# Intersex Genital Mutilation

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

**NGO Report (for Session)**
**to the 8th Report of Finland on the**
**Convention against Torture (CAT)**

## Compiled by:

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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, government, ethics and human rights bodies 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 ill-treatment**, and called for **legislation** to **(a)** end the practice, **(b)** ensure redress and compensation, and **(c)** to provide access to free counselling (CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; CAT/C/AUT/CO/6, paras 44-45; CAT/C/DNK/CO/6-7, paras 42-43; CAT/C/CHN-HKG/CO/4-5, paras 28-29; CAT/C/FRA/CO/7, paras 32-33; CAT/C/NLD/CO/7, paras 52-53).

In addition, **CCPR** has already **considered IGM in Finland** as **inhuman treatment** (CCPR/C/FIN/CO/7, paras 20+21(c)) and **CRC** and **CEDAW** as a **harmful practice** (CRC/C/FIN/CO/5-6, paras 24(a)+(b); CEDAW/C/FIN/CO/8, paras 21(b)+22(b)).

In total, UN treaty bodies **CRC, CAT, CCPR, CEDAW** and **CRPD** have so far issued **90 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. 23).

NGO Report (for Session) to the 8th Report of Finland
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# Introduction

## 1. Intersex human rights and IGM in Finland

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. 9-11).

IGM practices in Finland have already been reviewed by **CCPR** in 2021 (CCPR/C/FIN/CO/7, paras 20+21(c)), **CEDAW** in 2022 (CEDAW/C/FIN/CO/8, paras 21(b)+22(b)) and **CRC** in 2023 (CRC/C/FIN/CO/5-6, paras 24(a)+(b)) with all Committees **recognising** IGM in Finland as constituting **cruel, inhuman or degrading treatment** and a **harmful practice**.

Finland has **repeatedly pledged** to protect intersex children and to **prohibit** IGM practices, and has previously claimed to **prepare legislation** (CRC/C/FIN/RQ/5-6, paras 62+63).

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 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!"* [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 90 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 and intersex NGO **Intersukupuolisten ihmisoikeudet – ISIO ry**.[5] And we would like to acknowledge **Mika Venhola**.[6] [7]

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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/?page_id=1206
6 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/
7 Mika Venhola, Miina Savolainen (2016), Intersukupuolisten lasten hoitoeettiset lähtökohdat. Yhteenveto 29.4.2015 seminaa-rista Ruotsin ja Suomen eettisille neuvottelukunnille, SMERille ja ETENElle [Ethical

## 3. Methodology

This thematic NGO report is an update to the **2023 CRC Finland NGO Report (for Session)**[8] by the same Rapporteurs. Own translations from Finnish texts are automatic translations revised by the Rapporteurs.

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

8 https://intersex.shadowreport.org/public/2023-CRC-Finland-NGO-Zwischengeschlecht-Intersex-IGM.pdf

## A. Precedents

### 1. Previous Concluding Observations

#### a) Inhuman Treatment: CCPR 2021, CCPR/C/FIN/CO/7, paras 20+21(c)

***Sexual orientation, gender identity and intersex status***

*20. The Committee is concerned about social stigmatization, discrimination and violence against persons based on their sexual orientation or gender identity. While noting the ongoing process to amend the Trans Act, the Committee is concerned about the lengthy procedure for legal gender recognition and the requirements to be sterilized and diagnosed with "transsexualism", which is defined as a mental disorder. It is further concerned that consenting transgender children may be unable to access the procedure for legal gender recognition. The Committee is also concerned that irreversible and invasive medical interventions continue to be performed on intersex children. It notes with concern that such actions are often based on a stereotyped vision of gender roles and carried out before children are of an age to allow them to give their full, free and informed consent (arts. 3, 7, 9, 17, 24 and 26).*

*21.* ***The State party should take legislative and other measures to:***

*[…]*

*(c)* ***Effectively prevent the performance of irreversible medical interventions, especially surgical operations, on intersex children who are not yet capable of giving their full, free and informed consent, unless such procedures constitute an absolute medical necessity, and ensure access to effective remedies for victims of such interventions.***

#### b) Harmful Practices: CEDAW 2022, CEDAW/C/FIN/CO/8, paras 21(b)+22(b)

***Harmful practices***

*21. The Committee notes the proposed amendment of the law on verification of gender to remove the requirement of proof of sterilization for a transsexual person. It also notes that a working group was established to prepare best practice guidance to help health-care professionals advise parents with intersex children. The Committee further notes that forced marriage is punishable as human trafficking or as coercion. The Committee notes with concern, however: […]*

*(b) The performance of surgical interventions on intersex children with the aim of "normalizing" their genitalia;*

*[…]*

*22.* ***Recalling joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2019) on harmful practices, and the Committee's previous recommendations (CEDAW/C/FIN/CO/7, paras. 17 and 29), the Committee recommends that the State party:***

*[…]*

*(b)* ***Specifically criminalize surgical interventions on the genitalia of intersex children, unless medically necessary;***

### c) Harmful Practices: CRC 2023, CRC/C/FIN/CO/5-6, paras 24(a)+(b)

*Harmful practices*

*24.* ***Recalling joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2019) on harmful practices, the Committee recommends that the State party:***

*(a)* ***Ensure that the performance of unnecessary medical or surgical treatment on intersex children is safely deferred until the children are able to provide their informed consent, and provide adequate social, medical and psychological services, counselling and support for intersex children and their families;***

*(b)* ***Provide reparations and support to intersex children who received unnecessary medical or surgical treatment, including irreversible medical interventions, sometimes without their consent, by ensuring that their access to justice is not hindered by any statute of limitations;***

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

### 1. IGM practices in Finland: Still no legal prohibition

In **Finland** (CCPR/C/FIN/CO/7, paras 20+21(c); CRC/C/FIN/CO/5-6, paras 24(a)+(b); CEDAW/C/FIN/CO/8, paras 21(b)+22(b)), same as in the **fellow Nordic states** of *Denmark* (CAT/C/DNK/CO/6-7, paras 42-43; CAT/C/DNK/CO/8, paras 32-33); CRC/C/DNK/CO/5, paras 24+12), *Sweden* (CRC/C/SWE/QPR/6-7, paras 20(a)+40(d)), *Iceland* (CRC/C/ISL/CO/5-6, para 26(b)+(c)), and in **many more State parties**,[9] 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 by IGM practices, as well as the severe pain and suffering caused by it, and has **repeatedly pledged to protect** intersex children from IGM practices (see below, p. 11-12).

However, so far, the **Finnish government fails to *"take effective legislative, administrative, judicial or other measures"*** to protect intersex children.

In contrast to the lack of legal protection from IGM practices, **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.[10] 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**.[11] [12]

### 2. Public criticism by intersex advocates, NGOs, Government agencies

This lack of appropriate and effective action by the Finnish government stands in stark contrast to **longstanding criticism and appeals** by intersex advocates and their organisations, namely

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9 Currently we count **90 Concluding observations on IGM practices**, see https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

10 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

11 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

12 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/

**ISIO ry**,[13] seconded by Finnish NGOs **SETA**[14] and **Amnesty Finland**,[15] as well as by Finnish public bodies including the Finnish **National Advisory Board on Social Welfare and Health Care Ethics (ETENE)**, [16] the **Ombudsman for Children**, [17] [18] [19] the **Ombudsman for Equality**,[20] [21] the **Finnish Human Rights Centre (NHRI)**[22] and the **Ministry of Justice**,[23] as well as by some **health care professionals**.[24] [25]

What's more, also a **2019 study commissioned by the Finnish government**[26] corroborated the **severe mental and physical pain and suffering caused by IGM practices**, namely *"various types of physical pain"* and *"self-destructive behaviour, depression, anxiety, panic disorders, dissociative disorders"*, with survivors ***"describ[ing] their experiences in terms of sexual***

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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/?page_id=803

14 Seta and OII Europe (2019), "Finnish government should take action to ensure intersex people's physical integrity and self-determination", https://seta.fi/2019/05/10/seta-and-oii-europe-finnish-government-should-take-action-to-ensure-intersex-peoples-physical-integrity-and-self-determination/

15 Amnesty International (2021), "Amnesty International's statement to the United Nations Human Rights Committee on the occasion of the review of Finland", https://www.amnesty.fi/amnesty-internationals-statement-to-the-united-nations-human-rights-committee-on-the-occasion-of-the-review-of-finland/

16 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

17 Ombudsman for Children (Lapsiasiavaltuutettu), Roundtable Discussion 12 May 2016 Intersex children and clinical practice, https://lapsiasia.fi/-/-intersukupuoliset-lapset-ja-hoitokaytannot-

18 Ombudsman for Children (2016), "Intersukupuolisten lasten oikeuksia vahvistettava" ("The rights of intersex children need to be strengthened"), https://lapsiasia.fi/-/-lapsiasiavaltuutettu-intersukupuolisten-lasten-oikeuksia-vahvistettava-

19 Ombudsman for Equality and Ombudsman for Children (2017), "Intersukupuolisilla on oikeus omaan kehoonsa" ("Intersex people have the right to their own body"), https://tasa-arvo.fi/-/tasa-arvovaltuutettu-ja-lapsiasiavaltuutettu-intersukupuolisilla-lapsilla-on-oikeus-omaan-kehoonsa

20 Ibid.

21 Ombudsman for Equality (2018), "Ombudsman for Equality's report to Parliament 2018", https://tasa-arvo.fi/documents/25249985/49416869/Ombudsman+for+Equality's+Report+to+Parliament+2018+(PDF).pdf/63a9737d-c5a3-1e00-cc4c-5118b5780c1c/Ombudsman+for+Equality's+Report+to+Parliament+2018+(PDF).pdf

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

23 2019 qualitative Intersex Study commissioned by the Ministry of Justice, see above footnote 11

24 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/

25 Mika Venhola, Miina Savolainen (2016), Intersukupuolisten lasten hoitoeettiset lähtökohdat. Yhteenveto 29.4.2015 seminaa-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

26 Tikli Oikarinen (2020), "No information or options. Study on the rights and experiences of intersex people in Finland", commissioned and published by the Ministry of Justice and the Ministry for Foreign Affairs, 28.2.2019, p. 109, 113 (p. 115, 119 in PDF), https://um.fi/documents/35732/0/IP1709011_STUDY_ON_THE_RIGHTS_AND_EXPERIENCES_sahkoinen_5.pdf

***violence and sexual abuse."*** Further, the study issued the following **recommendations**:

> *"1. Intersex people's rights to bodily integrity and self-determination should be ensured.* ***Any non-vital surgeries or other interventions performed to 'normalise' intersex children's sex characteristics without the child's informed consent should be prohibited.*** *With the exception of situations where a child's health is at immediate risk, no interventions aiming to modify sex characteristics should be performed until the child is capable of making an independent decision on the matter.*
>
> *[…]*
>
> *3.* ***Intersex people and their parents should be guaranteed access to psychosocial support and peer support.*** *Adequate resources should be secured for organisations providing psychosocial and peer support."*

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

### a) National Action Plan on Fundamental and Human Rights 2017-2019

The **2017 National Action Plan on Fundamental and Human Rights 2017-2019**[27] (see also State Party Report, para 22) of the **Ministry of Justice** stipulated the undertaking of a ***"Study on the rights and experiences of intersex children"***, inter alia **explicitly referring to CRC**. Published in 2019 by the Ministry of Justice, this study corroborated the **severe mental and physical pain and suffering** caused by IGM practices, and **recommended a prohibition** (see above, p. 13-14).

### b) Government Programme 2019

The **2019 Government Programme**[28] of the former Sanna Marin government **pledged to protect intersex children** and to **end IGM practices**, *"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."*

### c) UNHRC45 Statement, 01.10.2020

On occasion of the **45th Session of the Human Rights Council** the **State party** supported a public statement calling to ***"protect […] intersex adults and children*** *[…] so that they live free* ***from violence and harmful practices****. Governments should* ***investigate human rights violations and abuses*** *against intersex people,* ***ensure accountability****, […] and* ***provide victims with access to remedy."***[29]

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27 Ministry of Justice Finland (2017), "National Action Plan on Fundamental and Human Rights 2017-2019", p. 85, https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/79849/OMML_25_2017.pdf

28 "Inclusive and competent Finland – a socially, economically and ecologically sustainable society. Programme of Prime Minister Sanna Marin's Government 2019", 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://web.archive.org/web/20230326112622/https://valtioneuvosto.fi/en/marin/government-programme/strengthening-the-rule-of-law

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

### d) Government Action Plan for Gender Equality 2020–2023

The **2021 National Action Plan on Fundamental and Human Rights 2017-2019**[30] of the **Ministry of Social Affairs and Health** pledged **to protect intersex children** and to **abolish IGM practices**, *"6.4. Strengthen the right of self-determination of intersex children and discontinue cosmetic and medically non-essential genital surgical procedures on small children."*

### e) UNHRC48 Statement, 04.10.2021

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

> *"Intersex persons also need to be protected from **violence** and States must **ensure accountability** for these acts. […]*
>
> *Furthermore, there is also a need to take measures to protect the **autonomy** of intersex children and adults and their rights to health and to **physical and mental integrity** so that they live **free from violence and harmful practices**. Medically unnecessary surgeries, hormonal treatments and other invasive or irreversible non-vital medical procedures without their free, prior, full and informed consent are **harmful to the full enjoyment of the human rights** of intersex persons.*
>
> *We call on all member states to take measures to combat violence and discrimination against intersex persons, develop policies in close consultations with those affected, **ensure accountability**, reverse discriminatory laws and **provide victims with access to remedy**."* [31]

### f) UNHRC54 Statement, 04.10.2023

On occasion of the **54th Session of the Human Rights Council** the **State party** initiated a public follow-up statement reiterating the call to prohibit harmful practices and inhuman treatment and to ensure access to justice:

> *"4. Because their bodies are perceived as different, intersex persons, including children, face stigma, misconception and **violence, such as forced, coercive, irreversible and non-vital medical interventions.** These include so-called "normalising" surgeries that can have **life-long negative impacts on their physical and mental health.** These harmful practices **should be urgently stopped.** Human rights of intersex persons need to be respected, so that they can **live free from violence, cruel, inhuman, or degrading treatment and harmful practices.** […]*
>
> *8. We call on all States to increase efforts to combat violence, harmful practices and discrimination on the basis of sex characteristics, address their root causes, and **implement protective laws and policies in close consultations with those affected,** in order to ensure the full realization of human rights of intersex persons."*[32]

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30 Ministry of Social Affairs and Health (2021), "Making Finland a Global Leader in Gender Equality. Government Action Plan for Gender Equality 2020–2023", p. 46 (p. 47 in PDF), https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/162844/STM_2021_10_J.pdf

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

32 Statement initiated by Finland (and supported by 55 other States) during the 54th Session of the Human Rights Council on 4 October 2023, https://finlandabroad.fi/web/geneve/current-affairs/-/asset_publisher/h5w4iTUJhNne/content/general-debate-item-8/384951

## 4. Most Common IGM Forms advocated and perpetrated by Finland

Despite Finland's repeated pledges to end IGM, **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)**

While the 2016 Background Report of the **National Advisory Board on Social Welfare and Health Care Ethics (ETENE)**[33] (p. 6/p. 7 in PDF), reiterated in the **2019 Intersex Study** commissioned by the **Ministry of Justice**[34] (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.

Data on IGM procedures are scarce. Notably, the **2020 CCPR State Party Report** (CCPR/C/FIN/7, paras 108-114) also included some, though arguably partial (see below, p. 16, 17) numbers:

> *"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."*

Also, the **2019 Intersex Study**[35] commissioned by the Ministry of Justice **confirmed the ongoing practice** (p. 44/p. 50 in PDF):

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33 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

34 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

35 Ibid.

*"[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 [36]

The **Finnish Urological Association (Suomen Urologiyhdistys)** endorses the current **2023 Guidelines of the European Association of Urology (EAU)**, [37] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2023**[38] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:[39]

> *"The issue of whether gonads should be removed and the timining of such surgery remains controversial and has been altogether questioned in some forms of DSD. Patients with, for example, CAIS benefit from the presence of testicles and the resultant aromatisation of the naturally occuring testosterone to oestrogens. The risk of malignant gonadal transformation in this subcategory is low (1.5%) with cases of malignancy first appearing after the second decade of life, thus allowing for the safe deferal of gonadectomy until after puberty [1248, 1249]."*

Further, regarding *"whether and when to pursue gonadal or genital surgery"*,[40] the Guidelines refer to the ***"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"***,[41] which advocates "gonadectomies":

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

Also, the **"2016 Global Disorders of Sex Development Consensus Statement"**[42] 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)[43]:

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

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

38 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2023.pdf

39 Ibid., p. 94

40 Ibid., p. 93

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

42 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

43 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<br>– Self-examination<br>– Annual ultrasound (post-puberty)<br>Post-pubertal biopsy<br>– Based on ultrasound and results of first biopsy<br>– If CIS becomes GB → gonadectomy<br>Low threshold for gonadectomy if ambiguous genitalia | Bilateral gonadectomy at diagnosis | Low threshold for gonadectomy if ambiguous genitalia<br><br>If intact, gonadectomy depends on gender identity |
| Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders | Undescended testes – Orchiopexy with biopsy<br>– Self-examination<br>– Annual ultrasound (post-puberty)<br><br>Post-pubertal biopsy<br>– Bilateral, CIS → gonadectomy/irradiation<br>Repeat biopsy at 10 years of age<br>– Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation | Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy<br><br>Complete AIS – Postpubertal gonadectomy or follow-up<br>– GCC risk low, allow spontaneous puberty | Partial AIS and testosterone synthesis disorders – Bilateral biopsy<br><br>– Low threshold for gonadectomy<br>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**[44] 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", Dilation[45]

The **Finnish Urological Association (Suomen Urologiyhdistys)** endorses the current **2023 Guidelines of the European Association of Urology (EAU)**,[46] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2023**[47] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.17 *"Disorders of sex development"***,[48] despite admitting that *"Surgery that alters appearance is not urgent"*[49] and

44 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

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

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

47 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2023.pdf

48 Ibid., p. 89

that *"adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give informed consent"*,[50] 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"* [51] and making *"well-informed decisions [...] on their behalf"*, and further **explicitly refusing *"prohibition regulations"*** of unnecessary early surgery,[52] referring to the 2018 ESPU Open Letter to the Council of Europe (COE),[53] which further invokes **parents' *"social, and cultural considerations"*** as justifications for early surgery (p. 2).

Accordingly, the **2020 CCPR State Party Report** (CCPR/C/FIN/7, para 112) admitted 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:[54]

> *"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 (glucocorticol 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, Finnish medical homepages recommend early genital surgery for infants with CAH, for example:

> *"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."* [55]

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):

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49 Ibid., p. 93
50 Ibid., p. 93
51 Ibid., p. 93
52 Ibid., p. 94
53 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf
54 https://www.orpha.net/data/patho/Pro/other/SynnynnainenlisamunuaistenhyperplasiaFifiAbs648.pdf
55 http://laakarinkirja.info/tauti/congenitaalinen-lisamunuaisen-hyperplasia.html

*"4. Upper body and abdomen, genitals*

*a. congenital […]*

***ii. female genital abnormalities"*** [56]

### c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[57]

The **Finnish Urological Association (Suomen Urologiyhdistys)** endorses the current **2023 Guidelines of the European Association of Urology (EAU)**, [58] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2023**[59] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.6 *"Hypospadias"***, [60] the ESPU/EAU Guidelines' **section 3.6.5.3 *"Age at surgery"*** explicitly promotes, ***"The age at surgery for primary hypospadias repair is usually 6-18 (24) months."*** [61] – despite admitting to the *"risk of complications"* [62] and *"aesthetic[…]"* and *"cosmetic"* justifications.[63]

Accordingly, the **2020 CCPR State Party Report** (CCPR/C/FIN/7, para 112) admitted 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. 21-22).

Accordingly, **terveyskyla.fi**, *"a public online service developed by Finnish university hospitals"*, i.e. the **5 above-mentioned University Hospitals practicing IGM**, states on its homepage on ***"Lower urethral obstruction (hypospadias) in boys"***:[64]

> *"In Finland, **about 100 boys are born each year with hypospadias**."*
>
> ***"Hypospadias is treated with surgery.** However, mild hypospadias do not need to be treated. The aim of treatment is to **achieve a as normal penis as possible**, both functionally and cosmetically. Functionally, the aim is to achieve a sufficiently strong and forward flow of urine."*

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

57 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

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

59 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2023.pdf

60 Ibid., p. 27

61 Ibid., p. 29

62 Ibid., p. 28

63 Ibid., p. 28

64 https://www.terveyskyla.fi/lastentalo/tietoa-lasten-sairauksista/lasten-ja-nuorten-urologia/virtsaputken-alahalkio-(hypospadia)-pojilla

***"Hypospadias repair surgery***

***The most common age for corrective surgery is one year,*** *but it is possible to have the operation later, for example if the need for surgery is still being considered. The operation is performed under anaesthesia and lasts a few hours. The area is also anaesthetised, which reduces post-operative pain."*

Also, the **2019 Intersex Study**[65] 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):

*"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.*

65 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

*'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:[66]

*"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 Finnish *"paediatric surgery"* homepage of the **Tampere University Hospital (TAYS)**, states:[67]

*"Problems treated by paediatric surgery include: [...] **Congenital urinary and genital abnormalities"***

Further, the current Finnish *"hypospadias"* homepage of the **Tampere University Hospital (TAYS)** prescribes:[68]

*"Only the mildest forms of hypospadias, which have only a cosmetic disadvantage, can be left may not be operated on. 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:[69]

*"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."*

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66 https://www.hus.fi/en/treatments-and-examinations/pediatric-urology

67 https://www.pirha.fi/palvelut/sairaalat-tays/lasten-ja-nuorten-sairaalapalvelut/lastenkirurgia

68 https://www.pirha.fi/palvelut/sairaalat-tays/lasten-ja-nuorten-sairaalapalvelut/lastenkirurgia/virtsaputken-alahalkio

69 https://www.tyks.fi/hoidot-ja-tutkimukset/sukupuolielinten-synnynnaiset-hairiot

And the Finnish *“Division of labour (Annexe 2)”* of the **Kuopio University Hospital (KYS)** lists under *“Table 13: Demanding Surgery Concentration Plan 2014”* (p. 51):[70]

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

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):[71]

> ***“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)**[72] (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.[73]

## 5. Finnish Doctors and Government consciously dismissing Intersex Human Rights

The persistence of IGM practices in Finland is a **matter of public record**.[74]

However, **Finnish paediatric surgeons**, despite **openly admitting to knowledge of relevant criticisms** by intersex advocates, human rights and ethics bodies,[75] 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 repeatedly **pledging** to prevent IGM practices, so far **fails to take practical and legislative measures** to implement this pledge.

## 6. Lack of Independent Data Collection and Monitoring

With **no official 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”.

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70 https://web.archive.org/web/20220120091626/https://www.psshp.fi/documents/7796350/7871976/Liite2.pdf/d76808ff-6526-484d-8e2b-16af91e70e88

71 https://web.archive.org/web/20220120162115/https://www.forna.fi/images/PDF_tiedostot/Pinsetit/pinsetti_2012_3.pdf

72 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

73 Personal communication, 2020

74 See above p. 10-12

75 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

**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**"*) [76] and in the **records of the public health system (Care Register)** which reimburses all relevant IGM procedures.

**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, and would need to cover at least the following **NOMESCO codes**:[77]

**IGM 3**
KFC 10 Bilateral orchiectomy
LAE 20 Bilateral oophorectomy
LAE 21 Bilateral laparoscopic oophorectomy

**IGM 2**
LEE 40 Construction of vagina in sex transformation surgery
LEE 96 Other repair of vagina
LEW 96 Other operation on vagina
LEW 97 Other laparoscopic operation on vagina
LFC 00 Partial excision of vulva
LFC 96 Other partial excision of vulva or perineum
LFE 10 Plastic repair of vulva
LFE 96 Other repair of vulva or perineum
LFW 96 Other operation on vulva or perineum

**IGM 1**
KGH 20 Correction of induration or curvature of penis
KGH 60 Correction of hypospadia
KGH 80 Plastic repair of skin of penis
KGH 96 Other reconstructive operation on penis
KGW 96 Other operation on penis

## 7. 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.[78] So far, in Finland there was **no case** of a victim of IGM practices succeeding in going to court.

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76 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

77 NOMESCO (Nordic Medico-Statistical Committee) (2010), NOMESCO Classification of Surgical Procedures (NCSP), version 1.15, https://norden.diva-portal.org/smash/get/diva2:970547/FULLTEXT01.pdf

78 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.

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.[79]

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

79 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:*

**Intersex Genital Mutilation**

The Committee takes note of the Government initiatives pledging to protect intersex children. However, it remains seriously concerned about cases of unnecessary and irreversible surgery and other medical treatment on intersex children without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases (arts. 2, 12, 14 and 16).

**The Committee recommends that the State party:**

- **Ensure that the State party's legislation explicitly prohibits the performance of involuntary, deferrable surgical or other medical procedures on intersex infants and children;**
- **Extend the statute of limitations to enable criminal and civil remedies;**
- **Provide adequate counselling and support for families of intersex children;**
- **Provide health care and psychosocial support to intersex persons who have been subjected to involuntary procedures;**
- **Systematically collect disaggregated data with a view to understanding the extent of these harmful practices so that children at risk can be more easily identified and their abuse prevented.**

# Annexe 1 – 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)”*, [80] 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.*** [81]

## 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.[82]

In **regions without universal access to paediatric health care**, there are reports of **infanticide**[83] of intersex children, of **abandonment**,[84] of **expulsion**,[85] of **massive bullying** preventing the

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

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

82 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

83 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

84 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

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),[86] and of **murder**.[87]

Governing State bodies, public and private healthcare providers, national and international medical bodies and individual doctors have traditionally been **framing and "treating"** healthy intersex children as **suffering from a form of disability in the medical definition**, and in need to be **"cured" surgically**, often **with openly racist, eugenic and suprematist implications**.[88] [89] [90] [91]

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**,[92] 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.**[93] **UN Treaty bodies have so far issued 90 Concluding Observations condemning IGM practices accordingly.**[94]

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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

86 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

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

88 2014 CRC NGO Report, p. 52, 69, 84, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

89 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

90 "The Racist Roots of Intersex Genital Mutilations" https://stopigm.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

91 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

92 See "IGM Practices – Non-Consensual, Unnecessary Medical Interventions", ibid., p. 38–47

93 **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

94 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**[95] [96] 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,**[97] 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.[98] [99]

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

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"*,[104] *"a special provision on sexual orientation and*

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

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

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

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

99 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

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

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

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

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

104 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"* [105], transgender guidelines[106] or *"Gender Identity"* [107] [108] 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** [109] and public **representation.**[110]

### 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**[111] [112] [113] [114] – 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.**[115] [116] [117]

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105 CCPR120 Switzerland, https://stopigm.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120

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

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

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

109 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

110 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

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

112 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, https://stopigm.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

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

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

116 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

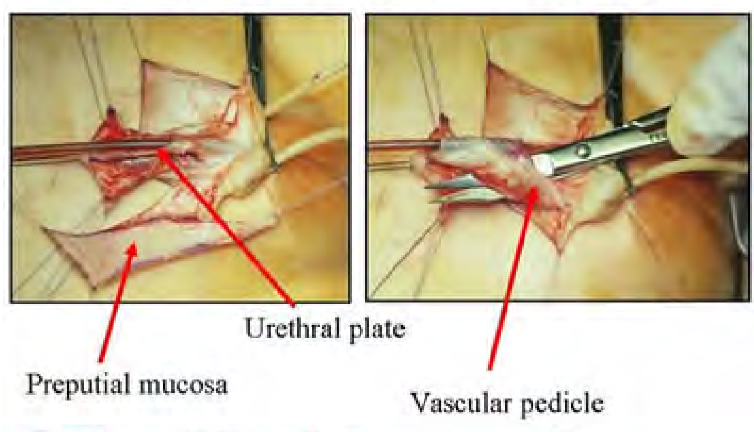
117 For example Ministry of Health Austria (2019), see 2019 CRC Intersex NGO Report (for Session), p. 4-5, https://intersex.shadowreport.org/public/2019-CRC-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf

## Annexe 2 – “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 / Duckett - results

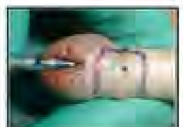
- Elbakry (BJUI 88: 590-595, 2001): 42% complications
  - 5 breakdowns (7%)
  - 17 fistulæ (23%)
  - Urethral strictures (9%)
  - Urethral diverticulæ (4%)
- Asopa / Duckett tube
  - 3.7% (El-Kasaby J Urol 136: 643-644, 1986)
  - 69% (Parsons BJU 25: 186-188, 1984)
  - 15% (Duckett - 1986)

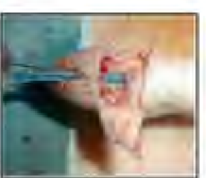
- No standardized procedures
- Personal experience of the surgeon
- Importance of a uro-endocrine approach of complex cases to increase the healing abilities of the penile tissues

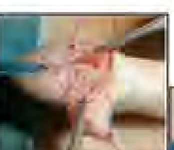
**Official Diagnosis "Hypospadias Cripple"**
**= made a "cripple" by repeat cosmetic surgeries**

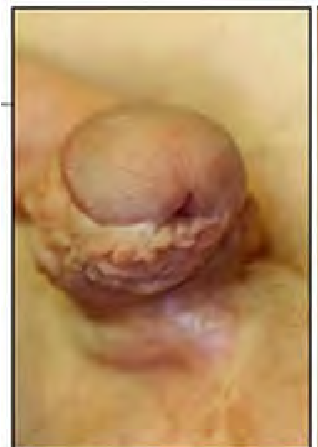
## Treatment of isolated fistulæ

- 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

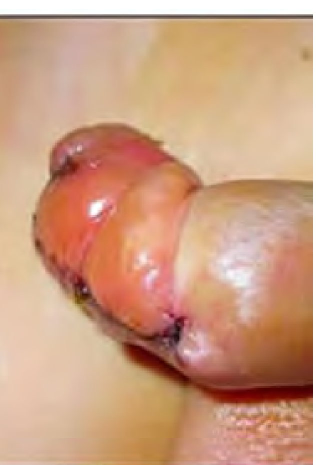








Bad cosmetic result



infection

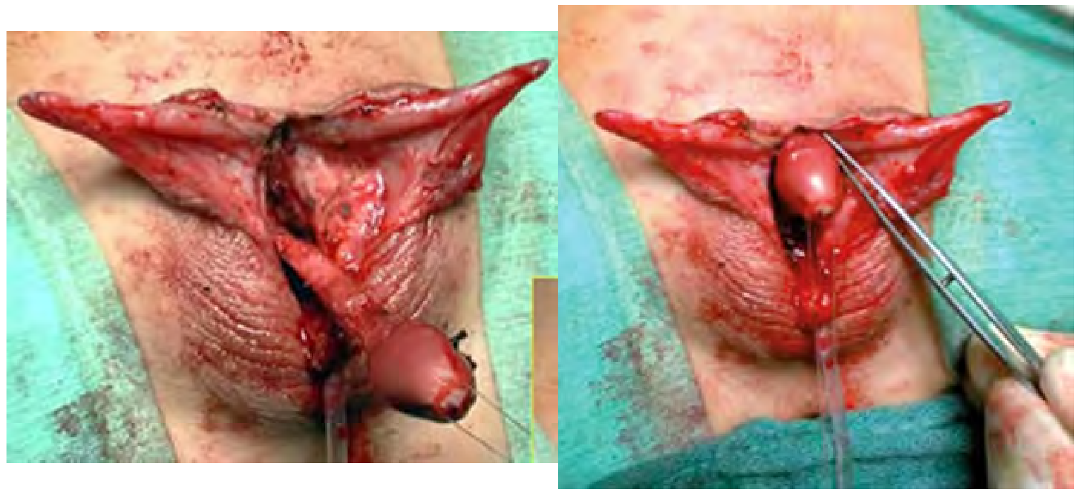
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

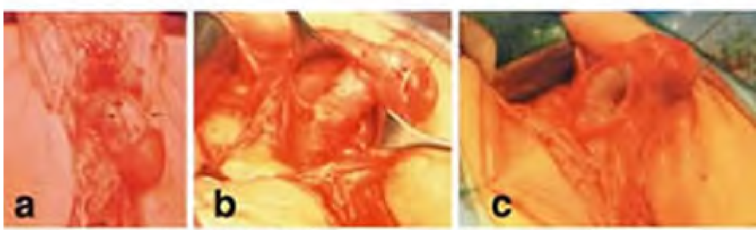
**Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include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

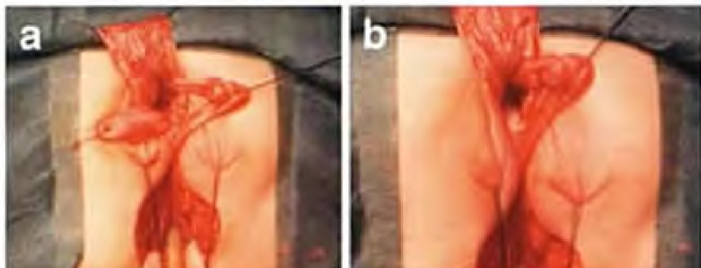


**Source:** Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004

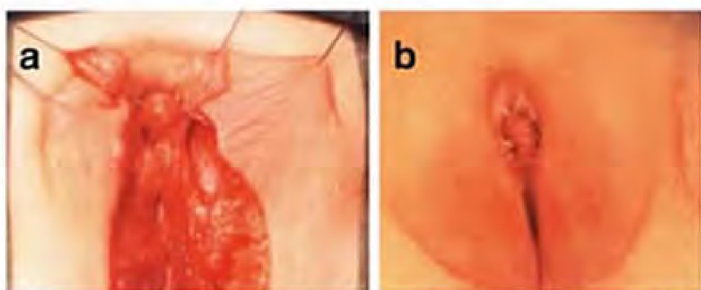
10. Indikationen und Ergebnisse von Korrekturoperationen beim inters[…]



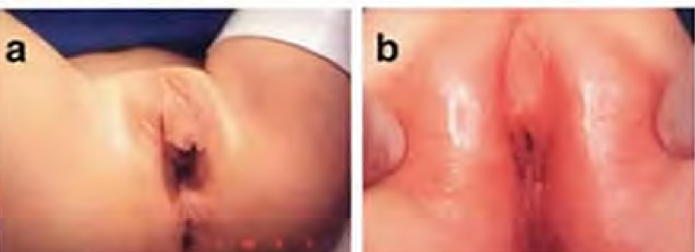

***6a-c:*** Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).




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



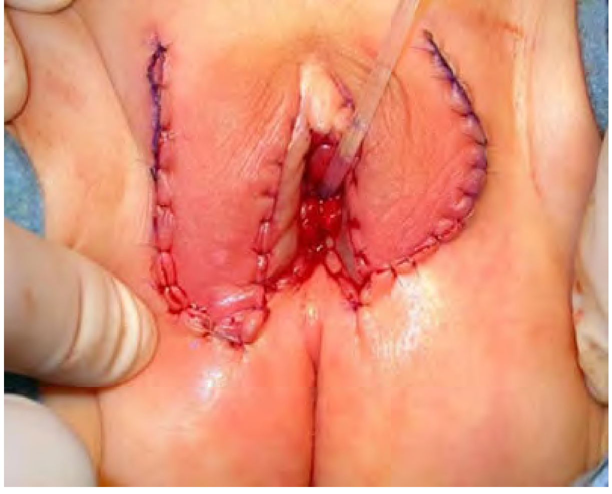

***8a+b:*** Refixation der Corpora cavernosa clitoridis. "Materialknappheit" bei der Rekon[…]
[…]n clitoridis und der kleinen Labien.




***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 praeputium clitoridis and the inner labia.***



**Source:** Pierre Mouriquand: "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

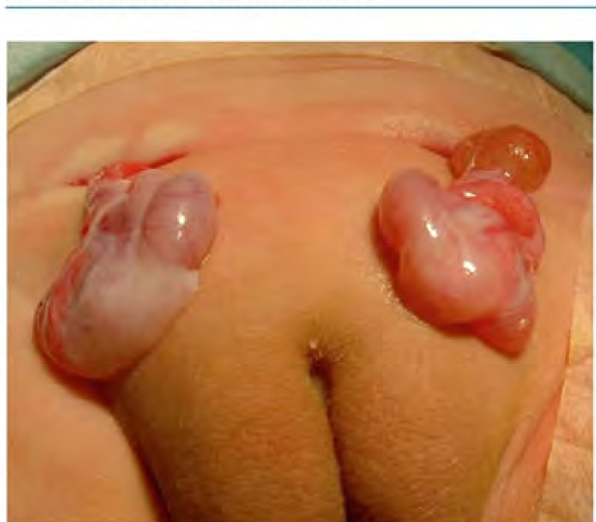


**Fig. 91.6** An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

**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

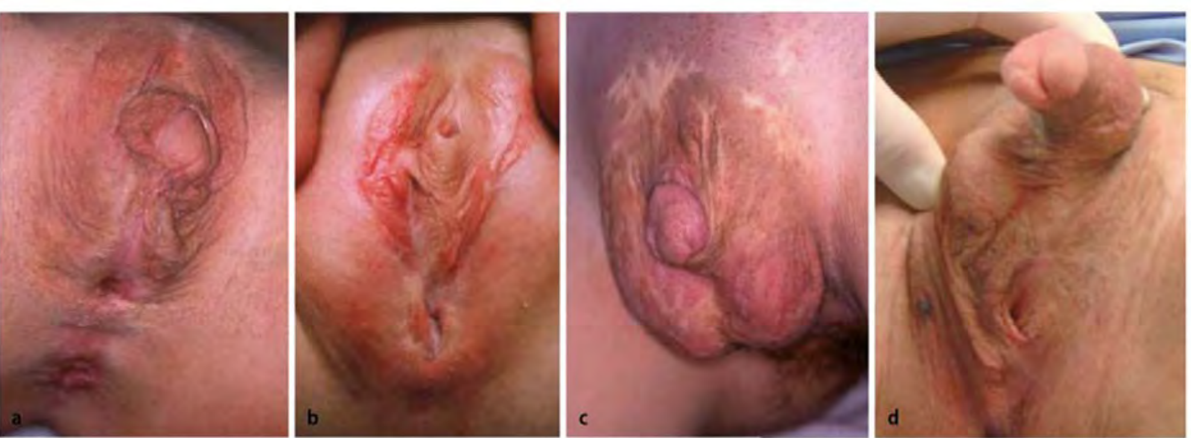
| Risk | Type of DSD | Preva-lence % |
|---|---|---|
| High | GD in general | 12* |
| | 46,XY GD | 30 |
| | Frasier syndrome | 60 |
| | Denys-Drash syndrome | 40 |
| | 45,X/46,XY GD | 15–40 |
| Intermediate | PAIS | 15 |
| | 17β-hydroxysteroid dehydrogenase deficiency | 17 |
| Low | CAIS | 0.8 |
| | Ovotesticular DSD | 2.6 |
| Unknown | 5α-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.

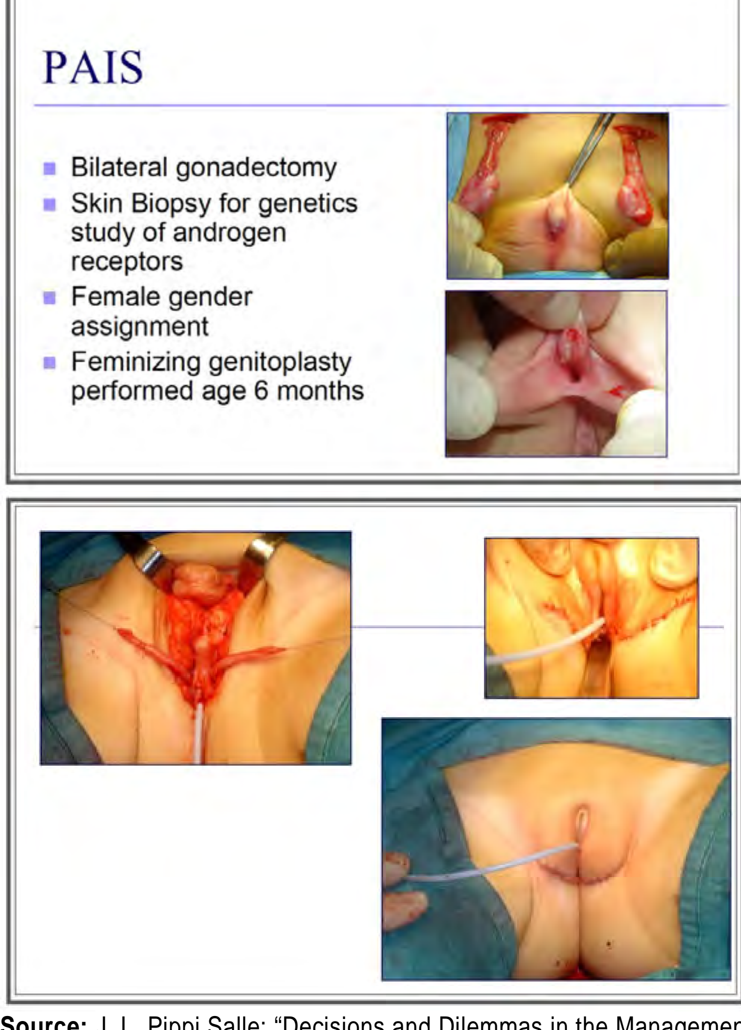
**Source:** J. Pleskacova, R. Hersmus, J. Wolter Oosterhuis, B.A. Setyawati, S.M. Faradz, Martine Cools, Katja P. Wolffenbuttel, J. Lebl, Stenvert L.S. Drop, Leendert H.J. Looijenga: "Tumor risk in disorders of sex development," in: *Sexual Development* 2010 Sep;4(4-5):259-69.

**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”




**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.




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