Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Reproductive Anatomy

NGO Report (for Session)
to the 5th Periodic Report of Portugal on the
International Covenant on Civil and Political Rights (CCPR)

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Executive Summary

Despite a formal prohibition introduced in Law No. 38/2018, in Portugal **all typical forms of Intersex Genital Mutilation (IGM) persist with impunity**, facilitated and **paid for by the State party** via the **public health system**, and perpetrated by **public University Hospitals** and **private health-care providers alike**. The **categorical failure** of Law No. 38/2018 to adequately protect intersex children from **cruel, inhuman or degrading treatment** is even more obvious in comparison with the State party's **vastly superior, current anti-FGM legislation and policies.**

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

In 2019, **CRC recognised IGM in Portugal as a harmful practice** and urged the State party to *"[c]ontinue to implement measures, including legal and administrative"* to effectively combat IGM (CRC/C/PRT/CO/5-6, para 28(b)). To this day, the **State party fails to act**.

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

In total, UN treaty bodies **CRC, CAT, CCPR, CEDAW** and **CRPD** have so far issued **48 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. 15).

NGO Report to the 5th Report of Portugal on the International Covenant on Civil and Political Rights (CCPR)

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A. Introduction

1. Portugal: Intersex Human Rights, State Report, LOI and Replies

In 2018, Portugal introduced **Law No. 38/2018**,[1] *"The right to self-determination of gender identity and expression and to protection of the sex characteristics of every person"*, which formally outlawed IGM. However, as this NGO report demonstrates, this current **legislation fails to include any sanctions** against IGM perpetrators, but instead contains several **known legal loopholes** and is generally **not enforced**. Accordingly, **CRC** raised IGM under **harmful practices** in its recent **Concluding Observations** to Portugal urging the State party to *"[c]ontinue to implement measures, including legal and administrative, to guarantee that no child, including intersex, is subjected to unnecessary medical or surgical treatment, during infancy or childhood"* (CRC/C/PRT/CO/5-6, para 28(b))

While **Portugal's 5th State report** to CCPR mentioned combatting harmful practices in the context of the "Action Plan for preventing and combating all forms of violence against women, gender violence and domestic violence of ENIND" (para 194(f)), IGM was not included. The only time intersex was alluded to was in the context of the "V National Plan for preventing and combating domestic and gender violence 2014-2017" and its action plan covering "LGBTI rights", again without including IGM (para 193).

The **List of Issues** mentioned intersex in the context of above-mentioned Law No. 38/2018 asking about the bill's content and timeline for adoption (para 6).

The **Replies to the List of Issues** alluded to **IGM** in the context of above-mentioned Law No. 38/2018 which *"became immediately in force and established the right to […] the* ***protection of each person's sex characteristics"*** (para 32), and ***"[f]orbids treatments and interventions at any age without the person's consent except in cases of proven risk for the person's health"*** (para 34). A 2019 report by the Portuguese **Commission for Citizen Ship and Gender Equality (CIG)**[2] published by UNECE further specifies that Law No. 38/2018 explicitly includes ***"the prohibition of surgeries on intersex children"*** (p. 7), and that the ENIND "Action plan for combatting discrimination on the grounds of sexual orientation, gender identity and expression and sex characteristics" 2018-2021 explicitly aims to *"to prevent and combat all forms of violence against LGBTI people in public and private life"*, which surely should include combatting IGM (p. 24), and refers to a CIG campaign *"to prevent violence against LGBTI people"*,[3] which implies to protect the physical integrity of intersex persons (p. 82).

The Replies to the LOI further mention intersex in the context of *"new measures to prevent discrimination as in legal documents"* (para 33) and *"the first volume of the first Health Strategy for LGBTI Persons, produced by the General Directorate of Health, dedicated to the promotion of […] intersex persons' health"* (para 36).

However, as this Thematic NGO Report demonstrates, the current and ongoing **harmful medical practices on intersex children in Portugal persist** – advocated, facilitated and **paid for by the**

1 https://dre.pt/pesquisa/-/search/115933863/details/maximized

2 https://www.unece.org/fileadmin/DAM/Gender/Beijing_20/Portugal.pdf

3 https://www.cig.gov.pt/acoes-no-terreno/campanhas/campanha-trans-intersexo-direitoaser/ , on intersex see last video: "I'm intersex and my body deserves to exist."

State party, and perpetrated both by public university hospitals and private health-care providers – and constitute a **serious breach** of Portugal's obligations under the Covenant.

2. About the Rapporteurs

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

- **StopIGM.org / Zwischengeschlecht.org** is an international intersex human rights NGO based in Switzerland, working to end IGM practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!"* [4] According to its charter,[5] 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, [6] substantially contributing to the so far 48 Treaty body Concluding Observations recognising IGM as a serious human rights violation.[7]

  Since **2018**, StopIGM.org has critically followed **Portugal's legislative initiatives** aimed at combatting IGM practices, [8] resulting in the **current insufficient legislation** against IGM. Based on our 2019 Intersex NGO Report, **CRC** recognised IGM in Portugal as a **harmful practice** (CRC/C/PRT/CO/5-6, para 28(b)).

3. Methodology

This thematic NGO report is a localised update to the **2019 CRC Portugal NGO Report (for Session)**[9] by the same Rapporteurs.

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

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

6 http://intersex.shadowreport.org

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

8 http://stop.genitalmutilation.org/post/Portugal-New-law-fails-to-protect-intersex-children
https://www.reuters.com/article/portugal-lgbt-lawmaking/portugal-approves-law-to-boost-transgender-rights-protect-intersex-infants-idUSL1N1RQ0ZP

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

B. IGM in Portugal: Pervasive despite prohibition, Gov fails to act

1. Overview: IGM practices in Portugal pervasive due to legal gaps and loopholes

While **Portugal** has to be commended for being the second State[10] to **formally outlaw** IGM practices in **2018 (Law No. 38/2018**, see also p. 5, 11-14), nonetheless, as this chapter demonstrates, to this day **IGM persists** in Portugal, as there remain **serious gaps** in the current legislation, which contains several **legal loopholes** and generally **falls short** of minimal requirements under the Covenant.

In particular, **under the current law in Portugal** there are

- **no *effective* legal or other protections** in place to **prevent all IGM practices** constituting **cruel, inhuman or degrading treatment** and **non-consensual medical or scientific experimentation**,
- **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,
- **no extraterritorial protections** in place.

To this day **all forms of IGM practices remain widespread and ongoing** in Portugal, persistently **advocated, prescribed and perpetrated** in state funded University Children's Hospitals, **advocated and paid for by the State party** via the public health system, as well as by private health insurances.

2. Most Common IGM Forms advocated by and perpetrated by Portugal

This section demonstrates that **Portuguese intersex children continue to be submitted to IGM practices**, advocated, facilitated and **paid for by the State party via the public health system** (National Health Service: Serviço Nacional de Saúde, SNS), as well as by the **health subsystems** (insurances for certain professionals including some municipal employees), and by **private insurances and health care providers**:

a) IGM 3 Sterilising Procedures [11]

The private hospital chain **"Hospital da Luz"**, advocates on its homepage under ***"Paediatric Surgery"*** procedures including surgery for ***"Incorrect descent of the testicles in the scrotum"*** and generally ***"Genital and urinary malformations and diseases"***, which are both known to include removal of healthy testes and mixed gonads.[12]

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10 After Malta, which introduced formal prohibition in 2015, and in 2018 amended the law to include sanctions. However, the law is not enforced, and also in Malta IGM still persists, see 2019 CRC Intersex NGO Report for Malta, http://intersex.shadowreport.org/public/2019-CRC-Malta-NGO-Zwischengeschlecht-Intersex-IGM.pdf, and the resulting CRC Concluding Observations explicitly recognising IGM in Malta as a harmful practice (CRC/C/MLT/CO/3-6, paras 28-29)

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

12 https://www.hospitaldaluz.pt/pt/servicos-e-medicos/especialidades/159/cirurgia-pediatrica#tabp-0

b) IGM 2 "Feminising Surgery" [13]

The Portuguese online **Paediatric Encyclopedia "Pedipedia Pro"** under the *"high-level patronage"* of the presidents of Portugal, Cape Verde, East Timor and São Tomé and Príncipe, in its current entry on *"Congenital Adrenal Hyperplasia (CAH)"* advocates surgery in cases of *"ambiguous genitalia"* (CAH is mostly associated with "clitoromegaly" and "malformation of the vagina").[14]

Accordingly, a **2019 multicenter study** of patients with classical Congenital Adrenal Hyperplasia (CAH) followed in 6 national hospitals presented at the **70th Annual Congress of the Portuguese Society of Endocrinology, Diabetes and Metabolism (SPEDM)** notes:[15]

> *"Thirteen patients presented with virilization at birth and 12 were submitted to genital reconstruction surgery."*

The 2016 **postgraduate course** *"The role of Minimal Invasive Surgery in Müllerian Malformations"* by the **Medical School of the University of Minho** included lectures and ***"Interactive Live Surgery"*** sessions by the well-known Argentine IGM paediatric surgeon Maria Marcela Bailez (Garrahan Children's Hospital, Argentina [16] – see also below p. 25) on *"Laparoscopic sigmoid colon vaginoplasty"* and its *"surgical complications"*.[17]

A 2011 publication by doctors of the **Coimbra University Hospitals** and the **National Institute for Health Dr. Ricardo Jorge** is even more open in **advocating unnecessary, early genital surgery based on psychosocial indications:**

> *"When there are alterations in the external genitalia, **surgical intervention is necessary, with clitoroplasty and introitoplasty, usually in the first 12 to 18 months of life**, trying to minimize **psychosocial problems**, allowing a normal sexual life, since there are no alterations in the internal organs."* [18]

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

14 *"Situations of ambiguous genitalia also require evaluation by a specialized surgical team in order to better decide and schedule intervention if it is indicated."*, http://www.pedipedia.org/pro/artigo-profissional/hiperplasia-supra-renal-congenita

15 Sílvia Paredes, Liliana Fonseca, Sandra Belo, Pedro Souteiro, Ana Ferreira, Marta Ferreira, Joana Maciel, Maria Lopes Pereira e Grupo de Estudo dos Tumores da Supra-rena (2019), CO 45. HIPERPLASIA CONGÉNITA DA SUPRARRENAL POR DÉFICE DE 21-HIDROXILASE NA POPULAÇÃO ADULTA PORTUGUESA: UM ESTUDO ULTICÊNTRICO, in: Revista Portuguesa de Endocrinologia, Diabetes e Metabolismo, Volume 14, Supplement 1, p. 15 in PDF, p. 26 in document, http://www.spedm.pt/wp-content/uploads/2019/04/Miolo_CongressoSPEDM-pag-espelhadas.pdf

16 See also CRC/C/ARG/CO/5-6, para 26; and 2018 CRC Intersex NGO Report Argentina, http://intersex.shadowreport.org/public/2018-CRC-Argentina-Intersex-Justicia-Brujula-StopIGM_v2.pdf

17 https://www.med.uminho.pt/en/Post-Graduation/courses/MDA/Pages/Programme.aspx

18 Alexandra Vieira, Sandra P Aiva, Carla Baptista, Luísa Ruas, Júlia Silva, João Gonçalves, Francisco Carrilho, Manuela Carvalheiro (2011), Hiperplasia Congénita da Suprarrenal de Expressão Tardia por Deficiência de 21-Hidroxilase. Revisão da Literatura e Estudo Genético Preconcepção de Cinco Casais, Acta Med Port 2011; 24: 099-110, p. 103, https://www.researchgate.net/publication/277057691_Hiperplasia_Congenita_da_Suprarrenal_de_Expressao_Tardia_por_Deficiencia_de_21-Hidroxilase

c) IGM 1 "Masculinising Surgery" [19]

The Portuguese online **Paediatric Encyclopedia "Pedipedia Pro"** under the *"high-level patronage"* of the presidents of Portugal, Cape Verde, East Timor, São Tomé and Príncipe, in its current entry on ***"Hypospadias"***, under *"Therapy"* exclusively advocates **early *"Surgery"*** based on ***"aesthetic"* indications**, but conveniently **fails to actually mention the notoriously high complication rates**:

> *"The **definitive correction** consists of orthoplasty (penis straightening) and neo-urethroplasty (making the neo-urethra and glandular placement of the neo-meatus).*
>
> ***It should ideally be done between 12-15 months of age and should be definitively completed by the age of three**. It is intended to provide an **aesthetic** and functional reconstitution as complete as possible, before the preschool period.*
>
> ***There is no ideal or universal surgical technique**, so the option should be determined by the type of lesion and the surgeon's experience. Ideally, the **correction should be made in a single time**, in order to reduce your personal, family and social costs as much as possible."* [20]

Also, the current **"Pedipedia Pro"** entry on ***"Micropenis"*** openly advocates unnecessary surgery including **partial amputation of the micro-penis**, but again **fails to mention complication rates**:

> ***"Surgery***
>
> *Circumcision should be avoided or postponed until the child has been properly evaluated and, if necessary, prior treatment with testosterone will facilitate its implementation. […] (2,3).*
>
> ***[Feminising] Genitoplasty,** in the context of gender reassignment in the most severe cases, **can be considered.** However, since boys with micro-penis and testicles in their scrotum respond to testosterone treatment and given their male gender identity, in most situations this option is increasingly challenged (1,2,4).*
>
> ***Clinical/therapeutic algorithm***
>
> *The treatment of micro-penis should focus on the optimization of normal sexual function, appropriate body image and **normal urination in a standing position** (2-4)."* [21]

In addition, also the current entry on ***"Hypospadias"*** in the Portuguese online **Paediatric Encyclopedia "Medipédia"** edited by the **"Instituto Pedro Nunes (IPN)"** openly advocates **unnecessary early surgery**, but again completely **fails to mention the notorious complication rates**:

> ***"The treatment is surgical.** When the defect is slight and if the urinary meatus is only slightly displaced in relation to the tip of the glans, the therapy should be carried out **during the first two years of life** and a single intervention is enough to reconstruct the urethra and place the meatus in its normal position. On the other hand, when the defect is associated with the presence of a fibrous tape on the lower face of the penis, surgical treatment is usually carried*

19 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

20 http://www.pedipedia.org/pro/artigo-profissional/hipospadias

21 http://www.pedipedia.org/pro/artigo-profissional/micropenis

*out in two stages. In a first operation, carried out during the **first year of life**, the fibrous tape must be removed to enable the normal development of the erectile bodies of the penis. Afterwards, after a period that can last from a few months to a year, the urethral canal must be reconstructed so that it reaches the tip of the glans. In order to facilitate healing, the urine flow is temporarily diverted through a drain that diverts the urine to the wall of the abdomen and perineum. Finally, this artificial meatus must be closed when the new urethral canal is already functional."* [22]

Accordingly, **Portuguese hospitals**[23] [24] continue to advocate IGM 1 in the ***"first year of life"***.

What's more, the **Braga University Hospital** (University of Minho) offers courses with ***"Live Surgery"***, notably both before Law No. 38/2018 went in force in 2017,[25] as well as **after the Law was in force** in September 2018.[26] The 2017 course was also widely publicised.[27] [28] [29]

d) IGM 4 Prenatal "Therapy" [30]

A 2014 publication by doctors of the Endocrinology Service of the **Portuguese Institute of Oncology of Coimbra Francisco Gentil** and the **Centre for Research in Health Sciences (CICS) of the University of Beira Interior, Covilhã**, while admitting to the serious risks of the prenatal "therapy" both for the intersex fetuses and the pregnant mothers, and further admitting that the "therapy" is in no way a cure to any actual *"disease"*, in the end nonetheless **advocates this harmful and unnecessary procedure:**

"Prenatal therapy

***Since prenatal therapy presents a risk of fetal malformations and non-negligible iatrogenicity in pregnant women,** it is recommended that it be used only in very specific situations and according to the protocols of each center [1,24]. This therapy blocks adrenal production of the fetus and is reserved only for pregnancies at risk of fetus with classic female congenital adrenal hyperplasia in order to avoid virilisation or genital ambiguity. However, it is important to inform parents that this **therapy does not avoid the need to perform postnatal treatment** in babies with congenital adrenal hyperplasia, i.e., **it does not prevent the appearance of any disease.** The treatment consists of administering dexamethasone to the pregnant woman, since it crosses the placenta at a dose of 20 ug/kg/day (according to pregestational weight), with a maximum of 1.5 mg/day divided into 3 administrations, and should be started before the 8th week of gestation [3]. Success is achieved in*

22 https://www.medipedia.pt/home/home.php?module=artigoEnc&id=653#4

23 For example, CUF Porto Hospital: *"As for the treatment, it should be done until the end of the first year of life, ideally between 8 and 10 months of life (before starting to walk), with or without hormonal treatment prior to surgery, and whenever possible in a single surgical time."*, https://www.saudecuf.pt/unidades/porto-hospital/centros/centro-da-crianca-e-do-adolescente/doencas-nas-criancas/hipospadias

24 For example, Hospital da Luz, https://www.hospitaldaluz.pt/pt/servicos-e-medicos/especialidades/159/cirurgia-pediatrica#tabp-0

25 https://www.gaps.gr/el/hypospadias-repair-exoscopic-live-surgery-icvsem-uminho-september-7-8-2017/

26 Hypospadias Repair Exoscopic Live Surgery → Programme, https://www.med.uminho.pt/en/mis-courses/hypospadias

27 https://www.atlasdasaude.pt/publico/content/perito-em-malformacao-congenita-do-penis-apresenta-tecnica-inovadora

28 https://www.sabado.pt/ciencia---saude/detalhe/perito-em-malformacao-congenita-do-penis-vai-expor-em-braga-tecnica-inovadora

29 http://www.bragatv.pt/conceituado-cirurgiao-pediatrico-americano-da-curso-no-hospital-de-braga/

30 See 2016 CEDAW NGO Report France, p. 50, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

80-85% of cases [1] and the reasons for failure are essentially a late start of treatment, lack of adherence or subtherapeutic dose. Dexamethasone should be interrupted when the fetus is male or when the prenatal diagnosis excludes the classic form of the disease [4]. ***This therapy presents risks for the fetus, such as congenital malformations such as hypertrophied heart septum or orofacial clefts*** *[1].* ***About 10% of pregnant women undergoing this therapy may have iatrogenic Cushing syndrome, excessive weight gain, high blood pressure or gestational diabetes*** *[1,10].”* [31]

Similarly, also a 2011 publication by doctors of the Pediatric Endocrinology Unit and the Medical Genetics Service of the **Coimbra Paediatric Hospital**, and of the Service of Neonatology of the **Maternity of Bissaya Barreto** in Coimbra continues to **advocate the risky “therapy”** despite reporting that it resulted in **sepsis and other complications of the baby concerned**. [32]

Finally, there is **no indication that the practice would have stopped or otherwise changed** since above reported cases.

3. How the Portuguese Law No. 38/2018 fails Intersex Children

In April 2018, the **Portuguese Parliament** adopted a new **Law No. 75/XIII/2**,[33] which has been likened[34] to the insufficient[35] Maltese Intersex Law, and reportedly endeavours to *“ban medically unnecessary surgery on the genitals of intersex infants”*.[36] However, in May 2018 the Portuguese President **vetoed** this Law.

In July 2018, a revised version, **Law No. 38/2018**,[37] *“The right to self-determination of gender identity and expression and to protection of the sex characteristics of every person”* was **adopted** by the Parliament and **came into force in August 2018**. Unfortunately, the Law’s articles concerning intersex children and IGM contain the same **shortcomings, omissions** and **legal loopholes** already criticised[38] by intersex advocates in the previous version, namely that it *“doesn’t explicitly prohibit intersex genital mutilation (IGM), nor criminalize or adequately sanction IGM, nor address obstacles to access to justice and redress for IGM survivors”*. **Law No. 38/2018’s** relevant articles **stipulate** (unofficial translation, our emphasis):

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31 Teresa Azevedoa, Teresa Martinsa, Manuel Carlos Lemosa, Fernando Rodriguesa (2014), Hiperplasia congénita da suprarrenal não clássica – aspetos relevantes para a prática clínica, Revista Portuguesa de Endocrinologia, Diabetes e Metabolismo 2014;9(1):59–64, p. 63, https://www.researchgate.net/publication/260807640_Hiperplasia_congenita_da_suprarrenal_nao_classica_-_aspetos_relevantes_para_a_pratica_clinica

32 Carolina Cordinhã, Sofia Morais, Rita Cardoso, Lina Ramos, Adelaide Taborda, Alice Mirante (2011), Congenital adrenal hyperplasia: when the same genotype have different phenotypes…, Revista Portuguesa de Endocrinologia, Diabetes e Metabolismo 2011:1:41-46, english abstract p. 42, http://rihuc.huc.min-saude.pt/bitstream/10400.4/1412/1/HiperplasiaSR.pdf

33 http://app.parlamento.pt/webutils/docs/doc.pdf?path=6148523063446f764c324679626d56304c334e706447567a4c31684a53556c4d5a5763765130394e4c7a464451554e45544563765247396a6457316c626e527663306c7561574e7059585270646d46446232317063334e686279387a5a4755304d44417a5a4330324d6a686a4c5451335a6a4d7459544d314f53307a4d475a6c4e5445794f544d304d6a51756347526d&fich=3de4003d-628c-47f3-a359-30fe51293424.pdf&Inline=true

34 Piet de Bruyn (2017), “C. Explanatory memorandum by Mr Piet De Bruyn, rapporteur”, in: Parliamentary Assembly of the Council of Europe (2017), Report: Promoting the human rights of and eliminating discrimination against intersex people, COE Doc. 14404, p. 14, para 48, http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-en.asp?FileId=24027

35 See CRC/C/MLT/CO/3-6, paras 28-29

36 https://www.reuters.com/article/portugal-lgbt-lawmaking/portugal-approves-law-to-boost-transgender-rights-protect-intersex-infants-idUSL1N1RQ0ZP

37 https://dre.pt/pesquisa/-/search/115933863/details/maximized

38 http://stop.genitalmutilation.org/post/Portugal-New-law-fails-to-protect-intersex-children https://www.reuters.com/article/portugal-lgbt-lawmaking/portugal-approves-law-to-boost-transgender-rights-protect-intersex-infants-idUSL1N1RQ0ZP

CHAPTER I
General provisions

[…]

Article 4
Protection of sex characteristics
*Everyone has the **right to preserve** primary and secondary sex characteristics.*

Article 5
Changes in the body and sex characteristics of the minor intersex person
*Except in situations of established health risk, surgical, pharmacological or other treatments and operations involving changes to the body and sex characteristics of the intersex minor shall not be carried out **until such time as his or her gender identity has been established.***

[…]

CHAPTER IV
Means of defence

[…]

Article 14
Liability
*1 – The practice of any **discriminatory act**, by action or omission, confers to the injured person the right to an indemnity, for material and non-material damages, **by way of extra-contractual civil liability, in accordance with the Civil Code**.*

Conclusion, despite good intentions Law No. 38/2018 **categorically fails to adequately protect** intersex children from **inhuman treatment** and harmful practices, namely IGM. Also, the Law is clearly not line with the **General Comment No. 20**, which regarding legislative and other measures explicitly obliges State parties to

- *"afford everyone **protection through legislative and other measures as may be necessary** against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity."* (para 2)
- *"inform the Committee of the **legislative, administrative, judicial and other measures** they take to **prevent and punish** acts of torture and cruel, inhuman and degrading treatment in any territory under their jurisdiction."* (para 8)
- *"indicate how their legal system effectively guarantees the **immediate termination** of all the acts prohibited by article 7 as well as **appropriate redress**. The **right to lodge complaints** against maltreatment prohibited by article 7 must be recognized in the domestic law. **Complaints must be investigated promptly and impartially by competent authorities so as to make the remedy effective.** The reports of States parties should provide specific information on the remedies available to victims of maltreatment and the procedure that complainants must follow, and **statistics on the number of complaints and how they have been dealt with**."* (para 14)
- ***"guarantee freedom from such acts within their jurisdiction**; and to **ensure that they do not occur in the future**. States may not deprive individuals of the **right to an effective remedy, including compensation and such full rehabilitation as may be possible**."* (para 15)

In particular, the Portuguese Intersex Law **fails to include the following necessary provisions** in line with the **General Comment No. 20** and the previous CRC Concluding observation referring to the CRC-CEDAW Joint General Comment No. 18/31 "on harmful practices" (CRC/C/PRT/CO/5-6, para 28(b)) explicitly obliging State parties to

- explicitly prohibit IGM by **criminalising or adequately sanctioning** the practice (but instead **limits** the legal recourse of IGM survivors to *"extra-contractual civil liability, in accordance with the Civil Code"*, see Law No. 38/2018, art. 14),
- **address obstacles to access to justice and redress** for IGM survivors, namely the **statutes of limitations**,
- guarantee **extraterritorial protections**,
- guarantee **informed consent of the capable intersex person themselves** in case of non-urgent procedures (but instead exclusively relies on whether *"his or her gender identity has been established"*, see Law No. 38/2018, art. 5).

The **categorical failure** of the Portuguese Intersex Law to adequately protect intersex children from harmful practices becomes even more apparent in **comparison with the current Portuguese FGM legislation**: [39]

> *"Following Portugal's ratification of the Istanbul Convention in August 2015, **FGM is a specified crime under Law nº 83/2015 of the Portuguese Penal Code**. According to Article 144 A on Female Genital Mutilation, the **perpetrator of FGM may be sentenced to a prison** term of two to 10 years. **All preparatory acts** related to FGM, namely sending or arranging the travel of a woman or girl abroad to be submitted to FGM, helping, incentivising or supporting the practice of FGM abroad or in national territory (e.g. by collecting money to pay for the procedure) is **punishable by up to 3 years in prison**."* [40]
>
> *"The principle of **extraterritoriality is also applicable**, making FGM punishable even if committed outside the country. With the new revision of the penal code (Article 144 A), the **prescription period** for qualified crimes has changed from 10 to **15 years**). Moreover, if the victim was a minor, prescription cannot extinguish the criminal procedure **before the offended is 23 years**."* [41]
>
> ***"Criminalization of FGM** has brought so far to a **public known case**, which finally did not end in prosecution."* [42]

This discrepancy is also evident in the **State party's reply to the List of Issues**: Concerning FGM, reports various initiatives to combat FGM, including *"[t]raining of professionals in key positions to prevent, detect and assist victims of FGM, with a focus on healthcare, education, social security, police forces and local administration"* (paras 95-99), while concerning IGM the State party seems to think merely enacting the insufficient and toothless Law No. 38/2018 and a *"Health Strategy for LGBTI Persons"* would suffice despite that IGM persists with impunity, including in public University hospitals (paras 32-36).

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39 Despite that the current Portuguese legal protections against FGM are vastly superior than those against IGM, that doesn't mean that the FGM law doesn't still have shortcomings, see e.g. APF, End FGM (2018), Joint Shadow Report – PORTUGAL, https://rm.coe.int/shadow-report-portugal-v4/16808b5f67

40 United to End FGM (UEFGM), https://uefgm.org/index.php/legislative-framework-pt/

41 APF, End FGM European Network (2018), Joint Shadow Report – PORTUGAL, p. 3, https://rm.coe.int/shadow-report-portugal-v4/16808b5f67

42 Ibid., p. 7

And while the State party further claims that its new **National Strategy for Equality and Non Discrimination 2018–2030** would also include Action plans *"for combatting discrimination on the grounds of […]* ***sexual characteristics****"* and *"for preventing and combatting against* ***violence against women*** *and domestic violence"* including ***"harmful practices"*** (State report, paras 193-194; see also Replies to CRC LOI, CRC/C/PRT/Q/5-6/Add.1, paras 23-24), apparently the National Strategy nonetheless **fails to adequately address intersex children and IGM practices**.

Conclusion, both the Portuguese Law No. 38/2018 and the National Strategy for Equality and Non-Discrimination 2018–2030 (NSEND) aimed at protecting intersex children from IGM practices on the one hand **fail to meet the minimal requirements set out by the Covenant and General Comment No. 20**, and on the other hand so far, Law No. 38/2018 is simply **not enforced**.

4. Portuguese Doctors and Government consciously dismissing Intersex Human Rights

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

Portuguese paediatric surgeons, despite **openly admitting to knowledge of relevant criticisms** by human rights and ethics bodies, nonetheless continue to **consciously refuse to stop advocating, practicing and participating in IGM practices**.

Also, Portuguese government bodies continue to ignore the full human rights implications of IGM.

5. Lack of Independent Data Collection and Monitoring

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

Also, in Portugal there are no statistics on intersex birth and on IGM practices available, which was also admitted in the State party's **(non-)reply to the recent CRC List of Issues** (CRC/C/PRT/Q/5-6/Add.1, paras 100-101)**.**

6. Obstacles to redress, fair and adequate compensation

Also in **Portugal** 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 Portugal there was **no case** of a victim of IGM practices succeeding in going to court.

This situation is clearly not in line with Portugal'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 Recommendations

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

Intersex genital mutilation

Taking note of the Law No. 38/2018 and the ENIND Action plan for combatting discrimination on the grounds of sexual orientation, gender identity and expression and sex characteristics 2018-2021, the Committee remains seriously concerned about medically unnecessary and irreversible surgery and other treatment on intersex children without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases (arts. 3, 7, 9, 17, 24 and 26).

The State party should:

(a) Ensure that the State party's legislation explicitly prohibits all forms of intersex genital mutilation, by criminalising or adequately sanctioning unnecessary medical or surgical treatment during infancy or childhood, and provide families with intersex children with adequate counselling and support;

(b) Adopt legal provisions and repeal time-limits in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible, and undertake investigation of incidents of surgical and other medical treatment of intersex children without their informed consent;

(c) Systematically collect disaggregated data on harmful practices in the State party, including on intersex genital mutilation, and make information on the ways to combat these practices widely available;

(d) Educate and train medical, psychological and education professionals on intersex as a natural bodily variation and on the consequences of unnecessary surgical and other medical interventions for intersex children.

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

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

This Committee has repeatedly **recognised IGM** practices as a **serious violation of Covenant**, [44] and **arts. 3, 7, 9, 17, 24, 26** as applicable.

Art. 3: Equal Right of Men and Women

On the basis of their "indeterminate sex," intersex children are singled out for experimental harmful treatments, including surgical "genital corrections" and potentially sterilising procedures, that would be ***"considered inhumane"* on "normal" children**,[45] e.g. "normal" boys and girls, so that, according to a specialised surgeon, *"any cutting, no matter how incompetently executed, is a kindness."* [46] Generally, medical justifications for IGM are often rooted in **gender-based stereotypes**. Clearly, IGM practices therefore also violate Article 3.

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

Like this Committee, the **Committee against Torture**[47] has repeatedly **considered IGM to constitute inhuman treatment** falling under the non-derogable prohibition of torture (same as FGM and gender-based violence). Intersex advocates consider harmful practices and inhuman treatment as the **most important human rights frameworks** to effectively combat IGM. [48]

Concerning **involuntary medical or scientific experimentation**, as generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental**. While due to the general avoidance of follow-up by doctors, IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition. However, internationally there are **many examples proving also a strict definition to apply**. [49] For decades, intersex children have been regularly described and exploited by scientists as an ***"experiment of nature"***.[50] [51] [52] Often **twins, siblings, mothers or other family members or**

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

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

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

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

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

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

50 See e.g. Kang H-J, Imperato-McGinley J, Zhu Y-S, Rosenwaks Z. 5alpha-reductase-2 Deficiency's Effect on Human Fertility. *Fertility and sterility*. 2014;101(2):310-316, at p. 5, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4031759/pdf/nihms578345.pdf

relatives of intersex children are used as controls.[53] [54] Generally, intersex children, while being submitted to IGM practices or thereafter, are often used as **subjects in scientific research**, particularly in the field of genetics, also in **Portugal** and internationally with the contribution of **Portuguese IGM doctors**.[55] [56]

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

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

- *"afford everyone **protection through legislative and other measures as may be necessary** against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity."* (para 2)
- *"inform the Committee of the **legislative, administrative, judicial and other measures** they take to **prevent and punish** acts of torture and cruel, inhuman and degrading treatment in any territory under their jurisdiction."* (para 8)
- *"indicate how their legal system effectively guarantees the **immediate termination** of all the acts prohibited by article 7 as well as **appropriate redress**. The **right to lodge complaints** against maltreatment prohibited by article 7 must be recognized in the domestic law. **Complaints must be investigated promptly and impartially by competent authorities so as to make the remedy effective.** The reports of States parties should*

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51 Clarnette, T.D; Sugita, Y.; Hutson, J.M.: Genital anomalies in human and animal models reveal the mechanisms and hormones governing testicular descent, *British Journal of Urology* (1997), 79, 99–112, at 99, http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf

52 U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied zwischen Mädchen und Jungen, Männern und Frauen?, Monatsschr Kinderheilkd 2003 · 151:586–593, at 591, see also: Lang C.; Kuhnle U.: Intersexuality and Alternative Gender Categories in Non-Western Cultures, Horm Res 2008;69:240–250

53 See e.g. Dittmann, R. W., Kappes, M. H., Kappes, M. E., Borger, D., Stegner, H., Willig, R. H., Wallis, H. (1990). "Congenital adrenal hyperplasia. I: Gender-related behavior and attitudes in female patients and sisters." Psychoneuroendocrinology 15(5-6): 401-420,
see also: Ralf W. Dittmann, "Pränatal wirksame Hormone und Verhaltensmerkmale von Patientinnen mit den beiden klassischen Varianten des 21-Hydroxylase-Defektes. Ein Beitrag zur Psychoendokrinologie des Adrenogenitalen Syndroms", European University Studies, Bern: 1989

54 For an example of studies on intersex twins by German gynaecologist Ernst Philipp in collaboration with Swiss endocrinologist Andrea Prader, see Marion Hulverscheidt (2016), Begriffsdefinitionen "Intersexualität" VII: Eine einheitliche Betrachtung des Zwittertums – der Kieler Gynäkologe Ernst, http://intersex.hypotheses.org/3976

55 Joana Rosmaninho-Salgado, Joana Serra Caetano, Susana Gomes, Iris Pereira-Caetano, Rita Cardoso, Isabel Dinis, Lina Ramos, Fabiana Ramos, Ana Luisa Carvalho, Ana Garabal, Joaquim Sá, Sofia Maia, Sérgio B. Sousa, Jorge M Saraiva, João Gonçalves, Alice Mirante (2018), CO 46. HIPERPLASIA CONGÉNITA DA SUPRAR-RENAL: MUTAÇÕES NO GENE CYP21A2 NUMA POPULAÇÃO PEDIÁTRICA PORTUGUESA, in: Revista Portuguesa de Endocrinologia, Diabetes e Metabolismo, Volume 13(1), p. 56 in PDF, p. 57 in document, https://www.spedmjournal.com/magazine_download.php?id=23

56 In September 2020 the 5th Joint Meeting of the European Society for Paediatric Urology (ESPU) and the American Societies for Pediatric Urology (SPU) will be hosted in Portugal with local support, https://congress2020.espu.org/ The ESPU is a known propagator and practitioner of IGM, see e.g. 2019 CCPR Belgium NGO Report, p. 13, 14, 20, http://intersex.shadowreport.org/public/2019-CCPR-Belgium-NGO-Intersex-StopIGM.pdf

provide specific information on the remedies available to victims of maltreatment and the procedure that complainants must follow, and ***statistics on the number of complaints and how they have been dealt with****."* (para 14)

- ***"guarantee freedom from such acts within their jurisdiction****; and to* ***ensure that they do not occur in the future****. States may not deprive individuals of the* ***right to an effective remedy, including compensation and such full rehabilitation as may be possible****."* (para 15)

Art. 9: Liberty and Security of the Person

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

Art. 17: Arbitrary or Unlawful Interference with Privacy

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

Art. 24: Child Protection

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

Art. 26: Equal Protection of the Law

Intersex children have the **same rights to effective protections** from IGM as for example girls against FGM. However, if there are any legal protections against IGM at all, these are **regularly considerably weaker** than those against FGM or gender-based violence. Concerning IGM, this is also the case in **Portugal** (see p. 11-14), and clearly not in line with article 26.

2. Lack of Independent Data Collection and Monitoring

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

Also in Portugal, there are no official statistics on intersex births and on IGM practices available.[57] When asked about statistics, the Government either **claims there are none available** or simply **fails to answer**.[58]

57 See 2019 CRC Portugal NGO Report, p. 5, http://intersex.shadowreport.org/public/2019-CRC-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf Replies to CRC LOI, CRC/C/PRT/Q/5-6/Add.1, where Portugal claimed ***"No cases [of intersex births] were reported in 2016, 2017 and 2018"*** (para 100), and **failed to provide any answer on IGM practices** (para 101)

58 Ibid.

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)"*, [59] 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. [60]

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.[61]

In **regions without universal access to paediatric health care**, there are reports of **infanticide**[62] of intersex children, of **abandonment**,[63] of **expulsion**,[64] of **massive bullying** preventing the

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

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

61 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

62 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

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

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),[65] and of **murder**.[66]

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**.[67] [68] [69] [70]

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**,[71] 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.[72] UN Treaty bodies have so far issued 48 Concluding Observations condemning IGM practices accordingly.[73]

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64 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

65 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

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

67 2014 CRC NGO Report, p. 52, 69, 84, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

68 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

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

70 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

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

72 **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

73 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**[74] [75] 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,[76] 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.[77]

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"*,[78] and again IGM survivors as *"transgender children"*,[79] *"transsexual children who underwent difficult treatments and surgeries"*, and IGM as a form of *"discrimination against transgender and intersex children"* [80] and as *"sex assignment surgery"* while referring to *"access to gender reassignment-related treatments"*.[81]

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

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

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

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

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

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

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

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

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

82 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"* [83], transgender guidelines[84] or *"Gender Identity"* [85] [86] 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** [87] and public **representation**.[88]

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** [89] [90] [91] – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee). This is also evident in the **insufficient Portuguese Government initiatives** (see p. 5, 11-14).

Even worse, **Health ministries** construe UN Treaty body 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.**[92]

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

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

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

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

87 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

88 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

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

90 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

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

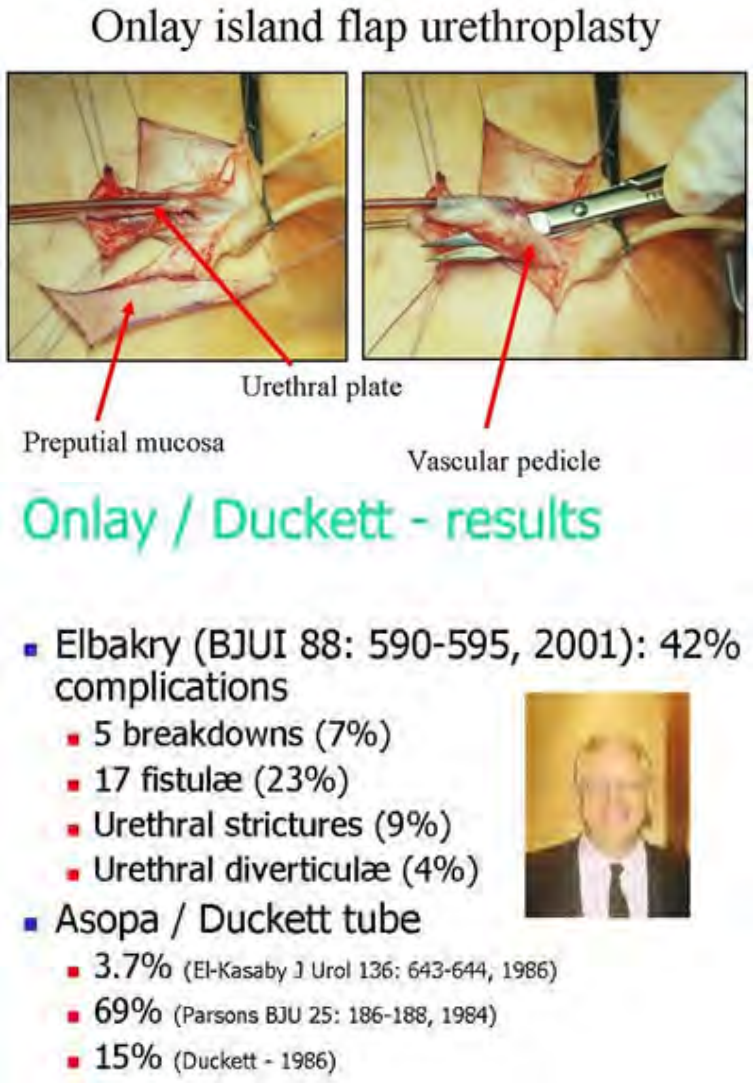
92 See for example Ministry of Health Chile (2016), http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile

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

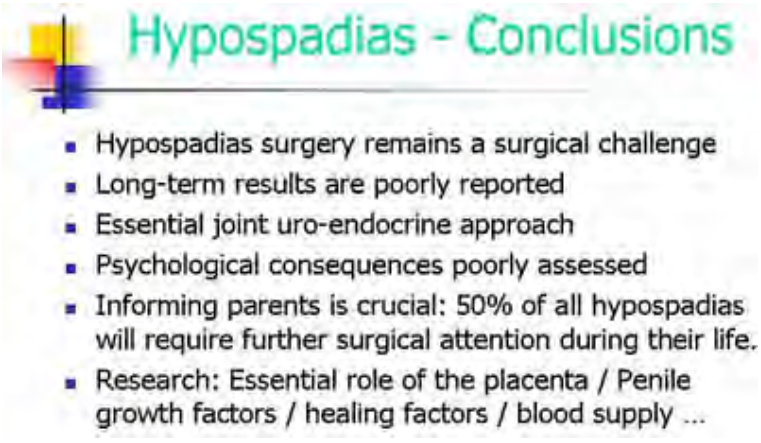
Official Diagnosis "Hypospadias Cripple"
= made a "cripple" by repeat cosmetic surgeries

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

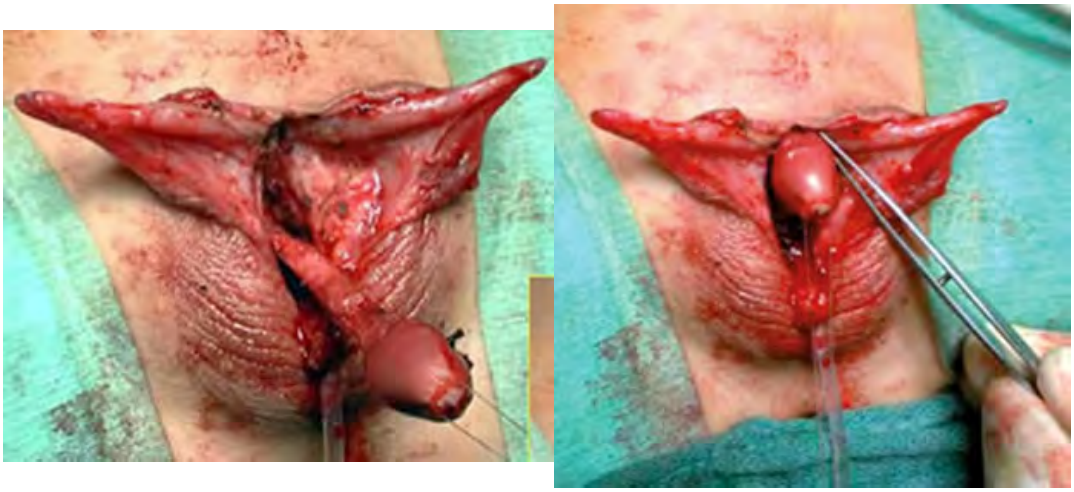


Source: Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

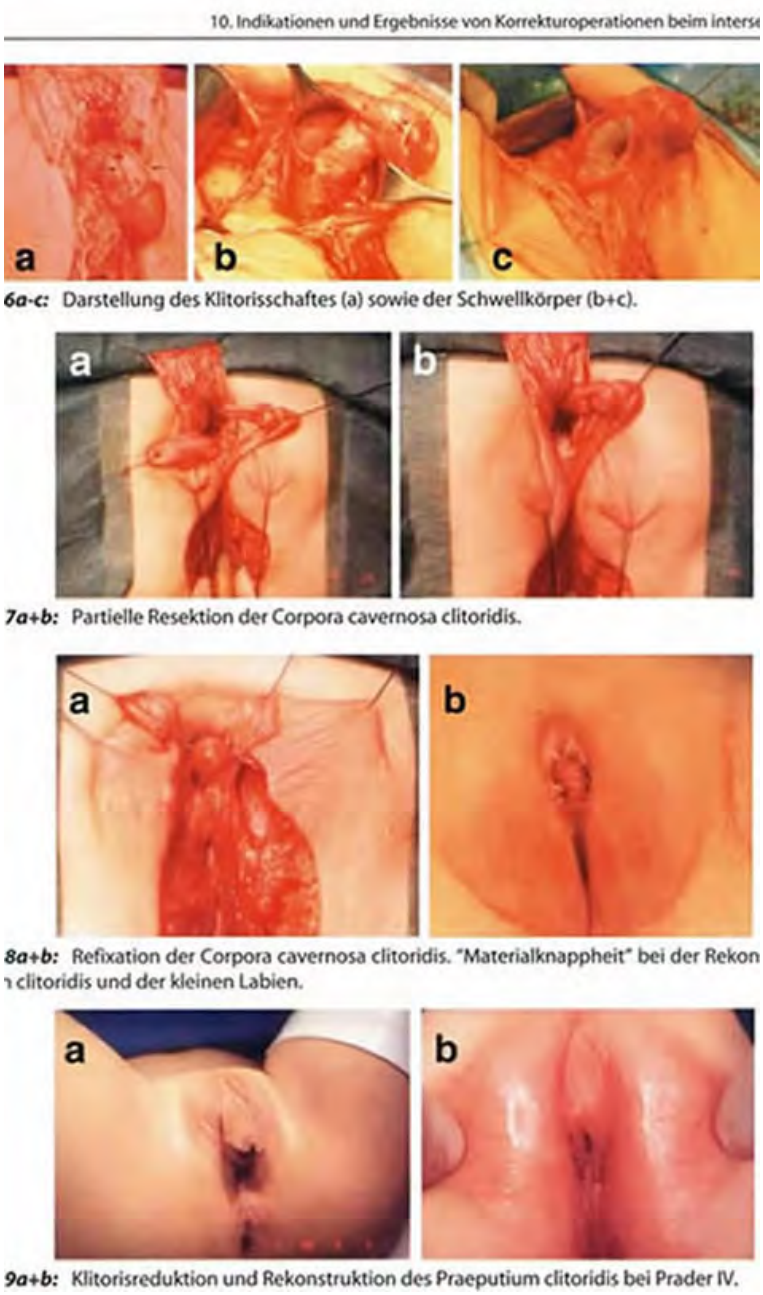
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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.

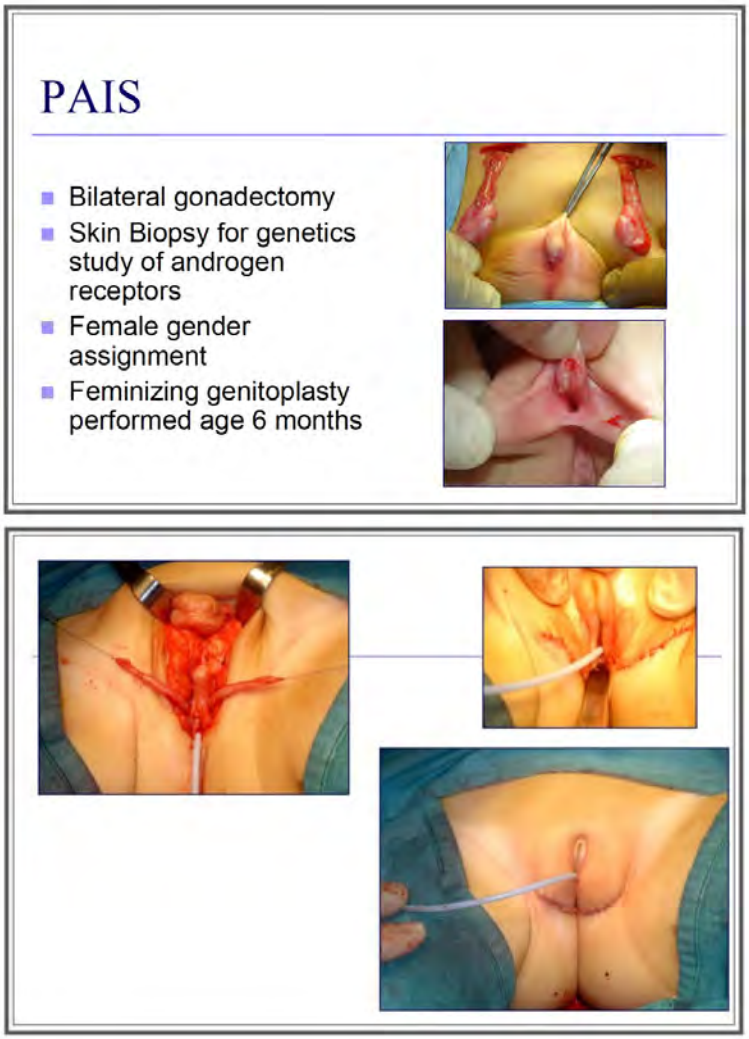
Source: J. Pleskacova, R. Hersmus, J. Wolter Oosterhuis, B.A. Setyawati, S.M. Faradz, Martine Cools, Katja P. Wolffenbuttel, J. Lebl, Stenvert L.S. Drop, Leendert H.J. Looijenga: "Tumor risk in disorders of sex development," in: *Sexual Development* 2010 Sep;4(4-5):259-69.

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.

Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Reproductive Anatomy

NGO Report (for Session)
to the 5th Periodic Report of Portugal on the International Covenant on Civil and Political Rights (CCPR)