Intersex Genital Mutilation in Sweden: Update to LOIPR Report

Dear Committee on the Rights of the Child

All typical forms of Intersex Genital Mutilation are still practised in Sweden, facilitated and paid for by the State party via the public health system. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support. Despite having incorporated CRC into law, and repeated calls and claims by Government agencies to protect intersex children, Sweden fails to do so.

1. Sweden's commitment to "protect intersex children from violence and harmful practices", "investigate abuses", "ensure accountability" and "access to remedy"

a) UNHRC45 Statement, 01.10.2020

On occasion of the **45th Session of the Human Rights Council** the **State party** supported a public statement calling to ***"protect […] intersex adults and children*** *[…] so that they live free* ***from violence and harmful practices***. *Governments should* ***investigate human rights violations and abuses*** *against intersex people,* ***ensure accountability****, […] and* ***provide victims with access to remedy."*** [1]

1 Statement supported by Sweden (and 34 other States) during the 45th Session of the Human Rights Council on 1 October 2020, https://www.dfat.gov.au/international-relations/themes/human-rights/hrc-statements/45th-session-human-rights-council/joint-statement-led-austria-rights-intersex-persons

b) UNHRC48 Statement, 04.10.2021

On occasion of the **48th Session of the Human Rights Council** the **State party** supported a public follow-up statement reiterating the call to end harmful practices and ensure access to justice:

> *"Intersex persons also need to be protected from **violence** and States must **ensure accountability** for these acts. […]*
>
> *Furthermore, there is also a need to take measures to protect the **autonomy** of intersex children and adults and their rights to health and to **physical and mental integrity** so that they live **free from violence and harmful practices**. Medically unnecessary surgeries, hormonal treatments and other invasive or irreversible non-vital medical procedures without their free, prior, full and informed consent are **harmful to the full enjoyment of the human rights** of intersex persons.*
>
> *We call on all member states to take measures to combat violence and discrimination against intersex persons, develop policies in close consultations with those affected, **ensure accountability**, reverse discriminatory laws and **provide victims with access to remedy**."* [2]

2. IGM practices persist, insufficient protections, Government fails to act

Despite above mentioned calls, **to this day, in Sweden all forms of IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by the state funded **University Hospitals**, and **paid for by the State** via the **public health system** under the responsibility of the **Ministry of Health and Social Affairs** and the **Regional Councils** (see our 2020 NGO Report for LOIPR, p. 6-11).

In addition, also in 2022 Swedish medical bodies continue to endorse international medical guidelines prescribing all forms of IGM practices:

a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones [3]

The **Swedish Urology Association (Svensk Urologisk Förening)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,[4] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2022**[5] of the European Society for Paediatric Urology (ESPU) and th European Association of Urology (EAU) which stress:[6]

> *"Individuals with DSD have an increased risk of developing cancers of the germ cell lineage, malignant germ cell tumours or germ cell cancer in comparison with to the general population."*

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2 Statement supported by Sweden (and 52 other States) during the 48th Session of the Human Rights Council on 4 October 2021, https://www.bmeia.gv.at/oev-genf/speeches/alle/2021/10/united-nations-human-rights-council-48th-session-joint-statement-on-the-human-rights-of-intersex-persons/

3 For general information, see 2016 CEDAW NGO Report France, p. 47, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

4 https://uroweb.org/guidelines/endorsement/

5 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf

6 Ibid., p. 89

Further, regarding *"whether and when to pursue gonadal or genital surgery"*,[7] the Guidelines refer to the ***"ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)"***,[8] which advocates "gonadectomies":

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

Also, the **"2016 Global Disorders of Sex Development Consensus Statement"**[9] refers to the *"ESPU/SPU standpoint"*, advocates *"gonadectomy"* – even when admitting *"low"* cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)[10]:

Table 2. GCC risk: clinical management

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

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation[11]

The **Swedish Urology Association (Svensk Urologisk Förening)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,[12] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2022**[13] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.17 *"Disorders of sex development"***,[14] despite admitting that *"Surgery that alters appearance is not urgent"* [15] and that *"adverse outcomes have led to recommendations to delay unnecessary*

7 Ibid., p. 88
8 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf
9 Lee et al., "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care", Horm Res Paediatr 2016;85:158–180, https://www.karger.com/Article/Pdf/442975
10 Ibid., at 180 (fn 111)
11 For general information, see 2016 CEDAW NGO Report France, p. 48, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
12 https://uroweb.org/guidelines/endorsement/
13 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf
14 Ibid., p. 86
15 Ibid., p. 88

[clitoral] surgery to an age when the patient can give inform consent",[16] the ESPU/EAU Guidelines nonetheless explicitly **refuse to postpone non-emergency surgery**, but in contrary **insist to continue with non-emergency genital surgery** (including 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"* and making *"well-informed decisions […] on their behalf"*, and further **explicitly refusing *"prohibition regulations"*** of unnecessary early surgery,[17] referring to the 2018 ESPU Open Letter to the Council of Europe (COE),[18] which further invokes **parents' *"social, and cultural considerations"*** as justifications for early surgery (p. 2).

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[19]

The **Swedish Urology Association (Svensk Urologisk Förening)** still endorses the unchanged, current **2022 Guidelines of the European Association of Urology (EAU)**,[20] which include the current **ESPU/EAU *"Paediatric Urology"* Guidelines 2022**[21] of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.6 *"Hypospadias"***,[22] the ESPU/EAU Guidelines' **section 3.6.5.3 *"Age at surgery"*** nonetheless explicitly promotes, ***"The age at surgery for primary hypospadias repair is usually 6-18 (24) months."*** [23] – despite admitting to the *"risk of complications"* [24] and *"aesthetic[…]"* and *"cosmetic"* justifications.[25]

3. National Board of Health and Welfare NBWH advocates IGM practices

Accordingly, the Swedish **National Board of Health and Welfare (NBHW – Socialstyrelsen)** continues to allow or prescribe all forms of IGM practices in its **2020 recommendations** *"Care and treatment in conditions affecting development ('DSD'). Knowledge support with national recommendations"*.[26]

These 2020 NBHW recommendations were also mentioned in the **State Report** (para 20(a)), **claiming** the recommendations would *"strengthen the child's rights and to contribute towards greater restrictiveness regarding surgical interventions"*. However, these **claims are not substantiated** by the NBHW recommendations themselves.

While the NBHW recommendations have to be **commended** for issuing ***"strong positive recommendations"*** for ***"specialised psychosocial support*** *for parents […] [and] children, youths and adults with DSD"* (p. 36-41) as well as for intersex persons' ***"right to information*** *about their diagnosis and treatment history"* (p. 32-35), regrettably they **fail to acknowledge and protect intersex children's human rights**:

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16 Ibid., p. 88
17 Ibid., p. 89
18 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf
19 For general information, see 2016 CEDAW NGO Report France, p. 48-49, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf
20 https://uroweb.org/guidelines/endorsement/
21 https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Paediatric-Urology-2022.pdf
22 Ibid., p. 26
23 Ibid., p. 27
24 Ibid., p. 27
25 Ibid., p. 27
26 https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2020-4-6695.pdf

In fact, the NBHW recommendations contain **one reference to human rights** (p. 20), however, this reference is **not** to intersex children, but to trans persons.

And the NBHW recommendations contain **some references to children's rights** (p. 21), even explicitly referring to **CRC**, however, only to articles 2, 3, 6 and 12, while conveniently **omitting any reference to the crucial article 24(3)** on harmful practices. What's worse, in the following paragraphs, the recommendations explicitly state that in Sweden **parent's rights trump children's rights**, specifically: *"The provisions of the Parents' Code (FB) on the rights and duties of **guardians may limit the right of newborns and young children to self-determination and bodily integrity**"* (p. 21).

Accordingly, the NBHW recommendations explicitly **allow or prescribe all forms of IGM practices:**

a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation Plus arbitrary imposition of hormones [27]

While NBHW recommendations issue a *"weak positive recommendation"* to delay gonadectomy until puberty,

> *"Health care providers **can withhold gonadectomy in 46,XY CAIS until the onset of puberty**, when the patient can be informed and involved in the discussion about how to manage the malignancy risk going forward."* (p. 59),

in fact, **abolishing** gonadectonies is **not** recommended. Accordingly, the NBHW recommendations explicitly state, ***"the practice to date has been to perform gonadectomy before or after puberty"*** (p. 60).

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labiaplasty", Dilation[28]

Despite explicitly noting that *"the experience-based knowledge of experts suggests that the procedures are **not medically necessary**, and that they may cause **scarring and reduced sensitivity** in adulthood"* (p. 67), the NBHW recommendations **continues to allow them**, despite issuing the following *"weak negative recommendation"*:

> *"In exceptional cases [i.e. "in cases of higher degree of virilisation"], health care providers **may perform clitoral surgery and/or vulvar/vaginoplasty at 46.XX CAH before the person can be involved in deciding if and when surgery should be performed."*** (p. 67)

What's worse, the ***"rationale"*** given by the NBHW recommendations for still allowing IGM 2 are the usual and well-worn (alleged) ***"[increased] risk of psychosocial distress to the child** […] when genital surgery is not performed"*, as well as the ***"lack of prospective, comparative studies** demonstrating the benefits and risks of surgery"* (which once more are still conveniently not available despite again being promised to be delivered soon, see footnote 17 in the NBHW recommendations) (p. 67-68).

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27 For general information, see 2016 CEDAW NGO Report France, p. 47, http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

28 For general information, see 2016 CEDAW NGO Report France, p. 48, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[29]

For "*hypospadias surgery*", notably the most frequent IGM practice, the NBHW recommendations give **no actual recommendations** due to low "*priority*", but ***"provide only a description of practice"*** in order "*to give visibility to care measures that are often commented on at an overall level in the ethical debate*" (p. 12). This description **confirms the prevalence of early IGM 1** in Sweden (p. 69):

> ***"Practice description - masculinising surgery***
>
> *Once a child's gender has been assessed, and the DSD team in consultation with parents has decided that the child should be assigned male gender, this may involve the* ***need for masculinising surgery****. This involves* ***correcting the child's often severe hypospadias****. Often the testicles also need to be descended surgically, from the abdomen or groin down to the scrotum, to improve the possibility of future fertility. Sometimes the position and appearance of the scrotum is also corrected.*
>
> *The operations are usually performed in one or more sessions, starting* ***before the age of 12 months."***

What's more, the NBHW recommendations **claim *"hypospadias surgery"* to be *"reversible overall"*** – as if the often **massive scars and frequent complications**, including loss of sexual sensation, can be **magically made to disappear:**

> *"As with all surgery,* ***scarring may occur****, but the* ***surgery is considered to be reconstructive and reversible overall****. [18]* ***No tissue is removed*** *during the procedure,* ***except*** *that the foreskin is often used in the reconstruction of the urethra and cannot then be repaired.*
>
> *[18] If the person later wishes to have female genital surgery, the surgical possibilities to create female genitalia are considered unchanged. In male-to-female genital surgery, the urethra is shortened to a female meatus, which means that the entire part of the urethra reconstructed due to hypospadias is removed. Information obtained from G. Kratz, Scientific Council for Plastic Surgery, National Board of Health and Welfare, ref. no. 18836/2018-41."*

4. Lack of independent data collection and monitoring

As the State Party itself admit in its "Annex to State Party Report", regarding intersex children and IGM practices, to this day ***"There are no national statistics within this area."*** (40(d), p. 27)

29 For general information, see 2016 CEDAW NGO Report France, p. 48-49, https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

5. Suggested Questions for the dialogue

Harmful practices on intersex children: We are concerned about reports of unnecessary genital surgery and other procedures on intersex children without their informed consent. These treatments can cause severe physical and psychological suffering, and can be considered as genital mutilation. We are also concerned about the lack of access to justice and redress in such cases.

My questions:

- **Please provide data on irreversible medical or surgical treatment of intersex children, disaggregated by type of intervention and age at intervention, including on hypospadias surgery.**
- **Which criminal or civil remedies are available for intersex people who have undergone involuntary irreversible medical or surgical treatment as children, and are these remedies subject to any statute of limitations?**

6. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Sweden, the Committee includes the following measures in their recommendations to the Swedish Government (in line with this Committee's previous recommendations on IGM practices).

Harmful practices: Intersex genital mutilation

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.

With reference to the 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 (2019) on harmful practices, and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

- **Ensure that the State party's legislation explicitly prohibits the performance of unnecessary medical or surgical treatment on intersex children where those procedures may be safely deferred until children are able to provide their informed consent, and provide reparations for children who received unnecessary treatment, including by extending the statute of limitations.**
- **Provide families with intersex children with adequate counselling and support.**
- **Systematically collect data with a view to understanding the extent of these harmful practices so that children at risk can be more easily identified and their abuse prevented.**

Thank you for your consideration and kind regards,

Daniela Truffer & Markus Bauer (StopIGM.org / Zwischengeschlecht.org)