## Intersex Genital Mutilation

**Human Rights Violations Of Children With Variations Of Reproductive Anatomy** 



NGO Report (for Session) to the 5<sup>th</sup> to 6<sup>th</sup> Report of Switzerland on the Convention on the Rights of the Child (CRC)

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#### This NGO Report online:

https://intersex.shadowreport.org/public/2021-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-StopIGM.pdf







#### **Executive Summary**

All typical forms of IGM practices are still practiced in Switzerland today, facilitated and paid for by the State party via the Swiss Federal Invalidity Insurance. Switzerland explicitly "rejects" to implement the Concluding Observations on intersex children. Swiss University and Cantonal Children's Hospitals continue to advocate and practice IGM with impunity, while Government agencies keep denying the practice, including in the State Report.

Switzerland is thus in breach of its obligations under CRC to (a) take effective legislative, administrative, judicial or other measures to prevent harmful practices on intersex children causing severe mental and physical pain and suffering of the persons concerned, and (b) ensure access to redress and justice, including fair and adequate compensation and as full as possible rehabilitation for victims, as stipulated in CRC art. 24 para. 3 in conjunction with the CRC-CEDAW Joint general comment No. 18/31 "on harmful practices".

This Committee has already recognised IGM practices in Switzerland to constitute a harmful practice under the Convention in Concluding Observations, as did CEDAW, and CAT and CCPR as cruel, inhuman or degrading treatment.

In total, UN treaty bodies CRC, CEDAW, CAT, CCPR and CRPD have so far issued 52 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 more than **25 years**, intersex people have denounced IGM as **harmful** and **traumatising**, as western **genital mutilation**, as **child sexual abuse** and **torture**, and called for **remedies**.

This NGO Report has been compiled by the international NGO StopIGM.org / Zwischengeschlecht.org, and the Swiss peer support groups Intersex.ch and SI Selbsthilfe Intersexualität. It contains Suggested Recommendations (see p. 24).

## NGO Report for Session to the 5<sup>th</sup> to 6<sup>th</sup> Report of Switzerland on the Convention on the Rights of the Child (CRC)

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#### A. Introduction

#### 1. Intersex, IGM and Human Rights in Switzerland

The Swiss Government officially "rejects" to implement the Concluding Observations on harmful practices on intersex children, unduly focusing on civil gender registration reform instead. This NGO Report demonstrates that at least 9 University and Cantonal Children's Hospitals continue practicing IGM with impunity, paid for by the State party via the Swiss Federal Invalidity Insurance. It further substantiates that the Government denials of the ongoing harmful medical practice, also evident in the State Report, are not correct and do not correspond to the facts.

#### 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!*" <sup>1</sup> According to its charter, <sup>2</sup> StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to UN treaty bodies. <sup>3</sup>
- Intersex.ch is a Swiss intersex peer support group founded in 2005.<sup>4</sup>
- SI Selbsthilfe Intersexualität is a Swiss peer support group for parents of intersex children founded in 2003.

#### 3. Methodology

This thematic NGO report follows up on the **2014 thematic CRC NGO Report**<sup>5</sup> and the **2019 thematic CRC NGO Report for LOIPR**<sup>6</sup> by the same rapporteurs, and the resulting **Concluding observations** by this Committee (CRC/C/CHE/CO/2-4, paras 42-43).

<sup>1</sup> https://Zwischengeschlecht.org/ English pages: https://StopIGM.org/

<sup>2 &</sup>lt;a href="https://zwischengeschlecht.org/post/Statuten">https://zwischengeschlecht.org/post/Statuten</a>

<sup>3</sup> https://intersex.shadowreport.org/

<sup>4 &</sup>lt;a href="https://intersex.ch/">https://intersex.ch/</a>

<sup>5</sup> https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\_v2.pdf

<sup>6</sup> https://intersex.shadowreport.org/public/2019-CRC-LOIPR-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf

- B. Precedents: Concl Obs, LOI(PR), State Report on IGM in Switzerland
- 1. Previous Concluding Observations, LOI
- a) Harmful Practices: 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) Harmful Practices: 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.

#### c) Inhuman Treatment: 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.

## d) Inhuman Treatment: 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.

## e) Inhuman Treatment, Exploitation, Violence and Abuse, Integrity of the Person: CRPD 2019, CRPD/C/CHE/Q/1, paras 12(e)-14(e)

#### Freedom from torture or cruel, inhuman or degrading treatment or punishment (art. 15)

#### 12. Please provide information on: [...]

(e) Criminal and civil remedies available to persons with disabilities, including intersex persons with disabilities, who have undergone involuntary sterilization or unnecessary and irreversible medical or surgical treatment, procedures to access medical records and whether remedies are subject to any statutes of limitations.

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

#### 13. Please provide information on: [...]

(e) Measures taken to promote the physical, cognitive and psychological recovery and rehabilitation and social reintegration of intersex persons who have undergone involuntary procedures, including those who underwent irreversible surgical procedures as children with parental consent, and steps taken to ensure that such measures are covered by medical insurance.

#### Protecting the integrity of the person (art. 17)

#### 14. Please provide information on: [...]

(b) Measures taken to ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood (CRC/C/EHE/CO/2-4, para. 43 (b); CAT/C/CHE/CO/7, para. 20 (a); CEDAW/C/CHE/CO/4-5, para. 25 (c); and CCPR/C/CHE/CO/4, para. 25), and data on the number of irreversible surgical and other procedures that are performed on intersex children, disaggregated by age and geographic location.

- 2. Current 5<sup>th</sup> to 6<sup>th</sup> CRC Cycle: LOIPR and State Report
- a) LOIPR: CRC/C/CHE/QPR/5-6, para 16(b)
- D. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39) [...]

#### Harmful practices

- 16. Please provide information on the measures taken to: [...]
- (b) Ensure that intersex children are not subjected to unnecessary medical or surgical treatment, and to provide adequate counselling, support and access to effective remedies for the victims subjected to such treatment during childhood. Please provide information on whether unnecessary medical or surgical treatment for intersex children is still covered by disability insurance;

#### b) State Report: CRC/CHE/5-6, paras 113-121

Harmful practices [...]

#### Reply to §16b

- 113. The Swiss National Advisory Commission on Biomedical Ethics [NEK-CNE] has dealt with intersex issues on behalf of the Government and published a position paper containing a number of recommendations, the majority of which concerning the Confederation have been or are being implemented.
- 114. With regard to medical or surgical treatment, the Government considers that current practice respects the rights of intersex persons. Premature or unnecessary interventions are contrary to the law governing physical integrity. Wherever possible, a decision should be taken only when the child is old enough, if the treatment would have irreversible consequences. According to experts, the best interests of the child take precedence over medical interventions and treatments.
- 115. The general legal rights of patients apply to the treatment of intersex children. Intersex children have the right to medical treatment and care in accordance with the state of the art of medical science, the right to information and consent and the right to protection of their personal data. According to the CEC's [Central Ethics Committee (CEC) of the Swiss Academies of Arts and Sciences (SAMW-ASSM)] position paper of 2016, "the care of the families concerned has been improved in Switzerland and the recommendations of the Swiss National Advisory Commission on Biomedical Ethics [NEK-CNE] and international standards are respected as far as possible. In principle, parents in this distressing situation are now advised and supported by an interdisciplinary team from birth. In doing so, all decisions regarding treatment and interventions must be oriented towards the good of the child and taken in the sense of shared decision making.
- 116. Social security provides for appropriate coverage of necessary treatment. In social law, this is a birth defect [Geburtsgebrechen (Gg)-Infirmités Congénitales (IC)], i.e. "an illness present at the completed birth of the child". Coverage by the Swiss Federal Invalidity Insurance [Invalidenversicherung (IV)-Assurance Invalidité (AI)] ends on the 20th birthday of the insured person. After this date, the Compulsory Health Insurance [OKP-AOS] takes over.

- 117. A surgical operation for the purpose of assigning a sex to a child who is incapable of judgement constitutes in principle an illicit physical injury if it is not necessary to safeguard the child's life or health (Art. 122 para. 2 of the Criminal Code). The offender could be the doctor in the case of an intervention without the consent of the legal representatives, or even the latter if they have validly consented to the unnecessary intervention.
- 118. See §10 (draft on sex change in civil status).
- 119. According to the Federal Office of Public Health [FOPH-BAG-OFSP] data, about 40 children for whom it is not clear whether they are a girl or a boy are born each year in Switzerland. For other children, it is their later sexual development that leads to this uncertainty.
- 120 According to the Basel Children's Hospital, in Switzerland these cases are usually managed by interdisciplinary teams. Surgical indications are nowadays treated very restrictively. Data on intersex children are recorded in the European Disorder of Sex Development Registry [I-DSD Registry]. Patients have the right to consult their files at any time. Throughout Switzerland, meetings of all specialists involved in the care of intersex children are held regularly; these specialists usually work in paediatric hospitals.
- 121. The information from the cantons confirms these statements. Intersex children are examined in university centres or specialised hospitals and cared for by interdisciplinary teams. Unnecessary medical and surgical interventions are avoided. Children and parents are carefully supported and monitored.
- 122. See §23d ([Federal Invalidity Insurance] measures).

#### C. IGM practices in Switzerland: Updates to LOIPR NGO Report

This section documents recent developments not mentioned in our LOIPR NGO Report and follows-up to findings presented there.

- 1. Switzerland: Still no protections for intersex people, State party rejects COs In Switzerland the lack of protections of intersex children from harmful practices and inhuman treatment remains unchanged. In particular, 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 non-consensual, medically unnecessary, irreversible surgery and other harmful treatments a.k.a. 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

All forms of **IGM practices remain widespread and ongoing** – advocated, facilitated and **paid for by the State party** via the **Swiss Federal Invalidity Insurance** (Invalidenversicherung IV – Assurance Invalidité AI) according to its **List of Birth Defects** (Liste der Geburtsgebrechen – Liste des Infirmités Congénitales) covering intersex surgeries on children until the age of 20, but not for consenting adults.<sup>7</sup>

At the same time, as also evident in the State report, the Swiss government continues to

- deny the ongoing practice,
- reject repeated UN recommendations by CRC, CAT, CEDAW, CCPR,
- claim "free psychosocial support" would be "impossible" to finance,
- claim the existing legislation would be sufficient to protect intersex children,
- refuse to take effective measures,
- enable perpetrator institutions to destroy medical records during "scientific review" of practice funded by the Swiss National Science Foundation (SNSF).

In particular, the **Swiss government still officially rejects to implement this Committee's recommendations on harmful practices on intersex children**, as documented in its December 2018 report "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".<sup>8</sup>

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, <a href="http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\_Intersexualitaet\_En.pdf">http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\_Intersexualitaet\_En.pdf</a>
For the relevant numbers in the List of Birth Defects, see <a href="https://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen">https://blog.zwischengeschlecht.info/pages/Kosmetische-Genitaloperationen-Ziffern-Liste-der-Geburtsgebrechen</a>
For relevant numbers in most frequent current IGM practices see 2017 CCPR Swiss NGO Report, p. 8-10, <a href="https://intersex.shadowreport.org/public/2017-CCPR-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf">https://intersex.shadowreport.org/public/2017-CCPR-Swiss-NGO-Zwischengeschlecht-Intersex-IGM.pdf</a>

Full report (19.12.2018), <a href="https://biblio.parlament.ch/e-docs/1901442546.pdf">https://biblio.parlament.ch/e-docs/1901442546.pdf</a>
Media release (19.12.2018), "Convention on the Rights of the Child: Report on further measures for implementation", <a href="https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-73468.html">https://www.admin.ch/gov/de/start/dokumentation/medienmitteilungen.msg-id-73468.html</a>

Notably, the **justification** of the Federal Government for **not implementing para. 43(b)** of the Concluding Observations concerning harmful practices on intersex children, but to **explicitly and officially** "reject" it, was the Federal Government's decision to **prioritise civil registry reform instead**, i.e. easier change of gender marker mostly for trans people ("Amendment of the Civil Code (CC; SR 210)."). Despite the fact that **civil registry reform is in no way a remedy for IGM practices**, and despite that neither intersex NGOs, nor this or other Committees **ever called for it**, but to **effectively address harmful practices** against intersex children.

#### 2. IGM Practices continue with impunity

#### a) Endorsed International Guidelines prescribing IGM still in force

The Swiss Society of Urology ("Schweizerische Gesellschaft für Urologie – Société Suisse d'Urologie – SWISS UROLOGY") still endorses the 2021 Guidelines of the European Association of Urology (EAU), 10 which include the – concerning IGM unchanged – current ESPU/EAU "Paediatric Urology" Guidelines 2021 of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which promote IGM practices, in particular IGM 3: "removal of testes", 12 IGM 2: partial clitoris amputation on young children based on "social and emotional conditions" and substituted decision-making by "parents and caregivers implicitly act[ing] in the best interest of their children", 13 and IGM 1: "The age at surgery for primary hypospadias repair is usually 6-18 (24) months." 14

#### b) Secret National DSD Guidelines prescribing IGM still in force

The 2019 "Switzerland-wide agreement of DSD treatment teams" prescribing IGM practices if "the parents cannot bear to live with the 'shame'" of having an intersex child remain in force. While the agreement itself is still kept secret and not published, the Press release and public interviews by doctors marking its introduction in spring 2019 make clear that it prescribes IGM. 15

c) "Multidisciplinary DSD Teams" still dominated by surgeons and endocrinologists According to a 2018 poster by members of the "Working Group DSD of the Swiss Society for Pediatric Endocrinology and Diabetology (AG DSD SGPED)" presented at the 57th Annual Meeting of the European Society for Paediatric Endocrinology (ESPE 2018), the Swiss "Multidisciplinary DSD Teams" continue to be dominated by paediatric surgeons ("Ped. surgery", "Ped. urology") and paediatric endocrinologists ("Ped. endocrinology"): 16

10 <a href="https://uroweb.org/guidelines/endorsement/">https://uroweb.org/guidelines/endorsement/</a>

<sup>9</sup> p. 58 of the report (p. 70 in PDF)

<sup>11 &</sup>lt;u>https://uroweb.org/wp-content/uploads/EAU-Guideline</u>s-on-Paediatric-Urology-2021-1.pdf

For details and relevant quotes, see 2021 CRC Bulgaria LOIPR NGO Report, p. 8-9, <a href="https://intersex.shadowreport.org/public/2021-CRC-Bulgaria-LOIPR-NGO-Intersex-StopIGM.pdf">https://intersex.shadowreport.org/public/2021-CRC-Bulgaria-LOIPR-NGO-Intersex-StopIGM.pdf</a>

<sup>13</sup> For details and relevant quotes, see ibid., p. 10

<sup>14</sup> For details and relevant quotes, see ibid., p. 11

<sup>15</sup> For details and relevant quotes, see our 2019 CRC Switzerland LOIPR NGO Report, p. 11

Grit Sommer, Daniel Konrad, Beatrice Kuhlmann, Dagmar L'Allemand, Franziska Phan-Hug, Michael Hauschild, Valerie Schwitzgebel, Paolo Tonella, Melanie Hess, Urs Zumsteg, Anna Lauber-Biason, Christa E. Flück, for the Working Group DSD of the Swiss Society for Pediatric Endocrinology and Diabetology (AG DSD SGPED) (2018), "Current medical care of children and adolescents with disorders of sex development in Switzerland", poster P2-P346 at ESPE 2018, https://abstracts.eurospe.org/hrp/0089/eposters/hrp0089p2-p346\_eposter.pdf

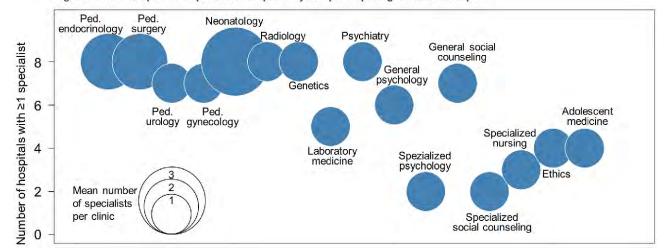


Fig.1: Number of specialists per medical speciality in 8 participating children's hospitals.

The poster further admits, "specialized DSD psychologists and adult DSD specialists [are] lacking".

#### d) "Multidisciplinary DSD Teams" still prefer and practice early IGM

According to a presentation at the **September 2019** "European Congress for Paediatric Endocrinology" (i.e. the **58th Annual Meeting of the European Society for Paediatric Endocrinology ESPE**) co-authored by a doctor from the Berne University Children's Hospital and based on data of the **I-DSD/CAH Registry** (of which the Swiss IGM hospitals are members), the "Multidisciplinary DSD Teams" still **prefer and practice early "feminising genital corrections" (IGM 2):**<sup>17</sup>

"Genital surgery has been performed in 251 (76%). Clitoral surgery been performed in 231 (92%), vaginal surgery in 204 (81%) and a combination of clitoral and vaginal surgery had been performed in 186 (74%). Of the 251 who had surgery, 18 (7%) had vaginal but no clitoral surgery whilst 42 (17%) had clitoral but no vaginal surgery. Mean age at first surgery was 2.5 years (0-15), with clitoral surgery and vaginal surgery at 2.6 years (range) and 3.2 years (range), respectively. [...] The Chicago Consensus Statement on DSD (comparison of data before and after 2006) did not have any significant influence on the timing or probability of surgery."

#### e) Swiss Cantonal and University Hospitals continuing IGM with impunity

"SwissPedNet – the Swiss Research Network of Clinical Pediatric Hubs" <sup>18</sup> includes 5 university children's hospitals and 4 cantonal children's hospitals, which all continue to practice IGM:

Doris Hebenstreit, Faisal Ahmed, on behalf of the contributing centres within the I-DSD registry and I-CAH registry, Alexander Springer, Christoph Krall, Nils Krone, Niels Birkebaek, Tatjana Milenkovic, Birgit Koehler, Christa Flueck (Pediatric Endocrinology, Diabetology and Metabolism, Department of Pediatrics, University Hospital Inselspital, University of Bern, 3010 Bern, Switzerland; Department of BioMedical Research, University Hospital Inselspital, University of Bern, Bern, Switzerland), Ruth Krone, Antonio Balsamo, Rodolfo Rey, Carlo Acerini, Alya Guven, Tulay Guran, Feyza Darendeliler, Sabah Alvi, Marta Korbonits, Walter Bonfig, Eduardo Correa Costa, Richard Ross, Violeta Iotova, Daniel Konrad, Jillian Bryce, Hedi Claahsen van der Grinten, Liat de Vries, Contemporary surgical approach in CAH 46XX – Results from the I-DSD/I-CAH Registries, presentation at ESPE 2019, see Abstract Book, p. 96, https://www.karger.com/Article/Pdf/501868

https://www.swisspednet.ch/header/about-us/

#### • Basel University Children's Hospital (UKBB)

The "Paediatric Surgery" homepage of the UKBB offers under "Urology" surgery for "Hypospadias" (IGM 1). 19

#### • Bern University Children's Hospital (Inselspital)

The "Paediatric Urology" homepage of the Children's Clinic of the Inselspital offers under "Diagnosis and treatment" "Hypospadias and reconstruction of the urethra: All forms of surgical correction incl. use of oral mucosa" (IGM 1).<sup>20</sup>

#### • Geneva University Children's Hospital (HUG)

The "Disorders of Sex Development" homepage of the Department for Paediatric Surgery of the HUG advocates "Treatment: [...] Important decisions about the direction of treatment will be made in consultation with the parents and then with the child according to his or her understanding and age. Treatment may be medical, surgical or a combination of both and may extend into adulthood." (IGM 1-3).<sup>21</sup>

The "Malformation of the penis" homepage of the Department for Paediatric Surgery of the HUG advocates "Treatment: [...] The definitive treatment is surgical, allowing in the same operation to correct the curvature of the penis and to bring the urinary meatus to the top of the glans by reconstructing the urethra. The foreskin is usually used for this, so the penis will look circumcised after the operation. Some reconstruction techniques require several operations. [...]

Prognosis: As the operation is performed on hypoplastic tissue, the rate of post-operative complications is significant. These are mainly healing problems, the most frequent of which are:

- **Fistulas** (leakage along the path of the reconstructed urethra)
- **Dehiscence** (partial or total reopening of the reconstruction).
- More rarely, **stenosis** (narrowing of the new urinary meatus).

The likelihood of complications depends on the extent of the initial damage.

#### Most complications require re-intervention." (IGM 1). 22

The brochure "Your child is going to be operated on for hypospadias" of the Department for Paediatric Surgery of the HUG advocates "Reconstructive surgery is recommended to avoid difficulties during urination and cosmetic problems. The aim is also to prevent difficulties during the sexual act and the risk of infertility later on. The ideal age for the operation is between 1 and 2 years." (IGM 1). <sup>23</sup>

And a 2017 thesis "Management of disorders of sexual development: State of the art. A Surgeon's perspective in Western Switzerland" by HUG paediatric surgeon Jacques Birraux openly promotes "early surgery" regarding "masculinization genitoplasty" (IGM 1), as well as "feminization genitoplasty" (IGM 2) (see also below, p. 25-26).<sup>24</sup>

<sup>19</sup> https://www.ukbb.ch/en/ukbb/departments-services/surgery.php#anchor\_9a0a567a\_Accordion-Urology

<sup>20 &</sup>lt;a href="http://www.kinderklinik.insel.ch/de/unser-angebot/urologie/">http://www.kinderklinik.insel.ch/de/unser-angebot/urologie/</a>

<sup>21 &</sup>lt;u>https://www.hug.ch/chirurgie-pediatrique/desordre-du-developpement-sexuel</u>

<sup>22</sup> https://www.hug-ge.ch/chirurgie-pediatrique/malformation-de-la-verge

<sup>23 &</sup>lt;u>https://www.hug-ge.ch/chirurgie-pediatrique/votre-enfant-va-etre-opere-hypospadias</u>

<sup>24</sup> See p. 37 in thesis, p. 40 in PDF, <a href="https://archive-ouverte.unige.ch/unige:103975">https://archive-ouverte.unige.ch/unige:103975</a>

#### • Lausanne University Children's Hospital (CHUV)

The "Paediatric Urology" homepage of the CHUV homepages states under "Most frequent reasons for consultation: [...]

Problems affecting the genitals (pathological phimosis, **hypospadias**, penis curvature, synechia of the labia minora, etc.) [...]

In an interdisciplinary team we also treat rarer conditions, such as

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variations in sexual development [...]
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rare abnormalities of the genital tract (urogenital sinus, duplication of the internal genital tract...) [...]" (IGM 1-2).<sup>25</sup>

#### • Zurich University Children's Hospital (Kispi Zürich)

The "Urology" homepage of the Children's Hospital Zurich offers under "Full spectrum of diagnostics and therapy" "Surgeries on the external genitals: cryptorchidism (undescended testis), hypospadias and epispadias (urethral malformation), correction of intersex genitals" (IGM 1-3).<sup>26</sup>

#### • Aarau Cantonal Children's Hospital

The "Range of services paediatric surgery" homepage of the Cantonal Hospital Aarau offers under "Urology", "We treat among other things: Undescended testicles, [...] Hypospadias, [...] Penile curvature" (IGM 1), and under "Plastic surgery", "We treat among other things: [...] Gynecomastia" (IGM 1)<sup>27</sup>

#### • Lucerne Cantonal Children's Hospital

The "Kidneys, urinary tract, bladder and genital organs in children and adolescents" homepage of the Lucerne Children's Hospital offers:

#### "Paediatric surgery: Paediatric urology is a focal point

Paediatric urology covers the entire spectrum of diagnostics as well as non-operative (conservative) and operative treatment. Our services include the treatment of diseases, malformations and injuries of the kidneys and urinary tract and the male and female reproductive organs. We treat, among other things: [...]

Malformations of the urethra (hypospadias, epispadias)

*Undescended testis*" (**IGM 1**)<sup>28</sup>

#### • St. Gallen Cantonal Children's Hospital (Eastern Switzerland Children's Hospital)

The "Urology" homepage of the Eastern Switzerland Children's Hospital offers under "Range of services: [...]

<sup>25 &</sup>lt;a href="https://www.chuv.ch/fr/dfme/dfme-home/enfants-famille/specialites-medicales/chirurgie-de-lenfant-et-de-ladolescent/urologie-pediatrique">https://www.chuv.ch/fr/dfme/dfme-home/enfants-famille/specialites-medicales/chirurgie-de-lenfant-et-de-ladolescent/urologie-pediatrique</a>

<sup>26</sup> https://www.kispi.uzh.ch/de/patienten-und-angehoerige/fachbereiche/urologie/Seiten/default.aspx#a=akk3

<sup>27 &</sup>lt;u>https://www.ksa.ch/zentren-kliniken/kinderchirurgie/leistungsangebot</u>

<sup>28 &</sup>lt;u>https://www.luks.ch/standorte/standort-luzern/kinderspital/leistungsangebot-kinderspital/nieren-harnwege-blase-und-geschlechtsorgane-bei-kindern-und-jugendlichen</u>

Congenital urethral malformations are corrected according to the latest findings and also examined in terms of function during the course of the operation. A team consisting of surgeons, radiologists, hormone specialists and psychologists takes care of the family and the child according to need and the severity of the disease."

And under "Conditions [...]

Congenital urethral malformations [...]

Congenital undescended testicles [...]

Deformities of the genitals" (IGM 1-3)<sup>29</sup>

And the current flyer for parents titled "Multiprofessional Consultation" in cases of "Disorders of Sex Development", advocates under "Therapy": "Corrective surgery" for "Hypertrophy of the clitoris" (IGM 2).<sup>30</sup>

• EOC Ticino Cantonal Children's Hospital (Ente Ospedaliero Cantonale Ticino)
Since 2004, the EOC offers "hypospadias repair" (IGM1) in Bellinzona. 31

The "SwissPedNet" comprising of the above 9 IGM clinics is the official clinical research organisation of the "Swiss Society of Paediatrics (SGP/SSP)", which in turn is a member of the "Child Rights Network Switzerland" and successfully pressured the Network to corrupt the section on IGM in its NGO Coalition Report (for Session) to this Committee (see below, p. 19-20).

#### f) Swiss IGM doctors experimenting on African intersex children

A paediatric surgeon from the **Geneva University Children's Hospital**, Jacques Birraux, personally **experimented on at least 487 African intersex children** in Yaounde (Cameroon) performing **IGM 1-3**, <sup>32</sup> <sup>33</sup> <sup>34</sup> including on a **5-year-old African intersex child** to establish a "new **surgical technique**" for **IGM 2**: "vaginoplasty", <sup>35</sup> with a geneticist from the **Geneva University** 

30 https://www.kispisg.ch/downloads/kompetenzen/endokrinologie/flyer\_sprechstunde\_eng\_def.pdf

<sup>29 &</sup>lt;a href="https://www.kispisg.ch/de/fachbereiche/kompetenzen/urologie">https://www.kispisg.ch/de/fachbereiche/kompetenzen/urologie</a>

 $<sup>31 \</sup>qquad \underline{https://www.eoc.ch/en/Media-e-comunicazione/Comunicati/2004/Compie-5-anni-il-Servizio-cantonale-di-chirurgia--pediatrica.html\#}$ 

Jacques Birraux (2017), "Management of disorders of sexual development: State of the art. A Surgeon's perspective in Western Switzerland". Thesis, see chapter "II. C) Acquired knowledge in Cameroon", p. 7-13 (p. 10-16 in PDF), <a href="https://archive-ouverte.unige.ch/unige:103975">https://archive-ouverte.unige.ch/unige:103975</a>

Birraux Jacques (Paediatric Surgery, Department of Pediatrics Children's Hospital, University Hospital of Geneva, **Switzerland**), Dahoun Sophie, Rougemont-Pidoux Anne-Laure, Le Coultre Claude, Mouriquand Pierre, Plotton Ingrid, Morel Yves, Gay Claire-Lise; Tardy Véronique, Mouafo Faustin, Mure Pierre-Yves, "Gender Assignment in 46XX Ovotesticular DSD: Experience learned from a series of 16 consecutive children". Manuscr Prep.

Céline M Girardin, Mirjam Dirlewanger, Frédérique Sloan-Béna, Serge Nef, Anne-Laure Rougemont, Jacques Birraux, Valerie M Schwitzgebel (2014), Geneva University Children's Hospital, "46, XX Ovotesticular Disorder of Sex Development: Potential Role of 13q31.1", poster P1-D3-97, 53rd Annual Meeting of the ESPE, <a href="https://abstracts.eurospe.org/hrp/0082/eposters/hrp0082p1-d3-97\_eposter.pdf">https://abstracts.eurospe.org/hrp/0082/eposters/hrp0082p1-d3-97\_eposter.pdf</a>

Jacques Birraux (Paediatric Surgery, Department of Pediatrics Children's Hospital, University Hospital of Geneva, **Switzerland**), Faustin Tambo Mouafo, Sophie Dahoun (Medical Genetic, Department of Genetics, University Hospital of Geneva, **Switzerland**), Veronique Tardy, Yves Morel, Pierre Mouriquand, Claude Le Coultre, Pierre-Yves Mure (2015), "Laparoscopic-assisted vaginal pull-through: A new approach for congenital adrenal hyperplasia patients with high urogenital sinus", Afr J Paediatr Surg 2015;12:177-80, <a href="https://www.afrjpaedsurg.org/article.asp?issn=0189-6725;year=2015;volume=12;issue=3;spage=177;epage=180;aulast=Birraux">https://www.afrjpaedsurg.org/article.asp?issn=0189-6725;year=2015;volume=12;issue=3;spage=177;epage=180;aulast=Birraux</a>

Hospital acting as co-author.<sup>36</sup> Needless to say, such practices are strongly condemned by African intersex advocates, as well as the lack of access to redress for African intersex persons in such cases.<sup>37</sup>

#### g) Swiss International DSD Symposia promoting IGM, including "live surgeries"

The Lucerne Cantonal Children's Hospital facilitated the "14<sup>th</sup> Symposium of the Working Group Paediatric Urology of the German Society for Paediatric Surgery (DGKCH) and the Swiss Society for Paediatric Urology (swissPU) 2017" in Lucerne including "live surgery", namely "Hypospadia subcoronaria", "Modified MAGPI", "Hypospadia penilis" (IGM 1), performed at the Lucerne Children's Hospital.<sup>38</sup>

And the **Berne University Children's Hospital (Inselspital)** will facilitate the "8th I-DSD Symposium 2021", including a session on "hypospadias repair" (IGM 1).<sup>39</sup>

#### h) Cantonal parliamentary questions establishing that IGM persists

While the **Federal and Cantonal Governments** continue to **deny** that IGM practices persist, and the **State report** (para 119) claims only "about 40" intersex children are born in Switzerland each year, a **2020 reply by the Zurich Cantonal Government to a Parliamentary question** revealed much higher numbers, namely **85-135 IGM procedures practiced annually at the Zurich University Children's Hospital alone**, all of them paid for by the **Swiss Federal Invalidity Insurance** (IV). <sup>40</sup>

To this day, the **Great Council of the Republic and Canton of Geneva** remains the only Parliament in Switzerland to pass a prohibition of IGM practices in 2019 by adopting **two motions** calling on the Cantonal government to explicitly "prohibit" the "mutilations of intersex persons" (see also our LOIPR NGO Report, p. 14). 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". Unfortunately, this is far from the truth (see above p. 15). However, in October 2019 the **Cantonal Government (Conseil d'État) refused to implement it**, again under

Jacques Birraux (Paediatric Surgery, Department of Pediatrics Children's Hospital, University Hospital of Geneva, **Switzerland**), Faustin Tambo Mouafo, Sophie Dahoun (Medical Genetic, Department of Genetics, University Hospital of Geneva, **Switzerland**), Veronique Tardy, Yves Morel, Pierre Mouriquand, Claude Le Coultre, Pierre-Yves Mure (2015), "Laparoscopic-assisted vaginal pull-through: A new approach for congenital adrenal hyperplasia patients with high urogenital sinus", Afr J Paediatr Surg 2015;12:177-80, <a href="https://www.afrjpaedsurg.org/article.asp?issn=0189-6725;year=2015;volume=12;issue=3;spage=177;epage=180;aulast=Birraux">https://www.afrjpaedsurg.org/article.asp?issn=0189-6725;year=2015;volume=12;issue=3;spage=177;epage=180;aulast=Birraux</a>

<sup>37</sup> Julius Kaggwa, SIPD Uganda, personal communication, January 2020

<sup>38</sup> https://docplayer.org/docview/67/57305366/#file=/storage/67/57305366/57305366.pdf

<sup>36</sup> https://docphayer.org/docytew/07/37303300/#fffe=/storage/07/37303300/37303300.pc

 $<sup>\</sup>underline{\text{https://idsdorg.files.wordpress.com/2020/08/i-dsd-2021-bern-v3.0-1.pdf}}$ 

<sup>40</sup> Answer of the Cantonal Government KR-Nr. 37/2020, https://parlzhcdws.cmicloud.ch/parlzh5/cdws/Files/59a6b9dc8b7b4c118adde0d55c0968d1-332/1/pdf

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

<sup>42</sup> See statements of Céline Zuber-Roy and Mauro Poggia, http://ge.ch/grandconseil/memorial/seances/020111/66/7/

the pretext that IGM allegedly has not been practised for a long time.<sup>43</sup> Only in 2020, after an Open Letter<sup>44</sup> by StopIGM.org, resulting media coverage<sup>45</sup> and an **Urgent Parliamentary Question**<sup>46</sup> initiated by StopIGM.org, the **Cantonal Government finally acknowledged** in a response the persistence of IGM and **promised** further investigation:<sup>47</sup>

"Indeed, surgeries for VSD that did not respect ethical recommendations were performed at the HUG during the period 2010-2018. The State Council is currently undertaking a fact-finding exercise with the HUG and the Swiss Invalidity Insurance in order to establish the facts."

So far, however, these promises have not been fulfilled.

#### i) Swiss IGM doctors corrupting the "Child Rights Network Switzerland"

In the last 2<sup>nd</sup> to 4<sup>th</sup> cycle of Switzerland leading to the very first Concluding Observation on IGM practices by this Committee also the National Coalition NGO Reports by Child Rights Network Switzerland included valuable sections on "Intersex Genital Mutilation" (INT/CRC/NGO/CHE/18021, p. 25-26; INT/CRC/NGO/CHE/19283, p. 10), as well as a section on Male Genital Mutilation (MGM).

However, as more strong Concluding Observations on IGM practices were issued by CRC, CEDAW, CAT, CCPR and CRPD condemning IGM as a harmful practice and inhuman treatment, and political pressure to criminalise IGM practices increased in many State parties, international and national medical societies representing IGM doctors started an orchestrated campaign to discredit intersex human rights in order to be able to continue practicing IGM with impunity.<sup>48</sup>

Obviously, the Swiss Society of Paediatrics (SGP/SSP) representing the 9 University and Children's Hospitals practising IGM (see above, p. 17), and also a member of the Child Rights Network Switzerland, also takes part in this international campaign.

Accordingly, when the **draft of the National Coalition NGO Report for LOIPR** by Child Rights Network Switzerland for the current cycle again contained a section on Intersex Genital Mutilation, the **Swiss Society of Paediatrics lobbied** the Network Secretariat to "substantially alter" this section to make it IGM friendly. Shockingly, the **Secretariat promptly complied.** Only when StopIGM.org / Zwischengeschlecht.org, in the meantime also a member of the Network, **vehemently protested to the then Board** of the Network, these "substantial alterations" were **reversed in the eleventh hour**. Therefore, Zwischengeschlecht.org agreed to be mentioned in the list of member organisations supporting the report. (However, the section on Male Genital Mutilation (MGM), which was also "substantially altered" at the behest of the Swiss Society of Paediatrics which were similarly protested by an NGO of persons concerned, was eventually removed entirely.)

19

Answer of the Cantonal Government M 2541-A, <a href="https://ge.ch/grandconseil/data/texte/M02541A.pdf">https://ge.ch/grandconseil/data/texte/M02541A.pdf</a> Answer of the Cantonal Government M 2491-B, <a href="https://ge.ch/grandconseil/data/texte/M02491B.pdf">https://ge.ch/grandconseil/data/texte/M02491B.pdf</a>

<sup>44</sup> https://intersex.shadowreport.org/public/Lettre-ouverte-Mauro-Poggia-Mutilations-aux-HUG.pdf

<sup>45 &</sup>lt;u>https://www.rts.ch/play/tv/19h30/video/les-operations-sur-des-patients-intersexes-doivent-etre-consenties?urn=urn:rts:video:10816273</u>

<sup>46</sup> Urgent Written Question QUE 1201, https://ge.ch/grandconseil/data/texte/QUE01201.pdf

<sup>47</sup> Answer of the Cantonal Government QUE 1201-A, <a href="https://ge.ch/grandconseil/data/texte/QUE01201A.pdf">https://ge.ch/grandconseil/data/texte/QUE01201A.pdf</a>

See for example internal procedures initiated by the Secretary of the European Society for Paediatric Urology (ESPU) to start a North American-European "think tank' for this issue", October 2018

For the **National Coalition Report for the Session** by Child Rights Network Switzerland, the Swiss Society of Paediatrics obviously **increased their lobbying efforts**. Accordingly, already the draft of the section of IGM produced by the **Network Secretariat** was IGM and doctor-friendly from the start. As the Network Secretariat admitted, again due to **pressure behind the scenes** by the Swiss Society of Paediatrics as IGM representatives:<sup>49</sup>

"The network is a heterogeneous entity and thus has to consider or at least discuss the input of all member organisations. As you know, there are organisations represented in the network that have a different view on the topic of intersex, namely the Swiss Society for Paediatrics."

After renewed internal protests by StopIGM.org the draft was amended to some extent, but still marked a significant step back compared to the previous Network reports and the many Concluding Observations on IGM by this and other Committees. Namely the final draft excluded updates substantiating the ongoing practice (see above, p. 13-17) and Parliamentary initiatives (see above, p. 18-19). Also, the Suggested Recommendations mark a significant step back, as they include only vague and non-committal calls to "implement the NEK recommendations" and to "establish a legal basis" to regulate IGM, instead of – in line with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 "on harmful practices" regularly invoked by this Committee, including in its last Concluding Observations to Switzerland, with the NEK Recommendations, and with the specific demands of intersex NGOs – explicitly calling to criminalise IGM practices and to guarantee access to justice, redress and compensation to IGM survivors, including by addressing obstacles to access to justice, namely the statutes of limitations.

Since the **current Board of the Network sustained this doctor-friendly version** approved by the Swiss Society for Paediatrics, **StopIGM.org no longer supports** the Report for Session of the "Child Rights Network Switzerland".

Instead, we would like to **urge the Committee to uphold the human rights of intersex children being at risk, and of IGM survivors seeking justice** (instead of the "rights" of IGM perpetrators to continue with impunity).

<sup>49</sup> Email from the Network Secretariat dated 31 August 2020

#### D. Fact-checking the State Report

113. The Swiss National Advisory Commission on Biomedical Ethics [NEK-CNE] has dealt with intersex issues on behalf of the Government and published a position paper containing a number of recommendations, the majority of which concerning the Confederation have been or are being implemented.

Fact: As substantiated in our NGO Report for LOIPR (p. 12-13, 15-16, 14), for the most crucial NEK-CNE recommendations this is clearly not the case. Namely Recommendation No. 12 concerning a prohibition of IGM under Criminal Law and adapting the statutes of limitations preventing access to justice, redress and compensation for IGM survivors, decidedly has not "been or [is] being implemented", and concerning Recommendation No. 5 stipulating free psychosocial support for intersex children and parents, the Federal Government explicitly refuses to implement it, claiming it would be "impossible" to finance.

114. With regard to medical or surgical treatment, the Government considers that current practice respects the rights of intersex persons. Premature or unnecessary interventions are contrary to the law governing physical integrity. Wherever possible, a decision should be taken only when the child is old enough, if the treatment would have irreversible consequences. According to experts, the best interests of the child take precedence over medical interventions and treatments.

**Fact:** As substantiated in this NGO Report, the "current practice" of **IGM persisting with impunity** (see above, p. 13-19) clearly **does not respect** the rights of intersex persons and despite that IGM practices are indeed a serious violation of the "law governing physical integrity", this unspecified "law" is clearly **not enforced**.

115. The general legal rights of patients apply to the treatment of intersex children. Intersex children have the right to medical treatment and care in accordance with the state of the art of medical science, the right to information and consent and the right to protection of their personal data. According to the CEC's [Central Ethics Committee (CEC) of the Swiss Academies of Arts and Sciences (SAMW-ASSM)] position paper of 2016, "the care of the families concerned has been improved in Switzerland and the recommendations of the Swiss National Advisory Commission on Biomedical Ethics [NEK-CNE] and international standards are respected as far as possible. In principle, parents in this distressing situation are now advised and supported by an interdisciplinary team from birth. In doing so, all decisions regarding treatment and interventions must be oriented towards the good of the child and taken in the sense of shared decision making."

**Fact:** As already substantiated above concerning paras 113 and 114 of the State report, the crucial **NEK-CNE Recommendations** are clearly **not** "respected" (notably also the SAMW-ASSM sort of admits to this by adding the caveat "respected as far as possible"), and also under the current "improved care" **IGM persists with impunity**. Merely repeating these unsubstantiated claims doesn't make them true. Further, as substantiated in this NGO Report (see above, p. 13-14), the "interdisciplinary team[s]" continue to be dominated by **paediatric surgeons and endocrinologists**, i.e. the past and current IGM perpetrators.

116. Social security provides for appropriate coverage of necessary treatment. In social law, this is a birth defect [Geburtsgebrechen (Gg)-Infirmités Congénitales (IC)], i.e. "an illness present at the completed birth of the child". Coverage by the Swiss Federal Invalidity Insurance [Invalidenversicherung (IV)-Assurance Invalidité (AI)] ends on the 20th birthday of the insured person. After this date, the Compulsory Health Insurance [OKP-AOS] takes over.

Fact: As substantiated in this NGO Report (see above, p. 12), to this day all forms of IGM practices remain paid for by the Swiss Federal Invalidity Insurance (Invalidenversicherung IV

- Assurance Invalidité AI) according to its **List of Birth Defects** (Liste der Geburtsgebrechen – Liste des Infirmités Congénitales) covering intersex surgeries on children until the age of 20, but not for consenting adults. So, regarding this Committee's **actual question** "whether unnecessary medical or surgical treatment for intersex children is still covered by disability insurance", the actual answer would be "**ves**".

117. A surgical operation for the purpose of assigning a sex to a child who is incapable of judgement constitutes in principle an illicit physical injury if it is not necessary to safeguard the child's life or health (Art. 122 para. 2 of the Criminal Code). The offender could be the doctor in the case of an intervention without the consent of the legal representatives, or even the latter if they have validly consented to the unnecessary intervention.

Fact: As substantiated in our 2014 CRC NGO Report (INT/CRC/NGO/CHE/18022, p. 13-14), <sup>50</sup> genital surgery is **not necessary for** "assigning a sex to a child", but IGM practices are "non-consensual, medically unnecessary, irreversible, cosmetic 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, but justified by 'psychosocial indications [...] shaped by the clinician's own values', the latter informed by societal and cultural norms and beliefs [...]". Regarding Art. 122 para. 2 of the Criminal Code, concerning IGM practices, it is clearly **not enforced**, as IGM persists with impunity. What's more, concerning early genital surgery on a child under 16 years, under Art. 122 para. 2 in conjunction with Art. 97 para. 2 the **statutes of limitations expire after the age of 25**, while most IGM survivors need often considerably more time to deal with the **trauma associated with IGM** in order to be able to press charges. Further, Art. 122 para. 2 does **not include extraterritorial protections**. In consequence, to this day **no Swiss IGM survivor ever succeeded in pressing charges**, whether under Art. 122 nor under other articles.

118. See §10 (draft on sex change in civil status).

Fact: As reiterated in this NGO Report (see above, p. 13), civil registry reform is in no way a remedy for IGM practices, and neither this or any other Committee ever called for doing so, nor do intersex NGOs. However, in order to distract from the actual problem of IGM persisting with impunity, unduly focusing on gender identity issues and civil gender registration reform instead, is a well-known ruse of State parties seeking to evade questions on harmful practices on intersex persons. Accordingly, the official justification of the Federal Government for rejecting to implement this Committee's Concluding Observations' para. 43(b) harmful practices on intersex children, but to prioritise the "draft on sex change in civil status" instead, clearly fits the bill.

119. According to the Federal Office of Public Health [FOPH-BAG-OFSP] data, about 40 children for whom it is not clear whether they are a girl or a boy are born each year in Switzerland. For other children, it is their later sexual development that leads to this uncertainty.

Fact: As substantiated in this NGO Report (see above, p. 18), a 2020 reply by the Zurich Cantonal Government to a Parliamentary question documented 85-135 IGM procedures practiced annually at the Zurich University Children's Hospital alone. Regarding the often-repeated false claim of only "about 40" intersex children born in Switzerland annually, this figure derives from a "Estimated number of children with DSD" aged <17 years and treated in

<sup>50</sup> https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\_v2.pdf

8 University and Cantonal Children's Hospitals, namely "*Total DSD diagnoses:* 748" (i.e. 748 children: 18 year groups = 41.56 intersex children annually). However, these "*Total DSD diagnoses*" include only a **partial selection** of intersex children at risk of being submitted to IGM, and namely **omit the most frequent relevant diagnosis**, i.e. hypospadias.<sup>51</sup>

120 According to the Basel Children's Hospital, in Switzerland these cases are usually managed by interdisciplinary teams. Surgical indications are nowadays treated very restrictively. Data on intersex children are recorded in the European Disorder of Sex Development Registry [I-DSD Registry]. Patients have the right to consult their files at any time. Throughout Switzerland, meetings of all specialists involved in the care of intersex children are held regularly; these specialists usually work in paediatric hospitals.

Fact: As substantiated in this NGO Report (see above, p. 13-14), the "interdisciplinary teams" continue to be dominated by paediatric surgeons and endocrinologists, i.e. the past and current IGM perpetrators. Further, according to 2020 reply by the Geneva Cantonal Government to an Urgent Parliamentary Question, medical records are only kept for 10 years, <sup>52</sup> i.e. intersex persons are clearly not able to "consult their files at any time". Concerning the regularly-held "meetings of all specialists involved in the care of intersex children", these are indeed the IGM "specialists" that issued the unpublished, secret 2019 "Switzerland-wide agreement of DSD treatment teams" prescribing IGM practices if "the parents cannot bear to live with the 'shame'" of having an intersex child remaining in force to this day (see above, p. 13).

121. The information from the cantons confirms these statements. Intersex children are examined in university centres or specialised hospitals and cared for by interdisciplinary teams. Unnecessary medical and surgical interventions are avoided. Children and parents are carefully supported and monitored.

Fact: Concerning the "university centres or specialised hospitals", these are indeed the ones practising IGM to this day, see above, p. 15-17. Concerning the "interdisciplinary teams", again, as substantiated in this NGO Report (see above, p. 13-14), these continue to be dominated by paediatric surgeons and endocrinologists, i.e. the past and current IGM perpetrators. Ultimately, as substantiated above (see p. 13-19), in Switzerland IGM practices are evidently not "avoided", but persist with impunity.

122. See §23d ([Federal Invalidity Insurance] measures).

While according to the **Swiss Federal Invalidity Insurance** intersex is indeed considered as a "birth defect", it is however **not considered as a** "mental disorder" allowing for psychiatric or psychological therapies as described in para. 181 of the State report, nor are intersex children and their families in need of "occupational rehabilitation". Therefore, according to private communications from DSD doctors, for intersex diagnoses the **Invalidity Insurance only covers for surgical procedures**, but **not** psychosocial support, so that the hospitals that offer it, do so at their **loss** (which is one reason why the Federal Government argues **free psychosocial** support would be "impossible" to finance, see above concerning para 113 of the State report).

See: Grit Sommer, Daniel Konrad, Beatrice Kuhlmann, Dagmar L'Allemand, Franziska Phan-Hug, Michael Hauschild, Valerie Schwitzgebel, Paolo Tonella, Melanie Hess, Urs Zumsteg, Anna Lauber-Biason, Christa E. Flück, for the Working Group DSD of the Swiss Society for Pediatric Endocrinology and Diabetology (AG DSD SGPED) (2018), "Current medical care of children and adolescents with disorders of sex development in Switzerland", poster P2-P346 at ESPE 2018, <a href="https://abstracts.eurospe.org/hrp/0089/eposters/hrp0089p2-p346">https://abstracts.eurospe.org/hrp/0089/eposters/hrp0089p2-p346</a> eposter.pdf

<sup>52</sup> Answer of the Cantonal Government QUE 1201-A, https://ge.ch/grandconseil/data/texte/QUE01201A.pdf

### E. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Switzerland, the Committee includes the following measures in their recommendations to the Swiss Government:

#### **Harmful Practices: Intersex Genital Mutilation (art. 24(3))**

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

In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

- (a) Ensure that the State party's legislation explicitly prohibits all forms of intersex genital mutilation in the criminal code, and provide families with intersex children with adequate counselling and support;
- (b) Adopt legal provisions and repeal time-limits in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible;
- (c) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;
- (d) Educate and train medical, psychological and education professionals on intersex as a natural bodily variation and on the consequences of unnecessary surgical and other medical interventions for intersex children.

# F. Annexe – "IGM in Medical Textbooks: Current Practice" IGM 2 – "Feminising" Procedures: Partial Clitoris Amputation (Uni Geneva)

**Source:** Jacques Birraux (2017), "Management of disorders of sexual development: State of the art. A Surgeon's perspective in Western Switzerland". Thesis. Excerpt from "Feminization genitoplasty" (p. 33-35 in thesis, p. 30-32 in PDF), <a href="https://archive-ouverte.unige.ch/unige:103975">https://archive-ouverte.unige.ch/unige:103975</a>

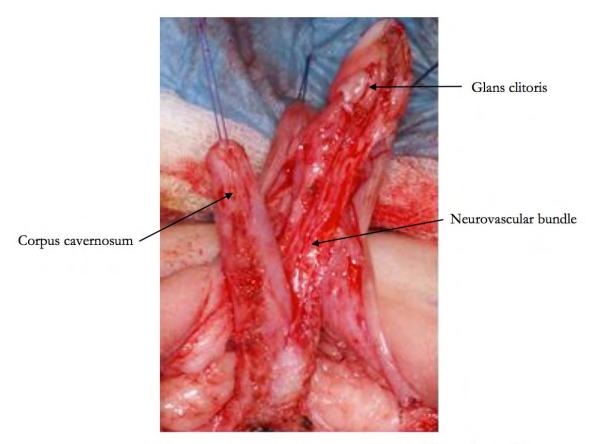
#### HCS Prader V:



Personal material

#### b) Surgery

The goals of feminization surgery have already been summarized. The genitoplasty can be divided in 2 steps: clitoridoplasty, the most controversial part<sup>52</sup>, and vaginoplasty with perineoplasty aiming to lower the vagina to the perineum.



Personal material

## Result at the end of surgery:



Personal material