

## Submission for study on the right to sexual and reproductive health rights of girls with disabilities

### 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!*”<sup>1</sup> As stated in its charter,<sup>2</sup> StopIGM.org works to support persons concerned seeking redress and justice, and regularly reports to UN treaty bodies, including CRPD, often in collaboration with local intersex persons and organisations.<sup>3</sup>

### 2. Scope of this submission

This submission focuses on Intersex Genital Mutilations (IGM) perpetrated on intersex children. It briefly explains intersex and IGM, underlying harmful stereotypes and prejudice, and the negative impact also on the sexual and reproductive rights of the persons concerned; it references UN treaty bodies, including CRPD, consistently recognising IGM practices as violence, a harmful practice, ill-treatment, involuntary human experimentation; and it discusses examples of relevant initiatives and policies and their shortcomings.

### 3. Intersex and IGM Practices

#### a) Intersex = Variations of Sex Anatomy<sup>4</sup>

**Intersex people** are born with **Variations of Sex Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**. 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,**

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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 2016 CEDAW NGO Report France, p. 39–44.

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

**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**.<sup>5</sup>

**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 with less or little access to paediatric health care, there are reports of infanticide of intersex children,<sup>6</sup> of abandonment,<sup>7</sup> of massive bullying preventing the persons concerned from attending school (recognised by CRC as amounting to a harmful practice),<sup>8</sup> and of murder.<sup>9</sup>

### **4. “Inferior”, “Abnormal”, “Deformed”: Intersex, IGM and the CRPD**

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 need to be “cured” surgically, often **with racist, eugenic and supremacist undertones**.<sup>10 11 12 13</sup>

It is important to note that Intersex is an **umbrella term** for many diverse variations and “diagnoses”, of which only a few **specific and comparatively rare conditions** represent an **immediate medical situation or impairment**, notably Congenital Adrenal Hyperplasia (CAH) in the salt-losing form which constitutes a vital (metabolic) medical need for daily hormone substitution of lacking cortisol – *however, this does NOT constitute a need for genital surgeries!*

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, see 2015 CRC Briefing, slide 46,

[http://intersex.shadowreport.org/public/Zwischengeschlecht\\_2015-CRC-Briefing\\_Intersex-IGM\\_web.pdf](http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf)

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

7 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 Nepal, see relevant excerpts from testimonies from “Stories of Intersex People from Nepal” here <http://stop.genitalmutilation.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3>

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

10 2014 CRC NGO Report, p. 52, 69, 84

11 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>

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

13 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>

Nonetheless, doctors persistently **use this specific exception as a justification for imposing unnecessary genital surgery and other treatments on ALL** persons with variations of sex anatomy to “fix” them.<sup>14</sup>

Thus, **as a result of having been submitted to IGM practices**, most intersex people have actual **physical and psychological impairments and medical needs** (chronic pain, loss of sexual sensibility, lifelong psychological trauma, metabolic problems, and need for daily hormone substitution after castration, etc.). Many can’t work anymore, and live in poverty due to **persistent barriers** preventing them from full and effective participation in society on an equal basis as well as from the full enjoyment of all human rights, including their rights to physical integrity and self-determination, their rights to freedom from violence, harmful practices and torture or ill-treatment, their rights to the best attainable standard of health, and their rights to justice, redress and compensation. For example in Germany, many IGM survivors are officially **recognised as “disabled” due to the consequences of IGM**.<sup>15</sup>

On top, both IGM survivors and intersex persons having escaped surgery are facing (fear of) **stigmatisation, ostracism and rejection** by modern society because of their (sometimes) “unusual appearance”, compounded by **doctors’ constant conjuring up the birth of an intersex child as a “psycho-social emergency”** and qualifying it as a **“Disorder” in need of urgent involuntary “treatment”**.

Accordingly, the easier an intersex trait can be tested prenatally, **the higher the (selective) abortion rates**,<sup>16</sup> most intersex diagnoses are listed as permissible for deselection in State sponsored **preimplantation genetic diagnosis (PGD) guidelines**<sup>17</sup>, and e.g. in Switzerland **IGM practices are paid for by the Federal Disability Insurance**.<sup>18</sup>

In consequence, intersex persons and organisations are applying the **social model of disability** to devise strategies in their fight for bodily integrity and recognition as fully human beings, often in collaboration with disability groups. As *Jay Hayes-Light* of UKIA, an IGM survivor as well as wheelchair user (due to an accident not related with his intersex condition) puts it:<sup>19</sup>

*“Medical practitioners view intersex as something that needs to be fixed. We are regarded as deformed, somehow in deficit anatomically, and therefore the way to fix it is to cobble us*

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14 This excuse constitutes also the historic root for imposing systematic unnecessary early surgeries, see 2014 CRC NGO report, p. 54–56

15 For example in Germany, see 2015 CRPD Germany NGO Report, p. 16, [http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany\\_NGO-Report\\_Zwischengeschlecht\\_Intersex-IGM.doc](http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany_NGO-Report_Zwischengeschlecht_Intersex-IGM.doc)

16 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>

17 For example in the UK, see <http://guide.hfea.gov.uk/pgd/>, See also 2014 CRC NGO Report, p. 76, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

18 For example in the UK, see <http://guide.hfea.gov.uk/pgd/>, See also 2014 CRC NGO Report, p. 76, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

19 <https://www.theguardian.com/world/2016/jul/02/male-and-female-what-is-it-like-to-be-intersex>

*together into what they deem to be an acceptable format, instead of allowing us to exist in society.”*

## 5. Harmful Stereotypes and Prejudice

### a) Intersex is NOT a “Subhuman Species”

As shown and referenced above under 4., harmful stereotypes, norms, values, taboos and attitudes of and towards intersex people, often with racist, eugenic and supremacist undertones framing them as “**inferior**”, “**deformed**”, “**disordered**” or “**degenerated**” or a “**bad omen**” remain widespread and still inform the harmful western medical practice today, as well as other practices including infanticide and abandonment.

### b) 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.

**Intersex persons and their organisations have spoken out clearly against instrumentalising or misrepresenting intersex issues,**<sup>20</sup> 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**.

Nonetheless, the **pervasiveness and persistence** of these harmful misconceptions remains, as illustrated for example in two recent UN press releases misrepresenting IGM as “*sex alignment surgeries*” (i.e. voluntary procedures on transsexual or transgender persons), and IGM survivors as “*transsexual children*”,<sup>21</sup> and State parties referring to e.g. transgender guidelines<sup>22</sup> or “*Gender Identity Law*”<sup>23</sup> when asked about IGM by e.g. Treaty bodies.

## 6. Negative Impact also on Sexual and Reproductive Rights

IGM practices cause known **specific lifelong severe physical and mental pain and suffering inextricably linked to sexuality and reproduction**, including loss or impairment of sexual

20 For references, see 2016 CEDAW France NGO Report, p. 45. <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

21 For relevant excerpts and references, see <http://stop.genitalmutilation.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60>

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

23 CAT 60 Argentina, unofficial transcript see <http://stop.genitalmutilation.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture>

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, less sexual activity, dissatisfaction with functional and aesthetic results,<sup>24</sup> also resulting in violation the IGM survivors' sexual and reproductive rights.

Accordingly, the **CESCR General comment No. 22** (2016) on the right to sexual and reproductive health (art. 12) includes harmful medical practices on intersex persons, stating (our emphasis):

*“59. Violations of the obligation to protect occur when a State fails to take effective steps to prevent third parties from undermining the enjoyment of the right to sexual and reproductive health. This includes the **failure to prohibit and take measures to prevent all forms of violence and coercion** committed by private individuals and entities, including domestic violence, rape (including marital rape), sexual assault, abuse and harassment, including during conflict, post-conflict and transition situations; violence targeting lesbian, gay, bisexual, transgender and intersex persons or women seeking abortion or post-abortion care; harmful practices such as female genital mutilation, child and forced marriage, **forced sterilization**, forced abortion and forced pregnancy; and medically unnecessary, **irreversible and involuntary surgery and treatment performed on intersex infants or children.**”*

## 7. Human Rights and Treaty Bodies Denouncing IGM

So far, UN treaty bodies have issued **22 Concluding observations** denouncing IGM practices and **calling for legislation to end the practice**,<sup>25</sup> with **CRPD** considering IGM as a violation of the integrity of the person (art. 17), and in their latest LoIPR also as “*abuse, ill-treatment, sexual violence and/or exploitation*” (art. 16, see CRPD/C/GBR/Q/1, para. 11); **CAT** as constituting at least ill-treatment (referring to arts. 2, 12, 14, 16); **CRC** and **CEDAW** as 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”); and also the **HRCtee** is currently investigating IGM as a violation of CCRP arts. 7 (torture and non-therapeutic experimentation on minors) and 24 (rights of the child) (CCPR/C/CHE/QPR/4, paras. 21–22).

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:<sup>26</sup>

*“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 children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free*

24 See 2016 CAT France NGO Report, p. 46, <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

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

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



*from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers.”*

## 8. 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 by the NHS)<sup>27</sup> and **Germany** (around **1700 IGM procedures annually** paid for by the public health system).<sup>28</sup>

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

**South Africa**<sup>29</sup> and **France**<sup>30</sup> are still the only States officially recognising IGM constituting a harmful practice, but so far without enacting legislation accordingly. **Malta**<sup>31</sup> and **Argentina**<sup>32</sup> are still the only countries formally banning IGM, but both without any sanctions or known progress. **Human rights agencies reports** regularly fail to identify the above under 7. listed, most important applicable human rights frameworks, and only call for legislation regarding “*Gender Identity Registration*” and “*Discrimination*”, but fail to do so in order to end IGM practices and the impunity of the perpetrators and accessories, thus perpetuating the above under 5.b) mentioned harmful stereotypes, appropriation and colonisation of intersex politics, and erasure of IGM and IGM survivors and their legitimate concerns and demands.<sup>33 34</sup>

27 See 2017 CRPD UK NGO Report, p. 11–14, <http://intersex.shadowreport.org/public/2017-CRPD-PSWG-UK-NGO-Coalition-Intersex-IGM.doc>

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

29 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/>

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

31 See <http://stop.genitalmutilation.org/post/Intersex-politics-that-ignore-the-daily-mutilations-PINKWASHING-OF-IGM-PRACTICES>

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

33 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8, [http://stop.genitalmutilation.org/public/S3\\_Zwischengeschlecht\\_UN-Expert-Meeting-2015\\_web.pdf](http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf)

See also <http://stop.genitalmutilation.org/post/IDAHOT-2015-Let-s-Talk-About-Intersex-Appropriation>

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