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



NGO Report to the 3rd to 6th Report of Malta on the Convention on the Rights of the Child (CRC) Compiled by:

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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.

Malta 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 **40** Concluding Observations on IGM, 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 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 3rd to 6th Report of Malta on the Convention on the Rights of the Child (CRC)

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A. Introduction

1. Malta: Intersex Human Rights and State Report

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.¹ 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**.

Notably, Malta's 3^{rd} to 6^{th} State report to CRC did mention intersex, but only in the context of "*The Trans, Gender Variant and Intersex Students in Schools Policy (2015)*" (para 42), but didn't mention IGM. However, this Thematic NGO Report demonstrates that the current 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 Convention.

2. About the Rapporteurs

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

• StopIGM.org / Zwischengeschlecht.org is an international intersex human rights NGO based in Switzerland, working to end IGM practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!*" ² According to its charter, ³ StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to relevant UN treaty bodies, often in collaboration with local intersex persons and organisations, ⁴ substantially contributing to the so far 40 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.

^{1 &}lt;u>http://stop.genitalmutilation.org/post/Public-Statement-by-the-Third-International-Intersex-Forum-Malta-2013</u>

^{2 &}lt;u>http://Zwischengeschlecht.org/</u> English homepage: <u>http://stop.genitalmutilation.org</u>

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

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

^{5 &}lt;u>http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations</u>

3. Methodology

This thematic NGO report is a localised update to the **2018 CRC Belgium NGO Report (for Session**)⁶ by partly the same Rapporteurs.

 $^{6 \}qquad \underline{http://intersex.shadowreport.org/public/2018-CRC-Belgium-NGO-Zwischengeschlecht-Intersex-IGM.pdf}$

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 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 CRC.

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, 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), **Belgium** (see also 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, and **aims to protect** intersex children at risk of IGM no less than girls at risk of FGM, to this day the State party **fails to collect and disseminate disaggregated data** on IGM practices and **allows 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 examination [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, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

^{8 &}lt;u>https://deputyprimeminister.gov.mt/en/MDH/Pages/MDH-Urology-Outreach.aspx</u>
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, <u>https://www.um.edu.mt/library/oar/handle/123456789/15834</u>

¹¹ 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"

b) IGM 2 "Feminising Surgery" ¹⁶ 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*" ¹⁷, p. 166-167.

^{12 &}lt;u>http://www.asm.eu.com/surgicaltraining/trainingcurricula.html</u>

^{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,

https://deputyprimeminister.gov.mt/en/regcounc/msac/Documents/Malta%20Plastic%20Surgery%20SAC%20Curriculum%202014.pdf15http://www.bupa.com.mt/who-we-are/health-wellbeing/item/surgical-correction-of-hypospadias

¹⁶ For general information, see 2016 CEDAW NGO Report France, p. 48, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

¹⁷ Specialist Advisory Committee (SAC) (2014), HST Training Programme and Curriculum Plastic,

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,¹⁸ Belgium,¹⁹ and arguably also to Italy.²⁰ This is also in general terms officially admitted by the Maltese Government, ²¹ as well as more specifically indicated in the aforementioned "Malta Plastic Surgery SAC Curriculum 2014",²² 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."

c) Other forms of IGM practices

While the Rapporteurs currently have no data on further practices, namely IGM 3 sterilising procedures²³ and IGM 4 prenatal "therapy", ²⁴ we have to assume also these forms of IGM are practiced either domestically in Malta or overseas in contractual hospitals.

3. How the Maltese GIGESC Act fails Intersex Children

In 2015, Malta passed the Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC Act), ²⁵ which under art. 14 explicitly makes it "unlawful" to perform IGM practices, but initially included no sanctions at all. A 2018 amendment²⁶ eventually introduced sanctions, namely "punishment of imprisonment not exceeding five years, or [...] a fine (multa) of not less than five thousand euro (\in 5,000) and not more than twenty thousand euro (\in 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".²⁷ However, this is not true, as the sanctions for FGM are actually double

	Reconstructive and Aesthetic Surgery,
	https://deputyprimeminister.gov.mt/en/regcounc/msac/Documents/Malta%20Plastic%20Surgery%20SAC%20Curriculum%202014.pdf
18	See 2017 CRPD UK NGO Report, p. 9,
	http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf
19	See 2018 CRC Belgium NGO Report, p. 7,
	http://intersex.shadowreport.org/public/2018-CRC-Belgium-NGO-Zwischengeschlecht-Intersex-IGM.pdf
20	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
21	Ibid.
22	Specialist Advisory Committee (SAC) (2014), HST Training Programme and Curriculum Plastic,
	Descendent in and Anotheric Conserve

- 2 Reconstructive and Aesthetic Surgery,
- $\underline{https://deputyprime minister.gov.mt/en/regcounc/msac/Documents/Malta% 20 Plastic% 20 Sac % 20 Curriculum% 20 20 14.pdf \end{tabular}$ For general information, see 2016 CEDAW NGO Report France, p. 47, 23 http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

- http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1 25
- 26 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, 27 available at http://www.lgbtiq.gov.mt/

²⁴ Ibid., p. 50

("*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.).²⁸

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*".²⁹

Regarding **IGM**, the GIGESC Act further **fails** to meet the stipulation of the Joint General Comment 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)).

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"**,³⁰ the most frequent IGM practice (and apparently the only one that is performed in Malta itself, see also p. 8-9), as "*whether cases of hypospadias are covered by the above prohibition may fall to be determined later by the courts.*" ³¹ For other IGM practices, Malta is **sending children overseas** for surgery, reportedly to the UK,³² Belgium,³³ and arguably also to Italy³⁴ – 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 CRC art. 24(3) and the Joint General Comment No. 18**, and on the other hand so far the law is simply **not enforced**.

^{28 &}lt;u>http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8574</u>

²⁹ Helena Dalli, Minister for European Affairs and Equality (04.02.2019), <u>https://eige.europa.eu/news/female-genital-mutilation-illegal-malta-girls-are-not-safe</u>

³⁰ Piet de Bruyn (2017), Report: Promoting the human rights of and eliminating discrimination against intersex people, COE Doc. 14404, p. 14, para 47, <u>http://semantic-</u> pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbnQvbncveG1sL1hSZWYvWDJILURXL WV4dHIuYXNwP2ZpbGVpZD0yNDAyNyZsYW5nPUVO&xsl=aHR0cDovL3NlbWFudGljcGFjZS5uZXQv WHNsdC9QZGYvWFJIZi1XRC1BVC1YTUwyUERGLnhzbA==&xsltparams=ZmlsZWlkPTI0MDI3

³¹ Ibid.

³² See 2017 CRPD UK NGO Report, p. 9, http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf

³³ See 2018 CRC Belgium NGO Report, p. 7, http://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,
 https://ec.europa.eu/health/sites/health/files/ern/docs/20170309 rt3 05 dalmas pres en.pdf

4. Maltese Doctors and Gov consciously dismissing Intersex Human Rights

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

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.

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

6. 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.³⁵ 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 Convention.

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 Malta, the Committee includes the following measures in their recommendations to the Maltese Government (in line with CRC's previous recommendations e.g. to 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 Malta as a Violation of CRC

1. The Treatment of Intersex Children in Malta 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

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

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

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

³⁶ For a more extensive version, see 2017 CRC Spain NGO Report, p. 12-13, <u>http://intersex.shadowreport.org/public/2017-CRC-Spain-NGO-Brujula-Zwischengeschlecht-Intersex-IGM.pdf</u>

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)

³⁹ 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)

⁴⁰ 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: <u>http://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf</u>

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

"equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period, and that the perpetrators and those who aid or condone such practices are held accountable" (para 55 (0))

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

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

Conclusion, **IGM practices in Malta** – 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

⁴¹ 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 **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 even once they do.⁴⁵ So far there was no case of a victim of IGM practices succeeding in going to a Maltese court.

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

⁴⁵ 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 infanticide⁴⁷ 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 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 http://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.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda ; for Uganda, see also 2015 CRC Briefing, slide 46, http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf
 For Kenya, see also http://www.bbc.com/news/world-africa-39780214
 For Mexico, see 2018 CEDAW NGO Joint Statement, http://stop.genitalmutilation.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018

 $\underline{http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf}{}$

⁴⁶ 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

⁴⁸ 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

⁴⁹ 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

⁵⁰ For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see <u>http://stop.genitalmutilation.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3</u>

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

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

⁵³ In the WHO "World Atlas of Birth Defects (2nd Edition)", many intersex diagnoses are listed, including *"indeterminate sex"* and *"hypospadias":*

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 breach of international law.⁵⁷ UN Treaty bodies have so far issued 40 Concluding Observations condemning IGM practices.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

^{54 &}quot;The Racist Roots of Intersex Genital Mutilations" <u>http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM</u>

⁵⁵ 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 &}lt;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 &}lt;u>http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf</u>

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

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

⁶³ For references, see 2016 CEDAW France NGO Report, p. 45 http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

⁶⁴ For example ACHPR Commissioner Lawrence Murugu Mute (Kenya), see <u>http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT</u>

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

⁶⁶ CRC77 Spain, <u>http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children</u>

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

⁶⁸ CAT/C/DNK/QPR/8, para 32

⁶⁹ CRC73 New Zealand, <u>http://stop.genitalmutilation.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child</u>

gender identity", "*civil registry*" and "*sexual reassignment surgery*" ⁷⁰, transgender guidelines⁷¹ 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

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

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

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

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

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, <u>http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf</u> 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), <u>http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD</u>

⁷⁵ See e.g. "Instrumentalizing intersex: 'The fact that LGBTs in particular embrace intersex is due to an excess of projection' - Georg Klauda (2002)", <u>http://stop.genitalmutilation.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002</u>

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

⁷⁷ 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), <u>http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile</u>

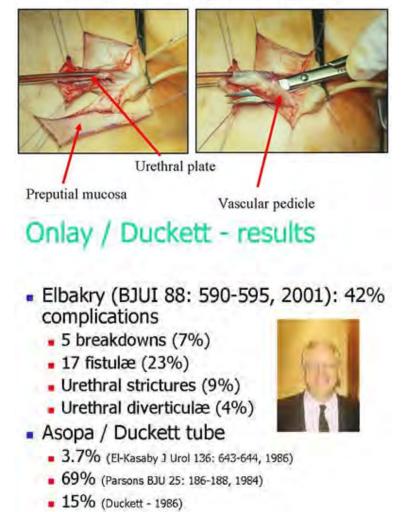
Annexe 3 – "IGM in Medical Textbooks: Current Practice"

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



Hypospadias - Procedures for cripple hypospadias

- 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 well-vascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
- Suprapubic diversion ? Elbakry













Bad cosmetic result

infection



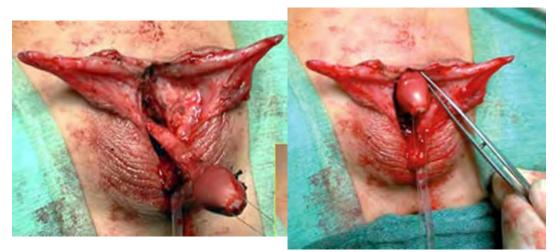
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

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

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

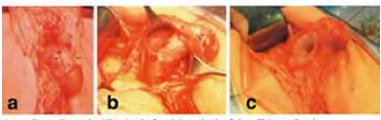
Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include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

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

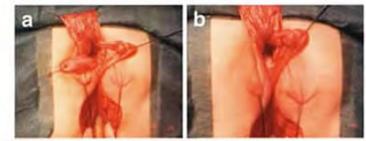


Source: Christian Radmayr: Molekulare Grundlagen und Diagnostik des Intersex, 2004

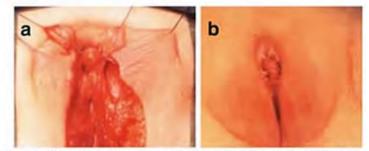
10. Indikationen und Ergebnisse von Korrekturoperationen beim interse



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.

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

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

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome, * Might reach more than 30%, if gonadectomy has not been performed.

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



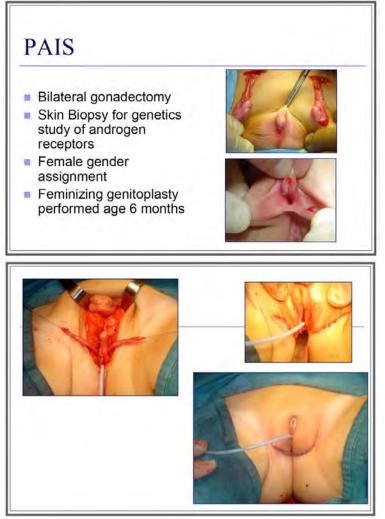
Source: J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

"Bad results" / "Gonadectomy, Feminizing Genitoplasty"



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

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



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

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



NGO Report to the 3rd to 6th Report of Malta on the Convention on the Rights of the Child (CRC)