v1.5

Intersex Genital Mutilations

Human Rights Violations Of Persons With Variations Of Sex Anatomy

NGO Report
for List of Issues Prior to Reporting (LoIPR)
for the 4th Periodic Report of Switzerland
on the International Covenant on Civil and Political Rights (CCPR)

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Contents

Introduction

People born with intersex conditions, or variations of sex anatomy, face a wide range of violations to their rights to bodily integrity and individual autonomy, as well as to their sexual and reproductive rights. While intersex people may face several problems, in the "developed world" the most pressing are the ongoing Intersex Genital Mutilations (IGMs), which present a distinct and unique issue constituting significant human rights violations. Swiss Universities, State and Private Clinics keep performing IGMs, including non-consensual, irreversible, unnecessary cosmetic genital surgeries, sterilising procedures, human experimentation, medical display and photography of the genitals, forced excessive genital examinations, and other unnecessary harmful medical treatments on intersex infants and adolescents – treatments described by persons concerned as genital mutilations, and as a form of child sexual abuse.

This NGO Report submitted to the Human Rights Committee aims to demonstrate how the current medical treatment of intersex persons and especially intersex children in Switzerland constitutes a breach of Switzerland's obligations under the International Covenant on Civil and Political Rights.

IGMs cause lifelong serious physical and psychological complications, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, serious problems with passing urine, increased sexual anxieties, less sexual activity, dissatisfaction with functional and aesthetic results, 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.

IGMs have repeatedly been recognised by UN and other human rights and ethics bodies as serious human rights violations constituting at least cruel, inhumane or degrading treatment, or even torture.

Swiss Universities and State Children's Hospitals have been at the heart of the global implementation of these systematic human rights violations, and the Swiss State not only does nothing to prevent this continued abuse, but in fact colludes to keep it hidden from public view and legal scrutiny. In addition, the Swiss State keeps providing public funds for these treatments, as well as for related "medical research" by the perpetrators.

Thus, Switzerland stands in violation of its duty to protect intersex persons under the International Covenant on Civil and Political Rights (Art. 7). What's more, intersex children are singled out for these unnecessary experimental treatments on the basis of their "indeterminate sex" (Art. 2, 3, 26, 27).

This report, drawing heavily on the same Rapporteurs's 2014 CRC NGO Report,[1] has been prepared by the Swiss NGO *Zwischengeschlecht.org* in collaboration with Swiss peer support groups *Intersex.ch* and *SI Selbsthilfe Intersexualität*:
Zwischengeschlecht.org, founded in 2007, is an international Human Rights NGO based in Switzerland, lead by intersex persons, their partners, families and friends, and works to represent the interests of intersex people and their relatives, raise awareness, and fight IGMs and other human rights violations perpetrated on intersex people, according to their motto, *"Human Rights for Hermaphrodites, too!"*[2]

1 Zwischengeschlecht.org, Intersex.ch, SI Selbsthilfe Intersexualität: NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC). Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

2 http://zwischengeschlecht.org/, English pages: http://StopIGM.org/

Intersex.ch is a Swiss intersex peer support group founded in 2005.[3]
The Verein *SI Selbsthilfe Intersexualität* is a Swiss peer support group for parents of intersex children founded in 2003.[4]

Intersex Genital Mutilations and other human rights violations of persons with variations of sex anatomy are a special and emerging human rights issue, unfortunately still often neglected by human rights bodies concerned, mostly due to lack of access to comprehensive information. However, to assess the current practice at national level, it is crucial to gain some general knowledge of the most pressing human rights violations faced by intersex people in Switzerland as well as all over the "developed world." Therefore, this NGO report also includes some summarised general information on intersex and IGMs. For further reference, the Rapporteurs would like to refer the Committee to the thematic Supplements "IGM – Historical Overview" and "The 17 Most Common Form of IGMs" included in our 2014 CRC NGO Report.[5]

The Rapporteurs are aware that IGMs are a global issue, which can't be solved on a national level alone. However, due to its pivotal role in internationally establishing systematic unnecessary intersex surgeries on children, Switzerland would be a most appropriate place to begin with.

3 http://intersex.ch/
4 http://si-global.ch/
5 Supplement 1: "IGM – Historical Overview", p. 49–62
Supplement 2: "The 17 Most Common Forms of IGMs", p. 48–76
Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

A. What is Intersex?

1. Variations of Sex Anatomy

Intersex persons, also known as hermaphrodites, or persons with Differences of Sex Development (DSD), are people born with "atypical" sex and reproductive anatomies, 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 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. 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 and/or other variations of sex anatomy. (For more information and references on genital development and appearance, see our 2014 CRC NGO Report (A 2–3, p. 8–10.) [6]

2. How common is Intersex?

Swiss hospitals, government agencies and health assurances, as well as the Swiss federal invalidity assurance (Invalidenversicherung IV) covering intersex surgeries on children until the age of 20,[7] **refuse to disclose statistics and costs**, there are no exact figures or statistics

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

7 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.

available (for contradicting figures given by Swiss Cantonal, Federal Governments, as well as Clinics and doctors in **Zurich**, **Luzern**, **Bern, Basel, St. Gallen,** see Annexe 2 "Swiss Federal, Cantonal Government Clinics on IGMs (2009–2012)" in our 2014 CRC NGO Report, p. 43–47).[8] Also, the definition of intersex is often arbitrarily changed by doctors and government agencies in order to get favourable (i.e. lower) figures. Therefore, 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,[9] and

b) 1:4500 or less[10] 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%"*.[11]

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".**[12]

20/2012, at 15–17, http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHzLpZeg7t,lnp6I0NTU042l2Z6ln1ad1IZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--

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

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

10 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

11 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.

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

B. IGMs / Non-Consensual, Unnecessary Medical Interventions

1. What are Intersex Genital Mutilations (IGMs)?

Intersex Genital Mutilations include non-consensual,[13] medically unnecessary,[14 15] irreversible,[16] cosmetic[17] 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,[18 19] but justified by *"psychosocial indications [...] shaped by the clinician's own values"*,[20] the latter informed by societal and cultural norms and beliefs,[21 22] enabling clinicians to withhold crucial information from both patients and parents,[23 24] and to submit healthy intersex children to risky and harmful invasive procedures *"simply because their bodies did not fit social norms"*.[25]

13 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 actually *can't* legally consent to medically unnecessary cosmetic genital surgeries on their healthy children, see **p. 22, Article 3: "Best Interest"**.

14 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

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

16 *"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

17 ***"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

18 *"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

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

20 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.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHzLpZeg7t,lnp6I0NTU042l2Z6ln1ad1IZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--

21 ibid., at 18 and 15.

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

23 *"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

24 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

25 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**.[26] 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.[27] [28]

In addition to the usual risks of anaesthesia and surgery in infancy, IGMs 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.[29] [30]

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**.[31] For a more comprehensive list and sources, see our 2014 CRC NGO Report, p. 63-76. [32]

a) Clitoris Amputation/"Reduction", "Vaginoplasty", Forced Vaginal Dilatation

"I can still remember, how it once felt differently between my legs."[33]

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) attracted mounting criticism within the medical community and were mostly abandoned between 1900 and 1945, **amputations of "enlarged clitorises" took a sharp rise after 1950**, and in the 1960s became the predominant

26 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

27 ibid., at 3

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

29 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 2–7, http://www.aph.gov.au/DocumentStore.ashx?id=432c5135-4336-472e-bb24-59c89eb4a643

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

31 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

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

33 2014 CRC NGO Report, Case No. 3, p. 36–38. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

medical standard for "ambiguous" newborns allover the "developed world," according to the infamous surgeon's motto, *"you can dig a hole, but you can't build a pole"*, i.e. it's surgically possible to remove an "enlarged clitoris" (i.e. longer than 9 mm) or an "inadequately small penis" (i.e. shorter than 2.5 cm), as well as to enlarge an existing "insufficient vagina", or create an artificial "neo vagina", but it's surgically not possible to actually build an "adequate penis".

For four decades, doctors again and again claimed early clitoris amputation on intersex children would ***not* interfere with orgasmic function**.[34] Only in the 1980s–1990s, intersex clitoris amputations were eventually replaced by "more modern" techniques a.k.a. **"clitoral reduction"** **(see p. 28)**, 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. 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!"*[35]

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

Switzerland has been crucial for the introduction of systematic early clitoris amputations and "vaginoplasty" on intersex children on a global scale.[36] Clitoris amputations justified by psychosocial indications were taught in Swiss university paediatric surgery courses as a suitable *"therapy"* for intersex children diagnosed with *"hypertrophic clitoris"* until at least 1975.[37] Despite recent public denials by Swiss doctors, hospitals, and health departments, **systematic early "clitoris reductions"** and **"vaginoplasty"** performed on intersex infants "too young to remember afterwards", and justified by **psychosocial indications**, are still considered imperative in most **Swiss University Children's Clinics**.

b) Hypospadias "Repair"

"My operated genital is extremely touch-sensitive and hurts very much when I'm aroused."[38]

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 **(see p. 27)**.

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 **Swiss *"pilot study"***, surgery is *"intended to change the anato-*

34 see 2014 CRC NGO Report, p. 57–58. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

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

36 see 2014 CRC NGO Report, p. 54, 56. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

37 see 2014 CRC NGO Report, p. 87. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

38 2014 CRC NGO Report, Case No. 1, p. 32–33. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

my such that the penis looks normal."[39] The current AWMF guidelines with **Swiss participation** explicitly include *"aestetical-psychological reasons"*.[40]

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!), [41] while in medical publications on hypospadias, *"[d]ocumentation on complication rates has declined in the last 10 years"*. [42]

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.

Switzerland was leading in introducing hypospadias surgeries in German language European countries after World War II.[43] 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 also in Switzerland. In **Swiss University Children's Hospitals**, systematic hypospadias "repair" within the first 18 months of life is still considered imperative for children concerned and raised as boys.

c) Castrations / "Gonadectomies" / Hysterectomies / (Secondary) Sterilisation

"At 2 1/2 months they castrated me, and threw my healthy testicles in the garbage bin."[44]

Intersex children are frequently subjected to treatments that **terminate or permanently reduce their reproductive capacity**. While some intersex people are born infertile, and some retain their fertility after medical treatment, many undergo **early removal** of viable (and **hormone producing**) gonads (e.g. testes, ovaries, ovotestes) or other reproductive organs (e.g. uterus) **(see p. 29)**, leaving them with *"permanent, irreversible infertility and severe mental suffering"*.[45] When unnecessary sterilising procedures 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.** [46] What's more, also in **Switzerland**, persons concerned often have to **pay themselves for adequate Replacement Hormones**. Even some doctors have been criticising unnecessary intersex gonadectomies for decades,

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39 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

40 Deutsche Gesellschaft für Kinderchirurgie (2002), AWMF-Leitlinie 006/026 Hypospadie, http://www.awmf.org/uploads/tx_szleitlinien/006-026.pdf

41 see 2014 CRC NGO Report, p. 65, 77. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

42 see 2014 CRC NGO Report, p. 66. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

43 E.g. Ernst Bilke, born 1958 in South Germany, was sent to Basel for paediatric hypospadias "repair", because the local German doctors refused to do it, wanting to make him into a girl instead, see Ulla Fröhling (2003), Leben zwischen den Geschlechtern, at 90–105

44 2014 CRC NGO Report, Case No. 2, p. 33–36. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

45 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

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

e.g. renowned Swiss endocrinologist G. A. Hauser (of MRKH fame), *"The castration of patients without a tumour converts symptomless individuals into* ***invalids suffering from all the unpleasant consequences of castration.****"*[47]

For almost two decades, persons concerned have protested unnecessary gonadectomies and other irreversible, potentially 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, and urged to remove gonads only in known limited cases with lack of hormone production and actual high cancer risk (e.g. certain forms of 46,XY Gonadal Dysgenesis). 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, [48] but which obviously persist), namely the infamous premise, ***"We don't want to breed mutants."***

Nonetheless, and despite recent discussions in medical circles, **unnecessary gonadectomies** and other sterilising treatments persist in most **Swiss University Children's Hospitals**. Only a while ago, in a Swiss Cantonal Children's Hospital, 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?"***

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 from Switzerland**. [49]

Nonetheless, in **Switzerland** it's still paediatricians, endocrinologists and surgeons managing diagnostics and counselling of parents literally from *"day one."*[50] 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"*. [51]

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"*, [52] severely compounding shame, isolation and psychological trauma in the aftermath of IGMs.

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47 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)

48 see 2014 CRC NGO Report, p. 52. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

49 see 2014 CRC NGO Report, p. 71. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

50 e.g. Eastern Switzerland Children's Hospital St. Gallen (2014), Zwischen den Geschlechtern, slide 8, http://www.kispisg.ch/downloads_cms/09_vortrag_zwischen_den_geschlechtern_2.pdf

51 see 2014 CRC NGO Report, p. 72. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

52 see 2014 CRC NGO Report, p. 72. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

e) Other Unnecessary and Harmful Medical Interventions and Treatments

"The assistant called in some colleagues to inspect and to touch my genitals as well." [53]

Other harmful treatments include Forced Mastectomy,[54] Imposition of Hormones,[55] Forced Excessive Genital Exams, Medical Display and (Genital) Photography,[56] Human Experimentation,[57] Denial of Needed Health Care,[58] Prenatal "Therapy",[59] Selective (Late Term) Abortion,[60] Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses .[61]

3. How Common are Intersex Genital Mutilations?

Same as with intersex births (see above), Swiss Hospitals, Government Agencies and Health Assurances, as well as the **Swiss federal invalidity assurance** (**Invalidenversicherung IV**) covering intersex surgeries on children until the age of 20, **refuse to disclose statistics and costs**, as well as ignoring repeated calls for **independent data collection and monitoring**.

What's more, Swiss doctors, government and other institutions involved in IGMs, if questioned about statistics, are notorious for going to extreme lengths following internationally 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 (**Swiss Federal Government, Zurich**, **Luzern**, **Basel**,[62] or **b) flatly denying any occurrence or knowledge** of IGMs, 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 IGM (**Bern**).[63] Or, in the rare cases of studies actually "disclosing" numbers, yet another related tactic involves **c) manipulation of statistics**, e.g. the world's largest outcome study on 439 participants, with **Swiss participation**, the 2008 **"Netzwerk DSD"** intersex study, in official publications only gave an overall total figure of *"**almost 81%** of all participants had at least once surgery [...] most of them before entering school."*[64]

53 2014 CRC NGO Report, Case No. 3, p. 36–38. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

54 see 2014 CRC NGO Report, p. 7. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

55 see 2014 CRC NGO Report, p. 70. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

56 see 2014 CRC NGO Report, p. 73. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

57 see 2014 CRC NGO Report, p. 74. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

58 see 2014 CRC NGO Report, p. 75. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

59 see 2014 CRC NGO Report, p. 75. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

60 see 2014 CRC NGO Report, p. 76. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

61 see 2014 CRC NGO Report, p. 76. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

62 2014 CRC NGO Report, p. 43–47. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

63 2014 CRC NGO Report, p. 43–44. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

64 Eva Kleinemeier, Martina Jürgensen (2008), Erste Ergebnisse der Klinischen Evaluationsstudie

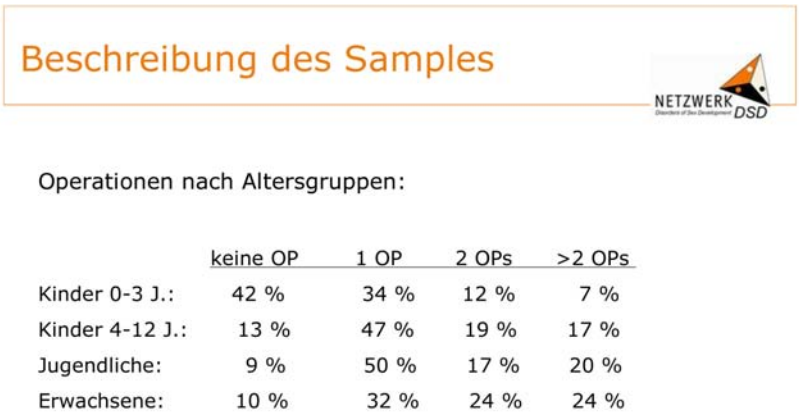

Figure 3 "Surgeries by Age Groups" (No Surgery, 1 Surgery, 2 Surgeries, >2 Surgeries, Children 0–3 Years, Children 4-12 Years, Adolescents, Adults)
Source: Martina Jürgensen: "Klinische Evaluationsstudie im Netzwerk DSD/Intersexualität: Zentrale Ergebnisse", Presentation 27.05.2009, Slide 6, http://kastrationsspital.ch/public/Corpus-delicti_27-5-09.pdf

However, the most significant numbers on intersex children submitted to IGMs available stem from a semi-official 2009 presentation of the same **"Netzwerk DSD"** intersex study with participation of **Swiss Cantonal Clinics** (**Bern** and **St. Gallen**),[65] revealing that, contrary to declarations by doctors as well as cantonal and federal governments,[66] in the most relevant **age groups of 4+ years, 87%–91%** have been submitted to IGMs 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, though especially with "hypospadias repair", **a dozen or more repeat surgeries** are not uncommon).

Considering about 82'000 live births annually in Switzerland, and using the estimate of 1:500–1:1000 children born with variations of sex anatomy (see above p. 7), this sums up to about **annually 82–164 intersex births**, and about **74–148 initial cosmetic genital surgeries on intersex children** in Switzerland.

In contrast, the **Swiss Federal Government** claims annually 1–2 intersex births on the national level, and on average 30 intersex children aged 0–20 years, as well as total estimate of 100–200 intersex people living in Switzerland.[67] The **Zurich University Children's Hospital** serving *"20-25% of the Swiss population"* claims on average 1 cosmetic genital surgery on children with variations of sex anatomy every year – while unofficially performing 1–2 "hypospadias corrections" *every week* alone.[68] The **Luzern Cantonal Children's Hospital** serving *"about 10% of the Swiss population"* also claims on average 1 cosmetic genital surgery on children with variations of sex anatomy every year – while its chief surgeon publicly boasts of 50 intersex surgeries in 30 years.[69] The **Bern University Children's Hospital "Insel"** claims zero surgeries annually on an estimated *"about 40 children with DSD born annually"* – while lead-

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im Netzwerk Störungen der Geschlechtsentwicklung/Intersexualität in Deutschland, Österreich und Schweiz, Januar 2005 bis Dezember 2007, at 16, http://www.netzwerk-dsd.uk-sh.de/fileadmin/documents/netzwerk/evalstudie/Bericht_Klinische_Evaluationsstudie.pdf

65 http://www.netzwerk-dsd.uk-sh.de/index.php?id=28

66 2014 CRC NGO Report, p. 43–47. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

67 2014 CRC NGO Report, p. 46. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

68 2014 CRC NGO Report, p. 43. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

69 2014 CRC NGO Report, p. 43. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

ing doctors publicly admit surgeries taking place.[70] The **University Children's Hospital of Basel** (**UKBB**) claims annually about 22 children born with variations of sex anatomy in the region, while only admitting to 1 genital surgery on intersex children *"in the more strict definition"* every 5 years.[71] And the **Eastern Switzerland Children's Hospital** claims *"less than one clitoral reduction plastic surgery annually (using the nerve-sparing method),"* again without disclosure of other cosmetic genital surgeries.[72] Conclusion, while all listed parties closely follow the established patterns of non-disclosure and denial, their differing claims don't add up by far.

What's more, though for Switzerland officially no current figures are available, internationally the **total number** of cosmetic genital surgeries performed on intersex children evidentially **is still rising**.[73] [74]

4. 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****"*, [75] and stressed the imminent need for **disinterested** research and analysis

Currently, millions of Euros are spent on "intersex research projects" involving **Swiss funding** [76] and/or **participation**,[77] as well as **Swiss Federal Government representation**.[78]

"DSD-Life" and **"DSDnet"**, two current examples, are **conducted by the perpetrators themselves**, e.g. in "DSDnet" paediatric endocrinologists,[79] and in "DSD-Life" paediatric endocrinologists and paediatric surgeons[80] taking the lead – exactly the professional groups responsible for IGMs in the first place. If other disciplines are included at all in the "multi-

70 2014 CRC NGO Report, p. 43. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

71 2014 CRC NGO Report, p. 44. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

72 2014 CRC NGO Report, p. 44. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

73 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

74 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, http://www.leggo.it/NEWS/ITALIA/boom_di_bimbi_con_sesso_quot_incerto_quot_a_roma_aumentano_del_50_per_cento/notizie/294638.shtml

75 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)

76 http://www.fp7peoplenetwork.eu/200811214/fp7/fp7-the-7th-framework-programme-of-the-european-union-for-research-and-development.html

77 e.g. "DSDnet": **Bern**, **Lausanne**, http://www.cost.eu/domains_actions/bmbs/Actions/BM1303?management
"Netzwerk DSD": **Bern**, **St. Gallen**, http://www.netzwerk-dsd.uk-sh.de/index.php?id=28

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

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

80 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

disciplinary 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"**.

What's more, all of these "research projects" continue to openly advocate IGMs,[81] as well as to promote the usual psychosocial and non-factual justifications, e.g. **"DSDnet"** (with **Swiss funding**, **Swiss participation**, and **Swiss Government Representation**, see above).

5. Lack of Independent Data Collection and Monitoring

With no statistics available on intersex births, let alone surgeries and costs, and perpetrators, governments and health departments obviously consistently colluding to keep it that way as long as anyhow possible, persons concerned as well as civil society **lack possibilities to effectually 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 IGMs respond by suppressing complication rates, as well as refusing to talk to journalists "on record".[82]

6. Urgent Need for Legislation to Ensure an End to IGMs

For more than two decades, persons concerned and sympathetic clinicians and academics have tried to reason with the perpetrators, and for 18 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 finally end IGMs.

In 2012, the **Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE)** was the first official body to eventually pay heed to this call and support legal measures, followed by the Special Rapporteur on Torture and the Council of Europe (COE) in 2013 (see Bibliography). **Swiss 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, *"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****."*[83]

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

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

83 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

D. The Treatment of Intersex Persons in Switzerland as a Violation of International Law

1. Switzerland's Commitment to the Protection of the Rights of Intersex People

By ratifying the **International Covenant on Civil and Political Rights** (**CCPR**) , Switzerland has committed itself to ensuring that no child within its jurisdiction is subject to torture and other cruel, inhuman or degrading treatment or punishment (CIDT), nor to other human rights violations specified in the convention. In addition, Switzerland has ratified the **Convention against Torture** (**CAT**), and the **European Convention on Human Rights** (**ECHR**), which both prohibit CIDT, as well as the **Convention on the Rights of the Child** (**CRC**) containing a similar clause prohibiting CIDT, as well as stressing the best interest of the child and the right of children to be heard. Last but not least, the **Swiss Federal Constitution** (**SFC**)[84] ensures the right to life and personal freedom, particularly the right to physical and mental integrity, and explicitly prohibits CIDT (Article 10), emphasises the right of special protection of the integrity of children and young people (Art. 11), as well as ensuring the respect for, and the protection of, their dignity (Art. 7), and ensuring equality and non-discrimination (Art. 8).

2. Intersex People denouncing IGMs as Human Rights Violations

> *"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[85]

For 21 years now, intersex people from all over the world, and their organisations have been publicly denouncing IGMs as destructive of sexual sensation, and as a violation of basic human rights, notably the right to physical integrity.[86] For 18 years, they have lobbied for legislation against IGMs to end the impunity of perpetrators due to statutes of limitation.[87] For 17 years, they have been invoking the UN Conventions to fight IGMs,[88] and for 10 years they have been reporting IGM to the UN as a human rights violation.[89]

In **Switzerland**, like 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 as a **human rights issue**,[90] as **harmful and**

84 http://www.admin.ch/ch/e/rs/1/101.en.pdf
85 Mauro Cabral (2004), NGO Statement: Intersexuality, http://ilga.org/ilga/en/article/61
86 Cheryl Chase (1993), Letter to The Sciences RE: The Five Sexes, http://www.isna.org/articles/chase1995a
87 Cheryl Chase (1996), Female Genital Mutilation in the U.S. Discussion, https://www.h-net.org/~women/threads/mut.html
88 Cheryl Chase (1998), ISNA's Amicus Brief on Intersex Genital Surgery, http://www.isna.org/node/97
89 Mauro Cabral (2004), NGO Statement: Intersexuality, http://ilga.org/ilga/en/article/61
90 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

traumatising,[91] as a **western form of genital mutilation**,[92] as **child sexual abuse**,[93] and have called for **legislation to end it**.[94]

3. UN, Human Rights and Ethics Bodies acknowledging Human Rights Violations of Intersex People

The UN Committees CEDAW, CESCR, CAT, and CRPD, the UN High Commissioner for Human Rights (UNHCHR) , the UN Special Rapporteur on Torture (SRT), the World Health Organisation together with OHCHR, UN Women, UNAIDS, UNDP, UNFPA, and UNICEF (WHO Interagency Statement), the Council of Europe (COE), and last but not least the Swiss National Advisory Commission on Biomedical Ethics (NEK) have already recognised the human rights violations perpetrated on intersex persons, and call for legislative measures (NEK, SRT, COE), historical reappraisal, acknowledgement by society of suffering inflicted (NEK, WHO Interagency Statement), compensation for victims (NEK, CAT, WHO Interagency Statement), and data collection and monitoring (CRPD, WHO Interagency Statement). (For sources and relevant excerpts, see Bibliography.)

4. Violated Articles of the Covenant

This section will demonstrate that IGMs, including unnecessary, irreversible cosmetic genital surgeries, and other harmful medical treatments referred to above, constitute human rights violations under Articles 2, 3, 7, 26, and 27 of the International Covenant on Civil and Political Rights. Due to the short time-frame when compling this NGO Report, the following list may not be comprehensive. The Rapporteurs appeal to the discretion of the Committee to identify further breaches.

Article 2: Non-Discrimination, Constitutional and Legal Framework within which the Covenant is Implemented, and Access to Remedies)
Article 3: Equal Rights of Men and Women
Article 26: Equality before the Law

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,[95] e.g. "normal" boys and girls, so that, according to a specialised surgeon, *"any cutting, no matter how incompetently executed, is a kindness."*[96] Clearly, IGMs therefore not only violate Articles 2 and 3 CCRC, but also Articles 8 (protection from discrimination) and 7 (protection of human dignity) of the Swiss

91 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

92 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

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

94 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

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

96 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

Federal Constitution (SFC).[97]

While some states, e.g. South Africa[98] and Australia,[99] included "intersex status" in anti-discrimination legislation, Switzerland still fails to enact similar legislation to ensure its obligations under the CCPR.

Article 7: Prohibition of Torture

The Special Rapporteur on Torture (SRT) [100] and the Committee against Torture (CAT) [101] already recognise IGMs as serious human rights violations constituting Cruel, Inhuman or Degrading Treatment (CIDT), or even torture. IGMs clearly violate Article 7 CCPR, as well as General Comment 20 stressing that the purpose of Article 7 is *"to protect both the dignity and the physical and mental integrity of the individual"*, and noting that this includes mental suffering as well as physical pain, both inflicted by IGMs, and further maintaining that *"it is the duty of the State Party to afford everyone protection through legislative and other measures as may be necessary against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity."* In addition, IGMs include non-therapeutic experimentation on minors expressedly forbidden under Article 7.

Article 27: Rights of Minorities

During the Middle Ages and up to 1900, the existence of hermaphrodites in society, and of Intersex as a natural variation, was common knowledge, in humans as well as in (farm) animals, and hermaphrodites were not only quite rightly integrated in the social fabric, but also recognised and protected both by the Canon Law of the Church and Civil Right Codes, that included specific "Hermaphrodite Articles", granting them the privilege of choosing their legal sex before reaching adulthood ("Sex Oath"), possibly overthrowing the earlier decision granted to their parents. Thus, unlike today, the intersex people were allowed to decide themselves whether to live (and to be able to marry) as males or females.[102] Only after abolishing these "Hermaphrodite Articles" during the Modern Age due to the medical takeover of their right to self determination by the emerging modern medicine,[103] and followed by systematic early "genital corrections" of all intersex newborns after 1950,[104] intersex people as a distinct biological and social minority group all but vanished from western societies. Thus, IGMs also represent a violation of the commitment to protection of minorities according to Article 27 CCPR

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97 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 181

98 Promotion of Equality and Prevention of Unfair Discrimination Act 2000, online: http://www.saflii.org/za/legis/consol_act/poeapouda2000637/

99 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013, online: http://www.comlaw.gov.au/Details/C2013A00098

100 **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

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

102 see 2014 CRC NGO Report, p. 49. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

103 see 2014 CRC NGO Report, p. 49–50. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

104 see 2014 CRC NGO Report, p. 53–56. Online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

E. Conclusion: Switzerland is Failing its Obligations towards Intersex Persons under the International Covenant on Civil and Political Rights

The surgeries and other harmful treatments intersex people endure in Switzerland 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 of the suffering this causes. The Swiss State is responsible for these violations amounting to CIDT or even torture, committed by publicly funded University Children's Hospitals, Cantonal Children's Clinics, and private doctors, relying on money from the federal invalidity assurance (Invalidenversicherung IV), mandatory health insurance, and public grants.

IGMs are common knowledge and have been repeatedly reported in the media, and Swiss authorities have been repeatedly called to take action in cantonal and federal parliaments, as well as by the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE). Nonetheless, to this day Switzerland fails to prevent these grave violations from happening both in public and in private settings, as well as to introduce appropriate legislation to protect the right to physical integrity also for intersex children, but instead allows the human rights violations on intersex children and adolescents to continue unhindered.

In additions, to this day Switzerland fails to include "intersex status" in anti-discrimination legislation.

Switzerland is thus in breach of its obligation to protect intersex children affirmed in Articles 2, 3, 7, 26, and 27 of the International Covenant on Civil and Political Rights.

F. Recommendations

The Rapporteurs respectfully suggest that the Committee includes the following questions to the Swiss Government regarding the treatment of intersex persons in its List of Issues Prior to Reporting:

> How many irreversible surgical and sterilising procedures have been undertaken on intersex children before an age at which they are able to provide informed consent? Please provide up to date statistics.
>
> Does the State party plan to stop this practice?
>
> Does the State party plan to implement the recommendations of the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), *"On the management of differences of sex development. Ethical issues relating to 'intersexuality'"*?

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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.

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 read-

ily 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 SRT, 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: OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement , May 2014, paras 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.*

2. State Bodies Recognising Human Rights Violations of Intersex Children

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

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

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.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en&download=NHzLpZeg7t,-lnp6I0NTU042l2Z6ln1ad1IZn4Z2qZpnO2Yuq2Z6gpJCKfX96f2ym162epYbg2c_JjKbNoKSn6A--

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

2004: CESCR Argentina, Mauro Cabral
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), unpublished submission

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,
2 unpublished submissions for forthcoming WHO Statement on Involuntary Sterilization

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 International Lesbian and Gay Association
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

5. Swiss Government Documents

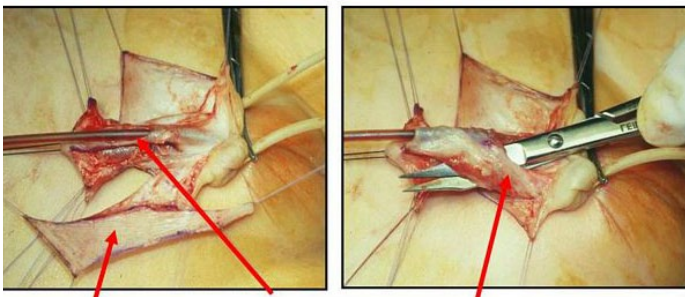
For a comprehensive list of sources and quotes translated in English, see:
Annexe 2 "Swiss Cantonal, Federal Governments, and Clinics on IGMs", in: 2014 CRC NGO Report, p. 43–44, 45–47, online: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

1. "Hypospadias Repair" a.k.a. "Masculinising Surgeries"

"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!"*

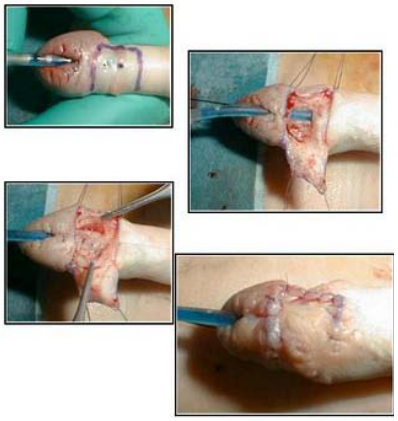
Nonetheless, clinicians recommend these surgeries without medical need explicitly *"for psychological and aesthetic reasons."* Most hospitals advise early surgeries, usually *"between 12 and 24 months of age."* While survivors criticise a.o. impairment or total loss of sexual sensation and painful scars,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

Onlay island flap urethroplasty



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



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)

Bad cosmetic result

infection

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

Hypospadias - Conclusions

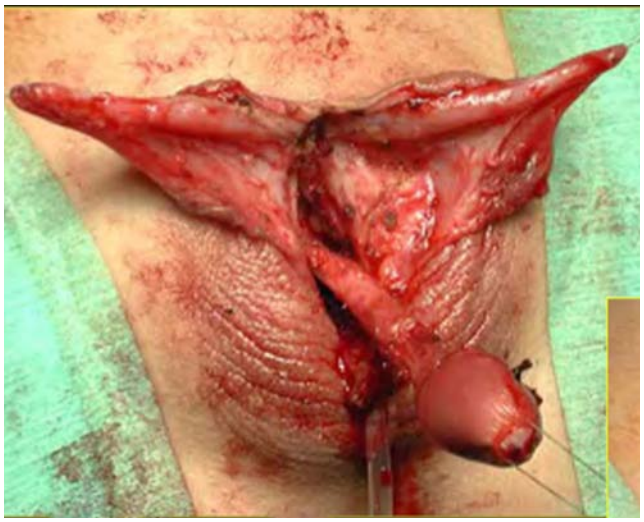
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

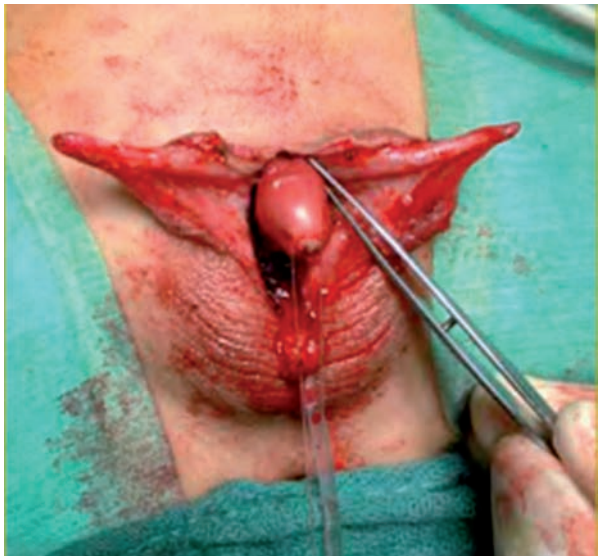
Source: Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

2. "Clitoral Reduction", "Vaginoplasty" a.k.a. "Feminising Surgeries"

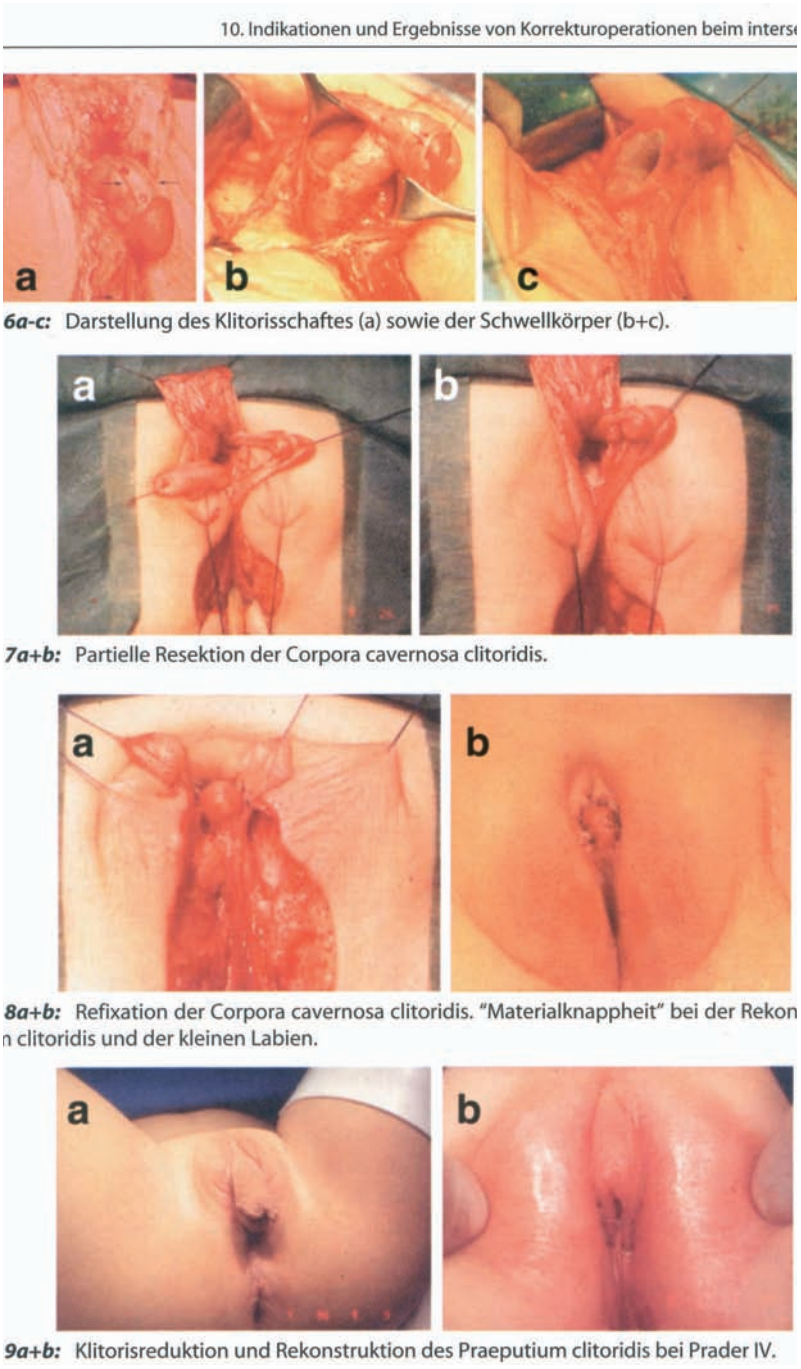
Partial amputation of clitoris, often in combination with surgically opening or widening of the vagina. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include "46,XY Partial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

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





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



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

Bottom Left - Source: Pierre Mouriquand: "Chirurgie des anomalies du développement sexuel - 2007", at 81: "Labioplastie"

3. Castration / "Gonadectomy" / Hysterectomy / (Secondary) Sterilisation

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)", or 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 true reason is "better manageability." Although in many cases persons concerned have no or limited fertility, the gonads by themselves are usually healthy and important hormone-producing organs.

Nonetheless, clinicians still continue to recommend and perform early gonadectomies – despite all the known negative effects of castration, a.o. depression, obesity, metabolic and circulatory troubles, osteoporosis, reduction of cognitive abilities, loss of libido. Plus a resulting lifelong dependency on artificial hormones (and adequate hormones are often not covered by health insurance, but have to be paid by the survivors out of their own purse).

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

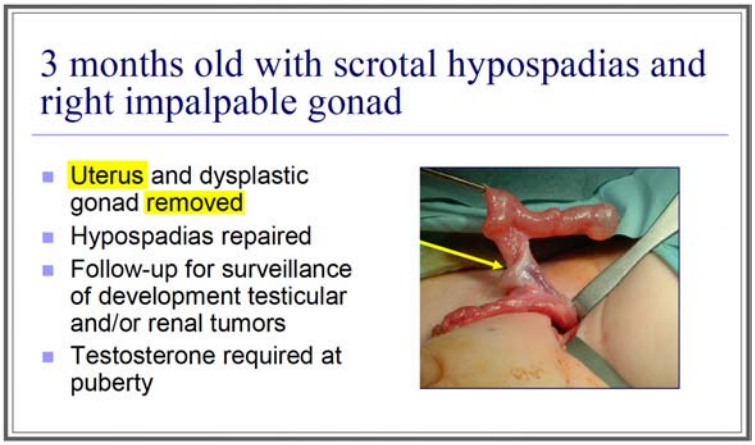


Table 1. Prevalence of type II GCT in various forms of DSD

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.

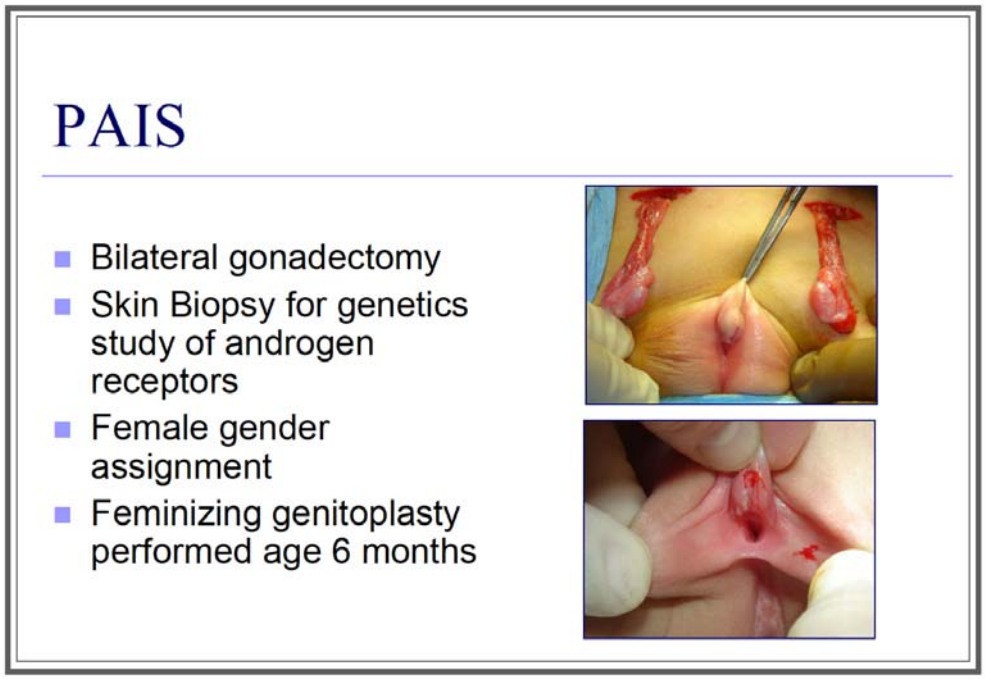
Source (top left): Maria Marcela Bailez: "Intersex Disorders," in: P. Puri and M. Höllwarth (eds.), *Pediatric Surgery: Diagnosis and Management*, Berlin Heidelberg 2009

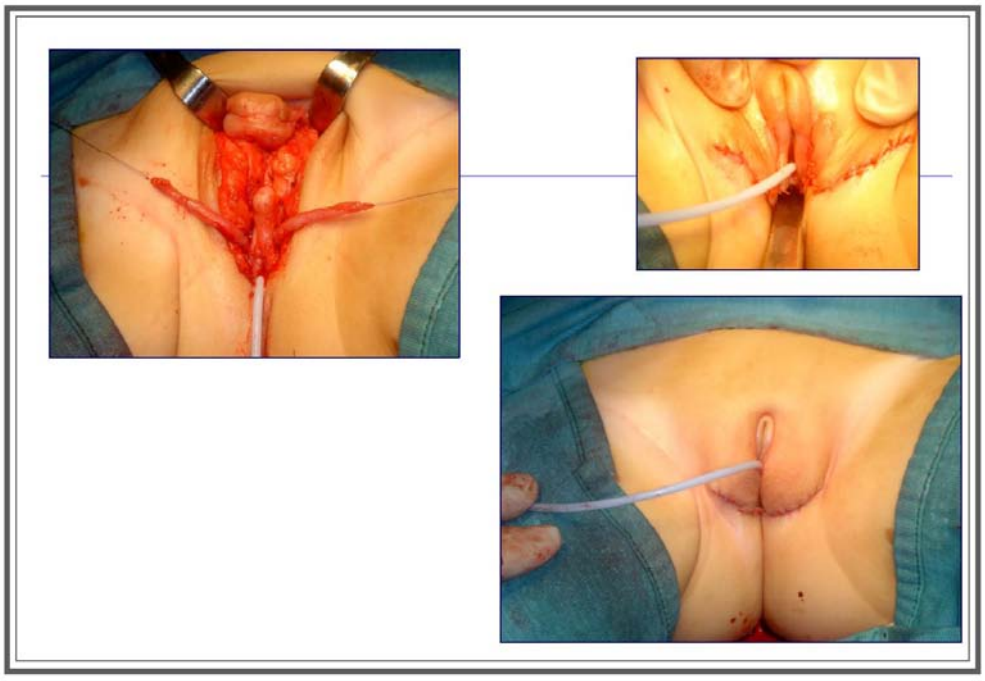
Source (top right): J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20

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

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





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

STOP Intersex Genital Mutilation!

by Zwischengeschlecht.org, Intersex.ch,
and SI Selbsthilfe Intersexualität