular DSD 1”*

### **c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”<sup>34</sup>**

The **Czech Urological Society (Česká urologická společnost ČLS JEP)** endorses the current 2019 Guidelines of the European Association of Urology (EAU),<sup>35</sup> which include the current 2019 ESPU/EAU “*Paediatric Urology*” Guidelines<sup>36</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) (see p. 14). In **chapter 3.5 “Hypospadias”**,<sup>37</sup> the ESPU/EAU Guidelines’ **section 3.5.5.3 “Age at surgery”** nonetheless explicitly promotes, **“The age at surgery for primary hypospadias repair is usually 6-18 (24) months.”**<sup>38</sup> – despite admitting to the **“risk of complications”**<sup>39</sup> and **“aesthetic[...]**” and **“cosmetic”** justifications.<sup>40</sup>

32 Trachta J, Mushtaq I, Rousková B, Škába R, “Kvalita života po feminizující genitoplastice” (“Quality of life after feminising genitoplasty”),

[https://www.cus.cz/wp-content/uploads/2018/07/19\\_dr\\_trachta\\_-\\_kvalita\\_zivota\\_po\\_feminizujici\\_genitoplastice.pdf](https://www.cus.cz/wp-content/uploads/2018/07/19_dr_trachta_-_kvalita_zivota_po_feminizujici_genitoplastice.pdf)

33 The contributing UK surgeon Dr. Imran Mushtaq is a **notorious advocate of early IGM procedures: “Until such time as there is a change in the law, parents will continue to have the right to decide if their child should or should not have genital surgery in infancy or childhood.”**, see 2016 CRC UK Intersex NGO Report, p. 10,

[http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

34 For general information, see 2016 CEDAW NGO Report France, p. 48-49.

<http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

35 See p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>

36 <https://uroweb.org/guideline/paediatric-urology/>

37 [https://uroweb.org/guideline/paediatric-urology/#3\\_5](https://uroweb.org/guideline/paediatric-urology/#3_5)

38 [https://uroweb.org/guideline/paediatric-urology/#3\\_5\\_5\\_3](https://uroweb.org/guideline/paediatric-urology/#3_5_5_3)

39 [https://uroweb.org/guideline/paediatric-urology/#3\\_5\\_5\\_1](https://uroweb.org/guideline/paediatric-urology/#3_5_5_1)

40 Ibid.

Accordingly, a **2017 medical article** “*Nursing care of a patient with hypospadias*” by specialists from the Urology Clinics of the **Vinohrady University Hospital in Prague** and the **General University Hospital in Prague**, both of the **Charles University in Prague**, summarises:<sup>41</sup>

*“Hypospadias can cause psychological trauma, urinating and ejaculatory disorders, and inability to have sexual intercourse in chordee-related disorders. The defect is assessed by a paediatric urologist and treated surgically.”* (p. 187)

#### **“Therapy**

*Hypospadias can be treated surgically. From the literature review point of view, the Guidelines of the European Association of Urology – Paediatric Urology from 2017 can be used for the recommended procedures for the treatment of hypospadias. The Czech doctor Doc. Dr. Radim Kocvara is among the authors of the European guidelines.*

*In the Czech and Slovak Republics there are centres of paediatric urology which have their recommended procedures for surgical treatment, e.g. in the Hradec Králové University Hospital – Dr. Ivo Novak; at the Motol University Hospital in Prague – Dr. Jan Kříž and at the Ostrava University Hospital – Doc. Dr. Jan Krhut. Each paediatric urology centre has its own clear procedure for surgical treatment and a specialist who deals with this issue.”* (p. 188)

Accordingly, the current **2019 Parental Consent Form “Hypospadias (in children)”** at the **Ostrava University Hospital of the University of Ostrava** highlights the **psychosocial justifications** for the surgery, while insisting that there is **“no alternative”**:<sup>42</sup>

*“[...] this condition requires surgical correction to prevent possible complications in your child's life (both psychological and physical) [...]*

*In many cases, when the opening of the urethra is on the underside of the penis, the boy must perform different manoeuvres when urinating in order to urinate while standing like his friends or classmates. If this fails, the patient may suffer from various psychological problems, or urination may only be performed while sitting. Then it is appropriate to move the opening to the top of the penis. This developmental disorder has no effect on the boy's future sexual life, such as an erection or the ability to have children.*

#### **Alternative Treatments:**

*There are no alternatives, in order to solve the congenital defect completely, surgery is necessary, often it is necessary to proceed in stages - divided into several phases (according to the age of the child).”*

And the current **Parental Consent Form “Urethroplasty in children”** of the **Hradec Králové University Hospital of the University of Ostrava** again insists that there is **“no alternative to surgery”**:<sup>43</sup>

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41 Lucie Králová, Pavla Kordulová (2017), Ošetrovatelská péče u pacienta s hypospadií, in: Urol. praxi 2017; 18(4): 187–190, <https://www.urologiepropraxi.cz/pdfs/uro/2017/04/11.pdf>

42 Ostrava University Hospital (2019), “Informovaný souhlas rodiče s výkonem: Hypospadiie (u dětí)”, [https://www.fno.cz/documents/informovane-souhlasy/Hypospadiie\\_\(u\\_deti\)\\_IS\\_r04.pdf](https://www.fno.cz/documents/informovane-souhlasy/Hypospadiie_(u_deti)_IS_r04.pdf)

43 Urological Clinic of the University Hospital Hradec Králové, “POUČENÍ K URETROPLASTICE U DĚTÍ” (“Instructions on Urethroplasty in Children”), <http://www.cus.cz/wp-content/uploads/2013/07/hypospadiie.doc>

*“Your child was born with a congenital defect – not fully developed urethra (hypospadiac penis) and is ordered for surgical correction of the defect. The defect may have varying degrees – from change only in cosmetics to severe functional disorders (urination, sex life) – see picture.”*

**“Alternative Treatments:**

*A small displacement of the opening (on the glans) is a cosmetic defect that does not need to be corrected. There is no alternative to surgery. The operation is always decided by the legal guardian, eventually by the boy (in the case older boys, ideally by both parties).”*

Accordingly, a **2013 presentation** on **“complications of urethroplasty and their solution in children with hypospadias”** by doctors of the Urology Clinic of the **Hradec Králové University Hospital** gives the following **numbers for IGM 1 procedures**:<sup>44</sup>

*“We retrospectively evaluated a group operated in 2003–2012 for 14 glandular, 184 coronary, 32 penile and 50 scrotal, perineal or chordee-related hypospadias. The age at the time of surgery was 26 times under 1 year, 187 times 1-3 years and 67 times older than 3 years. A total of 328 times were operated on the urethra [...].”*

And the Paediatric Surgery Clinic of the **Motol University Hospital Prague** of the **Charles University Prague** (2<sup>nd</sup> Faculty of Medicine) regularly lists **“hypospadias”** in its Annual Reports under **“New methods and procedures”** to **“be used in such malformed children”**, e.g. **2014**,<sup>45</sup> **2015**<sup>46</sup> and **2016**<sup>47</sup> (however, the Annual Reports **fail to disclose actual numbers** of hypospadias procedures).

Also, in **2017** the Paediatric Surgery Clinic of the **Motol University Hospital Prague** in collaboration with the **Great Ormond Street Hospital (London UK)**<sup>48</sup> held an **“International Course of Reconstruction Operations in Paediatric Urology”** including **hypospadias “repair”**.<sup>49</sup>

*“Directly in the operating room, Czech and Slovak paediatric urologists adopted techniques for [...] surgery of proximal hypospadias.”*

And in **2016** and **2017**, the Paediatric Surgery Clinic of the **Motol University Hospital** conducted **“Training programs at the Takeo Hospital in Cambodia”** teaching **hypospadias “repair”**.<sup>50</sup>

*“Cambodia's health services do not have the capacity to operate a large number of congenital urological disorders, hypospadias and epispadias. During two visits, Dr. J. Trachta led the*

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44 Novák I., Kuliaček P. (2013), “Hypospadiac – námi pozorované komplikace po uretroplastikách, jejich řešení”, 59th Annual Conference of the Czech Urological Society 2013 Pilsen, in: *Ces Urol* 2013; 17(Suppl 1): 21–96, p. 93, [https://www.czechurol.cz/incpdfs/inf-990000-1400\\_10\\_005.pdf](https://www.czechurol.cz/incpdfs/inf-990000-1400_10_005.pdf)

45 See p. 20, [http://www.fnmotol.cz/\\_sys\\_/FileStorage/download/2/1417/vyrocnizprava-2014-fn-motol.pdf](http://www.fnmotol.cz/_sys_/FileStorage/download/2/1417/vyrocnizprava-2014-fn-motol.pdf)

46 See p. 21, [http://www.fnmotol.cz/\\_sys\\_/FileStorage/download/2/1681/vyrocnizprava-2016.pdf](http://www.fnmotol.cz/_sys_/FileStorage/download/2/1681/vyrocnizprava-2016.pdf)

47 See p. 22, [http://www.fnmotol.cz/\\_sys\\_/FileStorage/download/2/1945/vyrocnizprava\\_cz\\_2017d.pdf](http://www.fnmotol.cz/_sys_/FileStorage/download/2/1945/vyrocnizprava_cz_2017d.pdf)

48 The featured UK surgeon Dr. Imran Mushtaq is a **notorious advocate of early IGM procedures**: **“Until such time as there is a change in the law, parents will continue to have the right to decide if their child should or should not have genital surgery in infancy or childhood.”**, see 2016 CRC UK Intersex NGO Report, p. 10, [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

49 “Mezinárodní kurz rekonstrukčních operací v dětské urologii”, <https://www.lf2.cuni.cz/klinika-detske-chirurgie-2-lf-uk-a-fn-motol/jine-uspechy>

50 “Klinika spolupracuje s nemocnicí Takeo v Kambodži, založila v ní výukový program”, <https://www.lf2.cuni.cz/klinika-detske-chirurgie-2-lf-uk-a-fn-motol/jine-uspechy>

*training of local staff and operated 20 local children with severe forms of hypospadias and epispadias [...]. In 2017, the program continued with a repeated trip with operations on 8 children and training of another group of local staff.”*

In addition, the Paediatric Clinic of the Department of Urology of the **General University Hospital in Prague** of the **Charles University Prague** (1<sup>st</sup> Faculty of Medicine) offers on its homepage:

*“The department provides facilities for surgical and diagnostic procedures in **children from the earliest age up to 18 years**. It is an exceptional workplace that provides comprehensive urological care for paediatric patients, including so-called super-consecutive care for patients from the Czech Republic, but **also from Slovakia**.*

[...]

*Spectrum of treatment in the children's department of the Urology Clinic of the General Teaching Hospital:*

[...]

**Male genital and urethral diseases:**

- **reconstructive surgery of hypospadias, epispadias, congenital and acquired urinary stenosis including endoscopic treatment**
- **correction of congenital and acquired penile curvature**
- **cryptorchism treatment”**

And a **2017 presentation “Hypospadias yesterday, today and tomorrow”** by a doctor of the Urology Clinic of the **Olomouc University Hospital** of the **Palacký University in Olomouc** at the 2017 medical conference “XXXIV. Days of Practical and Hospital Paediatrics” in Olomouc states:<sup>51</sup>

*“Surgical treatment is indicated in case of poor cosmetic or functional condition of the hypospadiac penis. The aim of the operation is to move a sufficiently wide opening of the newly formed urethra to the top of the glans, to **straighten the penis for sexual intercourse** and to **achieve the best cosmetic effect**.*

*At the Department of Urology of the **University Hospital Olomouc** we perform penile reconstruction **after the third year of age.**”*

And a **2014 presentation “Is the urethral stent necessary for distal hypospadias surgery?”** by doctors of the Urology Clinic of the **Olomouc University Hospital** gives the following **partial numbers for IGM 1 procedures**:<sup>52</sup>

*“57 patients from 1 January 2009 to 31 December 2013 with a modified Mathieu procedure for hypospadias”*

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51 Oldřich Šmakal (2017), “Hypospadié včera, dnes a zítra”, in: *Pediatr. praxi* 2017; 18(Suppl B) KONGRES PEDIATRŮ A DĚTSKÝCH SESTER, p. 15,

[https://www.pediatriepropraxi.cz/incpdfs/act-000256-0001\\_10\\_001.pdf](https://www.pediatriepropraxi.cz/incpdfs/act-000256-0001_10_001.pdf)

52 Vrána J., Šmakal O., Šarapatka J, Hartmann I., (2014), “Je nutné zavedení uretrálního stentu při operaci distální hypospadié?”, *Konference dětských urologů, nefrologů a pediatriů* (Conference of paediatric urologists, nephrologists and pediatricians), in: *Ces Urol* 2014; 18(2): 155–176, p. 165,

<https://docplayer.cz/docview/20/980783/#file=/storage/20/980783/980783.pdf>

And the **Brno University Hospital of the Masaryk University in Brno** offers on its homepage:<sup>53</sup>

*“The Department of Paediatric Urology KDCHOT is an accredited department of the Ministry of Health of the Czech Republic for paediatric urology, covering the southern half of Moravia, with a wider overlap for some serious diseases.*

*It is mainly involved in the treatment of congenital malformations of the upper and lower urinary tract, congenital malformations of the external genitalia, neurogenic and functional disorders of the urinary tract, as well as therapy of acquired infectious and non-infectious diseases of the urinary system and external genitalia. [...]*

*Common urological diseases [...]*

- **Hypospadias, Epispadias**

*[...]*

- **Disorders of sexual differentiation**

- **Testicular position disorders – testicular retention”**

And the **St. Anne’s University Hospital Brno of the Masaryk University in Brno** offers under **“frequently performed treatments”**.<sup>54</sup>

**“Hypospadias**

*[...] The patient should be monitored as soon as the defect is diagnosed in order to ensure that the treatment is properly timed according to the current condition and to prevent further damage. The reconstruction is then carried out around 3-4 years, when the penis is sufficiently developed, the child is able to cooperate and the stay in hospital is better tolerated.”*

#### **d) Czech University Hospitals involved in International IGM Networks**

In 2017, the “European Reference Network” was launched to ensure better treatment for patients with rare diseases within the European Union.<sup>55</sup> Unfortunately, **2 of the newly created “ERNs” also specialise in the proliferation and practice of IGM**, namely the **“Network Urogenital Diseases” a.k.a. “eUROGEN”** and the **“Network on Endocrine Conditions” a.k.a. “Endo-ERN”**.<sup>56</sup> Like with earlier international networks led by IGM perpetrators, e.g. “I-DSD”,<sup>57</sup> Czech University Hospitals are again involved.

Czech **“Endo-ERN” members** participating in the IGM-related Main Thematic Group **“MTG7: Sex Development & Maturation”** include the **Motol University Hospital Prague of the Charles University Prague (2nd Faculty of Medicine)** and the **Vinohrady University Hospital in Prague of the Charles University Prague (3. Faculty of Medicine)**.<sup>58</sup>

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53 <https://www.fnbrno.cz/detska-nemocnice/klinika-detske-chirurgie-ortopedie-a-traumatologie/oddeleni-8-urologie-brisni-chirurgie/t4279>

54 <https://iweb3.fnusa.cz/pro-pacienty-a-navstevy/pracoviste/kpec-zakladni-informace/informace-o-lecbe-a-nejcasteji-provadenych-zakrocich/#tab-id-5>

55 [https://ec.europa.eu/health/sites/health/files/ern/docs/2017\\_brochure\\_en.pdf](https://ec.europa.eu/health/sites/health/files/ern/docs/2017_brochure_en.pdf)

56 See <http://stop.genitalmutilation.org/post/eUROGEN-EU-funded-Intersex-Genital-Mutilators>

57 The Open Letter to “I-DSD 2017” lists Czech University Clinics involved in current international IGM projects, see p. 1, [http://stop.genitalmutilation.org/public/Open\\_Letter\\_I-DSD\\_Copenhagen\\_2017.pdf](http://stop.genitalmutilation.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf)

58 <https://endo-ern.eu/about/reference-centres/>

### 3. The Czech Government fails to act despite criticism

The persistence of IGM practices in Czechia is a **matter of public record**, same as the **longstanding criticism and appeals** by intersex persons, NGOs, academics, and individual doctors.<sup>59 60 61 62 63 64</sup>

However, to this day the **Czech 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 protect intersex children from harmful practices, but instead **allows IGM doctors to continue practicing with impunity**.

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

The **Czech Government fails to collect and disclose disaggregated data** on intersex persons and IGM practices. 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”.

### 5. Obstacles to redress, fair and adequate compensation

Also in **Czechia** 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.<sup>65</sup> So far, in Czechia there was **no case** of a victim of IGM practices succeeding in going to court, despite survivors criticising the practice in public.

**This situation is clearly not in line with Czechia’s obligations under the Convention.**

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- 59 Blesk.cz, 18.02.2018, “Mají v těle varlata i vaječníky. Intersexuálové šokují, Češi je ‘neskousli’”, <https://www.blesk.cz/clanek/zpravy-udalosti/523751/maji-v-tele-varlata-i-vajecniky-intersexualove-sokuji-cesi-je-neskousli.html>
- 60 Olga Pechová, Martina Štěpánková, “The Status of Lesbian, Gay, Bisexual, Transgender and Intersex Rights in the Czech Republic”, 2007 CCPR NGO Report, see p. 9 (“Intersex children”), [https://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/CZE/INT\\_CCPR\\_NGO\\_CZE\\_90\\_8518\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/CZE/INT_CCPR_NGO_CZE_90_8518_E.pdf)
- 61 Anna Peštová (2013), “Mediální zobrazení intersexuality ve sportu” (“Media depiction of intersexuality in sports”), Thesis, Charles University Prague, see p. 21-22 (“2.1.6 Medical practice and its consequences”), [https://dspace.cuni.cz/bitstream/handle/20.500.11956/57031/DPTX\\_2009\\_2\\_11240\\_0\\_296399\\_0\\_85179.pdf](https://dspace.cuni.cz/bitstream/handle/20.500.11956/57031/DPTX_2009_2_11240_0_296399_0_85179.pdf)
- 62 Barbora Janečková, Ondřej Kašpárek, Vladimír Seifert, Kateřina Knoppová, Gabriela Zigová (2012), “Intersexualita. Závěrečná práce do předmětu GEN145 Tělo na poli umění a sociologie”, Thesis Za FSS MU / Za FaVU VUT Brno, see p. 5-6 (“Contemporary medical practice”), <http://atd.ffa.vutbr.cz/up/prilohy/28012012124700-intersexualita.pdf>
- 63 Centrum pro lidská práva a demokracii (Czech Centre for Human Rights and Democracy), Bulletin lidských práv (Czech Human Rights Review), No. 1, vol. 7, Jan-Feb 2020, p. 12 (referring to CCPR/C/BEL/CO/6, paras 21-22), [https://www.centrumlidskaprava.cz/sites/default/files/attachement/bulletin/Bulletin\\_leden-unor\\_2020.pdf](https://www.centrumlidskaprava.cz/sites/default/files/attachement/bulletin/Bulletin_leden-unor_2020.pdf)
- 64 Jana Kaprová (2013), “Pathogenesis of germ cell tumor development: Application of current knowledge in early diagnostics in patients with disorders of sex development.”, Dissertation, Charles University Prague, 2nd Faculty of Medicine, <https://is.cuni.cz/webapps/zpp/download/140041152>
- 65 Globally, no survivor of early surgeries **ever** managed to have their case heard in court. All relevant court cases (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

## C. Suggested Recommendations

*The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Czechia, the Committee includes the following measures in their recommendations to the Czech Government (in line with this Committee's previous recommendations on IGM practices):*

### **Harmful practices: Intersex genital mutilation**

The Committee remains seriously concerned about cases of medically unnecessary and irreversible surgery and other treatment on intersex children without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases.

**In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:**

- (a) Ensure that the State party's legislation explicitly prohibits all forms of intersex genital mutilation, by criminalising or adequately sanctioning unnecessary medical or surgical treatment during infancy or childhood, including extraterritorial protections, and provide families with intersex children with adequate counselling and support;**
- (b) Adopt legal provisions and repeal time-limits in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible, and undertake investigation of incidents of surgical and other medical treatment of intersex children without their informed consent;**
- (c) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;**
- (d) Educate and train medical, psychological and education professionals on intersex as a natural bodily variation and on the consequences of unnecessary surgical and other medical interventions for intersex children.**

## Annexe 1 – IGM Practices in Czechia as a Violation of CRC

### 1. The Treatment of Intersex Children in Czechia as Harmful Practice and Violence

#### a) Harmful Practice (art. 24(3) and JGC No. 18)<sup>66</sup>

**Article 24 para 3 CRC** calls on states to abolish harmful “*traditional practices prejudicial to the health of children*”. While the initial point of reference for the term was the example of Female Genital Mutilation/Cutting (FGM/C), the term consciously wasn’t limited to FGM/C, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.<sup>67</sup>

**This Committee has repeatedly considered IGM as a harmful practice, and the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices as applicable.**<sup>68</sup>

Also **CEDAW** has repeatedly considered IGM as a **harmful practice**, and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 on harmful practices as applicable.<sup>69</sup>

Harmful practices (and inhuman treatment) have been identified by intersex advocates as the **most effective, well established and applicable human rights frameworks** to eliminate IGM practices and to end the impunity of the perpetrators.<sup>70</sup>

The **CRC-CEDAW Joint General Comment/Recommendation No. 18/31 “on harmful practices”** “*call[s] upon States parties to explicitly prohibit by law and adequately sanction or criminalize harmful practices, in accordance with the gravity of the offence and harm caused, provide for means of prevention, protection, recovery, reintegration and redress for victims and combat impunity for harmful practices*” (para 13).

Particularly, the Joint General Comment/Recommendation further underlines the need for a “**Holistic framework for addressing harmful practices**” (paras 31–36), including “**legislative, policy and other appropriate measures that must be taken to ensure full compliance with [state parties’] obligations under the Conventions to eliminate harmful practices**” (para 2), as well as

“*Data collection and monitoring*” (paras 37–39)

“*Legislation and its enforcement*” (paras 40–55), particularly:

“*adequate civil and/or administrative legislative provisions*” (para 55 (d))

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66 For a more extensive version, see 2017 CRC Spain NGO Report, p. 12-13,

<http://intersex.shadowreport.org/public/2017-CRC-Spain-NGO-Brujula-Zwischengeschlecht-Intersex-IGM.pdf>

67 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 371

68 CRC/C/CHE/CO/2-4, paras 42-43; CRC/C/CHL/CO/4-5, paras 48-49; CRC/C/FRA/CO/5, paras 47-48; CRC/C/IRL/CO/3-4, paras 39-40; CRC/C/NPL/CO/3-5, paras 41-42; CRC/C/GBR/CO/5, paras 46-47; CRC/C/NZL/CO/5, paras 25+15; CRC/C/ZAF/CO/2, paras 39-40+23-24; CRC/C/DNK/CO/5, paras 24+12; CRC/C/ESP/CO/5-6, para 24; CRC/C/ARG/CO/5-6, para 26; CRC/C/ITA/CO/5-6, para 23; CRC/C/BEL/CO/5-6, paras 25(b)+26(e); CRC/C/MLT/CO/3-6, paras 28-29; CRC/C/AUS/CO/5-6, paras 25(b)+26(e); CRC/C/PRT/CO/5-6, paras 28(b); CRC/C/AUT/CO/5-6, para 27(a)-(b)

69 CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f; CEDAW/C/CHE/CO/4-5, paras 24-25, 38-39; CEDAW/C/NLD/CO/6, paras 21-22, 23-24; CEDAW/C/DEU/CO/7-8, paras 23-24; CEDAW/C/IRL/CO/6-7, paras 24-25; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d); CEDAW/C/LUX/CO/6-7, paras 27b-c+28b-c; CEDAW/C/MEX/CO/9, para 21-22; CEDAW/C/NZL/CO/8, paras 23(c)-24(c); CEDAW/C/AUS/CO/8, paras 25(c)-26(c); CEDAW/C/LIE/CO/5, paras 35+36(c); CEDAW/C/NPL/CO/6, paras 18(c)-19(c)

70 Daniela Truffer, Markus Bauer / [Zwischengeschlecht.org](http://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: [http://StopIGM.org/public/S3\\_Zwischengeschlecht\\_UN-Expert-Meeting-2015\\_web.pdf](http://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf)

*“provisions on regular evaluation and monitoring, including in relation to implementation, enforcement and follow-up”* (para 55 (n))

*“equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period, and that the perpetrators and those who aid or condone such practices are held accountable”* (para 55 (o))

*“equal access to legal remedies and appropriate reparations in practice”* (para 55 (q)).

Last but not least, the Joint General Comment explicitly stipulates: *“Where medical professionals or government employees or civil servants are involved or complicit in carrying out harmful practices, their status and responsibility, including to report, should be seen as an aggravating circumstance in the determination of criminal sanctions or administrative sanctions such as loss of a professional licence or termination of contract, which should be preceded by the issuance of warnings. Systematic training for relevant professionals is considered to be an effective preventive measure in this regard.”* (para 50)

Conclusion, **IGM practices in Czechia**– as well as the **failure of the state party to enact effective legislative, administrative, social and educational measures** to eliminate them and to ensure effective access to remedies and redress for IGM survivors – clearly violate Article 24 CRC, as well as the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices.

## **b) Violence against Children (art. 19 and GC No. 13)** <sup>71</sup>

Similarly, the Committee has also considered IGM practices as violence against children, and Art. 19 and the General Comment No. 13 also offer strong provisions to combat IGM practices.

## **2. Required Legislative Provisions to Ensure Protection from IGM Practices, Impunity of the Perpetrators (CRC art. 24(3) and JGC No. 18)**

Article 24 para. 3 of the Convention in conjunction with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 “on harmful practices” (2014) underline state parties’ obligations to *“explicitly prohibit by law and adequately sanction or criminalize harmful practices”* (JGC 18/31, para 13), as well as to *“adopt or amend legislation with a view to effectively addressing and eliminating harmful practices”* (JGC 18/31, para 55), and specifically to ensure *“that the perpetrators and those who aid or condone such practices are held accountable”* (JGC 18/31, para 55 (o)).

Accordingly, with regards to IGM practices, and referring to Article 24 para 3 and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31, CRC repeatedly recognised the obligation for State parties to *“[e]nsure that the State party’s legislation prohibits all forms of harmful practices [including intersex genital mutilation]”*,<sup>72</sup> as well as to *“ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned”*,<sup>73</sup> and to *“[u]ndertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation”*.<sup>74</sup>

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71 For a more extensive version with sources, see 2016 CRC UK Thematic NGO Report, p. 57, [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

72 CRC/C/ZAF/CO/2, 27 October 2016 paras 39–40

73 CRC/C/CHE/CO/2-4, 26 February 2015, para 43

74 CRC/C/DNK/CO5, 26 October 2017, para 24

### 3. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation (CRC art. 24(3) and JGC No. 18)

Article 24 para. 3 of the Convention in conjunction with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 “on harmful practices” clearly stipulate the right of victims of IGM practices to “*equal access to legal remedies and appropriate reparations*” (JGC 18/31, para 55 (q)), and specifically to ensure that “*children subjected to harmful practices have equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period*” (JGC 18/31, para 55 (o)).

However, also in **Czechia** 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 even once they do.<sup>75</sup> So far there was no case of a victim of IGM practices succeeding in going to an Czech court.

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<sup>75</sup> Globally, no survivor of early surgeries **ever** managed to have their case heard in court. All relevant court cases (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

## 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>76</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>77</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>78</sup>

In **regions without universal access to paediatric health care**, there are reports of **infanticide**<sup>79</sup> of intersex children, of **abandonment**,<sup>80</sup> of **expulsion**,<sup>81</sup> of **massive bullying** preventing the

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76 The currently still official medical terminology “Disorders of Sex Development” is strongly refused by persons concerned. See 2014 CRC NGO Report, p. 12 “Terminology”.

77 [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

78 For references and general information, see 2015 CAT NGO Report Austria, p. 30-35,

<http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf>

79 For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, <http://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,

<http://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:

[http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-](http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda)

[Abandonment-Expulsion-Uganda-Kenya-Rwanda](http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda) ; for Uganda, see also 2015 CRC Briefing, slide 46, [http://intersex.shadowreport.org/public/Zwischengeschlecht\\_2015-CRC-Briefing\\_Intersex-IGM\\_web.pdf](http://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,

<http://stop.genitalmutilation.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018>

80 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:

<http://stop.genitalmutilation.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,

<http://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf>

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),<sup>82</sup> and of **murder**.<sup>83</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 supremacist implications**.<sup>84 85 86 87</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>88</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>89</sup> **UN Treaty bodies have so far issued 50 Concluding Observations condemning IGM practices accordingly.**<sup>90</sup>

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81 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:

<http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

82 For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see

<http://stop.genitalmutilation.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3>

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

84 2014 CRC NGO Report, p. 52, 69, 84, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

85 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>

86 “The Racist Roots of Intersex Genital Mutilations” <http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM>

87 For 500 years of “scientific” prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7,

<http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

88 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, *ibid.*, p. 38–47

89 **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”,

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

90 <http://stop.genitalmutilation.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>91 92</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>93</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>94 95</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>96</sup> and again IGM survivors as “*transgender children*”,<sup>97</sup> “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”<sup>98</sup> and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.<sup>99</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>100</sup> “*a special provision on sexual orientation and*

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91 CRC67 Denmark, <http://stop.genitalmutilation.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark>

92 CEDAW66 Ukraine, <http://stop.genitalmutilation.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics>

93 For references, see 2016 CEDAW France NGO Report, p. 45

<http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

94 For example ACHPR Commissioner Lawrence Murugu Mute, see

<http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT>

95 2018 Report of the Kenya National Commission on Human Rights (KNCHR), p. 15,

[https://www.knchr.org/Portals/0/GroupRightsReports/Equal%20In%20Dignity%20and%20Rights\\_Promoting%20The%20Rights%20Of%20Intersex%20Persons%20In%20Kenya.pdf?ver=2018-06-06-161118-323](https://www.knchr.org/Portals/0/GroupRightsReports/Equal%20In%20Dignity%20and%20Rights_Promoting%20The%20Rights%20Of%20Intersex%20Persons%20In%20Kenya.pdf?ver=2018-06-06-161118-323)

96 CAT60 Argentina, <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60>

97 CRC77 Spain, <http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children>

98 CRC76 Denmark, <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67>

99 CAT/C/DNK/QPR/8, para 32

100 CRC73 New Zealand, <http://stop.genitalmutilation.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child>

*gender identity*”, “*civil registry*” and “*sexual reassignment surgery*”<sup>101</sup>, transgender guidelines<sup>102</sup> or “*Gender Identity*”<sup>103 104</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 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>105</sup> and public **representation**.<sup>106</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>107 108 109 110</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>111 112</sup>

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101 CCPR120 Switzerland, <http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120>

102 CAT56 Austria, <http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations>

103 CAT60 Argentina, <http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture>

104 CRPD18 UK, <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

105 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, <http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf>

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), <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

106 See e.g. “Instrumentalizing intersex: ‘The fact that LGBTs in particular embrace intersex is due to an excess of projection’ - Georg Klauda (2002)”, <http://stop.genitalmutilation.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002>

107 For example Amnesty (2017), see <http://stop.genitalmutilation.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors>

108 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8,

[http://stop.genitalmutilation.org/public/S3\\_Zwischengeschlecht\\_UN-Expert-Meeting-2015\\_web.pdf](http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf)

109 For example CEDAW Italy (2017), see <http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN>

110 For example CEDAW Austria (2019): CEDAW/C/AUT/CO/9, paras 34(h), 35(h)

111 For example Ministry of Health Chile (2016), see

<http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile>

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

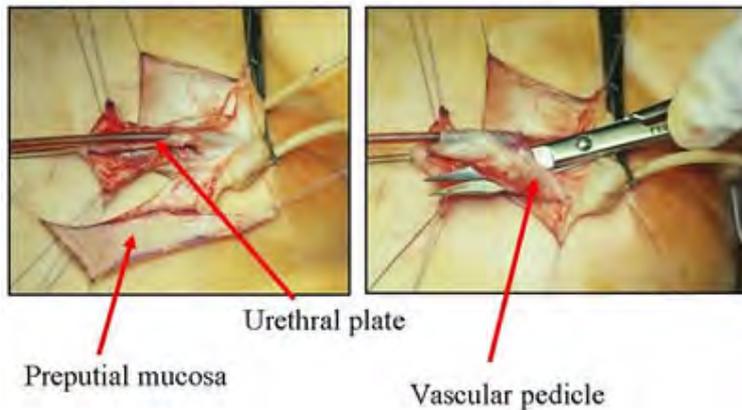
## Annexe 3 – “IGM in Medical Textbooks: Current Practice”

### IGM 1 – “Masculinising Surgery”: “Hypospadias Repair”

“Hypospadias,” i.e. when the urethral opening is not on the tip of the penis, but somewhere on the underside between the tip and the scrotum, is arguably the most prevalent diagnosis for cosmetic genital surgeries. Procedures include dissection of the penis to “relocate” the urinary meatus. Very high complication rates, as well as repeated “redo procedures” — “5.8 operations (mean) along their lives ... and still most of them are not satisfied with results!”

Nonetheless, clinicians recommend these surgeries without medical need explicitly “for psychological and aesthetic reasons.” Most hospitals advise early surgeries, usually “between 12 and 24 months of age.” While survivors criticise a.o. impairment or total loss of sexual sensation and painful scars, doctors still fail to provide evidence of benefit for the recipients of the surgeries.

#### Onlay island flap urethroplasty



#### Onlay / Duckett - results

- Elbakry (BJUI 88: 590-595, 2001): 42% complications
  - 5 breakdowns (7%)
  - 17 fistulae (23%)
  - Urethral strictures (9%)
  - Urethral diverticulae (4%)
- Asopa / Duckett tube
  - 3.7% (El-Kasaby J Urol 136: 643-644, 1986)
  - 69% (Parsons BJU 25: 186-188, 1984)
  - 15% (Duckett - 1986)



## Hypospadias - Procedures for cripple hypospadias

- No standardized procedures
- Personal experience of the surgeon
- Importance of a uro-endocrine approach of complex cases to increase the healing abilities of the penile tissues



Official Diagnosis "Hypospadias Cripple"  
= made a "cripple" by repeat cosmetic surgeries

## Treatment of isolated fistulae

- Rectangular skin incision around the fistula orifice, often lateral
- Dissection and excision of the fistula tract
- Urethral suture
- Multilayer cover with well-vascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
- Suprapubic diversion ? Elbakry



Bad cosmetic result



infection

## Hypospadias - Conclusions

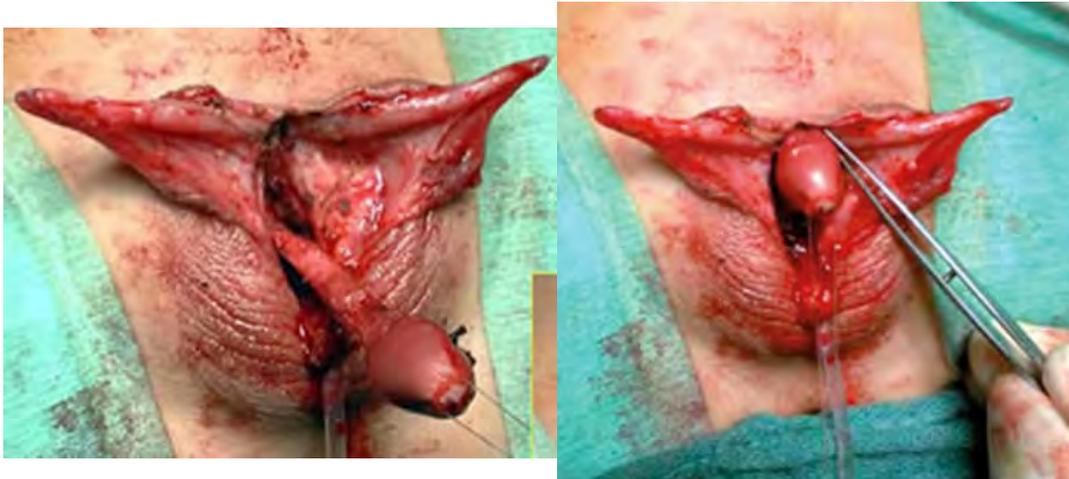
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: Essential role of the placenta / Penile growth factors / healing factors / blood supply ...

Source: Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

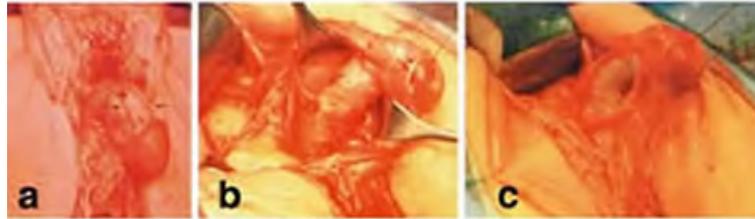
### IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include "46,XY Partial Androgen Insufficiency Syndrome (PAIS)" and "46,XY Leydig Cell Hypoplasia").

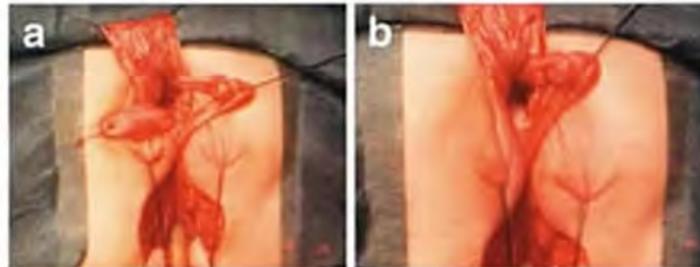
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "*in the first 2 years of life*", most commonly "*between 6 and 12 months,*" and only 10.5% of surgeons recommend letting the persons concerned decide themselves later.



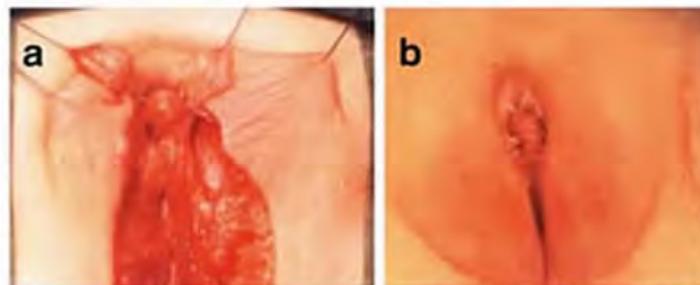
Source: Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



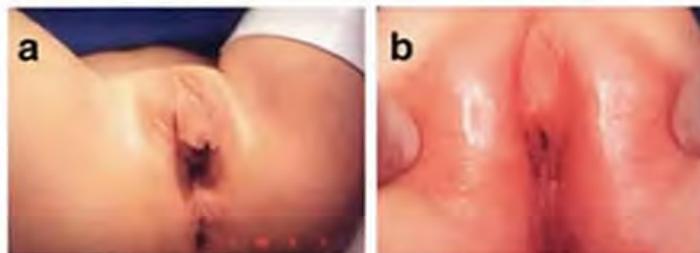
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



7a+b: Partielle Resektion der Corpora cavernosa clitoridis.



8a+b: Refixation der Corpora cavernosa clitoridis. "Materialknappheit" bei der Rekonstruktion der Corpora cavernosa clitoridis und der kleinen Labien.



9a+b: Klitorisreduktion und Rekonstruktion des Praeputium clitoridis bei Prader IV.

Source: Finke/Höhne: *Intersexualität bei Kindern*, 2008

Caption 8b: "Material shortage" [of skin] while reconstructing the prepuce clitoridis and the inner labia.



Source: Pierre Mouriouand: "Chirurgie des anomalies du développement sexuel - 2007", at 81: "Labioplastie"

### IGM 3 – Sterilising Surgery: Castration / “Gonadectomy” / Hysterectomy

Removal of healthy testicles, ovaries, or ovotestes, and other potentially fertile reproductive organs. “46,XY Complete Androgen Insufficiency Syndrome (CAIS)” is arguably the 3rd most common diagnosis for cosmetic genital surgeries, other diagnoses include “46,XY Partial Androgen Insufficiency Syndrome (PAIS)”, male-assigned persons with “46,XX Congenital Adrenal Hyperplasia (CAH)”, and other male assigned persons, who have their healthy ovaries and/or uteruses removed.

Castrations usually take place under the pretext of an allegedly blanket high risk of cancer, despite that an actual high risk which would justify immediate removal is only present in specific cases (see table below), and the admitted true reason is “better manageability.” Contrary to doctors claims, it is known that the gonads by themselves are usually healthy and “effective” hormone-producing organs, often with “*complete spermatogenesis [...] suitable for cryopreservation.*”

Nonetheless, clinicians still continue to recommend and perform early gonadectomies – despite all the known negative effects of castration, including depression, obesity, serious metabolic and circulatory troubles, osteoporosis, reduction of cognitive abilities, loss of libido. Plus a resulting lifelong dependency on artificial hormones (with adequate hormones often not covered by health insurance, but to be paid by the survivors out of their own purse).

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**Fig. 91.6** An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

**Source:** Maria Marcela Bailez: “Intersex Disorders,” in: P. Puri and M. Höllwarth (eds.), *Pediatric Surgery: Diagnosis and Management*, Berlin Heidelberg 2009.

**Table 1.** Prevalence of type II GCT in various forms of DSD

Risk	Type of DSD	Prevalence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15-40
Intermediate	PAIS	15
	17 $\beta$ -hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5 $\alpha$ -reductase deficiency	?
	Leydig cell hypoplasia	?

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome.  
\* Might reach more than 30%, if gonadectomy has not been performed.

**Source:** J. Pleskacova, R. Hersmus, J. Wolter Oosterhuis, B.A. Setyawati, S.M. Faradz, Martine Cools, Katja P. Wolffenbuttel, J. Lebl, Stenvert L.S. Drop, Leendert H.J. Looijenga: "Tumor risk in disorders of sex development," in: *Sexual Development* 2010 Sep;4(4-5):259-69.

### 3 months old with scrotal hypospadias and right impalpable gonad

- Uterus and dysplastic gonad removed
- Hypospadias repaired
- Follow-up for surveillance of development testicular and/or renal tumors
- Testosterone required at puberty



**Source:** J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

## “Bad results” / “Gonadectomy, Feminizing Genitoplasty”



Abb. 2 ▲ a, b Schlechte Korrekturergebnisse nach Feminisierung und c, d nach Hypospadiekorrektur

**Caption:** 2a,b: “*Bad Results of Correction after Feminisation, and*”, c,d: “*after Hypospadias Repair*” – Source: M. Westenfelder: “Medizinische und juristische Aspekte zur Behandlung intersexueller Differenzierungsstörungen,” *Der Urologe* 5 / 2011 p. 593–599.

### PAIS

- Bilateral gonadectomy
- Skin Biopsy for genetics study of androgen receptors
- Female gender assignment
- Feminizing genitoplasty performed age 6 months








**Source:** J. L. Pippi Salle: “Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)”, 2007, at 20.