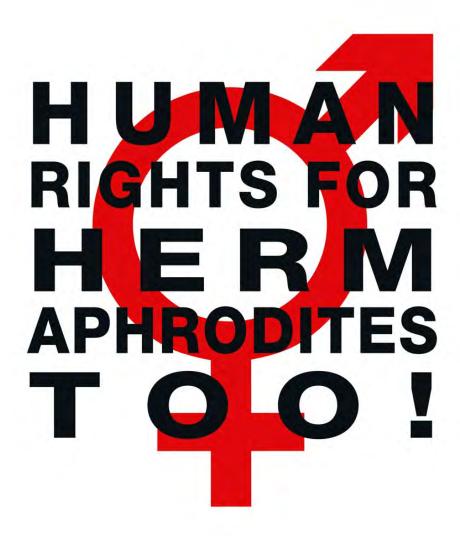
# Intersex Genital Mutilation

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



NGO Report (for Session)
to the 7<sup>th</sup> Report of Germany on the
International Covenant on Civil and Political Rights
(CCPR)

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 $\underline{https://intersex.shadowreport.org/public/2021-CCPR-Germany-NGO-Intersex-StopIGM.pdf}$ 



#### **Executive Summary**

Despite a new 2021 "Law on the Protection of Children with Variants of Sex Development", all typical forms of IGM practices are still widespread in Germany today, facilitated and paid for by the State party via the public health care system, and practiced with impunity. Latest available statistics indicate about 1,900 involuntary, non-urgent interventions annually. Survivors of IGM continue to be denied access to justice and reparations due to lack of effective legal prohibition and the statutes of limitations.

This Committee has consistently recognised IGM practices to constitute inhuman treatment in Concluding Observations, invoking Articles 2, 3, 7, 9, 17, 24 and 26.

Germany is thus in breach of its obligations under the Covenant to (a) take effective legislative, administrative, judicial or other measures to prevent inhuman treatment and involuntary experimentation on intersex children causing severe mental and physical pain and suffering of the persons concerned, and (b) ensure equal access to justice and redress, including fair and adequate compensation and as full as possible rehabilitation for victims, as stipulated in the CCPR in conjunction with the General comment No. 20.

In total, UN treaty bodies CRC, CEDAW, CAT, CCPR and CRPD have so far issued 54 Concluding Observations recognising IGM as a serious violation of non-derogable human rights, 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 **Thematic NGO Report** was compiled by the international intersex NGO **Zwischengeschlecht.org / StopIGM.org.** It contains **Suggested Recommendations (p. 20).** 

# NGO Report (for Session) to the 7<sup>th</sup> Report of Germany on the International Covenant on Civil and Political Rights (CCPR)

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#### A. Introduction

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

Germany has been reviewed by **CAT** (2011), **CRPD** (2015) and **CEDAW** (2017), with all Committees **recognising** IGM in Germany as constituting **cruel**, **inhuman or degrading treatment or torture**, a **violation of integrity** and a **harmful practice** respectively.

Nonetheless, **Germany continues to deny** the serious nature of the violations constituted by IGM practices, and, despite recently having adopted a "Law on the Protection of Children with Variants of Sex Development" aimed at prohibiting IGM practices, **refuses to take effective legislative**, **administrative**, **judicial or other measures**, including prohibition under Criminal Law, to protect intersex children from cruel, inhuman or degrading treatment. This NGO Report demonstrates that the persisting **harmful medical practice on intersex persons in Germany** – advocated, facilitated and **paid for by the State party**, and practiced with **impunity** –, as well as the ongoing **denial of access to justice and reparations** for IGM survivors, constitute **serious breaches** of Germany's obligations under the Covenant.

#### 2. About the Rapporteurs

This NGO report has been prepared by the international intersex NGO *StopIGM.org / Zwischengeschlecht.org*:

• 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!" According to its charter, StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to relevant UN treaty bodies, often in collaboration with local intersex advocates and NGOs, substantially contributing to the so far 54 Treaty body Concluding Observations recognising IGM as a serious human rights violation.

**StopIGM.org** includes members from Germany and has been active in Germany since **2007**, supporting intersex persons suing IGM perpetrators, publicly confronting individual perpetrators and hospitals, documenting the ongoing practice, raising awareness in the media, collaborating with members of parliament on parliamentary questions on the federal and on the Länder level, and testifying before the German National Ethics Council, calling for effective remedies to end the practice, and previously reported on IGM in Germany to CCPR, CAT, CRPD, CEDAW and CRC.

In personal capacity co-founder Daniela Truffer is also a member of the German intersex self-help group XY-Women, serving as a first contacter for 7 years, and of the German Association of Intersex People, serving as chair when it first submitted a thematic report to a UN Treaty body, leading to the first ever recommendations on intersex in 2009.

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

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

<sup>3 &</sup>lt;a href="https://intersex.shadowreport.org">https://intersex.shadowreport.org</a>

<sup>4</sup> https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

# 3. Methodology This thematic NGO report is an update to the 2018 CCPR NGO Report for LOIPR<sup>5</sup> by the same Rapporteurs.

<sup>5 &</sup>lt;u>https://intersex.shadowreport.org/public/2018-CCPR-LOIPR-Germany-NGO-Zwischengeschlecht-Intersex-IGM.pdf</u>

#### **B. Precedents**

#### 1. 2011 Concluding Observations on Intersex (CAT/C/DEU/CO/5, para 20)

#### Intersex people

20. The Committee takes note of the information received during the dialogue that the Ethical Council has undertaken to review the reported practices of routine surgical alterations in children born with sexual organs that are not readily categorized as male or female, also called intersex persons, with a view to evaluating and possibly changing current practice. However, the Committee remains concerned at cases where gonads have been removed and cosmetic surgeries on reproductive organs have been performed that entail lifelong hormonal medication, without effective, informed consent of the concerned individuals or their legal guardians, where neither investigation, nor measures of redress have been introduced. The Committee remains further concerned at the lack of legal provisions providing redress and compensation in such cases (arts. 2, 10, 12, 14 and 16).

#### The Committee recommends that the State party:

- (a) Ensure the effective application of legal and medical standards following the best practices of granting informed consent to medical and surgical treatment of intersex people, including full information, orally and in writing, on the suggested treatment, its justification and alternatives;
- (b) Undertake investigation of incidents 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;
- (c) Educate and train medical and psychological professionals on the range of sexual, and related biological and physical, diversity; and
- (d) Properly inform patients and their parents of the consequences of unnecessary surgical and other medical interventions for intersex people.

# 2. 2015 Concluding Observations on Intersex (CRPD/C/DEU/CO/1, paras 37-38) Protecting the integrity of the person (art. 17)

- 37. The Committee is concerned about: (a) the use of compulsory and involuntary treatment, in particular for persons with psychosocial disabilities in institutions and older persons in residential care; (b) the lack of data on involuntary placement and treatment; (c) the practice of carrying out forced sterilization and coercive abortions on adults with disabilities on the basis of substituted consent; and (d) the lack of implementation of the 2011 recommendations of the Committee against Torture (see CAT/C/DEU/CO/5, para. 20) regarding upholding the bodily integrity of intersex children.
- 38. The Committee recommends that the State party take the measures, including of a legislative nature, necessary to:
- (a) Repeal section 1905 of the German Civil Code and explicitly prohibit in law sterilization without the full and informed consent of the individual concerned, eliminating all

exceptions, including those based upon substituted consent or court approval;

- (b) Ensure that all psychiatric treatments and services are always delivered with the free and informed consent of the individual concerned;
- (c) Investigate human rights violations in psychiatric and older persons care settings in all Länder;
- (d) Implement all the recommendations of the Committee against Torture (ibid.) relevant to intersex children.

# 3. 2017 Concluding Observations on Intersex (CEDAW/C/DEU/CO/7-8, paras 23-24) *Harmful practices*

23. The Committee welcomes the adoption of legislative and other measures to combat harmful practices, including the forty-seventh Criminal Law Amendment Act (2013) prohibiting female genital mutilation and the establishment of an inter- ministerial working group on intersexuality/transsexuality. Nevertheless, the Committee is concerned about:

[...]

- (d) The lack of clear legislative provisions prohibiting the performance of unnecessary medical procedures on infants and children of indeterminate sex until they reach an age at which they are able to provide their free, prior and informed consent;
- (e) Inadequate support and the lack of effective remedies for intersex persons who have undergone medically unnecessary surgical procedures at a very early age, often with irreversible consequences, resulting in long-term physical and psychological suffering.
- 24. 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 (2014) on harmful practices, the Committee recommends that the State party:

[...]

- (d) Adopt clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age at which they can provide their free, prior and informed consent; provide the families of intersex children with adequate counselling and support; and ensure that the German Medical Association provides information to medical professionals on the legal prohibition of unnecessary surgical or other medical interventions for intersex children;
- (e) Ensure the effective access to justice, including by amending the statute of limitations, of intersex persons who have undergone unnecessary surgical or other medical treatment without their free, prior and informed consent; and consider the proposal of the German Ethics Council to establish a State compensation fund.

#### 4. 2018 List of Issues prior to Reporting (LOIPR) (CCPR/C/DEU/QPR/7, para 13)

#### Children with variations of sex characteristics (intersex) (arts. 7, 9, 17, 24 and 26)

13. Please respond to reports of non-emergency, invasive and irreversible surgical or other medical treatment carried out on infants and children with variations of sex characteristics (intersex), including sterilizing, feminizing, and masculinizing procedures, without fully informed, prior and free consent. Please clarify: (a) whether there are plans to ban such procedures unless they are an absolute medical necessity or are consented to by sufficiently mature intersex individuals themselves; and (b) whether any binding guidelines for medical professionals on the treatment of individuals with variations of sex characteristics have been adopted. Please report on the measures taken to address obstacles in access to justice and redress for individuals who were subjected to such surgical or other interventions as children, including statutes of limitations for filing claims.

#### 5. 2020 State Party Report (CCPR/C/DEU/7, paras 100-106)

Children with variations of sex characteristics (intersex) (arts. 7, 9, 17, 24 and 26)

#### Reply to paragraph 13 of the list of issues

- 100. Following the concluding observations of the Committee, the Federal Government mandated a report by the German Ethics Council (an independent council of experts) on the situation of intersex persons in Germany. In its report in 2012 the Council recommended that surgical and other medical measures concerning infants and children should be permitted only if these are strictly necessary in light of the best interest of the child. The Federal Government has initiated legislative procedures to address the question of surgical and other medical treatment of intersex children. The parties forming the current government have agreed to introduce legislation providing that such procedures shall be permitted only in cases of immediate concern and in order to prevent life-threatening situations.
- 101. In preparation for the drafting process, the BMJV held an interdisciplinary symposium in October 2018 with the participation of experts from various fields (medicine, law, psychology, gender studies), as well as affected individuals and their representatives, and interest groups. The symposium showed that all participants largely agreed that a ban should be introduced. However, the question of which precise form this ban should take encountered a great deal of discussion.
- 102. The draft bill is currently under consideration by the relevant ministries. A cabinet decision is expected within the first few months of 2020.
- 103. A 2016 study supported by the BMFSFJ on the current relevance of cosmetic operations of children with "ambiguous" genitalia contained an analysis of the first ever complete survey in Germany of the frequency of genitoplasty in children diagnosed with so-called "disorders of sexual development". The study retrospectively evaluated case-related data from hospital statistics on feminisation and masculinisation surgeries performed on genitals in German hospitals between 2005 and 2014. Based on the agreement of the current governing coalition, under which sex reassignment surgery in children should be permitted only in imperative cases and to avert an immediate threat to a child's life, the University of Bochum examined in 2018 how the frequency of feminisation and masculinisation surgeries on children's genitals had developed

over recent years. The notable overall result of the analysis is that the number of children under the age of 10 with congenital variations in physical sex characteristics who underwent inpatient feminisation or masculinisation surgery in a German hospital remained relatively stable between 2005 and 2016 when considered in relation to the number of diagnoses. There is no indication that there was a decrease in the number of feminising or masculinising genital surgeries on children unable to consent. This result is consistent with that of the first study (2016) covering the period between 2005 and 2014.

- 104. In addition, since spring 2019, the BMFSFJ has been engaged in targeted nationwide public awareness raising and educational work through its online "Rainbow Web Portal" to spread the information that a variation in physical sex development in itself does not usually require medical treatment and that account must be taken of the child's right to develop their own gender identity.
- 105. Moreover, preparations are currently ongoing to create a dialogue forum to expand counselling and support services for intersex people and their relatives, and to improve and secure the quality of such services. The dialogue forum is planned to be launched in late March/early April 2020.
- 106. The Federal Association of Intersex People (Bundesverband Intersexuelle Menschen e. V.) was commissioned by the BMFSFJ to create a curriculum for qualified counselling of intersex people and their families. Taking the form of guidelines, this curriculum will be used as a basis for improving the quality of the counselling and support available to intersex people.

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

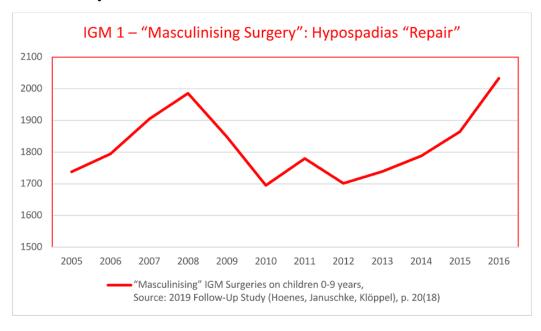
- 1. Overview: IGM practices in Germany: Still pervasive, no effective protections In Germany, as well as in many more State parties, 6 there are
  - **no effective legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM**
  - no measures in place to ensure systematic data collection and monitoring of IGM
  - no legal or other measures in place to ensure the accountability of IGM perpetrators
  - no legal or other measures in place to ensure access to redress and justice for adult IGM survivors

Despite adopting a new Law aimed at prohibiting IGM practices which entered in force on 12 May 2021, to this day the **German government refuses** to "take effective legislative, administrative, judicial or other measures" to protect intersex children, **denying survivors of IGM practices access to justice and redress.** 

#### 2. 2019 Follow-up study on IGM underlines persisting practice

In 2016, two studies using partial data from the "Diagnosis Related Groups (DRG)" of intersex surgeries in German hospitals financed by the Public Health System reported on average 1,700 IGM procedures every year (see our 2018 NGO Report for LOIPR, p. 10-14).

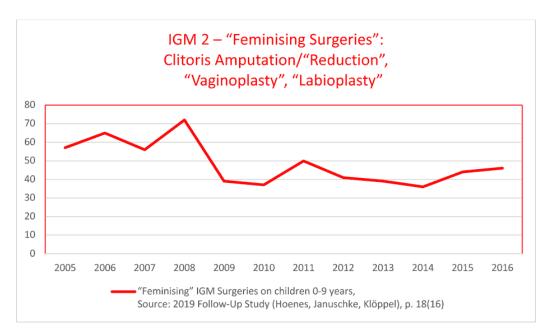
In the meantime, a new **2019** "Follow-up study" on IGM practices<sup>7</sup> commissioned by the Federal Government again using partial data from the "Diagnosis Related Groups (DRG)" reported on average almost **1,900** "masculinising" and "feminising" surgeries every year on intersex children **0-9** years alone:



 $<sup>6 \</sup>qquad See \ \underline{https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations} \\$ 

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Josch Hoenes, Eugen Januschke, Ulrike Klöppel (2019), "Häufigkeit normangleichender Operationen 'uneindeutiger' Genitalien im Kindesalter. Follow Up-Studie", <a href="https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-4">https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-4</a>



While the "Follow-up study" fails to document sterilising procedures, partial figures published by the "Statistisches Bundesamt (Destatis)" 8 show that also IGM 3 continues:

DRG-Statistik 2016 - Vollstationäre Patientinnen und Patienten in Krankenhäusern <sup>1</sup>
Operationen und Prozeduren (OPS Version 2016)

1.3 Operationen und Prozeduren auf Ebene des 4-stelligen OPS-Schlüssels und Altersgruppen

1.3.3 Weiblich

UP3-	Ins-			
Schlüssel <sup>2</sup>	gesamt 3	unter 1	1-5	5 - 10
5-622 Orchidektomie	173	1	4	
5-624 Orchidopexie	3	1	1	
5-625 Exploration bei Kryptorchismus	1	-	1	
5-626 Operative Verlagerung eines Abdominalhodens	1		1	G.
5-627 Rekonstruktion des Hodens	1		-	
5-629 Andere Operationen am Hoden	1		- 6	
5-630 Operative Behandlung einer Varikozele und einer Hydrocele funiculi spermatici	4	1		
5-631 Exzision im Bereich der Epididymis	481			
5-633 Epididymektomie	1			
5-634 Rekonstruktion des Funiculus spermaticus	1			
5-636 Destruktion, Ligatur und Resektion des Ductus deferens	1			
5-639 Andere Operationen an Funiculus spermaticus, Epididymis und Ductus deferens	1		-	
5-640 Operationen am Präputium	9	4.	1	

#### 3. Insufficient 2021 Law introducing § 1631e BGB aimed at prohibiting IGM

After 25 years of endless "discussions" and "careful examination" without any actual consequences, the current German government has to be commended for finally adopting a Law aimed at prohibiting IGM practices in March 2021 – insufficient as it may be:

In January 2020, the **Ministry of Justice and Consumer Protection (BMJV)** presented a **preliminary Draft Law (RefE)** aimed at prohibiting IGM practices ("*Draft Law for the protection of children from sex-modifying surgical interventions*"). However, it **failed to provide adequate protections** for intersex children. <sup>10</sup>

In November 2020, the **German Federal Government** presented an amended "*Draft Law for the protection of children with variants of sex development*" (DS 19/24686, 25.11.2020), <sup>11</sup> which in March 2021 was again amended by the **Committee on Legal Affairs and Consumer Protection** 

<sup>8</sup> Statistisches Bundesamt (Destatis) (2017), "DRG-Statistik 2016. Operationen und Prozeduren auf Basis des 4-stelligen OPS der vollstationären Patientinnen und Patienten in Krankenhäusern", p. 50, https://www.statistischebibliothek.de/mir/servlets/MCRFileNodeServlet/DEHeft\_derivate\_00048786/5231401167014\_korr16012018.pdf

<sup>9</sup> https://www.bmjv.de/SharedDocs/Gesetzgebungsverfahren/Dokumente/RefE\_Verbot\_OP\_Geschlechtsaenderung\_Kind.pdf?\_blob=publicationFile&v=2

<sup>10</sup> See <a href="https://stopigm.org/german-draft-law-fails-intersex-children/">https://stopigm.org/german-draft-law-fails-intersex-children/</a>

 $<sup>11 \</sup>quad \underline{https://dip21.bundestag.de/dip21/btd/19/246/1924686.pdf}$ 

(DS 19/27929, 24.03.2021)<sup>12</sup> and eventually **adopted** by the **German Federal Parliament** (**Bundestag**) on 25.03.2021<sup>13</sup> and **published** in the Federal Law Gazette on 21.05.2021 as "Law on the Protection of Children with Variants of Sex Development of 12 May 2021": <sup>14</sup>

Basically, this **new Law** introduces in **Art. 1** a new § **1631e** in the **Civil Law** (**BGE**) which **in some cases limits parental consent** to unnecessary surgery on intersex children (§ 1631e (1)-(3)), and requires them to seek **autorisation by the Family Court** (§ 1631e (3)-(5)).

"Parental custody does not include the right to consent to treatment of a child who is incapable of giving consent and has a variant of sex development, or to carry out such treatment oneself, which, without any further reason for the treatment being added, is carried out solely with the intention of aligning the child's physical appearance with that of the male or female sex." (Civil Law (BGB), § 1631e (1))

Further, the Law obliges medical practitioners, "where treatment has been carried out on the internal or external sex characteristics, [to] keep the patient's file until the day on which the person treated reaches the age of 48 years." (§ 1631e (6))

Also, in Art. 6 on "Evaluation" of the new Law stipulates a review and possible amendments within five years:

"The Federal Government shall review the effectiveness of the provisions of Articles 1 and 3 of this Act within five years of their entry into force and shall submit a report thereon to the German Bundestag."

#### However, this new Law

- only partially restricts IGM 2 and IGM 3, while in turn explicitly allows, among other things, the most frequent unnecessary interventions, i.e. IGM 1
- fails to criminalise or adequately sanction IGM practices
- fails to address **obstacles to access to justice and redress**, namely the **statutes of limitation**
- fails to implement minimal requirements as stipulated in UN Conventions, inter alia CCPR art. 2 in conjunction with General Comment No. 31 (para 8) and art. 7 in conjunction with General Comment No. 20 (paras 2, 8, 14).

Particularly the lack of criminalisation or adequate sanctions and the lack of addressing the statutes of limitation, as well as the failure to establish a national register for relevant medical records, was also criticised by several experts at a hearing by the Federal Committee on Legal Affairs and Consumer Protection on 13.01.2021. 15 16 17

13 <u>https://www.bundestag.de/dokumente/textarchiv/2021/kw12-de-geschlechterentwicklung-kinder-830122</u>

<sup>12</sup> https://dserver.bundestag.de/btd/19/279/1927929.pdf

<sup>14</sup> https://www.bmjv.de/SharedDocs/Gesetzgebungsverfahren/Dokumente/Bgbl\_Varianten\_der\_Geschlechtsentwicklung.pdf?\_blob=publicationFile&v=3

German Institute for Human Rights (DIMR), <a href="https://www.bundestag.de/resource/blob/816910/9efleb47e5d5954c6164ee9dec3a3bb8/stellungnahme-kittel\_dim-data.pdf">https://www.bundestag.de/resource/blob/816910/9efleb47e5d5954c6164ee9dec3a3bb8/stellungnahme-kittel\_dim-data.pdf</a>

<sup>16</sup> Dr Ulrike Klöppel, https://www.bundestag.de/resource/blob/816514/8705e20395ba739e8881d13bca030aff/stellungnahme-kloeppel-data.pdf

<sup>17</sup> Dr Konstanze Plett, https://www.bundestag.de/resource/blob/816780/9f83fb0ab7d697f86581f5eb87293a44/stellungnahme-plett-data.pdf

After the adoption of the new Law, its **shortcomings and loopholes** were again **widely criticised** by **intersex NGOs**<sup>18</sup> 19 20 21 and **legal experts**. 22

The lack of sanctions was also highlighted by doctors involved in IGM practices: <sup>23</sup>

"[...] Olaf Hiort - a professor at the University Hospital in Luebeck - said he hoped [the German ban] would 'curb uncontrolled operations'.

He noted, however, that while there was now a ban, 'there is no penalty'."

#### 4. Medical guidelines prescribing IGM practices remain in force

Despite the new Law, the German Urological Association ("Deutsche Gesellschaft für Urologie (DGU)"), same as its counterpart in Finland (CCPR/C/FIN/CO/7, paras 20+21(c)),<sup>24</sup> still endorses the 2021 Guidelines of the European Association of Urology (EAU),<sup>25</sup> which include the current ESPU/EAU "Paediatric Urology" Guidelines 2021<sup>26</sup> of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which promote all forms of IGM practices, in particular IGM 3: "removal of testes",<sup>27</sup> 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",<sup>28</sup> and IGM 1: "The age at surgery for primary hypospadias repair is usually 6-18 (24) months."

# 5. Statutes of limitations and lack of effective prohibition: Main obstacles preventing access to justice for IGM survivors

Generally, the **statutes of limitation** prevent survivors of early childhood IGM Practices to call a court, because IGM survivors often do not find out about their medical history until much later in life, which in combination **refusal of hospitals to provide access to medical records** and severe trauma caused by IGM Practices regularly prove to amount to a insurmountable obstacle.<sup>30</sup>

This is well-known to and publicly admitted by the Government at least regarding Civil Law, referring to "claims" of intersex advocates for "prolongation of limitation periods for asserting civil claims under medical malpractice law".<sup>31</sup>

<sup>18</sup> https://im-ev.de/wp-content/uploads/2021/03/2021-03-26-PM-Verbot-von-Operationen.pdf

<sup>19 &</sup>lt;u>https://blog.zwischengeschlecht.info/post/2021/04/18/Das-deutsche-Intersex-Gesetz-und-die-Schweiz</u>

<sup>20 &</sup>lt;u>https://oiigermany.org/ein-steiniger-weg-fuer-menschenrechte/</u>

<sup>21 &</sup>lt;a href="https://oiieurope.org/a-good-first-step-germany-adopts-law-banning-igm/">https://oiieurope.org/a-good-first-step-germany-adopts-law-banning-igm/</a>

<sup>22</sup> https://www.lto.de/recht/justiz/j/gesetz-zum-verbot-geschlechszuweisender-operationen-bei-intergeschlechtlichen-kindern-in-kraft-menschenrechte/

<sup>23 &</sup>lt;u>https://www.reuters.com/article/us-germany-lgbt-health-idUSKBN2BI2MC</u>

<sup>24</sup> See our 2021 CCPR Finland Intersex NGO Report for Session, p. 11-14, https://intersex.shadowreport.org/public/2021-CCPR-Finland-NGO-Zwischengeschlecht-Intersex-IGM.pdf

<sup>25 &</sup>lt;u>https://uroweb.org/guidelines/endorsement/</u>

<sup>26 &</sup>lt;a href="https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf">https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf</a>

For details and relevant quotes, see 2021 CCPR Finland Intersex NGO Report for Session, p. 11-12, <a href="https://intersex.shadowreport.org/public/2021-CCPR-Finland-NGO-Zwischengeschlecht-Intersex-IGM.pdf">https://intersex.shadowreport.org/public/2021-CCPR-Finland-NGO-Zwischengeschlecht-Intersex-IGM.pdf</a>

For details and relevant quotes, see ibid., p. 12-13

<sup>29</sup> For details and relevant quotes, see ibid., p. 14

Globally, no survivor of early surgeries **ever** managed to have their case heard in court. All relevant court cases (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

<sup>31</sup> Interministerial Working Group (2016), "Focus on the situation of trans- and intersexual people". Status

Also the fact that the **lack of effective legislative prohibition of IGM** practices constitutes yet another insurmountable obstacle to IGM survivors seeking redress has been **publicly admitted by the Federal government**, <sup>32</sup> as well as by **various Social Courts** (see below).

#### 6. IGM Practices: Known German Case Law

As already mentioned in our 2018 NGO Report for LOIPR (p. 16-17), the lack of access to justice, redress and compensation for survivors of IGM practices in Germany is well known and near total. The following updated and expanded section demonstrates that also in 2021 this is still true:

#### a) Criminal Law: 0 cases

No survivor of IGM practices ever succeeded in filing criminal charges.

In case of average early surgeries "in the first two years of life", all statutes of limitations have long passed before survivors come of age.

To this day, persons concerned and their organisations in vain call for a legal review of the statutes of limitations in cases of IGM practices, referring to current and recent legal reviews regarding adjournment or suspension of the statutes of limitation in cases of child sexual abuse (§§ 176 ff. StGB), and female genital mutilation (§ 226a StGB).

Already in 2014, also the **24th Conference of Ministers for Women's Issues and Equality** (GFMK) explicitly called for a "legal ban of medically unnecessary surgical and pharmacological [...] interventions on intersex minors," explicitly referring to the need of intersex children for similar protection against sterilisation (§ 1631c BGB) and female genital mutilation (§ 226a StGB) that other children and girls already enjoy.<sup>33</sup>

On occasion of the adoption of the new insufficient Law § 1631e BGB, its **lack of criminalisation or adequate sanctions** and the **lack of addressing the statutes of limitation** has again been **widely criticised** by intersex NGOs and legal experts (see above, p. 13-14).

#### b) Civil Law: 1 successful adult case, 2 adult settlements

No survivor of childhood IGM practices ever succeeded in filing civil charges.

Only 3 survivors of IGM practices so far succeeded in filing civil charges – all of them only for surgeries they were submitted to as adults of 18 years or older.

All other survivors of IGM practices attempting to sue so far were prevented by the statutes of limitations.

information of the BMFSFJ. Accompanying material to the Interministerial Working Group on Inter-& Transsexuality - Volume 5, Berlin, p. 17, <a href="https://www.bmfsfj.de/blob/112092/f199e9c4b77f89d0a5aa825228384e08/imag-band-5-situation-von-trans-und-intersexuellen-menschen-data.pdf">https://www.bmfsfj.de/blob/112092/f199e9c4b77f89d0a5aa825228384e08/imag-band-5-situation-von-trans-und-intersexuellen-menschen-data.pdf</a>

- The Coalition Agreement 2018-21 of the current Government explicitly promises: "We will make it clear by law that [...] medical interventions on [intersex] children are only permissible in cases that cannot be postponed and in order to avert danger to life."
  - CDU, CSU und SPD (2018): Coalition Agreement for 19th Legislative Term, p. 21, lines 797-799. https://www.cdu.de/system/tdf/media/dokumente/koalitionsvertrag 2018.pdf?file=1
- 33 at 52-54 http://www.gleichstellungsministerkonferenz.de/documents/2014\_10\_13\_Beschluesse\_GESAMT\_Extern.pdf

Already in 2009 during an intersex hearing of the State Parliament of Hamburg, specialised local lawyer Dr. Oliver Tolmein stated: "Interestingly, a great many [intersex] persons come to our lawyer's office wanting to sue their doctors for damages [however, so far all were prevented by the statutes of limitations]".<sup>34</sup>

Case 1: The first case in Cologne 2007-2009 filed by Christiane Völling concerned the removal of ovaries and uterus without informed consent and resulted in a surgeon being sentenced to pay 100'000 Euros damages. 35 36 37

Case 2: Case filed 2012 in Munich.<sup>38</sup> In the meantime the claimant agreed to a **settlement** as the person couldn't afford to continue a costly, lengthy Civil Law suit.

Case 3: Case filed 2011 in Nuremberg<sup>39</sup> by Michaela Raab concerning involuntary partial clitoris amputation and gonadectomy (castration), with a **first instance verdict on 17.12.2015** sentencing the Erlangen University Clinic to **pay damages**. <sup>40</sup> <sup>41</sup> After the defendants lodged an appeal, the case rested **3 years without activity** in the **second instance** at the Higher Court (**OLG**), <sup>42</sup> Eventually, a court date was set for **07.02.2019** to "appraise the facts" and "attempt a settlement". In the end, Michaela Raab, **worn down and tire**d after 8 years of legal proceedings and **without the necessary funds** to continue a costly, lengthy Civil Law suit, accepted a settlement of 40,000 Euros, as reported in a local newspaper: <sup>43</sup>

"Michaela Raab demanded 250,000 euros plus a pension through lawyer Paul Haubrich - and has now settled for 40,000 euros in a settlement before the Higher Court. The representatives of the university hospital (annual budget 2017: 769 million euros, 7586 employees, 1194 of them doctors) say the insurance would not cover the period in question. More than 40,000 euros could not be financed. Theoretically, Michaela Raab is free to reject the settlement and continue to fight with the clinic. But after the OLG comes the BGH [Federal Supreme Court] - and the financial risk of litigation is incalculable for Michaela Raab."

#### c) Victim's Compensation Law (OEG): 4 failed/ongoing Cases

The Victims Compensation Law (Opferentschädigungsgesetz, OEG) was introduced with the **stated intent** "to create a financial compensation in cases of the state failing its mission to prevent crimes". 44

Wortprotokoll, at 11 <a href="http://kastrationsspital.ch/public/19\_10\_HH\_Wortpr\_Intersex.pdf">http://kastrationsspital.ch/public/19\_10\_HH\_Wortpr\_Intersex.pdf</a>

<sup>35</sup> OLG Köln 03.09.2008, Az. 5 U 51/08 http://www.justiz.nrw.de/nrwe/olgs/koeln/j2008/5 U 51 08beschluss20080903.html

<sup>36</sup> LG Köln 12.08.2009, Az. 25 O 179/07 <a href="http://www.justiz.nrw.de/nrwe/lgs/koeln/lg\_koeln/j2009/25\_O\_179\_07schlussurteil20090812.html">http://www.justiz.nrw.de/nrwe/lgs/koeln/lg\_koeln/j2009/25\_O\_179\_07schlussurteil20090812.html</a>

DPA (2009), Christiane Völling: Hermaphrodite wins damage claim over removal of reproductive organs, <a href="https://zwischengeschlecht.org/pages/Hermaphrodite-wins-damage-claim">https://zwischengeschlecht.org/pages/Hermaphrodite-wins-damage-claim</a>

<sup>38</sup> LG München, Az. 9 O 27981/12.

<sup>39</sup> LG Nürnberg-Fürth, Az. 4 O 7000/11. 1st day in court was 26.02.2015.

<sup>40</sup> Sentence LG Nürnberg-Fürth, 17.12.2015, Az. 4 O 7000/11.

 $<sup>41 \</sup>quad StopIGM.org~(2015), \\ \underline{\text{https://stopigm.org/post/Nuremberg-Hermaphrodite-Lawsuit-Damages-and-Compensation-for-Intersex-Genital-Mutilations}}$ 

<sup>42</sup> OLG Nürnberg, Az. 5 U 53/16.

<sup>43</sup> Ulrike Löw (2019), "Penis-Amputation': Intersexuelle verklagt Uni-Klinik Erlangen" ("Penis amputation': Intersex woman sues Erlangen University Hospital"), nordbayern.de,

<a href="https://www.nordbayern.de/region/nuernberg/penis-amputation-intersexuelle-verklagt-uni-klinik-erlangen-1.8603872">https://www.nordbayern.de/region/nuernberg/penis-amputation-intersexuelle-verklagt-uni-klinik-erlangen-1.8603872</a>

<sup>44</sup> Franziska Brachthäuser, Theresa Richarz (2014): Zwischen Norm und Geschlecht – Erste Entwürfe möglicher

So far, no survivor of IGM practices succeeded in winning any compensation, with the courts consistently denying compensation to IGM victims, including by explicitly stating that for the plaintiff to be eligible for compensation, "there would have to be laws [against IGM practices] in place. However, there aren't." (see below Case 2)

Another case, originally initiated in Hamburg in 2009 (!), has currently been dragging on for almost 12 years, so far with court after court concluding that non-consensual full clitoridectomy and medical experimentation with "Androcur" would constitute "state of the art" legal medical interventions "serv[ing] the well-being of the patient", and that - contrary to CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24; CCPR/C/DEU/QPR/7, para 13 – "[a]lso a human experiment and torture [or CIDT] is not to be assumed" (see below Case 4).

Case 1:45 Survivor of IGM practices with acknowledged disability grade (GdB) due to IGM, unable to work. Right to compensation denied by court in 2012, on the grounds of lacking "hostile intent" ("feindselige Absicht") of perpetrating doctors, referring to lack of "own financial interests of treating clinicians". 46

Case 2: Survivor of IGM practices with acknowledged disability grade (GdB) of 80% due to IGM, unable to work. Right to compensation denied by court in 2012, on the grounds of lacking "hostile intent" ("feindselige Absicht") of perpetrating doctors. As mentioned above (D.2.), in addition the court explicitly stated, for the plaintiff to be eligible for compensation "there would have to be laws [against IGM practices] in place. However, there aren't." "47

Case 3: Survivor of IGM practices with acknowledged disability grade (GdB) of 60% due to IGM, unable to work. Right to compensation denied by court in 2014, on the grounds of lacking "hostile intent" ("feindselige Absicht") of perpetrating doctors.<sup>48</sup>

Case 4: Survivor of IGM practices with acknowledged disability grade (GdB) of 50% due to IGM, unable to work. Born 1972, at age 5 the person concerned was submitted to a nonconsensual full clitoridectomy and vaginoplasty, and from 1979-1983 to involuntary human experimentation with "Androcur" (the risky, meanwhile discredited preparation best known for its application for "chemical castration" of sex offenders). On 29.10.2009 the person concerned first submitted an informal application for OEG compensation, together with the application for

nationaler Entschädigungs- und Schadensersatzansprüche intersexueller Menschen gegen die Bundesrepublik Deutschland, Humboldt Law Clinic: Menschenrechte, Working Paper Nr. 5, at 22-24 (p. 19-21 in PDF) http://hlcmr.de/wp-content/uploads/2015/01/Working\_Paper\_Nr.5.pdf

- Although this person is personally known to the rapporteurs, here the case details are taken from: Franziska Brachthäuser, Theresa Richarz (2014): Zwischen Norm und Geschlecht - Erste Entwürfe möglicher nationaler Entschädigungs- und Schadensersatzansprüche intersexueller Menschen gegen die Bundesrepublik Deutschland, Humboldt Law Clinic Menschenrechte (HLCMR) Working Paper Nr. 5, at 9, 11 (i.e. 6, 8 according to page numbers within document)
  - http://hlcmr.de/wp-content/uploads/2015/01/Working Paper Nr.5.pdf
  - (All other cases are based on personal interviews.)
- SG Trier, 07.02.2012 Az. S 6 VG 10/11 Tr. (unpublished)
- SG Bayreuth, 01.08.2012, Az. S 4 VG 5/11 (unpublished); see also relevant quote in Nürnberger Nachrichten (04.11.2013) https://web.archive.org/web/20131114044728/http://www.nordbayern.de/nuernbergernachrichten/region-bayern/schmerzliche-suche-nach-dem-eigenen-geschlecht-1.3257295
- SG Nürnberg, 16.07.2014, Az. S 15 VG 9/12 (unpublished)

disability grade. On 25.06.2010 the person followed-up with a formal application to the State Ministry for Work, Social Affairs, Family and Intergration (BASFI) Hamburg. 49 On 19.03.2012 the lawyer of the person concerned explicitly informed the State ministry of the recent CAT Concluding Observations for Germany on IGM (CAT/C/DEU/CO/5, para 20).

Right to compensation denied by State ministry in 2013, on the grounds of lacking "hostile intent" ("feindselige Absicht"), stating the deeds in question, including non-consensual full clitoridectomy and human experimentation with "Androcur, would not constitute a punishable criminal offense.<sup>50</sup>

On 02.04.2013 the person concerned lodged an appeal at the Social Court Hamburg.<sup>51</sup> There. the case rested for over 69 months.

On 19.12.2018 the Social court eventually denied compensation, <sup>52</sup> arguing the non-consensual full clitoridectomy and medical experimentation with "Androcur" would constitute a legal medical therapy for intersex children still recommended today, which would "serve the wellbeing of the patient", further directly contradicting the CAT Concluding Observations on intersex interventions in Germany, considered as inhuman treatment under CAT arts. 2, 10, 12, 14 and 16 (CAT/C/DEU/CO/5, para 20):

"At the beginning of the 70's of the last century an early correction of the external genital at Prader stage III was recommended. Even today, surgery in the first two years of life is recommended. It is only since a few years that the choice of the timing of surgery has been controversially discussed in science. Since the surgery corresponds to the state of science, i.e. serves the well-being of the patient, an assault in the sense of the OEG is not given. Also a human experiment and torture [or CIDT] is not to be assumed." (p. 3-4)

Accordingly, in its conclusion the Social Court Hamburg reiterated, the IGM practices in question would not constitute "punishable medical interventions", but again "objectively [...] serve [the] well-being" of the person concerned:

"The plaintiff has not become a victim of violence in the sense of the OEG, because neither the surgery at the age of five nor the treatment with Androcur nor the bladder puncture are punishable medical interventions, which objectively, i.e. from the point of view of a reasonable third party, did not serve their well-being." (p. 8)

On 21.01.2019 the person concerned lodged an appeal against this verdict at the Higher Social Court Hamburg (Landessozialgericht LSG Hamburg), which on 13.07.2021 rejected the appeal.<sup>53</sup> again ruling the "full clitoris amputation" ("clitoridectomy") would have lacked "hostile intent" ("feindselige Absicht"), would not constitute "torture and other cruel, inhuman or degrading treatment", but would essentially be "covered by a curative mandate of the treating doctors".

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<sup>49</sup> Az. FS 53123-17770/10-OEG (unpublished).

State Ministry for Work, Social Affairs, Family and Intergration (BASFI) Hamburg, 19.03.2013, Az. FS 53123-50 17770/10-OEG (unpublished)

SG Hamburg, Az. S 12 VE 46/14

SG Hamburg, 19.12.2018, Az. S 12 VE 46/14, https://zwischengeschlecht.org/public/Hamburg-Intersex-OEG-Urteil-19-12-2018 S-12-VE 46-14 web.pdf

<sup>53</sup> LSG Hamburg, 13.07.2021, Az. L 3 VE 1/19 (unpublished)

On 13.08.2021 the person concerned therefore lodged an appeal at the **Federal Social Court** (Bundessozialgericht BSG),<sup>54</sup> bracing for more slow-moving proceedings in this case soon to be **dragging on for no less than 12 years.** 

This situation is clearly not in line with Germany's obligations under the Covenant.

#### d) Compensation Fund

A longstanding demand is a **compensation fund for IGM survivors** unable to pursue legal avenues, for example due to the statutes of limitations. In 2012 the **German Ethics Council** recommended to **establish a compensation fund.**<sup>55</sup> And in 2017 **CEDAW** explicitly obliged Germany (CEDAW/C/DEU/CO/7-8, paras 23-24) to "consider the proposal of the German Ethics Council to **establish a State compensation fund**".

This all is **well-known to and publicly admitted by** the Government confirming in 2016, "Other claims touch on the question of the establishment of a compensation fund for people who have had sex-assigning surgeries in the past".<sup>56</sup>

However, to this day the Government refuses to undertake any actual steps, again ...

<sup>54</sup> BSG, Az. B 9 V 32/21 B

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<sup>55</sup> Stellungnahme "Intersexualität", 14. Februar 2012 (BT – Drs. 17/9088), S. 176
Interministerial Working Group (2016), "Focus on the situation of trans- and intersexual people". Status information of the BMFSFJ. Accompanying material to the Interministerial Working Group on Inter- & Transsexuality - Volume 5, Berlin, p. 17, <a href="https://www.bmfsfj.de/blob/112092/f199e9c4b77f89d0a5aa825228384e08/imag-band-5-situation-von-trans-und-intersexuellen-menschen-data.pdf">https://www.bmfsfj.de/blob/112092/f199e9c4b77f89d0a5aa825228384e08/imag-band-5-situation-von-trans-und-intersexuellen-menschen-data.pdf</a>

## D. Suggested Recommendations

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

#### **Intersex persons**

While welcoming the recent adoption of the Law on the Protection of Children with Variants of Sex Development (12 May 2021), the Committee remains concerned, however, about irreversible and invasive medical procedures being performed on intersex children before they are able to provide fully informed and free consent, which can cause severe suffering, and the lack of redress and compensation in such cases (arts. 2, 3, 7, 9, 17, 24 and 26).

The State party should strengthen the measures to end the performance of irreversible medical acts, especially surgical operations, on intersex children who are not yet capable of giving their full, free and informed consent, except in cases where such interventions are absolutely necessary for medical reasons. Access to effective remedies for victims of such interventions should also be ensured, including by amending the statute of limitations.

#### Annexe 1 – IGM Practices in Germany as a Violation of CCPR

#### 1. The Treatment of Intersex Children in Germany as Inhuman Treatment

This Committee has repeatedly **recognised IGM** practices as a **serious violation of Covenant**, <sup>57</sup> and **arts. 2, 3, 7, 9, 17, 24, 26** as applicable.

#### Art. 2: Non-Discrimination, Legal Implementation, Remedies and Reparations

On the basis of being born with intersex traits, intersex children are singled out for experimental harmful treatments, including surgical "genital corrections" and potentially sterilising procedures, that would be "considered inhumane" on "normal" children, see.g. "normal" boys and girls, while on intersex children, according to a specialised surgeon, "any cutting, no matter how incompetently executed, is a kindness." While similar inhuman treatment of other children is criminalised in the German Penal Law and perpetrators are persecuted, intersex children have no such legal protections and no access to justice, redress, rehabilitation and reparation. Clearly, IGM practices therefore violate Article 2.

#### Art. 3: Equal Right of Men and Women

On the basis of their "indeterminate sex," intersex children are singled out for inhuman treatment, namely IGM practices. Generally, medical justifications for IGM are often rooted in gender-based stereotypes. Further, while Female Genital Mutilation (FGM) is criminalised in the German Penal Law, with also extraterritorial protections in force, IGM practices remain legally permitted. Clearly, IGM practices therefore also violate Article 3.

# Art. 7: Cruel, Inhuman or Degrading Treatment, and Involuntary Medical or Scientific Experimentation

Like this Committee, the **Committee against Torture**<sup>60</sup> has repeatedly **considered IGM to constitute inhuman treatment** falling under the non-derogable prohibition of torture (same as FGM and gender-based violence). Intersex advocates consider harmful practices and inhuman treatment as the **most important human rights frameworks** to effectively combat IGM. <sup>61</sup>

Concerning **involuntary medical or scientific experimentation**, as generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental**. While due to the general avoidance of follow-up by doctors, IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition. However, internationally there are **many examples proving also a strict definition to apply**. <sup>62</sup>

<sup>57</sup> See CCPR/C/CHE/CO/4, paras 24-25; CCPR/C/AUS/CO/6, paras 25-26; CCPR/C/DEU/QPR/7, para 13; CCPR/C/BEL/CO/6, paras 21-22; CCPR/C/MEX/CO/6, paras 12-13

Alice Domurat Dreger (2006), Intersex and Human Rights: The Long View, in: Sharon Sytsma (ed.) (2006), Ethics and Intersex: 73-86, at 75

<sup>59</sup> Cheryl Chase (1998), Surgical Progress Is Not the Answer to Intersexuality, in: Alice Dreger (ed.) (1999), Intersex in the Age of Ethics:148–159, at 150

<sup>60</sup> See CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; CAT/C/AUT/CO/6, paras 44-45; CAT/C/CHN-HKG/CO/4-5, paras 28-29; CAT/C/DNK/CO/6-7, paras 42-43; CAT/C/FRA/CO/7, paras 34-35; CAT/C/NLD/CO/7, paras 52-53; CAT/C/GBR/CO/6, paras 64-65

Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: "Ending the Impunity of the Perpetrators!" Input at "Ending Human Rights Violations Against Intersex Persons." OHCHR Expert Meeting, Geneva 16–17.09.2015, online: <a href="https://stopigm.org/public/S3">https://stopigm.org/public/S3</a> Zwischengeschlecht UN-Expert-Meeting-2015 web.pdf

<sup>62</sup> See e.g. Case Study No. 1 in 2015 CAT Austria NGO Report (p. 13-15), explaining how of two intersex cousins, one was castrated at age 5 or 6 and the other only at age 10 "to document the difference", <a href="https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf">https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf</a>

For decades, intersex children have been regularly described and exploited by scientists as an "experiment of nature". 63 64 65 Often twins, siblings, mothers or other family members or relatives of intersex children are used as controls. 66 67 Generally, intersex children, while being submitted to IGM practices or thereafter, are often used as subjects in scientific research, particularly in the field of genetics, also in Germany and internationally with the contribution of German IGM doctors.

Thus, intersex children surely also fall under "persons not capable of giving valid consent" deserving "special protection in regard to such experiments" according to **General comment No. 20** (para 7), and involuntary experimental intersex treatments in **Germany** surely also constitute **involuntary medical or scientific experimentation in breach of article 7**.

What's more, regarding legislative and other measures, General comment No. 20 explicitly obliges State parties to

- "afford everyone protection through legislative and other measures as may be necessary against the acts prohibited by article 7, whether inflicted by people acting in their official capacity, outside their official capacity or in a private capacity." (para 2)
- "inform the Committee of the legislative, administrative, judicial and other measures they take to prevent and punish acts of torture and cruel, inhuman and degrading treatment in any territory under their jurisdiction." (para 8)
- "indicate how their legal system effectively guarantees the immediate termination of all the acts prohibited by article 7 as well as appropriate redress. The right to lodge complaints against maltreatment prohibited by article 7 must be recognized in the domestic law. Complaints must be investigated promptly and impartially by competent authorities so as to make the remedy effective. The reports of States parties should provide specific information on the remedies available to victims of maltreatment and the procedure that complainants must follow, and statistics on the number of complaints and how they have been dealt with." (para 14)

<sup>63</sup> See e.g. Kang H-J, Imperato-McGinley J, Zhu Y-S, Rosenwaks Z. 5alpha-reductase-2 Deficiency's Effect on Human Fertility. *Fertility and sterility*. 2014;101(2):310-316, at p. 5, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4031759/pdf/nihms578345.pdf

Clarnette, T.D; Sugita, Y.; Hutson, J.M.: Genital anomalies in human and animal models reveal the mechanisms and hormones governing testicular descent, *British Journal of Urology* (1997), 79, 99–112, at 99, <a href="http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf">http://onlinelibrary.wiley.com/doi/10.1046/j.1464-410X.1997.25622.x/pdf</a>

U. Kuhnle; W. Kral; Geschlechtsentwicklung zwischen Genen und Hormonen. Worin liegt der Unterschied zwischen Mädchen und Jungen, Männern und Frauen?, Monatsschr Kinderheilkd 2003 · 151:586–593, at 591, see also: Lang C.; Kuhnle U.: Intersexuality and Alternative Gender Categories in Non-Western Cultures, Horm Res 2008;69:240–250

See e.g. Dittmann, R. W., Kappes, M. H., Kappes, M. E., Borger, D., Stegner, H., Willig, R. H., Wallis, H. (1990). "Congenital adrenal hyperplasia. I: Gender-related behavior and attitudes in female patients and sisters." Psychoneuroendocrinology 15(5-6): 401-420, see also: Ralf W. Dittmann, "Pränatal wirksame Hormone und Verhaltensmerkmale von Patientinnen mit den beiden klassischen Varianten des 21-Hydroxylase-Defektes. Ein Beitrag zur Psychoendokrinologie des Adrenogenitalen Syndroms", European University Studies, Bern: 1989

For an example of studies on intersex twins by German gynaecologist Ernst Philipp in collaboration with Swiss endocrinologist Andrea Prader, see Marion Hulverscheidt (2016), Begriffsdefinitionen "Intersexualität" VII: Eine einheitliche Betrachtung des Zwittertums – der Kieler Gynäkologe Ernst, <a href="http://intersex.hypotheses.org/3976">http://intersex.hypotheses.org/3976</a>

• "guarantee freedom from such acts within their jurisdiction; and to ensure that they do not occur in the future. States may not deprive individuals of the right to an effective remedy, including compensation and such full rehabilitation as may be possible." (para 15)

#### Art. 9: Liberty and Security of the Person

As IGM practices cause known, severe physical and mental **pain and suffering** and are often practices with impunity in **public institutions**, including under **direct tutelage of the State** in case of intersex orphans under guardianship of Social services, where they are often submitted to IGM before they're given up for adoption, this surely also violates article 9.

#### Art. 17: Arbitrary or Unlawful Interference with Privacy

While intersex children are regularly **lied to about diagnosis and treatment**, and often even the fact that have an intersex condition is **concealed** from them, on the other hand **doctors regularly share and publish private details** about them in medical publications and text books. Often intersex persons and their parents are also **blackmailed by threatening to expose their intersex status**, if they don't do this or comply with that, notably but not limited to sports. This clearly violates article 17.

#### Art. 24: Child Protection

As IGM practices are **mostly performed on very young children**, they surely constitute a violation of the right to protection of the intersex children concerned, and therefore of article 24.

#### Art. 26: Equal Protection of the Law

Intersex children have the **same rights to effective protections** from IGM as for example girls against Female Genital Mutilation (FGM). However, while **FGM is criminalised** in the German Penal Law, with also extraterritorial protections in force, **IGM practices remain legally permitted**. This is clearly not in line with article 26.

#### 2. Lack of Independent Data Collection and Monitoring

With no statistics available on intersex births, let alone surgeries and 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".

Also in Germany, there are no official statistics on intersex births and on IGM practices available.

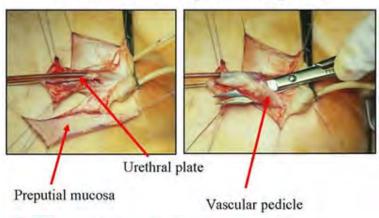
#### Annexe 2 - "IGM in Medical Textbooks: Current Practice"

#### IGM 1 - "Masculinising Surgery": "Hypospadias Repair"

"Hypospadias," i.e. when the urethral opening is not on the tip of the penis, but somewhere on the underside between the tip and the scrotum, is arguably the most prevalent diagnosis for cosmetic genital surgeries. Procedures include dissection of the penis to "relocate" the urinary meatus. Very high complication rates, as well as repeated "redo procedures" — "5.8 operations (mean) along their lives ... and still most of them are not satisfied with results!"

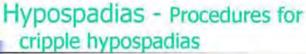
Nonetheless, clinicians recommend these surgeries without medical need explicitly "for psychological and aesthetic reasons." Most hospitals advise early surgeries, usually "between 12 and 24 months of age." While survivors criticise a.o. impairment or total loss of sexual sensation and painful scars, doctors still fail to provide evidence of benefit for the recipients of the surgeries.

## Onlay island flap urethroplasty



## Onlay / Duckett - results

- Elbakry (BJUI 88: 590-595, 2001): 42% complications
- 5 breakdowns (7%)
  - 17 fistulæ (23%)
- Urethral strictures (9%)
  - Urethral diverticulæ (4%)
- Asopa / Duckett tube
  - 3.7% (El-Kasaby J Urol 136: 643-644, 1986)
  - 69% (Parsons BJU 25: 186-188, 1984)
  - 15% (Duckett 1986)



- No standardized procedures
- Personal experience of the surgeon
- Importance of a uroendocrine approach of complex cases to increase the healing abilities of the penile tissues



Official Diagnosis "Hypospadias Cripple" = made a "cripple" by repeat cosmetic surgeries

## Treatment of isolated fistulæ

- Rectangular skin incision around the fistula orifice, often lateral
- Dissection and excision of the fistula tract
- Urethral suture
- Multilayer cover with wellvascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
- Suprapubic diversion ?
   Elbakry











**Bad cosmetic result** 



infection



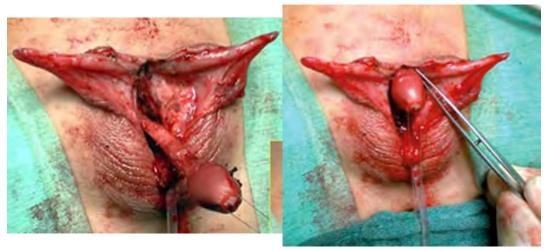
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: Essential role of the placenta / Penile growth factors / healing factors / blood supply ...

Source: Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

#### IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include "46,XY Partial Androgen Insufficiency Syndrome (PAIS)" and "46,XY Leydig Cell Hypoplasia").

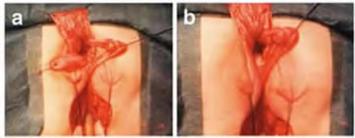
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "in the first 2 years of life", most commonly "between 6 and 12 months," and only 10.5% of surgeons recommend letting the persons concerned decide themselves later.



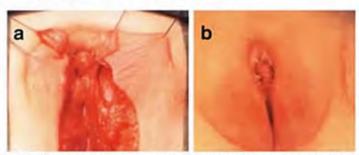
Source: Christian Radmayr: Molekulare Grundlagen und Diagnostik des Intersex, 2004



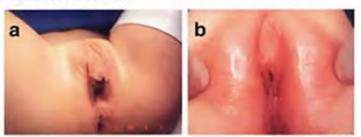
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



7a+b: Partielle Resektion der Corpora cavernosa clitoridis.



8a+b: Refixation der Corpora cavernosa clitoridis. "Materialknappheit" bei der Rekon n clitoridis und der kleinen Labien.



9a+b: Klitorisreduktion und Rekonstruktion des Praeputium clitoridis bei Prader IV.

Source: Finke/Höhne: Intersexualität bei Kindern, 2008

Caption 8b: "Material shortage" [of skin] while reconstructing the praeputium clitoridis and the inner labia.



Source: Pierre Mouriquand: "Chirurgie des anomalies du développement sexuel - 2007", at 81: "Labioplastie"

#### IGM 3 - Sterilising Surgery: Castration / "Gonadectomy" / Hysterectomy

Removal of healthy testicles, ovaries, or ovotestes, and other potentially fertile reproductive organs. "46,XY Complete Androgen Insufficiency Syndrome (CAIS)" is arguably the 3rd most common diagnosis for cosmetic genital surgeries, other diagnoses include "46,XY Partial Androgen Insufficiency Syndrome (PAIS)", male-assigned persons with "46,XX Congenital Adrenal Hyperplasia (CAH)", and other male assigned persons, who have their healthy ovaries and/or uteruses removed.

Castrations usually take place under the pretext of an allegedly blanket high risk of cancer, despite that an actual high risk which would justify immediate removal is only present in specific cases (see table below), and the admitted true reason is "better manageability." Contrary to doctors claims, it is known that the gonads by themselves are usually healthy and "effective" hormone-producing organs, often with "complete spermatogenesis [...] suitable for cryopreservation."

Nonetheless, clinicians still continue to recommend and perform early gonadectomies – despite all the known negative effects of castration, including depression, obesity, serious metabolic and circulatory troubles, osteoporosis, reduction of cognitive abilities, loss of libido. Plus a resulting lifelong dependency on artificial hormones (with adequate hormones often not covered by health insurance, but to be paid by the survivors out of their own purse).



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Fig. 91.6 An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

**Source:** Maria Marcela Bailez: "Intersex Disorders," in: P. Puri and M. Höllwarth (eds.), *Pediatric Surgery: Diagnosis and Management*, Berlin Heidelberg 2009.

Table 1. Prevalence of type II GCT in various forms of DSD

Risk	Type of DSD	Preva- lence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15-40
Intermediate	PAIS 17β-hydroxysteroid dehydrogenase	15
	deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5α-reductase deficiency	?
	Leydig cell hypoplasia	3

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome,
\* Might reach more than 30%, if gonadectomy has not been performed.

**Source:** J. Pleskacova, R. Hersmus, J. Wolter Oosterhuis, B.A. Setyawati, S.M. Faradz, Martine Cools, Katja P. Wolffenbuttel, J. Lebl, Stenvert L.S. Drop, Leendert H.J. Looijenga: "Tumor risk in disorders of sex development," in: Sexual Development 2010 Sep;4(4-5):259-69.



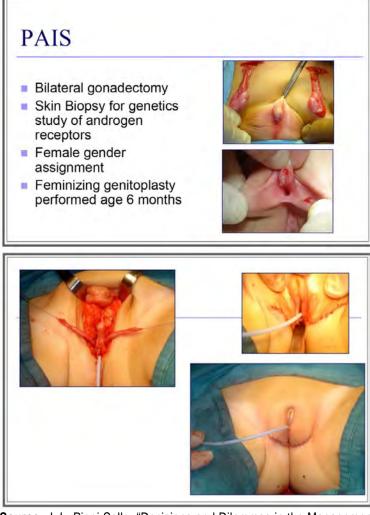
**Source:** J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

#### "Bad results" / "Gonadectomy, Feminising Genitoplasty"



Abb. 2 ▲ a, b Schlechte Korrekturergebnisse nach Feminisierung und c, d nach Hypospadiekorrektur

Caption: 2a,b: "Bad Results of Correction after Feminisation, and", c,d: "after Hypospadias Repair" – Source: M. Westenfelder: "Medizinische und juristische Aspekte zur Behandlung intersexueller Differenzierungsstörungen," Der Urologe 5 / 2011 p. 593–599.



**Source:** J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)", 2007, at 20.