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



NGO Report (for LOI) to the 1st Periodic Report of Switzerland on the Convention on the Rights of Persons with Disabilities (CRPD)

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Executive Summary

All typical forms of IGM are still practiced in Switzerland today, facilitated and paid for by the State party via the "Swiss Federal Invalidity Insurance" and its "List of Birth Defects".

CRC, **CAT**, **CEDAW** and **CCPR** have already recognised IGM in **Switzerland** as a **serious violation**, namely harmful practice and inhuman treatment. Instead of taking appropriate action, **Switzerland openly and explicitly** *"rejects"* to implement the Concluding Observations, **downgrading and trivialising** the practice as a mere "*discrimination*" or "*health*" issue instead. Emboldened by such official protection, Swiss IGM doctors **publicly insist to continue**.

This Committee has **repeatedly recognised IGM** as a serious violation in **Concluding observations, LOIs** and **General Comments**. As shown, IGM practices in **Switzerland** constitute **the same or similar violations** as those previously specified and addressed by the Committee.

In total, UN treaty bodies CRC, CEDAW, CAT, CCPR and CRPD have so far issued 42 Concluding Observations on IGM, typically obliging State parties to enact legislation to (a) end the practice and (b) ensure redress and compensation, plus (c) access to free counselling. Also, the UN Special Rapporteurs on Torture (SRT) and on Health (SRH), the UN High Commissioner for Human Rights (UNHCHR), the World Health Organisation (WHO), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples' Rights (ACHPR) and the Council of Europe (COE) recognise IGM as a serious violation of non-derogable human rights.

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

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

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

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

This Thematic NGO Report has been compiled by the international NGO StopIGM.org / Zwischengeschlecht.org, the Swiss peer support groups Intersex.ch and SI Selbsthilfe Intersexualität. It contains Suggested Questions for the LOI (see p. 13).

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A. Introduction

1. Intersex, IGM and Human Rights in Switzerland

IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been repeatedly **recognised by multiple UN treaty bodies**¹ **including CRPD** as constituting a **serious violation**, namely harmful practice, violence and inhuman treatment. **CRC**, **CAT**, **CEDAW** and **CCPR** have already recognised **IGM in Switzerland** to constitute a serious violation accordingly.

This NGO Report demonstrates that the current **harmful medical practice on intersex persons** in Switzerland persists, advocated and paid for by the State party via the "Swiss Federal Invalidity Insurance" and its "List of Birth Defects". Switzerland categorically fails its obligations under a number of international human rights treaties. Worse, the State party openly and explicitly "*rejects*" to implement Concluding Observations on IGM, downgrading and trivialising the practice as a mere "*discrimination*" or "*health*" issue instead, which is also evident in the State report (para 32). This report further demonstrates that IGM practices in Switzerland constitute the same or similar violations as those previously specified and addressed by the Committee concerning other countries or in General Comments.

2. About the Rapporteurs

This NGO report has been prepared by the Swiss-based international intersex NGO *StopIGM.org* / *Zwischengeschlecht.org* in collaboration with Swiss peer support groups *Intersex.ch* and *SI Selbsthilfe Intersexualität:*

- StopIGM.org / Zwischengeschlecht.org is an international intersex human rights NGO based in Switzerland, working to end IGM Practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!*"² According to its charter,³ StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to UN treaty bodies.⁴
- Intersex.ch is a Swiss intersex peer support group founded in 2005.⁵
- SI Selbsthilfe Intersexualität is a Swiss peer support group for parents of intersex children founded in 2003.

3. Methodology

This thematic NGO report is an updated and adapted summary of the **2019 thematic CRC NGO Report (for LOIPR)** for **Switzerland** by the same rapporteurs.⁶

It contains 2 Annexes with more comprehensive information on "Intersex, IGM and Disability" and "IGM in Switzerland: Facts, Figures, Sources".

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

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

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

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

^{5 &}lt;u>http://intersex.ch/</u>

^{6 &}lt;u>http://intersex.shadowreport.org/public/2019-CRC-LOIPR-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

B. Precedents: Concluding Observations on IGM and State Report

1. COs: Harmful Practices and CRC-CEDAW Joint General Comment No. 18/31 a) CRC 2015, CRC/C/CHE/CO/2-4, paras 42-43

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, without 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.

43. The Committee draws the attention of the State party to the joint recommendation/general comment No. 31 of the Committee on the Elimination of Discrimination against Women and No. 18 of the Committee on the Rights of the Child on harmful practices (2014), and urges the State party to:

[...]

(b) In line with the recommendations of the National Advisory Commission on Biomedical Ethics on ethical issues relating to intersexuality, ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to the children concerned, and provide families with intersex children with adequate counselling and support.

b) CEDAW 2016, CEDAW/C/CHE/CO/4-5, paras 24-25

Harmful practices

24. The Committee welcomes the adoption of legislative and other measures to combat harmful practices, including female genital mutilation, intersex genital mutilation, child marriage and forced marriage. Nevertheless, the Committee is concerned about:

[...]

(c) Insufficient support for intersex persons who have undergone involuntary and medically unnecessary disfiguring surgical procedures when they were babies and children, often with irreversible consequences, resulting in significant physical and psychological suffering;

(d) The pressure placed on parents of intersex children by medical professionals, the media and society at large, which often forces them to give their consent for so-called "medical procedures", justified by psychosocial indications; and the fact that intersex children and adults are often unaware of the procedures to which they have been subjected, while access to legal remedies for intersex persons affected by unnecessary medical procedures is extremely limited, with the statute of limitations often expiring by the time that intersex children reach adulthood;

(e) The lack of integration of intersex persons and their families into interdisciplinary working groups and the failure to consult those directly affected by these procedures in decisions that affect their lives.

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

(a) Systematically collect disaggregated data on harmful practices in the State party [...]

(c) Ensure that, in line with recommendations by the Swiss National Advisory Commission on Biomedical Ethics, no child is subjected to unnecessary medical or surgical treatment during infancy or childhood, adopt legislation to protect the bodily integrity, autonomy and self-determination of intersex persons and provide families with intersex children with adequate counselling and support;

(d) Adopt legal provisions, under the guidance of the courts, in order to provide redress to intersex persons affected by cases of surgical or other medical treatment without their free, prior and informed consent by or that of their parents;

(e) Educate and train medical professionals on the harmful impact of unnecessary surgical or other medical interventions for intersex children and ensure that the views of intersex persons are fully considered by the interdisciplinary working groups established to review these procedures.

2. Concluding Observations: Cruel, Inhuman or Degrading Treatment

a) CAT 2015, CAT/C/CHE/CO/7, para 20

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.

b) CCPR 2017, CCPR/C/CHE/CO/4, paras 24-25

Intersex persons

24. The Committee takes note of the work of the National Advisory Commission on Biomedical Ethics regarding intersexuality and of the 6 July 2016 press statement by the Federal Council. It remains concerned, however, that the performance of surgical procedures on intersex children, causing physical and mental suffering, is still not strictly regulated. It also wishes to express concern that the conduct of surgery without consent has not yet given rise to any inquiry, sanction or reparation (arts. 3, 7, 24 and 26).

25. The State party should: (a) take all necessary measures to ensure that no child undergoes unnecessary surgery intended to assign sex; (b) see to it that medical records are accessible and that inquiries are launched in cases where intersex persons are subjected to treatment or surgical procedures without their effective consent; and (c) ensure that psychological assistance and reparation, including compensation, are provided for victims of needless surgical procedures.

3. 2016 State Report for CRPD on Intersex (CRPD/C/CHE/1, para 35)

Specific Rights

Article 5 – Equality and non-discrimination

[...]

35. On the basis of a study by the Swiss Centre of Expertise in Human Rights, [11] the Federal Council has stated in a report on the right to protection against discrimination that Swiss legislation as a whole offers sufficient protection against discrimination [12]. There were however gaps in the field of private law and with regard to the rights of lesbian, gay, transgender and **intersex persons**. A number of recommendations to improve protection against discrimination are being studied in detail. With regard to the equality of persons with disabilities, an audit is being carried out as part of a report on disability policy requested by the Federal Council, which is to be submitted at the end of 2016.

[11] CSDH, Der Zugang zur Justiz in Diskriminierungsfällen synthesebericht, Berne, 2015 (see ch/dam/data/bj/aktuell/news/2016/2016-05-25 /synthesebericht-d.pdf http://www.ejpd.admin). [correct link: <u>http://www.ejpd.admin.ch/dam/data/bj/aktuell/news/2016/2016-05-25/synthesebericht-d.pdf</u>]

[12] The Right to Protection against Discrimination, Report of the Federal Council of 25 May 2016, in response to the Naef postulate (12.3543) of 14 June 2012.

C. IGM in Switzerland: State-sponsored and pervasive, Gov fails to act

1. Overview: Still no protections for intersex people, State party denies violations

In Switzerland (2015: CRC/C/CHE/CO/2-4, paras 42-43; 2015: CAT/C/CHE/CO/7, para 20; 2016: CEDAW/C/CHE/CO/4-5, paras 24–25, 38–39; 2017: CCPR/C/CHE/CO/4, paras 24-25), same as in the neighbouring states of *Germany* (CRPD/C/DEU/CO/1, paras 37-38; CAT/C/DEU/CO/5, para 20; CEDAW/C/DEU/CO/7-8, paras 23–24), *Italy* (CRPD/C/ITA/CO/1, paras 45-46; CRC/C/ITA/CO/5-6, para 23), *Liechtenstein* (CEDAW/C/LIE/CO/5, paras 35-36, *Austria* (CAT/C/AUT/CO/6, paras 44-45) and *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33; CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f), there are still

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

To this day, in Switzerland

- all forms of IGM practices remain widespread and ongoing (see p. 18),
- IGM is advocated, facilitated and paid for via "Swiss Federal Invalidity Insurance" and its "List of Birth Defects" covering all the most frequent IGM procedures (see p. 18),
- "informed consent" is usually obtained from legal guardians via substitute decision-making (see p. 18, see also p. 11),
- IGM doctors publicly insist to continue with IGM (see p. 20),
- there is a high prevalence of **selective abortions due to a prenatal intersex diagnosis** (see p. 22).

To this day, the Swiss government

- **denies** the ongoing practice (see p. 23),
- "rejects" repeated UN recommendations by CRC, CAT, CEDAW, CCPR (see p. 24),
- downgrades and trivialises IGM as a "discrimination" or "health" issue (see p. 19),
- refuses to take effective measures to end IGM practices (see p. 25),
- refuses to collect disaggregated data on intersex and IGM (see p. 22),
- forces IGM survivors to pay for rehabilitation out of their own pocket (see p. 26),
- claims "free psychosocial support" would be "impossible" to finance (see p. 23),
- claims the existing legislation would be sufficient to protect intersex children (see p. 25),
- **enables IGM institutions to destroy medical records** during a "*scientific review*" of historic IGM practices funded by the Swiss National Science Foundation (SNSF) (see p. 27).

2. IGM in Switzerland as a Violation of the CRPD

a) Switzerland: Framing intersex people as "invalids", promoting IGM as "cure"

In Switzerland, doctors and medical bodies, in complicity with healthcare providers and governing State bodies, have traditionally been framing and "treating" intersex variations as a form of disability in the medical definition in need to be "cured" or "corrected" surgically, often with racist, eugenic and suprematist undertones (see p. 14). To this day, such harmful stereotypes and prejudices framing intersex as "inferior", "deformed", "disordered", "degenerated" or a "bad omen" remain widespread and still inform the harmful medical practice (see p. 14).

IGM practices include **non-consensual**, **unnecessary**, **irreversible** genital surgeries, and/or other harmful medical procedures that would not be considered for "normal" children, practised **without evidence of benefit** for the children concerned (see p. 15).

IGM is mostly performed on **children at a very young age**, therefore "informed consent" is usually obtained from legal guardians via **substitute decision-making**, typically from **parents** finding themselves in a **very vulnerable situation** (see p. 18, 20).

Typical forms of IGM include "masculinising" and "feminising", "corrective" genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, involuntary human experimentation and denial of needed health care (see p. 15).

In Switzerland, IGM practices are paid for by the "Federal Invalidity Insurance" (see p. 18), and Switzerland played a crucial role in historically establishing such harmful stereotypes as medical diagnoses and in proliferating IGM as a "*cure*" internationally (see p. 21).

b) IGM as a violation of the Convention on the Rights of Persons with Disabilities General Comment No. 3, para 32 explicitly considers IGM (same as FGM) as a serious violation of non-derogable human rights, namely inhuman treatment:

"Certain forms of violence, exploitation and abuse may be considered as cruel, inhuman or degrading treatment or punishment and as breaching a number of international human rights treaties. Among them are: [...] female genital mutilation and surgery or treatment performed on intersex children without their informed consent; [...]" (GC3, para 32)

Further, GC3, para 44 specifies that substitute decision-making⁷ and restricting or removing legal capacity "can facilitate forced interventions, such as [...] female genital mutilation, surgery or treatment performed on intersex children without their informed consent [...]".

General Comment No. 6, para 33 specifies the "consultation obligations of State parties":

"[...] article 4 (3) and article 33 (3) of the Convention emphasize the important role that organizations of persons with disabilities must play in the implementation and monitoring of the Convention. States parties must ensure that they consult closely and actively involve such organizations, which represent the vast diversity in society, including children, autistic persons, persons with a genetic or neurological condition, persons with rare and chronic diseases, persons with albinism, lesbian, gay, bisexual, transgender or intersex persons, indigenous peoples, rural communities, older persons, women, victims of armed conflicts and persons with an ethnic minority or migrant background. [...]" (GC6, para 33)

See also Disabled People's Organisations Australia (2018), Submission to the Australian Human Rights Commission, p. 8, 10-12 in submission (p. 9, 11-13 in DOCX), http://dpoa.org.au/wp-content/uploads/2018/10/DPOA_AHRC_IntersexConsultationPaper_300918.docx

Accordingly, the Committee has repeatedly recognised IGM as a serious violation in Concluding observations⁸ and LOIs,⁹ most frequently under Article 17 "Protecting the integrity of the person", but occasionally also under art. 15 (inhuman treatment) and art. 16 (violence). Lack of consultation and representation of intersex organisations by State parties has also been raised by the Committee in the interactive dialogue and in COs.¹⁰

As shown, **IGM practices in Switzerland constitute the same or similar, serious human rights violations** as those previously specified and addressed by the Committee concerning IGM practices in other counties or in general.

In addition, as shown **IGM practices in Switzerland have already been recognise**d as a serious human rights violation by **CRC**, **CAT**, **CEDAW and CCPR**, similarly considering IGM as violence, genital mutilation, inhuman treatment and a harmful practice.

We therefore kindly ask the Committee to raise IGM in the List of Issues for Switzerland.

COs, see CRPD/C/GBR/CO/1, paras 10(a)-11(a)

⁸ CRPD/C/DEU/CO/1, paras 37-38; CRPD/C/CHL/CO/1, paras 41-42; CRPD/C/URY/CO, para 44; CRPD/C/ITA/CO/1, paras 45-46; CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41; CRPD/C/MAR/CO/1, paras 36-37

⁹ CRPD/C/DEU/Q/1, para 12; CRPD/C/AUS/QPR/2-3, para 20; CRPD/C/DEU/QPR/2-3, para 16(b); CRPD/C/AUT/QPR/2-3, para 36

¹⁰ Dialogue, see Theresia Degener (CRPD18 United Kingdom): "[...] the answers related to female genital mutilation, but I was talking about intersex genital mutilation. And in regard to that I think while it is commendable to give 45'000 pounds to LGBTI community, it does not mean that this money reaches intersex persons and that the harmful practices which I mentioned yesterday, which this Committee and other Treaty Body Committees consider as ill-treatment and in some instances as torture, will be stopped, and I'm afraid that giving some money to civil society is not enough in order to stop serious human rights violations", full transcript: http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD

D. Suggested Questions for the LOI

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

Intersex Genital Mutilation

- How many non-urgent, irreversible surgical and other procedures have been undertaken on intersex minors? Please provide detailed statistics on sterilising, feminising, and masculinising procedures, disaggregated by age groups and region (Kantone).
- Does the State party plan to stop this practice and to implement the relevant recommendations by CRC, CAT, CEDAW and CCPR? If yes, what measures does it plan to implement, and by when?
- Please indicate which criminal or civil remedies are available for intersex people who have undergone involuntary sterilisation or unnecessary and irreversible medical or surgical treatment of intersex children without their informed consent, and whether these remedies are subject to any statute of limitations?
- Please indicate which means of rehabilitation are available for intersex people who have undergone involuntary procedures?
- Please indicate which means of psychosocial support, including peer support, are available for intersex children and their families?

Annexe 1 – Intersex, IGM and Disability

1. Framing Intersex People as "Invalids", Selling Genital Mutilation as "Cure"

Doctors and medical bodies, in complicity with healthcare providers and governing State bodies, have traditionally been **framing and "treating" intersex variations as a form of disability in the medical definition** in need to be "*cured*" or "*corrected*" surgically, often with racist, eugenic and suprematist undertones.^{11 12 13 14}

To this day, such harmful stereotypes and prejudices framing intersex as "*inferior*", "*deformed*", "*disordered*", "*degenerated*" or a "*bad omen*" remain widespread and still inform the current harmful western medical practice, as well as other practices including infanticide and child abandonment. For example, in Pakistan intersex is considered a "*congenital genitalia birth defect*" to be "*cured*" by surgery "*to make them normal persons again*." ¹⁵

In Switzerland, IGM practices are paid for by the "Federal Invalidity Insurance" (see p. 18), and Switzerland also played a crucial role in historically establishing such harmful stereotypes as medical diagnoses and in proliferating IGM as a "*cure*" internationally (see p. 21).

What's more, also **Switzerland** shows a high prevalence of **selective abortions due to a prenatal intersex diagnosis**, and the easier an intersex trait can be tested prenatally, **the higher the selective (late term) abortion rates** are (see p. 22.). Internationally, most intersex diagnoses are also listed as **permissible for genetic de-selection** in relevant State sponsored **pre-implantation genetic diagnosis (PGD)** guidelines.¹⁶

2. Intersex = Variations of Sex Anatomy

Intersex people, in the vernacular also known as hermaphrodites, or medically as persons with "*Disorders*" or "*Differences of Sex Development (DSD)*", ¹⁷ are people born with **Variations of Sex Anatomy**, or "atypical" sex anatomies and reproductive organs, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**. Most intersex conditions do *not* **represent a health problem**. A known exception is the condition Congenital Adrenal Hyperplasia (CAH), which in the salt-losing form requires hormonal treatment (but no surgery). The only exceptions requiring immediate medically necessary genital surgery is if there is no urethral opening or if the urine flow is otherwise obstructed.

 http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf
 "The Racist Roots of Intersex Genital Mutilations", http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

^{11 2014} CRC NGO Report, p. 52, 69, 84, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

¹² In the WHO "World Atlas of Birth Defects (2nd Edition)", many intersex diagnoses are listed, including *"indeterminate sex"* and *"hypospadias":*

¹⁴ For 500 years of "scientific" prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

¹⁵ Pakistani doctors in "The Nation", see http://stop.genitalmutilation.org/post/Pakistan-Intersex-children-birth-defects-patents-offered-surgery-to-make-them-normal-again Original source: https://www.thenews.com.pk/print/287739-100-infants-with-birth-defects-rehabilitated

¹⁶ For example, in the UK, see <u>https://www.hfea.gov.uk/pgd-conditions/</u>

¹⁷ The currently still official medical terminology "**Disorders of Sex Development**" is strongly refused by persons concerned. See 2014 CRC NGO Report, p. 12 "Terminology".

While intersex people may face several problems, in the "developed world" the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations, with **1 to 2 in 1000 newborns** at risk of being submitted to non-consensual "genital correction surgery".

3. IGM = Involuntary, unnecessary interventions via substitute decision-making

In "developed countries" with universal access to paediatric health care 1 to 2 in 1000 newborns are at risk of being submitted to medical IGM practices, i.e. non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments that would not be considered for "normal" children, practiced without evidence of benefit for the children concerned, but justified by societal and cultural prejudice, stereotypes, norms and beliefs, and often directly financed by the state via the public health system.¹⁸

Typical forms of medical IGM include "feminising" or "masculinising", "corrective" genital surgery, sterilising procedures, imposition of hormones (including prenatal "therapy"), forced genital exams, vaginal dilations, medical display, human experimentation, selective (late term) abortions and denial of needed health care.

Typically, **medical IGM is performed at a very young age**, with doctors advocating unnecessary surgery in the first two years of life. Consent is obtained from legal guardians via **substitute decision-making**, usually from parents finding themselves in a **very vulnerable situation** (see also p. 18).

Medical IGM is known to cause **lifelong severe physical and mental pain and suffering**,¹⁹ sometimes **leading to disability**,²⁰ 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.

From countries without universal access to paediatric health care, there are reports of infanticide of intersex children,²¹ of abandonment,²² of expulsion,²³ of massive bullying

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

¹⁸ For references and general information, see "What are Intersex Genital Mutilations (IGM)?", 2016 CEDAW NGO Report France, p. 45–51,

¹⁹ See "IGM Practices – Non-Consensual, Unnecessary Medical Interventions", ibid., p. 38–47

²⁰ See 2015 CRPD Germany NGO Report, p. 17, 22-23, http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.docx

For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12, <u>http://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u> For South Africa, see also <u>https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens</u> For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: <u>http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda</u>; for Uganda, see also 2015 CRC Briefing, slide 46, <u>http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf</u> For Kenya, see also <u>http://www.bbc.com/news/world-africa-39780214</u>

preventing the persons concerned from attending school (recognised by CRC as amounting to a harmful practice), 24 and of **murder**. 25

4. Intersex is NOT THE SAME as LGBT

Unfortunately, there are several **harmful stereotypes and misconceptions about intersex** still prevailing in public, including if intersex is counterfactually described as being the same as or a subset of LGBT, e.g. if intersex and/or intersex status are misrepresented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality, ²⁶ or as a form of sexual preference.

The underlying reasons for persistence of these harmful misconceptions include **lack of awareness**, third party groups **instrumentalising** intersex as a means to an end for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

Intersex persons and their organisations have **spoken out clearly against instrumentalising or misrepresenting intersex issues**,²⁷ maintaining that Intersex Genital Mutilations present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT community, and thus need to be **adequately addressed in a separate section** as **specific intersex issues**. Also, **human rights experts** are increasingly warning of the **harmful conflation** of intersex and LGBT.²⁸

Nonetheless, the **pervasiveness and persistence** of these harmful misconceptions remains, in particular by **State parties** constantly **misrepresenting intersex and IGM as sexual orientation or gender identity issues** in an attempt to **deflect from criticism**, instead referring to e.g. "gender reassignment surgery" (i.e. voluntary procedures on transsexual or transgender persons) and "gender assignment surgery for children",²⁹ "sexual orientation and gender identity", "civil

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

 For example in China, see 2015 Hong Kong, China NGO Report, p. 15, http://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf

²³ For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source: http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda

²⁴ For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see http://stop.genitalmutilation.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3

²⁵ For example in Kenya, see <u>https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/</u>

²⁶ E.g. the Swiss Federal Government in 2011 in answers to parliamentary 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

²⁷ For references, see 2016 CEDAW NGO Report France, p. 40, fn 49. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

²⁸ For example ACHPR Commissioner Lawrence Murugu Mute (Kenya), see http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT

²⁹ CRC73 New Zealand, <u>http://stop.genitalmutilation.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child</u>

registry" and "sexual reassignment surgery" ³⁰, when asked about IGM by Treaty bodies.

Typically, **Switzerland** only included **intersex under "LGBTI discrimination"** in the State Report, and **officially rejected to implement** the CRC recommendations on harmful practices on intersex children, prioritising **civil registry reform** instead (i.e. easier change of gender markers in official documents – notably **not an intersex demand**, but an LGBT demand mostly benefitting trans persons (see also p. 19).

5. IGM is NOT a "Discrimination" Issue

An interrelated diversionary tactic is the increasing misrepresentation by State parties of IGM as "*discrimination issue*" instead of a serious violation of non-derogable human rights, namely inhuman treatment and a harmful practice (see also CRPD/C/G/3, para 32), in combination with the misrepresentation of intersex human rights defenders as "*fringe elements*", and their legitimate demands and criticism of such downgrading and trivialising of IGM as "*extreme views*".

This is also evident in the Swiss State report, and in descriptions of intersex advocates by IGM doctors in the media (see p. 20).

6. IGM is NOT a "Health" Issue

Another interrelated, alarming new trend is the **increasing misrepresentation of IGM as** *"health issue"* instead of a serious human rights violation, namely inhuman treatment and a harmful practice (see also CRPD/C/G/3, para 32), in combination with the **promotion of** *"self-regulation"* of IGM by the current perpetrators ^{31 32 33} instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health Ministries** construe UN Treaty body Concluding observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse** for "self-regulation" promoting state-sponsored IGM practices to continue with impunity. ³⁴

³⁰ CCPR120 Switzerland, <u>http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120</u>

³¹ For example Amnesty (2017), see http://stop.genitalmutilation.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors

³² For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, http://stop.genitalmutilation.org/public/S3 Zwischengeschlecht UN-Expert-Meeting-2015 web.pdf

³³ For example CEDAW (2017), see, <u>http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN</u>

³⁴ See e.g. Ministry of Health Chile (2016), <u>http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile</u>

Annexe 2 – IGM in Switzerland: Facts, Figures, Sources

1. IGM advocated and paid for by the "Swiss Federal Invalidity Insurance"

In Switzerland, all forms of IGM practices remain widespread and ongoing³⁵ – advocated, facilitated and paid for by the State party via the "Swiss Federal Invalidity Insurance"³⁶ ("Invalidenversicherung (IV)",³⁷ "Assurance-invalidité (AI)",³⁸ "Assicurazione per l'invalidità (AI)")³⁹ according to the Numbers in the "List of Birth Defects" ("Liste der Geburtsgebrechen",⁴⁰ "Liste des infirmités congénitales",⁴¹ "Elenco delle infermità congenite"),⁴² which includes all the most frequent intersex diagnoses and covers all the most frequent IGM procedures on children, including IGM 3: sterilising procedures (No.s 355, 359, 466, 488), IGM 2: "feminising" procedures including partial clitoris amputation and "vaginoplasty" (No.s 358, 359, 465, 466) and IGM 1: "masculinising" procedures including cosmetic surgery on the penis a.k.a. "hypospadias repair" (No.s 352, 359, 466). (However, consensual procedures on adults are not covered by the "Swiss Federal Invalidity Insurance".)⁴³

As IGM is mostly performed on very young children, "informed consent" is usually obtained from legal guardians via substitute decision-making, typically from parents finding themselves in a very vulnerable situation, many of them in a state of shock after the unexpected birth of an atypical child, completely uninformed due to the persisting societal taboo of intersex as a natural variation, often overwhelmed by feelings of guilt and shame, under undue pressure from doctors to "sign quickly" because "it's the best for your child" and the "only chance to lead a normal life".

³⁵ For additional evidence and sources, see 2017 CCPR Swiss NGO Report, p. 8-11, http://intersex.shadowreport.org/public/2017-CCPR-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf

³⁶ While the English designation featured on the official federal homepage says "*Disability Insurance (DI*)", it is noteworthy that in all the **official swiss languages** all the **official designations** do in fact translate to "**Invalidity Insurance [II]**", <u>https://www.ahv-iv.ch/en/Social-insurances/Disability-insurance-DI</u>

^{37 &}lt;u>https://www.ahv-iv.ch/de/Sozialversicherungen/Invalidenversicherung-IV</u>

³⁸ https://www.ahv-iv.ch/fr/Assurances-sociales/Assurance-invalidit%C3%A9-AI

^{39 &}lt;u>https://www.ahv-iv.ch/it/Assicurazioni-sociali/Assicurazione-per-linvalidit%C3%A0-AI</u>

^{40 &}lt;u>https://www.admin.ch/opc/de/classified-compilation/19850317/index.html#app1ahref1</u>

⁴¹ https://www.admin.ch/opc/fr/classified-compilation/19850317/index.html#app1ahref1

^{42 &}lt;u>https://www.admin.ch/opc/it/classified-compilation/19850317/index.html#app1ahref1</u>

⁴³ See Swiss National Advisory Commission on Biomedical Ethics NEK-CNE (2012), On the management of differences of sex development. Ethical issues relating to "intersexuality", No. 20/2012, at 15-17, <u>http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf</u> For numbers and corresponding diagnoses concerning intersex and IGM in the "List of Birth Defects", see <u>http://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen</u> For List-numbers of the most frequent current IGM practices, see 2017 CCPR Swiss NGO Report, p. 8-10, http://intersex.shadowreport.org/public/2017-CCPR-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf

2. Downgrading and Trivialising IGM as a "Discrimination" or "Health" Issue

The Rapporteurs are concerned about the **increasing misrepresentation by State parties of IGM as a** *"discrimination issue"* instead of a serious violation of non-derogable human rights, namely inhuman treatment and a harmful practice (see also CRPD/C/G/3, para 32), in combination with the **misrepresentation of intersex human rights defenders as** *"fringe elements"*, and their legitimate demands and criticism of such downgrading and trivialising of IGM as *"extreme views"*.

This is also **evident in the Swiss State report**, where **intersex is only mentioned under art. 5** (equality and non-discrimination), despite the multiple previous Concluding Observations recognising IGM in Switzerland as inhuman treatment and a harmful practice (see also CRPD/C/G/3, para 32), and **in contradiction to this Committee's previous recommendations** on intersex under art. 17 "*Protecting the integrity of the person*".⁴⁴

It is also evident in a **report referenced in the State report (footnote 11)** by the Swiss Center of Expertise in Human Rights (SCHR), where intersex advocates criticising the downgrading and trivialising of IGM are framed as **fringe individuals** – despite that at the point when the report was finalised (June 2015), human rights and ethics bodies including the Swiss National Ethics Commission NEK-CNE (November 2012) and CRC (February 2015) had already and unmistakably condemned IGM in Switzerland as a serious violation of non-derogable rights:

"In the area of intersex [...] Furthermore, *individual interviewees* demand that sex-aligning surgeries [sic!] in young children be recognised as *human rights violations* and bodily mutilation – and *not just as discrimination*." ⁴⁵

And it is evident in marginalising descriptions of intersex advocates by **IGM doctors in the media**, e.g. how a Swiss paediatrician, then president "Central Ethics Commission (ZEK)" of the "Swiss Academy of Medical Sciences (SAMW-ASSM)" and president of the medical association "Swiss Pediatrics (SSP)", characterised the Co-Rapporteurs and their public call for intersex human rights in a 2011 interview (see also p. 20):

"For Chief Physician Christian Kind, the demands of 'Zwischengeschlecht.org' go too far." ⁴⁶

Similarly, a prominent Swiss IGM surgeon publicly characterised the Co-Rapporteurs in 2019:

"The views of Zwischengeschlecht.org are very extreme" 47

Notably, at this point, in addition to NEK-CNE and CRC, also CAT, CEDAW and CCPR had unmistakably condemned IGM in Switzerland as a serious violation of non-derogable human rights.

⁴⁴ CRPD/C/DEU/CO/1, paras 37-38; CRPD/C/CHL/CO/1, paras 41-42; CRPD/C/URY/CO, para 44; CRPD/C/ITA/CO/1, paras 45-46; CRPD/C/GBR/CO/1, paras 10(a)-11(a), 38-41; CRPD/C/MAR/CO/1, paras 36-37

⁴⁵ Swiss Center of Expertise in Human Rights (SCHR) (2015), p. 25 in report (p. 35 in PDF), https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-73468.html

⁴⁶ Jeanette Herzog, Zwist um Zwitter-Operationen, St. Galler Tagblatt (11.02.2011), https://www.tagblatt.ch/ostschweiz/zwist-um-zwitter-operationen-ld.670674

⁴⁷ Christian Felix (2019), "Unser Kind heisst Amelia-Leandro", Der Landbote, 10.01.2019, p. 5, http://kastrationsspital.ch/public/Landbote_2019-01-10_S-1_5_intersex_web.pdf

3. IGM doctors publicly insist to continue with IGM via substitute decision-making

Emboldened by such official protection, in spring 2019 Swiss IGM doctors announced a new *"Switzerland-wide agreement of DSD treatment teams"*. While the agreement itself was **kept secret and not published**, the Press release nonetheless makes it clear that in the end non-consensual, unnecessary genital surgery and other treatment on intersex children **at the behest of doctors and parents** will continue:⁴⁸

"The treatment teams have agreed on a basic attitude for the treatment of patients: The surgical interventions on the child's genitals, which were strongly criticised in the past, should no longer be an independent treatment method in all Swiss clinics, but should only be carried out in conjunction with comprehensive care and accompaniment of the family - and whenever possible with the informed consent of the adolescent affected person."

This insistence on continuing with **cosmetic procedures** justified by **psycho-social indications** and with "consent" obtained via **substitute decision-making** was also reaffirmed in a media interview on the agreement by surgeon **Dr. Rita Gobet** (Zurich University Children's Hospital):⁴⁹

"Do not forbid surgeries

Sex-aligning surgeries should still be possible and not banned, as demanded by an initiative in the Geneva cantonal parliament last year. 'If, despite the counselling, the parents cannot bear to live with the "shame" and a whole team comes to the conclusion that surgery is the best solution, it should remain possible,' says Rita Gobet. Otherwise, there is a risk that a black market will develop or that those affected will go abroad for the operation'."

These 2019 allegations of a dangerous foreign black market by a Swiss IGM surgeon in turn highlight **how little has changed** in Switzerland, as they strikingly resemble the **2011 sentiments** of IGM paediatrician **Dr. Christian Kind** (then president "Central Ethics Commission (ZEK)" of the "Swiss Academy of Medical Sciences (SAMW-ASSM)" and president of the medical association "Swiss Pediatrics (SSP)":⁵⁰

"[...] For Chief Physician Christian Kind, the demands of 'Zwischengeschlecht.org' go too far [...] According to Christian Kind, whether or not a child will undergo a sex-aligning surgery has a lot to do with the parents: 'If the parents cannot accept an intersex child, then it may be better for the child's well-being to operate.'

'Better here than in the East'

Daniela Truffer disagrees. 'The integrity of the child must have the highest priority. If a child screams too loudly for the parents' taste, you don't remove his vocal chords either.'

Christian Kind sees this pragmatically: 'I prefer to treat the children here rather than have the parents go to the East and have the operation carried out there'. [...]"

⁴⁸ Zurich University Children's Clinic, Media Release (13.05.2019): "DSD: Switzerland-wide agreement of treatment teams",

https://www.kispi.uzh.ch/de/medien/medien/medien/2019/Documents/190513_Medien/mitteilung_DSD%20Einigung%20Behandlung.pdf 49 Katrin Oller: "Intersexualität: Operation soll letzte Option sein", Der Landbote (13.05.2019),

https://www.landbote.ch/front/Intersexualitaet-Operation-soll-letzte-Option-sein/story/31642497 50 Jeanette Herzog, Zwist um Zwitter-Operationen, St. Galler Tagblatt (11.02.2011),

https://www.tagblatt.ch/ostschweiz/zwist-um-zwitter-operationen-ld.670674

4. Switzerland's historic role in framing intersex people as *"invalids"* and promoting IGM as a *"cure"*

Doctors and medical bodies, in complicity with healthcare providers and governing State bodies, have traditionally been **framing and "treating" intersex variations as a form of disability in the medical definition** in need to be "*cured*" or "*corrected*" surgically, often with racist, eugenic and suprematist undertones (see p. 14).

To this day, in **Switzerland**, such harmful stereotypes and prejudices are deeply ingrained, with the "Swiss Federal Invalidity Insurance" advocating, facilitating and financing IGM practices by framing healthy intersex children as "*invalids*" suffering from a "*birth defect*" and prescribing involuntary, unnecessary genital surgery and other procedures via substituted decisionmaking as a "*cure*" representing a particularly striking example of such stereotypes and prejudices in action (see also p. 18.).

In addition, starting in the 1920s Swiss doctors and eugenicists have been instrumental in internationally establishing and consolidating medical diagnoses framing intersex children as "disabled" and using them as a justification for IGM practices. For example, prominent Swiss gynaecologist and eugenicist Hans Guggisberg (1880-1977) co-authored the publication of the racist medical diagnosis "Intersexual Constitution", which introduced the term "intersexual" in human medicine. The new diagnosis claimed intersex was caused by racial "miscegenation" and described women diagnosed with it as "biologically inferior", prone to mental illnesses (e.g. "schizoid"), with "hypertrophied clitoris", as "most frequent in Jews" and "not fit for marriage". Initially conceived by the Austrian gynaecologist Paul Mathes (1871-1923) who in the 1920s already advocated "surgical correction", namely clitoris amputation, "[i]n cases where the intersexual woman was too far removed from the male ideal". It was first published in 1924 by Guggisberg after Mathes's death, and soon became internationally popular with prominent eugenicists and Nazi doctors, including Fritz Lenz, Hans Naujoks, Lothar Gottlieb Tirala, Robert Stigler, Wilhelm Weibel, Walther Stoeckel, and kept being used in medical textbooks until the 1950s.⁵¹

What's more, starting in 1950 Swiss paediatric endocrinologists and surgeons were also instrumental in introducing systematic early genital surgery and other procedures in Europe, including by introducing the term *"intersexuality"* in paediatrics as a medical diagnosis, and also in proliferating the current practice globally. ⁵²

To this day, in Switzerland there has been no coming to terms with neither the historic nor the ongoing harmful misrepresentation of healthy intersex children as "*invalid*", "*inferior*", "*disordered*" and "*deformed*", nor with the ongoing mutilations.

See also 2015 CAT NGO Report Austria, p. 55, http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf See also (in German)

⁵¹ See Helga Satzinger (2009), Racial Purity, Stable Genes, and Sex Difference. Gender in the Making of Genetic Concepts by Richard Goldschmidt and Fritz Lenz, 1916-1936. In: Susanne Heim, Carola Sachse, Mark Walker, The Kaiser Wilhelm Society for the Advancement of Science under National Socialism, Cambridge University Press, p. 145-172, at 161-162

 <u>http://blog.zwischengeschlecht.info/post/2012/06/21/Intersex-Typ-Schizoid-Weibel-Frauenheilkunde-1944</u>
 See 2014 CRC NGO Report, p. 54-56, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

5. Selective Intersex Abortion Rates: Klinefelter Syndrome (XXY) 74%, "Indeterminate Sex" 47%, Hypospadias 2%

Switzerland shows a high prevalence of selective abortions due to a prenatal intersex diagnosis, and the easier an intersex trait can be tested prenatally, the higher the selective (late term) abortion rates are, e.g.

- Klinefelter Syndrome (Karyotype XXY): **74%**⁵³
- "Indeterminate Sex": **47%**⁵⁴
- Hypospadias: 2%⁵⁵

Above figures are taken from comparative international registers and studies. Compared with the other countries listed, Switzerland has the 2nd to 3rd highest abortion rates.⁵⁶

6. No data collection and monitoring

Switzerland has been repeatedly recommended to **collect disaggregated data** on IGM, to **investigate cases of non-consensual unnecessary surgery**, and to **monitor** the practice.⁵⁷ However, also here the Swiss government has a long history of **promise but not deliver**.

For example, during the **2015 CRC review of Switzerland**, the Swiss delegation again promised that "the government wishes to collect information on surgery on intersex grounds. For the time being we have no clear data, the Federal Office for Statistics and the Federal Office for Public Health are now working together to develop a design for the collection of data, and the information on such surgery will allow us to gain a better appraisal of the situation".⁵⁸ However, ins **2016 CCPR State report**, Switzerland nonetheless just reiterated its **old incomplete 2011** figure of "1-3 treatments per age group" (CCPR/C/CHE/CO/4, para 188, fn 97).

To this day **not even reliable figures on IGM practices are available.**⁵⁹ The indefensibility of this situation is even implicitly **admitted by IGM doctors themselves**, e.g. by IGM surgeon Dr Jacques Birraux (HUG Geneva) in a 2019 media interview:

"Although this may seem absurd, we don't have any figures," says Dr. Jacques Birraux. "We'll need another decade to get Swiss figures." ⁶⁰

⁵³ Céline M. Girardin, Guy van Vliet (2011), Counseling of a couple faced with a prenatal diagnosis of Klinefelter syndrome, Acta Paediatrica 100:917-922

⁵⁴ International Centre for Birth Defects (ICBD) of the International Clearinghouse for Birth Defects Monitoring Systems, European Surveillance of Congenital Anomalies (EUROCAT), Human Genetics Programme of the World Health Organization (WHO) (2003), World Atlas of Birth Defects (2nd Edition), p. 184, <u>http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf</u>

⁵⁵ Ibid., p. 178

⁵⁶ For more information, see <u>http://stop.genitalmutilation.org/post/Selective-Intersex-Abortions-Hypospadias-Intersex-XXY</u>

⁵⁷ NEK-CNE, Recommendation 9; CEDAW/C/CHE/CO/4-5, paras 24-25; CCPR/C/CHE/CO/4, paras 24-25; CAT/C/CHE/CO/7, para 20; CRC/C/CHE/CO/2-4, paras 42-43

⁵⁸ Transcript, <u>http://stop.genitalmutilation.org/post/Transcript-Intersex-QA-CRC-Geneva-2015</u>

⁵⁹ See Interpellation National Council 18.3470, Operations on children affected by a variation of sex development. More transparency, <u>https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20183470</u>

⁶⁰ Lucie Fehlbaum, "Avancée inédite contre la mutilation des intersexes", 20minutes 18.04.2019, https://www.20min.ch/ro/news/geneve/story/Un--gigantesque-pas-en-avant--pour-les-intersexes-26455395

7. No free psychosocial support for intersex children and families

Switzerland has been repeatedly recommended to provide families with intersex children with adequate counselling and support.⁶¹

However, to this day the Swiss government claims "*free psychosocial support*" for persons and families concerned would be "*impossible*" to finance, and therefore also this recommendation would not be implemented⁶² (while claiming all other recommendation would "*already [be] implemented or in the process of being implemented*").

8. Swiss government denies the ongoing practice

There has been more than a decade of public criticism of IGM practices in Switzerland, including by members of the Federal parliament (National Council), the Swiss National Ethics Commission (NEK-CNE) and since 2015 also by CRC, CAT, CEDAW and CCPR.

Nonetheless, the **Swiss government**, despite 2016 finally **acknowledging** IGM practices having been "denounced at the political level by the Federal Parliament and Council as well as by the National Ethics Commission in its Opinion No. 20/2012 'On the management of differences of sex development. Ethical issues relating to intersexuality'",⁶³ and further **acknowledging** that IGM practices result in "considerable consequential damage and severe suffering of persons concerned",⁶⁴ to this day not only undeviatingly **refuses** to take effective action (see p. 25), nor to facilitate data collection (see p. 22), but instead to this day **continues to publicly deny the practice against better knowledge**, including by claiming

- IGM practices would be strictly a thing of the "*past*"⁶⁵
- the recommendations of the Swiss National Ethics Commission (NEK-CNE) concerning the Federal Government would all be "already implemented or in the process of being implemented" (with the only exception of the "free psychosocial support" for persons and families concerned which would be "impossible" to finance).⁶⁶

⁶¹ NEK-CNE, Recommendation 5; CRC/C/CHE/CO/2-4, paras 42-43; CAT/C/CHE/CO/7, para 20 ; CEDAW/C/CHE/CO/4-5, paras 24-25; CCPR/C/CHE/CO/4, paras 24-25

⁶² Swiss Federal Council, press release 06.07.2016, Personnes aux caractéristiques sexuelles ambiguës : sensibiliser davantage, <u>https://www.admin.ch/gov/fr/accueil/documentation/communiques.msg-id-62507.html</u>

⁶³ CCPR/C/CHE/4, para 188

⁶⁴ Swiss Federal Council, press release 06.07.2016, Personnes aux caractéristiques sexuelles ambiguës : sensibiliser davantage, <u>https://www.admin.ch/gov/fr/accueil/documentation/communiques.msg-id-62507.html</u>

⁶⁵ Ibid.

⁶⁶ Ibid.

9. Swiss Gov "rejects" CRC, CEDAW, CAT, CCPR Concluding Observations

Typically, the Swiss government officially rejected to implement the CRC Concluding Observations on harmful practices on intersex children, as documented in its December 2018 Implementation report.⁶⁷ While it's commendable that the Swiss government now officially acknowledged the CRC "criticism" of the "handling of harmful practices such as female genital mutilation or surgical interventions on intersex children" under "Violence against children",⁶⁸ in the end the Swiss government nonetheless decided explicitly not to implement CRC recommendation 43(b), but to officially "reject" it, and to prioritise civil registry reform instead, i.e. easier change of gender markers in official documents ("Amendment of the Civil Code (CC; SR 210)"), described as a "parallel review process [...] [c]urrently in the evaluation phase at the normative approach level")⁶⁹ – despite the fact that this is notably not an intersex demand, but an LGBT demand mostly benefitting trans persons, and that civil registry reform is in no way a remedy for IGM practices, and that accordingly no intersex NGO or UN Treaty body ever called for this, but rather to effectively address inhuman treatment and harmful practices against intersex children.

Regarding the **CAT**, **CEDAW** and **CCPR** Concluding observations on IGM, while the **Swiss** government so far did not yet officially "reject" to implement these, it's evident that Switzerland has not yet implemented them either, and the constant denial of the ongoing IGM practices by the Swiss government (see also p. 23) and the increasing trivialising and downgrading of IGM by the Swiss government (see also p. 19) leave little doubt of its de-facto rejection of *any* recommendation considering IGM a serious human rights violation, and little realistic hope for change in the foreseeable future.

⁶⁷ Swiss Federal Council (19.12.2018), "Measures to close gaps in the implementation of the Convention on the Rights of the Child. Report of the Federal Council as a result of the recommendations of the UN Committee on the Rights of the Child to Switzerland of 4 February 2015", <u>https://biblio.parlament.ch/e-docs/1901442546.pdf</u> Media release (19.12.2018), "*Convention on the Rights of the Child: Report on further measures for implementation*", <u>https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-73468.html</u>

<sup>p. 8 of the report (p. 18 in PDF):
"Violence against children [...] In addition to the demand for an explicit ban on corporal punishment, this topic also includes the handling of harmful practices such as female genital mutilation or surgical interventions on intersex children, the handling of mistreatment, abuse, neglect and domestic violence. The lack of data on these crimes and offences is also the subject of international criticism."</sup>

⁶⁹ p. 58 of the report (p. 70 in PDF)

10. Switzerland refuses to take appropriate action against IGM practices

Switzerland has been repeatedly urged to "[t]ake the necessary legislative, administrative and other measures" to stop IGM practices.⁷⁰

On Human Rights Day 2015, Co-Rapporteurs Zwischengeschlecht.org had again urged the Swiss government in an Open Letter to **legislate against IGM practices**, referring to the **Swiss National Ethics Commission NEK-CNE** and the **CAT** and **CRC** Concluding observations.⁷¹ The government decided to accept the Open Letter as a Petition.⁷²

Based on **false claims** by the Federal government IGM would be strictly a thing of the "*past*" and legislative measures unnecessary, the **Legal Affairs Committees** both of the Council of States (**LAC-S**, 23.01.2017)⁷³ and the National Council (**LAC-N**, 06.04.2017),⁷⁴ while conceding that "*premature unnecessary*" genital surgery "*constitutes a violation of the right to physical integrity*", stated the existing **legislation would be** "*sufficient*" **to protect** intersex children, and there would be "*no further need for legislation*", with **LAC-N** further claiming, "We believe medical professionals are nowadays sufficiently sensitised to the issue and only undertake such interventions when they are justified." ⁷⁵

In consequence, both **LAC-N** and **LAC-S** then **moved to reject** legislation as recommended by CAT, CRC, CEDAW and NEK-CNE, with both the **Council of the State** (16.03.2017)⁷⁶ and the **National Council** (16.06.2017)⁷⁷ following suit.

To this day, the Canton of Geneva remains the only community where the Parliament actually moved to prohibit IGM practices: On 10 April 2019, the **Great Council of the Republic and Canton of Geneva** adopted **two motions** calling on the Cantonal government to explicitly *"prohibit"* the *"mutilations of intersex persons"*.⁷⁸ Notably, during the debate before the adoption, both a member of the **Great Council** and a member of the **Cantonal government** proclaimed that at the Geneva University Hospital (HUG) **allegedly there had been** *"no operations since 2012"*.⁷⁹ Unfortunately, this is far from the truth.⁸⁰

⁷⁰ NEK-CNE, Recommendation 12; CAT/C/CHE/CO/7, para 20; CEDAW/C/CHE/CO/4-5, paras 24-25; CCPR/C/CHE/CO/4, paras 24-25; CRC/C/CHE/CO/2-4, paras 42-43

^{71 &}lt;u>http://zwischengeschlecht.org/public/Offener_Brief_Zwischengeschlecht_Bern_10-12-2015.pdf</u>

⁷² ibid., p. 3

^{73 &}lt;u>https://www.parlament.ch/centers/kb/Documents/2015/Kommissionsbericht_RK-S_15.2043_2017-01-23.pdf</u>

https://www.parlament.ch/centers/kb/Documents/2015/Kommissionsbericht RK-N 15.2043 2017-04-06.pdf
 ibid.

^{76 &}lt;u>https://www.parlament.ch/de/ratsbetrieb/amtliches-bulletin/amtliches-bulletin-die-verhandlungen?SubjectId=39798</u>

 $[\]label{eq:constraint} 77 \qquad \underline{https://www.parlament.ch/de/ratsbetrieb/amtliches-bulletin/amtliches-bulletin-die-verhandlungen?SubjectId=40660}$

⁷⁸ Motion 2491 "to end the mutilations of intersex people", <u>http://ge.ch/grandconseil/search?search=2491</u> Motion 2541 "No more mutilations practiced on intersex people", <u>http://ge.ch/grandconseil/search?search=2541</u> Protocol of the Great Council of the Republic and Canton of Geneva (10 April 2019, 21:00-22:35, Item 123), <u>http://ge.ch/grandconseil/sessions/seances-pv-lion/22/?session=66</u> See also statement of StopIGM.org to the Great Council (26.09.2018), <u>http://stop.genitalmutilation.org/public/StopIGM-Geneve-M2491-mutilations-personnes-intersexes.pdf</u>

⁷⁹ See statements of Céline Zuber-Roy (21h47:21) and Mauro Poggia (21h48:21), http://ge.ch/grandconseil/sessions/video/020111/66/

⁸⁰ For example, Dr Jacques Birraux's 2017 thesis "Management of disorders of sexual development: State of the art. A Surgeon's perspective in Western Switzerland", openly promotes "early surgery" regarding "masculinization genitoplasty", as well as "feminization genitoplasty" (p. 37 in thesis, p. 40 in PDF),

11. No access to redress and rehabilitation for IGM survivors

Switzerland has been repeatedly urged to "adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation" to stop IGM practices.⁸¹

Nonetheless, to this day the **statutes of limitation** prevent 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, which in combination with severe trauma caused by IGM practices often proves to amount to a severe obstacle,⁸² as also in **Switzerland** the statutes of limitations effectively **prohibit survivors of early childhood IGM practices to call a court**.

This has also been confirmed by Swiss paediatric surgeon **Dr. Blaise Meyrat**, who in 2015 plainly stated:

"Things hardly evolve in the medical world. In my opinion, only the fear of the judge will make things change. We need statutes of limitation long enough so that victims may sue as adults." ⁸³

Accordingly, so far in Switzerland **no victim of IGM practices succeeded in going to court** or obtaining redress and compensation ever. In addition, **IGM survivors suffering from trauma** d are forced to at least partly **cover expenses for rehabilitation out of their own pocket**. ⁸⁴

https://archive-ouverte.unige.ch/unige:103975

Also the HUG homepage continues to openly advocate various IGM practices, stressing "*The ideal age to perform the surgery is between 1 and 2 years.*", see statement of StopIGM.org to the Great Council (26.09.2018), p. 8, http://stop.genitalmutilation.org/public/StopIGM-Geneve-M2491-mutilations-personnes-intersexes.pdf

- 81 NEK-CNE, Recommendation 12; CAT/C/CHE/CO/7, para 20; CEDAW/C/CHE/CO/4-5, paras 24-25; CCPR/C/CHE/CO/4, paras 24-25; CRC/C/CHE/CO/2-4, paras 42-43
- 82 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.
- 83 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
- 84 For example, while Co-Rapporteur Daniela Truffer's IGM procedures were all paid in full by the "Swiss Federal Invalidity Insurance", for the psychotherapy to deal with the resulting trauma, she had to pay one third out of her own pocket, see Daniela Truffer (2016), It's a Human Rights Issue!, in Georgiann Davis (ed.), Normalizing Intersex: The Transformative Power of Stories (Narrative Inquiry in Bioethics), Johns Hopkins University Press, p. 26-29 in journal (p. 33-36 in PDF), at p. 28 in the journal (p. 35 in PDF)

12. IGM institutions destroying medical records during a "scientific review"

Switzerland has been explicitly recommended to **guarantee IGM survivors access to their medical records**,⁸⁵ as this can be very important to them also for rehabilitation purposes.

However, in 2016 the Zurich University Hospital was allowed to destroy about 80% of its historic medical files documenting IGM practices⁸⁶ as part of a "scientific review of the treatment of children with differences of sex development (DSD children)" funded by the Swiss National Science Foundation (SNSF) with Sfr 500'000.-⁸⁷ and led by the perpetrator institutions Zurich University Hospital and Zurich University themselves, but without adequate consultation of intersex persons and their organisations. As a result, for example a member of the self-help group Intersex.ch⁸⁸ who wanted to access his files, was told that, while at the Zurich State Archives there was still a note in the register confirming in 1945 and 1946 he was in treatment at the Department of Surgery of the Zurich University Children's Hospital, the actual files were no longer available.⁸⁹ This outrageous destruction of evidence was also corroborated by a Parliamentary inquiry in the Cantonal Council of Zurich.⁹⁰

⁸⁵ CCPR/C/CHE/CO/4, para 25(b)

⁸⁶ i.e. 90% of all cases of IGM 1 "masculinising surgeries (hypospadias corrections)". Personal communication and e-mails with doctor and historian of the Zurich University Children's Hospital, April 2016; Personal communication with Zurich State Archives, June 2016

⁸⁷ see Press Release SFNF 10.10.2016, <u>http://www.snf.ch/en/researchinFocus/newsroom/Pages/news-161010-press-release-reviewing-the-treatment-of-differences-of-sex-development.aspx</u>

⁸⁸ See **Case No. 1** in the 2014 CRC Swiss NGO Report, p. 32-33 <u>http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf</u>

⁸⁹ E-mails Zurich State Archives, 19.01.2017 and 21.03.2017

 ⁹⁰ See Zurich Cantonal Council inquiry (328/2018): Destruction of files concerning operations on children with variations of sex development in the Zurich Children's Hospital, http://www.kantonsrat.zh.ch/Geschaefte/Geschaefte.aspx?GeschaeftID=515cf4f3-1641-43f0-8fe4-9e28b9bf28df
 StopIGM.org (28.10.2018), "Zurich University Children's Hospital: Destruction of medical recrds instead of reappraisal", http://stop.genitalmutilation.org/post/Intersex-Awareness-Day-2018
 Fabian Baumgartner, Jan Hudec (2018): Akten von Intersex-Patienten vernichtet, NZZ 01.11.2018, p. 29, https://www.nzz.ch/zuerich/die-intersex-kinder-weshalb-akten-zu-umstrittener-behandlung-am-zuercher-kinderspital-vernichtet-worden-sind-ld.1432386
 Katrin Oller: Intersexualität: Bei Aufarbeitung wurden Akten vernichtet, Der Landbote 31.12.2018, https://www.landbote.ch/ueberregional/intersexualitaet-bei-aufarbeitung-wurden-akten-vernichtet/story/24989187