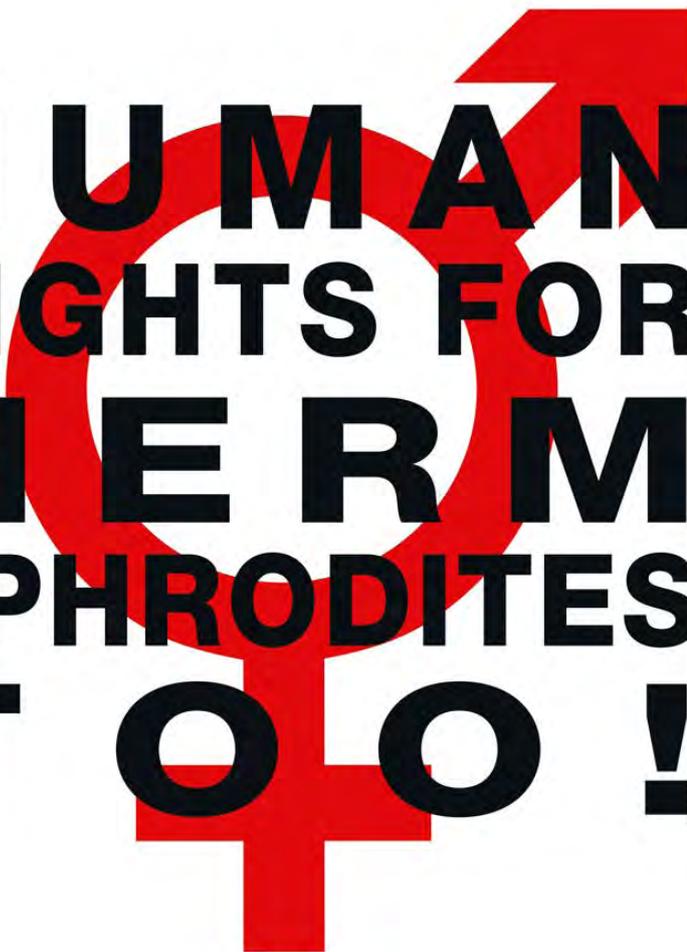


# Intersex Genital Mutilations

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



**HUMAN  
RIGHTS FOR  
HERM  
APHRODITES  
TOO !**

NGO Report (for LOI)  
to the 5<sup>th</sup> to 6<sup>th</sup> Report of Iceland on the  
Convention on the Rights of the Child (CRC)

## Compiled by:

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**February 2020**

This NGO Report online:

<http://intersex.shadowreport.org/public/2020-CRC-Iceland-NGO-Zwischengeschlecht-Intersex-IGM.pdf>



## Executive Summary

**All typical forms of Intersex Genital Mutilation are still practised in Iceland, facilitated and paid for by the State party via the public health system.** Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and **denied appropriate support.** Despite having incorporated CRC into law, and **repeated promises** by the Government to **enact legislation to prohibit** IGM practices, including in the **State report** (para 45), **Iceland fails to do so.**

**Iceland** 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 **49 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 Questions** (see p. 14).

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

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## A. Introduction

### 1. Iceland: Intersex Human Rights and State Report

Iceland has **incorporated the Convention as a whole** into Icelandic law. A **Parliamentary Ombudsman** is tasked to monitor legislation if it is compatible with fundamental and human rights. The **Ombudsman for Children** tasked to promote policies concluded in a **2015 Opinion** that IGM practices **violate CRC and thus Icelandic law**.

The **2017 Coalition agreement** of the current Government promises to **implement a law explicitly prohibiting** IGM practices. This promise is reiterated and strengthened in the **State Report dated 2018** (para 45):

*“The platform of the current coalition government sets out a goal for Iceland to join the vanguard when it comes to the rights of LGBTQIA+ people. To that end, work began in 2018 on a bill on self-determination based on gender awareness in the Ministry of Welfare in accordance with the recent resolution from the Council of Europe on the human rights of intersex people [calling to “prohibit medically unnecessary sex-“normalising” surgery, sterilisation and other treatments practised on intersex children without their informed consent”].”*

However, as this NGO Report demonstrates, the **Government bill 1184 “A bill on sexual autonomy”** submitted to Parliament and adopted in 2019, **did not contain** an article stipulating a prohibition of IGM practices (contained in the first Draft of the bill). Instead, the bill merely contained a **“Provisional provision”** stipulating to establish an **open-ended “working group” dominated by medical practitioners** to draft an amendment bill at some point later, with no guarantee for actual results before the next election in 2021. At the same time, all forms of IGM practices continue to be perpetrated in Iceland, advocated, facilitated and **paid for by the State party**, causing **severe physical and mental pain and suffering**. This constitutes a **serious breach** of Iceland’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>1</sup> According to its charter,<sup>2</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>3</sup> substantially contributing to the so far 49 Treaty body Concluding Observations recognising IGM as a serious human rights violation.<sup>4</sup>

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

2 <http://zwischen-geschlecht.org/post/Statuten>

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

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

In addition, the Rapporteurs would like to acknowledge the work of **Kitty Anderson**<sup>5 6</sup> and **Intersex Ísland**.<sup>7</sup>

### 3. Methodology

This thematic NGO report is a localised update to the **2019 CRC Portugal NGO Report (for Session)**<sup>8</sup> by the same Rapporteurs.

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5 <https://www.interfaceproject.org/kitty-anderson> transcript: <https://www.interfaceproject.org/transcript-kitty-anderson>

6 <https://gayiceland.is/2019/will-not-put-iceland-in-the-front-when-it-comes-to-lgbti-issues/>

7 <https://intersex.samtokin78.is/>

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

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

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

In **Iceland**, same as in the **states** of *Denmark* (CRC/C/DNK/CO/5, paras 24+12; CAT/C/DNK/CO/6-7, paras 42-43), the *United Kingdom* (CRC/C/GBR/CO/5, paras 46-47; CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41; CAT/C/GBR/CO/6, paras 64-65), *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), *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>9</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.

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

To this day, in Iceland all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated by the state funded National University Hospital “Landspítali”, and paid for by the State via the public health system.

Currently practiced forms of IGM in Iceland include:

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

**Castration / “Gonadectomy” / Hysterectomy /  
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation  
Plus arbitrary imposition of hormones**<sup>10</sup>

There is **testimony** of Icelandic intersex persons submitted to “**gonadectomy**”, and the resulting **suffering**, for example by Kitty Anderson:

*“I had surgery as a child to remove, what I was told was, non-functioning gonadal tissue. It wasn't until I was 22 that I learned the fact that I had been born with testes. Internal testes.*

*That was kind of rough for me because when I was told I also found out that my mother had known since I was six weeks old. For me that was a hard moment because it was such a huge breach of trust that people could keep something like this from me for such a long time. I had a lot of shame at that time in my life because I was told that I wouldn't find other people like myself.”<sup>11</sup>*

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9 Currently we count **49 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>

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

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

11 Kitty Anderson, video interview 2017, <https://www.interfaceproject.org/transcript-kitty-anderson>

Also Kitty's cousin Briet who is 14 years younger was submitted to “**gonadectomy**” and reports **negative consequences**:

*“When I was eight and a half months old, I had a hernia. The doctors said they needed to fix that, and since they were already operating, they could take out my gonads. They said they were useless and the risk of cancer was too high. [...]”*

*When I was around 10-12, [the doctors] said I had to go on hormones. They said that I didn't have any gonads anymore because they took them out, and because of that, I had to have hormones. I knew that they had been taken out – I had the scars. [...]*

*I want to try testosterone, but I'm worried about how this doctor will react. I have osteopenia and there is some research showing that testosterone helps with this, but this doctor has reacted badly to Kitty asking for this in the past.*

*When I was little, I didn't care, but now I'm pretty pissed about it. All of this could possibly have been prevented. I don't know whether it's a good thing that the scars aren't that visible. I haven't had any apologies from the doctors. They still think that they did the right thing.”<sup>12</sup>*

The **Icelandic Urological Association (Islands Urologförening)** is associated with the European Association of Urology (EAU)<sup>13</sup> and the European Society for Paediatric Urology (ESPU).<sup>14</sup> The “**ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)**”<sup>15</sup> in turn 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>16</sup> which is co-authored by the “*ESPU/SPU standpoint*” co-authors Prof Dr Piet Hoebeke and Prof Dr Pierre Mouriquand and refers to the “*ESPU/SPU standpoint*”, advocates “**gonadectomy**” – even when admitting “*low*” cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)<sup>17</sup>.

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12 In: Amnesty International (2019), The Right to Health for People with Variations of Sex Characteristics in Iceland, p. 33-34, <https://www.amnesty.org/download/Documents/EUR2894982019ENGLISH.PDF>

**Note:** This Amnesty report, like other documents produced by the Amnesty “*Gender Unit*”, constantly **trivialises and downgrades IGM practices** from a serious violation of non-derogable human rights to a mere “health care” and “diversity” issue, and even **explicitly recommends to let IGM doctors continue with impunity by forgoing criminal penalties for IGM**, see p. 58. This harms intersex children and is **not in line with CRC art. 24(3) and other applicable human rights standards and regulations**.

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

14 The Icelandic Urological Association also endorses the ESPU/EAU “Paediatric Urology” Guidelines included in the EAU Guidelines, see *ibid.*, p. 5

15 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.jpurology.com/article/S1477-5131\(13\)00313-6/pdf](http://www.jpurology.com/article/S1477-5131(13)00313-6/pdf)

16 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>

17 *Ibid.*, at 180 (fn 111)

**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

## b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilation<sup>18</sup>

The Icelandic Urological Association (Islands Urologförening) endorses the current **2019 Guidelines of the European Association of Urology (EAU)**,<sup>19</sup> which include the current **2019 ESPU/EAU “Paediatric Urology” Guidelines**<sup>20</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) (see p. 14). In **chapter 3.16 “Disorders of sex development”**,<sup>21</sup> despite admitting that “Surgery that alters appearance is not urgent”<sup>22</sup> and that “adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give informed consent”,<sup>23</sup> the ESPU/EAU Guidelines nonetheless explicitly **refuse to postpone surgery unless “in emergency conditions”**, 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>24</sup> referring to the 2018 ESPU Open Letter to the Council of Europe (COE),<sup>25</sup> which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).

18 For general information, see 2016 CEDAW NGO Report France, p. 48.

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

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

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

21 [https://uroweb.org/guideline/paediatric-urology/#3\\_16](https://uroweb.org/guideline/paediatric-urology/#3_16)

22 [https://uroweb.org/guideline/paediatric-urology/#3\\_16\\_4](https://uroweb.org/guideline/paediatric-urology/#3_16_4)

23 Ibid.

24 Ibid.

25 [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)

Accordingly, the Government-funded<sup>26</sup> **National University Hospital “Landspítali”** in Reykjavik states on its homepage that **treatment for Congenital Adrenal Hyperplasia (CAH)**, an intersex diagnosis associated with genital variations (“enlarged” clitoris and “insufficiently small” vagina), **includes “difficult surgery”** (i.e. partial clitoris amputation and “vaginoplasty”).<sup>27</sup> This was also reported in the media.<sup>28 29</sup>

### c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”<sup>30</sup>

The **Icelandic Urological Association (Íslands Uroloförening)** endorses the current 2019 Guidelines of the European Association of Urology (EAU),<sup>31</sup> which include the current 2019 ESPU/EAU “*Paediatric Urology*” Guidelines<sup>32</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>33</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>34</sup> – despite admitting to the “*risk of complications*”<sup>35</sup> and “*aesthetic[...]*” and “*cosmetic*” justifications.<sup>36</sup>

Accordingly, the Government-funded<sup>37</sup> **National University Hospital “Landspítali”** in Reykjavik states on its homepage under “*educational resources*” on “**Hypospadias**”:<sup>38</sup>

#### **“Treatment**

*The only treatment available is surgery*

*In this way, the urethra can be moved to the right place by extending the urethra, correct the penis and adjusting the foreskin.*

*In more difficult cases, more than one operation is sometimes required [...]*”

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26 “Landspítali [...] is funded by the Ministry of Welfare, supervised by the Directorate of Health and provides specialised and general care [...]”,

<https://www.landspitali.is/um-landspitala/languages/landspitali-the-national-university-hospital-of-iceland/>

27 “Neonatal screening for congenital adrenal hyperplasia begins January 1”, <https://www.landspitali.is/um-landspitala/fjolmidlators/frettir/stok-frett/2017/12/29/Nyburaskimun-fyrir-medfaeddum-nyrnaheftuofvexti-hefst-1.-januar/>

28 Interview with Dr Leifur Franzson, project manager for neonatal screening at Landspítali (02.01.2018),

<https://www.visir.is/g/2018180109940/audveldara-ad-greina-stulkur-en-drengi?fbclid=IwAR0-w4VLuwfSMJBvTTAy5KnJNK6qpWE>

29 Same interview with Dr Leifur Franzson (02.01.2018), <http://dagmamma.is/index.php/frettir/35-frettir/793-audveldara-ad-greina-stulkur-en-drengi>

30 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>

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

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

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

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

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

36 Ibid.

37 “Landspítali [...] is funded by the Ministry of Welfare, supervised by the Directorate of Health and provides specialised and general care [...]”,

<https://www.landspitali.is/um-landspitala/languages/landspitali-the-national-university-hospital-of-iceland/>

38 <https://www.landspitali.is/sjuklingar-adstandendur/fraedsluefni/hypospadias-of-stutt-thvagrass/>

### 3. The Icelandic Government refuses to act

#### a) Legal and institutional background

Iceland has not only ratified the Convention on the Rights of the Child in 1992, but **CRC was also incorporated as a whole into Icelandic law** in 1993.<sup>39</sup>

There is a **Parliamentary Ombudsman** who has the objective of **monitoring shortcomings in legislation** to ensure that the fundamental rights and freedoms of the citizens are not violated in the course of public administration.<sup>40</sup>

There is also an **Ombudsman for Children (Umboðsmaður barna)**<sup>41</sup> appointed by the Prime Minister and tasked to “*take the lead in promoting policymaking discussion on children’s matters among the public*”.<sup>42</sup> In 2015 the Ombudsman for Children released an “**Opinion on the interventions of intersex children**”<sup>43</sup> which noted that unnecessary “*surgical procedures [...] changing the genitals and / or removing the gonads for the purpose of altering a child’s body*” **continue to be performed** on intersex children in Iceland, further noting **complaints of persons concerned** that they “*suffer from the physical and mental consequences of such actions, as well as the shame of the secrecy that prevails over their status.*” The Opinion stated that such unnecessary procedures constitute “*cruel, inhuman or degrading treatment*” and “*harmful practices*” in violation of CRC art. 24(3) and **Icelandic law 19/2013** (incorporation of CRC into law), and that children’s rights do “*not allow parents or healthcare professionals to make decisions about unnecessary interventions that permanently alter their bodies*”, further stressing the importance of providing “*adequate [psychosocial] support*”.

#### b) Government refuses to act despite repeated promises

In **2017**, the current **Icelandic government promised to prohibit IGM practices** in its **Coalition agreement** (p. 29):<sup>44</sup>

*“The government aims to put Iceland in the front rank regarding LGBTI people’s issues with ambitious legislation [...] in accordance with the recently-published resolution on the human rights of intersex people.”<sup>[45]</sup> The legislation should lay down provisions under which [...] individuals are to enjoy the right to respect of their physical persons and equality before the law irrespective of their [...] [sex] characteristics [...].”*

In **2018** the Government was working on an **initial Draft law** (also referred to in the **State report**, para 45, further quoting from the Coalition agreement). This initial Draft with input from

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39 Act on the Convention on the Right of the Child No. 19/2013 (Lög um samning Sameinuðu þjóðanna um réttindi barnsins)

40 The Office of Iceland’s Parliamentary Ombudsman was established in 1988 and is today governed by law No 85/1997, see: Hrefna Friðriksdóttir (2019), Protection of Children’s Rights in the Icelandic Constitution, in: Trude Haugli, Anna Nylund, Randi Sigurdson und Lena R.L. Bendiksen (ed.), Children’s Constitutional Rights in the Nordic Countries, p. 83-102, here p. 86,

<https://brill.com/downloadpdf/book/edcoll/9789004382817/BP000007.xml>

41 <https://barn.is/um-empaettid/upplysingar-a-erlendum-tungumalum/enska/>

42 Ombudsman for Children Act No 83/1994, art. 3(a)

43 <https://barn.is/um-empaettid/verkefni/adgerdir-a-intersex-boernum/>

44 <https://www.stjornarradid.is/lisalib/getfile.aspx?itemid=c0c3c70a-051d-11e8-9423-005056bc4d74>

45 i.e. the Council of Europe Parliamentary Assembly **Resolution 2191 (2017)** “Promoting the human rights of and eliminating discrimination against intersex people”, which “*calls on Council of Europe member States to: [...] 7.1.1. prohibit medically unnecessary sex-“normalising” surgery, sterilisation and other treatments practised on intersex children without their informed consent*”,

<https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=24232&lang=en>

persons concerned included a section that stipulated to **formally outlaw IGM practices**<sup>46</sup> (although the provision was **insufficient and not in line with CRC**, like similar ineffective provisions in Malta,<sup>47</sup> Portugal,<sup>48</sup> Argentina<sup>49</sup> and some autonomous regions in Spain<sup>50</sup>).

However, when in **2019** the Government presented the **Draft bill 1184**<sup>51</sup> to the Parliament, contrary to the promises in the Coalition agreement and the State report (para 45), the **crucial section on IGM had been removed**. Instead, the bill merely contained a **“Provisional provision”** stipulating to establish an **open-ended “working group” dominated by medical practitioners** to draft an amendment bill at some point later:

**“Provisional provisions.**

**I.**

*The Minister appoints a working group to discuss the issues of children born with atypical sex characteristics, including health services to them, and make suggestions for improvement. The group shall also be entrusted with the drafting of a bill amending this Act, which shall include adding to the Act provisions relating to changes in the sex traits of children born with atypical sex traits. The group shall include a paediatric surgeon, paediatric gynaecologist, paediatric psychologist, Intersex Iceland representative, representative of the Association '78, a gender scientist, ethicist and two lawyers, one with expertise in children's rights but the other in human rights. The group shall submit its conclusions and proposals as soon as possible after the entry into force of this Act.”*

In **June 2019** this **Draft bill 1184** was **adopted by Parliament**. The omission of an article to prohibit IGM practices was **widely criticised**,<sup>52 53 54 55</sup> and further, that there is no guarantee that the open-ended **“working group”** dominated by medical practitioners will produce any **results before the next election in 2021**.<sup>56</sup> Tellingly, as of February 2020 there has been **no news from open-ended “working group”**.

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46 “Kitty Anderson, the chairperson of Intersex Ísland [...] has been involved with consultations about the bill since May 2015, and she says that **some elements that were included in earlier drafts of the legislation have since been removed**.”, <https://gayiceland.is/2019/will-not-put-iceland-in-the-front-when-it-comes-to-lgbti-issues/>

47 CRC/C/MLT/CO/3-6, paras 28-29, on the ongoing practice despite the law, see 2019 CRC NGO Report, <http://intersex.shadowreport.org/public/2019-CRC-Malta-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

48 CRC/C/PRT/CO/5-6, paras 28(b), on the ongoing practice despite the law, see 2019 CCPR NGO Report, <http://intersex.shadowreport.org/public/2019-CRC-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

49 CRC/C/ARG/CO/5-6, para 26, on the ongoing practice despite the law, see 2018 CRC NGO Report, [http://intersex.shadowreport.org/public/2018-CRC-Argentina-Intersex-Justicia-Brujula-StopIGM\\_v2.pdf](http://intersex.shadowreport.org/public/2018-CRC-Argentina-Intersex-Justicia-Brujula-StopIGM_v2.pdf)

50 CRC/C/ESP/CO/5-6, para 24, on the failure of the regional laws, see <http://stop.genitalmutilation.org/post/How-Spains-Laws-fail-intersex-children>

51 “149. Legislative Assembly 2018–2019. Parliamentary document 1184 - 752. Government. A bill on sexual autonomy. From the Prime Minister.”, <https://www.althingi.is/altext/149/s/1184.html>

52 <https://gayiceland.is/2019/will-not-put-iceland-in-the-front-when-it-comes-to-lgbti-issues/>

53 <https://www.reuters.com/article/iceland-lgbt-health/icelands-intersex-children-at-risk-as-without-new-protection-activist-says-idUSL1N20E1RT>

54 <https://grapevine.is/news/2019/06/19/iceland-passes-major-gender-identity-law-the-fight-is-far-from-over/>

55 <https://www.amnesty.org/en/latest/news/2019/02/iceland-diverse-bodies-are-not-mistakes-to-be-corrected/>

56 “It’s problematic that there is no end date given for this work to be done,” [Kitty Anderson] says about the change. “In Iceland we sometimes like to say that committees are where issues go to die. And while this is an exaggeration of course, by giving this committee no time frame, this is something that could go on for the next few years. If this legislation isn’t enacted before the next election, then the government will have failed to uphold their government coalition agreement.”

<https://gayiceland.is/2019/will-not-put-iceland-in-the-front-when-it-comes-to-lgbti-issues/>

In addition, in **2018** Parliament also debated a proposal to **amend the Law against female genital mutilation**<sup>57</sup> by making it “gender-neutral” for children via removing the words “*girl*” and “*her*” in the first sentence of the first paragraph,<sup>58</sup> which would also have **made the Law directly applicable to intersex children**<sup>59</sup> (although the main discussion was about the inclusion of male circumcision). However, the proposed amendment was **not adopted by Parliament**. Nonetheless, the debate led to a **critical comment** on the hypocritical stance of Icelandic politics regarding IGM practices, particularly criticising the “*use [of intersex] as queer bait before elections*”.<sup>60</sup>

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

The **Icelandic Government refuses to collect and disclose disaggregated data** on intersex persons and IGM practices. When in **2015** a Member of Parliament **asked the Minister of Health** about intersex births and surgical interventions,<sup>61</sup> the Government **claimed there had only been 3 cases**, but failed to include all forms of IGM practices.<sup>62</sup> 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 **Iceland** 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>63</sup> So far, in Iceland 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 Iceland’s obligations under the Convention.**

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57 Art. 218a of the General Penal Code No. 19/1940, amendment of 2005

58 See Arndís A. K. Gunnarsdóttir (2018), “Banning ritual circumcision of children in Iceland”, *Revue du droit des religions* 6 | 2018, <http://journals.openedition.org/rdr/342>

59 Ibid., footnote 20

60 “*And yet, MPs of the Icelandic parliament have still somehow managed to put together a bill that proposes to ban male circumcision without medical reason. Something that almost seems to have come out of the blue since there was no special debate on the matter preceding it in Iceland.*

*So, why hasn’t the Icelandic parliament taken action in the matters of intersex people when genital procedures done on intersex children clearly violate their human rights? Why is it starting to look like our MP’s generally don’t take a serious interest in the human rights of intersex people at all? Are we to believe that protecting the rights of intersex people is merely something that political parties like to put in their policies and use as queer bait before elections?”*, <https://gayiceland.is/2018/ban-circumcision-iceland-humanity-hypocrisy/>

61 <https://www.althingi.is/altext/raeda/144/rad20150511T155856.html>

62 Presentation by Kitty Anderson, Brussels, October 2018

63 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 Questions for the LOI

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

### **Harmful practices: Intersex Genital Mutilation**

- **How many non-urgent, irreversible surgical and other procedures have been undertaken on intersex minors? Please provide detailed statistics on sterilising, feminising, and masculinising procedures, disaggregated by age group and diagnosis.**
- **Does the State party plan to stop this practice? If yes, what measures does it plan to implement, and by when?**
- **Please indicate which criminal or civil remedies are available for intersex people who have undergone involuntary sterilisation or unnecessary and irreversible medical or surgical treatment when they were children, and whether these remedies are subject to any statute of limitations?**
- **Please indicate which means of rehabilitation are available for intersex people who have undergone involuntary procedures?**
- **Please indicate which means of psychosocial support, including peer support, are available for intersex children and their families?**

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

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

#### a) Harmful Practice (art. 24(3) and JGC No. 18)<sup>64</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>65</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>66</sup>

Also the Icelandic **Ombudsman for Children (Umboðsmaður barna)** has recognised the ongoing OGM practices in Iceland as a “*harmful practice*” in violation of CRC art. 24(3) and **Icelandic law** (see above p. 11).

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>67</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>68</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

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64 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>

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

66 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)

67 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)

68 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)

“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))

“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 Iceland** – 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>69</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>70</sup> as well as to “ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood,

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69 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)

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

*guarantee bodily integrity, autonomy and self-determination to children concerned*”,<sup>71</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>72</sup>

### **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 **Iceland** 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>73</sup> So far there was no case of a victim of IGM practices succeeding in going to an Icelandic court.

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

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

73 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>74</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>75</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>76</sup>

In **regions without universal access to paediatric health care**, there are reports of **infanticide**<sup>77</sup> of intersex children, of **abandonment**,<sup>78</sup> of **expulsion**,<sup>79</sup> of **massive bullying** preventing the

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

75 [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)

76 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>

77 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>

78 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>80</sup> and of **murder**.<sup>81</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>82 83 84 85</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>86</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>87</sup> **UN Treaty bodies have so far issued 49 Concluding Observations condemning IGM practices accordingly.**<sup>88</sup>

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79 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>

80 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>

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

82 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)

83 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>

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

85 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>

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

87 **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>

88 <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>89 90</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>91</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>92 93</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>94</sup> and again IGM survivors as “*transgender children*”,<sup>95</sup> “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”<sup>96</sup> and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.<sup>97</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>98</sup> “*a special provision on sexual orientation and*

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

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

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

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

92 For example ACHPR Commissioner Lawrence Murugu Mute, see

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

93 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)

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

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

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

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

98 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>99</sup>, transgender guidelines<sup>100</sup> or “*Gender Identity*”<sup>101 102</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>103</sup> and public **representation**.<sup>104</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>105 106 107 108</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>109 110</sup>

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

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

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

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

103 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>

104 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>

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

106 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)

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

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

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

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

110 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>

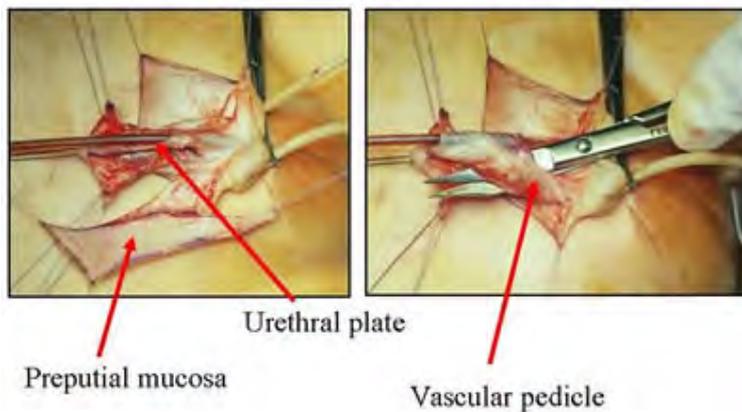
## Annexe 3 – “IGM in Medical Textbooks: Current Practice”

### 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

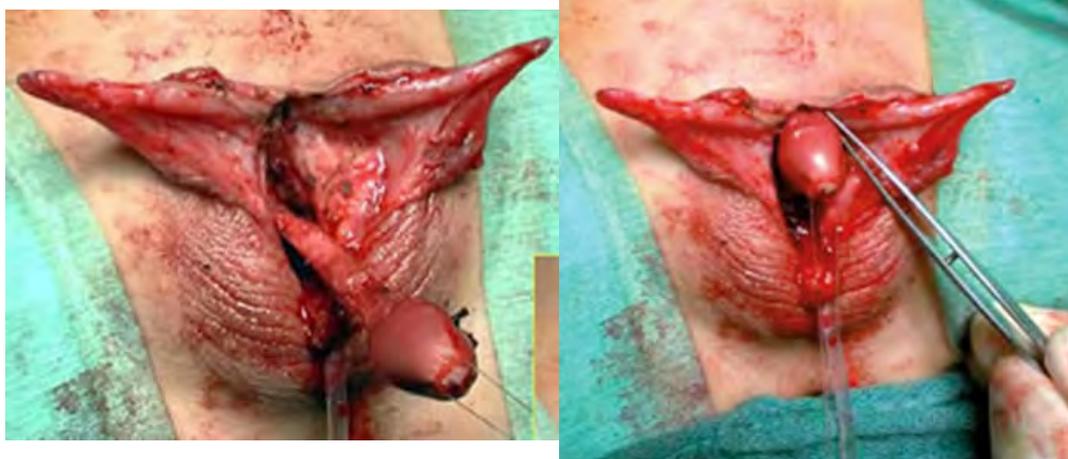
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

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

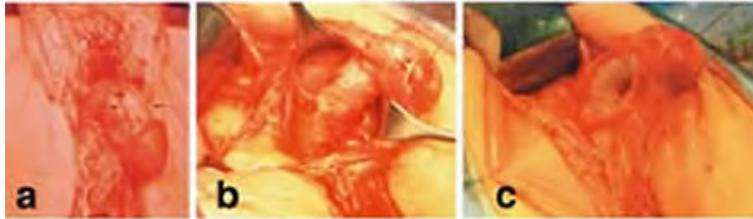
### IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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").

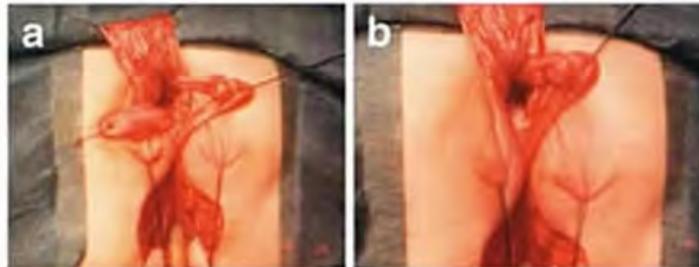
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "*in the first 2 years of life*", most commonly "*between 6 and 12 months,*" and only 10.5% of surgeons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



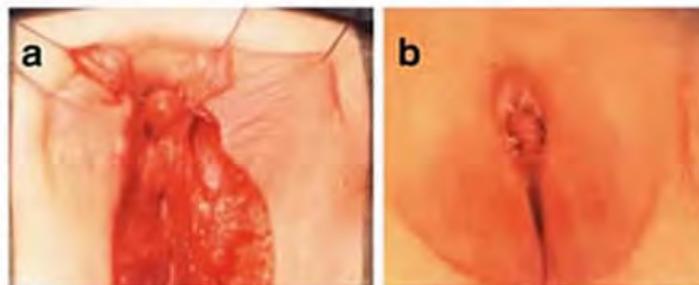
Source: Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



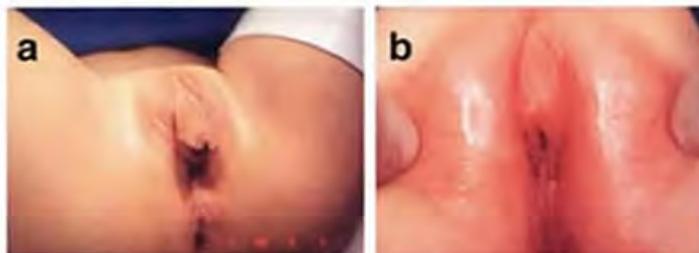
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



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).

91 M.M. Bailez • Intersex Disorders



**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.