Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report

to the 5th to 6th Report of Portugal on the Convention on the Rights of the Child (CRC)

Compiled by:

StopIGM.org / Zwischengeschlecht.org (International Intersex Human Rights NGO)

Markus Bauer, Daniela Truffer

Zwischengeschlecht.org P.O.Box 2122 CH-8031 Zurich

info_at_zwischengeschlecht.org
http://Zwischengeschlecht.org/
http://stop.genitalmutilation.org

August 2019

This NGO Report online:

 $\underline{http://intersex.shadowreport.org/public/2019\text{-}CRC\text{-}Portugal\text{-}NGO\text{-}Zwischengeschlecht\text{-}Intersex\text{-}IGM.pdf}$



Executive Summary

Despite a formal prohibition introduced in Law No. 38/2018, all typical forms of Intersex Genital Mutilation are still practised in Portugal, 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 harmful practices becomes even more apparent in comparison with the State party's vastly superior, current anti-FGM legislation and policies.

Portugal 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 42 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 Recommendations (see p. 13).

NGO Report

to the 5th to 6th Report of Portugal on the Convention on the Rights of the Child (CRC)

Table of Contents

IGM Practices in Portugal (p. 5-13)

Executive Summary	3
A. Introduction	
1. Portugal: Intersex Human Rights and State Report	
2. About the Rapporteurs	5
3. Methodology	5
B. IGM in Portugal: Pervasive despite prohibition, Gov fails to act	6
1. Overview: IGM practices in Portugal pervasive due to legal gaps and loopholes	
2. Most Common IGM Forms advocated by and perpetrated by Portugal	6
a) IGM 3 Sterilising Procedures	6
b) IGM 2 "Feminising Surgery"	6
c) IGM 1 "Masculinising Surgery"	7
d) IGM 4 Prenatal "Therapy"	
3. How the Portuguese Law No. 38/2018 fails Intersex Children	
4. Portuguese Doctors and Government consciously dismissing Intersex Human Rights	
5. Lack of Independent Data Collection and Monitoring	
6. Obstacles to redress, fair and adequate compensation	
C. Suggested Recommendations	. 13
Annexe 1 – IGM Practices in Portugal as a Violation of CRC	
1. The Treatment of Intersex Children in Portugal as Harmful Practice and Violence	
a) Harmful Practice (art. 24(3) and JGC No. 18)	
b) Violence against Children (art. 19 and GC No. 13)	
2. Required Legislative Provisions to Ensure Protection from IGM Practices,	
Impunity of the Perpetrators (CRC art. 24(3) and JGC No. 18)	15
3. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation	
(CRC art. 24(3) and JGC No. 18)	16
Annexe 2 – Background: Intersex, IGM, Harmful Practices and Stereotypes	17
1. IGM: Involuntary, unnecessary and harmful practices, based on stereotypes and prejudice	
2. Intersex = variations of reproductive anatomy	18
3. Harmful Stereotypes (2): Intersex is NOT THE SAME as Transgender or LGBT	
4. Harmful Stereotypes (3): Misrepresenting Genital Mutilation as "Health Care"	20
Annexe 3 – "IGM in Medical Textbooks: Current Practice"	21
IGM 1 – "Masculinising Surgery": "Hypospadias Repair"	21
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"	
IGM 3 – Sterilising Surgery: Castration / "Gonadectomy" / Hysterectomy	
"Bad results" / "Gonadectomy, Feminising Genitoplasty"	27

A. Introduction

1. Portugal: Intersex Human Rights and State Report

In 2018, Portugal introduced **Law No. 38/2018**, "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.

Notably, **Portugal's 5th and 6th State report** to CRC **didn't mention** intersex and IGM. Fortunately, the Committee's **List of Issues** (**LOI**) nonetheless included **questions about data on intersex births** (para 15(j)) and **IGM practices** (para 15(k)). However, in its **Replies to the LOI** the State party 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).

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Portugal** – advocated, facilitated and **paid for by the State party**, and perpetrated both by public university hospitals and private health-care providers – constitute a **serious breach** of Portugal's obligations under the Convention and other Covenants.

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!" According to its charter, 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, substantially contributing to the so far 42 Treaty body Concluding Observations recognising IGM as a serious human rights violation.

Since **2018**, StopIGM.org has critically followed **Portugal's legislative initiatives** aimed at combatting IGM practices, ⁶ resulting in the **current insufficient legislation**.

3. Methodology

This thematic NGO report is a localised update to the **2019 CRC Malta NGO Report (for Session)**⁷ by the same Rapporteurs.

^{1 &}lt;u>https://dre.pt/pesquisa/-/search/1159</u>33863/details/maximized

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

^{3 &}lt;u>http://zwischengeschlecht.org/post/Statuten</u>

^{4 &}lt;a href="http://intersex.shadowreport.org">http://intersex.shadowreport.org

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

^{6 &}lt;a href="http://stop.genitalmutilation.org/post/Portugal-New-law-fails-to-protect-intersex-children">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

⁷ http://intersex.shadowreport.org/public/2019-CRC-Malta-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 State⁸ to **formally outlaw** IGM practices in 2018 (Law No. 38/2018), nonetheless, as this chapter demonstrates, to this day in Portugal there remain **serious gaps** in the current legislation, which contains several **legal loopholes** and generally **falls short** of minimal requirements under CRC.

In particular, under the current law in Portugal there are

- no effective 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,
- **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 9

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. ¹⁰

b) IGM 2 "Feminising Surgery" 11

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

⁸ After Malta, see CRC/C/MLT/CO/3-6, paras 28-29

⁹ For general information, see 2016 CEDAW NGO Report France, p. 47, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

¹⁰ https://www.hospitaldaluz.pt/pt/servicos-e-medicos/especialidades/159/cirurgia-pediatrica#tabp-0

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

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"). 12

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 ¹³ – see also below p. 25) on "Laparoscopic sigmoid colon vaginoplasty" and its "surgical complications". ¹⁴

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 minimise psychosocial problems, allowing a normal sexual life, since there are no alterations in the internal organs." ¹⁵

c) IGM 1 "Masculinising Surgery" 16

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." ¹⁷

7

[&]quot;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

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

¹⁴ https://www.med.uminho.pt/en/Post-Graduation/courses/MDA/Pages/Programme.aspx

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

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

^{17 &}lt;u>http://www.pedipedia.org/pro/artigo-profissional/hipospadias</u>

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)." ¹⁸

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 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."

d) IGM 4 Prenatal "Therapy" 20

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:**

^{18 &}lt;u>http://www.pedipedia.org/pro/artigo-profissional/micropenis</u>

¹⁹ https://www.medipedia.pt/home/home.php?module=artigoEnc&id=653#4

²⁰ See 2016 CEDAW NGO Report France, p. 50, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

"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 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 introgenic Cushing syndrome, excessive weight gain, high blood pressure or gestational diabetes [1,10]." ²¹

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**. ²²

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**, ²³ which has been likened²⁴ to the insufficient²⁵ Maltese Intersex Law, and reportedly endeavours to "ban medically

https://www.researchgate.net/publication/260807640_Hiperplasia_congenita_da_suprarrenal_nao_classica_-_aspetos_relevantes_para_a_pratica_clinica

23

9

²¹ 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,

²² 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

http://app.parlamento.pt/webutils/docs/doc.pdf?path=6148523063446f764c324679626d56304c334e706447567a4c31684a5 3556c4d5a5763765130394e4c7a464451554e45544563765247396a6457316c626e527663306c7561574e7059585270646d46 446232317063334e686279387a5a4755304d44417a5a4330324d6a686a4c5451335a6a4d7459544d314f53307a4d475a6c4e5 445794f544d304d6a51756347526d&fich=3de4003d-628c-47f3-a359-30fe51293424.pdf&Inline=true

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

²⁵ See CRC/C/MLT/CO/3-6, paras 28-29

unnecessary surgery on the genitals of intersex infants". ²⁶ However, in May 2018 the Portuguese President **vetoed** this Law.

In July 2018, a revised version, **Law No. 38/2018**,²⁷ "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 ²⁸ 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):

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 harmful practices, namely IGM. Also, the Law is clearly not line with the CRC-CEDAW Joint General Recommendation No. 18/31 "on harmful practices", unmistakably obliging State parties 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),
- ensure "that the perpetrators and those who aid or condone such practices are held accountable" (JGC 18/31, para 55 (o)),

²⁶ https://www.reuters.com/article/portugal-lgbt-lawmaking/portugal-approves-law-to-boost-transgender-rights-protect-intersex-infants-idUSL1N1RQ0ZP

²⁷ https://dre.pt/pesquisa/-/search/115933863/details/maximized

^{28 &}lt;a href="http://stop.genitalmutilation.org/post/Portugal-New-law-fails-to-protect-intersex-children">https://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

- guarantee "equal access to legal remedies and appropriate reparations" to survivors (JGC 18/31, para 55 (q)),
- 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))

In particular, the Portuguese Intersex Law fails to include the following necessary provisions in line with the JGC 18/31 and previous Concluding observations 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 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 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**: ²⁹

"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**." ³⁰

"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." ³¹

"Criminalization of FGM has brought so far to a public known case, which finally did not end in prosecution." ³²

This discrepancy is also evident in the **State party's reply to the List of Issues** concerning **data collection and monitoring**: Concerning FGM, the State party notes that it "has already implemented the disaggregation of [...] the crime of female genital mutilation" (para 12) and

-

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

³⁰ United to End FGM (UEFGM), https://uefgm.org/index.php/legislative-framework-pt/

³¹ APF, End FGM European Network (2018), Joint Shadow Report – PORTUGAL, p. 3, https://rm.coe.int/shadow-report-portugal-v4/16808b5f67

³² Ibid., p. 7

provide figures of registered cases (para 96), concerning **intersex children** ³³ the State party claims, "*No cases were reported in 2016, 2017 and 2018 (source: Ministry of Justice)*" (para 100), and concerning **IGM** ³⁴ the State party **fails to provide any answer at all**, respectively erroneously claims to provide an answer in the reply on children living in prison (para 101).

And while the State party further claims that its new National Strategy for Equality and Non-Discrimination 2018–2030 (NSEND) 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 (Replies to LOI, 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 CRC art. 24(3) and the Joint General Comment No. 18**, 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, the Portuguese government 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 LOI (see 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.³⁵ 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.

34 See LOI, para 15(k)

³³ See LOI, para 15(j)

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 CRC's previous recommendations e.g. to Malta, Belgium, South Africa, Denmark and Switzerland):

Harmful practices: Intersex genital mutilation

The Committee remains seriously concerned about cases of medically unnecessary and irreversible surgery and other treatment on intersex children both domestic and overseas, without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases.

In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices, the Committee recommends that the State party:

- (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, including extraterritorial protections, 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 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 CRC

1. The Treatment of Intersex Children in Portugal as Harmful Practice and Violence a) Harmful Practice (art. 24(3) and JGC No. 18) ³⁶

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.³⁷

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.³⁸

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.³⁹

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.⁴⁰

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

[&]quot;Data collection and monitoring" (paras 37–39)

[&]quot;Legislation and its enforcement" (paras 40–55), particularly:

[&]quot;adequate civil and/or administrative legislative provisions" (para 55 (d))

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

³⁷ UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 371

³⁸ 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

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)

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

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 Portugal – 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) 41

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]", ⁴² 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", ⁴³ 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

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

[&]quot;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 (0))

[&]quot;equal access to legal remedies and appropriate reparations in practice" (para 55 (q)).

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

⁴² CRC/C/ZAF/CO/2, 27 October 2016 paras 39–40

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

victims of such treatment, including adequate compensation". 44

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 **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 even once they do. ⁴⁵ So far there was no case of a victim of IGM practices succeeding in going to a Portuguese court.

_

⁴⁴ CRC/C/DNK/CO5, 26 October 2017, para 24

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 – Background: Intersex, IGM, Harmful Practices and Stereotypes

1. IGM: Involuntary, unnecessary and harmful practices, based on stereotypes and prejudice

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. ⁴⁶

In **regions without universal access to paediatric health care**, there are reports of **infanticide**⁴⁷ of intersex children, of **abandonment**, ⁴⁸ of **expulsion**, ⁴⁹ of **massive bullying** preventing the persons concerned from attending school (recognised by CRC as amounting to a harmful practice), ⁵⁰ and of **murder**. ⁵¹

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**. ^{.52} ⁵³ ⁵⁴ ⁵⁵

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

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://intersex.shadowreport.org/public/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-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda; for Uganda, see also 2015 CRC Briefing Intersex-IGM web.pdf
For Kenya, see also 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://intersex-NGO-Statement-05-07-2018

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

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 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

⁵¹ For example in Kenya, see https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/

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

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**, ⁵⁶ 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.⁵⁷ UN Treaty bodies have so far issued 42 Concluding Observations condemning IGM practices accordingly.⁵⁸

2. 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

- 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
- 54 "The Racist Roots of Intersex Genital Mutilations" http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM
- 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
- 56 See "IGM Practices Non-Consensual, Unnecessary Medical Interventions", ibid., p. 38–47
- 57 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
- 58 <u>http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations</u>
- 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

3. Harmful Stereotypes (2): Intersex is NOT THE SAME as Transgender or LGBT

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^{61 62} 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, ⁶³ 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.⁶⁴

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", 65 and again IGM survivors as "transgender children", 66 "transsexual children who underwent difficult treatments and surgeries", and IGM as a form of "discrimination against transgender and intersex children" 67 and as "sex assignment surgery" while referring to "access to gender reassignment-related treatments". 68

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", ⁶⁹ "a special provision on sexual orientation and

⁶¹ CRC67 Denmark, http://stop.genitalmutilation.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark

⁶² CEDAW66 Ukraine, http://stop.genitalmutilation.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics

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

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

⁶⁵ CAT60 Argentina, http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60

 $^{66 \}quad CRC77 \; Spain, \\ \underline{\text{http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children}$

⁶⁷ CRC76 Denmark, http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67

⁶⁸ CAT/C/DNK/QPR/8, para 32

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" ⁷⁰, transgender guidelines ⁷¹ or "Gender Identity" ⁷² ⁷³ 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** ⁷⁴ and public **representation**. ⁷⁵

4. Harmful Stereotypes (3): Misrepresenting Genital Mutilation as "Health Care"

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as** "health-care issue" instead of a serious human rights violation, and the **promotion of** "self-regulation" of **IGM by the current perpetrators** ⁷⁶ ⁷⁷ ⁷⁸ – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

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.⁷⁹

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

⁷⁰ CCPR120 Switzerland, http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120

⁷¹ CAT56 Austria, http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations

⁷² CAT60 Argentina, http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture

⁷³ CRPD18 UK, http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

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

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

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

⁷⁸ For example CEDAW Italy (2017), see http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN

⁷⁹ See for example Ministry of Health Chile (2016), http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile

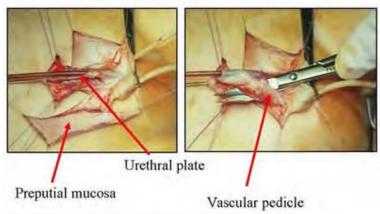
Annexe 3 – "IGM in Medical Textbooks: Current Practice"

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.

Onlay island flap urethroplasty



Onlay / Duckett - results

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



- No standardized procedures
- Personal experience of the surgeon
- Importance of a uroendocrine 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 wellvascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
- Suprapublic diversion ?
 Elbakry











Bad cosmetic result



infection



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

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

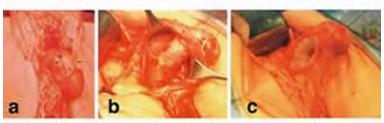
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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

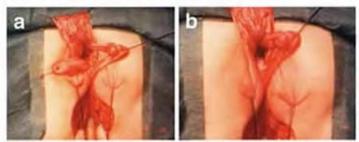
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "in the first 2 years of life", most commonly "between 6 and 12 months," and only 10.5% of surgeons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



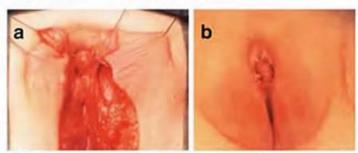
Source: Christian Radmayr: Molekulare Grundlagen und Diagnostik des Intersex, 2004



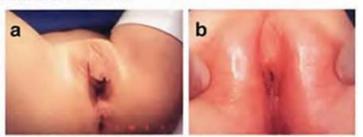
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



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



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



9a+b: Klitorisreduktion und Rekonstruktion des Praeputium clitoridis bei Prader IV.

Source: Finke/Höhne: Intersexualität bei Kindern, 2008

Caption 8b: "Material shortage" [of skin] while reconstructing the praeputium clitoridis and the inner labia.



Source: Pierre Mouriquand: "Chirurgie des anomalies du développement sexuel - 2007", at 81: "Labioplastie"

IGM 3 - Sterilising Surgery: Castration / "Gonadectomy" / Hysterectomy

Removal of healthy testicles, ovaries, or ovotestes, and other potentially fertile reproductive organs. "46,XY Complete Androgen Insufficiency Syndrome (CAIS)" is arguably the 3rd most common diagnosis for cosmetic genital surgeries, other diagnoses include "46,XY Partial Androgen Insufficiency Syndrome (PAIS)", male-assigned persons with "46,XX Congenital Adrenal Hyperplasia (CAH)", and other male assigned persons, who have their healthy ovaries and/or uteruses removed.

Castrations usually take place under the pretext of an allegedly blanket high risk of cancer, despite that an actual high risk which would justify immediate removal is only present in specific cases (see table below), and the admitted true reason is "better manageability." Contrary to doctors claims, it is known that the gonads by themselves are usually healthy and "effective" hormone-producing organs, often with "complete spermatogenesis [...] suitable for cryopreservation."

Nonetheless, clinicians still continue to recommend and perform early gonadectomies – despite all the known negative effects of castration, including depression, obesity, serious metabolic and circulatory troubles, osteoporosis, reduction of cognitive abilities, loss of libido. Plus a resulting lifelong dependency on artificial hormones (with adequate hormones often not covered by health insurance, but to be paid by the survivors out of their own purse).



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

Source: Maria Marcela Bailez: "Intersex Disorders," in: P. Puri and M. Höllwarth (eds.), *Pediatric Surgery: Diagnosis and Management*, Berlin Heidelberg 2009.

Table 1. Prevalence of type II GCT in various forms of DSD

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

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome,

* Might reach more than 30%, if gonadectomy has not been performed.

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



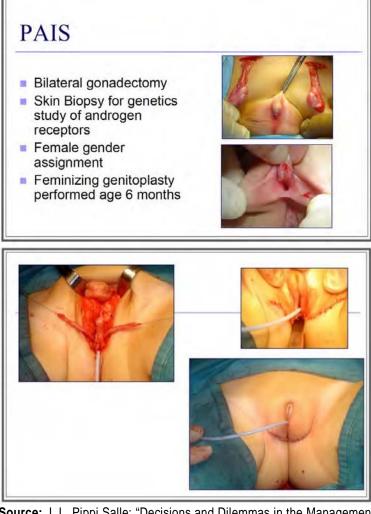
Source: J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

"Bad results" / "Gonadectomy, Feminising Genitoplasty"



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

to the 5th to 6th Report of Portugal on the Convention on the Rights of the Child (CRC)