

Intersex Genital Mutilation

Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for Session)
to the 7th Periodic Report of Finland on the
International Covenant on Civil and Political Rights
(CCPR)

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Executive Summary

In Finland **all typical forms of Intersex Genital Mutilation (IGM) persist with impunity, facilitated and paid for by the State party via the public health system.**

Finnish intersex advocates, NGOs, ethics and human rights and some medical professionals have **publicly criticised IGM practices** in Finland for years, **calling for a prohibition** of all non-urgent surgical and other procedures on intersex children before they can give informed consent, and for **equal access to justice and redress** for IGM survivors.

The **Finnish government admits to the ongoing practice, and pledges to protect intersex children from cosmetic genital surgery.** However, so far it **fails to take effective legislative and other measures.**

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

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

In total, UN treaty bodies **CRC, CAT, CCPR, CEDAW 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.

This **NGO Report** has been compiled by **StopIGM.org / Zwischengeschlecht.org**, an international intersex NGO. It contains **Suggested Recommendations** (see p. 19).

**NGO Report to the 7th Report of Finland
on the International Covenant on Civil and Political Rights (CCPR)**

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Introduction

1. Finland: Intersex Human Rights, LOIPR and State Report

Finnish intersex advocates, NGOs, ethics and human rights bodies, and some medical professionals have **publicly criticised IGM practices** in Finland, the **lack of protection** for intersex children from such inhuman treatment, and the **lack of access to justice, rehabilitation and redress** for IGM survivors for many years (see below, p. 9-10).

In response to this criticism, the **LOIPR** (para 9) asked about medically unnecessary irreversible surgeries and other medical treatment on intersex children without fully informed and free consent, new developments and research, efforts to adopt binding guidelines measures to facilitate effective access to justice and redress for individuals who have been subjected to such surgeries or other medical interventions.

In reply, the State report referred to the current **Government Programme pledging to protect intersex children from cosmetic genital surgery** (para 108), further referring to statements by the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) (para 109), the Ombudsman for Children and NGOs calling for a **ban of “all kinds of nonconsensual, medically unnecessary medical interventions such as hormonal treatment, and not only genital surgery”** and that *“information on intersex persons be added to the basic training and continuing education of professionals in the health care and education sectors”* (para 110). Also, the State report referred to the 2019 qualitative Intersex Study commissioned by the Ministry of Justice and the Ministry for Foreign Affairs, which again recommends *“that medically unnecessary surgery to ‘normalise’ genitals and any other measures undertaken without the informed consent of the child shall be prohibited”* (para 111). However, the State report did **not elaborate on access to justice and redress**.

Further, the State report **admits that involuntary, non-urgent surgical and other interventions on intersex children continue** (para 112). However, the **annual numbers** given (“5 to 40 operations on the genital area in boys” and “0 to 1” “corrective operations on the external genitalia of girls”) are **incomplete** (see below, p. 13, 14, 17-18).

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Finland persist** – advocated, facilitated and **paid for by the State party**, and perpetrated in all 5 relevant public University hospitals – and constitute a **serious breach** of Finland’s obligations under the Covenant.

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!*”¹ According to its charter,² 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,³ substantially contributing to the so far 50 Treaty body Concluding Observations recognising IGM as a serious human rights violation.⁴

In addition, the Rapporteurs would like to acknowledge the work of the intersex peer support group **Intersukupuolisuus.fi**⁵ and of the intersex NGO **Intersukupuolisten ihmisoikeudet – ISIO ry**.⁶ And we would like to acknowledge **Mika Venhola**.^{7 8}

3. Methodology

This thematic NGO report is a localised update to the **2020 CCPR Portugal NGO Report (for Session)**⁹ by the same Rapporteurs. Translations from Finnish texts are automatic translations revised by the Rapporteurs.

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

2 <https://zwischengeschlecht.org/post/Statuten>

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

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

5 <https://intersukupuolisuus.fi/etusivu/>

6 <https://intersukupuolisuus.fi/isio/>

7 Mika Venhola (2012), video statement on intersex surgery, recorded on occasion of the Genital Autonomy 2012 conference by James Loewen, <https://www.youtube.com/watch?v=riNtxjntqZE>

Partial transcript, see <https://ihra.org.au/7867/mika-venhola-video/>

8 Mika Venhola, Miina Savolainen (2016), Intersukupuolisten lasten hoitoeettiset lähtökohdat. Yhteenveto 29.4.2015 seminaari-rista Ruotsin ja Suomen eettisille neuvottelukunnille, SMERille ja ETENELLE [Ethical principles of care for intersex children. Summary of the seminar on 29 April 2015 for the Swedish and Finnish Ethical Advisory Boards, SMER and ETENE],

<https://lapsiasia.fi/documents/25250457/37287625/SmerEteneLausunto2015VenholaSavolainen-Copy.pdf>

9 <http://intersex.shadowreport.org/public/2020-CCPR-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

A. Precedents: List of Issues Prior to Reporting, State Report

1. 2019 List of Issues Prior to Reporting (LOIPR) (CCPR/C/FIN/QPR/7, para 9)

Discrimination on the grounds of gender identity and intersex status (arts. 2, 7, 9, 17, 24 and 26)

[...]

9. *Please respond to reports that infants and children with variations in sex characteristics (intersex) are subjected to medically unnecessary and irreversible “sex-normalizing” surgeries and other medical treatment without fully informed and free consent. Please report on: (a) any follow-up to the proposal made in 2016 by the National Advisory Board on Social Welfare and Health Care Ethics that measures to modify external sex characteristics of intersex children not be taken until they themselves can both define their gender and form a position on their sexuality; (b) the outcome of the study on the rights and experiences of intersex children, planned under the National Action Plan on Fundamental and Human Rights 2017–2019, and on any ensuing follow-up measures; (c) efforts to adopt national binding guidelines for medical professionals on the treatment of intersex individuals; and (d) measures to facilitate effective access to justice and redress for individuals who have been subjected to such surgeries or other medical interventions.*

2. State Party Report (CCPR/C/FIN/7, paras 108-114)

Reply to paragraph 9 of the list of issues

108. *According to the Government Programme, the right of self-determination of intersex children will be reinforced, and cosmetic, non-medical genital surgery for small children will be discontinued. Children belonging to gender minorities and their families will be supported with customised and timely services.*

109. *In 2016, the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) issued an opinion at its own initiative on treatment practices for intersex children in public health care. ETENE recommends that measures to modify external gender characteristics should not be taken until the child himself/herself can define his/her gender and form a position on his/her sexuality, with the exception of situations where the child’s health is in immediate danger.*

110. *The Ombudsman for Children has considered that treatments for intersex children do not necessarily have to be given until the child is old enough to give their consent, and that this should be addressed in legislation. NGOs have emphasized that it is essential that the ban should cover all kinds of nonconsensual, medically unnecessary medical interventions such as hormonal treatment, and not only genital surgery, and that changing treatment practices and reinforcing the human rights of intersex individuals also requires that information on intersex persons be added to the basic training and continuing education of professionals in the health care and education sectors.*

111. *As part of the National Action Plan on Fundamental and Human Rights, the Ministry of Justice and the Ministry for Foreign Affairs commissioned a qualitative study of the rights and experiences of intersex persons in 2019. The purpose of this study was to investigate how the decisions concerning intersex children made at birth and the treatments given to them in*

childhood and adolescence have affected their lives. The study examines the experiences of intersex persons and of their parents in Finnish health care and society at large. It also examines what kind of information and support have been offered to the parents of intersex children, and what information and support they feel they need. The study describes best practices for taking intersex children into account in daycare, at school, in leisure activities and in health care. The study recommends, inter alia, that medically unnecessary surgery to 'normalise' genitals and any other measures undertaken without the informed consent of the child shall be prohibited. Except for situations where the child's health is in immediate danger, no action should be taken to modify gender characteristics until the child is able to decide for himself/herself.

112. According to the Hospital District of Helsinki and Uusimaa (HUS), corrective surgery on genitals is at the moment basically only performed on those patients whose gender has been confirmed as male or female. In unclear cases, an endocrinological team will determine the gender. If the gender is unclear, the principle is that no surgery will be performed. If the patient or family demands an operation which can be considered medically feasible and which is consistent with international treatment practices, then the surgery is provided as far as possible. According to a report compiled at HUS on the basis of the Care Register, university hospitals perform about 5 to 40 operations on the genital area in boys per year, most of them having to do with a congenital malformation. The average number of corrective operations on the external genitalia of girls in the 2000s has been 0 to 1 per year.

113. The Action Plan of the Government of Åland for equal opportunities for LGBTI persons in Åland society contains a proposal whereby the Åland Health Care Service (ÅHS) should prepare an internal plan for LGBTI affairs and report to the Government of Åland under the Åland accessibility programme.

114. NGOs have expressed concern that Finland does not have a Current Care Guideline for the treatment of intersex persons and have noted that intersex identity should be considered as a possibility also in connection with the medical and informal care of the elderly, because the issue may be a traumatic one for the patient.

B. IGM in Finland: State-sponsored + pervasive, Gov fails to act

1. IGM practices in Finland: Pervasive and unchallenged

In **Finland**, same as in the **fellow Nordic and European Union member states** of *Denmark* (CAT/C/DNK/CO/6-7, paras 42-43; CRC/C/DNK/CO/5, paras 24+12), *Sweden* (CRC/C/SWE/QPR/6-7, paras 20(a)+40(d)), *Belgium* (CCPR/C/BEL/CO/6, paras 21-22; CRC/C/BEL/CO/5-6, paras 25(b)+26(e)), *Germany* (CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24; CCPR/C/DEU/QPR/7, para 13), *Portugal* (CCPR/C/PRT/CO/5, paras 16-17; CRC/C/PRT/CO/5-6, paras 28(b)), and in **many more State parties**,¹⁰ there are

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

The **Finnish government partially recognises** the serious violations constituted, and the severe pain and suffering caused by IGM practice¹¹ and **pledges to protect intersex children**: “*Intersex children’s right to self-determination will be strengthened, and cosmetic, non-medical surgeries on young children’s genitals will no longer be performed.*”¹² However, so far the **Finnish government fails to “take effective legislative, administrative, judicial or other measures”** to protect intersex children.

This lack of appropriate and effective action by the government continues in spite of **longstanding criticism and appeals** by intersex advocates and their organisations,^{13 14} seconded by public bodies including the **Finnish National Advisory Board on Social Welfare and Health Care Ethics (ETENE)**,¹⁵ the **Ombudsman for Children**,¹⁶ the **Finnish Human Rights Centre**

10 Currently we count **50 Concluding observations on IGM practices for 26 State parties in Europe, South America, Asia and Oceania**, see <https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

11 See Study on the experiences of intersex persons in Finland commissioned by the Ministry of Justice: Tikli Oikarinen (2019), No information or options. Study on the rights and experiences of intersex persons, Publications of the Ministry of Justice, Reports and guidelines 2019:3, https://um.fi/documents/35732/0/IP1709011_STUDY_ON_THE_RIGHTS_AND_EXPERIENCES_sahkoinen_5.pdf

12 See Government Programme, Objective 3. Strengthening the integrity of society (social inclusion, good ethnic relations, prevention of discrimination, breaking the cycle of cumulative social exclusion and inequality), <https://valtioneuvosto.fi/en/marin/government-programme/strengthening-the-rule-of-law>
See also State Report, para 108

13 Intersukupuolisten ihmisoikeudet – ISIO ry (Finnish Intersex NGO), “*Objectives [...] 1. There is a need for a law that prohibits all medical procedures (surgeries, hormone therapies) that modify a child’s sex characteristics, which can be postponed until the child is able to give his or her informed consent.*” <https://intersukupuolisuus.fi/tavoitteet/>

14 See State Report, para 110: “*NGOs have emphasized that it is essential that the ban should cover all kinds of nonconsensual, medically unnecessary medical interventions [...]*”

15 The National Advisory Board on Social Welfare and Health Care Ethics ETENE (2016), ETENE’s statement on the treatment of intersex children 4 April 2016, <https://etene.fi/documents/1429646/1561478/2016+POSITION+STATEMENT+intersex/77dc4b30-2a6d-4811-aa99-c30032f400b0/2016+POSITION+STATEMENT+intersex.pdf>

See also State Report, para 109

(NHRI)¹⁷ and the **Ministry of Justice**,¹⁸ as well as by some **health care professionals**.^{19 20}

In contrast, **in Finland all types of Female Genital Mutilation (FGM) are prohibited** in the general criminal law, namely according to §§5-7 on assault in the **Finnish Penal Code**. The principle of **extraterritoriality is applicable**, making FGM punishable even if it is committed outside the country.²¹ Further, in November 2020 **Finland's Parliament** has voted by a margin of 141 to 10 to **make the prohibition of FGM more explicit** in Finnish law, in partial support to a citizens' initiative with 61'000 signatories calling for the creation of a separate law to specifically ban the practice of FGM. While the Parliament did not back separate legislation, it agreed to **amendments clarifying the law on FGM to be written into the criminal code**.^{22 23}

2. Most Common IGM Forms advocated and perpetrated by Finland

To this day, in Finland all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated by the state funded **University Hospitals**, and **paid for by the State** via the **public health system** under the responsibility of the **Ministry of Social Affairs and Health** and the **Municipalities** (local governments).

In Finland, care for intersex children is centralised in five University Hospitals:

- **Helsinki University Hospital, Helsinki (HUS)**
- **Tampere University Hospital, Tampere (TAYS)**
- **Kuopio University Hospital, Kuopio (KYS)**
- **Turku University Hospital, Turku (TYKS)**
- **Oulu University Hospital, Oulu (OYS)**

16 Ombudsman for Children (Lapsiasiavaltuutettu), Roundtable Discussion 12 May 2016 Intersex children and clinical practice, <https://lapsiasia.fi/-/intersukupuoliset-lapset-ja-hoitokaytannot>
See also State Report, para 110

17 See 2019 CCPR NHRI Report (for LOIPR), para 32

18 2019 qualitative Intersex Study commissioned by the Ministry of Justice, see above footnote 11

19 Mika Venhola (2012), video statement on intersex surgery, recorded on occasion of the Genital Autonomy 2012 conference by James Loewen, <https://www.youtube.com/watch?v=riNtxjntqZE>
Partial transcript, see <https://ihra.org.au/7867/mika-venhola-video/>

20 Mika Venhola, Miina Savolainen (2016), Intersukupuolisten lasten hoitoeettiset lähtökohdat. Yhteenvedo 29.4.2015 seminaarista Ruotsin ja Suomen eettisille neuvottelukunnille, SMERille ja ETENELLE [Ethical principles of care for intersex children. Summary of the seminar on 29 April 2015 for the Swedish and Finnish Ethical Advisory Boards, SMER and ETENE],
<https://lapsiasia.fi/documents/25250457/37287625/SmerEteneLausunto2015VenholaSavolainen-Copy.pdf>

21 European Institute for Gender Equality (EIGE) (2013), Current situation and trends of female genital mutilation in Finland,
<https://lapsiasia.fi/documents/25250457/37287625/SmerEteneLausunto2015VenholaSavolainen-Copy.pdf>
http://eige.europa.eu/sites/default/files/documents/current_situation_and_trends_of_female_genital_mutilation_in_finland_en.pdf

22 yle.fi (2020), Parliament votes to clarify Finland's FGM laws,
https://yle.fi/uutiset/osasto/news/parliament_votes_to_clarify_finlands_fgm_laws/11635308

23 euractiv.com (2020), Ban on female genital mutilation in Finland to receive clarifications,
https://www.euractiv.com/section/politics/short_news/ban-on-female-genital-mutilation-in-finland-to-receive-clarifications/

While the 2016 Background Report of the **National Advisory Board on Social Welfare and Health Care Ethics (ETENE)**²⁴ (p. 6/p. 7 in PDF), reiterated in the **2019 Intersex Study** commissioned by the **Ministry of Justice**²⁵ (p. 26/p. 32 in PDF), **claims** that only the Helsinki University Hospital (HUS) and the Tampere University Hospital (TAYS) continue with non-consensual, unnecessary genital surgeries, and that the Oulu University Hospital (OYS) has stopped performing unnecessary surgeries, the following sections **demonstrate** that **all 5 University Hospitals** continue practising IGM.

Notably, the **State report** itself admits that “*corrective surgery on genitals*” of intersex children continues to be “*performed*” (para 112).

Also the **2019 Intersex Study**²⁶ commissioned by the Ministry of Justice **confirms** the ongoing practice (p. 44/p. 50 in PDF):

“[T]he experiences shared by the parents whose children were born between 2010 and 2019 go to show that interventions such as non-vital genital surgery are still being performed.”

Currently practiced forms of IGM in Finland include:

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
Plus arbitrary imposition of hormones**²⁷

The **Finnish Urological Association (Suomen Urologiyhdistys)** is associated with the European Association of Urology (EAU)²⁸ which in turn is affiliated with the European Society for Paediatric Urology (ESPU).²⁹ The “*ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)*”³⁰ 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**”³¹ refers to the “*ESPU/SPU standpoint*”, advocates “*gonadectomy*” – even when admitting “*low*” cancer risk

24 ETENE (2016). Intersukupuolisuus [Intersex]. Taustaraportti ETENEn kannanottoon [Background report to ETENE’s position statement],

<https://etene.fi/documents/1429646/2056382/IS-raportti20160331.pdf/58bf2412-48a9-4521-b5ae-81a3ee3bc07b/IS-raportti20160331.pdf>

25 Tikli Oikarinen (2019), No information or options. Study on the rights and experiences of intersex persons, Publications of the Ministry of Justice, Reports and guidelines 2019:3,

https://um.fi/documents/35732/0/IP1709011_STUDY_ON_THE_RIGHTS_AND_EXPERIENCES_sahkoinen_5.pdf

26 Ibid.

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

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

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

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

30 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)

31 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>

for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)³².

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 Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectomy 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, the **2019 Intersex Study**³³ commissioned by the Ministry of Justice **confirms** (p. 44/p. 50 in PDF):

“[T]wo intersex respondents reported that their doctors had recommended gonadectomy in their adolescence, citing cancer risk.”

And adds the following **testimony** (p. 48/p. 54 in PDF):

“Sara, born in the 1990s, underwent a gonadectomy during the current decade when they were a young adult. [...] Sara says that, had they been better informed of its potential effects, they would not have gone through with it.

‘In my opinion, the gonadectomy was only performed because it’s part of the ‘old’ way of treating AIS. In fact, it’s highly unlikely that the gonads will develop anything malignant. And why should something be cut off in the first place just because it might possibly cause a disease at some point in the future? After all, you don’t cut women’s breasts off just because they might possibly develop breast cancer.’”

b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilatation³⁴

The **Finnish Urological Association (Suomen Urologiyhdistys)** endorses the current **2019 Guidelines of the European Association of Urology (EAU)**,³⁵ which (see p. 14) include the current **2019 ESPU/EAU “Paediatric Urology” Guidelines**³⁶ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.16**

32 Ibid., at 180 (fn 111)

33 Tikli Oikarinen (2019), No information or options. Study on the rights and experiences of intersex persons, Publications of the Ministry of Justice, Reports and guidelines 2019:3, https://um.fi/documents/35732/0/IP1709011_STUDY_ON_THE_RIGHTS_AND_EXPERIENCES_sahkoinen_5.pdf

34 For general information, see 2016 CEDAW NGO Report France, p. 48. <https://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/>

“Disorders of sex development”,³⁷ despite admitting that *“Surgery that alters appearance is not urgent”*³⁸ and that *“adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give informed consent”*,³⁹ 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,⁴⁰ referring to the 2018 ESPU Open Letter to the Council of Europe (COE),⁴¹ which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).

Accordingly, the **State report** itself (para 112) admits to ongoing *“corrective operations on the external genitalia of girls”*, e.g. girls with intersex traits diagnosed with Congenital Adrenal Hyperplasia (CAH) or Androgen Insufficiency Syndrome (AIS). However, the stated *“average number of [...] 0 to 1 [procedures] per year”* seems to include **only procedures performed in the Hospital District of Helsinki and Uusimaa**, and includes **only selected relevant procedures**, as the State report doesn’t specify which diagnoses and procedures were included and which not, and apparently **“vaginoplasty”, “vulvoplasty” etc. are excluded**.

Also, the current **Finnish language Orphanet entry** on Congenital Adrenal Hyperplasia (CAH) states:⁴²

*“The disease is inherited in the autosomes recessively. The most common form, corresponding to about 95% of cases, is due to the lack of 21-hydroxylase. Fetal diagnosis is possible with DNA testing. Lifelong hormone therapy (glucocorticoid and mineralocorticoids in classical form and glucocorticoids in non-classical form) is necessary. **Genital abnormalities in women may require surgical treatment.** The incidence of the classical form has been estimated at 1/14000, but the non-classical form is more common.”*

Also, several Finnish medical homepages recommend early genital surgery for infants with CAH:

*“Surgical treatment of children born with unclear genitals is complex and controversial. [...] Early surgery should be considered for severely affected infants and only by experienced expert teams.”*⁴³

*“In addition to hormonal therapy, surgical repair of the genitals is performed. It is better to carry out the procedure as early as possible, but its timing needs to be discussed with the parents.”*⁴⁴

37 https://uroweb.org/guideline/paediatric-urology/#3_16

38 https://uroweb.org/guideline/paediatric-urology/#3_16_4

39 Ibid.

40 Ibid.

41 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf

42 <https://www.orpha.net/data/patho/Pro/other/Synnynnaistenlisamunuaistenhyperplasia-FifiAbs648.pdf>

43 <https://fi.techsymptom.com/53464-congenital-adrenal-hyperplasia-pro-51>

44 <http://laakarinkirja.info/tauti/congenitaalinen-lisamunuaisten-hyperplasia.html>

And the **University of Turku** (Faculty of Medicine) 2017-2019 **Specialist Training Study Guide** for “Plastic Surgery”, part of which can be completed in the field of “Paediatric Surgery” (p. 123 / p. 124 in PDF), includes (p. 119 / p. 120 in PDF):

“4. Upper body and abdomen, genitals

a. congenital

[...]

ii. female genital abnormalities”⁴⁵

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”⁴⁶

The **Finnish Urological Association (Suomen Urologiyhdistys)** endorses the current 2019 Guidelines of the European Association of Urology (EAU),⁴⁷ which include the current 2019 ESPU/EAU “Paediatric Urology” Guidelines⁴⁸ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) (see p. 14). In **chapter 3.5 “Hypospadias”**,⁴⁹ 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.*”⁵⁰ – despite admitting to the “*risk of complications*”⁵¹ and “*aesthetic[...]*” and “*cosmetic*” justifications.⁵²

Accordingly, the **State report** itself (para 112) admits to ongoing “**corrective surgery**” on the “**genital area in boys**”, e.g. boys with intersex traits diagnosed with hypospadias:

“According to a report compiled at HUS on the basis of the Care Register, university hospitals perform about 5 to 40 operations on the genital area in boys per year, most of them having to do with a congenital malformation.”

However, the stated number of “5 to 40 operations per year” seems to include **only procedures performed in the Hospital District of Helsinki and Uusimaa**, and arguably include **only selected relevant procedures**, as the State report doesn’t specify which diagnoses and procedures were included and which not (see also below p. 17-18).

Also, the **2019 Intersex Study**⁵³ commissioned by the Ministry of Justice includes the **testimony of a parent** concerning a **recent hypospadias surgery** of which **not even the parents were properly informed**, and resulting in **serious complications** requiring additional surgery (p. 52-53/p. 58-59 in PDF):

45 https://www.utu.fi/sites/default/files/public%3A//media/file/EL_opas%202017-19_final%20-%20v1118.pdf

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

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

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

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

49 https://uroweb.org/guideline/paediatric-urology/#3_5

50 https://uroweb.org/guideline/paediatric-urology/#3_5_5_3

51 https://uroweb.org/guideline/paediatric-urology/#3_5_5_1

52 Ibid.

53 Tikli Oikarinen (2019), No information or options. Study on the rights and experiences of intersex persons, Publications of the Ministry of Justice, Reports and guidelines 2019:3,

https://um.fi/documents/35732/0/IP1709011_STUDY_ON_THE_RIGHTS_AND_EXPERIENCES_sahkoinen_5.pdf

“Johanna, whose child was born in the current decade and is now at daycare age, described their experiences as follows:

‘We were just informed of the interventions. They neither said that “this is being considered”, nor asked like, “what do you think about this”. I don’t feel like I would have had any chance to question this doctor’s pronouncement.’

Johanna compared the ‘declaratory nature’ of the genital surgery performed on their child with another medical intervention received by their child around the same time period. This intervention was not related to the child being intersex and it was significantly less extensive than the genital surgery.

‘[...] Conversely, with the hypospadias surgery, I was offered no clarification whatsoever. Nor did I know to ask when I didn’t even understand what the surgery was like. And I didn’t realise that I should be afraid of the hypospadias surgery, even though I really should have. Had I realised it, I would have fought tooth and nail if necessary to have that discussion.’

[...]

‘Then came the appointment that was supposed to be the last. Throughout this whole follow-up period, the surgeon had told us that the recovery was progressing really well. The previous visits to the hospital had been really quick, but at the last time, it started to take longer for them again. Then the child emerged from there, and was tied to the bed again, like after the hypospadias surgery. I was like, what the hell. They told us, “The thing is that it doesn’t look like the urethra is really healing, so what we did now was we opened up the original urethra and what you’ll need to do now at home every day for a year is to thrust a catheter in and out of the constructed urethra, so that it will remain open. In one year’s time, there will be another surgery to close up the original urethral opening.”’

[...]

The child had been in a lot of pain after the first surgery, which had also made the situation very difficult for Johanna. They said that this was the point where they first began to question the medical interventions.

‘That was the point at which I began to think for the first time that “this can’t be how this should go”. I started looking for information and found out that this was not at all necessary. That I wouldn’t be doing any further damage to my child if I were to refuse these surgeries now. That all these operations could also be done later, if my child should want it at some point.’

Also, the current “*pediatric urology*” homepage of the **Helsinki University Hospital (HUS)** states:⁵⁴

*“Our most demanding cases in paediatric urology include **congenital defects** of the kidneys, bladder or **penis**; **disorders of sex development**; neurogenic urinary disorders due to congenital spinal cord defects; and tumor operations.”*

And the current “*paediatric surgery*” homepage of the **Tampere University Hospital (TAYS)** states:⁵⁵

*“**Hereditary urinary and genital organ abnormalities**, such as ureteral obstructions and **urethral hypospadias**”*

Further, the current Finnish “*hypospadias*” homepage of the **Tampere University Hospital (TAYS)** prescribes:⁵⁶

*“Only the mildest forms of hypospadias, which have only a cosmetic disadvantage, can be left uncut. We will discuss the matter with the parents. [...] **We perform surgery at the age of 1-1.5 years.**”*

*“**Fistulae develop in 5 to 30 percent of patients**, depending on the extent of surgery. We close the fistula at the earliest six months after the previous surgery. In this case, the in-patient treatment lasts a few days.*

***Urethral stenosis develops in less than 10 percent.** A mild stenosis should be stretched during anaesthesia.”*

And the current Finnish “*Congenital genital disorders*” homepage of the **Turku University Hospital (TYKS)** prescribes:⁵⁷

“The most common congenital genital disorder in boys is hypospadias, in which e.g. the urethral opening does not open to the tip of the glans but to the underside of the penis. [...]”

***Hypospadias is repaired with surgery, usually when the child is about 1 to 1.5 years old.** The child will be in the hospital’s paediatric ward after the procedure from a few days to a good week depending on the degree of hypospadias. Follow-up inspections are performed at the paediatric urology outpatient clinic.*

Surgeons at the Children and Adolescent Clinic have extensive experience in paediatric urology.”

And the current Finnish “*Division of labour (Annexe 2)*” of the **Kuopio University Hospital (KYS)** lists under “*Table 13: Demanding Surgery Concentration Plan 2014*” (p. 51):⁵⁸

*“demanding urology: urodynamic evaluation, **proximal hypospadias**, minimal-invasive urological surgery”*

54 <https://www.hus.fi/en/treatments-and-examinations/pediatric-urology>

55 https://www.tays.fi/en-US/Services/Paediatric_Surgery

56 https://www.tays.fi/fi-FI/Palvelut/Lastenkirurgia/Virtsaputken_alahalkio

57 <https://www.vsshp.fi/fi/hoito-ja-tutkimukset/Sivut/sukupuolielinten-synnynnaiset-hairiot.aspx>

58 <https://www.psshp.fi/documents/7796350/7871976/Liite2.pdf/d76808ff-6526-484d-8e2b-16af91e70e88>

Finally, a 2012 report from the **Oulu University Hospital (OYS)** titled “*Surgery from head to toe, from the premature baby to the teenager – the Oulu University Hospital Children's Surgery Department introduces itself*” states (p. 17):⁵⁹

“Urological surgeries include hypospadias, renal pelvis and ureteral stenosis repairs (PU and UV plastics), kidney removal, bladder neck incontinence plastics and bladder augmentations.”

And while the 2016 Background Report of the **National Advisory Board on Social Welfare and Health Care Ethics (ETENE)**⁶⁰ (p. 6/p. 7 in PDF) **claims** that the Oulu University Hospital (OYS) has stopped performing all unnecessary surgeries on intersex children, a doctor confirms that non-consensual, medically unnecessary **hypospadias “repair” surgery nonetheless continues to be performed in Oulu** to this day.⁶¹

3. Finnish Doctors and Government consciously dismissing Intersex Human Rights

The persistence of IGM practices in Finland is a **matter of public record**.⁶²

However, **Finnish paediatric surgeons**, despite **openly admitting to knowledge of relevant criticisms** by intersex advocates, human rights and ethics bodies,⁶³ nonetheless continue to **consciously refuse to consider any human rights concerns**, and to this day **refuse to disclose data of surgical and other interventions on intersex children**.

Also the **Finnish government**, despite **pledging** to prevent IGM practices, so far **fails to take practical and legislative measures** to implement this pledge.

4. Lack of Independent Data Collection and Monitoring

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

Also, in Finland there are no reliable statistics on intersex births and on IGM practices available, despite that such **data is available** in the **patient records of the relevant public University Hospitals** (e.g. a 2018 study “*identified 3206 patients who were evaluated for one or multiple ICD-10 diagnosis of interest in either Pediatric, Pediatric Endocrine and/or Pediatric Surgery Outpatient Clinics at the Helsinki University Hospital between 2004 and 2014*”)⁶⁴ and

59 https://www.forna.fi/images/PDF_tiedostot/Pinsetit/pinsetti_2012_3.pdf

60 ETENE (2016). Intersukupuolisuus [Intersex]. Taustaraportti ETENEn kannanottoon [Background report to ETENE’s position statement], <https://etene.fi/documents/1429646/2056382/IS-raportti20160331.pdf/58bf2412-48a9-4521-b5ae-81a3ee3bc07b/IS-raportti20160331.pdf>

61 Personal communication, 2020

62 See above footnotes 11-20

63 See for example ESPU 2018 Congress in Helsinki, Lecture: “DSD: At the crossroads of Medicine, Human Rights and Politics”, <https://www.espu.org/members/video-broadcast/319-lecture-dsd-at-the-crossroads-of-medicine-human-rights-and-politics-at-helsinki-congress-2018>

See also ESPU 2018 Open Letter to COE, on which above discussion was based,

https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf

64 Kohva, E., Miettinen, P. J., Taskinen, S., Hero, M., Tarkkanen, A., & Raivio, T. (2018). Disorders of sex development: timing of diagnosis and management in a single large tertiary center. *Endocrine connections*, 7(4), 595–603, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5911703/pdf/ec-7-595.pdf>

in the **records of the public health system (Care Register)** which reimburses all relevant IGM procedures (see also State report, para 112).

Reliable statistics on intersex births and IGM procedures would need to be **comprehensive** and **disaggregated by diagnosis, procedure, age at intervention and clinic** where the intervention took place (see also above p. 12, 13).

5. Obstacles to redress, fair and adequate compensation

Also in **Finland** 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.⁶⁵ So far, in Finland there was **no case** of a victim of IGM practices succeeding in going to court.

Notably, also a **complaint** by a Finnish IGM survivor about traumatising, non-consensual, unnecessary genital surgeries **filed with the Finnish Patient Insurance Centre** was **dismissed**, with the Patient Insurance Centre stating there was no malpractice because the procedure was in keeping with clinical practice guidelines, and the doctors consulted by the Patient Insurance Centre had also expressed the opinion that there was no need to review the clinical practice guidelines.⁶⁶

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

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

66 Tikli Oikarinen (2019), No information or options. Study on the rights and experiences of intersex persons, Publications of the Ministry of Justice, Reports and guidelines 2019:3, p. https://um.fi/documents/35732/0/IP1709011_STUDY_ON_THE_RIGHTS_AND_EXPERIENCES_sahkoinen_5.pdf

C. Suggested Recommendations

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

Intersex persons

The Committee takes note of the Government programme pledging to protect intersex children. It remains concerned, however, about irreversible and invasive medical procedures being performed on intersex children before they are able to provide fully informed and free consent, which can cause severe suffering, and the lack of redress and compensation in such cases (arts. 2, 3, 7, 9, 17, 24 and 26).

The State party should:

- (a) take all necessary measures to end irreversible medical treatment, especially surgery, on intersex children who are not yet capable of giving their free and informed consent, except in cases where such interventions are absolutely necessary for medical reasons, and**
- (b) ensure that psychological assistance and reparation, including compensation, are provided for victims of unnecessary surgical procedures.**

Annexe 1 – IGM Practices in Finland as a Violation of CCPR

1. The Treatment of Intersex Children in Finland as Inhuman Treatment

This Committee has repeatedly **recognised IGM practices as a serious violation of Covenant**,⁶⁷ and **arts. 2, 3, 7, 9, 17, 24, 26** as applicable.

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

On the basis of being born with intersex traits, intersex children are singled out for experimental harmful treatments, including surgical “genital corrections” and potentially sterilising procedures, that would be **“considered inhumane” on “normal” children**,⁶⁸ e.g. “normal” boys and girls, while on intersex children, according to a specialised surgeon, *“any cutting, no matter how incompetently executed, is a kindness.”*⁶⁹ While similar inhuman treatment of other children **is criminalised** in the Finnish Penal Law and perpetrators are persecuted, **intersex children have no such legal protections and no access to justice, redress, rehabilitation and reparation**. Clearly, IGM practices therefore violate Article 2.

Art. 3: Equal Right of Men and Women

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

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

Like this Committee, the **Committee against Torture**⁷⁰ has repeatedly **considered IGM to constitute inhuman treatment** falling under the non-derogable prohibition of torture (same as FGM and gender-based violence). Intersex advocates consider harmful practices and inhuman treatment as the **most important human rights frameworks** to effectively combat IGM.⁷¹

Concerning **involuntary medical or scientific experimentation**, as generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental**. While due to the general avoidance of follow-up by doctors, IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition. However, internationally there are **many examples proving also a strict definition to apply**.⁷²

67 See CCPR/C/CHE/CO/4, paras 24-25; CCPR/C/AUS/CO/6, paras 25-26; CCPR/C/DEU/QPR/7, para 13; CCPR/C/BEL/CO/6, paras 21-22; CCPR/C/MEX/CO/6, paras 12-13

68 Alice Domurat Dreger (2006), *Intersex and Human Rights: The Long View*, in: Sharon Sytsma (ed.) (2006), *Ethics and Intersex*: 73-86, at 75

69 Cheryl Chase (1998), *Surgical Progress Is Not the Answer to Intersexuality*, in: Alice Dreger (ed.) (1999), *Intersex in the Age of Ethics*: 148-159, at 150

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

71 Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: “Ending the Impunity of the Perpetrators!” Input at “Ending Human Rights Violations Against Intersex Persons.” OHCHR Expert Meeting, Geneva 16-17.09.2015, online: https://stopigm.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

For decades, intersex children have been regularly described and exploited by scientists as an “*experiment of nature*”.^{73 74 75} Often **twins, siblings, mothers or other family members or relatives** of intersex children are used as controls.^{76 77} Generally, intersex children, while being submitted to IGM practices or thereafter, are often used as **subjects in scientific research**, particularly in the field of genetics, also in **Finland** and internationally with the contribution of **Finnish IGM doctors**.^{78 79 80}

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

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

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

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- 73 See e.g. Kang H-J, Imperato-McGinley J, Zhu Y-S, Rosenwaks Z. 5alpha-reductase-2 Deficiency’s Effect on Human Fertility. *Fertility and sterility*. 2014;101(2):310-316, at p. 5, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4031759/pdf/nihms578345.pdf>
- 74 Clarnette, T.D; Sugita, Y.; Hutson, J.M.: Genital anomalies in human and animal models reveal the mechanisms and hormones governing testicular descent, *British Journal of Urology* (1997), 79, 99–112, at 99, <http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf>
- 75 U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied zwischen Mädchen und Jungen, Männern und Frauen?, *Monatsschr Kinderheilkd* 2003 · 151:586–593, at 591, see also: Lang C.; Kuhnle U.: Intersexuality and Alternative Gender Categories in Non-Western Cultures, *Horm Res* 2008;69:240–250
- 76 See e.g. Dittmann, R. W., Kappes, M. H., Kappes, M. E., Borger, D., Stegner, H., Willig, R. H., Wallis, H. (1990). “Congenital adrenal hyperplasia. I: Gender-related behavior and attitudes in female patients and sisters.” *Psychoneuroendocrinology* 15(5-6): 401-420, see also: Ralf W. Dittmann, “Pränatal wirksame Hormone und Verhaltensmerkmale von Patientinnen mit den beiden klassischen Varianten des 21-Hydroxylase-Defektes. Ein Beitrag zur Psychoendokrinologie des Adrenogenitalen Syndroms”, *European University Studies*, Bern: 1989
- 77 For an example of studies on intersex twins by German gynaecologist Ernst Philipp in collaboration with Swiss endocrinologist Andrea Prader, see Marion Hulverscheidt (2016), Begriffsdefinitionen “Intersexualität” VII: Eine einheitliche Betrachtung des Zwittertums – der Kieler Gynäkologe Ernst, <http://intersex.hypotheses.org/3976>
- 78 J Jääskeläinen, A Deeb, J W Schwabe, N P Mongan, H Martin, I A Hughes (2006), Human androgen receptor gene ligand-binding-domain mutations leading to disrupted interaction between the N- and C-terminal domains, *J Mol Endocrinol*. 2006 Apr;36(2):361-8. doi:10.1677/jme.1.01885, [https://jme.bioscientifica.com/configurable/contentpage/journals\\$002fjme\\$002f36\\$002f2\\$002f0360361.xml](https://jme.bioscientifica.com/configurable/contentpage/journals$002fjme$002f36$002f2$002f0360361.xml)
- 79 Johanna Känsäkoski, Jarmo Jääskeläinen, Tiina Jääskeläinen, Johanna Tommiska, Lilli Saarinen, Rainer Lehtonen, Sampsa Hautaniemi, Mikko J. Frilander, Jorma J. Palvimo, Jorma Toppari & Taneli Raivio (2016), Complete androgen insensitivity syndrome caused by a deep intronic pseudoexon-activating mutation in the androgen receptor gene, *Scientific Reports* volume 6, Article number: 32819 (2016), https://www.nature.com/articles/srep32819?error=cookies_not_supported&code=d053bbe4-fc9e-49cb-95f8-f1a1017c8290
- 80 In April 2018 the 29th Congress of the European Society for Paediatric Urology (ESPU) was hosted in Helsinki with local support, <https://congress2018.espu.org/> The ESPU is a known propagator and practitioner of IGM, see above p. 11-14

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

Art. 9: Liberty and Security of the Person

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

Art. 17: Arbitrary or Unlawful Interference with Privacy

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

Art. 24: Child Protection

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

Art. 26: Equal Protection of the Law

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

2. Lack of Independent Data Collection and Monitoring

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

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

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

1. Intersex = variations of reproductive anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with “Disorders” or “Differences of Sex Development (DSD)”,⁸¹ 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.*⁸²

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.⁸³

In **regions without universal access to paediatric health care**, there are reports of **infanticide**⁸⁴ of intersex children, of **abandonment**,⁸⁵ of **expulsion**,⁸⁶ of **massive bullying** preventing the

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

82 https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

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

84 For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, <https://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf>

For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12,

<https://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

For South Africa, see also <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens>

For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

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

; for Uganda, see also 2015 CRC Briefing, slide 46,

https://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf

For Kenya, see also <http://www.bbc.com/news/world-africa-39780214>

For Mexico, see 2018 CEDAW NGO Joint Statement,

<https://stopigm.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018>

85 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

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

For example in China, see 2015 Hong Kong, China NGO Report, p. 15,

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

86 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

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

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),⁸⁷ and of **murder**.⁸⁸

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**.^{89 90 91 92}

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**,⁹³ 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.⁹⁴ **UN Treaty bodies have so far issued 50 Concluding Observations condemning IGM practices accordingly.**⁹⁵

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

<https://stopigm.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3>

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

89 2014 CRC NGO Report, p. 52, 69, 84, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

90 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>

91 “The Racist Roots of Intersex Genital Mutilations”

<https://stopigm.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM>

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

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

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

94 **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>

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

3. Intersex is NOT THE SAME as LGBT or Transgender

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

The underlying reasons for such harmful misrepresentations include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**^{96 97} 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,⁹⁸ 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.^{99 100}

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*”,¹⁰¹ and again IGM survivors as “*transgender children*”,¹⁰² “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”¹⁰³ and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.¹⁰⁴

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*”,¹⁰⁵ “*a special provision on sexual orientation and*

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

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

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

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

99 For example ACHPR Commissioner Lawrence Murugu Mute, see

<https://stopigm.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT>

100 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

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

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

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

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

105 CRC73 New Zealand, <https://stopigm.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”¹⁰⁶, transgender guidelines¹⁰⁷ or “Gender Identity”^{108 109} 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**¹¹⁰ and public **representation**.¹¹¹

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**^{112 113 114 115} – 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**.^{116 117 118}

106 CCPR120 Switzerland,

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

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

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

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

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

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

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

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

https://stopigm.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

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

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

<https://stopigm.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile>

117 For example Ministry of Health France (2018), see 2020 CRC Intersex NGO Report (for LOIPR), p. 19,

<https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf>

118 For example Ministry of Health Austria (2019), see 2019 CRC Intersex NGO Report (for Session), p. 4-5,

<https://intersex.shadowreport.org/public/2019-CRC-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

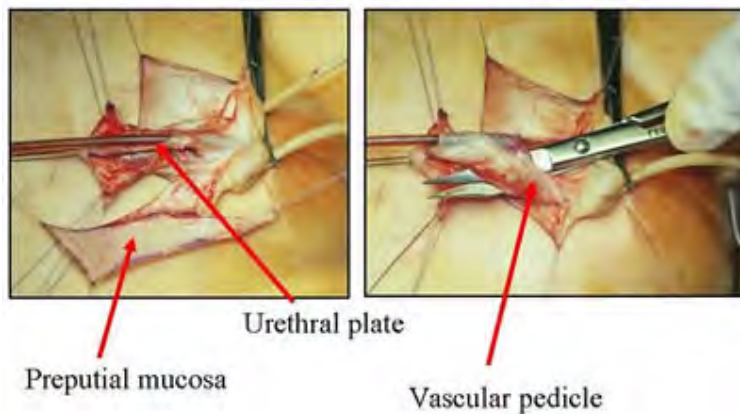
Annexe 3 – “IGM in Medical Textbooks: Current Practice”

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

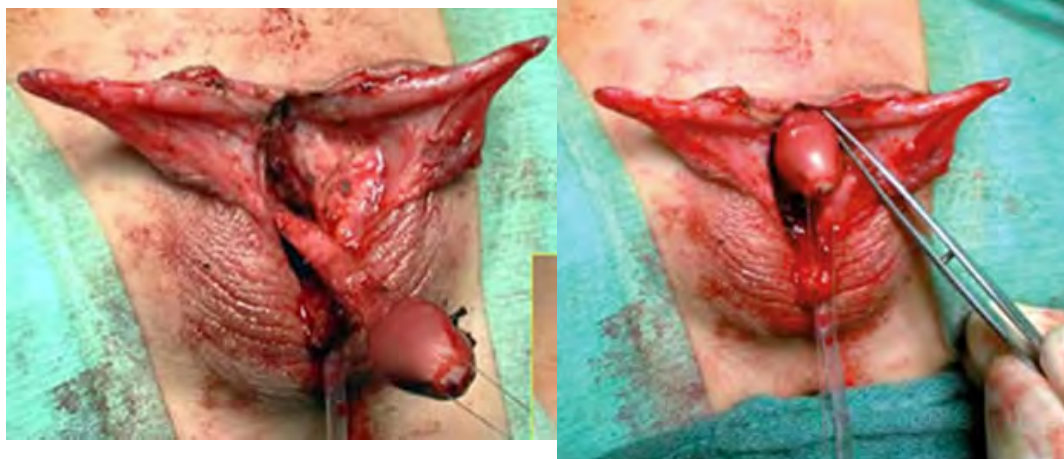
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: 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").

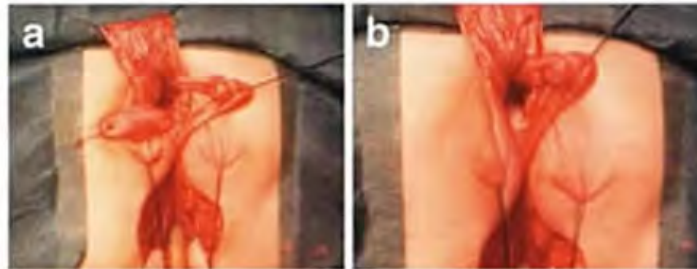
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "*in the first 2 years of life*", most commonly "*between 6 and 12 months,*" and only 10.5% of surgeons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



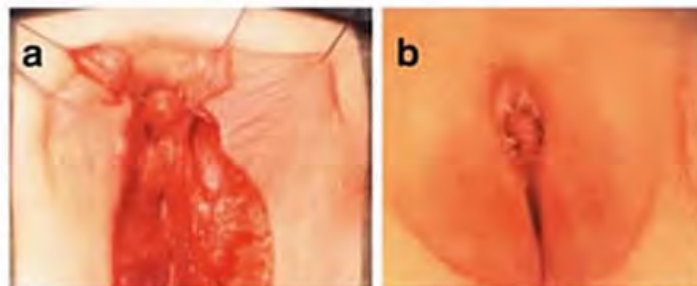
Source: Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



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 β -hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5 α -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, Feminising Genitoplasty”






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

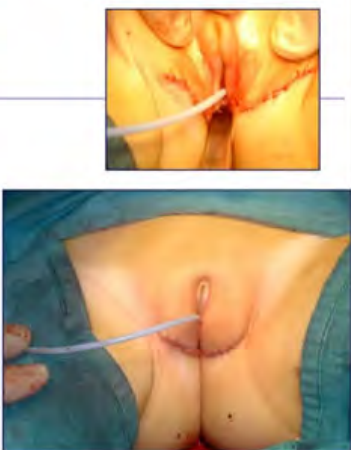
Caption: 2a,b: “Bad Results of Correction after Feminisation, and”, c,d: “after Hypospadias Repair” – Source: M. Westenfelder: “Medizinische und juristische Aspekte zur Behandlung intersexueller Differenzierungsstörungen,” *Der Urologe* 5 / 2011 p. 593–599.

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.