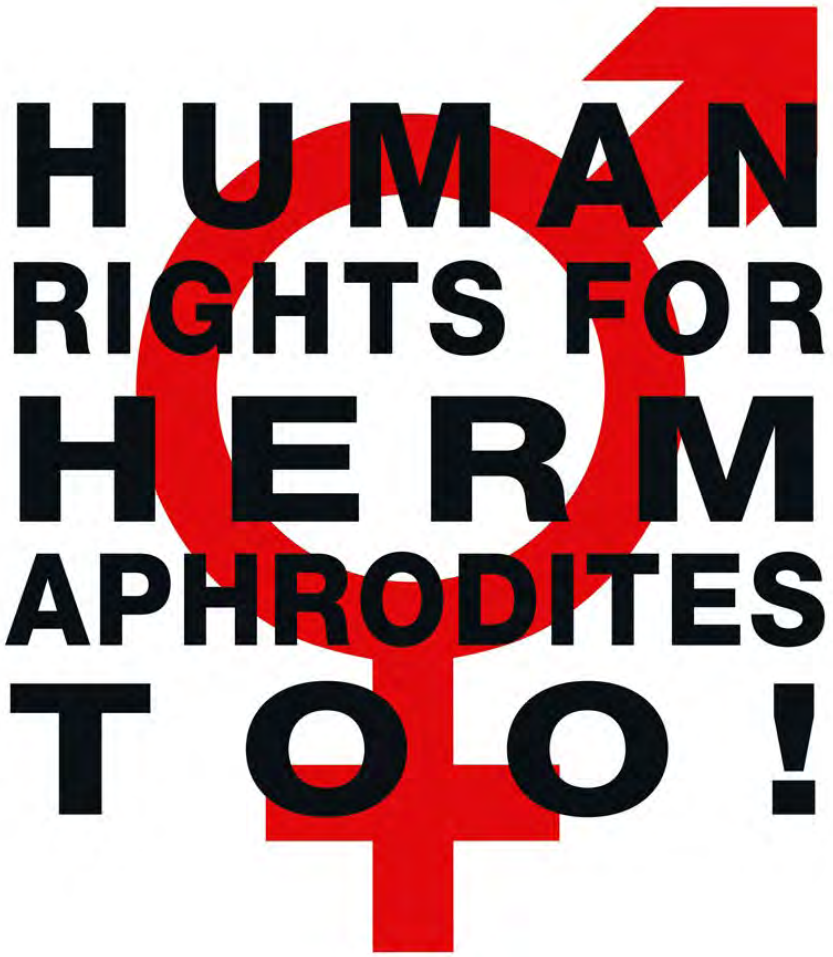
# Intersex Genital Mutilations

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




NGO Report (for LOIPR)
to the 6th to 7th Report of Sweden on the
Convention on the Rights of the Child (CRC)

## Compiled by:

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http://intersex.shadowreport.org/public/2020-CRC-Sweden-LOIPR-NGO-Zwischengeschlecht-Intersex-IGM.pdf

## Executive Summary

**All typical forms of Intersex Genital Mutilation are still practised in Sweden**, facilitated and **paid for by the State party** via the **public health system.** Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and **denied appropriate support.** Despite having **incorporated CRC into law**, and **repeated calls by Government agencies** to protect intersex children, **Sweden fails to do so**.

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

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

In total, UN treaty bodies **CRC, CEDAW, CAT, CCPR** and **CRPD** have so far issued **49 Concluding Observations** recognising **IGM** as a **serious violation of non-derogable human rights**, typically obliging State parties to **enact legislation** to **(a)** end the practice and **(b)** ensure redress and compensation, plus **(c)** access to free counselling. Also, the UN Special Rapporteurs on Torture (**SRT**) and on Health (**SRH**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**), the Inter-American Commission on Human Rights (**IACHR**), the African Commission on Human and Peoples' Rights (**ACHPR**) and the Council of Europe (**COE**) recognise IGM as a **serious violation of non-derogable human rights.**

**Intersex people** are born with **Variations of Reproductive Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations.

**IGM practices** include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures** that would not be considered for "normal" children, without evidence of benefit for the children concerned. **Typical forms of IGM** include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, involuntary human experimentation and denial of needed health care.

IGM practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, and less sexual activity.

For more than **25 years**, intersex people have denounced IGM as **harmful** and **traumatising**, as western **genital mutilation**, as **child sexual abuse** and **torture**, and called for **remedies**.

This **NGO Report** has been compiled by **StopIGM.org / Zwischengeschlecht.org**, an international intersex NGO. It contains **Suggested Questions** (see p. 13).

**NGO Report (for LOIPR)**
**to the 6th to 7th Report of Sweden**
**on the Convention on the Rights of the Child (CRC)**

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# IGM Practices in Sweden (p. 5-13)

# A. Introduction

## 1. Sweden: Intersex, IGM and Human Rights

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

In January 2020, Sweden has **incorporated the Convention as a whole** into Swedish law.

In 2017, the **Swedish National Board of Health and Welfare** and the **Swedish National Council on Medical Ethics** published reports confirming and criticising the ongoing IGM practices in Sweden.

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Sweden** – advocated, facilitated and **paid for by the State party** via the **public health system** under the responsibility of the **Ministry of Health and Social Affairs** and the **Regional Councils** – constitute a **serious breach** of Sweden'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!"* [2] According to its charter,[3] 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,[4] substantially contributing to the so far 49 Treaty body Concluding Observations recognising IGM as a serious human rights violation.[5]

In addition, the Rapporteurs would like to acknowledge the work of **Jameson Garland**.[6] [7]

## 3. Methodology

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

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1 **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

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

3 http://zwischengeschlecht.org/post/Statuten

4 http://intersex.shadowreport.org

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

6 Milton Diamond, Jameson Garland (2013), Evidence regarding cosmetic and medically unnecessary surgery on infants, Journal of Pediatric Urology (2014) 10, 2-7, https://www.hawaii.edu/PCSS/biblio/articles/2010to2014/2013-evidence.html

7 Jameson Garland (2018), The Legal Status of Intersex Persons in Sweden, in: Jens M. Scherpe, Anatol Dutta and Tobias Helms (ed.), The Legal Status of Intersex Persons, Cambridge, p. 255-280

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

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

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

In **Sweden**, same as in *Denmark* (CRC/C/DNK/CO/5, paras 24+12; CAT/C/DNK/CO/6-7, paras 42-43), the *United Kingdom* (CRC/C/GBR/CO/5, paras 46-47; CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41; CAT/C/GBR/CO/6, paras 64-65), *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 34-35; CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f), *Switzerland* (CRC/C/CHE/CO/2-4, paras 42-43; CEDAW/C/CHE/CO/4-5, paras 38-39; CAT/C/CHE/CO/7, para 20; CCPR/C/CHE/CO/4, paras 24-25), and in **many more State parties,**[9] there are

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

Despite calls to action also by the **National Board of Health and Welfare** (see p. 11) and the **Swedish National Council on Medical Ethics** (see p. 11), to this day the Government refuses to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to ***"take effective legislative, administrative, judicial or other measures"* to protect intersex children from harmful practices**.

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

**To this day, in Sweden 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 Health and Social Affairs** and the **Regional Councils**.

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

#### a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones [10]

The **Swedish Urology Association (Svensk Urologisk Förening)** is associated with the European Association of Urology (EAU)[11] which in turn is affiliated with the European Society for Paediatric Urology (ESPU).[12] The ***"ESPU/SPU standpoint on the surgical management of***

9 Currently we count **49 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see: http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

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

11 The Swedish Urology Association also endorses all EAU Guidelines, see current 2019 EAU Guidelines, p. 5, https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines

12 The Swedish Urology Association also endorses the ESPU/EAU "Paediatric Urology" Guidelines included in the EAU Guidelines, see ibid., p. 5

***Disorders of Sex Development (DSD)"***[13] 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",**[14] which is co-authored by paediatric endocrinologist Anna Nordenström (Women's and Children's Health, Karolinska Institutet, Karolinska University Hospital, Stockholm) and refers to the *"ESPU/SPU standpoint"*, advocates *"gonadectomy"* – even when admitting *"low"* cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)[15].

**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>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>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>Complete AIS – Postpubertal gonadectomy or follow-up<br>– GCC risk low, allow spontaneous puberty | Partial AIS and testosterone synthesis disorders – Bilateral biopsy<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

**Gonadectomies** on intersex persons diagnose with CAIS and their **known negative consequences** are also reported from Sweden in a **2017 medical publication** out of the **Karolinska University Hospital Stockholm**:[16]

> *"There are several case reports showing decreased vitality after gonadectomy in women with CAIS [7]. This is also our clinical impression. […] In our material, 16 out of 20 women with CAIS had been gonadectomized. […] Prospective studies would provide more information about the risk and/or potential benefit of not performing a gonadectomy in CAIS."*

13 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

14 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

15 Ibid., at 180 (fn 111)

16 Hedvig Engberg, Anna Strandqvist, Anna Nordenström, Agnieszka Butwicka, Agneta Nordenskjöld, Angelica Lindén Hirschberg, Louise Frisén (2017), Increased psychiatric morbidity in women with complete androgen insensitivity syndrome or complete gonadal dysgenesis, Journal of Psychosomatic Research 101 (2017), p. 122-127, here p. 124, https://www.sciencedirect.com/science/article/pii/S0022399917302404

### b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation[17]

The **Swedish Urology Association (Svensk Urologisk Förening)** endorses the current **2019 Guidelines of the European Association of Urology (EAU)**,[18] which (see p. 14) include the current **2019 ESPU/EAU *"Paediatric Urology"* Guidelines**[19] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.16 *"Disorders of sex development"***,[20] despite admitting that *"Surgery that alters appearance is not urgent"* [21] and that *"adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent"*,[22] 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,[23] referring to the 2018 ESPU Open Letter to the Council of Europe (COE), [24] which further invokes **parents' *"social, and cultural considerations"*** as justifications for early surgery (p. 2).

Accordingly, the **current CAH Guideline**[25] published by the **Swedish Paediatric Society (Svenska Barnläkarföreningen BLF)** and authored by paediatricians from the Department of Women's and Children's Health of the **Karolinska University Hospital** note in the section on ***"Surgical treatment of girls with virilisation"*** that *"surgery has been called into question"* and *"[t]he timing of surgery has also been discussed, among other things, with the argument that the girl herself should be able to help determine when irreversible cosmetic surgery is done"*, but admit that nonetheless **early *"feminising surgery of genitalia for CAH"* are still practiced in Sweden**, including ***"Clitoral Surgery"***, ***"Vulva Surgery"*** and ***"Vaginal Surgery"***, including *"during the infant years"*.

Also, the parent's association **"National Association for Congenital Adrenal Hyperplasia (Riksföreningen för CAH)"** recommends on their homepage:

> ***"Surgical treatment***
>
> *Girls with CAH often need surgery in their external genitals. A first operation, a reduction of the clitoris, is done as early as possible, preferably before the child is 6 months. When the girls have reached puberty, the labia and the slide opening are operated, if necessary. On trial, you try to operate completely already before the age of 2. As adults, girls can have a normal life*

17 For general information, see 2016 CEDAW NGO Report France, p. 48. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
18 See p. 5, https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines
19 https://uroweb.org/guideline/paediatric-urology/
20 https://uroweb.org/guideline/paediatric-urology/#3_16
21 https://uroweb.org/guideline/paediatric-urology/#3_16_4
22 Ibid.
23 Ibid.
24 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf
25 Anna Nordenström, Martin Ritzén (2016), BLF's delförening för endokrinologi och diabetes, Vårdprogram för kongenital binjurebarkhyperplasi CAH (adrenogenitalt syndrom, AGS), https://endodiab.barnlakarforeningen.se/wp-content/uploads/sites/9/2015/02/VP_2016-CAH.pdf

*together. They can have their own healthy children if they are well disposed to their treatment. Sometimes girls get problems, especially psychologically, because they think they look different in the genital area."*

And the **current DSD Guidelines**[26] published by the **Swedish Paediatric Society (Svenska Barnläkarföreningen BLF)** prescribe **early "feminising" surgery**:

***"Surgical treatment of girls***

*[…] Feminizing surgery (clitoris and vaginal plastic surgery) in case of pronounced virilisation should be performed at the age of 2-6 months. The procedure requires a surgeon with good experience in genital surgery. In case of mild or moderate clitoral hypertrophy, clitoral resection does not need to be performed and then any vaginal plastic may be delayed until puberty."*

Also, the **National Board of Health and Welfare (Socialstyrelsen)** in its 2017 **Report "Care and Treatment of Persons with Intersex Conditions: Mapping early care"**[27], based on interviews with Swedish medical practitioners, confirmed that **partial clitoris amputation and "vaginoplasty"** is still performed **in the first year of life** (p. 59, 76).

### c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[28]

The **Swedish Urology Association (Svensk Urologisk Förening)** endorses the current 2019 Guidelines of the European Association of Urology (EAU),[29] which include the current 2019 ESPU/EAU *"Paediatric Urology"* Guidelines[30] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) (see p. 14). In **chapter 3.5 *"Hypospadias"***,[31] 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."*** [32] – despite admitting to the *"risk of complications"* [33] and *"aesthetic[…]"* and *"cosmetic"* justifications.[34]

A **2017 medical dissertation *"Hypospadias Surgery. Clinical Aspects and Outcomes"*** [35] out of the Department for Paediatric Surgery of the **Skåne University Hospital** in Lund describes the known negative consequences of hypospadias "repair" (p. 30-31, 78):

*"Hypospadias surgery is beset with difficulty and complications. […] The term hypospadias cripple describes those patients who are affected by the greatest incidence of multiple*

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26 Handlingsprogram för Barnläkare Disorders of sex development, DSD, "Intersex", https://endodiab.barnlakarforeningen.se/wp-content/uploads/sites/9/2015/02/VP_2007_DSD_nationellt.pdf

27 "Vård och behandling av personer med intersexuella tillstånd: Kartläggning av det tidiga omhändertagandet", https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2017-1-24.pdf

28 For general information, see 2016 CEDAW NGO Report France, p. 48-49. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

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

30 https://uroweb.org/guideline/paediatric-urology/

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

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

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

34 Ibid.

35 Ann Nozohoor Ekmark (2017), Hypospadias Surgery. Clinical Aspects and Outcomes, medical dissertation, Lund University, Faculty of Medicine, https://portal.research.lu.se/portal/en/publications/hypospadias-surgery-clinical-aspects-and-outcomes(57677aae-79f2-4804-92ca-3918a37ba74a).html

*complications and failed repairs, in whom the penis may be scarred, hypovascular, and shortened. […]*

*Hypospadias patients might also have lower levels of sexual satisfaction with lower frequencies of ejaculation and orgasmic sensations and more frequent erectile problems compared with controls."*

The dissertation from the **Skåne University Hospital** further notes **controversies about early surgery** (p. 30):

***"Timing of hypospadias surgery***

*International expert recommendations suggest surgery of the male genitalia between the ages of 6 months and 18 months. This recommendation is based on surgical and anaesthetic considerations and on psychological considerations such as genital awareness and cognitive, emotional, and psychosexual development. However, there has been scant evidence to support these recommendations, and a more recent study did not support them. There is also rising support among patient groups for delaying aesthetic genital surgeries in cases of minor hypospadias without functional impairment until the patient himself is at an appropriate age to give informed consent."*

However, the **homepage of the Skåne University Hospital** prescribes under *"Surgical reconstruction of the urethra for boys (Hypospadias)"*:[36]

***"Surgery occurs either at an early age or at 4-5 years of age."***

Also, a **leaflet *"Hypospadias"*** [37] of the *"Urology Centre for children and adolescents"* of the **Uppsala University Hospital** prescribes early surgery:

***"Treatment of hypospadias***

*At a few months of age, the boy is usually called to a reception visit to see a paediatric urologist who will determine if the penis needs surgery**. If surgery is needed, this occurs at one to two years of age.** The purpose of the operation is to move the urethra to its proper place and straighten out any. crookedness. **Sometimes repeated operations are needed.**"*

And the **current DSD Guidelines**[38] published by the **Swedish Paediatric Society (Svenska Barnläkarföreningen BLF)** prescribe **early hypospadias "repair"**:

***"Surgical treatment of boys***

*Masculinising surgery is done at 6-18 months of age with erection of the penis and urethraplasty. In some cases, also surgery for retentio testis, bifid scrotum, or extirpation of Mullerian duct remnants."*

Also, the **National Board of Health and Welfare (Socialstyrelsen)** in its 2017 **Report "Care and Treatment of Persons with Intersex Conditions: Mapping early care"** [39], based on

36 https://vard.skane.se/skanes-universitetssjukhus-sus/undersokningar-och-behandlingar/kirurgisk-rekonstruktion-av-urinroret-pa-pojkar-hypospadi/

37 https://www.akademiska.se/contentassets/038f27c51fc04ed4ba4364eb1e3d99db/hypospadi.pdf

38 Handlingsprogram för Barnläkare Disorders of sex development, DSD, "Intersex", https://endodiab.barnlakarforeningen.se/wp-content/uploads/sites/9/2015/02/VP_2007_DSD_nationellt.pdf

39 "Vård och behandling av personer med intersexuella tillstånd: Kartläggning av det tidiga omhändertagandet", https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2017-1-24.pdf

interviews with Swedish medical practitioners, confirmed that **hypospadias "repair"** is still performed **in the first year of life, or before 4 ½ years** (p. 60).

## 3. The Swedish Government refuses to act

Sweden has not only ratified the Convention on the Rights of the Child, but as of **January 2020**, **CRC was also incorporated as a whole into Swedish law**.[40]

The **National Board of Health and Welfare (Socialstyrelsen)** is a Government agency under the *Ministry of Health and Social Affairs*. In 2017 it published a **Report "Care and Treatment of Persons with Intersex Conditions: Mapping early care"**[41] ("Vård och behandling av personer med intersexuella tillstånd: Kartläggning av det tidiga omhändertagandet"), based amongst other things on analysis of the relevant current medical Guidelines issued by the *Swedish Paediatric Society (Svenska Barnläkarföreningen BLF)* (see above) and on interviews with medical practitioners, parents and persons concerned. **The Report confirmed that unnecessary genital surgery on intersex children based on psychosocial and cultural indications is still taking place in Swedish "DSD Centres"**, namely

- **partial clitoris amputation and "vaginoplasty" in the first year of life** (p. 59, 76)
- **hypospadias "repair" in the first year of life or before 4 ½ years** (p. 60)

The **Swedish National Council on Medical Ethics (Statens Medicinsk-Etiska Råd SMER)** is a national body with an independent status affiliated with the *Ministry of Health and Social Affairs* who has the objective of advising the Swedish Government and Parliament on ethical biomedical issues. In 2017 SMER published a **Comment 2017:2 "The care of intersex children – ethical aspects of early surgical procedures"**[42] (Kommenterar 2017:2 "Vården av intersexuella barn – etiska aspekter på tidiga kirurgiska ingrepp"), which stated:

> ***"SMER's Comment***
>
> ***About early surgery***
>
> *Surgical procedures should not be done without a medical indication or on a weak indication with a lack of knowledge. However, the scientific evidence in the field is currently considered insufficient to provide guidance in decision-making on early surgical procedures. […]*
>
> ***SMER's assessment***
>
> *SMER emphasises that early surgical procedures may only be done when medically justified. Like ETENE [the Finnish National Advisory Board on Social Welfare and Health Care Ethics], SMER believes that interventions aimed at normalising external sex markers should not be carried out before the child can participate in decision-making. It is important to protect all children's rights to bodily integrity. […] Today, healthcare personnel and parents make decisions on sex of rearing and interventions […]. Support efforts to alleviate psychosocial pressure for early surgery are important."*

40 Act (2018:1197) on the Convention on the Rights of the Child (Lag (2018:1197) om Förenta nationernas konvention om barnets rättigheter)

41 https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2017-1-24.pdf

42 http://www.smer.se/wp-content/uploads/2017/03/Smer-kommenterar-2017_2-V%C3%A5rden-av-intersexuella-barn-etiska-aspekter-p%C3%A5-tidiga-kirurgiska-ingrepp3.pdf

However, despite these calls to action even from Government agencies, to this day the **Swedish Government refuses to act** to effectively protect intersex children from **harmful practices** – while at the same time, **in Sweden all forms of IGM practices persist**, 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 Health and Social Affairs** and the **Regional Councils**.

## 4. Lack of Independent Data Collection and Monitoring

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

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

Also in **Sweden** 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.[43] So far, in Sweden there was **no case** of a victim of IGM practices succeeding in going to court, despite survivors criticising the practice in public.

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

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

## C. Suggested Questions for the LOIPR

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

**Harmful practices: Intersex Genital Mutilation**

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

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

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

### a) Harmful Practice (art. 24(3) and JGC No. 18) [44]

**Article 24 para 3 CRC** calls on states to abolish harmful *"traditional practices prejudicial to the health of children"*. While the initial point of reference for the term was the example of Female Genital Mutilation/Cutting (FGM/C), the term consciously wasn't limited to FGM/C, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.[45]

**This Committee has repeatedly considered IGM as a harmful practice, and the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices as applicable.**[46]

Also **CEDAW** has repeatedly considered IGM as a **harmful practice**, and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 on harmful practices as applicable.[47]

Harmful practices (and inhuman treatment) have been identified by intersex advocates as the **most effective, well established and applicable human rights frameworks** to eliminate IGM practices and to end the impunity of the perpetrators.[48]

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

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

*"Data collection and monitoring"* (paras 37–39)

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

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

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44 For a more extensive version, see 2017 CRC Spain NGO Report, p. 12-13, http://intersex.shadowreport.org/public/2017-CRC-Spain-NGO-Brujula-Zwischengeschlecht-Intersex-IGM.pdf

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

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

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

48 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: http://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

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

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

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

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

### b) Violence against Children (art. 19 and GC No. 13) [49]

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

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

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

Accordingly, with regards to IGM practices, and referring to Article 24 para 3 and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31, CRC repeatedly recognised the obligation for State parties to ***"[e]nsure that the State party's legislation prohibits all forms of harmful practices [including intersex genital mutilation]"***,[50] as well as to ***"ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned"***,[51] and to *"[u]ndertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and **adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation"***.[52]

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49 For a more extensive version with sources, see 2016 CRC UK Thematic NGO Report, p. 57, http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

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

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

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

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

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

However, also in **Sweden** the **statutes of limitation** prohibit survivors of early childhood IGM practices to call a court, because persons concerned often **do not find out** about their medical history until much later in life, and **severe trauma** caused by IGM practices often prohibits them to act in time even once they do.[53] So far there was no case of a victim of IGM practices succeeding in going to an Swedish court.

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

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

### 1. Intersex = variations of reproductive anatomy

**Intersex persons**, in the vernacular also known as hermaphrodites, or medically as persons with *"Disorders"* or *"Differences of Sex Development (DSD)"*, [54] 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.***[55]

### 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.[56]

In **regions without universal access to paediatric health care**, there are reports of **infanticide**[57] of intersex children, of **abandonment**,[58] of **expulsion**,[59] of **massive bullying** preventing the

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

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

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

57 For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, http://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf
For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12, http://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf
For South Africa, see also https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens
For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda ; for Uganda, see also 2015 CRC Briefing, slide 46, http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf
For Kenya, see also http://www.bbc.com/news/world-africa-39780214
For Mexico, see 2018 CEDAW NGO Joint Statement, http://stop.genitalmutilation.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018

58 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda
For example in China, see 2015 Hong Kong, China NGO Report, p. 15, http://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf

59 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),[60] and of **murder**.[61]

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**.[62] [63] [64] [65]

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**,[66] 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.[67] UN Treaty bodies have so far issued 49 Concluding Observations condemning IGM practices accordingly.[68]**

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60 For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see http://stop.genitalmutilation.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3

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

62 2014 CRC NGO Report, p. 52, 69, 84, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

63 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

64 "The Racist Roots of Intersex Genital Mutilations" http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

65 For 500 years of "scientific" prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

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

67 **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

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

## 3. Intersex is NOT THE SAME as LGBT or Transgender

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

The underlying reasons for such harmful misrepresentations include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**[69] [70] 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,**[71] 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.[72] [73]

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"*,[74] and again IGM survivors as *"transgender children"*,[75] *"transsexual children who underwent difficult treatments and surgeries"*, and IGM as a form of *"discrimination against transgender and intersex children"* [76] and as *"sex assignment surgery"* while referring to *"access to gender reassignment-related treatments"*.[77]

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

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

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

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

72 For example ACHPR Commissioner Lawrence Murugu Mute, see http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT

73 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

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

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

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

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

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

*gender identity"*, *"civil registry"* and *"sexual reassignment surgery"* [79], transgender guidelines[80] or *"Gender Identity"* [81] [82] 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** [83] and public **representation**.[84]

## 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** [85] [86] [87] [88] – 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.**[89] [90]

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

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

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

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

83 For example in Scotland (UK), LGBT organisations have so far collected at least **£ 135,000.–** public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf
Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as "supporting intersex people", but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

84 See e.g. "Instrumentalizing intersex: 'The fact that LGBTs in particular embrace intersex is due to an excess of projection' - Georg Klauda (2002)", http://stop.genitalmutilation.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002

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

86 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

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

89 For example Ministry of Health Chile (2016), see http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile

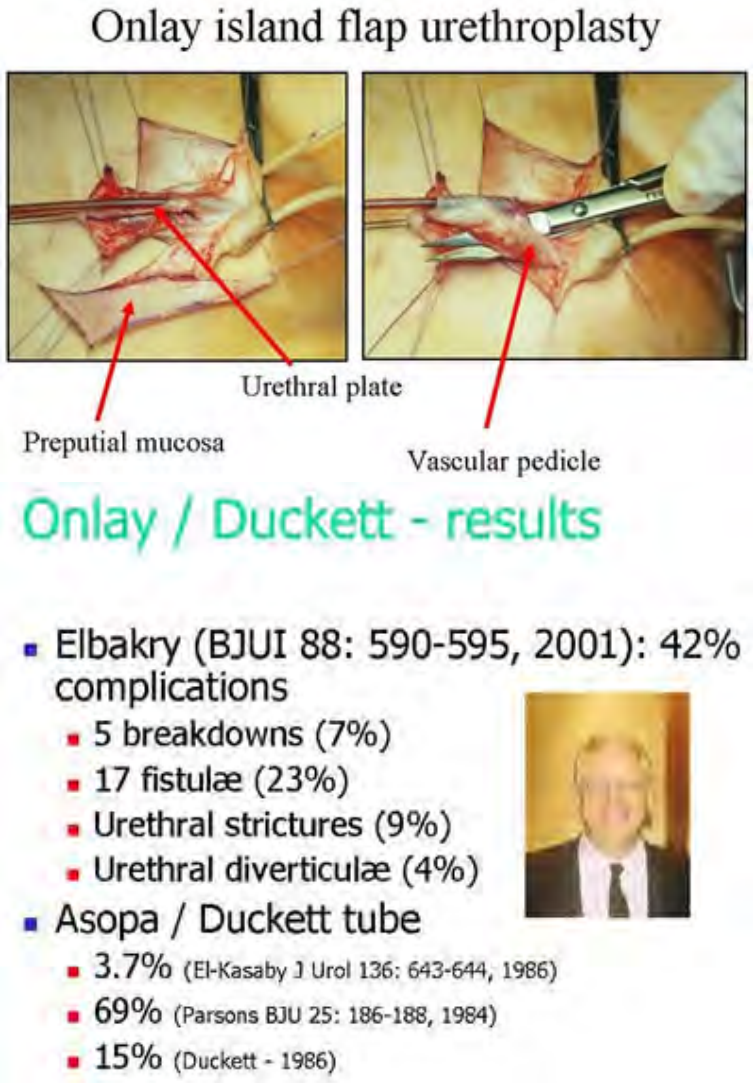
90 For example Ministry of Health Austria (2019), see 2019 CRC Intersex NGO Report (for Session), p. 4-5, http://intersex.shadowreport.org/public/2019-CRC-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf

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

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

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

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



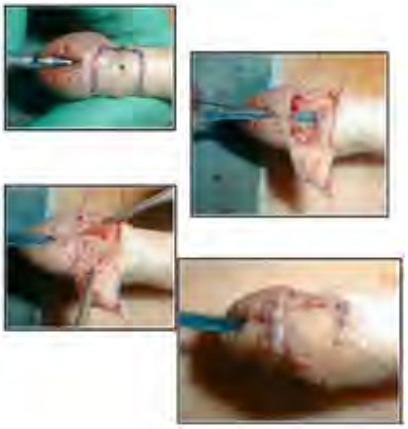
## Hypospadias - Procedures for cripple hypospadias

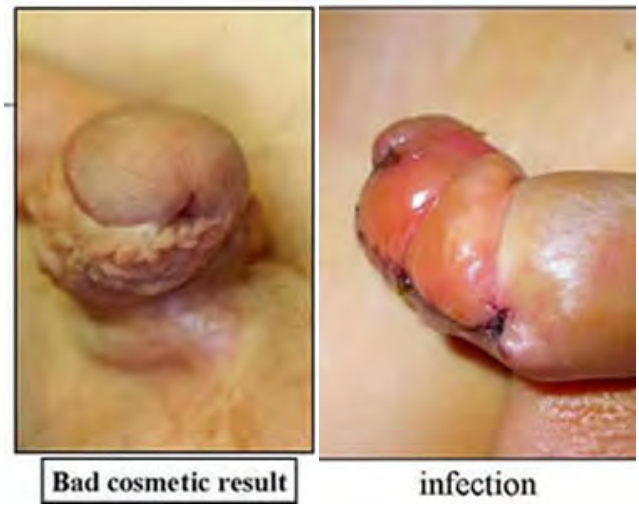
- No standardized procedures
- Personal experience of the surgeon
- Importance of a uro-endocrine approach of complex cases to increase the healing abilities of the penile tissues

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

## Treatment of isolated fistulæ

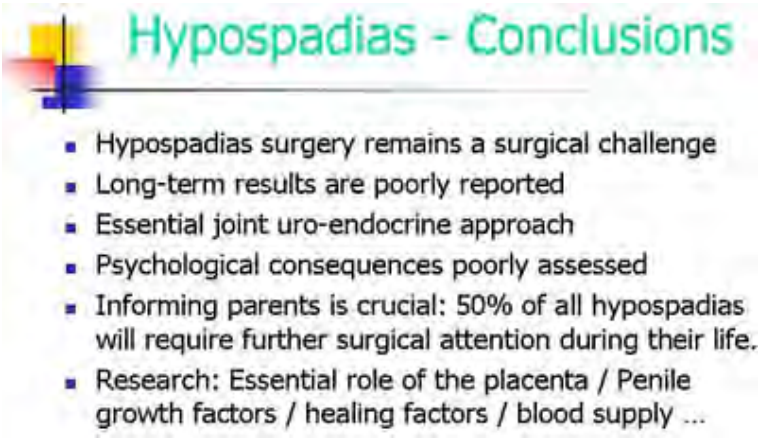
- Rectangular skin incision around the fistula orifice, often lateral
- Dissection and excision of the fistula tract
- Urethral suture
- Multilayer cover with well-vascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
-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





Bad cosmetic result

infection

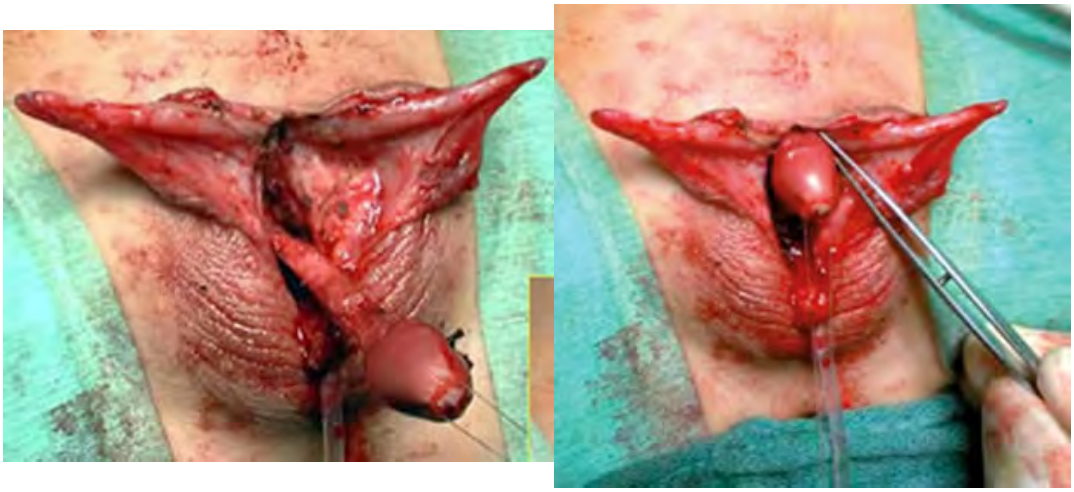



**Source:** Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

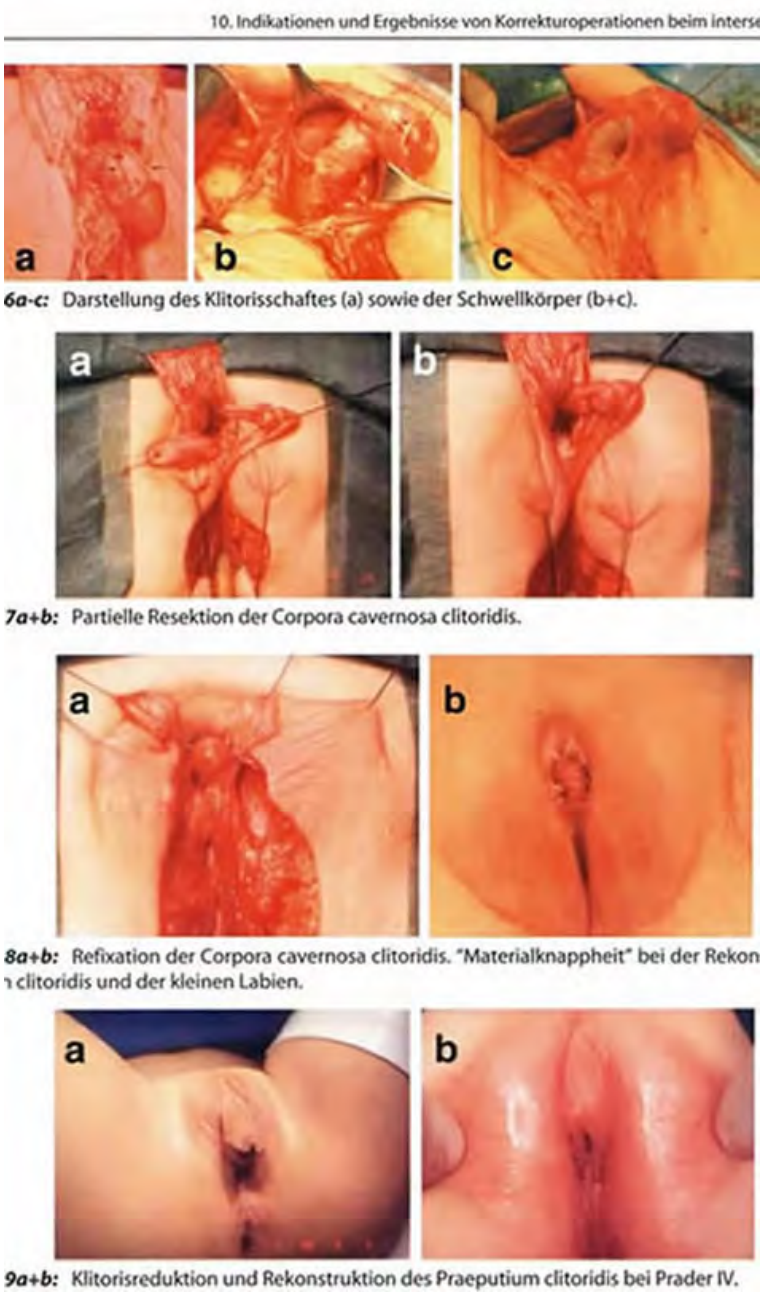
### IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

**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.**

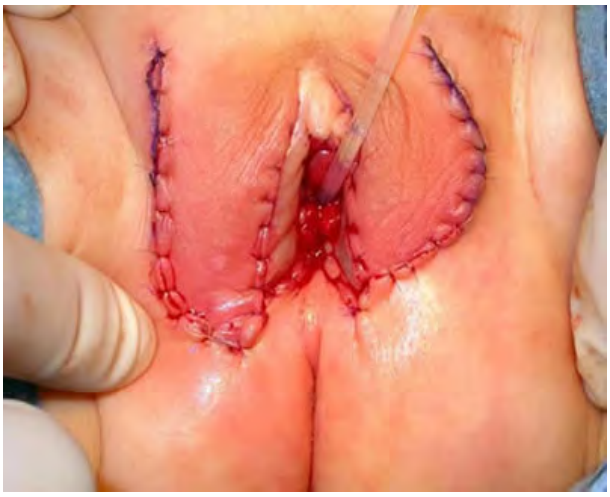


**Source:** Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004




**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).**

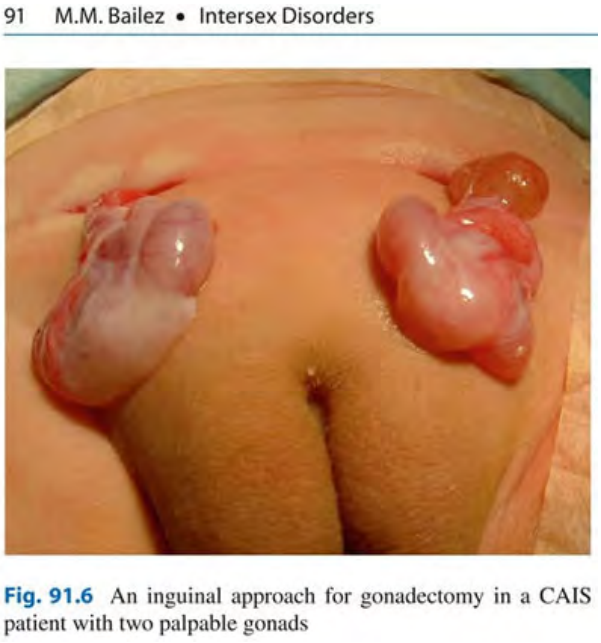



**Fig. 91.6** An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

**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 |
| | 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, Feminizing Genitoplasty”

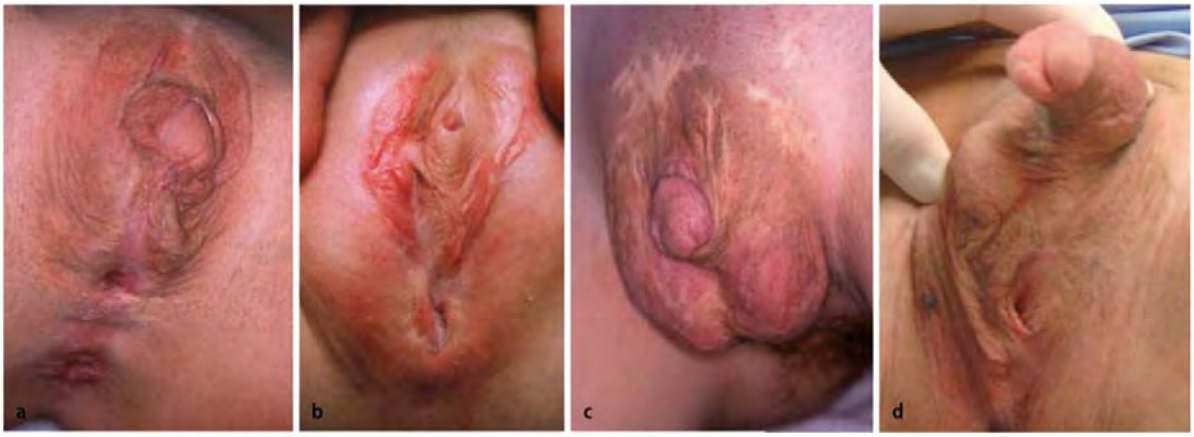
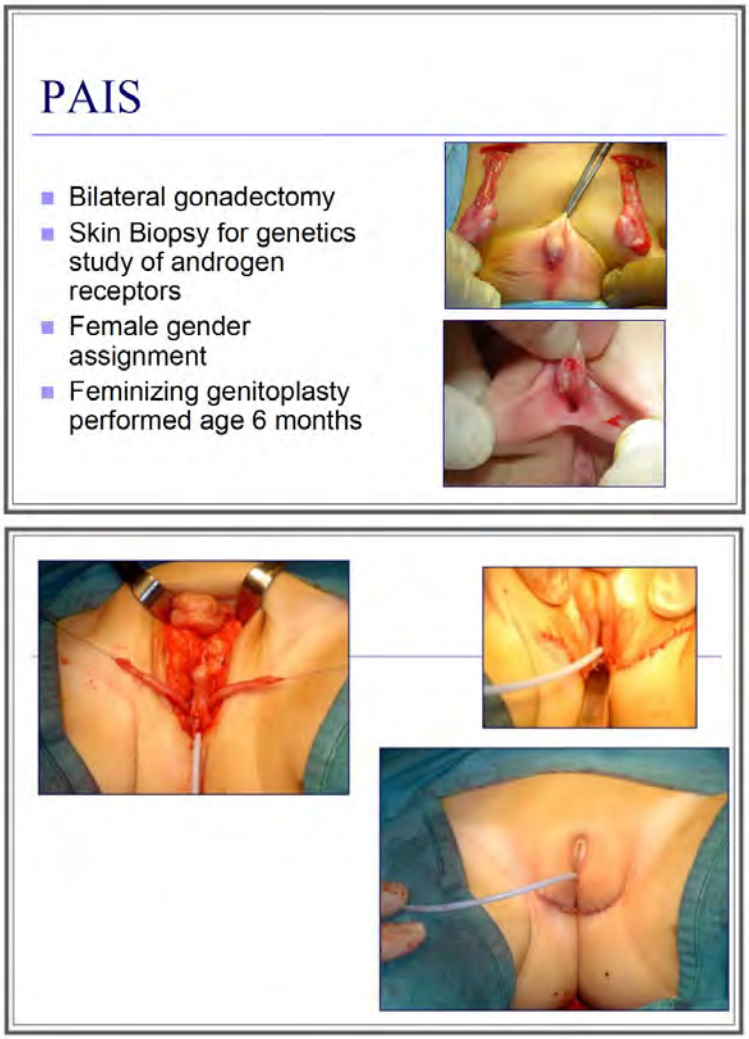



**Abb. 2** ▲ **a**, **b** Schlechte Korrekturergebnisse nach Feminisierung und **c**, **d** nach Hypospadiekorrektur

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




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