



Submission for OHCHR Study on Youth and Human Rights (HRC39)

1. Who we are

StopIGM.org / Zwischengeschlecht.org, founded in 2007, is an international intersex human rights NGO based in Switzerland, working to represent the interests of intersex people, IGM survivors and their relatives, to raise awareness and to end IGM practices and other human rights violations perpetrated on intersex people, according to our motto, “*Human Rights for Hermaphrodites, too!*”¹ As stated in its charter,² StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports on human rights violations in different countries to UN treaty bodies, including CRC, CAT, CEDAW, CRPD and HRCttee, often in collaboration with local intersex persons and organisations.³

2. Scope of this submission

This submission focuses on **Intersex Genital Mutilations (IGM)** perpetrated on intersex children, adolescents and young adults. It briefly explains intersex and IGM, as well as underlying harmful stereotypes and prejudice; it highlights the special vulnerability of older intersex teens/young adults in some countries; it references UN treaty bodies CRC, CEDAW, CAT, CRPD and HRCttee (CCPR) and regional bodies including COE, ACHPR and IACHR consistently recognising IGM practices as a serious violation of non-derogable human rights, namely as genital mutilation and violence, a harmful practice, ill-treatment, involuntary human experimentation; it notes the contrasting lack of recognition by the HRC including in UPRs; and it discusses examples of relevant recent initiatives and policies and their shortcomings – in the hope that the Human Rights Council will take a stand against the serious human rights violations intersex people around the globe continue to suffer from.

3. Background: Intersex and IGM Practices

a) Intersex = Variations of Sex Anatomy⁴

Intersex people are born with **Variations of Sex Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic

1 <http://Zwischengeschlecht.org/> English pages: <http://StopIGM.org/>

2 <http://Zwischengeschlecht.org/post/Statuten>

3 <http://intersex.shadowreport.org>

4 For general information, see e.g. 2016 CEDAW NGO Report France, p. 39–44.

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

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**. While intersex people may face several problems, in the “developed world” the most pressing are the ongoing **Intersex Genital Mutilations (IGM)**, which present a distinct and unique issue constituting significant human rights violations.

b) IGM Practices = Harmful, involuntary, unnecessary medical interventions

In “**developed countries**” with universal access to paediatric health care **1 to 2 in 1000 newborns** are at risk of being submitted to **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 states**.⁵

Typical forms of 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) abortion and denial of needed health care, causing known **lifelong severe physical and mental pain and suffering**.

c) Infanticide, Abandonment, Bullying, Murder

From **countries without universal access to paediatric health care**, there are reports of infanticide of intersex children,⁶ of abandonment,⁷ of expulsion,⁸ of massive bullying preventing the persons concerned from attending school (recognised by CRC as amounting

5 For references and general information, see “What are Intersex Genital Mutilations (IGM)?”, 2016 CEDAW NGO Report France, p. 45–51, <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

6 For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12, <http://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf>
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 Uganda, see also 2015 CRC Briefing, slide 46, http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf

For Kenya, see also <http://www.bbc.com/news/world-africa-39780214>

7 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>

8 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>

to a harmful practice),⁹ and of murder.¹⁰

4. “Inferior”, “Abnormal”, “Deformed”: Harmful Stereotypes and Prejudice

Individual doctors, national and international medical bodies, public and private healthcare providers have traditionally been **framing and “treating” intersex variations as a form of disability in the medical definition** in need to be “cured” surgically, often **with racist, eugenic and supremacist 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 abandonment (see above 3b–c).

Accordingly, the easier an intersex trait can be tested prenatally, **the higher the selective (late term) abortion rates**.¹⁵ Most intersex diagnoses are also listed as permissible for deselection in State sponsored **preimplantation genetic diagnosis (PGD) guidelines**¹⁶, and e.g. in Switzerland **IGM practices are paid for by the Federal Disability Insurance**.¹⁷

5. Intersex is NOT THE SAME as LGBT or SOGI

Unfortunately, there are also other, often interrelated **harmful misconceptions about intersex** still prevailing in public, notably if intersex is counterfactually described as being the same as or a subset of LGBT or SOGI, e.g. if intersex and/or intersex status are represented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality, or as a form of sexual preference.

The underlying reasons for such 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.

9 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>

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

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*”:

<http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf>

13 “The Racist Roots of Intersex Genital Mutilations” <http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM>

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 For stats and references, see “Selective Intersex Abortions: XXY 74%, Indeterminate Sex 47%, Hypospadias 2%”, <http://stop.genitalmutilation.org/post/Selective-Intersex-Abortions-Hypospadias-Intersex-XXY>

16 For example in the UK, see <http://guide.hfea.gov.uk/pgd/>

17 See 2014 CRC Switzerland NGO Report, p. 76, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

Intersex persons and their organisations have spoken out clearly against instrumentalising or misrepresenting intersex issues,¹⁸ maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT or SOGI 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.¹⁹

Regrettably, **these harmful misrepresentations seem to be on the rise also at the UN**, for example in recent **UN press releases** and **Summary records** misrepresenting IGM as “*sex alignment surgeries*” (i.e. voluntary procedures on transsexual or transgender persons), IGM survivors as “*transsexual children*”, and intersex NGOs as “*a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination*”,²⁰ and again IGM survivors as “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”,²¹ and **State parties** are frequently referring to e.g. transgender guidelines²² or “*Gender Identity Law*”²³ when asked about IGM by e.g. Treaty bodies.

What’s more, **LGBT organisations** (including “LGBTI” organisations without actual intersex representation or advocacy) are using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus depriving actual intersex organisations (which mostly have no significant funding, if any) of much needed resources.²⁴

18 For references, see 2016 CEDAW France NGO Report, p. 45.

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

19 For example ACHPR Commissioner Lawrence Murugu Mute (Kenya), see

<http://stop.genitalmutilation.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT>

20 CAT60 Argentina, <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60>

21 CRC76 Denmark, <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67>

22 CAT56 Austria, see <http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations>

23 CAT60 Argentina, unofficial transcript see <http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture>

24 For example in Scotland (UK), LGBT organisations have so far collected at least £ 135,000.– public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, <http://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf>

Typically, during the interactive dialogue with CRCD, the UK delegation nonetheless tried to sell this glaring misappropriation as “supporting intersex people”, but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

6. Special Vulnerability of Some Young Intersex People

In some countries where paediatric IGM practices are pervasive, older intersex teens and young adults are exposed to **special vulnerability due to the fact that there are specific age limits to some health care coverage**, i.e. when elective surgery including non-urgent cosmetic genital surgery is only paid for until a certain age, usually corresponding to full age. In this case, those youths are under **undue pressure to quickly “consent”** to unnecessary surgery or risk losing coverage. In practice this leads to increased numbers of **young intersex people “consenting” to unnecessary and traumatising procedures which they bitterly regret later.**²⁵

7. IGM Practises as a Serious Violation of Non-Derogable Human Rights: UN Treaty Bodies, Experts and Regional Bodies Denouncing IGM

So far, **UN treaty bodies** have issued **28 Concluding observations** denouncing IGM practices as a serious violation of non-derogable human rights and **calling for legislation to end the practice to 17 State parties** in Europe (9 countries), South Africa (2), Asia (2) and Oceania (2):²⁶

- **CRC** and **CEDAW** recognise IGM practices as **genital mutilation** and a **harmful practice** (CRC art. 24(3) and CEDAW art. 5 in conjunction with CEDAW-CRC Joint general recommendation/comment 31/18 “on harmful practices”).
- **CAT** recognises IGM practices as constituting at least **cruel, inhuman or degrading treatment** (referring to CAT arts. 2, 12, 14, 16).
- **CRPD** considers IGM practices as a **violation of the integrity of the person** (CRPD art. 17) and as **exploitation, violence and abuse** (CRPD art. 16).
- The Human Rights Committee (**CCPR**) recognises IGM practices as constituting **cruel, inhuman or degrading treatment, a harmful practice and non-consensual medical or scientific experimentation** (referring to CCPR arts. 3, 7, 24, 26).

On occasion of Intersex Awareness Day 2016, a **joint statement** of 11 human rights experts of the **UN** (CAT, CRC, CRPD, SPT, SR Torture, SR Health, SR Violence against Women, Special Representative of the UN Secretary-General on Violence against Children), the Council of Europe (**COE**), the African Commission on Human and Peoples' Rights (**ACHPR**) and the Inter-American Commission on Human Rights (**IACHR**) denounced IGM practices, and stated:²⁷

“States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and

25 For example in Canada, non-urgent surgery is only covered by the health system until 18, see personal testimony here, <http://stop.genitalmutilation.org/post/Bearing-Witness-To-IGM-Canada>

For example in Switzerland, the Federal Disability Insurance (IV) only covers surgery until the age of 20, leading to pressure, see Opinion 20/2012 by the National Ethics Commission, p. 16–17, https://www.nek-cne.admin.ch/inhalte/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf

26 For a regularly updated list, see <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

27 <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers.”

A **2017 European Parliament Resolution**²⁸ recognised,

“intersex persons subject to genital mutilation also experience [serious short- and long-term] effects on their physical, psychological and sexual and reproductive health”,

and explicitly

*“Call[ed] on the Member States to **prevent, ban and prosecute** female genital mutilation and **genital mutilation affecting intersex persons**, and to provide mental health support, in conjunction with physical care, to victims and to those individuals likely to be targeted”*.

Similarly, a **2017 COE Parliamentary Assembly Resolution**²⁹ recognised IGM practices as *“involv[ing] serious breaches of physical integrity”*, and explicitly

“call[ed] on Council of Europe member States to:

7.1. with regard to effectively protecting children’s right to physical integrity and bodily autonomy and to empowering intersex people as regards these rights:

*7.1.1. **prohibit medically unnecessary sex-“normalising” surgery, sterilisation and other treatments practised on intersex children without their informed consent;**”*

8. Lack of Recognition of Intersex Human Rights by HRC and in UPRs

In stark contrast to aforementioned Treaty and Regional bodies, the **Human Rights Council (HRC) so far fails to acknowledge and recognise** the serious human rights violations perpetrated on intersex people, despite that they have been repeatedly highlighted for example on occasion of Universal Periodic Reviews (UPRs).³⁰

It is the impression of the Rapporteurs that this contrast stems likely from the fact that, while Treaty bodies are composed of independent experts, in the HRC the **State parties peer-reviewing each other** are as a rule either representatives of IGM perpetrator states

28 “European Parliament resolution of 14 February 2017 on promoting gender equality in mental health and clinical research (2016/2096(INI))”, <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2017-0028+0+DOC+XML+V0//EN>

29 PACE Resolution 2191 (2017), Promoting the human rights of and eliminating discrimination against intersex people, <http://semantic-pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbmQvbnceG1sL1hSZWYvWDJILURXLWV4dHIuYXNwP2ZpbGVpZD0yNDIzMiZsYW5nPUVO&xsl=aHR0cDovL3NlbWFudGljcGFjZS5uZXQvWHNsdC9QZGYvWFJlZi1XRRC1BVC1YTUwyUERGLnhzbA==&xsltparams=ZmlsZWlkP TI0MjMy>

30 See for example UPR Switzerland 2012, <http://intersex.shadowreport.org/category/UPR-2012>; UPR Ireland 2016, <http://stop.genitalmutilation.org/post/Israel-addresses-Intersex-Mutilations-during-UN-Human-Rights-Council-Review-of-Ireland>; UPR Switzerland 2017, see paras 13–15, https://www.sante-sexuelle.ch/wp-content/uploads/2017/03/UPR_SWITZERLAND-FINAL.pdf

(i.e. “developed” countries with universal access to paediatric services facilitating IGM) or representatives of “developing” countries which may not criticise the perpetrator states due to being (financially) dependent on them.

9. Lack of Data Collection and Monitoring

With still hardly any statistics available on intersex births, let alone IGM procedures and their costs, and **perpetrators, governments and health departments colluding to keep it that way as long as anyhow possible**, persons concerned as well as civil society **lack possibilities to effectively highlight and monitor** the ongoing mutilations. What’s more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists “on record”.

Rare examples of partial data of IGM procedures include statistics from the **United Kingdom** (around **2860 IGM procedures annually** paid for by the National Health System NHS)³¹ and **Germany** (around **1700 IGM procedures annually** paid for by the public health system).³²

10. Policies and Reports failing to Recognise Intersex Human Rights, Urgent Need for Criminalisation of IGM Practices

South Africa³³ and **France**³⁴ are still the only States officially recognising IGM constituting a harmful practice, but so far **without enacting legislation** accordingly.

Argentina, Malta and the **Community of Madrid (Spain)** are still the only countries formally banning IGM, however, **without any sanctions and/or enforcement of the law**:

- In 2012, **Argentina** passed a **gender identity law (Number 26.743)** that explicitly prohibits surgical interventions to be performed on children with the purpose of modifying their sex characteristics without consent from the child and permission from a judge. This law has been applied to transgender children but it is **not enforced regarding intersex children**. While hospital officials admit that under Law 26.743 “*judicial authorization should be requested for [intersex] surgical cases*”, they publicly flaunt the law referring to “*more adequate regulation [...] from scientific societies or institutions*” which promote IGM.³⁵

31 See 2016 CRC UK NGO Report, p. 8-12, http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

32 See 2017 CEDAW Germany NGO Report, p. 8–10, <http://intersex.shadowreport.org/public/2017-CEDAW-Germany-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

33 CRC74 Constructive dialogue, unofficial transcript: <http://stop.genitalmutilation.org/post/LIVE-South-Africa-Questioned-Over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child>
See also Mail & Guardian (27.10.2016), <https://mg.co.za/article/2016-10-27-00-sa-joins-the-global-fight-to-stop-unnecessary-genital-surgery-on-intersex-babies/>

34 See <http://stop.genitalmutilation.org/post/France-condemns-mutilations-of-intersex-children-proposes-prohibition>

35 See 2017 CAT Argentina NGO Report, p. 10, 13–14, <http://intersex.shadowreport.org/public/2017-CAT-Justicia-Intersex-Zwischengeschlecht-IGM.pdf>

11. Conclusion: HRC Should Recognise Intersex Human Rights – and Act!

“[W]hen I listened to your answers yesterday, I thought there was a misunderstanding because [...] 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 the 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.”

– **Theresia Degener**, Chairperson CRPD18, Geneva 24.08.2017 ⁴¹

With the above powerful statement made during the interactive dialogue with the United Kingdom, Theresia Degener nailed **3 major issues concerning intersex human rights** that the Rapporteurs hope also the Human Rights Council (HRC) will hopefully soon acknowledge and address:

1. The often still **total denial** of perpetrator states of the **human rights implications of IGM practices**, characterised by how State parties regularly answer on FGM when in fact they were asked about IGM.
2. The harmful **misrepresentation of intersex and IGM as an LGBT or SOGI issue**, and the interrelated **misappropriation of intersex funding** by LGBT organisations.
3. The urgent need to **adequately address IGM practices as the serious violation of non-derogable human rights that they in fact constitute**, and in particular the burning necessity to **criminalise or adequately sanction** IGM practices, including infanticide and abandonment prevalent in countries without universal access to paediatric services, in order to **end the impunity** of the perpetrators, to **ensure protection** of children, adolescents and young persons at risk, and to **guarantee access to justice and redress** for IGM survivors, including by **abolishing or adequately prolonging the statutes of limitations** that to this day prevent survivors from calling a court.

In the name of intersex children and youths, particularly those at risk of being submitted to IGM practices or already suffering the consequences, we would therefore like to kindly ask the High Commissioner to **make a strong case for acknowledging and recognising the serious human rights violations intersex people suffer around the globe**, and to urge the Human Rights Council to **take a stand to enforce the human rights of intersex people everywhere**.

Thank you!

Kind regards,

Daniela Truffer, Markus Bauer / StopIGM.org

⁴¹ Full transcript (Session 2, 11:47h) available at <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>