v2.0

Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Sex Anatomy

NGO Report
to the 5th Periodic Report of the United Kingdom
on the Convention on the Rights of the Child (CRC)

+ Supplement "IGM Practices and the CRC"

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http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

Executive Summary

The United Kingdom of Great Britain and Northern Ireland is in breach of its obligations under the Convention on the Rights of the Child to **(a) take effective legislative, administrative, judicial or other measures to prevent non-urgent, unnecessary surgery and other medical treatment carried out on intersex children** without the effective, informed consent of those concerned, causing severe mental and physical pain and suffering, and **(b) to ensure impartial investigation, access to redress, and the right to fair and adequate compensation and rehabilitation for victims**. (Art. 24 para. 3 in conjunction with CRC and CEDAW Joint General Comment No. 18/31 "on harmful practices"). (**A**, **B**, **C**)

This Committee has already recognised IGM practices as a breach of the Convention in previous **Concluding Observations** for **Switzerland, Chile, Ireland**, and **France**, and called for **(a)** guarantee bodily integrity, autonomy and self-determination to children concerned, **(b)** adopting legal provisions to ensure redress and compensation, and **(c)** provide access to free counselling. (**A**, **F, Bibliography**)

Also **CAT**, **CEDAW**, **CRPD**, the UN Special Rapporteur on Torture (**SRT**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**) and the Council of Europe (**COE**) call for **legislative remedy** and **access to redress and justice** for victims (**Bibliography**).

Intersex people are born with **Variations of Sex 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 (**D**).

IGM Practices include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments** that would not be considered for "normal" children, without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs. (**E.1.**) **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 (**E.2.**, **"IGM in Medical Textbooks"**).

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, less sexual activity, dissatisfaction with functional and aesthetic results. (**E**, **Cases No. 1–10**)

All typical IGM forms are still practised in the UK today. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. (**A**, **E**, **Cases No. 1–10**, **"IGM in Medical Textbooks"**).

For more than 20 years, intersex people have criticised IGM as **harmful** and **traumatising**, as a form of **genital mutilation** and **child sexual abuse**, as **torture or ill-treatment**, and called for legislation to prevent it and to ensure remedies (**F**).

This **Thematic NGO Report** has been compiled by the international intersex NGO **StopIGM.org / Zwischengeschlecht.org** in collaboration with UK intersex human rights defenders **ISUK**, **OII-UK** and **UKIA**. It contains **Concluding Recommendations** (**C**).

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Introduction

State Report and Intersex in the UK

The United Kingdom of Great Britain and Northern Ireland will be considered for its fifth periodic review by the Committee on the Rights of the Child in its 72th Session in 2016. In the UK, **doctors in public, university and private clinics** are regularly performing **IGM practices**, i.e. non-consensual, medically unnecessary, irreversible cosmetic genital surgeries, sterilising procedures, and other harmful treatments on intersex children, which have been described by survivors as genital mutilation and torture. IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been repeatedly **recognised by this Committee** and other **UN bodies** as constituting **violence**, a **harmful practice** and **torture or ill-treatment.**

Unfortunately, human rights violations of intersex children and adults weren't mentioned in the State Report. However, this NGO Report demonstrates that the current **medical treatment of intersex infants and children in the UK** constitutes a serious breach of the UK's obligations under the Convention on the Rights of the Child.

The United Kingdom not only does nothing to prevent this abuse, but in fact directly finances it via the public health assurances and via funding the public university clinics and paediatric hospitals, thus violating its duty to prevent harmful practices. To this day the UK Government **refuses to take appropriate legislative, administrative and other measures** to protect intersex children, and refuses survivors the right to justice, redress and compensation.

About the Rapporteurs

This NGO report has been prepared by the international intersex NGO *StopIGM.org / Zwischengeschlecht.org* in collaboration with UK intersex persons and advocates *Holly Greenberry and Dawn Vago (ISUK)*, *Leslie Jaye (OII-UK)*, *Dr J. Hayes-Light (UKIA)*:

- **StopIGM.org / Zwischengeschlecht.org,** founded in 2007, is an international Human Rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to represent the interests of intersex people and their relatives, raise awareness, and fight IGM Practices and other human rights violations perpetrated on intersex people, according to its motto, *"Human Rights for Hermaphrodites, too!"*[1] According to its charter,[2] Zwischengeschlecht.org works to support persons concerned seeking redress and justice, and has continuously collaborated with members of parliament and human rights bodies in order to call on Governments and Clinics to collect and disclose statistics of intersex births and IGM practices, and to prevent them.
- ***Holly Greenberry*** and ***Dawn Vago*** are UK intersex persons, survivors of IGM practices and intersex human rights defenders working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.[3] They are co-founders of **IntersexUK** (**ISUK**).[4]

1 http://Zwischengeschlecht.org/, English pages: http://StopIGM.org/
2 http://zwischengeschlecht.org/post/Statuten
3 http://www.independent.co.uk/news/uk/home-news/special-report-intersex-women-speak-out-to-protect-the-next-generation-8974892.html
4 http://intersexuk.org

- ***Leslie Jaye*** is a UK intersex person, survivor of IGM practices and intersex human rights defender working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.[5] She served as chair of **OII-UK**.[6]
- ***Dr J. Hayes-Light*** is a UK intersex person, survivor of IGM practices and intersex human rights defender working to improve the well-being and human rights of intersex persons, and to raise awareness on intersex issues.[7] He serves as director of **The UK Intersex Association** (**UKIA**).[8]

In addition, the Rapporteurs would like to acknowledge the work of the **Androgen Insensitivity Syndrome Support Group UK** (**AISSG UK**)[9] and **Margaret Simmonds**.[10] We would like to acknowledge the work of **Michel O'Brien**.[11] And we would like to acknowledge the work of **Ellie Magritte**[12] and **dsdfamilies.org**.[13]

Methodology

This thematic NGO report is a localised and updated **addition to the thematic CRC NGO Reports** for **Switzerland** (**2014**), **Ireland** (**2015**) **and France** (**2015**) by partly the same rapporteurs.

This Report includes **10 anonymised personal testimonies of UK survivors of IGM practices** compiled by the Rapporteurs, based on (a) written submissions solicited for this NGO report by the Rapporteurs and ISUK, (b) interviews conducted for this NGO report, and (c) written testimonies available online via AISSG UK[14] and Hypospadias UK[15] (see source given at the end of each testimony). They show in an exemplary manner how different forms IGM are practiced in the UK without informed consent by the persons concerned and/or their parents, and cause **severe physical and mental pain and suffering**.

Background: IGM and Intersex Human Rights

Intersex Genital Mutilations are still an **"emerging human rights issue,"** unfortunately often neglected due to lack of access to comprehensive information. To assess the current practice at national level, some general knowledge on the matter is crucial. For further reference, and to facilitate access to more comprehensive information for the Committee, the rapporteurs attached abbreviated **thematic supplements**.[16]

The rapporteurs are aware that **IGM practices are a global issue, which can't be solved on a national level alone.** However, this report illustrates why the **UK** is a State party to which it would be timely and most appropriate to issue strong recommendations.

5 http://intersexday.org/en/statement-oiiuk-iad-2015/
6 http://oiiuk.org
7 https://www.vice.com/en_uk/read/the-group-campaigning-for-better-intersex-rights
8 http://ukia.co.uk
9 http://www.aissg.org/
10 Margaret Simmonds: 'Girls/women in inverted commas – facing "reality" as an XY-female', University of Sussex 2012, http://sro.sussex.ac.uk/43431/1/Simmonds,_Margaret.pdf
11 http://oiiinternational.com/653/holistic-for-whom/
12 http://www.dsdfamilies.org/docs/conf/working_together.pdf
13 http://www.dsdfamilies.org/
14 http://www.aissg.org/41_STORIES.HTM
15 http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/
16 Abbreviated from *"IGM – Historical Overview"* and *"IGM – The 17 Most Common Forms"* contained in the *2014 CRC Thematic NGO Report*, online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

A. IGM Practices in the United Kingdom

1. Lack of Protection for Intersex Persons, IGM Practices Remain Pervasive

a) Overview

In the **United Kingdom of Great Britain and Northern Ireland**, same as in the states of *Switzerland* (CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20), *Ireland* (CRC/C/IRL/CO/3-4, paras 39-40), *France* (CRC/C/FRA/CO/5, paras 47-48) and *Chile* (UN CRC, CRC/C/CHL/CO/4-5, paras 48–49), 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 non-consensual, medically unnecessary, irreversible surgery and other harmful treatments a.k.a. IGM practices.

To this day, the **UK government refuses to *"take effective legislative, administrative, judicial or other measures"*** to protect intersex children, but instead counterfactually **claims *"genital surgery at a young age"* of intersex children to be a thing of the past** (same as public NHS University Children's Clinics, see below under A.2.3. "Lack of legislative provisions", p. 15).

At the same time, all forms of **IGM practices remain widespread and ongoing**, advocated, prescribed and perpetrated by publicly employed **NHS doctors** in **public NHS University, Regional Children's Clinics**, and Private Clinics, are advocated by **UK medical associations**, and are facilitated and paid for by the **public National Health Service (NHS)**.

b) Most Common IGM Forms advocated by NHS Doctors and Clinics

- **IGM 3: Sterilising Procedures** plus arbitrary imposition of hormones (see also **Cases No. 2–6, 8**), as advocated in the 2013 ***"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"***,[17] co-authored by Dr Peter Malone (University College Hospital UCLH, University College London Hospitals NHS Foundation Trust / Royal Berkshire Hospital, Royal Berkshire NHS Foundation Trust):

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

  Similarly, the **"2016 Global Disorders of Sex Development Consensus Statement",**[18] co-authored by Prof S. Faisal Ahmed (Paediatric Endocrinology, School of Medicine, University of Glasgow / Royal Hospital For Children, NHS Greater Glasgow and Clyde) – even when admitting *"low"* cancer risk (*"GCC risk"*) for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)[19]:

17 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

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

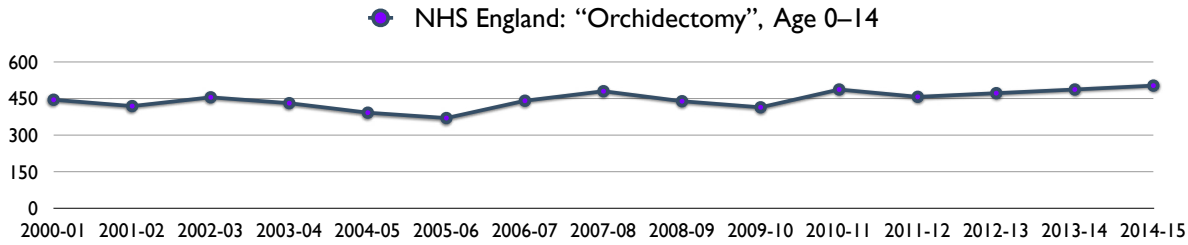
19 ibid, at 180 (fn 111)

Table 2. GCC risk: clinical management

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Based on ultrasound and results of first biopsy – If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectomy Intensive psychological counseling and follow-up
No data are available on the value of cryopreservation or safety if a precursor lesion for GCC is present.			

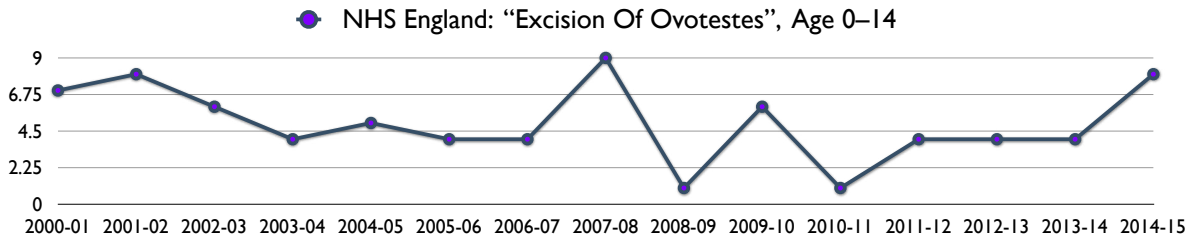
Source: Lee et al., in: Horm Res Paediatr 2016;85:158–180, at 174 (see fn 18)

Accordingly, the NHS frequently facilitates and pays for **removal of testes of children 0–14 years, including unnecessary removal in intersex children:**[20]



Source: NHS England: Hospital Episode Statistics (HES) – for details, see fn 20

And the NHS regularly facilitates and pays for **unnecessary removal of "atypical" gonadal tissue of intersex children:**[21]



Source: NHS England: Hospital Episode Statistics (HES) – for details, see fn 21

20 Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+England%22&area=&size=10&sort=Relevance: 2000-2014: "Main procedures and interventions: 4 character", N05.2, N06.3. 2014-15: N05.2, N05.3, N06.3, N06.6. Note: Numbers also include necessary treatments of non-intersex children.

21 Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+England%22&area=&size=10&sort=Relevance: 2000-2014: "Main procedures and interventions: 4 character", X15.3. 2014-15: X16.3-6 (see next example).

In addition, as the more refined statistics 2014-2015 for "gonadectomies" show, in England **often gonadectomies, including excision of ovotestes, still happen very early from 0-4 years,** when in any case actual cancer risk is hardly an issue**:**[22]

Total procedures and interventions: 4 character codes and descriptions		Age 0	Age 1-4	Age 5-9	Age 10-14
X16.3	Excision of gonad from abdomen	-	3	-	-
X16.4	Excision of gonad from pelvis	-	-	-	1
X16.5	Excision of gonad from inguinal canal	2	-	-	-
X16.6	Excision of gonad NEC	1	3	-	-
X16.8	Other specified operations for disorders of sex development	5	1	1	-

Source: NHS England: Hospital Episode Statistics (HES) – for details, see fn 22

- **IGM 2: Feminising Genital Surgeries** (see also **Cases No. 1–4, 8**): The ***"Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)"***[23] generally advocates early unnecessary surgeries as legitimate, framing the human rights issues involved as *"controversies"*:

> ***"Some parents may consider early genital surgery as a mechanism that could possibly protect their child from the risk of future stigma.*** *This will require a thorough discussion with several members of the MDT team including the clinical psychologist, surgeons, gynaecologist and nurses so that the parents are fully informed of the* ***controversies around undertaking or withholding early genital surgery."***

Above *"guidance"* remains remarkably similar to the 2011 ***"best practice by a multidisciplinary team (MDT) dedicated to children with DSD"*** as promoted by paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children GOSH NHS Foundation Trust / Senior Lecturer Institute of Child Health, London): [24]

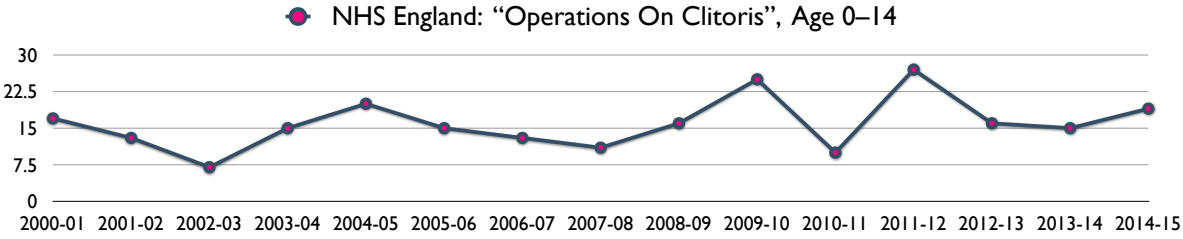
> ***"There is no subject that creates more controversy and debate*** *than that relating to 'feminising' genital surgery in infants and children with DSD. [...]"*
>
> ***"Many parents of children with DSD continue to express deep concerns about the appearance of the genitalia*** *and these concerns need to be taken seriously and managed in an appropriate manner. [...]"*
>
> ***"Clitoral surgery is generally considered when the clitoris is larger than 'normal'.*** *[...] "*
>
> ***"In girls with severe clitoral enlargement we remain happy to undertake clitoral reduction surgery,*** *provided the family are fully informed and cognisant of the potential risks and benefits."*
>
> ***"Until such time as there is a change in the law, parents will continue to have the right to decide*** *if their child should or should not have genital surgery in infancy or childhood. [...]"*

22 From Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+England%22&area=&size=10&sort=Relevance: 2014-15: "Total procedures and interventions: 4 character". Note: These procedures may not all constitute unnecessary treatments.

23 S. Faisal Ahmed et al., "Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015)", Clinical Endocrinology (2016) 84, 771–788, http://onlinelibrary.wiley.com/doi/10.1111/cen.12857/pdf

24 Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

Accordingly, the NHS persistently facilitates and pays for **clitoral surgery on children 0–14 years** on a regular basis – despite all ethics and human rights *"controversy and debate"*:[25]



Source: NHS England: Hospital Episode Statistics (HES) – for details, see fn 25

- **IGM 1: Masculinising Genital Surgeries** (see also **Cases No. 7, 9, 10**), as advocated by the "British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS)" in their online ***"Procedure Guide Hypospadias"***: [26]

  "There is no urgency to treat this condition, but once recognised you will be referred to a specialist to discuss surgery to correct the problem. [...]"

  "What surgery is available, and what techniques are involved?

  Surgery is recommended to make the penis look as natural as possible and to enable the child to stand up to pass urine. ***Corrective surgery for the treatment of hypospadias is often carried out 12 months after birth but can be done earlier or later.*** *[...]."*

  "Is this surgery available on the NHS?

  Surgery to correct hypospadias is widely available on the NHS."

UK NHS medical bodies and children's clinics generally **advocate early hypospadias "repair" justified by psychosocial "indications".** For example the **"Scottish Disorders of Sex Development Managed Clinical Network (SDSD)"** (NHS Scotland) recommends in its *"Information Leaflet Hypospadias for Parents"*: [27]

"Is there a right time for surgery?"

"We usually offer surgery before the child starts school, because we think this is best for your child socially. *[...]"*

Or the **"Norfolk and Norwich University Hospitals NHS Foundation Trust"** and **"Ipswich Hospital NHS Trust"** in their *"Information Leaflet on Hypospadias for Parents"*: [28]

"WHAT AGE WILL MY SON BE?"

"We prefer to perform the operation at ***about 12 months of age*** *or above."*

Or the **"University Hospitals Bristol NHS Foundation Trust"** in its *"Surgery for Hypospadias Family information leaflet"*: [29]

"Surgery usually takes place at 10-18 months of age *[...]"*

25 Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+England%22&area=&size=10&sort=Relevance: 2000-2012: "Total procedures and interventions: 3 character", P01. 2012-15: "All procedures and interventions: 4 character" P01.1, P01.2, P01.8.

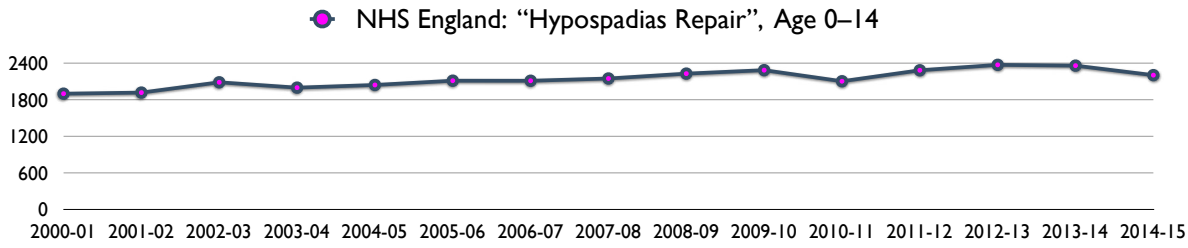
26 http://www.bapras.org.uk/public/patient-information/surgery-guides/hypospadias

27 http://www.sdsd.scot.nhs.uk/Information%20leaflets/New%20hypospadias%20leaflet%20for%20parents291211.pdf

28 http://www.nnuh.nhs.uk/publication/download/hypospadias-29-0-14

29 http://www.drmark.info/Dr_Mark/Information_leaflets_files/Hypospadias%20surgery_one%20and%20two%20stage_2012.pdf

Accordingly, the NHS very frequently facilitates and pays for **hypospadias "repair" on intersex children 0–14 years:** [30]



Source: NHS England: Hospital Episode Statistics (HES) – for details, see fn 30

- **Repeated Forced Genital Exams and Photography** (see also **Cases No. 1–3, 6**) are also **common place** in the UK, see e.g. the pictorial examples published by the *"Norfolk and Norwich University Hospitals NHS Foundation Trust"*. [31]

c) UK NHS Doctors consciously dismissing Intersex Human Rights Concerns

It must be duly noted that **UK paediatric surgeons** are **adamant advocates** of IGM practices, **consciously dismissing to consider any human rights concerns, despite openly admitting to knowledge of relevant criticisms** by human rights and ethics bodies.

For example, the 2013 *"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"*, co-authored by Dr Peter Malone (University College Hospital UCLH, University College London Hospitals NHS Foundation Trust / Royal Berkshire Hospital, Royal Berkshire NHS Foundation Trust) dismissed both the **2013 Report by the Special Rapporteur on Torture** and the 2012 Recommendations by the Swiss National Advisory Commission on Biomedical Ethics as ***"inappropriate and biased statements"*** and ***"biased and counterproductive reports"***, while insisting on continuing with IGM practices.[32]

And paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children NHS Foundation Trust / Senior Lecturer Institute of Child Health, London) freely admits **only *"a change in law"*** would prevent the hospital's *"multidisciplinary team (MDT) dedicated to children with DSD"* from continuing with IGM practices: [33]

> *"**Until such time as there is a change in the law, parents will continue to have the right to decide** if their child should or should not have genital surgery in infancy or childhood. [...]"*

This is the more severe, since over a decade of ongoing research published by **clinicians from the UCLH Middlesex Clinic caring for adult intersex persons** clearly documents the disastrous effects of non-consensual, unnecessary childhood treatments in the UK, so UK paediatric doctors specialising in such treatments are obviously fully aware of the severe pain and suffering caused by their actions.[34]

30 Figure derived from Hospital Episode Statistics (HES) available at http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22Hospital+Episode+Statistics%2C+Admitted+patient+care+England%22&area=&size=10&sort=Relevance: 2000-2012: "Main procedures and interventions: 4 character", M73.1. 2012-15: "All procedures and interventions: 4 character" M73.1.

31 See photos A–D on p. 5: http://www.nnuh.nhs.uk/publication/download/hypospadias-29-0-14

32 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

33 Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

34 see e.g. Sarah M. Creighton et al., (2013), Childhood surgery for ambiguous genitalia: glimpses

2. The Treatment of Intersex Children in the UK as a Harmful Practice and Violence

a) Harmful Practice [35]

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.[36]

The Committee has repeatedly considered IGM as a harmful practice, and the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices as applicable.[37]

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.[38]

The **Joint General Comment No. 18 "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 further underlines the need for a ***"Holistic framework*** *for addressing harmful practices"* (paras 31–36), including ***"legislative, policy and other appropriate measures*** *that must be taken to ensure full compliance with [state parties'] obligations under the Conventions to eliminate harmful practices"* (para 2), as well as

- *"Data collection and monitoring"* (paras 37–39)
- *"Legislation and its enforcement"* (paras 40–55), particularly:
- ***"adequate civil and/or administrative legislative provisions"*** (para 55 (d))
- *"provisions on* ***regular evaluation and monitoring****, including in relation to implementation, enforcement and follow-up"* (para 55 (n))
- ***"equal access to justice,*** *including by* ***addressing legal and practical barriers to initiating legal proceedings, such as the limitation period,*** *and that the* ***perpetrators and those who aid or condone such practices are held accountable"*** (para 55 (o))
- *"equal access to* ***legal remedies and appropriate reparations*** *in practice"* (para 55 (q)).

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of practice changes or more of the same?, Psychology & Sexuality 5(1):34-43
For a list of older relevant Middlesex publications, see http://www.intersexinitiative.org/articles/minto-creighton.html

35 For a more extensive version, see below p. 55

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

37 CRC/C/CHE/CO/2-4, 4 February 2015, paras 42–43: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En
CRC/C/CHL/CO/4-5, 2 October 2015, paras 48–49, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fCHL%2fCO%2f4-5&Lang=en

38 Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: "Ending the Impunity of the Perpetrators!" Input for Session 3: "Human Rights Standards and Intersex People – Progress and Challenges - Part 2" at "Ending Human Rights Violations Against Intersex Persons." OHCHR Expert Meeting, Geneva 16–17.09.2015, online: http://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

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

Thus, **IGM practices in the UK** – as well as the **complete failure of the state party to enact appropriate legislative, administrative, social and educational measures** to eliminate them and to ensure effective access to remedies and redress – clearly violate Article 24 CRC, as well as the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices.

b) Violence against Children

Similarly, the Committee has also considered IGM practices as violence against children, and Art. 19 and the General Comment No. 13 also offers strong provisions to combat IGM practices (see below **p. 57**)

3. Lack of Legislative Provisions to Ensure Protection from IGM Practices, Impunity of the Perpetrators

Article 24 para. 3 of the Convention in conjunction with the CRC/CEDAW Joint General Comment 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)).

Also Article 19 of the Convention calls upon states to ***"take all appropriate legislative, administrative, social and educational measures** to protect the child from all forms of physical or mental violence"*, and the General Comment No. 13 "The right of the child to freedom from all forms of violence" (2011) stipulates that state parties ***"ensur[e] absolute prohibition** of all forms of violence against children in all settings and effective and appropriate **sanctions against perpetrators**"* (GC 13, para 41 (d)).

Accordingly, with regards to IGM practices, and referring to Article 24 para 3 and the CRC/CEDAW Joint General Comment No. 18/31, this Committee already explicitly recognised the obligation for State parties 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"***, as well as 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"**.*[39]

However, to his day the **UK government refuses to even discuss, let alone enact appropriate legislative measures** to effectively eliminate IGM practices, nor to **address the factual impunity of the perpetrators.**

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39 CAT/C/CHE/CO/7, 14 August 2015, para 20: http://intersex.shadowreport.org/public/CAT_C_CHE_CO_7-Concl-Obs-Switzerland-2015_G1520151.pdf,

Worse, **UK government bodies**, while admitting to the harm done by the practice, are quick to actively shield IGM perpetrators from human rights criticism by simply **declaring the ongoing practice in the UK a topic of the past:**

> *"Intersex people are born with ambiguous primary physical sexual characteristics.* ***Until recently they would usually undergo genital surgery at a young age*** *to given them characteristics which are clearly either male or female. Medical professionals are now more likely to advise waiting until the child is older and* ***able to provide informed consent*** *to surgery, because of the implications surgery can have on future health and function."* [40]

The above 2016 denial by a **UK Equalities Committee** is remarkably similar to the below 2011 denial issued by the **Great Ormond Street Hospital for Children GOSH**,[41] once more framing intersex human rights concerns as mere *"different opinions"*:

> *"GOSH are aware of issues you have raised and the personal origins of your concerns.* ***We recognise that in the past such surgeries were carried out and the difficulties this has caused.*** *We would like to reassure you that in advanced centres such as our own your* ***concerns have been heard*** *and influence our decision making process .*
>
> ***Generally families are happy with the treatments now offered*** *but are obviously very keen to protect their children from public attention on this sensitive matter. As with any area of medicine with* ***difficult ethical balances to strike*** *on when and when not to offer treatment, this topic brings out a wide spectrum of opinion and we recognise the right of those with* ***different opinions*** *to express them."*

Around the same time as the above GOSH denial was issued, GOSH paediatric urologist Dr Imran Mushtaq (Great Ormond Street Hospital for Children NHS Foundation Trust / Senior Lecturer Institute of Child Health, UCL) freely admitted **only *"a change in law"*** would prevent the GOSH *"multidisciplinary team (MDT) dedicated to children with DSD"* from continuing with IGM: [42]

> ***"In girls with severe clitoral enlargement we remain happy to undertake clitoral reduction surgery,*** *provided the family are fully informed and cognisant of the potential risks and benefits."*
>
> ***"Until such time as there is a change in the law, parents will continue to have the right to decide*** *if their child should or should not have genital surgery in infancy or childhood. [...]"*

This situation with the **UK government** denying the ongoing practice while continuing to **protect the perpetrators** is clearly not in line with the **UK's obligations** under the Convention and CRC/CEDAW Joint General Comment No. 18/31.

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40 **House of Commons, Women and Equalities Committee,** *"Transgender Equality. First Report of Session 2015–16"*, at 5 (fn 3), http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf

41 Great Ormond Street Hospital (GOSH), reply 19.10.2011 to Open Letter of Concern 18.09.2011, http://Zwischengeschlecht.org/public/Great-Ormond-GOSH_NHS_Denial-19-10-2011.pdf

42 Imran Mushtaq, "Surgery in infants and children with DSD" (2011), http://dsdfamilies.org/docs/mednote/Surgery%20-%20Mushtaq.pdf

4. Obstacles to Redress, Fair and Adequate Compensation

Article 24 para. 3 of the Convention in conjunction with the CRC/CEDAW Joint General Comment 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)).

Article 19 of the Convention and the General Comment No. 13 "The right of the child to freedom from all forms of violence" also stipulate the right of victims to ***"effective access to redress and reparation"*** (GC 13, para 41 (f)), ***"including compensation to victims"*** (GC 13, para 56).

However, also in the **UK** 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.[43] So far there was no case of a victim of IGM practices succeeding in going to a UK court.

The **UK government** so far refuses 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 **refuses to initiate impartial investigations**, as well as data collection, monitoring, and disinterested research. In addition, hospitals are often **unwilling to provide full access to patient's files** (see also **Cases No. 1, 2, 9**).

This situation is not in line with the **UK's** obligations under the Convention.

43 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.

B. Conclusion: The UK is Failing its Obligations towards Intersex People under the Convention on the Rights of the Child

The surgeries and other harmful treatments intersex people endure cause severe physical and mental pain and suffering. Doctors perform the surgery for the discriminatory purpose of making a child fit into societal and cultural norms and beliefs, although there is plenty of evidence of the suffering this causes. The State party is responsible for these violations constituting a harmful practice, violence against children, and torture or at least ill-treatment, perpetrated by publicly funded doctors, clinics, and universities, as well as in private clinics, all relying on money from the mandatory health insurance, and public grants. Although in the meantime the pervasiveness of IGM practices is common knowledge, the UK nonetheless fails to prevent these grave violations, but allows the human rights violations of intersex children to continue unhindered.

Thus the **UK is in breach of its obligation to take effective legislative, administrative, judicial or other measures to prevent harmful practices** (Art. 24 para. 3 in conjunction with CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices"), as well as of its obligations under Articles 2, 3, 6, 8, 12, 16, 19, 23, 24.1, 34, 36, and 37 of the Convention on the Rights of the Child (see below **p. 53–58**).

Also in the UK, victims of IGM practices encounter severe obstacles in the pursuit of their **right to redress, fair and adequate compensation, including the means for as full rehabilitation as possible**.

Further the state party's efforts on **education and information regarding the human rights aspects of IGM practices in the training of medical personnel** are grossly insufficient with respect to the treatment of intersex people.

C. Recommendations

The Rapporteurs respectfully suggest that the Committee recommends the following measures to the UK Government with respect to the treatment of intersex Persons (based on the Committee's previous recommendations to ***Switzerland*** *and* ***Ireland****):*

Intersex Persons

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, the Committee recommends that the State party:

(a) **Ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, adopt legislation with a view to guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;**

(b) **Undertake 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; and,**

(c) **Educate and train medical and psychological professionals on the consequences of unnecessary surgical and other medical interventions for intersex children.**

Annexe 1 "UK Case Studies"

Case Study No. 1

Source: Written submission, interview.

Born 1963, presenting as male. After adrenal crisis diagnosed female with CAH.
1966 initial reduction of clitoris at three.
1967 clitoris completely amputated before fourth birthday at Great Ormond Street Hospital for Children (GOSH).
Remembers being led in to a room, students standing in a row at the wall, staring at their shoes while she is told to stand on a table and undress.
1978 start of several exploratory surgeries to explore the internal reproductive layout.
1980 attempt to create a neo-vagina at 17 led by Sir Jack Dewhurst at Chelsea Westminster Hospital. Announced as „minor correction" due before 18 to be paid for, the neo-vagina broke down as a consequence of not being sterile, leading to septicemia and 5 days in coma, followed by repair surgery a few weeks later.
Pre 2012, after discovering her GOSH patient number in her GP's notes, files subject access request to obtain medical records. GOSH first denies her ever having been a patient. Then says records are archived in microfilm cabinet. In September 2012, after repeated written complaints, GOSH apologises for not being able to find the records, and officially registers them as lost.

"I do not, and never have had a functional vagina, and nor do I have anything that could be described as a clitoris. I do have severe scarring in my groin, which gives me great pain almost every day."

"I have suffered a lifetime with flashbacks and nightmares about my experiences at Great Ormond Street, and the physical mutilations my body has suffered as a consequence of being born intersex. I have a formal diagnosis of PTSD in my GP's notes, and have struggled with bouts of depression at points in my life."

Case Study No. 2

Source: Written submission, interview.

Born 1966 at a private hospital in the UK with abdominal testes and a micropenis with hypospadias. Transferred to a general NHS hospital in Glasgow, and after that to another General Hospital in Manchester. Doctors unsure about sex, further tests revealed male chromosomes. Later diagnosed with 5 Alpha Reductase Deficiency.
Feminising surgery during first months on penis and scrotum, removal of testes.
1976 vaginoplasty at 10. Then refused any further surgery and the prescribed hormones.
In 1997, at age 19, decides to live as man and seeks reconstructive surgery.
Soon after he had a road traffic accident, which he survived severely hurt, but is in a wheelchair since that day.
His medical records contain information about the accident, but all documents concerning intersex treatment are gone.

"My family [at first] objected [to feminising surgery], but were advised that my life would be a living nightmare if I grew up looking so different. It wasn't possible (or so they were told) to make me look like a 'normal boy' so the best thing would be to make me look like a girl (on the outside). I wouldn't remember the operation nor have any idea that I was male, so would grow up a happy, well-adjusted girl. The 'only' drawback was that I would be infertile."

"Some surgery was performed in the first months of life to 'reduce' my penis to resemble a clitoris and my scrotum split open and sutured to resemble labia. Later, one testicle was found in my groin and surgically

removed (and in my case, my fertility). I had ultrasound tests and some abdominal surgery in order to find the second gonad, but this was unsuccessful. Following the surgeries, my health was poor due to what was to be a long legacy of [urethral tract] infections."

"When I first attended school, I had problems due to repeated genital and renal infections. For my first day in school I had to wear incontinence pants [...]."

"Concurrent with attending school I spent years attending hospital being prodded and poked by medics whilst a spotlight was shone on me and being made to feel like a specimen on a slab."

Case Study No. 3

Source: Written submission.

Born 1969 in Portsmouth, England, classified and raised as a girl.
1976 referred to Chelsea Hospital for Women in London because of abdominal pain. Professor Sir John Dewhurst diagnosis CAIS, tells parents "ovaries" have to be removed or she would die of cancer. Parents consent to surgery.
Ashamed of body after surgery, sexually abused by teenager at the age of 8.
1981 start of „hormone replacement therapy".
1982 drinking alcohol at 12, taking drugs from age 14.
1983 mother leaves the family, two suicide attempts.
1994 discovers truth about gonadectomy. Psychotherapies, in recovery from addiction for 14 years, meets other intersex person in her forties.
Still suffering from trauma, afraid of hospitals, nightmares before going to the doctor. Currently on anti-depressants for anxiety and low mood.

"He [Dewhurst] told my parents and I that I am a "special little girl" [...]. He said I was lucky to be diagnosed [...] (implying that other girls died from it)."

"Our family saw Dr Dewhurst as a God-like "saviour" figure and my parents went along with whatever he wanted from then on- as he had "saved" their little girl's life. [They] compl[ied] with his wish to see me in London every 6 months, ostensibly to check on my progress, in reality, not medically unnecessary. Although I believed these visits were to make sure the cancer wasn't active. [H]e would have between 8-15 medical students, who would all gather around my bed and examine my body- whilst he talked about me, as an interesting, rare & special specimen."

"[Later] I went to see a male gynaecologist who told me I had a small vagina and no womb and probably wouldn't grow public hair. He sent me home with an NHS kit of dildos- small to large; and told me to insert them every day. I felt so ashamed and embarrassed I threw them in the bin. I stopped doing sport at school as I didn't have periods and no pubic hair growing; and absolutely no support structure."

Case Study No. 4

Source: Written submission.

Born 1984 at Edinburgh Western General Hospital, classified and raised as girl.
1987 referred to Edinburgh Sick Kids Hospital for routine hernia operation, where the doctors found abdominal testes and removed them without consulting the parents first.
Diagnosis „Testicular Feminisation" was later changed to „Partial Androgen Insensitivity Syndrome", and finally to „Intersex".
1992 surgery to lengthen the vagina.
1994 (age 10) parents tell her that she cannot have children, but there is no counselling from constultant of Edinburgh Sick Kids Hospital.

1998 (age 14) learns she had been born with testes.

"[A]s my Mother awaited me coming out of surgery, the surgeon approached her and told her that whilst they were operating, they had discovered two internal undescended testes, and had removed them due to an alleged cancer risk. This was done with absolutely no consent from anyone, informed or otherwise, from either my parents or (obviously) myself - as I was three. The Surgeon who operated on myself informed my Mother about this in a hospital waiting room with around three or four people sitting nearby, who heard everything. She became rather upset and began crying."

"My parents continued to raise me as a girl, and a later operation were scheduled, without my consent, at the age of eight, to lengthen the vagina. I can remember all of my hospital stays vividly, and the first one in particular was horrendous. To say that I was only three, my memory of it was surprisingly vivid, as I screamed in terror, cried, and retched as the doctors attempted to administer the old-fashioned style of anaesthetic, with a mouth piece. To this day that hideous smell haunts me, the very memory of this incident sickens and upsets me."

Case Study No. 5

Source: Written submission.

Born 1988 in Leamington Spa England with a Cloacal Exstrophy, no visible genitalia, sex unknown. Given a boy's name. Later transferred to Birmingham Children's Hospital for first emergency surgery to close abdomen.
At ten months old first appointment with urologist of Great Ormond Street Hospital for Children (GOSH) in London to perform surgery to close abdomen and pelvis. Urologist persuades parents to also perform feminising surgery and to remove reproductive organs to avoid cancer risk.
Around 18 months surgery to close abdomen and pelvis, removal of reproductive organs. No further genital surgeries were performed. Raised as a girl.
1992 mother tells him that he originally was a boy. Growing up confused, always feeling like a boy.
"Hormone replacement therapy" during teenage years. Depression, suicide attempts, self harm.
Later in life routine chromosome test reveals XY chromosomes. Obtained medical records show that healthy testes were removed during childhood.

"[When the consultant urologist at GOSH explained] my parents should raise me as a girl, naturally they immediately dismissed his idea, they had had a little boy for almost a year, so where was the sense in changing that now. The consultant sat them down and explained that babies born with Cloacal Exstrophy were almost always raised female as being raised male had a massive detrimental effect on the physical and emotional wellbeing of the child."

"He went on to explain that as a male I wouldn't have a penis and that the psychological effect would lead to depression and maybe even suicide and that surgically reconstructing a penis wasn't viable. He explained that as a female he could construct a vagina and that with the right hormones I would grow up like any other little girl."

"Some soul searching later and my parents decided, that, if my life would be so much more difficult as a boy then raising me as a girl was the only option. They were told to pick a day to make the transition, they chose my first birthday. The night before my birthday they put me to bed then began changing all of my clothes from blue to pink [...]."

"Unfortunately there are many cases of Cloacal Exstrophy males who have been castrated and raised

female, it was and still is depending on where you are born the standard practice of care."

"Though it is to late to fix the damage of the past, it is vital that we protect these children in the future."

Case Study No. 6

Source: Written submission.

Born 1991 at the Sandwell Hospital, West Midlands, UK, classified and raised as girl.
1996 at the age of five referred to Birmingham Children's Hospital for surgery to fix a hernia. Doctors find an abdominal testis and performed a biopsy. Parents are coerced to make the decision to perform a gonadectomy to avoid high cancer risk. Both testes removed during another surgical procedure shortly after.
2002 at 11 told about her diagnosis, start of „hormone replacement therapy". Finally also had to deal with a doctor without any knowledge about her condition, which prescribed hormonal medication detrimental to bone health, leading to low bone density.
Today on the correct medication, but has to pay up monthly for two separate forms of medication for the rest of her life. Recently been diagnosed with Generalised Anxiety Disorder and moderate to severe depression.

"One vivid memory is when I was roughly about 7 or 8 years old, I remember feeling cornered in a room of around 8 adults. I felt on display for some kind of exhibition which I had no idea was about. I was asked questions by doctors, nurses and medical students, but I remember feeling unbelievably anxious and shy and I simply could not speak. At this point, I was asked to leave while the adults talked about my health, something I was kept in the dark about. I knew there was something wrong with me, but I was always told by professionals that it was "just a check-up for your hernia"."

"I went for annual check-ups in order for Dr. Kirk to review my progress with regards to pubescent changes, particularly breast growth. [...] [I]t felt wrong that I had to sit there while he examined closely and touched my breasts. When I was around 14, I was referred to Birmingham Women's Hospital. Mrs Blunt, the specialist I was in contact with at this time, was helpful and seemed to know quite a lot about my individual case. However, I remember having to have the length of my vagina examined, which was measured by Mrs Blunt penetrating a finger inside of my vaginal opening. [...] I was prescribed with dilators to stretch my vaginal opening so that I could have sexual intercourse in the future."

"[I] was persuaded not to tell anyone about my condition because nobody would accept me for the way I am. [...] I was never offered any form of psychological support, and [...] my parents found it difficult and uncomfortable to talk about. [...] I used to sit in my room and sometimes self-harm, feeling suicidal."

"Since reaching out to support networks on social networking sites that I found by myself, I feel so much more accepting of myself and realise that I'm not as abnormal and alone as first believed. In hindsight, I wish that my family and I were provided with more informative, psychological support to allow an autonomous decision with regards to life-changing surgery and other aspects."

Case Study No. 7

Source: http://www.aissg.org/stories/sophia.htm

Born 1964, diagnosed with 5-alpha reductase deficiency.
Hypospadias repair at age of 18 months.
Learning about her diagnosis in her forties.
Later in life, after many painful complications, opting for feminising surgery.
Angry about parent's and doctor's mismanagement, and about secrecy.

"I describe myself as someone who was the victim of a misinformed medical profession and a conformity

obsessed society. The problem is not one of "social interactions" or "sexology". The problem with me was being born with a metabolic condition that has symptoms people were all confused about. I never felt like a "little girl" or a "little boy". It was at an early age I just became numb to such notions. I actually thought the rest of the world was pathologically obsessed. I was sort of living in some nightmare populated by blank eyed zombies who saw nothing other than "sex" and "gender". And let's be honest here, was that the sort of thing a child should have to put up with?"

"My body is still a mess with numerous scars, my mind is also scarred by what happened to me as a child."

Case Study No. 8

Source: http://www.aissg.org/stories/sam.htm

Born 1985, diagnosed with PAIS
Gonadectomy at 18 months old, vaginoplasty at 1 ½ years old.
Under doctors' care at UCLH (Elizabeth Garrett Anderson Hospital) since about 14 or 15 years old.
In 2004 another surgery is performed to correct the poor results of the vaginal surgery as a toddler, with disastrous outcome: unable to place the vaginal opening where planned, the surgeons proceeded anyway. Complications, urethral problems, severe pain, also in the abdomen due to repeated laparoscopic examinations, followed by a bad infection, and a 4-5 month healing process.
The result is a ring of large scars, dilation doesn't work because of scaring, the vagina shrinks again.
Later another vaginoplasty is performed in Brazil, with better results, but still leaving the traces of the other surgeries on the exterior.

"Due to my anatomy downstairs they put the vagina where my perineum [area between labia/vulva and anus] once was, and in my opinion too far back and behind my vulva lips. It literally looked like I had sat on a metal fence spike and it was an injury!"

Case Study No. 9

Source: http://www.aissg.org/stories/liam.htm

Born 1986 with hypospadias, hypospadias „repair" surgery during childhood, discovers to have PAIS and hypospadias over the internet at the age of 25. The trigger was a psychotic episode and him starting to think he was a woman, and an admission to a psychiatric hospital. Suffers from psychosocial problems and incontinence.

"It was amazing, life changing, life affirming when the truth has finally come out. I've been admitted to a physchiatric hospital for psychosis and I'm now in a theraputic community in Scotland (...). I've never known that I had a defect at birth and not until I had my psychotic episode did I start to think I was a woman. Since then I've asked my dad (a GP) about it and my mum - but it became obvious that they weren't telling me what was going on; it's only till I typed in my symptoms to a google search did I find out about all the information firstly about hypospadias and then about Partial AIS and CAIS - when I did this 4 hours ago everything clicked into place and the relief of the truth came out. I'm writing to you because I fear that I may never get to meet any other sufferers or come to the meeting annual because of the cloak of deceipt that has been around me since my conscience and because of the lack of trust of those around me: and fear too partly because of psychosis."

"None of the medical professionals have been honest about [having hypospadias], and I would also like to

get a full copy of my medical records now that I feel I'm in a position so that it will not affect my mental health so that I can see exactly what went on."

Case Study No. 10

Source: 48 years old in the UK, http://www.hypospadiasuk.co.uk/life-stories-of-men-with-hypospadias/

Born 1960 with mid-shaft hypospadias.
Three-stage surgery between age 3 and 5 at Great Ormond Street Hospital for Children (GOSH) in London, surgery seemingly successful.
Discharged from aftercare at age 7.
During adolescence problems become more obvious, but unable to talk to parents or doctor about it. Years after the first complications, a diverticulum (sort of pocket our pouch off the urethra, where urine collected) developed, causing frequent pain and tendency to empty urine later, causing embarassment.
Physical problems getting worse in his 30s and 40s, stone in diverticulum, chronic urinary tract infections.
In 2007 finally seeking medical advice, GP's refers him immediately to consultant urologist at Guy's Hospital, which refers him to specialist at UCLH. Two-stage repair surgery followed to remove stone and diverticulum and rebuild urethra.

"I feel much better, both physically and personally. Physically, because I realise that the stone had been causing me a lot of low-level, chronic infections which were making me feel generally unwell. It was also quite uncomfortable during sex. Personally, because I have finally faced up to my "dark secret" and done something about it. It's hard to describe how great this feels – it's like a big weight being taken off my shoulders. Anyone who's gone through similar experiences will understand."

"I've had tremendous support from a couple of other men with HS whom I met through the old Yahoo groups. It was this experience, of meeting "sufferers", that initiated the whole process of being able to face up to my HS, tell my partner about it and seek medical advice."

"I've received very little information about what was going to happen to me, and absolutely no counselling whatsoever. I've been badly handled by incompetent hospital administrations who have routinely cocked up appointments, and then don't understand when I get angry or upset. There is absolutely no recognition of the fact that it's hard for a man to deal with issues relating to his genitals; you're expected to breeze through it exactly as you would if you were having your tonsils removed."

"I've been told now that anyone who had HS surgery in infancy is very likely to need a further repair in adulthood – but I had never heard that before. If that was more widely known, I would have consulted a doctor years ago, and saved myself a lot of unhappiness. I also think that any surgery which involves a man's genitals should be accompanied by some form of pre- and post-operative counselling."

Annexe 2 "Bibliography: IGM in Human Rights Mechanisms"

1. International Bodies Recognising Human Rights Violations of Intersex Persons

2006: UN WHO, Genomic resource centre, Gender and Genetics: Genetic Components of Sex and Gender (online)
http://www.who.int/genomics/gender/en/index1.html

Gender Assignment of Intersex Infants and Children

Intersex is defined as a congenital anomaly of the reproductive and sexual system. An estimate about the birth prevalence of intersex is difficult to make because there are no concrete parameters to the definition of intersex. The Intersex Initiative, a North-American based organization, estimates that one in 2,000 children, or five children per day in the United States, are born visibly intersex. (36) This estimate sits within range; from genital anomalies, such as hypospadias, with a birth prevalence of around 1:300 to complex genital anomalies in which sex assignment is difficult, with a birth prevalence of about 1:4500. (37) Many intersex children have undergone medical intervention for health reasons as well as for sociological and ideological reasons. An important consideration with respect to sex assignment is the ethics of surgically altering the genitalia of intersex children to "normalize" them.

Clitoral surgery for intersex conditions was promoted by Hugh Hampton Young in the United States in the late 1930s. Subsequently, a standardized intersex management strategy was developed by psychologists at Johns Hopkins University (USA) based on the idea that infants are gender neutral at birth. (38) Minto et al. note that "the theory of psychosexual neutrality at birth has now been replaced by a model of complex interaction between prenatal and postnatal factors that lead to the development of gender and, later, sexual identity". (39) However, currently in the United States and many Western European countries, the most likely clinical recommendation to the parents of intersex infants is to raise them as females, often involving surgery to feminize the appearance of the genitalia. (40)

Minto et al. conducted a study aiming to assess the effects of feminizing intersex surgery on adult sexual function in individuals with ambiguous genitalia. As part of this study, they noted a number of ethical issues in relation to this surgery, including that:

- *there is no evidence that feminizing genital surgery leads to improved psychosocial outcomes;*
- *feminizing genital surgery cannot guarantee that adult gender identity will develop as female; and that*
- *adult sexual function might be altered by removal of clitoral or phallic tissue. (41)*

2009: UN CEDAW, CEDAW/C/DEU/CO/6, 10 February 2009, para 61–62:
http://www2.ohchr.org/english/bodies/cedaw/docs/co/CEDAW-C-DEU-CO6.pdf

Cooperation with non-governmental organizations

61. [...] The Committee regrets, however, that the call for dialogue by non-governmental organizations of intersexual [...] people has not been favourably entertained by the State party.

62. The Committee request the State party to enter into dialogue with non-governmental organizations of intersexual [...] people in order to better understand their claims and to take effective action to protect their human rights.

Follow-up to concluding observations

67. The Committee requests the State party to provide, within two years, written information on the steps undertaken to implement the recommendations contained in paragraphs 40 and 62.

2009: UN SR Health, A/64/472, 10 August 2009, para 49:
http://www.refworld.org/pdfid/4aa762e30.pdf

IV. Vulnerable groups and informed consent

A. Children

49. Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent. [67] [Fn. 67: This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits; see, e.g., Colombian Constitutional Court, Sentencia SU-337/99 and Sentencia T-551/99.] Safeguards should be in place to protect children from parents withholding consent for a necessary emergency procedure.

2011: UNHCHR, A/HRC/19/41, 17 November 2011, para 57:
http://www.ohchr.org/Documents/Issues/Discrimination/A.HRC.19.41_English.pdf

"In addition, intersex children, who are born with atypical sex characteristics, are often subjected to discrimination and medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to fix their sex."

2011: UN CAT, CAT/C/DEU/CO/5, 12 December 2011, para 20:
http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

Intersex people

20. The Committee takes note of the information received during the dialogue that the Ethical Council has undertaken to review the reported practices of routine surgical alterations in children born with sexual organs that are not readily categorized as male or female, also called intersex persons, with a view to evaluating and possibly changing current practice. However, the Committee remains concerned at cases where gonads have been removed and cosmetic surgeries on reproductive organs have been performed that entail lifelong hormonal medication, without effective, informed consent of the concerned individuals or their legal guardians, where neither investigation, nor measures of redress have been introduced. The Committee remains further concerned at the lack of legal provisions providing redress and compensation in such cases (arts. 2, 10, 12, 14 and 16).

The Committee recommends that the State party:

(a) Ensure the effective application of legal and medical standards following the best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives;

(b) Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;

(c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity; and

(d) Properly inform patients and their parents of the consequences of unnecessary surgical and other medical interventions for intersex people.

2013: UN SR Torture, A/HRC/22/53, 1 February 2013, paras 77, 76, 88:
http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, "in an attempt to fix their sex", [107] leaving them with permanent, irreversible infertility and causing severe mental suffering.

76. [...] These procedures [genital-normalizing surgeries] are rarely medically necessary,[106] can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma (A/HRC/14/20, para. 23). [...]

88. The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, "reparative therapies" or "conversion therapies", when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.

2013: Council of Europe (COE), Resolution 1952 (2013) "Children's right to physical integrity", 1 October 2013, paras 2, 6, 7:
http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en

2. The Parliamentary Assembly is particularly worried about a category of violation of the physical integrity of children, which supporters of the procedures tend to present as beneficial to the children themselves despite clear evidence to the

contrary. This includes, amongst others, female genital mutilation, the circumcision of young boys for religious reasons, early childhood medical interventions in the case of intersex children and the submission to or coercion of children into piercings, tattoos or plastic surgery.

6. The Assembly strongly recommends that member States promote further awareness in their societies of the potential risks that some of the above mentioned procedures may have on children's physical and mental health, and take legislative and policy measures that help reinforce child protection in this context.

7. The Assembly therefore calls on member States to:

7.1. examine the prevalence of different categories of non-medically justified operations and interventions impacting on the physical integrity of children in their respective countries, as well as the specific practices related to them, and to carefully consider them in light of the best interests of the child in order to define specific lines of action for each of them;

7.2. initiate focused awareness-raising measures for each of these categories of violation of the physical integrity of children, to be carried out in the specific contexts where information may best be conveyed to families, such as the medical sector (hospitals and individual practitioners), schools, religious communities or service providers; [...]

7.4. initiate a public debate, including intercultural and interreligious dialogue, aimed at reaching a large consensus on the rights of children to protection against violations of their physical integrity according to human rights standards;

7.5. take the following measures with regard to specific categories of violation of children's physical integrity: [...]

7.5.3. undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support; [...]

7.7. raise awareness about the need to ensure the participation of children in decisions concerning their physical integrity wherever appropriate and possible, and to adopt specific legal provisions to ensure that certain operations and practices will not be carried out before a child is old enough to be consulted.

2014: UN CRPD, CRPD/C/DEU/Q/1, 17 April 2014, paras 12–13:

http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/DEU/CRPD_C_DEU_Q_1_17084_E.doc

Freedom from exploitation, violence and abuse (art. 16)

12. How many irreversible surgical procedures have been undertaken on intersexual children before an age at which they are able to provide informed consent? Does the State party plan to stop this practice?

13. Please provide up to date statistics on forced sterilizations of persons, i.e. without their free and informed consent.

2014: WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, and UNICEF, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement, May 2014, p 2, 6, 7:
http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

Background

Some groups, such as […] intersex persons, also have a long history of discrimination and abuse related to sterilization, which continues to this day. […] Intersex persons, in particular, have been subjected to cosmetic and other nonmedically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians. Such practices have also been recognized as human rights violations by international human rights bodies and national courts (15, 64).

[…] [I]ntersex persons

Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved (64; 147, para 57; 148; 149). As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health (64; 150, para 20; 151).

Medical procedures that might result in sterility may sometimes be justified because of benefits to health, including the reduction of cancer risk (152). Such treatments may be recommended for […] intersex persons; however, they may be proposed on the basis of weak evidence, without discussing alternative solutions that would retain the ability to procreate (151, 153–157). Parents often consent to surgery on behalf of their intersex children, including in circumstances where full information is lacking (151, 158, 159).

It has been recommended by human rights bodies, professional organizations and ethical bodies that full, free and informed consent should be ensured in connection with medical and surgical treatments for intersex persons (64, 150) and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent (15, 149). It has also been recommended that health-care professionals should be educated and trained about bodily diversity as well as sexual and related biological and physical diversity, and that professionals should properly inform patients and their parents of the consequences of surgical and other medical interventions (149; 150, para 20; 160–162).

Remedies and redress

- *Recognize past or present policies, patterns or practices of coercive sterilization, and issue statements of regret or apology to victims, as components of the right to remedy for these practices.*
- *Provide notification, through appropriate and humane means, to people who have been subjected to coercive sterilization, and who may be unaware of their situation, and provide information on the possibility of seeking administrative and judicial redress.*
- *Promptly, independently and impartially investigate all incidents of forced sterilization with due process guarantees for the alleged suspect, and ensure appropriate sanctions where responsibility has been established.*
- *Provide access, including through legal aid, to administrative and judicial redress mechanisms, remedies and reparations for all people who were subjected to forced, coercive or involuntary sterilization procedures, including compensation for the consequences and acknowledgement by governments and other responsible authorities of wrongs committed. Enable adults to seek redress for interventions to which they were subjected as children or infants.*
- *Guarantee access to reversal procedures, where possible, or assisted reproductive technologies for individuals who were subjected to forced, coercive or otherwise involuntary sterilization.*

Monitoring and compliance

- *Establish monitoring mechanisms for the prevention and documentation of forced, coercive and otherwise involuntary sterilization, and for the adoption of corrective policy and practice measures.*
- *Collect data regarding forced, coercive and otherwise involuntary sterilization, in order to assess the magnitude of the problem, identify which groups of people may be affected, and conduct a comprehensive situation and legal analysis.*
- *Providers of sterilization services should implement quality improvement programmes to ensure that recommendations aimed at preventing forced, coercive and otherwise involuntary sterilization are followed and procedures are properly documented.*
- *Establish mechanisms for obtaining patient feedback on the quality of services received, including from marginalized populations.*

2015 UN CRC, CRC/C/CHE/CO/2-4, 4 February 2015, paras 42–43:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En

D. Violence against children (arts. 19, 24, para. 3, 28, para. 2, 34, 37 (a) and 39) *[…]*

Harmful practices

42. While welcoming the adoption of a new provision of criminal law prohibiting genital mutilation, the Committee is deeply concerned at: […]

(b) Cases of medically unnecessary surgical and other procedures on intersex children, which often entail irreversible consequences and can cause severe physical and psychological suffering, without their informed consent, and the lack of redress and compensation in such cases.

43. The Committee draws the attention of the State party to the Joint General Comment No. 18 on harmful practices (2014), together with the Committee on the Elimination of Discrimination against Women, and urges the State party to: […]

(b) In line with the recommendations on ethical issues relating to intersexuality by the

National Advisory Commission on Biomedical Ethics, 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, and provide families with intersex children with adequate counselling and support.

2015: UN CRPD, CRPD/C/DEU/CO/1, 13 May 2015, p. 6–7, paras 37-38:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/DEU/CO/1

Protecting the integrity of the person (art. 17)

37. The Committee is concerned about: [...] c) the lack of implementation of the 2011 recommendations CAT/C/DEU/CO/5, para. 20, regarding upholding bodily integrity of intersex children.

38. The Committee recommends that the State party take the necessary measures, including of a legislative nature to:

> ***[...]***
>
> ***(d) Implement all the recommendations of CAT/C/DEU/CO/5, para. 20 relevant to intersex children.***

2015: Commissioner on Human Rights of the Council of Europe (COE), Issue Paper "Human rights and intersex people", 12 May 2015, p. 1–62:
https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383

2015: WHO, Report "Sexual health, human rights and the law", June 2015, p. 27-28:
http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

"A major concern for intersex people is that so-called sex normalizing procedures are often undertaken during their infancy and childhood, to alter their bodies, particularly the sexual organs, to make them conform to gendered physical norms, including through repeated surgeries, hormonal interventions and other measures. As a result, such children may be subjected to medically unnecessary, often irreversible, interventions that may have lifelong consequences for their physical and mental health, including irreversible termination of all or some of their reproductive and sexual capacity."

"Increasingly, concerns are being raised by intersex people, their caregivers, medical professionals and human rights bodies that these interventions often take place without the informed consent of the children involved and/or without even seeking the informed consent of their parents (178, 262, 264, 270–273)."

"It has also been recommended [by human rights bodies and ethical and health professional organizations] that investigation should be undertaken into incidents of surgical and other medical treatment of intersex people without informed consent and that legal provisions should be adopted in order to provide remedies and redress to the victims of such treatment, including adequate compensation (91, 264)."

2015: UN CAT, CAT/C/CHE/CO/7, 14 August 2015, para 20:
http://intersex.shadowreport.org/public/CAT_C_CHE_CO_7-Concl-Obs-Switzerland-2015_G1520151.pdf

Intersex persons

20. The Committee welcomes the Federal Council decision to give an opinion by the end of 2015 on the recommendations of the National Advisory Commission on Biomedical Ethics with regard to the unnecessary and in some cases irreversible surgical procedures that have been carried out on intersex persons (i.e. persons with variations in sexual anatomy) without the effective, informed consent of those concerned. However, the Committee notes with concern that these procedures, which reportedly caused physical and psychological suffering, have not as yet given rise to any inquiry, sanction or reparation (arts. 2, 12, 14 and 16).

The Committee recommends that, in light of the forthcoming decision by the Federal Council, the State party:

a) Take the necessary legislative, administrative and other measures to guarantee respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child, as recommended by the National Advisory Commission on Biomedical Ethics and the Committee on the Rights of the Child (see CRC/C/CHE/CO/2-4, para. 43 (b));

b) Guarantee counselling services and free psychosocial support for all persons concerned and their parents, and inform them that any decision on unnecessary treatment can be put off until the person concerned are able to decide for themselves;

c) Undertake investigation of reports of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation.

2015: UN CRC, CRC/C/CHL/CO/4-5, 2 October 2015, paras 48–49:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fCHL%2fCO%2f4-5&Lang=en

Harmful practices

48. While noting the proposed development of a protocol for the health care of intersex babies and children, the Committee is 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.

49. In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices, the Committee recommends that the State party expedite the development and implementation of a rights-based health care protocol for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary surgery or treatment during infancy or childhood, protecting the rights of the children concerned to physical and mental integrity, autonomy and self-determination, providing intersex children and their families with adequate counselling and support, including from peers, and ensuring effective remedy for victims, including redress and compensation.

2015: UN CAT, CAT/C/AUT/CO/6, 9 December 2015, paras 44–45:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fAUT%2fCO%2f6&Lang=en

Intersex Persons

44. The Committee appreciates the assurances provided by the delegation that surgical interventions on intersex children are carried out only when necessary, following medical and psychological opinions. It remains concerned however about reports on cases of unnecessary surgery and other medical treatment with life-long consequences to which intersex children would have been subjected without their informed consent. The Committee is further concerned at the lack of legal provisions providing redress and rehabilitation in such cases (arts. 14 and 16).

45. The State party should:

(a) Take the necessary legislative, administrative and other measures to guarantee the respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child;

(b) Guarantee impartial counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary and non-urgent surgery and other medical treatment to decide on the sex of the child and the possibility of postponing any decision on such treatment or surgery until the persons concerned can decide by themselves;

(c) Guarantee that full, free and informed consent is ensured in connection

with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give effective consent;

(d) Undertake investigation of instances of surgical interventions or other medical procedures performed on intersex people without effective consent, and ensure that the persons concerned are adequately compensated.

2015: UN CAT, CAT/C/DNK/CO/6-7, 9 December, paras 42–43: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDNK%2fCO%2f6-7&Lang=en

Intersex Persons

42. While taking note of the information provided by the delegation on the decision-making process related to treatment of intersex children, the Committee remains concerned at reports of unnecessary and irreversible surgery and other medical treatment with life-long consequences to which intersex children have been subjected before the age of 15 when their informed consent is required. The Committee is further concerned at hurdles faced by these persons when seeking redress and compensation in such cases (arts. 14 and 16).

43. The State party should:

(a) Take the necessary legislative, administrative and other measures to guarantee the respect for the physical integrity and autonomy of intersex persons and ensure that no one is subjected during infancy or childhood to unnecessary medical or surgical procedures;

(b) Guarantee counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary surgery and other medical treatment;

(c) ensure that full, free and informed consent is respected in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give full, free and informed consent;

(d) Provide adequate redress for the physical and psychological suffering caused by such practices to intersex persons.

2015: UN CAT, CAT/C/CHN-HKG/CO/4-5, 9 December 2015, paras 28–29: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fCHN-HKG%2fCO%2f5&Lang=en

[...] [I]ntersex Persons

28. [...] The Committee is also concerned that intersex children are subjected to unnecessary and irreversible surgery to determine their sex at an early stage. Furthermore, the Committee is concerned at the long term physical and psychological suffering caused by such practices (arts. 10, 12, 14 and 16).

29. HKSAR should:

[...]

(b) Guarantee impartial counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary and non-urgent surgery and other medical treatment to decide on the sex of the child and the possibility of postponing any decision on such treatment or surgery until the persons concerned can decide by themselves;

(c) Guarantee that full, free and informed consent is ensured in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give full, free and informed consent;

(d) Provide adequate redress for the physical and psychological suffering caused by such practices to some intersex persons.

2016 UN CRC, CRC/C/IRL/CO/3-4, 4 February 2016, paras 39-40:
http://stop.genitalmutilation.org/public/Ireland_Concl-Obs_CRC_C_IRL_CO_3-4_22988_E.doc

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

Harmful practices [CRC art. 24(3)]

39. The Committee notes as positive the adoption of the Gender Recognition Act of 2015 by the State party. However, the Committee remains concerned about cases of medically unnecessary surgeries and other procedures on intersex children before they are able to provide their informed consent, which often entail irreversible consequences and can cause severe physical and psychological suffering, and the lack of redress and compensation in such cases

40. The Committee recommends that the State party:

(a) 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, and provide families with intersex children with adequate counselling and support;

(b) Undertake 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; and,

(c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children.

2016 UN CRC, CRC/C/FRA/CO/5, 4 February 2016, paras 47-48:
http://stop.genitalmutilation.org/public/France_Concl-Obs_CRC_C_FRA_CO_5_22995_E.doc

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

Harmful practices [CRC art. 24(3)]

47. While noting with appreciation the progress made by the State party to eradicate female genital mutilation the Committee is, however, concerned by many young girls still at risk and the possible resurgence of the phenomenon. The Committee is also concerned that medically unnecessary and irreversible surgery and other treatment is routinely performed on intersex children.

48. Recalling the Committee's joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices, the Committee recommends that the State party gather data with a view to understanding the extent of these harmful practices with a view to better identify children at risk and prevent them. It recommends that the State party:

(a) Increase awareness of female genital mutilation in the State party among girls at risk, medical professionals, social workers, the police and gendarme officers, and magistrates;

(b) Develop and implement a rights-based health care protocol for intersex children, ensuring that children and their parents are appropriately informed of all options, that children are involved, to the largest extent, in decision-making about their treatment and care, and no child is subjected to unnecessary surgery or treatment.

2. State Bodies Recognising Human Rights Violations of Intersex Persons

2005: San Francisco Human Rights Commission (SFHRC), A Human Rights Investigation into the "Normalization" of Intersex People, 28 April 2005
http://sf-hrc.org/modules/showdocument.aspx?documentid=1798

2013: Australian Senate, Community Affairs References Committee, Involuntary or coerced sterilisation of intersex people in Australia, October 2013
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/~/media/Committees/Senate/committee/clac_ctte/involuntary_sterilisation/second_report/report.ashx

2014: German Conference of Women's and Equality Ministers (GFMK), Resolution of the 24th GFMK Conference, 1–2 October 2013
https://www.gleichstellungsministerkonferenz.de/documents/2014_10_13_Beschluesse_GESAMT_Extern.pdf

2015: Maltese Parliament, Gender Identity Gender Expression and Sex Characteristics Act (GIGESC), 14 April 2015, Article 14(1–5) "Right to bodily integrity and physical autonomy"
http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1

2015: Austrian Children's and Youth Attorneys (KiJAÖ) [NHRI], Position Paper on Intersex, [7 October 2015]
http://kija.at/images/KiJAOE-Positionspapier_zur_Intersexualitt_2015.pdf

3. National Ethics Bodies Recognising Human Rights Violations of Intersex Persons

2011: German Ethics Council, Opinion Intersexuality, 23 February 2012
http://www.ethikrat.org/files/opinion-intersexuality.pdf

2012: Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), On the management of differences of sex development. Ethical issues relating to "intersexuality", Opinion No. 20/2012, 9 November 2012
http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

4. NGO, NHRI Reports on Human Rights Violations of Intersex Persons

2004: CESCR Argentina, Mauro Cabral
https://web.archive.org/web/20100306083552/http://ilga.org/ilga/en/article/61

2008: CEDAW Germany, Intersexuelle Menschen e.V./XY-Frauen
http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CEDAW_2008.pdf

2010: CESCR Germany, Intersexuelle Menschen e.V./XY-Frauen
http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CESCR_2010.pdf

2011: CEDAW Costa Rica, IGLHRC / MULABI, p. 8–11
http://intersex.shadowreport.org/public/IGLHRC_Shadow-Report_Costa-Rica_CEDAW_2011.pdf

2011: CAT Germany, Intersexuelle Menschen e.V./XY-Frauen, Humboldt Law Clinic
http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf

2012: UPR Switzerland, Swiss NGO Coalition for the UPR, para 18
http://lib.ohchr.org/HRBodies/UPR/Documents/Session14/CH/JS3_UPR_CHE_S14_2012_JointSubmission3_E.pdf

2012: UN SRT, Advocates for Informed Choice (AIC),
http://intersex.shadowreport.org/public/AIC-Testimony-to-the-United-Nations-Special-Rapporteur-on-Torture_December-2012.pdf

2012: CRC Luxemburg, Radelux
http://www.ances.lu/attachments/article/162/RADELUX_sppl%20report%202012%20English%20Version.pdf

2012: WHO, Advocates for Informed Choice (AIC), Zwischengeschlecht.org, submissions for 2014 WHO Interagency Statement on Involuntary Sterilization (unpublished)

2013: CRPD Germany, BRK-Allianz, Germany, p. 36–37
http://www.brk-allianz.de/attachments/article/93/Alternative_Report_German_CRPD_Alliance_final.pdf

2013: UPR Germany, German Institute for Human Rights (GIHR), para 23
http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/GIHR_UPR_DEU_S16_2013_GermanInstituteforHumanRightsE.pdf
- German CRPD ALLIANCE, para 15
http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js4_upr16_deu_s16_2013_jointsubmission4_e.pdf
- National Coalition for the Implementation of the UN Convention on the Rights of the Child in Germany (NC), para 4
http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js5_upr_deu_s16_2013_jointsubmission5_e.pdf
- Forum Menschenrechte, paras 38, 39, 58
http://lib.ohchr.org/HRBodies/UPR/Documents/Session16/DE/js6_upr_deu_s16_2013_jointsubmission6_e.pdf

2013: CRC Germany, German Institute for Human Rights (GIHR), para 2.b.
http://www.institut-fuer-menschenrechte.de/uploads/tx_commerce/GIHR_Suggested_topics_to_be_taken_into_account_for_the_preparation_of_a_list_of_issues_by_the_CRC_on_the_implementation_of_the_Convention_on_the_Rights_of_the_Child_in_Germany.pdf
- National Coalition for the Implementation of the UN Convention on the Rights of the Child in Germany (NC), lines 789–791, 826–828
http://www2.ohchr.org/english/bodies/crc/docs/ngos/Germany_National%20Coalition%20for%20the%20Implementation%20of%20the%20UNCRC%20in%20Germany_CRC%20Report-CRCWG65.pdf

2013: Inter-American Commission on Human Rights, Advocates for Informed Choice (AIC)
http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643
+ Hearing

2014: UNHRC, Canadian HIV/AIDS Legal Network, joined by ILGA
http://oii.org.au/24756/intersex-human-rights-panel-meeting-un-human-rights-council/

2014: CRC Switzerland, Child Rights Network Switzerland, p. 25–26
http://www.netzwerk-kinderrechte.ch/fileadmin/nks/aktuelles/ngo-bericht-UN-ausschuss/NGO_Report_CRC_CRNetworkSwitzerland_English.pdf

2014: CRC Switzerland, Zwischengeschlecht.org, Intersex.ch, SI Selbsthilfe Intersexualität
http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

2014: CAT Australia, OII Australia, AISSGA, People with Disabilities, National LGBTI Health Alliance
https://oii.org.au/wp-content/uploads/2014/10/OII-Australia-CAT-submission.pdf

2014: CAT USA, Advocates for informed Choice (AIC)
http://intersex.shadowreport.org/public/USA-AIC-CAT-2014-2014_INT_CAT_CSS_USA_18525_E.pdf

2015: CAT New Zealand, ITANZ
https://www.hrc.co.nz/files/3914/2950/4674/ITANZ_Submission_on_CAT__13_Jan_2015.pdf

2015: CRPD Germany, Zwischengeschlecht.org
http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.pdf

2015: CAT Switzerland, Zwischengeschlecht.org
http://intersex.shadowreport.org/public/2015-CAT-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf

2015: CRC Chile, Observatorio de Derechos Humanos – Chile (Andrés Rivera Duarte), International Gay and Lesbian Human Rights Commission (IGLHR
http://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/CHL/INT_CRC_NGO_CHL_19433_E.pdf

2015: CAT Hong Kong, Beyond the Boundary - Knowing and Concerns Intersex (BBKCI)
http://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf

2015: CAT Austria, Verein Intersexueller Menschen Österreich VIMÖ, Zwischengeschlecht.org
http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf

2015: CAT Denmark, Ditte Dyreborg, Zwischengeschlecht.org
http://intersex.shadowreport.org/public/2015-CAT-Denmark-NGO-Zwischengeschlecht-Intersex-IGM.pdf

2016: CRC Ireland, Gavan Coleman, Zwischengeschlecht.org
http://intersex.shadowreport.org/public/2015-CRC-Ireland-NGO-Zwischengeschlecht-Intersex-IGM.pdf

2016: CRC France, Vincent Guillot, Zwischengeschlecht.org
http://intersex.shadowreport.org/public/2015-CRC-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

D. What is Intersex?

1. Variations of Sex Anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with "*Differences*[44] of Sex Development (DSD)," are people born with "atypical" sex anatomies and reproductive organs, including

a) "ambiguous genitalia", e.g. "enlarged" clitoris, urethral opening not on the tip of the penis, but somewhere below on the underside of the penis (Hypospadias), fused labia, absence of vagina (vaginal agenesis, or Mayer-Rokitansky-Küster-Hauser syndrome MRKH), unusually small penis or micropenis, breast development in "males"; and/or

b) atypical hormone producing organs, or **atypical hormonal response**, e.g. a mix of ovarian and testicular tissue in gonads (ovotestes, "True Hermaphroditism"), the adrenal gland of the kidneys (partly) producing androgens (e.g. testosterone) instead of cortisol (Congenital Adrenal Hyperplasia CAH), low response to testosterone (Androgen Insensitivity Syndrome AIS), undescended testes (e.g. in Complete Androgen Insensitivity Syndrome CAIS), little active testosterone producing Leydig cells in testes (Leydig Cell Hypoplasia), undifferentiated streak gonads (Gonadal Dysgenesis GD if both gonads are affected, or Mixed Gonadal Dysgenesis MGD with only one streak gonad); and/or

c) atypical genetic make-up, e.g. XXY (Klinefelter Syndrome), X0 (Ullrich Turner Syndrome), different karyotypes in different cells of the same body (mosaicism and chimera).

Variations of sex anatomy include

- "atypical characteristics" **either on one or on more of the above three planes** a)–c),
- **or**, while individual planes appear "perfectly normal", **together they "don't match"**, e.g. a newborn with male exterior genitals but an uterus, ovaries and karyotype XX (some cases of Congenital Adrenal Hyperplasia CAH), or with female exterior genitals but (abdominal) testicles and karyotype XY (Complete Androgen Insensitivity Syndrome CAIS).

While many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**.

Everybody started out as a hermaphrodite: Until the 7th week of gestation, every fetus has "indeterminate" genitals, two sets of basic reproductive duct structures, and bipotential gonads. Only after the 7th week of gestation, fetuses undergo sexual differentiation mostly resulting in typically male or female sex anatomy and reproductive organs (see Figure 1). However, with some fetuses, sex development happens along a less common pathway, e.g. due to unusual level of certain hormones, or an unusually high or low ability to respond to them, resulting in intersex children born with in-between genitals (see Figure 2) and/or other variations of sex anatomy.

For more information and references on genital development and appearance, please see 2014 CRC NGO Report (A 2–3, p. 8–10.) [45]

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44 The currently still official medical terminology **"Disorders of Sex Development" is strongly refused by persons concerned.** See 2014 CRC NGO Report, p. 12 "Terminology", online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

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

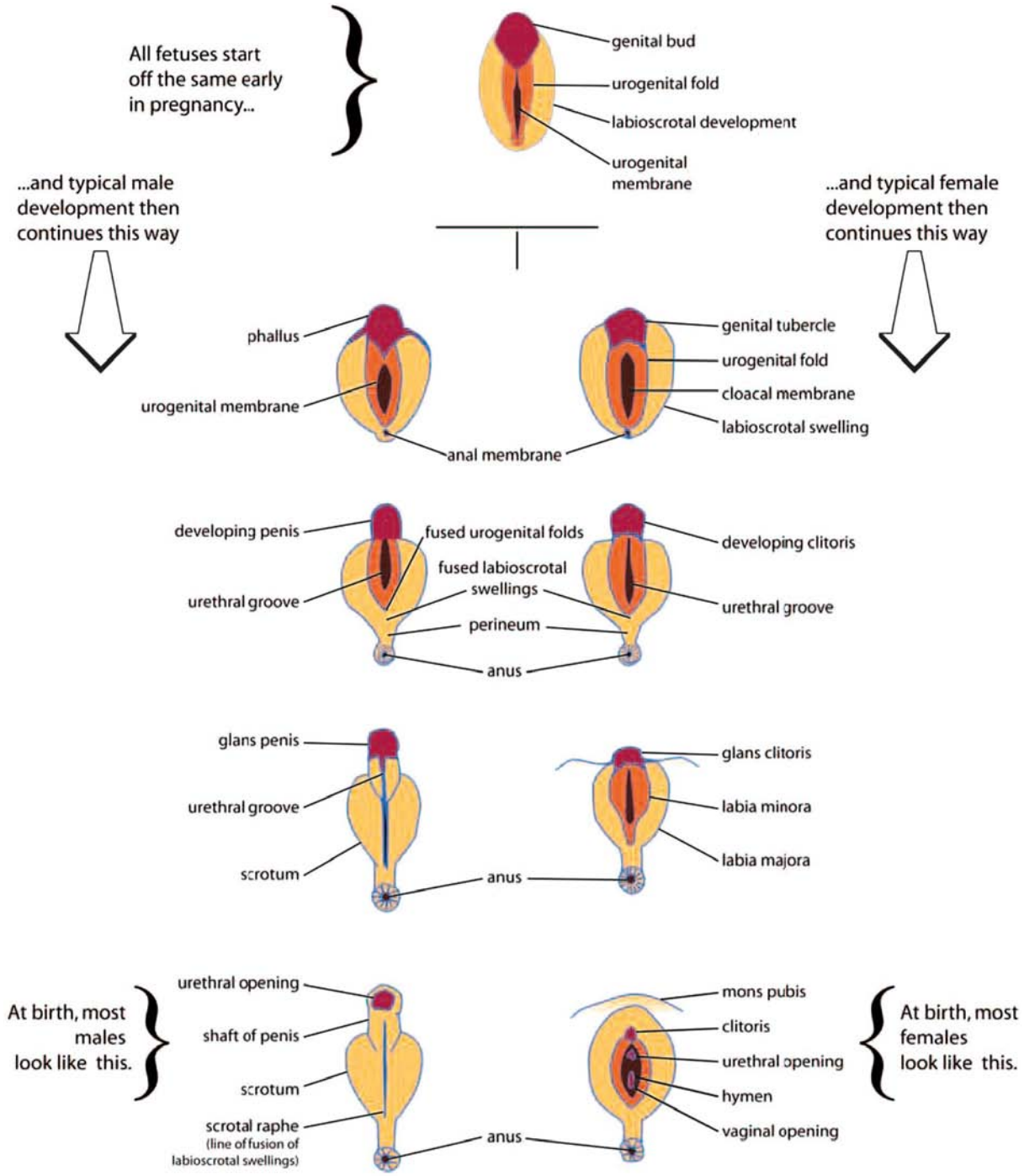

Figure 1 "Genital Development Before Birth"
Source: Accord Alliance (2006), Handbook for Parents, at 72, http://www.accordalliance.org/dsdguidelines/parents.pdf

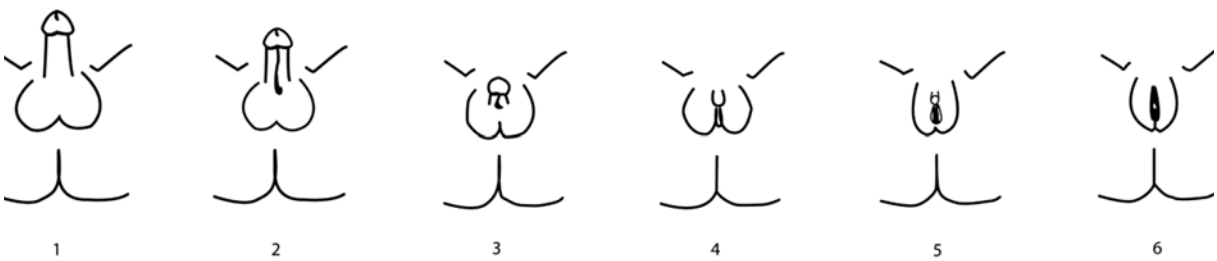

Figure 2 "Genital Variation" (Diagrams 1–6 corresponding to Prader Scale V–0)
Source: Accord Alliance (2006), Handbook for Parents, at 73, http://www.accordalliance.org/dsdguidelines/parents.pdf

2. How common is Intersex?

Since hospitals, government agencies and health insurances covering intersex surgeries on children until the age of 20,[46] **refuse to disclose statistics and costs**, there are no exact figures or statistics available). Also, the definition of intersex is often arbitrarily changed by doctors and government agencies in order to get favourable (i.e. lower) figures. Ultimately, all available numbers are mere estimates and extrapolations. Intersex persons and their organisations have been calling for **independent data collection and monitoring** for some time, however to no avail.

An often quoted number is 1:2000 newborns, however this obviously disregards variations of sex anatomy at risk of "masculinising corrections" (hypospadias). **In medical literature**, often two different sets of numbers and definitions are given depending on the objective:

a) **1:1000** if it's about getting access to new patients for paediatric genital surgery,[47] and

b) 1:4500 or less[48] if it's about countering public concerns regarding human rights violations, often only focusing on *"severe cases"* while refusing to give total numbers. On the other hand, researchers with an interest in criticising the gender binary often give numbers of up to *"as high as 2%"*.[49]

However, from a **human rights perspective**, the crucial question remains: How many children are at risk of human rights violations, e.g. by non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries or other similar treatments justified by a psychosocial indication? Here, the best known relevant number is **1:500 – 1:1000 children are submitted to (often repeated) non-consensual "genital corrections".[50]**

46 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to "intersexuality", Opinion No. 20/2012, at 15–17, http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

47 Rainer Finke, Sven-Olaf Höhne (eds.) (2008), Intersexualität bei Kindern, Preface, at 4

48 e.g. *"fewer than 2 out of every 10,000 births"*, Leonard Sax (2002), How common is intersex? a response to Anne Fausto-Sterling, The Journal of Sex Research 39(3):174-178, at 178

49 Melanie Blackless, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne, Ellen Lee (2000), How sexually dimorphic are we? Review and synthesis, American Journal of Human Biology 12:151-166.

50 Intersex Society of North America (ISNA), How common is intersex?, http://www.isna.org/faq/frequency

3. Intersex is NOT THE SAME as LGBT

Unfortunately, there are several **harmful misconceptions about intersex** still prevailing in public, some of which are LGBT-related, e.g. if intersex, and/or intersex status, are represented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality,[51] or as a strange, peculiar form of sexual preferences.

The underlying reasons for such misconceptions include **lack of public awareness** of the situation of real-life intersex persons and the real-live problems they're facing, as well as – often despite best intentions – a long **history of (political) appropriation of intersex** going back to the 19th century, including leading LGBT proponents, scholarly authorities and/or interest groups instrumentalising intersex as a means to an end for their own agenda, and/or presenting themselves as intersex and speaking publicly for intersex people.

While some intersex persons position themselves within an LGBT context and many intersex organisations collaborate with LGBT groups on an equal footing to address e.g. discrimination issues, **intersex persons and their organisations**, as well as their allies, again and again have **spoken out clearly against instrumentalising intersex issues as a means for other ends,**[52] maintaining that intersex stands for distinct and unique physical variations, and intersex status is *not* about gender identity or sexual orientation.

51 E.g. the **Swiss Federal Government** in 2011 in answers to patliamentary questions consistently described intersex as ***"True and Untrue Transsexualism"***, e.g. 11.3286, http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20113286

52 • Raven Kaldera (2001), Dangerous Intersections: Intersex and Transgender Differences, http://www.ravenkaldera.org/gender-archive/intersection/dangerous-intersections.html
• Emi Koyama, Lisa Weasel (2002), From Social Construction to Social Justice: Transforming How We Teach About Intersexuality, Women's Studies Quarterly 30(3-4), http://www.ipdx.org/pdf/wsq-intersex.pdf
• Chris Somers (2002), The appropriation of the Intersexed, dAISy, AIS Support Group Australia's Newsletter, Issue Sept 2002:20, http://www.aissga.org.au/daisy/dAISy%20Sept02.pdf
• Georg Klauda (2002), Fürsorgliche Belagerung. Über die Verstümmelung von Hermaphroditen, Out of Dahlem 1, http://web.archive.org/web/20070603233246/http://gigi.x-berg.de/texte/belagerung
• Morgan Holmes, in: Cindra Feuer (2005), Is there an I in LGBT?, Pride 05:63-64, at 64, http://stop.genitalverstuemmelung.org/public/Pride05_Feuer_Is-there-an-I-in-LGBT_web.pdf
• Joke Janssen (2006/2009), Theoretisch intersexuell. Wie intersexuelle Menschen zwischen den Zeilen bleiben, in: AG Queer Studies (eds.): Verqueerte Verhältnisse. Intersektionale, ökono-miekritische und strategische Interventionen, at 165-184f
• Gabriele Dietze (2006), Schnittpunkte. Gender Studies und Hermaphroditismus, in: Gabriele Dietze, Sabine Hark (eds.): Gender kontrovers. Genealogie und Grenzen einer Kategorie, 46-68, at 56
• Zwischengeschlecht.info (2007), Die Rede von der "psychischen Intersexualität", http://blog.zwischengeschlecht.info/post/2007/12/11/Die-Rede-von-der-psychischen-Intersexualitat
• Natasha Jiménez, Mauro Cabral (2009), Con voz propria. Conversatión con Natasha Jiménez, in: Mauro Cabral (ed.) (2009), Interdicciones. Escrituras de la intersexualidad en castellano, 123-130, at 128, http://www.mulabi.org/Interdicciones2.pdf
• OII Australia (2013), Discussion Paper: The term "Sex and Gender Diversity", and intersex people, http://oii.org.au/wp-content/uploads/downloads/2013/01/OII-SGD.pdf
• Public Statement by the Third International Intersex Forum (2013), http://old.ilga-europe.org/home/news/latest/intersex_forum_2013
• OII Australia (2014), NSW Registrar of Births, Deaths and Marriages v. Norrie: implications for intersex people, http://oii.org.au/wp-content/uploads/2014/01/OII-Aus-NSW-v-Norrie-High-Court.pdf

Although intersex children born with variations of sex anatomy 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**, which are different from those faced by the LGBT community. Therefore human rights violations of intersex people can't be addressed properly by framing and addressing them as LGBT issues, but need to be **adequately addressed in a separate section** as **specific intersex issues .**[53]

4. Terminology

There is no terminology universally accepted by all persons concerned. All current terms were or are used by medicine in connection with non-consensual, medically not necessary "genital corrections" (see **Annexe "Historical Overview"**), and/or as insult or verbal abuse in society, and/or have other negative connotations – but all have also been (re-)claimed by persons concerned and their organisations:

Intersex

+ Term most frequently used by persons concerned, especially human rights related; reclaimed since 1993.
– In public often leads to misconceptions like "intersex is a sexual orientation," "intersexuality is a sexual preference", etc.;
"Intersexual Constitution" was a racist/nazi medical diagnosis 1920s–1950s,
"Intersex Disorders" was the predominant medical term 1960s–2005.

Please do say: Intersex child, she's intersexed, this is an intersex human rights issue.

Please don't say: Intersexuality, intersexual, intersexuals – this is disregarded by many persons concerned today and bound to foster misconceptions.

Hermaphrodite

+ Term most frequently used by public, can dispel misconceptions of intersex as a sexual orientation, sexual preference, etc.; reclaimed since 1994.
– Can lead to misconceptions related to the ancient mythic notion of intersex persons "having both sets of genitals and being able to impregnate themselves"; considered as derogatory by some persons concerned;
"(Pseudo) Hermaphroditism" was the medical terminology until the 1950s, though it persisted and is sometimes still used by doctors even today.

Please do say: Intersex persons, in the vernacular also known as hermaphrodites, are people with variations of sex anatomy.

Please don't say: Are you a hermaphrodite? What do your genitals look like?

DSD (Disorders of Sex Development vs. Differences of Sex Development)

"Disorders of Sex Development", mostly referred to by the acronym "DSD", is the current medical term, introduced at the **"Chicago Consensus Conference 2005"** with limited input by persons concerned, but in an intransparent way and without proper consultation.[54] The new nomenclature also included a **new taxonomy** based on karyotype and focused on conditions (instead of the persisting "Pseudo Hermaphrodite" taxonomy based on gonadal

53 Zwischengeschlecht.org, Advocates for Informed Choice (AIC) (2013), CONCERNS Re: Intersex Genital Mutilation, Joint Statement for UN Special Rapporteur on Torture, 05.03.2013, http://zwischengeschlecht.org/public/Zwischengeschlecht_AIC_SRT-meeting.pdf

54 Peter Trinkl (2006), I Am Neither "Pseudo" nor "Disordered", in: Proceedings of the ISNA/GLMA DSD Symposium: 48-49, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

status and focused on "male" and "female"), also the new taxonomy was supposed to more clearly include genital variations irrespective of gender of rearing issues, such as hypospadias, Klinefelter, and MRKH,[55] [56] reflecting the new definition ***"congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical."*** [57] Furthermore, in some cases a more cautious approach to early surgery was suggested.
While the use of an acronym for medical purposes, the new taxonomy focused on conditions, clearer inclusion of all genital variations, and the instances of calling for more caution regarding early surgeries were welcomed by persons concerned and their organisations, the term **"disorders" was unequivocally abhorred** and condemned within the community,[58] because it frames the persons concerned as in need of being (surgically) "corrected", or "fixed", e.g. to *"relieve[...] parental distress"*.[59] However, clinicians readily embraced "disorders." "Variations of Sex Development (VSD)" [60] was proposed as a less stigmatising alternative in 2006, but rejected by medicine arguing the acronym VSD was already taken. Nonetheless, another proposal in 2008 of "Differences of Sex Development" [61] keeping the DSD acronym has been equally refused by doctors.
***Please do say: Differences** of Sex Development (DSD).*
Please don't say: Disorders of Sex Development (DSD).

Words are important, words can hurt – however, more important than a wrong word is the continuous regard – or disregard – of the human rights and dignity of the children concerned.

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55 David Sandberg PhD, Cheryl Chase, Eric Vilain: Report on Chicago Consensus Conference, in: Proceedings of the ISNA/GLMA DSD Symposium (2006): 17-38, at 22, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

56 Barbara Thomas: The Chicago Consensus – a patient perspective, at 2, http://www.aissg.org/PDFs/Barbara-Lubeck2-Talk.pdf

57 Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), Consensus statement on management of intersex disorders, Pediatrics 118:e488-e500, at e488, http://pediatrics.aappublications.org/content/118/2/e488.full.pdf

58 Peter Trinkl (2006), I Am Neither "Pseudo" nor "Disordered", in: Proceedings of the ISNA/GLMA DSD Symposium: 48-49, http://www.isna.org/files/DSD_Symposium_Proceedings.pdf

59 ***"It is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents [48–51]; the systematic evidence for this belief is lacking."*** Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), Consensus statement on management of intersex disorders, Pediatrics 118:e488-e500, at e491, http://pediatrics.aappublications.org/content/118/2/e488.full.pdf

60 Milton Diamond, Hazel Beh (2006), Variations of Sex Development Instead of Disorders of Sex Development, Letter to the Editor, published in: Archives of Disease in Childhood (26 July 2006), http://www.hawaii.edu/PCSS/biblio/articles/2005to2009/2006-variations.html

61 Milton Diamond, Hazel Beh (2008), Changes in the Management of Children with Intersex Conditions, Nature Clinical Practice, Endocrinology & Metabolism 4(1), http://www.hawaii.edu/PCSS/biblio/articles/2005to2009/2008-changes-in-management.html

E. IGM Practices – Non-Consensual, Unnecessary Medical Interventions

1. What are Intersex Genital Mutilations?

IGM Practices include non-consensual,[62] medically unnecessary,[63] [64] irreversible,[65] cosmetic[66] genital surgeries, and/or other similar medical treatments, including imposition of hormones, performed on children with variations of sex anatomy, without evidence of benefit for the children concerned,[67] [68] but justified by *"psychosocial indications [...] shaped by the clinician's own values"*,[69] the latter informed by societal and cultural norms and beliefs,[70] [71] enabling clinicians to withhold crucial information from both patients and parents,[72] [73] and to submit healthy intersex children to risky and harmful invasive procedures *"simply because their bodies did not fit social norms"*.[74]

62 **UN SRT (2013)**, A/HRC/22/53, at para 77: *"Children who are born with atypical sex characteristics are often subject to [...]* ***involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents****"*, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
On why parents *can't* legally consent to medically unnecessary cosmetic genital surgeries on their healthy children, including IGM Practices, see: Mirjam Werlen (2014), Persönlichkeitsschutz des Kindes. Abhandlungen zum Schweizerischen Recht 180, at N 1026 (A–C), N 1032, N 698 ff.

63 **Council of Europe (2013)**, Resolution 1952 (2013), at 2 (7.5.3.): ***"unnecessary medical or surgical treatment that is cosmetic rather than vital for health"***, http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en

64 Jörg Woweries (2010), Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit 0310: 18-22, at 20-21, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf

65 *"2. The surgery is irreversible.* ***Tissue removed from the clitoris can never be restored; scarring produced by surgery can never be undone.****"* Intersex Society of North America (ISNA) (1998), ISNA's Amicus Brief to the Constitutional Court of Colombia, http://www.isna.org/node/97

66 ***"It is generally felt that surgery that is performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents [48–51]; the systematic evidence for this belief is lacking."*** Peter A. Lee, Christopher P. Houk, S. Faisal Ahmed, Ieuan A. Hughes, LWPES/ESPE Consensus Group (2006), **Consensus statement on management of intersex disorders**, Pediatrics 118:e488-e500, at e491, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/

67 *"The final ethical problem was the* ***near total lack of evidence—indeed, a near total lack of interest in evidence—****that the concealment system was producing the good results intended."* Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75

68 Jörg Woweries (2010), Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit 0310: 18-22, at 21, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf

69 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to "intersexuality", Opinion No. 20/2012, at 16 (footn. 18), http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

70 ibid., at 18 and 15.

71 ***"sociological and ideological reasons"***, WHO Genomic Resource Centre, Genetic Components of Sex and Gender, http://www.who.int/genomics/gender/en/index1.html

72 *"In cases of intersex* ***clinicians were intentionally withholding and misrepresenting critical medical information****."* Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75

73 **UN SRT (2013)**, A/HRC/22/53, at para 77, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

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

Genital surgery is not necessary for gender assignment, and **atypical genitals are not in themselves a health issue**.[75] There are only very few situations where some surgery is necessary for medical reasons, such as to create an opening for urine to exit the body.[76] [77]

In addition to the usual risks of anaesthesia and surgery in infancy, IGM practices carry a **large number of known risks of physical and psychological harm**, 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.[78] [79]

2. Most Frequent Surgical and Other Harmful Medical Interventions

Due to space limitations, the following paragraphs summarise the most frequent and egregious forms only. **The injuries suffered by intersex people have not yet been adequately documented.**[80] For a more comprehensive list and sources, see *2014 CRC NGO Report, p. 63–76*.

a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy / (Secondary) Sterilisation

"At 2 1/2 months they castrated me, and threw my healthy testicles in the garbage bin." (CRC Case No. 2)

Intersex children are frequently subjected to treatments that **terminate or permanently reduce their reproductive capacity**. Contrary to doctor's claims, it is known that the gonads by themselves are usually healthy and ***"effective"* hormone-producing organs**, often with ***"complete spermatogenesis [...] suitable for cryopreservation."***[81] Nonetheless, many still undergo early removal of viable gonads (e.g. testes, ovaries, ovotestes) or other reproductive organs (e.g. uterus), leaving them with *"permanent, irreversible infertility and severe mental suffering"*[82] and **lifelong metabolic problems**. When unnecessary sterilising procedures

75 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation, at 2, http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643

76 ibid., at 3

77 Jörg Woweries (2010), Intersexualität: Eine kinderrechtliche Perspektive, frühe Kindheit 0310: 18-22, at 20, http://kastrationsspital.ch/public/fK_0310_Woweries.pdf

78 Anne Tamar-Mattis (2013), Report to the Inter-American Commission on Human Rights, at 2–7, http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643

79 Heinz-Jürgen Voß (2012), Intersexualität – Intersex. Eine Intervention, at 50–65

80 Rare examples of publications documenting and reviewing reports by persons concerned include:
- J. David Hester (2006), Intersex and the Rhetorics of Healing, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 47–72
- Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), Intersex in the Age of Ethics:148–159
- Katrina Karkazis (2008), Fixing Sex: Intersex, Medical Authority, and Lived Experience
- Kathrin Zehnder (2010), Zwitter beim Namen nennen. Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung
- Claudia Lang (2006), Intersexualität. Menschen zwischen den Geschlechtern

81 K. Czeloth et al., "Function of Uncorrected Cryptorchid Testes", 25th ESPU 2014, online

82 **UN SRT (2013)**, A/HRC/22/53, at para 77, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

are imposed on children e.g. to address a low or hypothetical risk of cancer, **the fertility of intersex people is not being valued as highly as that of non-intersex people.** [83] Survivors often have to **pay themselves for adequate Replacement Hormones**.

For almost two decades, persons concerned have protested unnecessary sterilising treatments, and denounced **non-factual and psychosocial justifications**, e.g *"psychological benefit"* to removing *"discordant"* reproductive structures, demanding access to screening for potential low cancer risks instead of preemptive castrations. Even some doctors have been criticising unnecessary intersex gonadectomies for decades, e.g. endocrinologist G. A. Hauser (the "H" in "MRKH Syndrome") stated, *"The castration of patients without a tumour converts symptomless individuals into* ***invalids suffering from all the unpleasant consequences of castration.*** *"* [84]

What's more, psychosocial justifications often reveal underlying racist preconceptions by clinicians (reminiscent of the **racist and eugenic medical views of intersex** predominant during the 1920s–1950s, but which obviously persist), namely the infamous premise, ***"We don't want to breed mutants."*** (see 2014 CRC NGO Report, p. 52, 69)

Nonetheless, and despite recent discussions in medical circles, **unnecessary gonadectomies** and other sterilising treatments persist internationally in **University Children's Hospitals**. Only a while ago, when the Rapporteurs criticised unnecessary gonadectomies, a paediatric surgeon replied: *"Well, if a CAIS person is living as female,* ***what do they need their testes for anyway?"***

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

"I can still remember, how it once felt differently between my legs." (**2014 CRC Case No. 3**)

In 19th Century Western Medicine, clitoris amputations a.k.a. ***"clitoridectomies"*** on girls were prevalent as a "cure" for a) masturbation, b) hysteria, and c) "enlarged clitoris." While amputations motivated by a) and b) were mostly abandoned between 1900 and 1945, **amputations of "enlarged clitorises" took a sharp rise after 1950**, and in the 1960s became the predominant medical standard for intersex children.

For four decades, doctors again and again claimed early clitoris amputation on intersex children **would *not* interfere with orgasmic function**.[85] Only in the 1980s–1990s, intersex clitoris amputations were eventually replaced by "more modern" techniques a.k.a. **"clitoral reduction"** (**p. 60**), again claimed to preserve orgasmic function, despite persons concerned reporting loss of sexual sensitivity, and/or painful scars – complaints also corroborated by recent medical studies.[86] Tellingly, a current paediatric surgeon's joke on the topic of potential loss of sexual sensation goes, *"They won't know what they're missing!"* [87]

Despite that in infants there's *no* medical (or other) need for surgically creating a vagina *"big enough for normal penetration"* (**"vaginoplasty"**), but significant risks of complications (e.g. painful scarring, vaginal stenosis), this is nonetheless standard practice. What's more, in order to prevent "shrinking" and stenosis, the "corrected" (neo) vagina has to be **forcibly dilated**

83 see 2014 CRC NGO Report, p. 68 http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

84 Georges André Hauser (1963), Testicular feminization, in: Claus Overzier (ed.) (1963), Intersexuality:255–276, relevant excerpts http://kastrationsspital.ch/public/Intersex_CAIS_Castration_1961_1963.pdf (original German edition 1961)

85 see 2014 CRC NGO Report, p. 57–58

86 Crouch NS, Minto CL, Laio LM, Woodhouse CR, Creighton SM (2004), Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia. BJU Int 93:135-138.

87 Personal communication by a doctor attending the 23rd Annual Meeting of ESPU, Zurich 2012

by continuously inserting solid objects, a practice experienced as a form of rape and child sexual abuse by persons concerned, and their parents.

Clitoris amputations justified by psychosocial indications were taught in Medical Universities as a suitable *"therapy"* for intersex children diagnosed with *"hypertrophic clitoris"* until the 1980s. Despite recent public denials by doctors, hospitals, and health departments, **systematic early "clitoris reductions"** and **"vaginoplasty"** performed on intersex infants and justified by **psychosocial indications**, are still practiced in most **University Children's Clinics** throughout the world.

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

"My operated genital is extremely touch-sensitive and hurts very much when I'm aroused." (**CRC Case No. 1**)

Hypospadias is a medical diagnosis describing a penis with the **urethral opening** ("meatus", or "pee hole") **not situated at the tip of the penis**, but somewhere below on the underside, due to incomplete tubularisation of the urethral folds during prenatal formation of the penis. Hypospadias "repair" aims at "relocating" the urethral opening to the tip of the penis. **The penis is sliced open,** and an artificial "urethra" is formed out of the foreskin, or skin grafts (**p. 59**).

Hypospadias per se does *not* constitute a medical necessity for interventions. The **justification** for early surgeries is **psychosocial**, e.g. to allow for *"sex-typical manner for urination (i.e. standing for males)."* According to a ***"pilot study"***, surgery is *"intended to change the anatomy such that the penis looks normal."*[88] The latest AWMF guidelines with international explicitly include *"aestetical-psychological reasons"*.[89]

Hypospadias "repair" is notorious for high **complication rates of 50%** and more, as well as causing serious medical problems where none had been before (e.g. urethral strictures leading to kidney failure requiring dialysis), and frequent "redo-surgeries". Tellingly, for more than 30 years, surgeons have been officially referring to "hopeless" cases of repeat failed "repair" surgeries as ***"hypospadias cripples"*** (i.e. made to a "cripple" by unnecessary surgeries, *not* by the condition!, **p. 59**), while in medical publications on hypospadias, *"[d]ocumentation on complication rates has declined in the last 10 years"* (see 2014 CRC NGO Report, p. 54–56).

For more than 15 years, persons concerned have been criticising **impairment or loss of sexual sensitivity**. However, doctors still refuse to even consider these claims, let alone promote appropriate, disinterested long-term outcome studies.

Since the "2nd Hypospadias Boom" in the 1990s, hypospadias "repair" is arguably by far the **most frequent** cosmetic genital surgery done on children with variations of sex anatomy internationally. In **University Children's Hospitals**, systematic hypospadias "repair" within the first 18 months of life is still considered common practice for children concerned and raised as boys.

d) Systematic Misinformation, "Code of Silence", Lack of Informed Consent

Systematic misinformation, refusal of access to peer support, and **directive counselling** by doctors frequently prevent parents from learning about options for postponing permanent interventions, which has been criticised by persons concerned and their parents for two decades, seconded by bioethicists, and corroborated by studies, including a **recent exploratory study** (see 2014 CRC NGO Report, p. 71).

88 Daniel Weber, Verena Schönbucher, Rita Gobet, A. Gerber, MA. Landolt (2009), Is there an ideal age for hypospadias repair? A pilot study, Journal of Pediatric Urology 5(5):345–350, at 351

89 Deutsche Gesellschaft für Kinderchirurgie (2002), AWMF-Leitlinie 006/026 Hypospadie, http://kastrationsspital.ch/public/006-026-hypospadie-dgkch-2002.pdf

Nonetheless, internationally it's still paediatricians, endocrinologists and surgeons managing diagnostics and counselling of parents literally from *"day one."*[90] Parents often complain that they only get access to psychological counselling if they consent to "corrective surgery" first, while doctors openly admit seeking early surgeries to **facilitate compliance**, e.g. referring to *"easier management when the patient is still in diapers"* (see 2014 CRC NGO Report, p. 72).

Intersex children are systematically lied to and refused access to peer support in order to keep them in the dark about being born intersex, and, if ever told at all, are **sworn to secrecy**, e.g. *"You are a rarity, will never meet another like yourself and should never talk about it to no one"* (see 2014 CRC Report, p. 72), severely compounding shame, isolation and psychological trauma in the aftermath of IGM practices.

e) Other Unnecessary and Harmful Medical Interventions and Treatments

"The assistant called in some colleagues to inspect and to touch my genitals as well." (**CRC Case No. 3**)

Other common harmful treatments include (as detailed in the **2014 CRC NGO Report**):[91]

- **Forced Mastectomy** (p. 70)
- **Imposition of Hormones** (p. 73)
- **Forced Excessive Genital Exams, Medical Display, (Genital) Photography** (p. 73)
- **Human Experimentation** (p. 74)
- **Denial of Needed Health Care** (p. 75)
- **Prenatal "Therapy"** (p. 75)
- **Selective (Late Term) Abortion** (p. 76)
- **Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses** (p. 76)

3. How Common are Intersex Genital Mutilations?

Same as with intersex births (see above **p. 34**), (university) hospitals, Government agencies and health insurance covering intersex surgeries on children, **refuse to disclose statistics and costs**, as well as ignoring repeated calls for **independent data collection and monitoring** (see below **p. 47**).

What's more, doctors, government and other institutions involved in IGM practices, if questioned about statistics, are notorious for going to extreme lengths following established patterns of **a) disclosing only tiniest fractions** of actual treatments, often **arbitrarily changing definitions** of intersex and variations of sex anatomies in order to justify favourable (i.e. lower) figures, or **b) flatly denying any occurrence or knowledge** of IGM Practices, while at the same time the same doctors and hospitals, including such under the auspices of said departments, are continuing to publicly promote and perform them. Or, in the rare cases of studies actually "disclosing" numbers, yet another related tactic involves **c) manipulation of statistics**. For example the world's largest outcome study on 439 participants, the 2008 **"Netzwerk DSD"** intersex study, in official publications only gave a **misleading** overall total figure of *"**almost 81%** of all participants had at least once surgery [...] most of them before entering school."*[92]

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90 e.g. Eastern Switzerland Children's Hospital St. Gallen (2014), Zwischen den Geschlechtern, slide 8, http://kastrationsspital.ch/public/kispisg_09_vortrag_zwischen_den_geschlechtern_2.pdf

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

92 Eva Kleinemeier, Martina Jürgensen (2008), Erste Ergebnisse der Klinischen Evaluationsstudie im Netzwerk Störungen der Geschlechtsentwicklung/Intersexualität in Deutschland, Österreich und Schweiz, Januar 2005 bis Dezember 2007, at 16, http://kastrationsspital.ch/public/Ber-

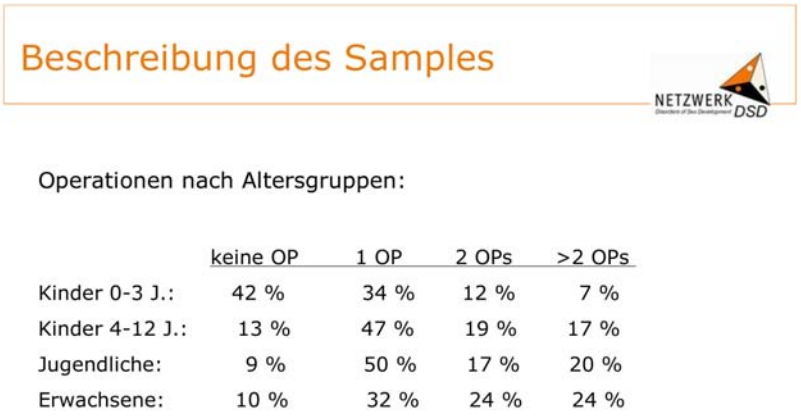

Figure 3 "Surgeries by Age Groups" (No Surgery, 1 Surgery, 2 Surgeries, >2 Surgeries, Children 0–3 Years, Children 4-12 Years, Adolescents, Adults)
Source: Martina Jürgensen: "Klinische Evaluationsstudie im Netzwerk DSD/Intersexualität: Zentrale Ergebnisse", Presentation 27.05.2009, Slide 6, http://kastrationsspital.ch/public/Corpus-delicti_27-5-09.pdf

The only published numbers that include a breakdown by age groups available from the **"Netzwerk DSD"** intersex study with participation of clinics in Germany, Austria and Switzerland[93] stem from a semi-official 2009 presentation. They reveal that, contrary to declarations by doctors as well as cantonal and federal governments, in the most relevant **age groups of 4+** years, **87%–91% have been submitted to IGM surgeries** at least once, with increasing numbers of repeat surgeries the older the children get (see **Figure 3** above – note, how the table conveniently stops at *">2"* surgeries, although, especially with "hypospadias repair", **a dozen or more repeat surgeries** are not uncommon).

What's more, although internationally no official statistics are available, internationally the **total number** of cosmetic genital surgeries performed on intersex children is known to be **still rising**.[94] [95]

4. Lack of Legislative Prevention of IGM Practices, Lack of Access to Redress and Justice for Victims

For more than two decades, persons concerned and sympathetic clinicians and academics have tried to reason with the perpetrators, and for 19 years they've been lobbying for legal measures, approaching governments as well as national and international ethics and human rights bodies year after year after year, calling for **specific legislation** to eliminate IGM practices, and criticising the **factual impunity of IGM doctors** due to **statutes of limitations** that – both in criminal and civil law – **expire long before survivors of early childhood IGM practices would be able to call a court**.

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icht_Klinische_Evaluationsstudie.pdf

93 https://web.archive.org/web/20130124010236/http://www.netzwerk-dsd.uk-sh.de/index.php?id=28

94 e.g. *"The UK National Health Services Hospital Episode Statistics in fact shows an* ***increase in the number of operations on the clitoris in under-14s since 2006***", Sarah M. Creighton, Lina Michala, Imran Mushtaq, Michal Yaron (2014), Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same?, Psychology & Sexuality 5(1):34-43, at 38

95 e.g. Italy: ***"Boom in Surgeries on Children with 'Indeterminate' Sex, in Rome 50% Increase during the Last 5 Years, 25% Increase on National Level"***, according to Aldo Morrone, Director General of the Ospedale San Camillo-Forlanini di Roma, quoted in: *"Boom di bimbi con sesso 'incerto', a Roma un aumento del 50 per cento"*, leggo.it 20.06.2013, https://web.archive.org/web/20131110113723/http://www.leggo.it/NEWS/ITALIA/boom_di_bimbi_con_sesso_quot_incerto_quot_a_roma_aumentano_del_50_per_cento/notizie/294638.shtml

In 2011, the **Committee against Torture (CAT)** was the first UN body to recognise the lack of adequate laws ensuring redress and investigations, explicitly calling on Germany to

> *"Undertake investigation of incidents of surgical and other medical treatment of intersex people without effective consent and* ***adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation.****"*[96]

In the meantime, the Committee against Torture issued similar recommendations to Switzerland, Austria, Denmark and Hong Kong, repeating its the call for *"legislative measures to ensure redress"* while adding, ***"to undertake legislative, administrative and other necessary measures to ensure the bodily integrity of intersex people, and that no-one is submitted to medical or surgical sex assignment treatments during childhood, which do not constitute a medical emergency"***.[97]

In 2012, the **Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE)** was the first national body to eventually support the call of survivors for legal measures, in Recommendation 12 explicitly urging a **legal review** of both **criminal law** and **civil liability implications**, as well as for a review of **associated statutes of limitations**, with explicit reference to Art. 124 Criminal Code (FGM).

Paediatric Surgeon Blaise Meyrat, one of only a handful of paediatric surgeons worldwide refusing to do unnecessary surgeries on intersex children, in 2013 was the first doctor to go on record and frankly admit that in the end **only legislation will succeed in ending IGM practices**, *"It's a pity that, because of a lack of ethical clarity in the medical profession, we have to get legislators involved, but* ***in my opinion it's the only solution****."*[98] And in 2015, on occasion of the 55th Session of the Committee against Torture, Meyrat added, ***"Only the fear of the judge will make things change. We need statutes of limitation long enough so that victims may sue as adults."***[99]

In 2013, the survivors's call for legislative measures was seconded by the **Special Rapporteur on Torture (SRT)**, who in his report on *"abuses in health-care settings that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment"* explicitly stated:

> *"Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, "in an attempt to fix their sex", leaving them with permanent, irreversible infertility and causing severe mental suffering.*
>
> *These procedures [genital-normalizing surgeries] are rarely medically necessary, can cause scarring, loss*

96 CAT/C/DEU/CO/5, 12 December 2011, para 20, http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

97 here: CAT/C/CHE/CO/7, 14 August 2015, para 20: http://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/CHE/CAT_C_CHE_CO_7_21385_F.pdf, see also: CAT/C/AUT/CO/6, 9 December 2015, paras 44–45, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fAUT%2fCO%2f6&Lang=en CAT/C/DNK/CO/6-7, 9 December, paras 42–43, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDNK%2fCO%2f6-7&Lang=en CAT/C/CHN-HKG/CO/4-5, 9 December 2015, paras 28–29, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fCHN-HKG%2fCO%2f5&Lang=en

98 Isabelle Eichenberger (2013), A human right: Third gender fights for recognition, http://www.swissinfo.ch/eng/swiss_news/Third_gender_fights_for_recognition.html?cid=34791620

99 Tribune de Genève / 24 heures, 03.08.2016, p. 5 respectively 6. English translation: http://stop.genitalmutilation.org/post/IGM-Only-Fear-of-the-Judge-Will-Make-Surgeons-Change

of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma (A/HRC/14/20, para. 23)."[100]

Also in 2013, this call was again seconded by the **Council of Europe (COE)** in their Resolution 1952 (2013) "Children's right to physical integrity", urging states to

"ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support"[101]

In 2014, an **Interagency Statement on Forced Sterilisation by the WHO and 6 more UN bodies** explicitly also criticised IGM practices in general:

"Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved."[102]

In addition, the WHO interagency statement explicitly called for ***"Remedies and redress"***, as well as for ***"Monitoring and Compliance."***

In 2015, the **Committee on the Rights of the Child (CRC)** criticised **Switzerland** for allowing IGM practices to continue, explicitly highlighting ***"the lack of redress and compensation in such cases,"*** and classifying IGM practices as ***"violence against children"*** and as a ***"harmful practice"***,[103] thus clearly implicating the urgent need for legislative measures to eliminate them, namely *"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".*

Also in 2015, in their recommendations to Chile, the Committee on the Rights of the Child added, ***"ensuring effective remedy for victims, including redress and compensation."***[104]

Also in 2015, the **Committee on the Rights of Persons with Disabilities (CRPD)**, referring to the 2011 CAT Concluding Observations, criticised the failure of ***"upholding bodily integrity of intersex children"***, and urged Germany to ***"take the necessary measures, including of a legislative nature*** *to [...] [i]mplement all the recommendations of CAT/C/DEU/CO/5, para. 20 relevant to intersex children."*[105]

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100 A/HRC/22/53, 1 February 2013, paras 77, 76: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

101 Council of Europe (COE), Resolution 1952 (2013) "Children's right to physical integrity", 1 October 2013, para 7: http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=20174&lang=en

102 OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement, May 2014, http://www.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1

103 CRC/C/CHE/CO/2-4, p. 8-9, paras. 42-43: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En

104 CRC/C/CHL/CO/4-5, 2 October 2015, paras 48–49, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fCHL%2fCO%2f4-5&Lang=en

105 CRPD/C/DEU/CO/1, p. 6–7, paras 37-38: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/DEU/CO/1

Again in 2015, the **WHO Report "Sexual health, human rights and the law"** reiterated:

> *"It has also been recommended [by human rights bodies and ethical and health professional organizations] that **investigation should be undertaken** into incidents of surgical and other medical treatment of intersex people without informed consent and that **legal provisions should be adopted** in order to provide remedies and redress to the victims of such treatment, including adequate compensation."*[106]

Nonetheless, globally so far without even a single exception, **states refuse to take legislative action to ensure access to redress for IGM survivors.**

5. Lack of Disinterested Review, Analysis, Outcome Studies and Research

Persons concerned and their organisations have stressed for almost two decades *"the unreliability of research conducted **in the setting where the harm was done**"*, [107] and stressed the imminent need for **impartial, disinterested investigation and research**, as called for in Art. 12 CAT and the Committee's own 2011 Concluding Observations,[108] as well as by the 2012 **Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE)** (Recommendation 9), the 2013 COE Resolution 1952 (para 7), and the 2014 WHO Interagency Statement.

However, to this day, despite repeated calls for impartial investigation and disinterested research, internationally the only "investigations" taking place are the "research" facilitated by the perpetrators themselves, relying on massive state funding.

The only exception proving the rule is an **exceptional preliminary research study** *"Historic Evaluation of Treatment of Persons with Differences of Sex Development"* [109] examining 22 cases of clitoris amputations at the **Zurich University Children's Clinic** between 1913 and 1968. This preliminary study was initiated and paid for by the University Children's Clinic (after considerable pressure by intersex NGOs and self-help groups). However, the clinic is still **struggling with funding** to adequately continue this ground-breaking project constituting a global first, and so far **no state body considered supporting it**.

On the other hand, currently the **European Union** and affiliated states are spending millions on exculpating "intersex research projects" facilited by, and in control of the perpetrators.[110]

"DSD-Life" (see **Figure 4**, above p. 43) and **"DSDnet"**, two current examples, are **conducted by the perpetrators themselves**, e.g. in "DSDnet" paediatric endocrinologists,[111] and in "DSD-Life" paediatric endocrinologists and paediatric surgeons[112] taking the lead – exactly the professional groups responsible for IGM practices in the first place. If other disciplines are included at all in the "multidisciplinary teams," like e.g. psychology or bioethics, let alone persons concerned, they only play a secondary role, and are only included at a later stage, and especially persons concerned serve mostly to recruit participants – same as in the precursor projects **"Netzwerk DSD"** and **"EuroDSD"**.

106 p. 27, http://apps.who.int/iris/bitstream/10665/175556/1/9789241564984_eng.pdf?ua=1

107 Tiger Howard Devore (1996), Endless Calls for "More Research" as Harmful Interventions Continue, Hermaphrodites With Attitude, Fall/Winter 1996:2, http://www.isna.org/files/hwa/winter1996.pdf (emphasis in original)

108 CAT/C/DEU/CO/5, 12 December 2011, para 20, http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf

109 http://www.kispi.uzh.ch/de/zuweiser/fachbereiche/urologie/Documents/Bericht_DSD_Sandra_Eder_Kinderspital_Zuerich.pdf

110 http://www.cost.eu/about_cost/who/%28type%29/5/%28wid%29/1438

111 http://www.cost.eu/domains_actions/bmbs/Actions/BM1303?management

112 http://www.dsd-life.eu/the-group/consortium/, for a more accessible graphic overview of the consortium see: http://stop.genitalmutilation.org/post/IGM-Primer-2-The-Global-Cartel

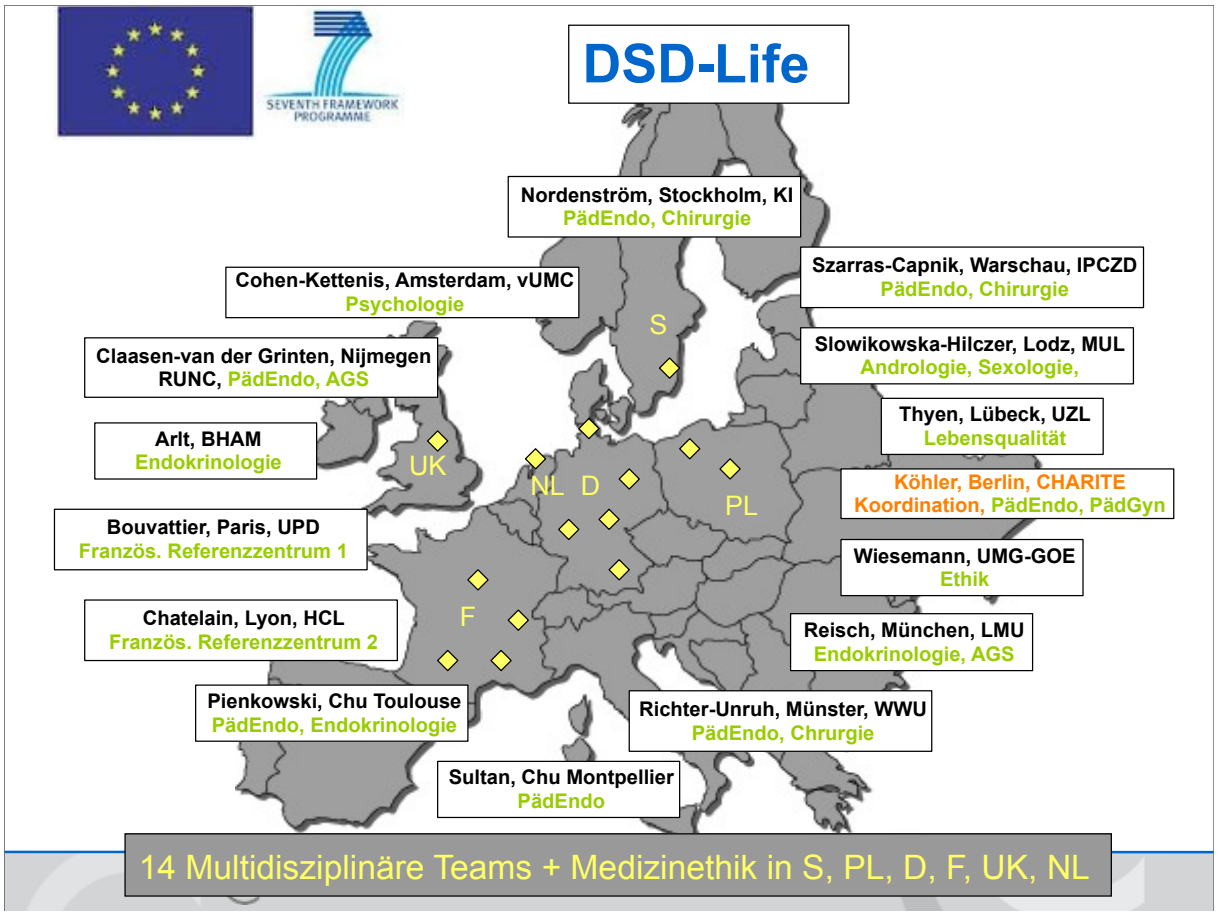

Figure 4 "DSD-Life" IGM Clinics

What's more, all of these perpetrator's "research projects" continue to openly advocate IGM, as well as to promote the usual psychosocial and non-factual justifications, e.g. **"DSDnet"**:

> *"Children with DSD may be born with genitalia that range from being atypical to truly ambiguous and the sex assignment process may be extremely challenging for families and health care professionals.* ***Often, multiple surgical interventions are performed for genital reconstruction to a male or female appearance. The gonads are often removed to avoid malignant development.***"[113]

On the other hand, to this day an **impartial investigation** into past and current IGM practices **isn't even considered by any state.**

6. Lack of Independent Data Collection and Monitoring

With no statistics available on intersex births, let alone surgeries and costs, and **perpetrators, governments and health departments colluding to keep it that way as long as anyhow possible**, persons concerned as well as civil society **lack possibilities to effectively highlight and monitor** the ongoing mutilations. What's more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists "on record".[114]

113: "DSDnet" (2013), Memorandum of Understanding, at 4, http://w3.cost.eu/fileadmin/domain_files/BMBS/Action_BM1303/mou/BM1303-e.pdf

114 Personal communication by journalist SRF (Swiss National Radio and TV), 2013

F. The Treatment of Intersex Persons as a Violation of the Convention on the Rights of the Child

> *"Genital mutilation of intersex children damages genital sensitivity in irreversible ways; it causes post-surgical trauma, and the internalization of brutal prejudices denying or stigmatizing the diversity that in reality human bodies show. [...] The difference in genitalia cannot justify, under any pretext whatsoever, ethical and political hierarchies: cannot justify mutilation, because it never normalizes but does the opposite. For us, mutilation creates a permanent status of human rights violation and inhumanity."*
>
> Mauro Cabral, CESCR NGO Statement 2004[115]

For 23 years now, intersex people from all over the world, and their organisations have been publicly denouncing IGM Practices as destructive of sexual sensation, and as a violation of basic human rights, notably the right to physical integrity.[116] For 19 years, they have lobbied for legislation against IGM Practices to end the impunity of perpetrators due to statutes of limitation.[117] For 18 years, they have been invoking UN Conventions,[118] and for 12 years they have been reporting IGM Practices to the UN as a human rights violation.[119]

In every intersex community, meanwhile several generations of intersex persons, their partners and families, as well as NGOs and other human rights and bioethics experts, have again and again described IGM Practices as a **human rights issue**,[120] as **harmful and traumatising**,[121] as **torture,**[122] as a **western form of genital mutilation**,[123] as **child sexual abuse**,[124] and have called for **legislation to end it**.[125]

The UN Committees **CRC**, **CAT**, **CRPD**, **CEDAW**, the **UN Special Rapporteur on Torture (SRT)**, the UN Special Rapporteur on Health (**SRH**), the **UN High Commissioner for Human Rights (UNHCHR)**, the **World Health Organisation (WHO)**, the **Council of Europe (COE)**, and last but not least the Swiss National Advisory Commission on Biomedical Ethics (**NEK-CNE**) have all recognised the treatment of intersex children as a **serious human rights violation**, have called for **legislative measures** (**CAT**, **SRT**,

115 Mauro Cabral (2004), NGO Statement: Intersexuality, online

116 Cheryl Chase (1993), Letter to The Sciences RE: The Five Sexes, http://www.isna.org/articles/chase1995a

117 Cheryl Chase (1996), Female Genital Mutilation in the U.S. Discussion, https://web.archive.org/web/20110602195403/http://h-net.org/~women/threads/mut.html

118 Cheryl Chase (1998), ISNA's Amicus Brief on Intersex Genital Surgery, http://www.isna.org/node/97

119 Mauro Cabral (2004), NGO Statement: Intersexuality, online

120 Clare O'Dea (2009), Doctors "playing God with children's sex", swissinfo 26.08.2009, http://www.swissinfo.ch/eng/Home/Archive/Doctors_playing_God_with_childrens_sex.html?cid=981950

121 Nikola Biller-Andorno (2006), Zum Umgang mit Intersex: Gibt es Wege jenseits der Zuordnung des «richtigen Geschlechts»? Schweizerische Ärztezeitung 47:2047-2048, at 2047, http://www.saez.ch/docs/saez/archiv/de/2006/2006-47/2006-47-283.PDF

122 http://blog.zwischengeschlecht.info/post/2008/12/30/Medizinische-Intervention-als-Folter-Michel-Reiter-3062000

123 Mirjam Werlen (2008), Rechtlicher Schutz für Kinder mit uneindeutigem Geschlecht, in: Michael Groneberg, Kathrin Zehnder (eds.) (2008), «Intersex». Geschlechtsanpassungen zum Wohle des Kindes? Erfahrungen und Analysen:178–215, at 184

124 Kathrin Zehnder (2010), Zwitter beim Namen nennen. Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung, at 201

125 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to "intersexuality", Opinion No. 20/2012, Recommendation 15, at 19, online

COE, **NEK-CNE**), **historical reappraisal** and acknowledgement by society of suffering inflicted (**NEK-CNE**), and for **access to redress and fair compensation for victims** (**CRC**, **CAT**, **CRPD**, **WHO**, **NEK-CNE**) (see **Bibliography, p. 25**).

1. State Parties' Commitment to the Protection of the Rights of the Child

By ratifying the **Convention on the Rights of the Child** (**CRC**), state parties have committed themselves to ensuring that no child within its jurisdiction is subject to **harmful practices** or **torture** and other cruel, inhuman or degrading treatment or punishment (**CIDT**), nor to other human rights violations specified in the convention. In addition, state parties may have ratified the **Convention against Torture** (**CAT**), and the **European Convention on Human Rights** (**ECHR**), which both prohibit ill-treatment, as well as the **International Covenant on Civil and Political Rights** (**ICCPR**) which in its Art. 7 contains a similar clause and explicitly includes freedom from forced medical experiments. Last but not least, the state parties' **Constitution** may ensure the right to life and personal freedom, particularly the right to physical and mental integrity, and may explicitly prohibits CIDT, emphasise the right of special protection of the integrity of children and young people, as well as ensuring the respect for, and the protection of, their dignity, and ensuring equality and non-discrimination.

2. Violated Articles of the Convention

This section will demonstrate that IGM practices, including unnecessary, irreversible cosmetic genital surgeries, and other harmful medical treatments referred to above, constitute human rights violations under **Articles 2, 3, 6, 8, 12, 16, 19, 23, 24, 34, 36, and 37** of the Convention on the Rights of the Child, as well as under the **CRC/CEDAW Joint General Comment No. 18/31 on harmful practices** (2014).

Article 2: Non-Discrimination

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, by reverting to a *"monster approach"* implying intersex children are *"so grotesque, so pathetic, any medical procedure aimed at normalizing them would be morally justified"*,[126] so that, according to a specialised surgeon, *"any cutting, no matter how incompetently executed, is a kindness."*[127] Clearly, IGM practices therefore not only violate Article 2 CRC, and in addition may violate similar provisions in the state parties' constitution.

Article 3: Best Interest of the Child

Consideration of best interests must embrace both short- and long-term considerations for the child, must be consistent with the spirit of the entire Convention, and cannot be interpreted in an overly culturally relativist way to deny e.g. protection against harmful practices.[128] The physical and mental suffering caused by IGM practices is well-established also in medical literature. Clearly, early "genital corrections" as *"the natural path"* best to be undertaken in the *"first two years of life"*, justified by notions of e.g. discarding *"abstract ethical and legal perspectives*

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

127 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

128 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 38

of future adolescents and their title to disposal over their bodies" in favour of *"the eminent best interest and welfare of the child growing up in his family,"* leading to the conclusion, *"If [...] it appears that a family is not capable of accepting a child with ambiguous genitals, for us it is the better way to perform a medically not urgently indicated surgery, than to expose the child to rejection and ostracism"*, go directly against Article 3 CRC, and in addition may violate similar provisions in the state parties' constitution.

Article 6: Children's Right to Life and Maximum Survival and Development

While after 60 years of systematic IGM practices there's still no evidence of benefits for the children concerned, the physical and mental suffering caused by IGM is well-established also in medical literature. What's more, the Preamble to the Convention on the Rights of the Child recalls the provision in the United Nations Declaration of the Rights of the Child that *"the child [...] needs special safeguards and care, [...] before as well as after birth,"* and *"[t]he Committee has commented adversely on [...] selective abortions [...]"*[129] Therefore, IGM practices, including prenatal "treatment" to eliminate intersex traits, as well as Selective (Late Term) Abortions and Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses, clearly violate Article 6 CRC.

Article 8: Preservation of Identity

As the Swiss National Advisory Commission on Biomedical Ethics has commented, "genital correction" surgery was one part of imposing a gendered identity on an infant.[130] What's more, IGM practices including deliberately performing "genital corrections" on intersex infants "too young to remember afterwards," followed by non-disclosure of the body an intersex child was born with, as well as hiding their medical history from them, persist. Therefore, IGM practices clearly are in violation of Article 8 CRC.

Article 12: Respect for the Views of the Child

Article 12 asserting the right of the child to express their views freely in all matters affecting the child, and the views of the child being given due weight in accordance with the age and maturity of the child, is a general principle of fundamental importance.[131] However, IGM practices deliberately create faits accomplis *before* the child is capable of forming his or her own views, as well as actively hindering the children to form and contribute their own views due to deliberately keeping them in the dark.

What's more, provisions in the state party's laws may include the concept of inalienable "highly" or "strictly personal rights", which can not be transferred to other persons, in fact legally barring parents from giving valid informed consent to "genital corrections" on behalf of their intersex children, and urging legislative measures to ensure protection of the right to participation of the child, as well as of their best interests.[132]

Therefore, IGM practices clearly violate Article 12 CRC, and go against CRC General Comment No 12 *"The right of the child to be heard"*.[133] In addition, IGM practices may violate similar

129 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 85

130 Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to "intersexuality", Opinion No. 20/2012, at 8, http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

131 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 149

132 Michelle Cottier (2013), Zivilrechtliche Aspekte der Intersexualität, at 8, http://www.merh.uzh.ch/veranstaltungen/archiv/intersexualitaet/CottierIntersexualitaet.pdf

133 German Institute for Human Rights (2013), Suggested topics to be taken into account by the Committee on the Rights of the Child, at 4, http://www.institut-fuer-menschenrechte.de/up-

provisions in the state parties' constitution.

Article 16: Child's Right to Privacy

Unnecessary, forced excessive genital exams, medical display and (genital) photography and other persisting forms of IGM practices clearly violate Article 16 CRC.

Article 23: Rights of Children with Disability

While some intersex children are born with conditions resulting in special needs (e.g. for daily cortisol substitution for salt-wasting CAH), many are made invalids only by IGM practices, e.g. by castration in children with (C)AIS, resulting in need for daily hormone doses from the age of puberty on for the rest of their lives, however health assurances refuse to pay for adequate Hormone Replacement Therapy (HRT) with testosterone. What's more, many children suffer from PTSDs as a result of IGM and other harmful treatments, but are refused adequate psychological and psychosocial support. Clearly, such treatments violate Article 23 CRC. Also the Committee on the Rights of Persons with Disabilities considered IGM practices as a violation of CRPD.[134]

Article 24: Child's Right to Health and Health Services, Harmful Practices CRC/CEDAW Joint General Comment No. 18/31 on Harmful Practices

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.[135]

Intersex persons have early stressed that they experience especially "genital corrections" as mutilating, and called these interventions Intersex Genital Mutilations, or IGM practices. Many experts have confirmed the similarities and the comparability of IGM to FGM/C, stressing how IGM as a harmful practice are not guided by medical evidence, but by traditional and sociocultural values. What's more, until FGM/C was widely recognised as the fundamental human rights violation that it is, doctors involved in IGM practices themselves have freely likened the practices, even defending the latter with the alleged harmlessness of the former, and until today continue to justify IGM practices with apologetics and objectifications of the victims typically also used to defend FGM/C.

The Committee has repeatedly considered IGM as a harmful practice, and the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices as applicable in Concluding Observations to **Switzerland, Chile, Ireland**, and **France.**[136]

Harmful practices (and inhuman treatment) have been identified by intersex advocates as the **most effective, well established and applicable human rights frameworks** to elimi-

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loads/tx_commerce/GIHR_Suggested_topics_to_be_taken_into_account_for_the_preparation_of_a_list_of_issues_by_the_CRC_on_the_implementation_of_the_Convention_on_the_Rights_of_the_Child_in_Germany.pdf

134 CRPD/C/DEU/CO/1, 13 May 2015, p. 6–7, paras 37-38, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/DEU/CO/1

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

136 CRC/C/CHE/CO/2-4, 4 February 2015, paras 42–43: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En
CRC/C/CHL/CO/4-5, 2 October 2015, paras 48–49, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fCHL%2fCO%2f4-5&Lang=en

nate IGM practices and to end the impunity of the perpetrators.[137]

The **Joint General Comment No. 18 "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 further underlines the need for a ***"Holistic framework*** *for addressing harmful practices"* (paras 31–36), including ***"legislative, policy and other appropriate measures*** *that must be taken to ensure full compliance with [state parties'] obligations under the Conventions to eliminate harmful practices"* (para 2), as well as

- *"Data collection and monitoring"* (paras 37–39)
- *"Legislation and its enforcement"* (paras 40–55), particularly:
- *"[complementary]* ***adequate civil and/or administrative legislative provisions"*** (para 55 (d))
- *"provisions on* ***regular evaluation and monitoring****, including in relation to implementation, enforcement and follow-up"* (para 55 (n))
- ***"equal access to justice,*** *including by* ***addressing legal and practical barriers to initiating legal proceedings, such as the limitation period,*** *and that the* ***perpetrators and those who aid or condone such practices are held accountable"*** (para 55 (o))
- *"equal access to* ***legal remedies and appropriate reparations*** *in practice"* (para 55 (q)).

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

In addition, with the proven harm afflicted by IGM, these practices are fundamentally incompatible with the right of the child to the enjoyment of the highest attainable standard of health affirmed in Article 24 para1 CRC.

Thus, IGM practices – as well as the complete failure of state parties to enact appropriate legislative, administrative, social and educational measures to eliminate them and to ensure effective access to remedies and redress – clearly violate Article 24 CRC, as well as the CRC/CEDAW Joint General Comment No. 18/31 on harmful practices.

137 Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: "Ending the Impunity of the Perpetrators!" Input for Session 3: "Human Rights Standards and Intersex People – Progress and Challenges - Part 2" 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

Article 19: Child's Right to Protection from All Forms of Violence
General Comment No. 13 "The right of the child to freedom from all forms of violence"
Article 34: Protection from All Forms of Sexual Exploitation of Children
Article 36: Protection from Other Forms of Exploitation

Persons concerned have denounced IGM practices in general, and especially "genital corrections," castrations / "gonadectomies" / hysterectomies / (secondary) sterilisations, human experimentation, forced excessive genital exams, medical display and (genital) photography, and vaginal dilations as physical and psychological violence, exploitation, and as a form of child sexual abuse; the latter has also been acknowledged by leading perpetrators for decades.[138]

The Committee has already considered IGM practices as a form of violence against children.[139]

Art. 19 CRC explicitly states that *"States Parties shall take* ***all appropriate legislative, administrative, social and educational measures*** *to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child."*

The **General Comment No. 13 "The right of the child to freedom from all forms of violence"** furthermore explicitly defines *"responsible adults in health-care [...] settings"* and *"professionals"* in *"medical [...] facilities"* as caregivers addressed by Art. 19 of the Convention (para 33–34), and stresses the need to ***"[r]eview and amend domestic legislation*** *in line with article 19 and its implementation within the holistic framework of the Convention, establishing a comprehensive policy on child rights and* ***ensuring absolute prohibition*** *of all forms of violence against children in all settings and effective and appropriate sanctions against perpetrators"* (para 41 (d)), and to ***"[e]nsure [...] effective access to redress and reparation"*** (para 41 (f)), respectively *"Effective remedies should be available,* ***including compensation to victims*** *and access to redress mechanisms and appeal or independent complaint mechanisms."* (para 56).

Thus, IGM practices – as well as the complete failure of state parties to enact appropriate legislative, administrative, social and educational measures to eliminate them and to ensure effective access to remedies and redress – clearly violate Articles 19, 34 and/or 36 CRC, as well as the General Comment No. 13 "The right of the child to freedom from all forms of violence".

138 John Money, Margareth Lamacz (1987), Genital Examination and Exposure Experienced as Nosocomial Sexual Abuse in Childhood, ‚Journal of Nervous and Mental Disease 175(12)

139 CRC/C/CHE/CO/2-4, 4 February 2015, "D. Violence against children" (p. 8) and paras 42–43, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/CHE/CO/2-4&Lang=En
CRC/C/CHL/CO/4-5, 2 October 2015, paras 48–49, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fCHL%2fCO%2f4-5&Lang=en

The Committee against Torture (CAT)[140] and the **Special Rapporteur on Torture (SRT)**[141] already recognise IGM practices as serious human rights violations constituting at least Ill-treatment. IGM practices thus clearly violate Article 37 CRC, and in addition may violate similar provisions in the state parties' constitution.

3. Lack of Legislative Provisions to Ensure Protection from IGM Practices, Impunity of the Perpetrators

Article 24 para. 3 of the Convention in conjunction with the CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices" underline state parties' obligations to ***"explicitly prohibit by law and adequately sanction or criminalize*** *harmful practices"*, as well as to ***"adopt or amend legislation*** *with a view to effectively addressing and eliminating harmful practices"*, and specifically to ensure *"that the* ***perpetrators and those who aid or condone such practices are held accountable"*** (see above Art. 24 and JGC 18/31).

Also Article 19 of the Convention and the General Comment No. 13 "The right of the child to freedom from all forms of violence" call upon states to ***"take all appropriate legislative, administrative, social and educational measures*** *to protect the child from all forms of physical or mental violence"*, to ***"[r]eview and amend domestic legislation*** *in line with article 19 and its implementation within the holistic framework of the Convention, establishing a comprehensive policy on child rights and ensuring absolute prohibition of all forms of violence against children in all settings and* ***effective and appropriate sanctions against perpetrators"*** (see above Art. 19 and GC 13).

However, to his day **Malta** is the only nation to at least formally outlaw IGM practices – but only in Civil Law, and without addressing accountability, or immunity of the perpetrators, nor sanctions, nor IGM performed abroad (arguably the majority of Maltese intersex children are sent to Italy for IGM treatments).[142]

Thus, globally the **lack of appropriate legislative measures** to effectively eliminate IGM practices prevails, as well as the factual **impunity of the perpetrators.**

This situation is not in line with state parties' obligations under Article 24 para. 3 of the Convention and the CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices", as well as under Art. 19 CRC and the General Comment No. 13 "The right of the child to freedom from all forms of violence".

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140 CAT/C/DEU/CO/5, 12 December 2011, para 20, http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.DEU.CO.5_en.pdf
CAT/C/CHE/CO/7, 14 August 2015, para 20: http://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/CHE/CAT_C_CHE_CO_7_21385_E.pdf
CAT/C/AUT/CO/6, 9 December 2015, paras 44–45, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fAUT%2fCO%2f6&Lang=en
CAT/C/DNK/CO/6-7, 9 December, paras 42–43, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fDNK%2fCO%2f6-7&Lang=en
CAT/C/CHN-HKG/CO/4-5, 9 December 2015, paras 28–29, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fCHN-HKG%2fCO%2f5&Lang=en

141 **UN SRT (2013)**, A/HRC/22/53, at para 77, 76, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

142 Maltese Parliament, Gender Identity Gender Expression and Sex Characteristics Act (GIGESC), 2 April 2015, Article 14(1–5) "Right to bodily integrity and physical autonomy", http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1

4. Obstacles to Redress, Fair and Adequate Compensation

Article 24 para. 3 of the Convention in conjunction with the CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices" clearly stipulate the right of victims of IGM practices to ***"equal access to legal remedies and appropriate reparations"***, 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"*** (see above Art. 24 and JGC 18).

Also Article 19 of the Convention and the General Comment No. 13 "The right of the child to freedom from all forms of violence" stipulate the right of victims of IGM practices to ***"effective access to redress and reparation"***, ***"including compensation to victims"*** (see above Art. 19 and GC 13).

However, currently without exception the **statutes of limitations** prohibit survivors of early childhood IGM practices to call a court, usually long before they become adults, despite the fact that 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.[143] Globally, **states refuse to take legislative action** to change that, as well as to facilitate impartial investigations, data collection, monitoring, and disinterested research. In addition, hospitals are often **unwilling to provide access to patient's files**.

This situation is not in line with state parties' obligations under Article 24 para. 3 of the Convention and the CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices", as well as under Art. 19 CRC and the General Comment No. 13 "The right of the child to freedom from all forms of violence".

5. Conclusion: Internationally, States are Failing their Obligations towards Intersex People under the Convention on the Rights of the Child

The surgeries and other harmful treatments intersex people endure cause severe physical and mental pain. Doctors perform the surgery for the discriminatory purpose of making a child fit into societal and cultural norms and beliefs, although there is plenty of evidence on the suffering this causes. State parties are responsible for these violations amounting to torture or at least ill-treatment, committed by often publicly funded doctors, clinics, and universities, as well as in private clinics, all relying on money from often mandatory health insurance, and public grants. Although in the meantime the pervasiveness IGM practices is common knowledge, and most state parties will have been repeatedly called to action both on state, federal, and international level, nonetheless they fail to prevent these grave violations both in public and in private settings, but allow the human rights violations on intersex children and adolescents to continue unhindered.

Internationally, States are thus in breach of its obligation to protect intersex children affirmed in **Articles 2, 3, 6, 8, 12, 16, 19, 23, 24, 34, 36, and 37** of the Convention on the Rights of the Child, as well as of the **CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices"** and the **General Comment No. 13 "The right of the child to freedom from all forms of violence"**.

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143 Globally, so far **no survivor of early surgeries ever** managed to have their case heard in court. All relevant court cases so far (3 in Germany, with 1 ending in a conviction of a surgeon and 2 more ongoing; and 1 ongoing case in the USA) were either about surgery of adults, or initiated by foster parents.

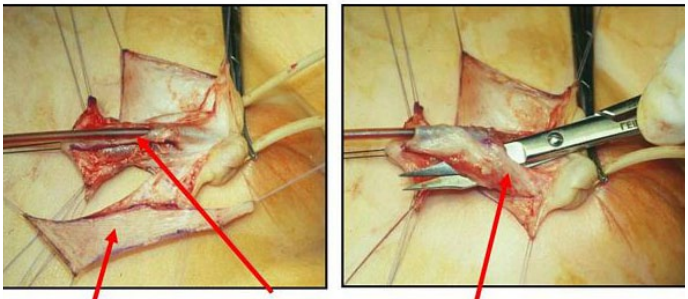
Supplement G. "IGM in Medical Textbooks – Part 1: Current Practice"

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)

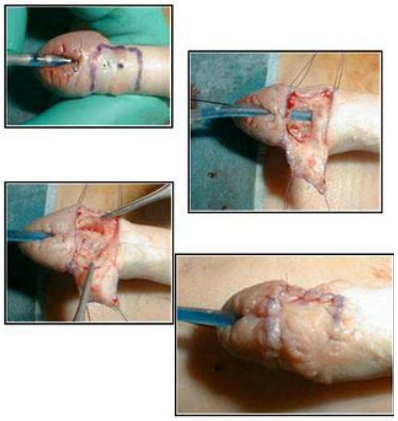
Hypospadias - Procedures for cripple hypospadias

- 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 fistulæ

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



Bad cosmetic result

infection

Hypospadias - Conclusions

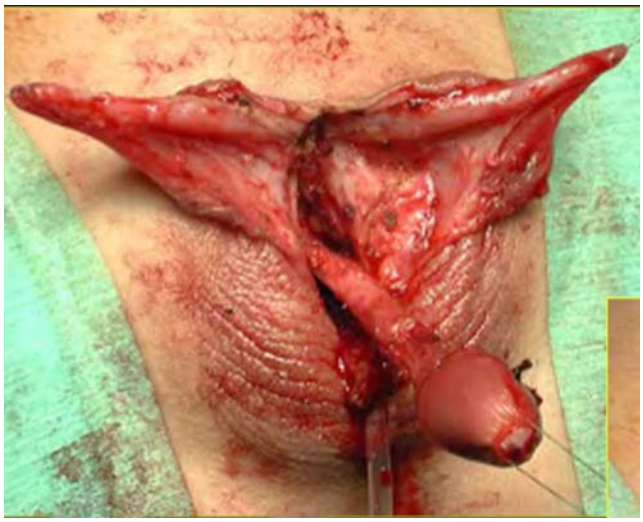
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

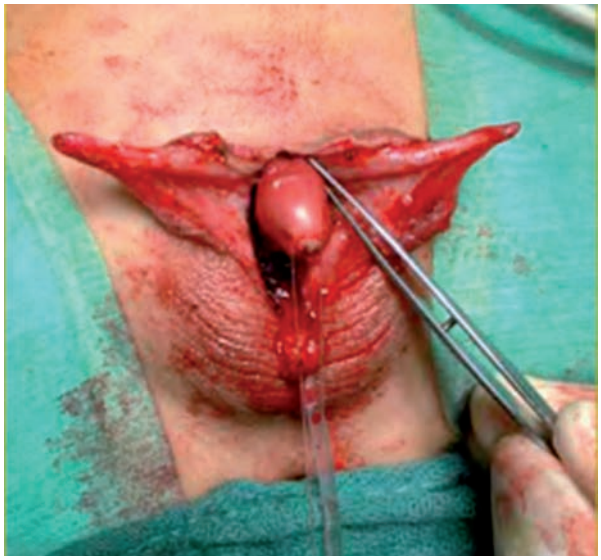
Source: Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

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

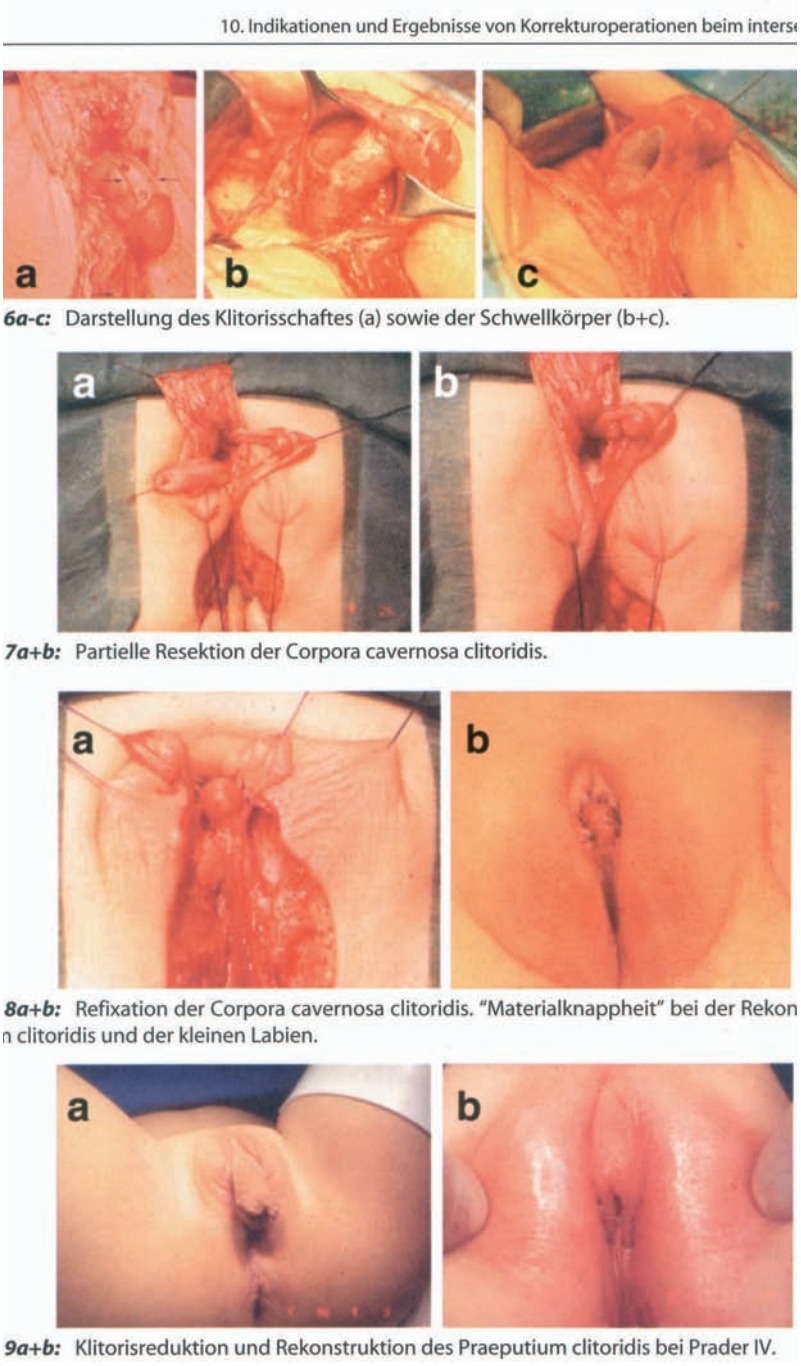
Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include "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 (above): Christian Radmayr: ***Molekulare Grundlagen und Diagnostik des Intersex***, 2004



Source (above): Finke/Höhne: *Intersexualität bei Kindern*, 2008
Note Caption 8b: ***"Material shortage" [of skin] while reconstructing the praeputium clitoridis and the inner labia.***

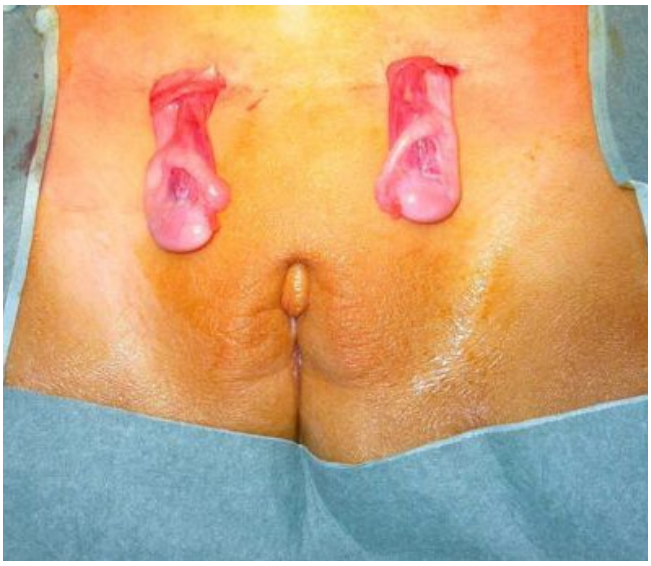
Source (left): Pierre Mouriquand: "Chirurgie des anomalies du développement sexuel - 2007", at 81: "Labioplastie"

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).



"46,XY DSD" [Complete Androgen Insufficiency Syndrome (CAIS)] Laparoscopic Gonadectomy

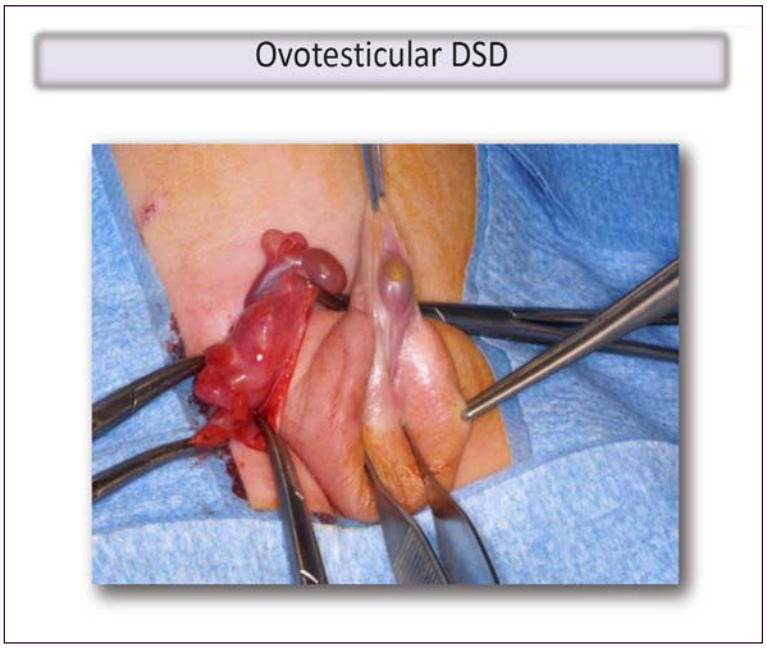


Table 1. Prevalence of type II GCT in various forms of DSD

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
	17β-hydroxysteroid dehydrogenase 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.

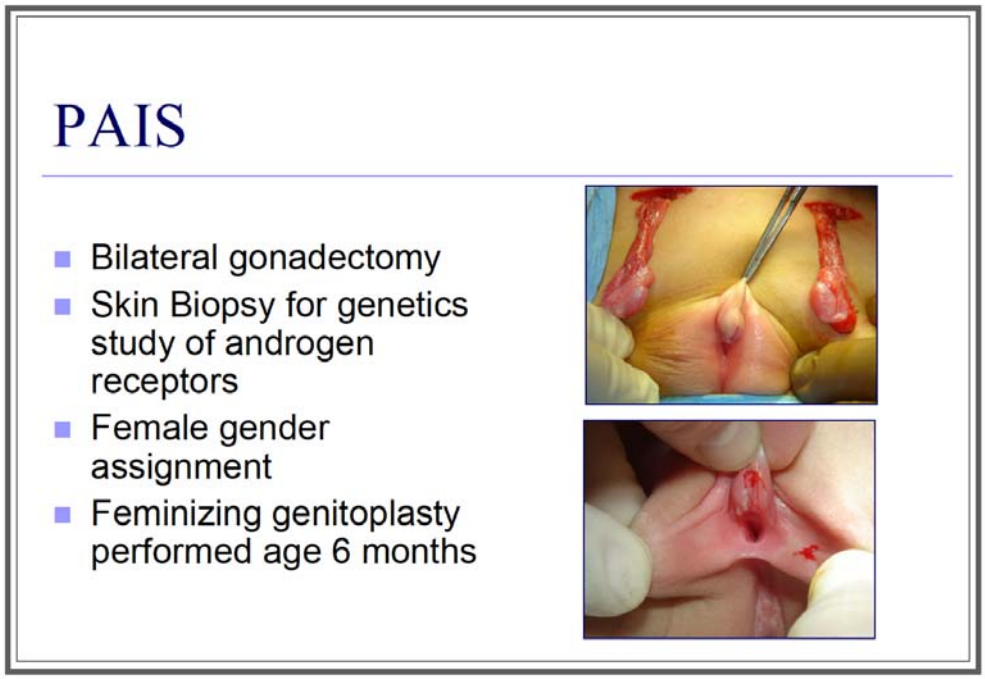
Source (top left): Pierre Mouriquand: "Anomalies congénitales du développement génito-sexuel (DSD). DESC 2012", slide 9

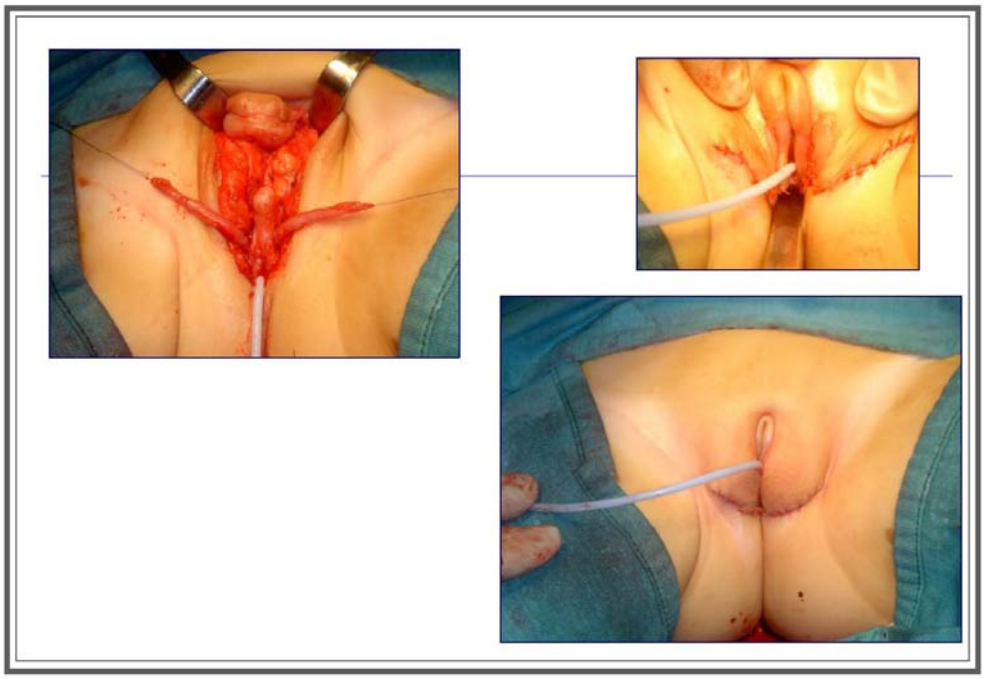
Source (top right): Pierre Mouriquand: "Anomalies du développement sexuel. DESC de Chirurgie Pédiatrique Session de Septembre 2009 - Paris", slide 11

Source (bottom left): 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.

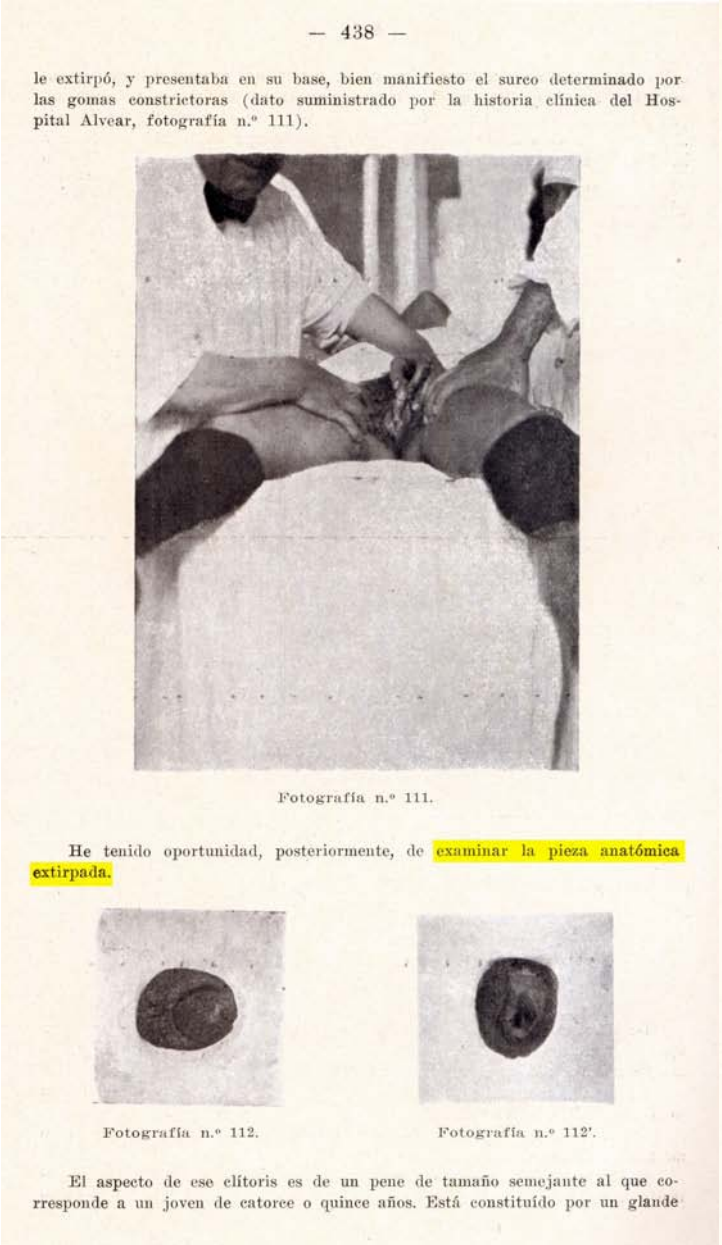
Abb. 2 ▲ **a, b** Schlechte Korrekturergebnisse nach Feminisierung und **c, d** nach Hypospadiekorrektur

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





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



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le extirpó, y presentaba en su base, bien manifiesto el surco determinado por las gomas constrictoras (dato suministrado por la historia clínica del Hospital Alvear, fotografía n.º 111).

Fotografía n.º 111.

He tenido oportunidad, posteriormente, de examinar la pieza anatómica extirpada.

Fotografía n.º 112.

Fotografía n.º 112'.

El aspecto de ese clítoris es de un pene de tamaño semejante al que corresponde a un joven de catorce o quince años. Está constituído por un glande

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quizá un poco exagerado, está cubierto por prepucio por su parte dorsal en casi toda su longitud. En su extremo anterior, termina por un glande, con su correspondiente surco balano-prepucial. Este glande es imperforado. Por debajo falta el prepucio y la uretra, existiendo sólo un débil surco en parte mucoso y en parte cutáneo. Detrás de la base de implantación de este miembro y vecino al periné, semioculto por un repliegue cutáneo, se advierte un orificio por donde sale orina, y por donde, introduciendo un estilete, se llega a una cavidad que, por su situación, debe ser la vejiga. Las bolsas escrotales no existen. En los repliegues cutáneos laterales, no se palpan glándulas sexuales, como tampoco en las regiones inguinales. No hay pelos en la piel del pubis.

Fuera de las deformidades de la esfera genital, muchas de las cuales se

Fotografía n.º 11.

ven en la fotografía, el niño presenta, por el resto, una buena constitución. Su estado general era muy bueno y se encontraba en perfectas condiciones de nutrición.

Habiéndose hecho el diagnóstico de hipospadia y teniendo en cuenta la corta edad del paciente así como la ausencia completa de trastornos funcionales, se resolvió esperar a que el niño cumpliera cuatro años de edad, para, entonces, someterlo a una intervención quirúrgica destinada a corregir su hipospadia.

Es cuando el niño cumplió cuatro años de edad, que fué traído nuevamente al Hospital, levantándosele el estado actual que a continuación exponemos. Fué, entonces, también, que se obtuvieron las fotografías números 13 y 14.

Niño en buen estado general y en regular estado de nutrición. Coloración normal de la piel y las mucosas. Buena constitución esquelética. Fuera de la anomalía existente en su aparato genital, no presenta ninguna otra deformidad aparente.

Examinado desnudo, llama inmediatamente la atención el insólito des-

Buenos Aires 1925: Medical Display, "Trophy Shots", and Cosmetic Genital Surgeries on Children

"Las deformidades de la sexualidad humana" by Carlos Lagos García (1880-1928) is arguably the first modern medical book dedicated exclusively to "genital abnormalities" and their surgical "cure". It was highly influential both in Europe and the Americas, pioneering forced medical display, "trophy shots" of amputated healthy genitals and reproductive organs, and advocating cosmetic surgeries on little children, both "feminising" and "masculinising" – expressly without actual medical necessity, but as "correction" for "anomalies".

Source: Carlos Lagos García: *Las deformidades de la sexualidad humana.* Buenos Aires, 1925, p. 438, 262.

Young to investigate the pelvic generative organs. It was decided to carry out the laparotomy through the inner edge of the right rectus muscle. A testicle was discovered on the left side, with a definite vas; also a Fallopian tube leading to an undeveloped uterus behind the bladder; and a Fallopian tube also on the right side, but no gonad. The conditions found are shown in the

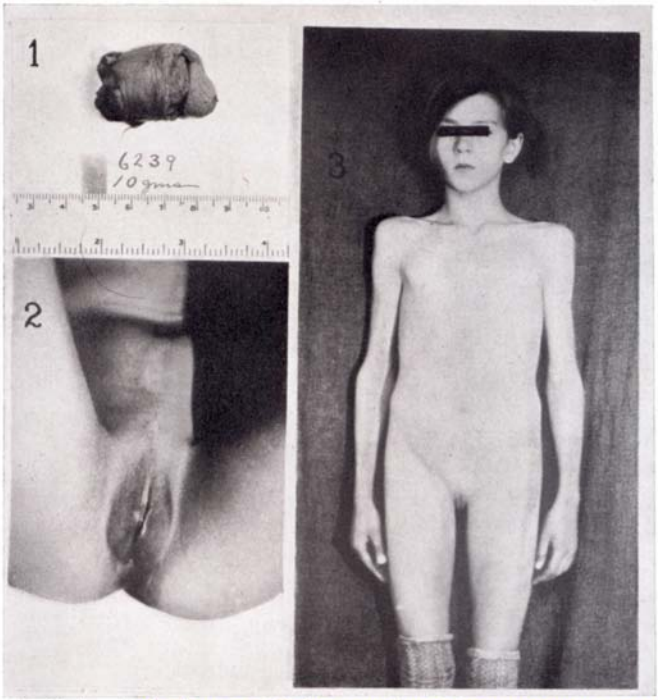


FIG. 63. Case 5. Age 9 years. *1*, Phallus supposed to be hypertrophied clitoris; *2* and *3*, condition after amputation. Note undeveloped labia majora. BUI 14127.

accompanying illustrations (fig. 65) by Mr. Didusch. Low down behind the bladder was a uterus about 1½ cm. wide, perhaps 1 cm. thick, and Fallopian tubes, which extended outward and backward (fig. 65, *2*). On the right side there was a scar (previous removal of the supposed ovary; found microscopically to be a gland). On the left side the tube ran backward, ended in a fimbriated end and partly encircled an ovoid body about 4 cm. long, 2½ cm. wide

and 1½ cm. thick, which was covered by smooth mucous membrane, rather firm, with no evidence of ovulation, which looked like a testicle (fig. 65, *3*). Posterior to this was a mesentery in which the vas deferens could be palpated for a short distance, and then disappeared in the deep tissues at the pelvic brim. This could not be followed downwards toward the urethra nor upwards.

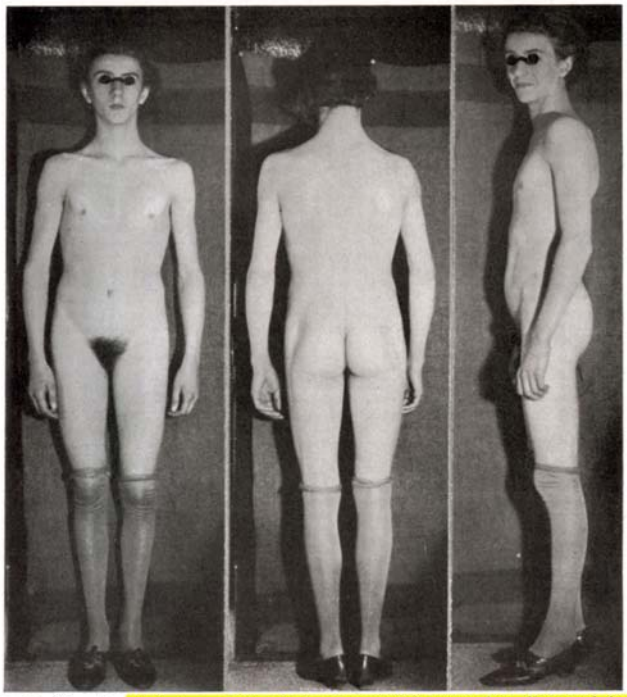


FIG. 64. Case 5. Patient, aged 15, raised as boy until 7 years; then diagnosed female. Phallus amputated; put in girl's clothes. At age of 16, operation for inguinal hernia, supposed ovary found to be testicle. Patient put back in male attire. BUI 14127.

No epididymis could be made out. The tip of the sex gland was excised and showed normal looking testicular tissue (fig. 65, *4*). After a long discussion, it was decided that, as the penis had been excised 6 years before, it would be best to excise the testicle with as much as possible of its mesentery containing the supposed vas deferens, and also a large part of the Fallopian tube. This was accordingly done (fig. 65, *5*). The peritoneal surfaces were then drawn

Baltimore 1937: Haphazard Decisions, more "Trophy Shots", Step by Step "Genital Corrections"

Hugh Hampton Young (1870-1945), "The Father of American Urology", also pioneered Intersex Genital Mutilations at the Johns Hopkins University Hospital in Baltimore – a fact nowadays often "neglected" in official hagiographies, despite that Young's disturbing textbook *"Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases"* was considered a breakthrough by his colleagues and was received globally. It saw two updated revisions, edited by Young's successors Howard W. Jones and William Wallace Scott, in 1958 and 1971 under the slightly modified title *"Hermaphroditism, Genital Anomalies, and Related Endocrine Disorders"*, and still contained many of Young's original step by step illustrated tutorials e.g. of *"Plastic operations to construct a vagina and amputate hypertrophied clitoris"*, or how to otherwise freely "cut up and re-assemble" so called *"Genital Abnormalities."* Also the Fig. 64 above right showing the tragically mutilated young person "Case 5 / BUI 14127" appeared again in Jones' and Scott's editions, although erroneously attributed to another "Case." For the 1958 edition, Young's colleague at Johns Hopkins and the "inventor" of systematic cosmetic genital surgeries on children, Lawson Wilkins, contributed a foreword, praising Young's original 1937 edition as a *"classic."*

Source: Hugh Hampton Young: *Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases*. Baltimore, 1937, p. 88-89.

Se manifesteront-elles dans le sens féminin : on peut alors se demander si des érections survenant dans la verge enlisée ne seront pas cause de gêne, peut-être même de douleur. Il sera toujours temps, à ce moment, d'amputer en totalité le membre à forme virile, si la femme avertie ne tient pas à conserver la sensibilité balanique.

Mais au moins, chez la fillette impubère que nous considérons, l'avenir n'est pas irrémédiablement orienté.

Ceci dit, nous apporterons nos observations personnelles concernant des fillettes à grande verge.

Fig. 56. — Cecilia M... (observation XII). (Alberto Lagos Garcia.)

Observation personnelle XII. — Bilan féminin après laparotomie. Amputation du clitoris. — Le Dr Alberto Lagos Garcia, frère du regretté chirurgien que nous avons si souvent cité, nous a envoyé en espagnol l'observation que nous résumons ici.

Cécilia M... est une fillette de trois ans (fig. 56). Clitoris de 2 centimètres (fig. 57), avec un orifice unique ouvert au-dessous de lui. Aucune glande n'est perceptible dans les bourrelets génitaux.

Laparotomie exploratrice : utérus atrophique, deux ovaires et deux trompes.

On enlève l'ovaire gauche pour examen histologique ; le laboratoire a répondu : ovaire.

Six mois après, incision qui sépare les deux bourrelets coalescents. Grâce à elle, on découvre deux conduits distincts, un antérieur, l'urètre, et un postérieur, qui est un vagin de 5 centimètres de profondeur et qui admet une sonde. Les bords de l'incision sont soigneusement ourlés.

Résection partielle du clitoris hypertrophique (fig. 58). Suites très simples. Il faudra procéder à des dilatations de son vagin.

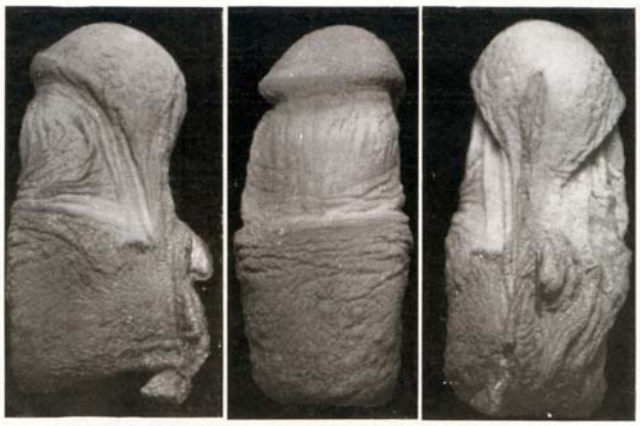


Fig. 93. — Le clitoris de Marguerite, après amputation (observation XX).

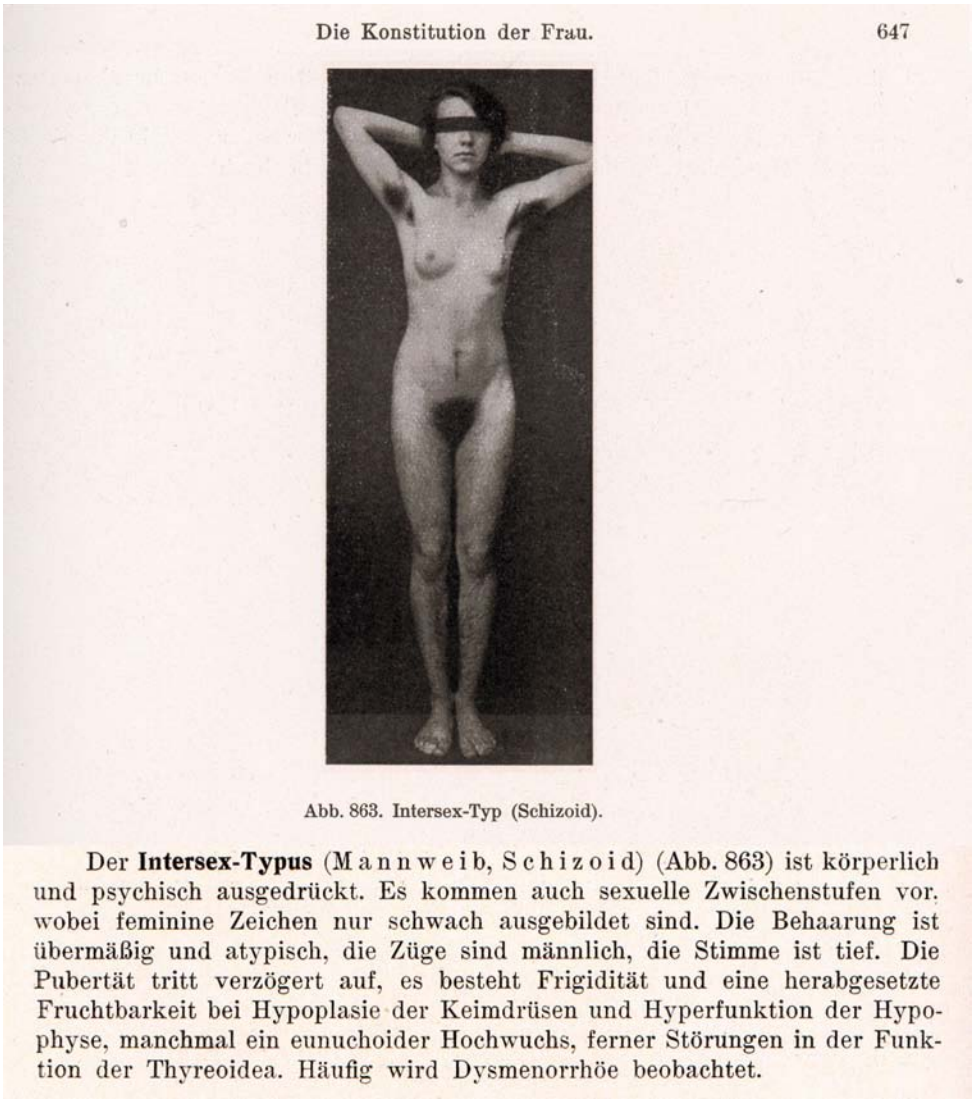
Fig. 94. — Aspect de la région génitale de Marguerite un mois après la dernière opération (observation XX).

Observation personnelle XXI. — Organes a forme masculine. Fonctions féminines. Ablation de la verge et des glandes. — Hortense F... est née le 26 décembre 1907, à Bathincourt (Belgique) ; elle a donc trente ans. Déclarée fille à sa naissance.

Paris 1939: "Embarrassing Erections", yet more "Trophy Shots", and even younger Children submitted to Cosmetic Genital Surgeries

Louis Ombrédanne (1871-1956) set the standard for "Hypospadias Repairs" a.k.a. "masculinising corrections" for more than 50 years, and even more so for medical musings on allegedly *"embarrassing and maybe even painful erections"* of *"enlarged clitorises"* (note how he's asking himself, NOT his patients), and was a teacher of Swiss paediatric surgeon Max Grob (Zurich University Children's Hospital). Ombrédanne's *"Hermaphrodites and Surgery"* drew heavily on Carlos Lagos García, as well as featuring a *"personal observation"* by García's Brother Alberto Lagos García involving a *"partial resection of the hypertrophied clitoris"* in combination with *"continued vaginal dilatations"* on a *"girl aged thee years"* (p. 248), and was received internationally from Zurich to Baltimore and beyond.

Source: Louis Ombrédanne: *Les Hermaphrodites et la Chirurgie.* Paris, 1939, p. 248, 284.



Die Konstitution der Frau. 647

Abb. 863. Intersex-Typ (Schizoid).

Der **Intersex-Typus** (Mannweib, Schizoid) (Abb. 863) ist körperlich und psychisch ausgedrückt. Es kommen auch sexuelle Zwischenstufen vor, wobei feminine Zeichen nur schwach ausgebildet sind. Die Behaarung ist übermäßig und atypisch, die Züge sind männlich, die Stimme ist tief. Die Pubertät tritt verzögert auf, es besteht Frigidität und eine herabgesetzte Fruchtbarkeit bei Hypoplasie der Keimdrüsen und Hyperfunktion der Hypophyse, manchmal ein eunuchoider Hochwuchs, ferner Störungen in der Funktion der Thyreoidea. Häufig wird Dysmenorrhöe beobachtet.

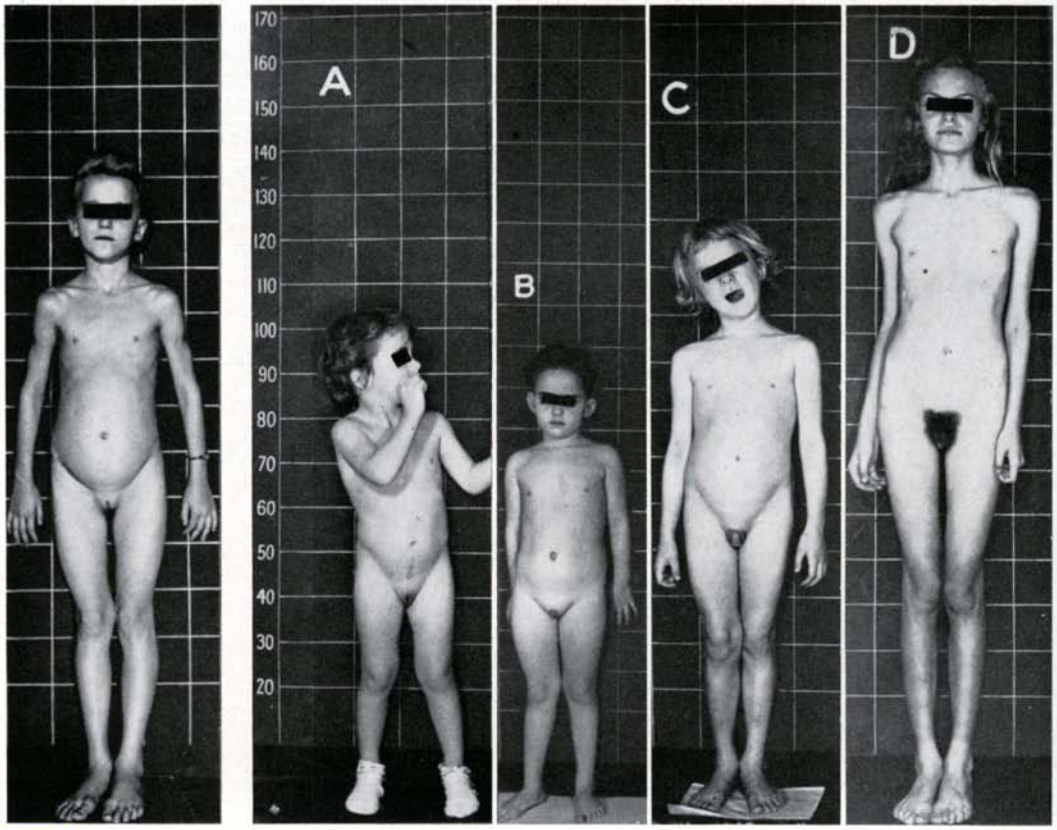
Wilhelm Weibel: *Lehrbuch der Frauenheilkunde*, Berlin/Wien 1944

1916–1950s: "Intersexuality = Bastardisation" caused by "Racial Mixing"; Racist Diagnosis "Intersexual Constitution"

Geneticist Richard Goldschmidt (1878–1958), before serving as director at the "Kaiser-Wilhelm-Institut für Biologie" in Berlin, coined the terms *"Intersex"* and *"Intersexuality"* when internationally publicising his experiments of crossbreeding *"different geographic races"* of gypsy moths during a stay in the USA (first in English, later in German), claiming to be able to produce *"hermaphroditic"* a.k.a. *"intersex"* specimens of any grade and shape at will, and thereafter extrapolating his findings to humans. Of Jewish descent, Goldschmidt was forced to leave the "Kaiser-Wilhelm-Institute" in 1936 and emigrated to the United States. Despite Goldschmidt's downplaying the "racial" background of his findings since the early 1930's and later renouncing the underlying genetic theories altogether, the term "Intersex" and its racial implications prevailed. The derived diagnosis *"Intersexual Constitution"* (published by Austrian Gynaecologist Paul Mathes and **Swiss Gynaecologist Hans Guggisberg** in 1924), allegedly most frequent amongst "Jews," and associated with "biological inferiority", mental illnesses (see above *"schizoid"*), *"hypertrophied clitoris,"* and a strict verdict *"not fit for marriage,"* was particularly popular among prominent eugenicists and Nazi doctors, amongst others Fritz Lenz, Lothar Gottlieb Tirala, Robert Stigler, Wilhelm Weibel, Walther Stoeckel, and kept being used in publications years after World War II.

Sources: Wilhelm Weibel: Lehrbuch der Frauenheilkunde, 7th ed., Berlin/Wien 1944 p. 647 (photo), 648 (text).
Richard Goldschmidt: "Die biologischen Grundlagen der konträren Sexualität und des Hermaphroditismus beim Menschen", in: Archiv für Rassen- und Gesellschaftsbiologie 12, 1916.
Paul Mathes, Hans Guggisberg: "Die Konstitutionstypen des Weibes, insbesondere der intersexuelle Typus", in: Josef Halban, Ludwig Seitz: Biologie und Pathologie des Weibes. Bd.3, 1924.
Helga Satzinger: Rasse, Gene und Geschlecht. Zur Konstituierung zentraler biologischer Begriffe bei Richard Goldschmidt und Fritz Lenz, 1916–1936. Research Program "History of the Kaiser Wilhelm Society in the National Socialist Era", Ergebnisse 15, 2004.

CONGENITAL ADRENAL HYPERPLASIA—FEMALE PSEUDOHERMAPHRODITISM



Normal age 9 yrs.	Age 2 yrs. 11 mos. Ht. age 4–3 Bone age 6–0 17–KS: 2 yrs. 9–12 mg/d. 3 yrs. 15–25 mg/d. Pubic hair appeared at 20 mos.	Age 4 yrs., 2 mos. Ht. age 5–0 Bone age 7–6 17–KS: 16–22 mg/d. No sexual hair.	Age 4 yrs., 5 mos. Ht. age 7–0 Bone age 11–0 17–KS: 17–22 mg/d. Pubic hair at 2¾ yrs.	Age 9 yrs. Ht. age 14–6 Bone age 15–0 17–KS: 14–22 mg/d.
	Small urogenital sinus. Siblings: 1. ♀ pseudohermaphrodite. 2. Female—normal. 3. ♂—macrogenitosomia 4. ♂—macrogenitosomia Clitoris amputated. Raised as girl. (H.L.H. A59183)	Urogenital sinus non-communicating. Raised as boy. Plastic operations on hypospadic penis and scrotum. (H.L.H. A52394)	Small urogenital sinus. Raised as girl. Clitoris excised. (H.L.H. A47344)	Pubic hair at 4½ yrs. Axillary hair at 8 yrs. Large urogenital sinus. Raised as girl. Clitoris excised. (H.L.H. A26544)

Patients all had enlarged phallus, urogenital sinus and absent vagina at birth. Patient B had been mistaken for a boy and raised as such.

NOTE the excessive somatic growth, advanced skeletal development, high 17-ketosteroid output and early appearance of sexual hair. Patients were well developed muscularly, but did not seem especially "masculine."

Baltimore 1950: From Experimentation to Medical Extermination

Lawson Wilkins (1894-1963), "The Father of Pediatric Endocrinology", and teacher of the famous Swiss paediatric endocrinologist Andrea Prader in 1950, was also the "inventor" of systematic cosmetic genital surgeries on children. As his monograph illustrates, in 1950 at Johns Hopkins in Baltimore, any child diagnosed "not normal" was submitted to drastic "Genital Corrections", either "feminising" or "masculinising". Often John Money gets erroneously credited as having "invented" the systematic mutilations, however, it was Wilkins (and Prader) who started systematic surgeries; Money "only" delivered a "scientific rationale" five years after the fact.

Source: Lawson Wilkins: *The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence.* Springfield, 1950. Alison Redick: *American History XY: The Medical Treatment of Intersex, 1916-1955*, Dissertation 2004

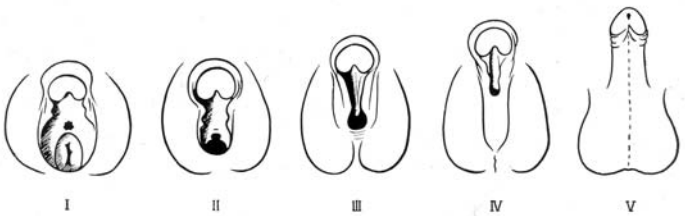


Abb. 673. Formen des äußern Genitale bei Mädchen mit adrenogenitalem Syndrom infolge angeborener NNR-Hyperplasie (nach Prader). Typ I: nur Clitoris vergrößert. Typ II: Vestibulum trichterförmig verengt, Urethral- und Vaginalöffnung getrennt, aber dicht übereinanderliegend. Typ III: Sinus urogenitalis mit etwa bleistiftdicker Mündung. Typ IV: Urethraartige Mündung des Sinus urogenitalis an der Basis der vergrößerten Clitoris (ähnlich einer Hypospadia peno-scrotalis beim Knaben). Typ V: Mündung des Sinus urogenitalis im Bereiche der Glans (selten).

als bei der echten Pubertas praecox. Im Röntgenbild läßt sich nach retroperitonealer Luftfüllung die vergrößerte Nebenniere meist gut erkennen (vgl. Abb. 668 und 669).

Äußere Genitalform: Für den Chirurgen sind die Veränderungen des äußern Genitale in therapeutischer und differentialdiagnostischer Hinsicht von besonderer Bedeutung. Es ist anzunehmen, daß der Grad der Vermännlichung der weiblichen Geschlechtsorgane beim adrenogenitalen Syndrom vom Zeitpunkt, in welchem die fetale Überproduktion androgener Hormone einsetzt, und von ihrer Intensität abhängt. Nach Prader, der 19 Fälle unserer Klinik zusammengestellt hat, lassen sich 5 verschiedene Typen auseinanderhalten (Abb. 673), die fließende Übergänge vom normalen weiblichen zum normalen männlichen äußern Genitale darstellen. Allen gemeinsam ist eine mehr oder weniger stark vergrößerte, erigierbare Clitoris. Diese ist dorsal und lateral von einem wohlentwickelten Praeputium umgeben. Auf der Ventralseite der Clitoris, die oft nach unten gekrümmt ist, findet sich eine rinnenförmige Eindellung, die zur Urogenitalöffnung hinzieht. Die Labia majora, die immer ausgebildet sind, zeigen eine scrotumartig gefältelte und pigmentierte Haut. Sie sind in ihren hintern Abschnitten oft miteinander zu einer Rhaphe verwachsen. Bei allen Formen fällt die abnorme Länge des Dammes auf.

Beim seltenen Typus I ist nur die Clitoris vergrößert, die Vulva zeigt sonst normale Verhältnisse. Diese Fälle werden deshalb oft im Säuglingsalter übersehen. Beim Typus II ist das Vestibulum trichterförmig verengt (Abb. 674). In seinem Grunde findet man nach Spreizung der Labien die Urethra- und Vaginalöffnung, die dicht übereinander liegen. Beim Typus III ist an der Basis der vergrößerten Clitoris nur eine einzige Uro-

Abb. 674. Äußeres Genitale bei Mädchen mit angeborenem adrenogenitalem Syndrom: Typ II.

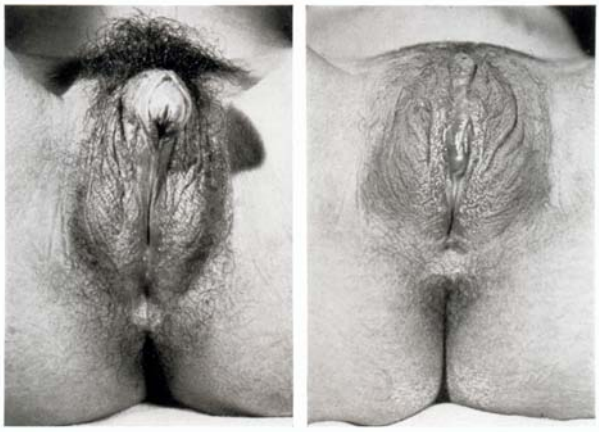


Abb. 679. Penisartige Vergrößerung der Clitoris bei angeborenem adrenogenitalem Syndrom. (7jähriges Mädchen.) a) Vor, b) nach Exstirpation der Clitoris.

Operative Korrektur des äußern Genitale: Beim Pseudohermaphroditismus femininus drängt sich eine operative Korrektur des äußern Genitale, d. h. die Entfernung der vergrößerten Clitoris und die Freilegung der Vaginalöffnung bei den beschriebenen Formentypen II–IV, auf. Die Amputation der Clitoris, die durch ihre Größe und Erektionen störend wirkt und diesen Mädchen beim Umkleiden, Baden usw. Verlegenheiten bereiten kann, ist sicher gerechtfertigt und wird nicht nur von den meisten Eltern, sondern – wie wir selbst erfahren haben – auch von solchen Patienten im Erwachsenenalter dringend gefordert. Die Clitorisamputation und die Freilegung der Vagina können in der gleichen Sitzung durchgeführt werden.

Technik: Die Haut des Clitorisschaftes wird unmittelbar vor der Symphyse zirkulär umschnitten. Nach Freilegung der Corpora cavernosa werden diese an der Symphyse mit einem Kocher abgeklemmt und distal davon quer durchtrennt. Wir belassen gewöhnlich einen ganz kurzen Clitorisstumpf, der zur Blutstillung mit einer Durchstechungsligatur versorgt und mit der überschüssigen Clitorishaut gedeckt wird (Abb. 679).

Zur Freilegung der Vagina wird zunächst eine Hohlsonde in die Mündung des Sinus urogenitalis eingeführt und in der Richtung des Dammes vorgeschoben (Abb. 677c). Hierauf ist die Haut über der Sonde so weit analwärts zu durchtrennen, bis der Introitus vaginae im hintern Wundwinkel allseitig frei liegt. Er schließt gewöhnlich unmittelbar an das Orificium externum der Urethra an und besitzt ein kleines Hymen. Die Schleimhautränder des eröffneten Sinus urogenitalis werden seitlich mit den Hauträndern, die zur Ausweitung des Vestibulum etwas reseziert werden, durch einige Knopfnähte vereinigt. Auf diese Weise gelingt es, wenn auch nicht normale anatomische Verhältnisse, so doch wenigstens ein ziemlich weites, trichterförmiges Vestibulum herzustellen (Abb. 676c).

Zurich 1957: Prader Scales, "Surely Justified" Clitoris Amputations, and even more "Embarrassing" Psychosocial Indications

Swiss paediatric surgeon Max Grob (1901-1976), trained in Paris by Ombrédanne, served as director of the Zurich University Children's Hospital's paediatric surgery unit 1939-1971, and in 1957 published his influential *"Textbook on Paediatric Surgery"* with contributing authors Margrit Stockmann (Luzern), and Marcel Bettex, then consulting paediatric surgeon in Zurich. Grob's *"Textbook"*, indiscriminatingly hailed by the Zurich University Children's Hospital till this day, stressed the *"special importance"* for surgeons of Andrea Prader's newly developed systematic classification of *"genital variations"* ("Prader Scales"). In its section on *"surgical correction of the external genital"* of children with 46,XX CAH (*"[T]he removal of the enlarged clitoris [...] suggests itself. [...] Technique: [...] Usually we leave a very short clitoris stump"*), Grob proclaimed the psychosocial justifications for cosmetic genital surgery on intersex children still prevalent today *"The amputation of the clitoris, which may appear bothersome due to its size and erections, and may lead to embarrassment for these girls in the changing room or while swimming, is surely justified."*) Grob became the founder and first president of the Swiss Society for Paediatric Surgery, and honorary member of the German, Austrian, British and U.S. societies. Grob's recommendations in the "Textbook" (*"surgical correction"* in case of Prader Stages II–V, arguably devised at least with input by Prader himself), represented the global standard until the "Chicago DSD Consensus Conference" in 2005 (changing it to III–V).

Source: Max Grob: *Lehrbuch der Kinderchirurgie*, with Margrit Stockmann and Marcel Bettex, Stuttgart, 1957, p. 583, 587.

Plastic Operations on the Genitalia

The surgical correction (see p. 474 *et seq.*) of the masculinized genitalia of girls with the congenital adrenogenital syndrome is desirable for several reasons: (1) in order to make the vagina a functional organ; (2) in order to prevent troublesome erections of the clitoris; (3) in order to prevent psychological conflicts, which are particularly liable to occur in girls with male characteristics.

Whenever possible surgery should be carried out before the children reach four years of age. In mild cases removal of the clitoris is all that is necessary. The clitoris should be *totally* removed and not just amputated, otherwise troublesome erections of the remaining stump may occur. As Hampson (1956) was able to show in a large series of women subjected to operation, removal of the clitoris does not interfere with the ability to achieve orgasm. If masculinization of the genitalia is more extreme further surgery may be required to open and enlarge the urogenital sinus.

Plastische Operationen an den Genitalien

Die operative Korrektur (s. S. 476 ff.) der vermännlichten Genitalien beim kongenitalen adrenogenitalen Syndrom des Mädchens ist aus mehreren Gründen indiziert, 1. um eine regelrechte Funktion der Vagina zu ermöglichen, 2. um die unangenehmen Klitoriserektionen zu verhindern, 3. um seelische Konflikte zu vermeiden, die den Mädchen aus dem Vorhandensein männlicher Attribute erwachsen können.

Nach Möglichkeit soll die Operation schon vor dem vierten Lebensjahr durchgeführt werden. Bei leichteren Fällen ist lediglich die Entfernung der Klitoris erforderlich. Das Organ soll dabei *exstirpiert* und nicht amputiert werden, da sich sonst lästige Erektionen des zurückgebliebenen Stumpfes einstellen können. Wie Hampson (1956) bei einer größeren Reihe operierter Frauen festgestellt hat, leidet die Orgasmusfähigkeit durch die Klitorisentfernung nicht. Ist das Genitale stärker vermännlicht, so muß darüberhinaus die Eröffnung des Sinus urogenitalis vorgenommen werden.

Source:
Jürgen R. Bierich: "The Adrenogenital Syndrome"
In: Overzier (ed.), "Intersexuality" (New York 1962, at 379) / "Intersexualität" (Stuttgart1961, at 387)

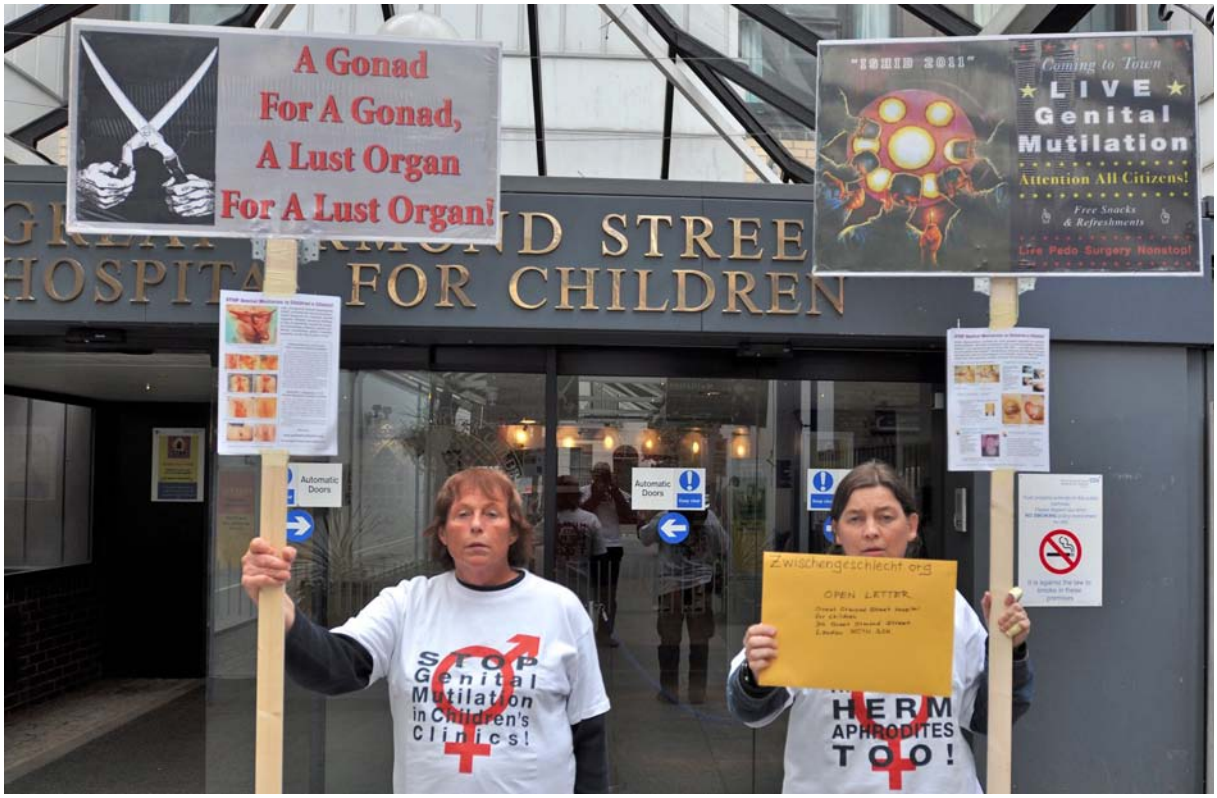
1956–1993: "The Clitoris is not essential for normal Coitus." "No Evidence of Loss of Orgasm after Clitoris Amputation."

The number of "Intersex-Experts" and involved clinicians claiming that amputating "enlarged" clitorises was a rational and beneficent thing to do is legion – e.g. Joan Hampson (1956), John Money (1956, 1971), Max Grob (1957, see above), Jürgen Bierich (1963, 1971), Robert E. Gross (1966), Marcel Bettex (1957, see above).
Even in 1993, surgeon Milton Edgerton claimed, unchallenged by his peers: *"Not one has complained of loss of sensation, even when the entire clitoris was removed."*

Since then: "Surgery is better now ..."

In 1993, Cheryl Chase founded the first Intersex Lobby Group ISNA by declaring: *"Unfortunately the surgery is immensely destructive of sexual sensation and of the sense of bodily integrity."* Since then, the mutilators just changed their mantra to *"Surgery is better now"* – again without evidence, but despite survivors deploring decrease or total loss of sexual sensation, painful scars and frequent complications also with the "modern improved techniques", and studies again and again corroborating their grievances.

Sources: See 2014 CRC NGO Report, p. 57–59, online:
http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf



StopIGM.org / Zwischengeschlecht.org

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