Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for LOIPR)
to the 3rd Report of Malta on the
International Covenant on Civil and Political Rights
(CCPR)

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Table of Contents

IGM Practices in Malta (p. 5-20)

Executive Summary	4
Suggested Question for the LOIPR	
Introduction	
1. Malta: Intersex, IGM and Human Rights	
2. About the Rapporteurs	
3. Methodology	
A. Precedents: Concluding Observations	
1. Harmful Practices, CRC-CEDAW Joint Gen. Comm. No. 18/31, Target 5.3 SDG	
a) CRC 2019 Concl Obs: CRC/C/MLT/CO/3-6, paras 28-29	
B. IGM in Malta: Pervasive despite prohibition, Gov fails to act	9
1. IGM practices in Malta: Pervasive both domestic and overseas due to loopholes	
2. Most Common IGM Forms advocated by and perpetrated by Malta	9
a) IGM 1 "Masculinising Surgery" practiced domestically in Malta	
b) IGM 2 "Feminising Surgery" practiced in Contractual Hospitals overseas	12
c) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy	13
d) IGM 4 – Prenatal "Therapy"	
3. IGM in Malta as a Violation of the Covenant	15
Art. 3: Equal Right of Men and Women	
Art. 7: Cruel, Inhuman or Degrading Treatment, and Involuntary Experimentation	
Art. 9: Liberty and Security of the Person	
Art. 17: Arbitrary or Unlawful Interference with Privacy	
Art. 24: Child Protection	
Art. 26: Equal Protection of the Law	
4. How the Maltese GIGESC Act fails Intersex Children	
5. Maltese Doctors and Government consciously dismissing Intersex Human Rights	
6. Lack of Independent Data Collection and Monitoring	
7. Obstacles to redress, fair and adequate compensation	
Annexe 1 – Intersex, IGM and Non-Derogable Human Rights	
1. Intersex = variations of reproductive anatomy	
2. IGM = Involuntary, unnecessary and harmful interventions	
3. Intersex is NOT THE SAME as LGBT or Transgender	
4. IGM is NOT a "Discrimination" Issue	
5. IGM is NOT a "Health" Issue	
Annexe 2 – "IGM in Medical Textbooks: Current Practice"	
IGM 1 – "Masculinising Surgery": "Hypospadias Repair"	
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"	27
IGM 3 – Sterilising Surgery: Castration / "Gonadectomy" / Hysterectomy	
"Bad results" / "Gonadectomy, Feminising Genitoplasty"	31

Executive Summary

Despite a pioneering formal prohibition introduced in 2015, all typical forms of Intersex Genital Mutilation are still practised in Malta, facilitated and paid for by the State party via the public health system, perpetrated both domestically and in contractual hospitals overseas. A 2018 amendment eventually also introduced sanctions for IGM, described by the Government as "equalis[ing] the penalties applicable to intersex genital mutilation to the penalties applicable to female genital mutilation". However, this claim is not true.

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 the ongoing IGM practices in Malta as a harmful practice and urged the State party to "[e]nsure that intersex children are not subjected to unnecessary medical or surgical procedures during infancy or childhood" and to "[i]nvestigate effectively incidents of surgical and other medical treatment of intersex children without informed consent and provide redress to victims of such treatment, including adequate compensation and rehabilitation" (CRC/C/MLT/CO/3-6, paras 28-29). To this day, the State party fails to act.

Malta 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 CCPR, CRC, CEDAW, CAT, and CRPD have so far issued 50 Concluding Observations recognising IGM as a serious violation of non-derogable human rights, typically obliging State parties to enact legislation to (a) end the practice and (b) ensure redress and compensation, plus (c) access to free counselling. Also, the UN Special Rapporteurs on Torture (SRT) and on Health (SRH), the UN High Commissioner for Human Rights (UNHCHR), the World Health Organisation (WHO), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples' Rights (ACHPR) and the Council of Europe (COE) recognise IGM as a serious violation of non-derogable human rights.

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

IGM practices include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures based on prejudice 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, human experimentation and denial of needed health care.

IGM Practices cause known lifelong severe physical and mental pain and suffering.

This NGO Report has been compiled by StopIGM.org / Zwischengeschlecht.org, an international intersex NGO. It contains Suggested Questions (see opposite p. 5).

Suggested Question for the LOIPR

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

Intersex genital mutilation (arts. 2, 3, 7, 24, 26)

- How many non-urgent, irreversible surgical and other procedures have been undertaken on intersex children before an age at which they are able to provide informed consent? Please provide detailed statistics on sterilising, feminising, masculinising procedures and imposition of hormones, including prenatal procedures.
- What measures does the State party plan to improve its legislation in order to effectively stop this practice?
- Please indicate which criminal or civil remedies are available for intersex people who have undergone involuntary sterilisation or unnecessary and irreversible medical or surgical treatment when they were children and whether these remedies are subject to any statute of limitations?
- Please indicate which means of rehabilitation are available for intersex people who have undergone involuntary procedures?

Introduction

1. Malta: Intersex, IGM and Human Rights

In 2013, the 3rd International Intersex Forum took place in Malta (with the Rapporteurs present, see also on the cover and below) and issued a groundbreaking public statement calling for legislative measures to end mutilating genital surgeries, non-consensual sterilisation and infanticide of intersex children, and to ensure adequate redress and the right to truth to IGM survivors. One session of the Forum was also attended by Helena Dalli, Minister for Social Dialogue, Consumer Affairs, and Civil Liberties. In 2015, Minister Dalli introduced the Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC Act), which formally outlawed, and after a 2018 amendment also sanctioned IGM, in a move described by the Government as "equalis[ing] the penalties applicable to intersex genital mutilation to the penalties applicable to female genital mutilation". However, as this NGO report demonstrates, the current legislation contains only comparatively weak sanctions, no extraterritorial protections but several legal loopholes and is generally not enforced.

In 2019, Malta has been reviewed by CRC which recognised "medically unnecessary" "surgical and other procedures" on intersex children "without their consent" in Malta as constituting a harmful practice and, referring to the CEDAW/CRC Joint General Comment No. 31/18 and target 5.3 of the Sustainable Development Goals, urged the State party to "[e]nsure that intersex children are not subjected to unnecessary medical or surgical procedures during infancy or childhood" and to "[i]nvestigate effectively incidents of surgical and other medical treatment of intersex children without informed consent and provide redress to victims of such treatment, including adequate compensation and rehabilitation" (CRC/C/MLT/CO/3-6, paras 28-29). However, despite promising an Interministerial Committee to follow-up on the (lack of) implementation of the Law, to this day, the State party fails to act.

As this Thematic NGO Report demonstrates, the current and **ongoing harmful medical practice on intersex children in Malta** – advocated, facilitated and **paid for by the State party**, and perpetrated both **domestically** in a local public university hospital and **overseas** in foreign contractual hospitals – constitutes a **serious breach** of Malta'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!*" ² According to its charter, ³ StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to relevant UN treaty bodies, often in collaboration with local intersex persons and organisations, ⁴ substantially

^{1 &}lt;a href="https://stopigm.org/post/Public-Statement-by-the-Third-International-Intersex-Forum-Malta-2013">https://stopigm.org/post/Public-Statement-by-the-Third-International-Intersex-Forum-Malta-2013

^{2 &}lt;a href="https://Zwischengeschlecht.org/">https://Zwischengeschlecht.org/ English homepage: https://StopIGM.org/

^{3 &}lt;a href="https://zwischengeschlecht.org/post/Statuten">https://zwischengeschlecht.org/post/Statuten

^{4 &}lt;u>https://intersex.shadowreport.org</u>

contributing to the so far 50 Treaty body Concluding Observations recognising IGM as a serious human rights violation.⁵

In 2013, the Rapporteurs took part in the 3rd International Intersex Forum in Malta and suggested the inclusion of "legislative measures" (to end IGM practices), access to "adequate redress" and the "right to truth" (for IGM survivors) in the public statement. On request, the Rapporteurs provided Minister Dalli's office with data proving that intersex births also take place in Malta and that IGM practices are part of the surgical training in Malta.

3. Methodology

This thematic NGO report is a localised update to the **2019 CRC Malta NGO Report (for Session)**⁶ by the same Rapporteurs.

 $\underline{ https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations}\\$

 $[\]underline{ https://intersex.shadowreport.org/public/2019-CRC-Malta-NGO-Zwischengeschlecht-Intersex-IGM.pdf}\\$

A. Precedents: Concluding Observations

- 1. Harmful Practices, CRC-CEDAW Joint Gen. Comm. No. 18/31, Target 5.3 SDG
- a) CRC 2019 Concl Obs: CRC/C/MLT/CO/3-6, paras 28-29

E. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39)

Harmful practices

28. While welcoming the State party's efforts to eliminate harmful practices against children, including the amendment to article 251 of the Criminal Code that criminalizes female genital mutilation, forced sterilization and forced marriage, and the adoption of the Gender Identity, Gender Expression and Sex Characteristics Act which provides for the recognition of gender identity on the basis of a person's self-identification rather than harmful medical and surgical requirements, the Committee remains concerned:

[...]

- (b) That there are cases of intersex children who have allegedly been subjected to surgical and other procedures, which were medically unnecessary, without their consent to such procedures, which often entail irreversible consequences and can cause severe physical and psychological suffering; and at the lack of redress and compensation in such cases.
- 29. With reference to joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices, and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

[...]

- (d) Ensure that intersex children are not subjected to unnecessary medical or surgical procedures during infancy or childhood, and guarantee the bodily integrity, autonomy and self-determination of the children concerned, and provide families with intersex children with adequate counselling and support;
- (e) Investigate effectively incidents of surgical and other medical treatment of intersex children without informed consent and provide redress to victims of such treatment, including adequate compensation and rehabilitation.

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

1. IGM practices in Malta: Pervasive both domestic and overseas due to loopholes

While Malta has to be commended for being the first State to formally outlaw IGM practices in the GIGESC Act 2015, and in 2018 amending the law to include sanctions in a move described by the Government as "equalis[ing] the penalties applicable to intersex genital mutilation to the penalties applicable to female genital mutilation". However, as this chapter demonstrates, this is far from true, as to this day in Malta 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 Malta there are

- no effective legal or other protections in place to prevent all IGM practices, both domestic and overseas, as stipulated in art. 24(3) and the Joint General Comment No. 18
- **no extraterritorial protections** in place, while children continue to be sent overseas for IGM by the Government
- no measures in place to ensure **data collection** and **monitoring** of IGM practices
- no effective legal measures in place to ensure the accountability of all IGM perpetrators and accessories
- no effective legal measures in place to ensure access to redress and justice for adult IGM survivors

To this day **all forms of IGM practices remain widespread and ongoing** in Malta (CRC/C/MLT/CO/3-6, paras 28-29), both domestic and overseas, persistently **advocated**, **prescribed and perpetrated** in **domestic** state funded University Children's Hospitals and contractual hospitals **overseas**, reportedly in the **UK** (see also CRC/C/GBR/CO/5, paras 46-47; CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41; CAT/C/GBR/CO/6, paras 64-65), **Belgium** (see also CCPR/C/BEL/CO/6, paras 21-22; CRC/C/BEL/CO/5-6, paras 25(b)+26(e)) and **Italy** (see also CRC/C/ITA/CO/5-6, para 23; CRPD/C/ITA/CO/1, paras 45-46), **advocated and paid for by the State party** via the public health system, as well as by private health insurances.

While Malta meanwhile **officially recognises** the serious human rights violations and suffering caused by IGM practices, **aims to protect** intersex children at risk of IGM no less than girls at risk of FGM, and **promises to follow-up on the (lack of) implementation** of the GIGESC Act formally prohibiting IGM practices, to this day the State party **fails to act accordingly**, as well as **to collect and disseminate disaggregated data** on IGM practices, therefore **allowing IGM practices to continue with impunity**.

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

This section demonstrates that Maltese intersex children continue to be submitted to IGM practices, advocated, facilitated and paid for by the State party via the public health system, as well as by private health insurances, and perpetrated both domestically in a local public university hospital and overseas in foreign contractual hospitals:

a) IGM 1 "Masculinising Surgery" 7 practiced domestically in Malta

• As advocated by the "Urology Outreach" at the Mater Dei Hospital (a service under the auspices of the Ministry for Health, offering "Advice and support to healthcare staff")⁸ on its official Facebook page:⁹

"Hypospadias

Hypospadias is a **birth abnormality** of the urethra (the tube through which urine flows out of the body) where the urinary opening is not at the usual location on the head of the penis. **It is the second-most common birth abnormality of the male reproductive system.** There are various locations where the meatus (the opening) may be located.

[...] This often causes spraying or deflected urine flow and those who suffere [sic] from it often pee whilst sitting down. [...]

Diagnosis is often confirmed during exanmination [sic] and treatment is by surgery, sometimes more than one episode as indicated."

• As advocated at the **Sixth Malta Medical School Conference** (2006) by paediatric surgeon Dr **Chris Fearne** (then Paediatric Surgical Unit, **St Luke's Hospital**, since 2016 **Minister of Health**), dryly admitting that **cosmetic hypospadias "repair" surgery** inevitably leads to **impairment or "loss of [sexual] sensation"** due to "scarring and disruption of the blood supply", while presenting an **experimental surgical technique** studied on **10 intersex children** with hypospadias "over a two year period at St Luke's Hospital": ¹⁰

"The classical aims of hypospadias surgery are 1. An appropriate urinary steam from the tip, 2. correction of chordee and 3. **good cosmesis**. To these one might add the **preservation of sensation**."

• As advocated at the **Seventh Malta Medical School Conference** (2009) by paediatric surgeons Dr J. Galea (Department of Surgery, Mater Dei Hospital, Malta) and Dr J. Cauchi (Department of Paediatric Surgery, Mater Dei Hospital, Malta), openly admitting that in **cosmetic hypospadias "repair" surgery** with optimal results at the first try remains an "elusive goal", presenting another "challenging" surgical experiment on 3 intersex children with hypospadias at Mater Dei Hospital:¹¹

"A one stage hypospadias repair with universal acceptance and consistent results remains an elusive goal. The number of repair techniques reflects the challenging nature of this condition. The aim of this paper is to present our experience with a two-stage repair in 3 different defects in order to illustrate the versatility of this approach."

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

⁸ https://deputyprimeminister.gov.mt/en/MDH/Pages/MDH-Urology-Outreach.aspx

⁹ Urology Outreach (10.04.2017), "Hypospadias", https://www.facebook.com/urologyoutreach/posts/1697135603648023

¹⁰ C Fearne (2006), "O-103: Modified Mathieu procedure for hypospadias repair", presentation at Sixth Malta Medical School Conference, abstract book p. 38, https://www.um.edu.mt/library/oar/handle/123456789/15834

J Galea, J Cauchi (2009), "PED 27: Two-stage hypospadias repair with free preputial graft - The spectrum of management", presentation at Seventh Malta Medical School Conference, abstract book p. 82, https://www.um.edu.mt/library/oar/handle/123456789/15864

• The Association of Surgeons of Malta (ASM)¹² and the Ministry for Health¹³ advocate and train cosmetic hypospadias "repair" surgery in the "Malta Plastic Surgery SAC Curriculum 2014", ¹⁴ which offers under "Genitourinary Reconstruction" a "Module 1: Hypospadias and allied conditions" (p. 163-165) aimed at:

"Objective: Acquire competence in the management of hypospadias and allied conditions including management of the family in addition to all aspects of the surgical management and complications."

The language of the Curriculum is telling, describing hypospadias as a "deformity" and a person with repeat "failed" hypospadias surgeries, which the doctors have given up as hopeless cases, as "hypospadias salvage/cripple patient" (p. 164).

• As advocated by the **private health insurance company Bupa** on its homepage on "Surgical correction of hypospadias": 15

"About surgical correction of hypospadias

[...] Surgical correction can create a urethral opening at the tip of your son's penis and straighten his penis to make it look as **normal** as possible. **Surgery is commonly carried out in babies aged between four and 18 months.** [...]"

"Recovering from surgical correction of hypospadias

[...] Contact the hospital or your GP if:

- your son complains of severe pain or shows signs that the pain is getting worse for example, babies and toddlers may cry more and may be difficult to settle
- his wound starts weeping, or you notice blood leaking from the stitches or a lot of blood in his urine (some oozing and pink spotting on the dressing or nappy are normal)
- the amount of urine from his catheter reduces or stops
- the bandage seems too tight or the tip of his penis turns blue or grey
- your son has a high temperature for more than 24 hours
- his catheter falls out"
- As advocated by the Ministry for Health in its "Factsheet: World Birth Defects Day 2019 Hypospadias" (p. 3): 16

"Management

Urologic referral is advised and is most important for patients in whom there is a potential functional issue. **Management revolves around surgical correction of the defect,** according to Keays & Dave (2017), surgical intervention for hypospadias can be

¹² http://www.asm.eu.com/surgicaltraining/trainingcurricula.html

^{13 &}lt;u>https://deputyprimeminister.gov.mt/en/regcounc/msac/Pages/training-programmes.aspx</u>

Specialist Advisory Committee (SAC) (2014), HST Training Programme and Curriculum Plastic, Reconstructive and Aesthetic Surgery,

 $[\]underline{https://deputyprimeminister.gov.mt/en/regcounc/msac/Documents/Malta\%20Plastic\%20Surgery\%20SAC\%20Curriculum\%202014.pdf}$

 $[\]underline{\text{http://www.bupa.com.mt/who-we-are/health-wellbeing/item/surgical-correction-of-hypospadias}}$

¹⁶ https://deputyprimeminister.gov.mt/en/dhir/Documents/Facts%20Sheets/World%20Birth%20Defect%20Day%202019%20Many%20Defects_One%20Voice.pdf

performed at any age, however, most authors recommend operative intervention at 6 to 18 months. The American Academy of Pediatrics suggests this period to limit psychological stress and subsequent behavioural problems which can be seen in toddlers undergoing genital surgery. [10]

Surgery for hypospadias is elective and the decision to operate is based on severity, **family** preference and surgeon's advice. [...]"

• To this day, the Maltese Association of Urology (otherwise known as the Maltese Association of Urology) ¹⁷ endorses the current 2020 Guidelines of the European Association of Urology (EAU), ¹⁸ which include the current 2020 ESPU/EAU "Paediatric Urology" Guidelines ¹⁹ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) (see p. 14). In chapter 3.5 "Hypospadias", ²⁰ the ESPU/EAU Guidelines' section 3.5.5.3 "Age at surgery" nonetheless explicitly promotes, "The age at surgery for primary hypospadias repair is usually 6-18 (24) months." ²¹ – despite admitting to the "risk of complications" ²² and "aesthetic[...]" and "cosmetic" justifications. ²³

b) IGM 2 "Feminising Surgery" ²⁴ practiced in Contractual Hospitals overseas

Apparently, the only "feminising" genital "corrective" surgery practiced domestically is the surgical construction of a vagina in case of "congenital absence of vagina (Meyer-Rokitansky Syndrome)", which is mostly done during or after adolescence, see the aforementioned "Malta Plastic Surgery SAC Curriculum 2014" ²⁵, p. 166-167.

All other "feminising" IGM surgeries, namely **clitoral "reduction" and "vaginoplasty"** including on intersex infants diagnosed with Congenital Adrenal Hyperplasia (CAH), are traditionally **referred to contractual hospitals overseas**, reportedly to the **UK**, ²⁶ **Belgium**, ²⁷ and arguably also to **Italy**. ²⁸ This is also in general terms officially admitted by the Maltese Government, ²⁹ as well as more specifically indicated in the aforementioned "*Malta Plastic*"

23 Ibid 24 For

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

¹⁷ https://maltacvs.org/voluntary/maltese-association-of-urology/

^{18 &}lt;u>https://uroweb.org/guidelines/endorsement/</u>

^{19 &}lt;a href="https://uroweb.org/guideline/paediatric-urology/">https://uroweb.org/guideline/paediatric-urology/

²⁰ https://uroweb.org/guideline/paediatric-urology/#3_5

²¹ https://uroweb.org/guideline/paediatric-urology/#3 5 5 3

²² https://uroweb.org/guideline/paediatric-urology/#3 5 5 1

²³ Ibid.

²⁵ Specialist Advisory Committee (SAC) (2014), HST Training Programme and Curriculum Plastic, Reconstructive and Aesthetic Surgery,

 $[\]underline{https://deputyprimeminister.gov.mt/en/regcounc/msac/Documents/Malta\%20Plastic\%20Surgery\%20SAC\%20Curriculum\%202014.pdf}$

²⁶ See 2017 CRPD UK NGO Report, p. 9, https://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf

²⁷ See 2018 CRC Belgium NGO Report, p. 7, https://intersex.shadowreport.org/public/2018-CRC-Belgium-NGO-Zwischengeschlecht-Intersex-IGM.pdf

Miriam Dalmas (2017), Consultant Public Health Medicine at Ministry for Health, Structures and processes for cross-border care referral, slide 5,

 $[\]underline{https://ec.europa.eu/health/sites/health/files/ern/docs/20170309\ rt3\ 05\ dalmas\ pres\ en.pdf}$

²⁹ Ibid.

Surgery SAC Curriculum 2014", 30 which on p. 167 explicitly states, "surgical correction of epispadias, female genital anomalies and ambiguous genitalia be inaccessible to many trainees", but nonetheless notes trainees

"Should demonstrate ability to formulate treatment plan for

- ambiguous genitalia – incidence, causes, associated features, investigations – chromosome profile, testosterone / sex steroid profile and approach to parents."

The Malta Association of Urology endorses the current 2020 Guidelines of the European Association of Urology (EAU), ³¹ which include the current 2020 ESPU/EAU "Paediatric Urology" Guidelines³² of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.16 "Disorders of sex development", ³³ despite admitting that "Surgery that alters appearance is not urgent" ³⁴ and that "adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent", ³⁵ the ESPU/EAU Guidelines nonetheless explicitly refuse to postpone non-emergency surgery, but in contrary insist to continue with non-emergency genital surgery (including partial clitoris amputation) on young children based on "social and emotional conditions" and substituted decision-making by "parents and caregivers implicitly act[ing] in the best interest of their children" and making "well-informed decisions [...] on their behalf", and further explicitly refusing "prohibition regulations" of unnecessary early surgery, ³⁶ referring to the 2018 ESPU Open Letter to the Council of Europe (COE), ³⁷ which further invokes parents" "social, and cultural considerations" as justifications for early surgery (p. 2).

c) IGM 3 – Sterilising Procedures practised domestically and/or overseas:
Castration / "Gonadectomy" / Hysterectomy /
Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation
Plus arbitrary imposition of hormones 38

The **Malta Association of Urology** is associated with the European Association of Urology (EAU)³⁹ which in turn is affiliated with the European Society for Paediatric Urology (ESPU).⁴⁰ The "ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"⁴¹ advocates "gonadectomies":

³⁰ Specialist Advisory Committee (SAC) (2014), HST Training Programme and Curriculum Plastic, Reconstructive and Aesthetic Surgery,

https://deputyprimeminister.gov.mt/en/regcounc/msac/Documents/Malta%20Plastic%20Surgery%20SAC%20Curriculum%202014.pdf

^{31 &}lt;a href="https://uroweb.org/guidelines/endorsement/">https://uroweb.org/guidelines/endorsement/

^{32 &}lt;a href="https://uroweb.org/guideline/paediatric-urology/">https://uroweb.org/guideline/paediatric-urology/

^{33 &}lt;u>https://uroweb.org/guideline/paediatric-urology/#3_16</u>

³⁴ https://uroweb.org/guideline/paediatric-urology/#3 16 4

³⁵ Ibid.

³⁶ Ibid.

³⁷ https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf

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

³⁹ The Malta Urology Association also endorses all EAU Guidelines, see https://uroweb.org/guidelines/endorsement/

The Malta Urology Association also endorses the ESPU/EAU "Paediatric Urology" Guidelines included in the EAU Guidelines, ibid.

P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p.

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

Also, the "2016 Global Disorders of Sex Development Consensus Statement", ⁴² which is coauthored by the "*ESPU/SPU standpoint*" co-authors Prof Dr Piet Hoebeke (UZ Ghent, Belgium, where also Maltese intersex children are sent for surgery) ⁴³ and Prof Dr Pierre Mouriquand and refers to the "*ESPU/SPU standpoint*", advocates "*gonadectomy*" – even when admitting "*low*" cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4) ⁴⁴.

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy Self-examination Annual ultrasound (post-puberty) Post-pubertal biopsy Based on ultrasound and results of first biopsy If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectom Intensive psychological
	Repeat biopsy at 10 years of age - Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	gonadectomy or follow-up GCC risk low, allow spontaneous puberty	counseling and follow-up

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174

d) IGM 4 - Prenatal "Therapy" 45

While the Rapporteurs currently have no data on **IGM 4 prenatal "therapy"**, we have to assume also this form of IGM is practiced either domestically in Malta or overseas in contractual hospitals.

^{8-10,} http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

⁴² Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, https://www.karger.com/Article/Pdf/442975

⁴³ See 2019 CCPR Belgium NGO Report, p. 15, https://intersex.shadowreport.org/public/2019-CCPR-Belgium-NGO-Intersex-StopIGM.pdf

Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, at 180 (fn 111), https://www.karger.com/Article/Pdf/442975

⁴⁵ See 2016 CEDAW NGO Report France, p. 50, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

3. IGM in Malta as a Violation of the Covenant

This Committee has already **recognised IGM** practices as a **serious violation of the Covenant**, ⁴⁶ 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, ⁴⁷ e.g. "normal" boys and girls, so that, according to a specialised surgeon, "any cutting, no matter how incompetently executed, is a kindness." ⁴⁸ 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** ⁴⁹ 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. ⁵⁰

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**. ⁵¹ For decades, intersex children have been regularly described and exploited by scientists as an "experiment of nature". ⁵² ⁵³ ⁵⁴ Often **twins, siblings, mothers or other family members or**

⁴⁶ See CCPR/C/CHE/CO/4, paras 24-25; CCPR/C/AUS/CO/6, paras 25-26; CCPR/C/BEL/CO/6, paras 21-22; CCPR/C/MEX/CO/6, paras 12-13; CCPR/C/PRT/CO/5, paras 16-17; CCPR/C/DEU/QPR/7, para 13; CCPR/C/FIN/QPR/7, para 9; CCPR/C/ESP/QPR/7, para 10

⁴⁷ Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75

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

⁴⁹ 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

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

⁵¹ See e.g. Case Study No. 1 in 2015 CAT Austria NGO Report (p. 13-15), explaining how **of two intersex cousins, one was castrated at age 5 or 6 and the other only at age 10** "to document the difference", https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf

⁵² 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

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

⁵⁴ U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied

relatives of intersex children are used as controls.⁵⁵ Generally, intersex children are often used as **subjects in scientific research**, particularly in the field of genetics.

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 Malta and associated research projects with Maltese participation including Endo-ERN" and "eUrogen" 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 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)

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

- 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
- 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, https://intersex.hypotheses.org/3976
- 57 https://endo-ern.eu/about/governance/management-board/
- 58 https://eurogen-ern.eu/coordination-visit-national-coordination-hub/
- 59 See National Coordination Hubs, p. 3, 5, 7, https://eurogen-ern.eu/wp-content/uploads/2016/11/ERN-eUROGEN-Strategy-for-Integration-of-APs.pdf
- 60 <u>https://stopigm.org/eurogen-eu-funded-intersex-genital-mutilators/</u>

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. This is also the case with the **Maltese GIGESC Act**, and clearly not in line with article 26 (see next section).

4. How the Maltese GIGESC Act fails Intersex Children

In 2015, Malta passed the Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC Act), 61 which under art. 14 explicitly makes it "unlawful" to perform IGM practices, but concerning IGM practices initially included no sanctions at all. A 2018 amendment 62 eventually introduced sanctions, namely "punishment of imprisonment not exceeding five years, or [...] a fine (multa) of not less than five thousand euro (\leq 5,000) and not more than twenty thousand euro (\leq 20,000)" (GIGESC art. 14.(2)).

The Maltese Government claims this newly introduced sanctions would "equalise the penalties applicable to intersex genital mutilation to the penalties applicable to female genital mutilation". ⁶³ However, this is **not true**, as the **sanctions for FGM are actually double** ("imprisonment for a term of five to ten years" with no possibility to get off with a fine) and included in the **Criminal Code** (art. 251E.). ⁶⁴

Similarly, **regarding IGM there are no extraterritorial protections**, while regarding FGM "extraterritoriality [is] in force, we aim to ensure that if female genital mutilation is done to girls when they go abroad, the crime will be prosecuted in Malta". 65

^{61 &}lt;u>http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1</u>

⁶² ACT No. XIII of 2018, para 31, http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=29057&l=1

Ministry for European Affairs and Equality (2018), "LGBTIQ Strategy & Action Plan 2018-2022", p. 7, available at http://www.lgbtiq.gov.mt/

^{64 &}lt;a href="http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8574">http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8574

Helena Dalli, Minister for European Affairs and Equality (04.02.2019), https://eige.europa.eu/news/female-genital-mutilation-illegal-malta-girls-are-not-safe

Thus, the GIGESC Act fails to meet the stipulation of the General Comment No. 20 explicitly obliging State parties to "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).

Further, in the case of FGM, not only those who perform the actual deed are guilty under the law, but also "[w]hosoever aids, abets, counsels, incites, procures or coerces a female to excise, infibulate or otherwise mutilate the whole or any part of her own genitalia, shall be guilty of an offence and shall be liable, on conviction, to the punishment laid down under this article." (Criminal Code, art. 251E.(6)) On the other hand, in the case of IGM the only ones punishable under the law are the "medical practitioners or other professionals" who perform the actual mutilation domestically (GIGESC art. 14.(1)+(2)), whereas doctors who refer children to be submitted to IGM in foreign hospitals (as it is often the case in Malta, see also p. 9-10) are a priori exempt from prosecution, same as whosoever aiding, abetting, counselling, inciting, procuring or coercing intersex children to be submitted to IGM.

What's more, according to statements of the Maltese Government, the law as it is **exempts IGM 1 "hypospadias repair"**, ⁶⁶ the most frequent IGM practice (and reportedly the only one that is performed in Malta itself, see also p. 10-14), as "whether cases of hypospadias are covered by the above prohibition may fall to be determined later by the courts." ⁶⁷ For other IGM practices, Malta is **sending children overseas** for surgery, reportedly to the UK, ⁶⁸ Belgium, ⁶⁹ and arguably also to Italy ⁷⁰ – **which the law does not prohibit and punish either.**

Conclusion, GIGESC art. 14 aimed at protecting intersex children from IGM practices on the one hand fails to meet the minimal requirements set out by the Covenant, particularly arts. 7 and 26, and the General Comment No. 20, particularly paras 14-15, and on the other hand so far the law is simply not enforced.

Piet de Bruyn (2017), Report: Promoting the human rights of and eliminating discrimination against intersex people, COE Doc. 14404, p. 14, para 47, http://semantic-pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbnQvbncveG1sL1hSZWYvWDJILURXL

WV4dHIuYXNwP2ZpbGVpZD0yNDAyNyZsYW5nPUVO&xsl=aHR0cDovL3NlbWFudGljcGFjZS5uZXQvWHNsdC9QZGYvWFJlZi1XRC1BVC1YTUwyUERGLnhzbA==&xsltparams=ZmlsZWlkPTI0MDI3

⁶⁷ Ibid.

See 2017 CRPD UK NGO Report, p. 9, https://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf

⁶⁹ See 2019 CCPR Belgium NGO Report, p. 15, https://intersex.shadowreport.org/public/2019-CCPR-Belgium-NGO-Intersex-StopIGM.pdf

Miriam Dalmas (2017), Consultant Public Health Medicine at Ministry for Health, Structures and processes for cross-border care referral, slide 5, https://ec.europa.eu/health/sites/health/files/ern/docs/20170309 rt3 05 dalmas pres en.pdf

5. Maltese Doctors and Government consciously dismissing Intersex Human Rights The persistence of IGM practices in Malta is a matter of public record, same as the **criticism** and appeals by intersex organisations and human rights bodies. 71 72 73 74 75

Maltese 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 Maltese government bodies continue to ignore the full human rights implications of IGM, as evidenced by statements that IGM 1 is exempt from the GIGESC Act, ⁷⁶ and the incorrect claim the sanctions introduced in 2018 would "equalise the penalties applicable to intersex genital mutilation to the penalties applicable to female genital mutilation". ⁷⁷

What's more, when confronted by CRC with the shortcomings of the GIGESC Act in 2019, the Maltese Government promised: "There will be an interministerial committee who will be following up the implementation of the law more closely, and this is currently being set up." ⁷⁸ However, so far no progress report has been made public.

6. 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 Malta, there are no statistics on intersex births and on IGM practices available.

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⁷¹ CRC/C/MLT/CO/3-6, paras 28-29

Public Statement by the Third International Intersex Forum, Malta 2013, https://stopigm.org/post/Public-Statement-by-the-Third-International-Intersex-Forum-Malta-2013

^{73 &}quot;Human rights for hermaphrodites too', international organisation tells Malta", Times of Malta, 15.05.2019, https://timesofmalta.com/articles/view/human-rights-for-hermaphrodites-too-international-organisation-tells.710086

Massimo Costa, "Intersex surgery on infants still carried out in Malta, despite ban, report indicates",
MaltaToday, 04.02.2020,
https://www.maltatoday.com.mt/news/national/100178/intersex_surgery_on_infants_still_carried_out_in_malta_despite_ban_report_indicates

John Paul Cordina, "Intersex children need stronger protections, report suggests", Newsbook, 04.02.2020, https://newsbook.com.mt/en/intersex-children-need-stronger-protections-report-suggests/

Piet de Bruyn (2017), Report: Promoting the human rights of and eliminating discrimination against intersex people, COE Doc. 14404, p. 14, para 47, <a href="http://semantic-pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbnQvbncveG1sL1hSZWYvWDJILURXLWV4dHIuYXNwP2ZpbGVpZD0yNDAyNyZsYW5nPUVO&xsl=aHR0cDovL3NlbWFudGljcGFjZS5uZXQvWHNsdC9QZGYvWFJIZi1XRC1BVC1YTUwyUERGLnhzbA==&xsltparams=ZmlsZWlkPTI0MDI3

⁷⁷ Ministry for European Affairs and Equality (2018), "LGBTIQ Strategy & Action Plan 2018-2022", p. 7, available at http://www.lgbtiq.gov.mt/

⁷⁸ See transcript CRC81 Session, https://stopigm.org/crc81-malta-questioned-about-intersex-genital-mutilation-by-un/

7. Obstacles to redress, fair and adequate compensation

Also in **Malta** 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.⁷⁹ So far, in Malta there was **no case** of a victim of IGM practices succeeding in going to court.

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

7

Globally, no survivor of early surgeries **ever** managed to have their case successfully 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 1 – Intersex, IGM and Non-Derogable Human Rights

1. Intersex = variations of reproductive anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with "Disorders" or "Differences of Sex Development (DSD)", ⁸⁰ are people born with variations of reproductive anatomy, or "atypical" reproductive organs, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**.

While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations, with **1 to 2 in 1000 newborns** at risk of being submitted to non-consensual "genital correction surgery".

For more information and references, see 2014 CRC Switzerland NGO Report, p. 7-12.81

2. IGM = Involuntary, unnecessary and harmful interventions

In "developed countries" with universal access to paediatric health care 1 to 2 in 1000 newborns are at risk of being submitted to medical IGM practices, i.e. non-consensual, unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments that would not be considered for "normal" children, practiced without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs, and often directly financed by the state via the public health system.⁸²

In regions without universal access to paediatric health care, there are reports of infanticide⁸³ of intersex children, of abandonment, ⁸⁴ of expulsion, ⁸⁵ of massive bullying preventing the

https://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf
For South Africa, see also https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens

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

https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda; for Uganda, see also 2015 CRC Briefing, slide 46,

 $\underline{https://intersex.shadowreport.org/public/Zwischengeschlecht_2015\text{-}CRC\text{-}Briefing_Intersex\text{-}IGM_web.pdf}$

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

For Mexico, see 2018 CEDAW NGO Joint Statement,

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

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

https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda
For example in China, see 2015 Hong Kong, China NGO Report, p. 15,

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

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

⁸¹ https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM v2.pdf

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

For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, https://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf
For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12,

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

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

Both in "developed" and "developing" countries, **harmful stereotypes and prejudice** framing intersex as "**inferior**", "**deformed**", "**disordered**", "**degenerated**" or a "**bad omen**" remain widespread, and to this day inform the current harmful **western medical practice**, as well as other practices including **infanticide** and **child abandonment**.

Typical forms of medical IGM include "feminising" or "masculinising", "corrective" genital surgery, sterilising procedures, imposition of hormones (including prenatal "therapy"), forced genital exams, vaginal dilations, medical display, human experimentation, selective (late term) abortions and denial of needed health care.

Medical IGM practices are known to cause **lifelong severe physical and mental pain and suffering**, ⁹² including loss or impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, incontinence, problems with passing urine (e.g. due to urethral stenosis after surgery), increased sexual anxieties, problems with desire, less sexual activity, dissatisfaction with functional and aesthetic results, lifelong trauma and mental suffering, elevated rates of self-harming behaviour and suicidal tendencies comparable to those among women who have experienced physical or (child) sexual abuse, impairment or loss of reproductive capabilities, lifelong dependency on daily doses of artificial hormones.

UN Treaty bodies and other human rights experts have consistently recognised IGM practices as a serious violation of non-derogable human rights. ⁹³ UN Treaty bodies have so far issued 50 Concluding Observations condemning IGM practices accordingly. ⁹⁴

- For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda
- For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see https://stopigm.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3
- 87 For example in Kenya, see https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/
- 88 2014 CRC NGO Report, p. 52, 69, 84, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf
- In the WHO "World Atlas of Birth Defects (2nd Edition)", many intersex diagnoses are listed, including "indeterminate sex" and "hypospadias":

 http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf
- 90 "The Racist Roots of Intersex Genital Mutilations" https://stopigm.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM
- 91 For 500 years of "scientific" prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
- 92 See "IGM Practices Non-Consensual, Unnecessary Medical Interventions", ibid., p. 38–47
- 93 CAT, CRC, CRPD, SPT, SRSG VAC, COE, ACHPR, IACHR (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E
- 94 https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

3. Intersex is NOT THE SAME as LGBT or Transgender

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

The underlying reasons for such harmful misrepresentations include lack of awareness, third party groups instrumentalising intersex as a means to an end^{95 96} for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

Intersex persons and their organisations have spoken out clearly against instrumentalising or misrepresenting intersex issues, 97 maintaining that IGM practices present a distinct and unique issue constituting significant human rights violations, which are different from those faced by the LGBT community, and thus need to be adequately addressed in a separate section as specific intersex issues.

Also, human rights experts are increasingly warning of the harmful conflation of intersex and LGBT 98 99

Regrettably, these harmful misrepresentations seem to be on the rise also at the UN, for example in recent UN press releases and Summary records misrepresenting IGM as "sex alignment surgeries" (i.e. voluntary procedures on transsexual or transgender persons), IGM survivors as "transsexual children", and intersex NGOs as "a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination", 100 and again IGM survivors as "transgender children", 101 "transsexual children who underwent difficult treatments and surgeries", and IGM as a form of "discrimination against transgender and intersex children" 102 and as "sex assignment surgery" while referring to "access to gender reassignment-related treatments". 103

Particularly State parties are constantly misrepresenting intersex and IGM as sexual orientation or gender identity issues in an attempt to deflect from criticism of the serious human rights violations resulting from IGM practices, instead referring to e.g. "gender reassignment surgery" (i.e. voluntary procedures on transsexual or transgender persons) and "gender assignment surgery for children", 104 "a special provision on sexual orientation and

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

 $CEDAW 66\ Ukraine, \ \underline{https://stopigm.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics}$ 96

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

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

²⁰¹⁸ Report of the Kenya National Commission on Human Rights (KNCHR), p. 15, https://www.knchr.org/Portals/0/GroupRightsReports/Equal%20In%20Dignity%20and%20Rights_Promoting% <u>20The%20Rights%20Of%20Intersex%20Persons%20In%20Kenya.pdf?ver=2018-06-06-161118-323</u>

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

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

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

¹⁰³ CAT/C/DNK/QPR/8, para 32

¹⁰⁴ CRC73 New Zealand, https://stopigm.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child

gender identity", "civil registry" and "sexual reassignment surgery" ¹⁰⁵, transgender guidelines ¹⁰⁶ or "Gender Identity" ¹⁰⁷ ¹⁰⁸ when asked about IGM by e.g. Treaty bodies.

What's more, **LGBT organisations** (including "LGBTI" organisations without actual intersex representation or advocacy) are using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus **depriving actual intersex organisations** (which mostly have no significant funding, if any) of much needed **resources** ¹⁰⁹ and public **representation**. ¹¹⁰

4. IGM is NOT a "Discrimination" Issue

An interrelated diversionary tactic is the increasing misrepresentation by State parties of IGM as "discrimination issue" instead of a serious violation of non-derogable human rights, namely inhuman treatment and a harmful practice, often in combination with the misrepresentation of intersex human rights defenders as "fringe elements", and their legitimate demands and criticism of such downgrading and trivialising of IGM as "extreme views".

5. IGM is NOT a "Health" Issue

An interrelated, alarming new trend is the increasing misrepresentation of IGM as "health-care issue" instead of a serious violation of non-derogable human rights, and the promotion of "self-regulation" of IGM by the current perpetrators 111 112 113 114 — instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health Ministries** construe UN Concluding observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse for "self-regulation" promoting state-sponsored IGM practices to continue with impunity.** 115 116 117

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

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

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

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

¹⁰⁹ For example in Scotland (UK), LGBT organisations have so far collected at least £ 135,000.— public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, https://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf
Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as "supporting intersex people", but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), https://stopigm.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

¹¹⁰ See e.g. "Instrumentalizing intersex: 'The fact that LGBTs in particular embrace intersex is due to an excess of projection' - Georg Klauda (2002)", https://stopigm.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002

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

For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, https://stopigm.org/public/S3 Zwischengeschlecht UN-Expert-Meeting-2015 web.pdf

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

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

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

¹¹⁶ For example Ministry of Health France (2018), see 2020 CRC Intersex NGO Report (for LOIPR), p. 19, https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf

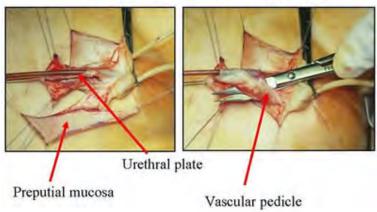
Annexe 2 – "IGM in Medical Textbooks: Current Practice"

IGM 1 - "Masculinising Surgery": "Hypospadias Repair"

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

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

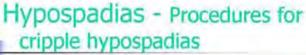
Onlay island flap urethroplasty



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)

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



- 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



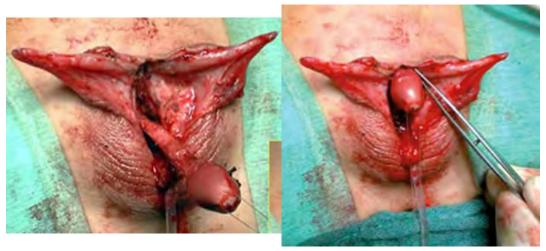
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

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

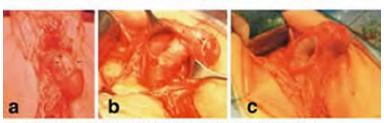
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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").

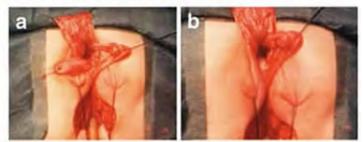
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "in the first 2 years of life", most commonly "between 6 and 12 months," and only 10.5% of surgeons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



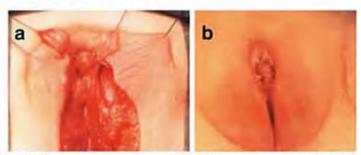
Source: Christian Radmayr: Molekulare Grundlagen und Diagnostik des Intersex, 2004



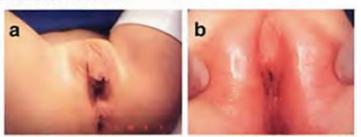
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



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).



91 M.M. Bailez • Intersex Disorders

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

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

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

Risk	Type of DSD	Preva- lence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15-40
Intermediate	PAIS 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.



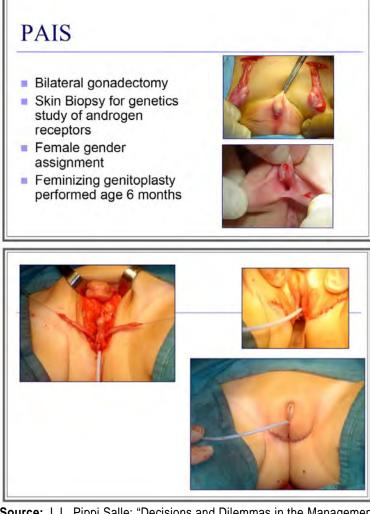
Source: J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

"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.