

Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Reproductive Anatomy



**Intersex &
Transgender
Luxembourg
a.s.b.l.**

**HUMAN
RIGHTS FOR
HERM
APHRODITES
T O O !**

NGO Report (for LOI)
to the 4th Report of Luxembourg on the
International Covenant on Civil and Political Rights
(CCPR)

Compiled by:

Intersex & Transgender Luxembourg (ITGL) a.s.b.l. (Local NGO)

Dr Erik Schneider

Association Intersex & Transgender Luxembourg a.s.b.l.

BP 2128

L-1021 Luxembourg

tgluxembourg_at_gmail.com

<https://itgl.lu/>

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

Markus Bauer, Daniela Truffer

Zwischengeschlecht.org

P.O.Box 2122

CH-8031 Zurich

info_at_zwischengeschlecht.org

<https://Zwischengeschlecht.org/>

<https://StopIGM.org/>

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Executive Summary

Despite 2018 Government pledges to “*prohibit*” IGM and to “*establish monitoring*”, in **Luxembourg all typical forms of Intersex Genital Mutilation (IGM) persist with impunity**, facilitated and **paid for by the State party** via the **Statutory Health Insurance System**, perpetrated both in the public **Hospital CHL** and in **foreign Contractual Hospitals**.

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

In 2018, **CEDAW recognised IGM in Luxembourg as a harmful practice** and recommends the State party to “*[s]pecifically prohibit*” IGM and to “*[a]dopt legal provisions to provide redress*” to victims (CEDAW/C/LUX/CO/6-7, para 28). To this day, the **State party fails to act**.

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

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

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

IGM practices include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures based on prejudice that would not be considered for “normal” children, without evidence of benefit for the children concerned. **Typical forms** of IGM include “masculinising” and “feminising”, “corrective” genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, human experimentation and denial of needed health care.

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

This **Thematic NGO Report** has been compiled by the NGOs **Intersex & Transgender Luxembourg a.s.b.l. (ITGL)** and **StopIGM.org / Zwischengeschlecht.org**.

It contains **Suggested Questions for the LOI** (see opposite p. 5).

Suggested Questions for the List of Issues

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

Intersex Genital Mutilation (arts. 2, 3, 7, 24, 26)

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

Introduction

1. Luxembourg: Intersex 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 bodies¹** including CCPR as constituting a harmful practice, violence and torture or **cruel, inhuman or degrading treatment**. However, intersex and IGM were **not mentioned in the 3rd Luxembourgian State Report**.

In contrast, in 2018 the State party pledged to “[p]rohibit medical treatments of ‘sexual normalisation’ without vital urgency that are practiced without the free and informed consent of the intersex person”, and to “[e]stablish monitoring of medical interventions on intersex minors, including treatment abroad” (National Action Plan for the Promotion of the Rights of Lesbian, Gay, Bisexual, Transgender and Intersex People, p. 48).

Also in 2018, Luxembourg has been reviewed by CEDAW which **recognised** “non-consensual, unnecessary genital surgery” and “other comparable procedures that violate the physical integrity” of intersex children in Luxembourg as constituting a **harmful practice** and, referring to the CEDAW/CRC Joint General Comment No. 31/18, recommended the State party to inter alia “[s]pecifically prohibit non-consensual [...] surgery on intersex persons” and to “[a]dopt legal provisions to provide redress to intersex persons who are victims of surgical or other medical interventions performed without their free, prior and informed consent” (CEDAW/C/LUX/CO/6-7, paras 27-28). However, to this day the State party **fails to act**, but instead **misrepresents** intersex as “a part of the LGBTI umbrella” suffering from “discrimination”.

This NGO Report demonstrates that the ongoing medicalised **harmful practice on intersex persons in Luxembourg** – advocated, facilitated and paid for by the State party, **both domestic and abroad** – constitutes a serious breach of Luxembourg’s obligations under the Covenant.

2. About the Rapporteurs

This NGO report has been prepared by the NGOs *Intersex & Transgender Luxembourg (ITGL)* and *StopIGM.org / Zwischengeschlecht.org*:

- **Intersex & Transgender Luxembourg (ITGL) a.s.b.l.²** is a local NGO working to raise public and institutional awareness of intersex issues and denouncing IGM practices,^{3 4} and providing continuing education to teaching and health care professionals.^{5 6} As due to the stigma associated with intersex and the comparatively small size of the Grand Duchy, in Luxembourg there are no publicly visible intersex persons,⁷ ITGL therefore consults and

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 <https://itgl.lu/about>

3 <https://www.rtl.lu/news/national/a/1130441.html>

4 “Intergeschlechtlichkeit in Luxemburg – Für ein Gesetz ohne Wenn und Aber”, Press Release 27.09.2019

5 https://www.slp.lu/wp-content/uploads/Journe%CC%81es-intersexes_20.21-03-2017_STD_papier-A4.pdf

6 <https://ssl.education.lu/ifen/descriptionformation?idFormation=194905>

7 Erik Schneider: “Luxemburg – die Intersex-freie Zone Europas?”, forum 341, June 2014, p. 4-6,

collaborates with intersex persons from neighbouring countries to adequately represent intersex issues, namely Kris Günther (Belgium),⁸ Thierry Bosman (Intersex Belgium),⁹ Vincent Guillot (France)¹⁰, and Daniela Truffer (StopIGM.org).¹¹ In its work, Intersex & Transgender Luxembourg keep a strict separation between intersex issues and other issues pertaining to their mandate.

- **StopIGM.org / Zwischengeschlecht.org**, founded in 2007, is an international intersex human rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to eliminate IGM practices and other human rights violations perpetrated on intersex people, according to its motto, “*Human Rights for Hermaphrodites, too!*”¹² According to its charter,¹³ Zwischengeschlecht.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies.¹⁴ **StopIGM.org has been publicly active in Luxembourg since 2017,**^{15 16 17 18} provided continuing education to teaching and health care professionals (in collaboration with ITGL),^{19 20} and consulted on intersex issues by the Comité LGBTI coordinated by the Ministry for Family Affairs and Comité interministériel des droits de l’homme presided by the Ministry for Foreign Affairs.

3. Methodology

This thematic NGO report is a localised update to the **2018 CRC Luxembourg NGO Report (for LOIPR)**²¹ by the same Rapporteurs.

https://www.forum.lu/wp-content/uploads/2014/06/7880_341_Schneider.pdf

- 8 See Revue Nr. 10, 18.03.2017 (in German),
http://web.archive.org/web/20200522181101/http://kastrationsspital.ch/public/luxembourg_revue-10_intersex_mars_2017_scan.pdf
- 9 <http://cet.lu/wp-content/uploads/2017/11/Aventure-intersexe-au-Luxembourg-Communique.pdf>
- 10 http://itgl.lu/wp-content/uploads/2015/04/2012_08_30_Programme_FR_final.pdf
- 11 See below footnotes 15-20s
- 12 <https://Zwischengeschlecht.org/> English pages: <https://StopIGM.org/>
- 13 <https://zwischengeschlecht.org/post/Statuten>
- 14 <https://intersex.shadowreport.org/>
- 15 <https://intersex.shadowreport.org/public/2017-CAT-Luxemburg-LOIPR-Zwischengeschlecht-Intersex-IGM.pdf>
- 16 “Le Quotidien” 21.03.2017, p. 3 (in French),
https://stopigm.org/wp-content/uploads/Luxembourg_LeQuotidien_Intersex_21-03-2017.pdf
- 17 Woxx 23.02.2017 (in German), <http://www.woxx.lu/intersex-das-tabuisierte-geschlecht/>
- 18 <https://blog.zwischengeschlecht.info/post/2018/02/04/Luxemburg-Intersex-Personen-besser-schutzen-RTL-03-02-2018>
- 19 https://www.slp.lu/wp-content/uploads/Journe%CC%81es-intersexes_20.21-03-2017_STD_papier-A4.pdf
- 20 <https://ssl.education.lu/ifen/descriptionformation?idFormation=194905>
- 21 <https://intersex.shadowreport.org/public/2018-CRC-PSWG-Luxembourg-NGO-Intersex-StopIGM.pdf>

A. Precedents: Concluding Observations, LOIPR

1. Harmful Practices and CRC-CEDAW Joint General Comment No. 18/31

a) CEDAW 2018 Concl Obs: CEDAW/C/LUX/CO/6-7, paras 27-28

Harmful practices

27. *The Committee takes note of the plans of the State party to adopt provisions on its extraterritorial obligations with regard to the elimination of female genital mutilation and other harmful practices, in the context of its planned ratification of the Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention). It notes the following with concern: [...]*

(b) The performance of medically irreversible sex reassignment surgery on intersex persons, a practice which is defined as non-consensual, unnecessary genital surgery and includes other comparable procedures that violate the physical integrity of such individuals;

(c) The lack of support for intersex persons who have undergone involuntary and medically unnecessary disfiguring surgical procedures when they were infants or children, often with irreversible consequences, resulting in significant physical and psychological suffering.

28. *In the light of joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices, the Committee recommends that the State party: [...]*

(b) Specifically prohibit non-consensual sex reassignment surgery on intersex persons, develop and implement a rights-based health-care protocol for intersex children that requires medical doctors to inform intersex children about all available options and requires their involvement in decision-making about medical interventions and the full respect of their choices;

(c) Adopt legal provisions to provide redress to intersex persons who are victims of surgical or other medical interventions performed without their free, prior and informed consent or that of their parents.

b) CRC 2019 List of Issues (LOIPR): CRC/C/LUX/QPR/5-6, paras 18+37

Harmful practices

18. *Please provide information on any regulation of and protocol for the treatment of intersex children. Please inform the Committee also about measures to provide families with intersex children with adequate counselling and support, and on rehabilitation and redress to intersex children who have undergone unnecessary and irreversible medical or surgical treatment.*

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

37. *Please provide data, disaggregated, on: [...]*

(b) The number of intersex children subjected to medically irreversible surgery [...];

(c) The number and type of protective measures provided to child victims of violence.

B. IGM in Luxembourg: State-sponsored + pervasive, Gov fails to act

1. IGM practices in Luxembourg: Pervasive and unchallenged

In **Luxembourg** (see CEDAW/C/LUX/CO/6-7, paras 27-28), same as in the **neighbouring states** of *Belgium* (CCPR/C/BEL/CO/6, paras 21-22; CRC/C/BEL/Q/5-6, para 8), *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32-33; CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f), *Germany* (CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, p. 6-7, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24), *Switzerland* (CCPR/C/CHE/CO/4, paras 24-25; CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20; CEDAW/C/CHE/CO/4-5, paras 38-39), and in **many more State parties**,²² there are

- **no legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM practices**
- **no measures** in place to ensure **data collection and monitoring** of IGM practices
- **no legal or other measures** in place to ensure the **accountability** of IGM perpetrators
- **no legal or other measures** in place to ensure **access to redress and justice** for adult IGM survivors

To this day, despite partially recognising the serious violations constituted by IGM practices and pledging to “*prohibit*” IGM and to “[*e*]stablish monitoring of medical interventions on intersex minors, including treatment abroad”,^{23 24 25} the **Luxembourgian government** fails to publicly acknowledge the severe pain and suffering caused by the ongoing IGM practices, let alone to “*take effective legislative, administrative, judicial or other measures*” to protect intersex children, in spite of **longstanding criticism and appeals** by intersex advocates and their organisations,²⁶ seconded by public bodies including the Luxembourgian **National Ethics Commission (CNE)**,²⁷ the **Ombudsman for Children and Adolescents (OKaJu)**,²⁸ the **Centre for Equal Treatment (CET)**,²⁹ the **Consultative Human Rights Commission (CCDH)**³⁰ and CEDAW.³¹

22 Currently we count **50 Concluding observations on IGM practices for 20 State parties in Europe, South America, Asia and Oceania**, see <https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

23 See proposed actions no. 2 and 3 in the 2018 LGBTI Action Plan, p. 48, <https://mfamigr.gouvernement.lu/dam-assets/publications/plan-strategie/lgbti/PAN-LGBTI-web-update.pdf> (see also below p. 15)

24 See also Parliamentary Motion No. 2870 proposing “*the prohibition [...] of non-emergency and non-life-saving treatments carried out without the consent of the persons concerned*” (p. 2), <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doMotionDetails&id=2870> (see also below p. 14)

25 See also 2018 Government Coalition Agreement 2018-2023, see below p. 15

26 See above footnotes 3-10, 16-21

27 Commission Nationale d’Éthique (2017), Avis 27, <https://cne.public.lu/dam-assets/fr/publications/avis/avis-27.pdf> (see also below p. 14)

28 Avis No. 7146.6 de l’Ombuds-Comité fir d’Rechter vum Kand, p. 2, [https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServingServletImpl?path=17D97C12C56E7F1B6BF5CF6696A7D6892392A95201BA66C42D282C785DC8C393E8B74A3529AE0D54F98416A13AFDE089\\$BCB9F0706091D4E1666231C9431E96C3](https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServingServletImpl?path=17D97C12C56E7F1B6BF5CF6696A7D6892392A95201BA66C42D282C785DC8C393E8B74A3529AE0D54F98416A13AFDE089$BCB9F0706091D4E1666231C9431E96C3)

29 Avis No. 7146.4 du Centre pour l’Égalité de traitement, p. 2, [https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServingServletImpl?path=3CC9BB4CAE5860EF2A075B3914D2CFA4B801E285F9600289875EAA257C17874D6A03AE4743ACB5C47156C8C1BF3C7A0C\\$600F810598D1C6666D6C87BB873BFCC0](https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServingServletImpl?path=3CC9BB4CAE5860EF2A075B3914D2CFA4B801E285F9600289875EAA257C17874D6A03AE4743ACB5C47156C8C1BF3C7A0C$600F810598D1C6666D6C87BB873BFCC0)

30 See below, p. 14

31 CEDAW/C/LUX/CO/6-7, paras 27-28

2. Most Common IGM Forms³² advocated and perpetrated by Luxembourg

To this day, in Luxembourg all forms of IGM practices remain widespread and ongoing, persistently advocated, prescribed and perpetrated both in the public state funded Hospital CHL, as well as in foreign Contractual Hospitals namely in Belgium, advocated and paid for by the State via the Statutory Health Insurance System as part of the public Social Security System.

According to public statements by paediatric endocrinologist Dr Michael Witsch (Centre Hospitalier de Luxembourg CHL), in Luxembourg intersex children are submitted to IGM practices if parents insist³³ or if the family can't otherwise deal with their intersex child.³⁴ According to public statements by Dr Yolanda Wagener, then Head of Division at the Ministry of Health, intersex children are also sent abroad for surgery.³⁵ This is also confirmed by a public statement of a parent of a intersex child "Sandro", who was sent to a "specialised hospital in Ghent",³⁶ i.e. UZ [University Clinic] Ghent,³⁷ and was consequently submitted to IGM 1 "masculinising" surgery ("hypospadias repair") at the age of 9 months.

This violation of extraterritorial protections by sending Luxembourgian intersex children to foreign contractual hospitals for IGM practices is even institutionalised in the "Belgian-Luxemburg DSD network and registry" and the "BSGPE (Belgian Study Group for Pediatric Endocrinology) Bellux DSD group",³⁸ in 2014 renamed "Belgian Society for Pediatric Endocrinology and Diabetology (BESPEED)", self-described as an association of "8 university clinics and other medical centres in Belgium and Luxemburg", including the "Clinique pédiatrique du Luxembourg" at the "Centre Hospitalier de Luxembourg CHL" and the "UZ [University Clinic] Ghent".³⁹

The "Centre Hospitalier de Luxembourg (CHL)" includes a "department of paediatric surgery" specialised in "urological surgery",⁴⁰ as well as a "department of urology" also offering "paediatric" services⁴¹ – departments known to facilitate IGM practices. The "UZ [University Clinic] Ghent" on the other hand is a well-known perpetrator of IGM practices which co-authored the 2016 Consensus Statement "Global Disorders of Sex Development

32 For more information, see 2016 CAT France NGO Report (p. 39–43),

<https://intersex.shadowreport.org/public/2016-CAT-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

33 "Le Quotidien" 21.03.2017, p. 2 (in French),

https://stopigm.org/wp-content/uploads/Luxembourg_LeQuotidien_Intersex_21-03-2017.pdf

German translation, <https://blog.zwischengeschlecht.info/post/2017/04/07/Ich-bin-kein-Monster-Luxemburg-IGM-Le-Quotidien>

34 See Revue Nr. 10, 18.03.2017, p. 20 (p. 9 in PDF),

http://web.archive.org/web/20200522181101/http://kastrationsspital.ch/public/luxembourg_revue-10_intersex_mars_2017_scan.pdf, relevant excerpts (in German):

<https://blog.zwischengeschlecht.info/post/2017/03/22/Revue-Luxemburg-Intersex-Kinder-in-Belgien-verstummelt>

35 See above footnote 32, "Le Quotidien"

36 Ibid.

37 "A multidisciplinary DSD team exists in Ghent for this problem. The DSD team consists of doctors and medical personnel from different specialties. The paediatric surgeons perform procedures that are necessary to construct the genitals of these patients",

<https://www.uzgent.be/nl/zorgaanbod/mdspecialismen/kindergeneeskunde/kinderurologie/Paginas/Aandoeningen-van-de-geslachtsontwikkeling.aspx>

38 "DSDnet" (2013), Memorandum of Understanding, p. 11,

http://www.dsdnet.eu/downloads.html?file=files/downloads/BM1303_Memorandum_of_Understanding.pdf

39 <http://www.bsgpe.be/>

40 <https://kannerkliniek.chl.lu/fr/service/chirurgie-pediatrique>

41 <https://centre.chl.lu/fr/service/urologie>

Update” advocating “*gonadectomy*” and other IGM practices,⁴² and generally promotes IGM practices on children.^{43 44}

Further, while there are **no specific Luxemburgian intersex medical guidelines**, the **Luxembourg Society of Urology** (Société Luxembourgeoise d’Urologie SLU) **officially endorses**⁴⁵ the relevant “*Paediatric Urology*” Guidelines of the European Association of Urology (EAU) and the European Society for Paediatric Urology (ESPU) which to this day **openly advocate IGM practices**.⁴⁶

3. IGM in Luxembourg as a Violation of the Covenant

This Committee has already **recognised IGM practices as a serious violation of the Covenant**,⁴⁷ and **arts. 3, 7, 9, 17, 24, 26** as applicable.

Art. 3: Equal Right of Men and Women

On the basis of their “indeterminate sex,” intersex children are singled out for experimental harmful treatments, including surgical “genital corrections” and potentially sterilising procedures, that would be “*considered inhumane*” on “**normal**” children,⁴⁸ e.g. “normal” boys and girls, so that, according to a specialised surgeon, “*any cutting, no matter how incompetently executed, is a kindness.*”⁴⁹ Generally, medical justifications for IGM are often rooted in **gender-based stereotypes**. Clearly, IGM practices therefore also violate Article 3.

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

Like this Committee, the **Committee against Torture**⁵⁰ has repeatedly **considered IGM to constitute inhuman treatment** falling under the non-derogable prohibition of torture (same as FGM and gender-based violence). Intersex advocates consider harmful practices and inhuman treatment as the **most important human rights frameworks** to effectively combat IGM.⁵¹

42 See 2016 CEDAW NGO Report for Switzerland, p. 8, <https://intersex.shadowreport.org/public/2016-CEDAW-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

43 Piet Hoebeke (University of Ghent), “Genital construction and its timing”, presentation at the 5th I-DSD Symposium 2015, see abstract book, p. 3, http://www.gla.ac.uk/media/media_408896_en.pdf

44 See 2018 CRC PSWG Belgium NGO Report, p. 10-12, <https://intersex.shadowreport.org/public/2018-CRC-PSWG-Belgium-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

45 See 2019 EAU Guidelines, p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>

46 See e.g. 2020 CRC Intersex Report for Sweden (for LOIPR), p. 7-8, <https://intersex.shadowreport.org/public/2020-CRC-Sweden-LOIPR-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

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

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

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

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

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

Concerning **involuntary medical or scientific experimentation**, as generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental**. While due to the general avoidance of follow-up by doctors, IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition. However, internationally there are **many examples proving also a strict definition to apply**.⁵² For decades, intersex children have been regularly described and exploited by scientists as an **“experiment of nature”**.^{53 54 55} Often **twins, siblings, mothers or other family members or relatives** of intersex children are used as controls.^{56 57} Generally, intersex children are often used as **subjects in scientific research**, particularly in the field of genetics.

Thus, intersex children surely also fall under *“persons not capable of giving valid consent”* deserving *“special protection in regard to such experiments”* according to **General comment No. 20** (para 7), and involuntary experimental intersex treatments in **Luxembourg** and associated research projects with **Luxembourgian participation** including the **“Belgian-Luxemburg DSD network and registry”**,^{58 59} **“Endo-ERN”**^{60 61} and **“eUrogen”**^{62 63 64} surely also constitute **involuntary medical or scientific experimentation in breach of article 7**.

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- 52 See e.g. Case Study No. 1 in 2015 CAT Austria NGO Report (p. 13-15), explaining how **of two intersex cousins, one was castrated at age 5 or 6 and the other only at age 10 “to document the difference”**, <https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOIE-Zwischengeschlecht-Intersex-IGM.pdf>
- 53 See e.g. Kang H-J, Imperato-McGinley J, Zhu Y-S, Rosenwaks Z. 5alpha-reductase-2 Deficiency’s Effect on Human Fertility. *Fertility and sterility*. 2014;101(2):310-316, at p. 5, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4031759/pdf/nihms578345.pdf>
- 54 Clarnette, T.D; Sugita, Y.; Hutson, J.M.: Genital anomalies in human and animal models reveal the mechanisms and hormones governing testicular descent, *British Journal of Urology* (1997), 79, 99–112, at 99, <http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf>
- 55 U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied zwischen Mädchen und Jungen, Männern und Frauen?, *Monatsschr Kinderheilkd* 2003 · 151:586–593, at 591, see also: Lang C.; · Kuhnle U.: Intersexuality and Alternative Gender Categories in Non-Western Cultures, *Horm Res* 2008;69:240–250
- 56 See e.g. Dittmann, R. W., Kappes, M. H., Kappes, M. E., Borger, D., Stegner, H., Willig, R. H., Wallis, H. (1990). “Congenital adrenal hyperplasia. I: Gender-related behavior and attitudes in female patients and sisters.” *Psychoneuroendocrinology* 15(5-6): 401-420, see also: Ralf W. Dittmann, “Pränatal wirksame Hormone und Verhaltensmerkmale von Patientinnen mit den beiden klassischen Varianten des 21-Hydroxylase-Defektes. Ein Beitrag zur Psychoendokrinologie des Adrenogenitalen Syndroms”, *European University Studies*, Bern: 1989
- 57 For an example of studies on intersex twins by German gynaecologist Ernst Philipp in collaboration with Swiss endocrinologist Andrea Prader, see Marion Hulverscheidt (2016), *Begriffsdefinitionen „Intersexualität“ VII: Eine einheitliche Betrachtung des Zwittertums – der Kieler Gynäkologe Ernst*, <https://intersex.hypotheses.org/3976>
- 58 <http://www.dsdnet.eu/other-networks.html>
- 59 See answer to the July 2019 Parliamentary Question No. 873 *“Atypical sexual development”*, p. 2, <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=17604>
- 60 <https://endo-ern.eu/about/governance/management-board/>
- 61 See Open Letter to “I-DSD 2017”, p. 2, https://stopigm.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf
- 62 <https://eurogen-ern.eu/coordination-visit-national-coordination-hub/>
- 63 See National Coordination Hubs, p. 3, 5, 7, <https://eurogen-ern.eu/wp-content/uploads/2016/11/ERN-eUROGEN-Strategy-for-Integration-of-APs.pdf>
- 64 <https://stopigm.org/eurogen-eu-funded-intersex-genital-mutilators/>

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

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

Art. 9: Liberty and Security of the Person

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

Art. 17: Arbitrary or Unlawful Interference with Privacy

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

Art. 24: Child Protection

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

Art. 26: Equal Protection of the Law

Intersex children have the **same rights to effective protections** from IGM as for example girls against FGM. However, if there are any legal protections against IGM at all, these are **regularly considerably weaker** than those against FGM. Despite the gaps in the local anti-FGM legislation (e.g. lack of extraterritorial protection), this is also the case in **Luxembourg**, and clearly not in line with article 26.

4. Luxembourgian Doctors and Government consciously dismissing Human Rights

The persistence of IGM practices in Luxembourg is a **matter of public record**, same as the **longstanding criticism and appeals by intersex persons, organisations**,⁶⁵ and expert bodies:

In a July 2017 opinion, the **National Ethics Commission (CNE)**, despite frequently mixing up intersex and transgender, officially acknowledged:⁶⁶

“Violations of the rights of intersex persons may amount to corporal mutilation in the form of so-called ‘normalisation’ surgical interventions, without their consent, in particular when these interventions are carried out at an early age.” (p. 1)

“These invasive treatments, most often without medical necessity, are performed in order to match physical appearance to the sex assigned at birth. Often carried out at an early age, in the obvious absence of the prior and fully informed consent of the person directly concerned, the best interests of the child are subordinated to the expectations of society. Parents, who are often influenced and uninformed, tend to follow the advice of the attending physician without necessarily considering the consequences of interventions on their child’s well-being. People who have undergone such interventions often feel mutilated afterwards. Psychological distress due to the negative consequences of surgery should not be neglected and can lead to self-harm and suicidal behaviour.” (p. 8)

A **2017 Opinion of the Ombuds Committee for the Rights of the Child (now Ombudsman for Children and Adolescents OKaJu)**⁶⁷ called for a **“ban”** of *“surgical interventions and non-vital hormonal treatments”* on intersex children *“without the informed consent”* of the person concerned, concluding: *“These irreversible surgeries are experienced by those concerned as torture, mutilation.”*

A **2017 Opinion of the Centre for Equal Treatment**⁶⁸ notes: *“For intersex associations, the most important thing is [...] preventing genital mutilation at birth or later.”*

A **2017 Opinion of the Consultative Human Rights Commission**⁶⁹ pledges: *“CCDH is considering the possibility of punishing unnecessary medical acts”* on intersex children.

In the **2018 Concluding Observations** for Luxembourg the **Committee on the Elimination of Discrimination against Women (CEDAW)** recognised *“non-consensual, unnecessary genital surgery”* and *“other comparable procedures that violate the physical integrity”* of intersex children in Luxembourg to constitute a **harmful practice** and, referring to the CEDAW/CRC Joint General Comment No. 31/18, recommended the State party to inter alia *“[s]pecifically prohibit non-consensual [...] surgery on intersex persons”* and to *“[a]dopt legal provisions to provide redress to intersex persons who are victims of surgical or other medical interventions performed without their free, prior and informed consent”* (CEDAW/C/LUX/CO/6-7, paras 27-28, full paras on intersex see also above, p. 8).

65 See above footnotes 3-10, 16-21

66 Commission Nationale d’Éthique (2017), Avis 27, <https://cne.public.lu/dam-assets/fr/publications/avis/avis-27.pdf>

67 Avis No. 7146.6 de l’Ombuds-Comité fir d’Rechter vum Kand, p. 2, [https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=17D97C12C56E7F1B6BF5CF6696A7D6892392A95201BA66C42D282C785DC8C393E8B74A3529AE0D54F98416A13AFDE089\\$BCB9F0706091D4E1666231C9431E96C3](https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=17D97C12C56E7F1B6BF5CF6696A7D6892392A95201BA66C42D282C785DC8C393E8B74A3529AE0D54F98416A13AFDE089$BCB9F0706091D4E1666231C9431E96C3)

68 Avis No. 7146.4 du Centre pour l’Égalité de traitement, p. 2, [https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=3CC9BB4CAE5860EF2A075B3914D2CFA4B801E285F9600289875EAA257C17874D6A03AE4743ACB5C47156C8C1BF3C7A0C\\$600F810598D1C6666D6C87BB873BFCC0](https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=3CC9BB4CAE5860EF2A075B3914D2CFA4B801E285F9600289875EAA257C17874D6A03AE4743ACB5C47156C8C1BF3C7A0C$600F810598D1C6666D6C87BB873BFCC0)

69 Avis No. 7146.5 de la Commission consultative des Droits de l’Homme, p. 4, [https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=A47ED78D31789DF591CF7012E59E2719476C9F4DE97AB6AC33C41FFA7FDA1FA62D92E9AC770A63B326A5E4159B210E20\\$C5A7F654025E1C25989589808E038ADB](https://chd.lu/wps/PA_RoleDesAffaires/FTSByteServletImpl?path=A47ED78D31789DF591CF7012E59E2719476C9F4DE97AB6AC33C41FFA7FDA1FA62D92E9AC770A63B326A5E4159B210E20$C5A7F654025E1C25989589808E038ADB)

And a **Parliamentary Motion No. 2870** adopted in Parliament on 25.07.2018 explicitly calls for *“the prohibition, in the case of intersex issues, of non-emergency and non-life-saving treatments carried out without the consent of the persons concerned”*.⁷⁰

Also, the **July 2018 Parliamentary Question No. 3946** *“Surgical procedures on intersex children”*,⁷¹ the **July 2019 Parliamentary Question No. 873** *“Atypical sexual development”*⁷² and the **November 2019 Parliamentary Question No. 1454** *“International Day of Intersex Solidarity”*⁷³ raised **data collection**, and **Question No. 1454** further **prohibition, rehabilitation and reparations**.

However, **Luxembourgian paediatric doctors**, despite **openly admitting to knowledge of relevant criticisms** by intersex advocates, human rights and ethics bodies,⁷⁴ nonetheless continue to **consciously refuse to consider any human rights concerns**, and to this day **refuse to disclose data of surgical and other interventions on intersex children**.⁷⁵

Also **Luxembourgian government bodies**, despite repeatedly **promising** to prevent IGM practices, to this day **fail to act**:

The **July 2018 “National Action Plan for the Promotion of the Rights of Lesbian, Gay, Bisexual, Transgender and Intersex People”** officially pledged to *“[p]rohibit medical treatments of ‘sexual normalisation’ without vital urgency that are practiced without the free and informed consent of the intersex person (and therefore stop reimbursement by public health funds)”*, and to *“[e]stablish monitoring of medical interventions on intersex minors, including treatment abroad”*.⁷⁶

Also, the **December 2018 “Government Coalition Agreement 2018-2023”**, while in its wording constituting a major **step backwards** from the National Action Plan, pledged to **prohibit at least some IGM practices** (i.e. the relatively rare intersex cases where the *“biological sex cannot be clearly determined”*): *“Surgical or medical interventions in minors who are incapable of discernment and whose biological sex cannot be clearly determined will be prohibited by law, except in cases of vital necessity.”*⁷⁷

However, so far the **Government fails** to take practical steps to implement these pledges. Instead Government communications continue to **publicly misrepresent** intersex as “a part of the LGBTI umbrella” suffering from *“discrimination”* only.^{78 79}

70 <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doMotionDetails&id=2870>

71 <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=16481>

72 <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=17604>

73 <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=18209>

74 See for example CHL paediatricians Dr Michael Witsch and Dr Marianne Becker, in Reporter, 23.07.2018, <https://www.reporter.lu/operationen-an-intersex-kindern-wenn-das-geschlecht-verordnet-wird/>

75 Ibid.

76 Ministry of Family Affairs (2018), National Action Plan for the Promotion of the Rights of Lesbian, Gay, Bisexual, Transgender and Intersex People, p. 48, <https://mfamigr.gouvernement.lu/dam-assets/publications/plan-strategie/lgbti/PAN-LGBTI-web-update.pdf>

77 2018 Government Coalition Agreement 2018-2023, p. 23,

https://ccdhd.public.lu/content/dam/ccdh/fr/archives/2019/accord_coalition_2018_2023/Accord-de-coalition-2018-2023.pdf

78 See for example a press release by the Ministry for Family Affairs on occasion of Intersex Awareness Day 2018 claiming to raise awareness of intersex issues, however, it fails to even mention involuntary genital surgery and other harmful practices on intersex children, exclusively referring to *“discrimination”* instead,

Accordingly, the **December 2019 Government Answer to the Parliamentary Question No. 1454**⁸⁰ openly admits that

- regarding the promised **prohibition** of IGM, there are still **no practical results**, referring to ongoing “*Inter-ministerial consultations on this matter*” (p. 2)
- regarding the promised **data collection**, it still “*does not have figures on the number of intersex children who have undergone medically irreversible surgical operations*”, instead **once more promising** “*more precise information regarding the fate of intersex children in the years to come*” (p. 2)
- regarding “*means of rehabilitation and reparation [...] for intersex children who have undergone unnecessary and irreversible medical or surgical treatment*”, that concerning **rehabilitation there are no specific means available**, “[s]ince medical situations differ greatly from one individual to another, any cases concerned should be treated individually with regard to rehabilitation”, while completely **failing to give any answer on reparation at all** (p. 3)

Also the **2020 CRC State Report under LOIPR**⁸¹ underlines the failure of the Government to act, again

- **admitting** that concerning **data collection** “*information on intersex children subjected to medically irreversible surgery is not available*” (para 198 (6))
- **failing** to give any answer on **actual regulation** of IGM practices, merely referring to the 2018 National LGBTI Action Plan pledge for “*prohibition*” instead (para 74)
- completely **failing** to give any **answer on redress** at all (paras 71-74)

At the same time, Government officials, politicians and doctors use the internationally established **pretexts and excuses to publicly oppose** effective prohibition of IGM practices:⁸²

“Health Minister Lydia Mutsch already sees a regulation as difficult. She says that a separate special law for intersex people could lead to ‘further stigmatisation’. There could also be problems with implementation. Most children would not be operated on in Luxembourg, which is why it is difficult to prosecute a doctor if he does not practice in this country. She therefore rather pleads for a directive that applies throughout Europe.”

“The Greens [...] have included a ban on genital surgery on [intersex] babies in their election manifesto. [...] Sam Tanson (Greens) is also in favour of such a ban. However, she adds: ‘A ban on these operations is right in principle. But the question is whether it is even necessary in Luxembourg.

https://gouvernement.lu/de/actualites/toutes_actualites/communiqués/2018/10-octobre/25-cahen-campagne.html

79 See also simple language documentation on intersex issues issued by the Ministry for Family Affairs, again failing to mention involuntary genital surgery and other harmful practices on intersex children at all, but exclusively referring to “discrimination” instead, openly declaring (p. 4) “*The aim is a policy against discrimination. We want diversity. That’s why we support LGBTI people. LGBTI is an abbreviation for five groups: Lesbians, gays, bi-sexuals, transgender and intersex people. At first glance, these people do not belong together. Their lives are very different. But they all have the same experience: discrimination.*”,

https://mfamigr.gouvernement.lu/dam-assets/campagnes/personnes_intersexes/2018-CAMPAGNE-Personnes-intersexes-Internet-Texte-Einfache-Sprache.pdf

80 <https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=18209>

81 CRC/C/LUX/5-6

82 Michèle Zählen (2018), “Wenn das Geschlecht verordnet wird”, in Reporter, 23.07.2018,

<https://www.reporter.lu/operationen-an-intersex-kindern-wenn-das-geschlecht-verordnet-wird/>

For that, one would first have to look at how many such operations are carried out in this country'. So, there is still some catching up to do before a law can be considered in concrete terms."

"However, [doctors] Witsch and Becker are against a complete ban on the treatment of infants and children. [...] A ban would increase the risk that parents might have their children operated on abroad, says Dr Witsch. He does not believe that this would be the better option. Although society has become more open, parents still struggle with the fate of their intersex child. This is another reason for the treatment, says Dr Witsch. 'Not every family can cope with the fact that their child is an intersex child. If the parents reject their child because it's neither boy nor girl, it will suffer.'"

5. Lack of Independent Data Collection and Monitoring

With no statistics available on intersex births, let alone surgeries and costs, and **doctors, 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, doctors in charge of IGM practices internationally respond by suppressing data, as well as refusing to talk to journalists "on record".

Also in Luxembourg, there are **no statistics** available on intersex birth and on IGM practices. In **2018**, the **Ministry for Social Security** announced plans to start data collection in **2020**.⁸³ However, in **December 2019** the **Ministry of Health**, the **Ministry of Family and Integration**, and the **Ministry of Justice** again **postponed** the collection of data while **once more promising** "*more precise information regarding the fate of intersex children in the years to come*".⁸⁴

The only partial figures available are from 2017 of hospitals stays concerning known diagnoses associated with **IGM 1: "Masculinising" Genital Surgeries a.k.a. Hypospadias "Repair"** ("*Q54 Hypospadias*")⁸⁵ and **IGM 3: Sterilising Procedures ("*Q53 Cryptorchidie*")**⁸⁶ published by the **Ministry of Health**:⁸⁷

83 See answer by the **Minister for Social Security** to **Parliamentary Question No. 3946**, which admits (p. 3), "*The Ministry for Health and the Ministry for Social Security do not have figures on surgical interventions carried out on intersex newborn children in Luxembourg or abroad. [...] However, as part of the hospital documentation gradually implemented under the law of 8 March 2018 on hospitals and hospital planning, this type of information is now systematically collected in hospitals. The number of diagnoses of intersex newborns, as well as the number and nature of surgical interventions performed as part of their care, will therefore be available for the compilation of national statistics from 2020 onwards, i.e. after the deployment of the provisions of the law.*"

<https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=16481>

84 See answer to **Parliamentary Question No. 1454**, which admits (p. 2), "*The Ministry of Health does not have figures on the number of intersex children who have undergone medically irreversible surgical operations, as there is no legal obligation to register such cases.*"

With the introduction of hospital documentation on the basis of article 38 of the Act of 8 March 2018 on hospital establishments and hospital planning, all hospitals now carry out a quantitative and qualitative analysis of their activity, including in particular the interventions, medical examinations and services provided by the health professionals involved in the care. This legal provision enables the Ministry of Health to gather more precise information on the fate of intersex children in the years to come."

<https://chd.lu/wps/portal/public/Accueil/TravailALaChambre/Recherche/RoleDesAffaires?action=doQuestpaDetails&id=18209>

85 For general information, see 2016 CEDAW NGO Report France, p. 48-49,

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

86 Ibid., p. 47

87 Ministry of Health (2017), "Carte sanitaire - Mise à jour 2017 : Fascicule 2 - Motifs de recours à l'hospitalisation selon la classification internationale des maladies (ICD 10)", p. 135,

<https://sante.public.lu/fr/publications/c/carte-sanitaire-2017-fascicule2/carte-sanitaire-2017-fascicule2.pdf>

Evolution des diagnostics de sortie les plus fréquents, 2006-2015

(nombre de séjours – Classement réalisé sur la moyenne 2011-2015 des séjours)

Code ICD 10 et Libellé	Moy. 2006-10	2011	2012	2013	2014	2015	Moy. 2011-15	Evol. 2006/10		Evol. 2011/15
Q53 Cryptorchidie	86,0	80	83	96	105	79	88,6	+23,8%	▲	-1,3%
Q62 Anomalies congénitales obstructives du bassinet et malformations congénitales de l'uretère	59,0	56	36	48	40	36	43,2	-47,4%	▼	-35,7%
Q79 Malformations congénitales du système ostéo-articulaire et des muscles, non classées ailleurs	21,4	25	24	37	55	40	36,2	/		+60,0%
Q17 Autres malformations congénitales de l'oreille	31,8	40	35	50	27	23	35,0	+38,5%	▲	-42,5%
Q54 Hypospadias	22,4	28	25	34	37	25	29,8	-3,8%	▼	-10,7%

Doctors in charge publicly refuse to disclose data, while at the same time claiming IGM practices would be “strictly a thing of the past”.⁸⁸

At the same time, this **ongoing refusal** to disclose data is used as a **pretext** to **postpone** effective measures against IGM practices, namely **prohibition**:⁸⁹

*“Sam Tanson (Greens) [...]: ‘A ban on these operations is **right in principle**. But the question is **whether it is even necessary** in Luxembourg. For that, **one would first have to look at how many such operations are carried out in this country**’.”*

6. Obstacles to redress, fair and adequate compensation

Also in **Luxembourg** 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.⁹⁰ So far, in Luxembourg there was **no case** of a victim of IGM practices succeeding in going to court.

The **Luxembourgian government** fails to ensure that non-consensual unnecessary IGM surgeries on minors are recognised as a form of **genital mutilation**, which would formally prohibit parents from giving “consent”. In addition, the State party **fails to initiate impartial investigations**, as well as data collection, monitoring, and disinterested research.⁹¹ What’s more, hospitals are often **unwilling to provide full access to patient’s files**.

Conclusion, also here the current situation is clearly **not in line with Luxembourg’s obligations** under the Covenant.

88 “How many such cases are treated in CHL? **Dr Witsch and Dr Becker do not disclose this**. Only this much: ‘The last operation will be about two years ago’, estimates Witsch.

‘The situation was different 30 or 40 years ago. Intersex people have experienced terrible things. It is absolutely understandable that they are traumatised,’ says Dr Witsch.”

Dr Michael Witsch and Dr Marianne Becker, in Reporter (2018),

<https://www.reporter.lu/operationen-an-intersex-kindern-wenn-das-geschlecht-verordnet-wird/>

89 Ibid.

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

91 For more on this topic see 2016 CEDAW NGO Report France, p. 55:

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

Annexe 1 – Intersex, IGM and Non-Derogable Human Rights

1. Intersex = variations of reproductive anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with “Disorders” or “Differences of Sex Development (DSD)”,⁹² 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.*⁹³

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.⁹⁴

In **regions without universal access to paediatric health care**, there are reports of **infanticide**⁹⁵ of intersex children, of **abandonment**,⁹⁶ of **expulsion**,⁹⁷ of **massive bullying** preventing the

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

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

94 For references and general information, see 2015 CAT NGO Report Austria, p. 30-35,

<https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf>

95 For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14,

<https://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf>

For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12,

<https://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

For South Africa, see also <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens>

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

<https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

; for Uganda, see also 2015 CRC Briefing, slide 46,

https://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,

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

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

<https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

For example in China, see 2015 Hong Kong, China NGO Report, p. 15,

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

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

<https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),⁹⁸ and of **murder**.⁹⁹

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 supremacist implications**.^{100 101 102 103}

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**,¹⁰⁴ 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.¹⁰⁵ **UN Treaty bodies have so far issued 50 Concluding Observations condemning IGM practices accordingly.**¹⁰⁶

98 For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see

<https://stopigm.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3>

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

100 2014 CRC NGO Report, p. 52, 69, 84, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

101 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>

102 “The Racist Roots of Intersex Genital Mutilations”

<https://stopigm.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM>

103 For 500 years of “scientific” prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7,

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

104 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, *ibid.*, p. 38–47

105 **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>

106 <https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

3. Intersex is NOT THE SAME as LGBT or Transgender

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

The underlying reasons for such harmful misrepresentations include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**^{107 108} 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,¹⁰⁹ 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.^{110 111}

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*”,¹¹² and again IGM survivors as “*transgender children*”,¹¹³ “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”¹¹⁴ and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.¹¹⁵

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*”,¹¹⁶ “*a special provision on sexual orientation and*

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

108 CEDAW66 Ukraine, <https://stopigm.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics>

109 For references, see 2016 CEDAW France NGO Report, p. 45

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

110 For example ACHPR Commissioner Lawrence Murugu Mute, see

<https://stopigm.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT>

111 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

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

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

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

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

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

gender identity”, “*civil registry*” and “*sexual reassignment surgery*”¹¹⁷, transgender guidelines¹¹⁸ or “*Gender Identity*”¹¹⁹¹²⁰ 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**¹²¹ and public **representation**.¹²²

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**¹²³¹²⁴¹²⁵¹²⁶ – 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**.¹²⁷¹²⁸¹²⁹

117 CCPR120 Switzerland,

<https://stopigm.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120>

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

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

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

121 For example in Scotland (UK), LGBT organisations have so far collected at least **£ 135,000.–** public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, <https://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf>

Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as “supporting intersex people”, but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), <https://stopigm.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

122 See e.g. “Instrumentalizing intersex: ‘The fact that LGBTs in particular embrace intersex is due to an excess of projection’ - Georg Klauda (2002)”, <https://stopigm.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002>

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

124 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8,

https://stopigm.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

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

127 For example Ministry of Health Chile (2016), see

<https://stopigm.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile>

128 For example Ministry of Health France (2018), see 2020 CRC Intersex NGO Report (for LOIPR), p. 19,

<https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf>

129 For example Ministry of Health Austria (2019), see 2019 CRC Intersex NGO Report (for Session), p. 4-5,

<https://intersex.shadowreport.org/public/2019-CRC-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

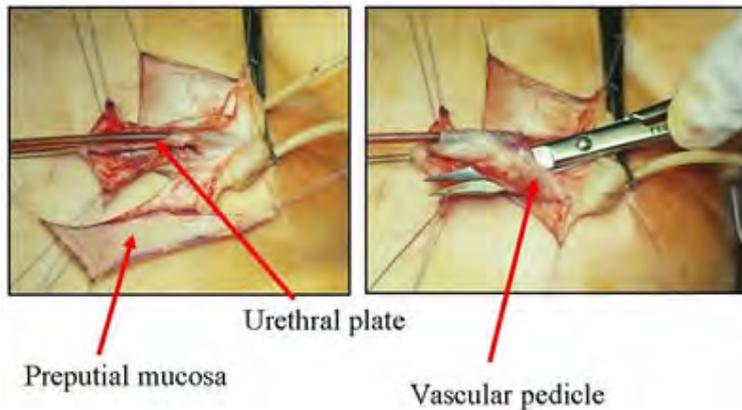
Annexe 2 – “IGM in Medical Textbooks: Current Practice”

IGM 1 – “Masculinising Surgery”: “Hypospadias Repair”

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

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

Onlay island flap urethroplasty



Onlay / Duckett - results

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



Hypospadias - Procedures for cripple hypospadias

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



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

Treatment of isolated fistulae

- 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 - Conclusions

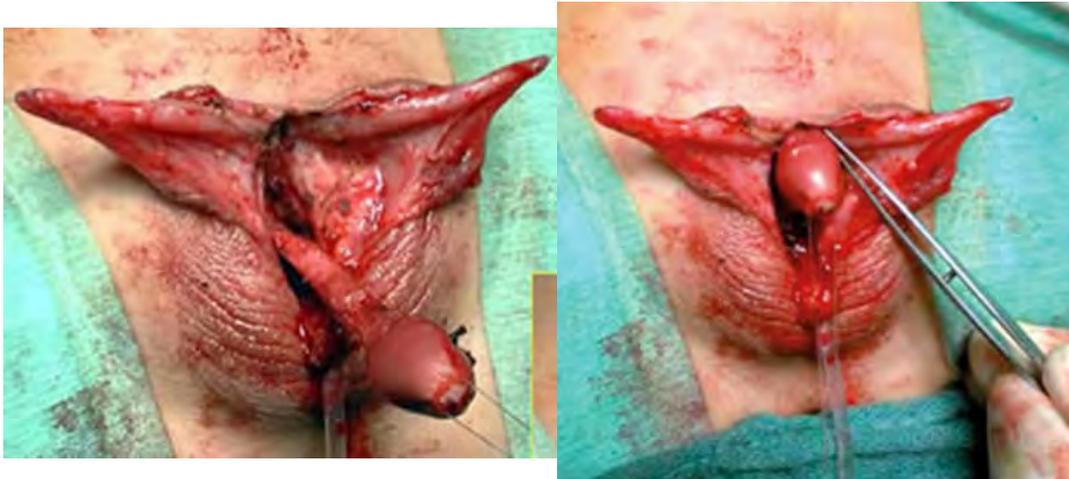
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

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

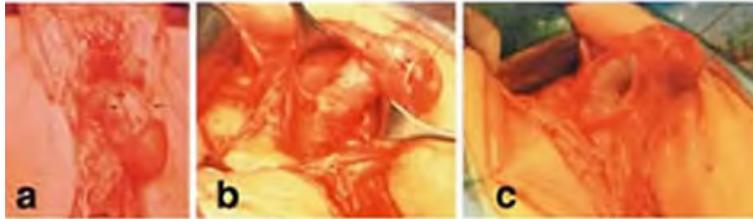
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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").

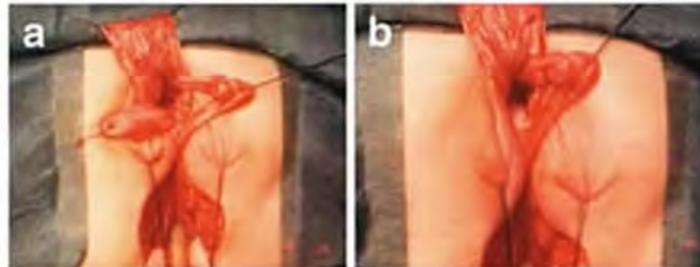
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "*in the first 2 years of life*", most commonly "*between 6 and 12 months,*" and only 10.5% of surgeons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



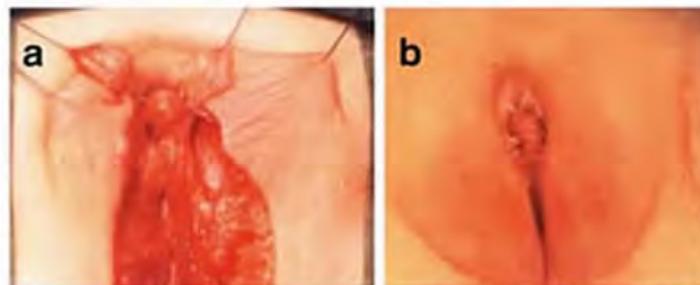
Source: Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



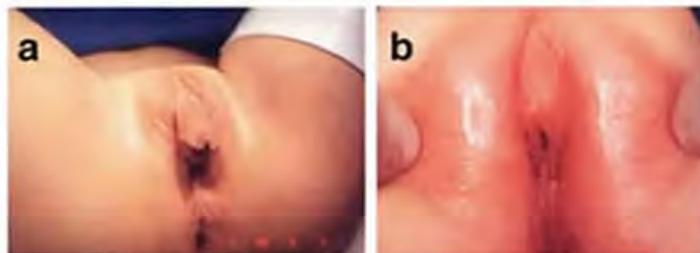
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



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



8a+b: Refixation der Corpora cavernosa clitoridis. "Materialknappheit" bei der Rekonstruktion der Corpora cavernosa 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 prepuce clitoridis and the inner labia.



Source: Pierre Mouriouand: "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	Prevalence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15-40
Intermediate	PAIS	15
	17 β -hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5 α -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.

3 months old with scrotal hypospadias and right impalpable gonad

- Uterus and dysplastic gonad removed
- Hypospadias repaired
- Follow-up for surveillance of development testicular and/or renal tumors
- Testosterone required at puberty



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

“Bad results” / “Gonadectomy, Feminising Genitoplasty”



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

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

PAIS

- Bilateral gonadectomy
- Skin Biopsy for genetics study of androgen receptors
- Female gender assignment
- Feminizing genitoplasty performed age 6 months








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