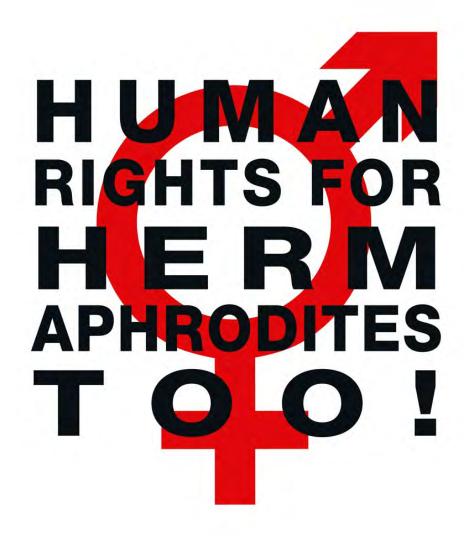
Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for Session) to the 4th to 6th Report of Tunisia on the Convention on the Rights of the Child (CRC)

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Executive Summary

All typical forms of Intersex Genital Mutilation are still practised in Tunisia in University Hospitals under the direct control of the Ministry of Health, facilitated and paid for by the State party via the public health system (Caisse Nationale d'Assurance Maladie CNAM) under the direct control of the Ministry of Social Affairs. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support.

Tunisia 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 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 that would not be considered for "normal" children, without evidence of benefit for the children concerned. Typical forms of IGM include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, involuntary human experimentation and denial of needed health care.

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

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

This NGO Report has been compiled by StopIGM.org / Zwischengeschlecht.org, an international intersex NGO. It contains Suggested Recommendations (see p. 14).

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A. Introduction

1. Tunisia: Intersex, IGM, Human Rights and State Report

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

The 4th to 6th Tunisian State Report of 2018 does mention harmful practices (para 142):

"142. A new offence has been introduced relating to "the mutilation or partial or total removal of female genitalia" (article 221 (3)), which is often related to harmful practices against girls, particularly circumcision."

However, intersex and IGM were not mentioned in the State Report.

The **List of Issues** asked for **statistical data on harmful practices** (para 16(b)):

- "16. Please provide, if available, updated statistical data disaggregated by age, sex, disability, ethnic origin, national origin, geographic location and socioeconomic status, for the past three years, on: [...]
- (b) Children who are victims of harmful practices, including child marriage or female genital mutilation, or who are at risk of such practices;"

However, so far no replies to the List of Issues are available.

This Thematic NGO Report demonstrates that the current and ongoing harmful medical practices on intersex children in Tunisia – advocated, facilitated and paid for by the State party via the tax-funded public health system (Caisse Nationale d'Assurance Maladie CNAM) under the direct control of the Ministry of Social Affairs, and practiced in state-funded University Hospitals under the direct control of the Ministry of Health – constitute a serious breach of Tunisia'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 50 Treaty body Concluding Observations recognising IGM as a serious human rights violation. ⁵

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

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

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

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

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

In addition, the Rapporteurs would like to acknowledge the work of the ${f Collectif}$ Intersex ${f Tunisien.}^6$

3. Methodology

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

6 <u>https://www.facebook.com/CollectifIntersexTunisien</u>

⁷ http://intersex.shadowreport.org/public/2019-CRC-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf

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

1. Overview: IGM practices in Tunisia: Pervasive and unchallenged

In **Tunisia**, same as in the fellow Mediterranean and/or African states of *Morocco* (CRPD/C/MAR/CO/1, paras 36-37); *Malta* (CRC/C/MLT/CO/3-6, paras 28-29), *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 34-35; CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f), *Spain* (CRC/C/ESP/CO/5-6, para 24), and *South Africa* (CRC/C/ZAF/CO/2, paras 39-40+23-24) and in **many more State parties,** 8 there are

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

To this day the Government fails to recognise the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to "take effective legislative, administrative, judicial or other measures" to protect intersex children from harmful practices.

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

To this day, in Tunisia all forms of IGM practices remain common and ongoing, persistently advocated, prescribed and perpetrated by state-funded University Hospitals under the direct control of the Ministry of Health, and paid for by the State via the tax-funded public health system (Caisse Nationale d'Assurance Maladie CNAM) under the direct control of the Ministry of Social Affairs.

There are at least 7 Tunisian University Hospitals with paediatric departments that practice IGM, all of them under the direct control of the Tunisian Ministry of Health:

- The University Children's Hospital Béchir-Hamza in Tunis of the Faculty of Medicine of Tunis
- The University Hospital La Rabta in Tunis of the Faculty of Medicine of Tunis
- The University Hospital Charles Nicolle in Tunis of the Faculty of Medicine of Tunis
- The University Hospital Habib Bourguiba in Sfax of the Faculty of Medicine of Sfax
- The University Hospital Hédi Chaker in Sfax of the Faculty of Medicine of Sfax
- The University Hospital Fattouma-Bourguiba in Monastir of the Faculty of Medicine of Monastir
- The University Hospital Sahloul in Sousse of the Faculty of Medicine of Sousse

⁸ Currently we count **50 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see: http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

Currently practiced forms of IGM in Tunisia include:

a) IGM 3 – Sterilising Procedures:
Castration / "Gonadectomy" / Hysterectomy /
Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation
Plus arbitrary imposition of hormones ⁹

A **2008 medical publication** by doctors from the **Fattouma-Bourguiba University Hospital in Monastir** describes unnecessary gonadectomies of 3 siblings in a Tunisian family diagnosed with CAIS, justified by an **alleged**¹⁰ **high cancer risk** ("potential risk of malignant degeneration", p. 219, 225) and **psychosocial indications**:¹¹

"Whether the diagnosis is made antenatally, in childhood or after puberty, the indication for gonadectomy is not in dispute, but there is no consensus as to the most appropriate time for it to be performed. Treatment with oestrogens is essential in these patients, its aim being to induce the development of secondary sexual characteristics (development of breasts and external genital organs [sic]). In addition, the treatment improves self-esteem and social integration, and prevents osteoporosis and cardiovascular disease." (p. 225)

However, regarding the mentioned prevention of "osteoporosis", the article tellingly notes:

"The study of changes in **bone density** in subjects with CAIS before and after orchiectomy shows that initial bone mass was low before and **worsened after gonadectomy**." (p. 224)

While the 2 elder siblings were 29 and 19 years old when submitted to gonadectomy soon after diagnosis, the youngest was still a child:

"M.Z., age 15, was also admitted for exploration of primary amenorrhea discovered in the course of a family investigation. [...] The patient benefited from bilateral laparoscopic gonadectomy." (p. 222)

Similarly, a **2012 medical presentation** by doctors from the **Hédi Chaker University Hospital in Sfax** again recommends unnecessary gonadectomy on intersex children diagnosed with CAIS, justified by an **alleged**¹² **high cancer risk** (slide 24), while at the same time admitting that the internal testes produce natural vital hormones:¹³

"According to most authors, **orchiectomy is preferable after puberty** in order to allow spontaneous secondary sexual development **thanks to the oestrogen produced from the aromatase of testosterone.**" (slide 24)

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

For actual cancer risks, see below p. 27. See also 2020 CRC Czechia Intersex Report, p. 7, http://intersex.shadowreport.org/public/2020-CRC-Czechia-NGO-Zwischengeschlecht-Intersex-IGM.pdf

D. Bel Hadj Youssef, M. Kacem, I. Khochtali, A. Moussa, Z. Saidani, W. Denguezli, R. Faleh, M. Sakouhi, A. Zakhama, S. Mahjoub, F. Paris, C. Sultan (2008), "Syndrome de résistance complète aux androgènes : nouvelle mutation chez une famille tunisienne" ("Complete androgen insensitivity syndrome: A novel mutation in a Tunisian family"), Annales d'Endocrinologie, Volume 69, no 3, pages 218-226 (Juin 2008), https://www.em-consulte.com/en/article/173795

For actual cancer risks, see below p. 27. See also 2020 CRC Czechia Intersex Report, p. 7, http://intersex.shadowreport.org/public/2020-CRC-Czechia-NGO-Zwischengeschlecht-Intersex-IGM.pdf

M. Abdelkafi, H. Fourati, E. Daoud, H. Tayari, N. Sellami, I. Kobbi, M. Bougamra, Z. Mnif (2012), "Syndrome du Testicule Féminisant: a Propos de 4 Cas" ("Feminising Testis Syndrome: About 4 Cases"), http://strtn.org/media/file_poster/SggVD3_113656.ppt

Further, a **2007 medical article** by doctors from the **Habib Bourguiba University Hospital in Sfax** advocates and describes the removal of "discordant reproductive structures", namely "hysterectomy" on an infant of **20 months** (p. 50) including graphic photos (p. 51), or bilateral gonadectomy in the case of abdominal testes:¹⁴

"H.A., a 20-month-old infant with no history of disease, was admitted for surgical treatment of bilateral cryptorchidism. [...]

A complete resection of the uterine formation and both fallopian tubes was performed at the same time as the fixation of the first testicle in the left bursa." (p. 50)

"Bilateral orchiectomy with hormone replacement therapy would also be indicated in cases of testicular atrophy associated with absent spermatogenesis and/or when their lowering into the scrotum is impossible due to the shortening of the spermatic cord [19]." (p. 52)

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation 15

A 2016 medical presentation by doctors of the Fattouma Bourguiba University Hospital in Monastir titled "Feminising surgery of female pseudohermaphrodism due to congenital adrenal hyperplasia" reports IGM 2 procedures, including graphic photos: 16

"Introduction

Feminising surgery of female pseudohermaphrodism due to congenital adrenal hyperplasia continues to be controversial. There is no consensus on the timing and technique of the operation.

Materials and methods

Retrospective study of anatomical, cosmetic, functional and psychological results in 48 patients operated for sexual ambiguity between 1996 and 2015. All patients had a one-step surgery including in most cases vaginoplasty, clitoridoplasty and labioplasty. One patient with an upper confluence of the urinary and genital tracts had complete mobilisation of the urogenital sinus. 45 patients with a short urogenital sinus had vaginoplasty using the classic perineal technique. All clitoridoplasties were performed with preservation of the dorsal vascular-nervous pedicle of the clitoris.

Results

The age of the patients varied between 2 months and 2 years. [...] The cosmetic result was good in 75% of the cases. There was 1 case of vaginal stenosis and 9 cases of recurrence of clitoral hypertrophy. One patient is married and had a normal course pregnancy.

Hammadi Fakhfakh, Lobna Ayadi, Ines Samet, Kamel Chabchoub, Mohamed Njeh, Salah Boujelben, Ali Bahloul, Tahya Boudawara, Mohamed Nabil Mhiri (2007), "Le syndrome de la persistance des dérivés mullèriens: A propos de quatre observations" ("Persistent Müllerian duct syndrome: About Four Observations"), Andrologie 2007, 17, No 1 49-54, https://link.springer.com/content/pdf/10.1007/BF03041155.pdf

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

M. Braiki (Dr), I. Miniaouib (Dr), A. Nouria (Pr) (2016) "Chirurgie féminisante des pseudohermaphrodismes féminins par hyperplasie congénitale des surrénales", poster, 33rd Congress of the French Society of Endocrinology 2016, https://www.congres-sfe.com/2016/eposters/a11ab4f6-572e-11e6-9efb-d97ff2406a52.pdf

Conclusion

Feminising surgery has satisfactory results. Repair of virilisation of the external genitalia should be done between 2 months and 6 months. Rigorous medical and psychological follow-up must be ensured."

A **2018 medical thesis** "*Technical development of surgery for intersex conditions*" reporting **2 Tunisian** patients diagnosed with Congenital Adrenal Hyperplasia (CAH) at **age 5 and 6 years** respectively, and subsequently both **submitted to** "*clitoridoplasty*" **and** "*labioplasty*" at an unnamed hospital in **Sousse** by the same unnamed surgeon (p. 7, 8, 3).¹⁷

A 2005 medical presentation by doctors of the La Rabta University Hospital in Tunis reports, "3 girls born with sexual ambiguity were operated on, 2 had their periods at the age of 12 years." 18

And a **2016 medical presentation** by doctors of the **Charles Nicolle University Hospital in Tunis** reports a 3 years old intersex child diagnosed with "Partial gonadal dysgenesis 46XY" submitted to **partial clitoris amputation and** "vaginoplasty": ¹⁹

"At the age of 3 years, the patient underwent an anastomotic corpus cavernosum resection and vaginoplasty. Gonad removal was performed at the age of 5 years."

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair" 20

A 2000 paediatric surgery thesis at the Faculty of Medicine of Tunis reports "93 cases" of intersex children diagnosed with hypospadias. ²¹ In addition, a 2016 paediatric thesis reports "45 paediatric cases" of intersex children diagnosed with the more infrequent diagnosis "posterior hypospadias". ²²

Accordingly, a **2017 medical presentation** by doctors of the **Béchir-Hamza University** Children's Hospital in Tunis describes a "prospective randomized study" on "children aged from 1 to 9 years, scheduled for hypospadias surgery, urethral fistula repair or circumcision". ²³

17 Sara Hormatallah, "Mise au point technique sur la chirurgie des états intersexuels" ("Technical development of surgery for intersex conditions") (2018), Thesis, Faculté de Médecine et de Pharmacie Marrakech, Université Cadi Ayyad, http://wd.fmpm.uca.ma/biblio/theses/annee-htm/FT/2018/these152-18.pdf

M. Chihaoui, B. Ftouhi, M. Kamoun, H. Slimane, Y. Morel (2005), "Déficit enzymatique en 11β-hydroxylase: à propos de 8 cas", Annales d'Endocrinologie, Vol 66, No 5 - octobre 2005, p. 482, https://www.em-consulte.com/en/article/76683

¹⁹ Ibtissem Oueslati, Najla Bchir, Emna Elfeleh, Karima Khiari, Néjib Ben Abdallah (2016), "Dysgénésie gonadique partielle 46XY: A propos d'un cas." ("Partial gonadal dysgenesis 46XY: About a case."), presentation, 33rd Congress of the French Society of Endocrinology, https://www.congres-sfe.com/2016/eposters/8e76cc84-867d-11e6-9b6a-c4e9428cfb44.pdf

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

Jalila Achour (2000), "Les hypospadias. A propos de 93 cas", thesis T0108/2000, Tunis, see p. 336, http://www.fmt.rnu.tn/index.php?id=500&tx_abdownloads_pi1%5Bcid%5D=617&no_cache=1

Soumaya Khaldi (2016), "L'hypospadias postérieur à propos de 45 cas pédiatriques", thesis T252/2016, Tunis, p. 343, http://www.fmt.rnu.tn/index.php?id=500&tx_abdownloads_pi1%5Bcid%5D=617&no_cache=1

Sonia B.K., Abbes A., Refka K., Hajer B. (2017), "Neurostimulation in the pudendal nerve block in pediatric surgery: a randomized controlled trial", EJA European Journal of Anaesthesiology Volume 34 | e-Supplement 55 | June 2017, p. 140, https://www.esahq.org/uploads/publications/ESA2017_HI.pdf

A 2009 paediatric surgery thesis at the Faculty of Medicine of Sfax reports "152 cases" of intersex children diagnosed with hypospadias.²⁴

Accordingly, a **2008 presentation** by doctors of the **Department of paediatric surgery** at the **Hédi Chaker University Hospital in Sfax** reports **89 cases** of paediatric "hypospadias repair" surgery:²⁵

"[H]ypospadias is one of the most common deformities of the urogenital system. A great diversity of procedures to correct hypospadias is suggested. In our department we use for the correction of the "distal" and "mid-shaft hypospadias defects mainly two different methods; the MATHIEU technique and the spongioplasty. We investigated retrospectively for both methods (MATHIEU group n:52 and spongioplasty group n:37) the outcome regarding the complication, the cosmetic satisfaction and the voiding and compared the results."

A **2015 urology thesis** at the **Faculty of Medicine of Sousse** on complications after "hypospadias repair" reports "**306 cases**" of intersex children diagnosed with hypospadias. ²⁶

Accordingly, a **2016 urology presentation** "Hypospadias surgery" by a surgeon of the University Hospital Sahloul in Sousse prescribes surgery on infants at age 6-18 months with an emphasis on psychosocial and "aesthetic" indications, while admitting high complication rates: ²⁷

- "Hypospadias surgery
- The treatment of hypospadias remains exclusively surgical.
- Purpose:
 - To bring the urethral opening into an anatomical position.
 - Correct the curvature.
 - Restore the penis to a more normal aesthetic appearance.
 - Urination in an upright position,
 - *normal sexuality*" (slide 7)
- "Age of repair
- Adult => Infant
- Infant 12-18 months
- even 6-9 months
- => Before the age of walking" (slide 40)

Mehdi Ben Dhaou (2009), "Les hypospadias. A propos de 152 cas", thesis TH/SF2873, Sfax, https://www.medecinesfax.org/fra/institut_these/sfax/imprimer/2872

Ben Dhaou M; Jallouli M; Kammoun H; Kallel N; Mhiri R (2009), "Results of the repair of distal hypospadia: Comparison between two techniques", abstract, VIIth Congress of the Mediterranean Association of Paediatric Surgery in association with VIIth Congress of the Maghrebine Federation of Paediatric Surgery, XIIth Annual Meeting of the Tunisian Association of Paediatric Surgery 2008, in: Annals of Pediatric Surgery Vol 5, No 1, January, 2009, PP 61-91, p. 70,

http://www.aps.eg.net/back_issue/vol5/issue1_january2009/pdf/11-Abstracts.pdf

Mohamed Wael Zemmiti (2015), "Traitement chirurgical des hypospadias: Etude descriptive des résultats selon les différentes techniques opératoires et analyse des facteurs influençant la survenue de fistules. A propos de 306 cas", thesis TH/SO3519, Sousse, https://www.medecinesfax.org/fra/institut these/sousse/imprimer/3523

Adnen Hidoussi (2016), "Chirurgie de l'hypospadias", presentation, Hopital Sahloul – Tunisie, https://www.uroleb.org/sites/default/files/Dr.%20Adnen_LR_Chirurgie de 1%E2%80%99hypospadias%20.pdf

"Complications

15 - 30 %

- *Stenosis* ... *Meatus* + + +
- Fistula !!!!
- Dehiscence
 - * Partial
 - * *Total*" (slide 44)

Further, a **2018 medical publication** by doctors of the **Department of paediatric surgery** at the **Fattouma Bourguiba University Hospital in Monastir** reports **90 intersex children** submitted to **early "hypospadias repair"**, noting a "rather high complication rate":²⁸

"Among the 90 cases of posterior hypospadias surgically treated at the Department of Paediatric Surgery at EPS Monastir during the period from January 2, 2006 to June 30, 2013, 35 cases were operated on using the Koyanagi technique, a rate of 38.8%." (p. 333)

"The average age at the time of the intervention was 28.8 months with extremes ranging from 12 to 55 months. It was noted that 45.7% of our patients (16/35) were operated on before the age of 2 years." (p. 334)

"Conclusion: Urethroplasty according to Koyanagi, is an interesting technique for the correction of posterior hypospadias especially in case of ventral curvature but with a rather high complication rate." (p. 332)

In addition, also the **Tunisian health website "Santé TN"** promotes **early "hypospadias repair" surgery** on intersex infants "between the 6th and 24th month", again with an **emphasis on psychosocial and "psychological" indications**: ²⁹

"Consequences of hypospadias

The child is unable to urinate standing up like his peers, which leads to serious psychological complications that are evident especially as he grows older and sometimes require the help of a psychologist. This is the prerogative of anterior hypospadias.

In addition to the psychological consequences, the discomfort caused by the curvature of the penis during sexual activity is not insignificant and also requires treatment by a sexologist.

Management of hypospadias

The diagnosis of hypospadias is always made at birth. Surgery is unavoidable and is best performed between the 6th and 24th month by a paediatric surgeon.

Patience on the part of the parents is required because the treatment can be cumbersome and expensive, especially for the more severe malformations."

S. Ben Youssef, A. Ksia, M. Ben Fredj, M. Messaoud, R. Laamiri, S. Belhassen, S. Mosbahi, B. Bouzzaffara, L. Sahnoun, M. Mekki, M. Belguith, A. Nouri (2018), "Intérêt de la technique de Koyanagi dans le traitement de l'hypospadias posterieur chez l'enfant" ("Interest in the technique of Koyanagi in the treatment of posterior hypospadias in children"), African Journal of Urology (2018) 24, 331–335, https://www.ajol.info/index.php/aju/article/view/182241/171619

²⁹ Santé TN (2012), "Hypospadias : c'est quoi et pourquoi ?", 16.01.2012, https://www.sante-tn.com/3m/maladies/hypospadias-cest-quoi-et-pourquoi/

Accordingly, on the **Tunisian online forum "Med.tn"** there is an example of a parent distressed by complications as a result of early hypospadias surgery: ³⁰

"Hypospadias

hello to you, here I have a boy who made an intervention D HYPOSPADIAS in 2015 at the age of 26 months, now he is going to make a 2nd intervention, MY QUESTION IS, is that hypospadias its success not at the first blow ... THANKS"

"Hypospadias surgery is characterised by its particularly high failure rate. If the operation goes well, no problem, but if it fails (fistula or stenosis or dehiscence) a surgical redo-surgery will be necessary. In addition, there are techniques in one or two steps (two operations) depending on the degree of hypospadias. It is best to refer to centres or to a surgeon who is experienced in this pathology.

Dr Walid CHARFI Surgeon Urologist"

3. The Tunisian Government fails to act despite criticism

The persistence of IGM practices in Tunisia is a matter of public record (see above), but in the public and in politics intersex people and their stories are still shrouded in secrecy and a taboo. At least since 2018 intersex persons in Tunisia have worked to raise awareness and spoken out against IGM practices on social media, but have suffered serious negative consequences for doing so, including having been rejected by the family and thrown on the street.

However, to this day the **Tunisia Government fails** to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to "take effective legislative, administrative, judicial or other measures" to protect intersex children from harmful practices, but instead allows IGM doctors to continue practicing with impunity.

4. Lack of Independent Data Collection and Monitoring

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

5. Obstacles to redress, fair and adequate compensation

Also in **Tunisia** 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.³¹ So far, in Tunisia there was **no case** of a victim of IGM practices succeeding in going to court.

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

³⁰ https://www.med.tn/question-medicale/urologie/lhypospadias-83.html

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 Tunisia, the Committee includes the following measures in their recommendations to the Tunisian Government (in line with this Committee's previous recommendations on IGM practices):

Harmful practices: Intersex genital mutilation

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

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 and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

- (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 Tunisia as a Violation of CRC

- 1. The Treatment of Intersex Children in Tunisia as Harmful Practice and Violence
- a) Harmful Practice (art. 24(3) and JGC No. 18) 32

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.³³

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.³⁴

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.³⁵

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.³⁶

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

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

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

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

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

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

³³ UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 371

³⁴ CRC/C/CHE/CO/2-4, paras 42-43; CRC/C/CHL/CO/4-5, paras 48-49; CRC/C/FRA/CO/5, paras 47-48; CRC/C/IRL/CO/3-4, paras 39-40; CRC/C/NPL/CO/3-5, paras 41-42; CRC/C/GBR/CO/5, paras 46-47; CRC/C/NZL/CO/5, paras 25+15; CRC/C/ZAF/CO/2, paras 39-40+23-24; CRC/C/DNK/CO/5, paras 24+12; CRC/C/ESP/CO/5-6, para 24; CRC/C/ARG/CO/5-6, para 26; CRC/C/ITA/CO/5-6, para 23; CRC/C/BEL/CO/5-6, paras 25(b)+26(e); CRC/C/MLT/CO/3-6, paras 28-29; CRC/C/AUS/CO/5-6, paras 25(b)+26(e); CRC/C/PRT/CO/5-6, paras 28(b); CRC/C/AUT/CO/5-6, para 27(a)-(b)

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

Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: "Ending the Impunity of the Perpetrators!" Input at "Ending Human Rights Violations Against Intersex Persons." OHCHR Expert Meeting, Geneva 16–17.09.2015, online: http://StopIGM.org/public/S3 Zwischengeschlecht UN-Expert-Meeting-2015 web.pdf

"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))

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 Tunisia** – 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) 37

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]", 38 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", 39 and to "[u]ndertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation". 40

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

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

For a more extensive version with sources, see 2016 CRC UK Thematic NGO Report, p. 57, http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM-v2.pdf

³⁸ CRC/C/ZAF/CO/2, 27 October 2016 paras 39–40

³⁹ CRC/C/CHE/CO/2-4, 26 February 2015, para 43

⁴⁰ CRC/C/DNK/CO5, 26 October 2017, para 24

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

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

However, also in **Tunisia** 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. ⁴¹ So far there was no case of a victim of IGM practices succeeding in going to an Tunisian court.

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

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

1. Intersex = variations of reproductive anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with "Disorders" or "Differences of Sex Development (DSD)", ⁴² 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. 7-12.43

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.⁴⁴

In regions without universal access to paediatric health care, there are reports of infanticide⁴⁵ of intersex children, of abandonment, ⁴⁶ of expulsion, ⁴⁷ of massive bullying preventing the

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

⁴³ http://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, http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf

For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, http://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf
For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12, http://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf
For South Africa, see also https://intersex.shadowreport.org/public/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens
For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: http://istop.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

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

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

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

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

persons concerned from attending school (recognised by CRC as amounting to a harmful practice), ⁴⁸ and of **murder**. ⁴⁹

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. ⁵⁰ 51 52 53

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**, ⁵⁴ 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.⁵⁵ UN Treaty bodies have so far issued 50 Concluding Observations condemning IGM practices accordingly.⁵⁶

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

⁴⁹ For example in Kenya, see https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/

^{50 2014} CRC NGO Report, p. 52, 69, 84, http://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

^{52 &}quot;The Racist Roots of Intersex Genital Mutilations" http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

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

⁵⁴ See "IGM Practices – Non-Consensual, Unnecessary Medical Interventions", ibid., p. 38–47

⁵⁵ **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

^{56 &}lt;u>http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations</u>

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^{57 58} 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, ⁵⁹ 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.⁶⁰ 61

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", 62 and again IGM survivors as "transgender children", 63 "transsexual children who underwent difficult treatments and surgeries", and IGM as a form of "discrimination against transgender and intersex children" 64 and as "sex assignment surgery" while referring to "access to gender reassignment-related treatments". 65

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", 66 "a special provision on sexual orientation and

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⁵⁷ CRC67 Denmark, http://stop.genitalmutilation.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark

⁵⁸ CEDAW66 Ukraine, http://stop.genitalmutilation.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics

⁵⁹ For references, see 2016 CEDAW France NGO Report, p. 45 http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

For example ACHPR Commissioner Lawrence Murugu Mute, see http://stop.genitalmutilation.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%20The%20Rights%20Of%20Intersex%20Persons%20In%20Kenya.pdf?ver=2018-06-06-161118-323

 $^{62 \}quad CAT60 \ Argentina, \ \underline{\text{http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60}$

⁶³ CRC77 Spain, http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children

⁶⁴ CRC76 Denmark, http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67

⁶⁵ CAT/C/DNK/QPR/8, para 32

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

gender identity", "civil registry" and "sexual reassignment surgery" ⁶⁷, transgender guidelines ⁶⁸ or "Gender Identity" ⁶⁹ ⁷⁰ 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** ⁷¹ and public **representation**. ⁷²

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 ⁷³ ⁷⁴ ⁷⁵ ⁷⁶ – 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.^{77 78}**

⁶⁷ CCPR120 Switzerland, http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120

⁶⁸ CAT56 Austria, http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations

⁶⁹ CAT60 Argentina, http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture

⁷⁰ CRPD18 UK, http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

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

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

⁷³ For example Amnesty (2017), see http://stop.genitalmutilation.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors

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

⁷⁵ For example CEDAW Italy (2017), see http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN

⁷⁶ For example CEDAW Austria (2019): CEDAW/C/AUT/CO/9, paras 34(h), 35(h)

⁷⁷ For example Ministry of Health Chile (2016), see http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile

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

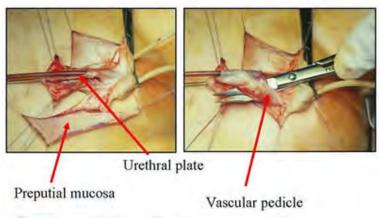
Annexe 3 – "IGM in Medical Textbooks: Current Practice"

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

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

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

Onlay island flap urethroplasty



Onlay / Duckett - results

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



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



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

Treatment of isolated fistulæ

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















infection



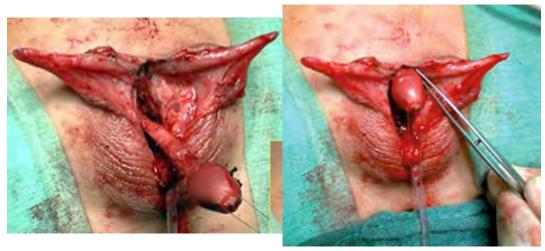
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

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

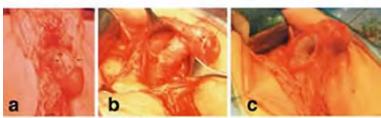
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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").

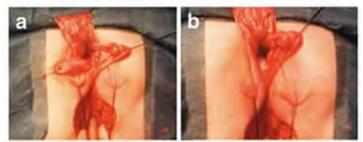
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "in the first 2 years of life", most commonly "between 6 and 12 months," and only 10.5% of surgeons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



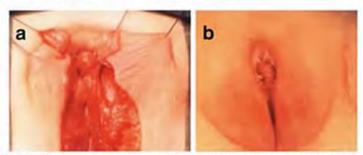
Source: Christian Radmayr: Molekulare Grundlagen und Diagnostik des Intersex, 2004



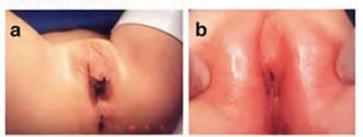
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



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.



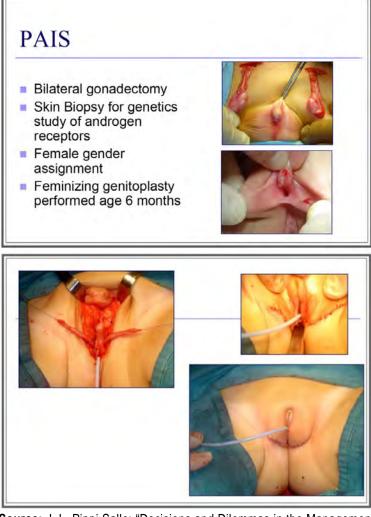
Source: J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

"Bad results" / "Gonadectomy, 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.