Intersex Genital Mutilations

Human Rights Violations Of Children With Variations Of Sex Anatomy

NGO Report
to the 7th Report of Italy
on the Convention on the Elimination of
All Forms of Discrimination against Women (CEDAW)

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Executive Summary

All typical forms of IGM practices are still practised in Italy today, facilitated and paid for by the State party via the National Health Service (Servizio Sanitario Nazionale, SSN). Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support.

Italy is in breach of its **obligations** under the Convention on the Elimination of All Forms of Discrimination against Women to **(a)** take effective legislative, administrative, judicial or other measures to **prevent involuntary, non-urgent surgery and other medical treatment of intersex persons based on prejudice**, and **(b)** to ensure **access to redress**, and the right to fair and adequate **compensation** and **rehabilitation** for victims (Arts. 1, 5 and 12, General Recommendations No. 19 and 31).

This Committee has consistently recognised IGM practices to constitute a harmful practice under the Convention in Concluding Observations. In addition, **CRPD** has already considered IGM practices in **Italy** as a serious human rights violation.

Also **CAT**, **CRC**, the UN Special Rapporteur on Torture (**SRT**), 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**), the Council of Europe (**COE**) and others have consistently recognised IGM practices as a breach of international law, and have so far issued **23 Concluding Observations on IGM**, typically obliging State parties to enact legislation to **(a)** end the practice and **(b)** ensure redress and compensation, plus **(c)** access to free counselling.

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. 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 based on prejudice** 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, 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, less sexual activity, dissatisfaction with functional and aesthetic results.

This **Thematic NGO Report** has been compiled by Italian Intersex advocate **Claudia Balsamo** in collaboration with the international intersex NGO **StopIGM.org / Zwischengeschlecht.org.** It contains **Suggested Recommendations** and an Annexe with **4 Case Studies**.

NGO Report to the 7th Report of Italy on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)

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Introduction

Background and State Report

IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been repeatedly **recognised by multiple UN treaty bodies**[1] **including CEDAW** as constituting a harmful practice, violence and torture or ill-treatment, however weren't mentioned in the 7th Italian State Report. This NGO Report demonstrates that the current **harmful medical practice on intersex persons in Italy** – advocated, facilitated and paid for by the State party – constitutes a serious breach of Italy's obligations under the Convention.

About the Rapporteurs

This NGO report has been prepared by Italian intersex person and advocate *Claudia Balsamo* in collaboration with the international intersex NGO *StopIGM.org / Zwischengeschlecht.org:*

- **Claudia Balsamo** is an Italian intersex person and advocate familiar with IGM Practices who has been working to improve the well-being and human rights of intersex people in Italy and Europe, and to raise awareness on intersex issues.[2] [3] [4] In 2006 she participated in the first meeting between people with AIS on Lake Como and participated in the formation of the self-help group AISIA (Associazione Italiana Sindrome di Insensibilità agli Androgeni)[5]. She served as AISIA's vice president until 2013. In 2015 Claudia Balsamo presented at the Notes on Rights and Freedom sponsored by the President of the Council of Ministers of Italy.[6]
- **StopIGM.org / Zwischengeschlecht.org**, founded in 2007, is an international intersex human rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to eliminate IGM practices and other human rights violations perpetrated on intersex people, according to its motto, "*Human Rights for Hermaphrodites, too!*" [7] According to its charter,[8] Zwischengeschlecht.org works to support persons concerned seeking redress and justice. StopIGM.org has been active in Italy since 2013[9] [10] [11] [12] [13] and regularly reports to UN treaty bodies.[14]

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[1] **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

[2] https://www.interfaceproject.org/claudia-balsamo/ transcript: https://www.interfaceproject.org/transcript-claudia-balsamo/

[3] http://www.altrapsicologia.it/wp-content/uploads/2016/04/InterSex-Padova.pdf

[4] http://www.comunicattive.org/intersex-esiste-nasce-un-approccio-colorato/

[5] http://www.aisia.org

[6] http://www.unar.it/unar/portal/wp-content/uploads/2015/02/Programma_notedirittieliberta_febbraio2015.pdf

[7] http://Zwischengeschlecht.org/ English pages: http://StopIGM.org/

[8] http://zwischengeschlecht.org/post/Statuten

[9] http://zwischengeschlecht.org/public/Open_Letter_9th-Joint-Meeting_2013.pdf

[10] http://espresso.repubblica.it/attualita/cronaca/2013/09/19/news/noi-intersex-chiediamo-rispetto-1.134087

[11] http://www.altrapsicologia.it/wp-content/uploads/2016/04/InterSex-Padova.pdf

In addition, the Rapporteurs would like to acknowledge the work of the self-help groups **AISIA** (Associazione Italiana Sindrome di Insensibilità agli Androgeni),[15] **Nascere Klinefelter**[16] and **Associazione ANIMrkhS**,[17] intersex advocates **Alessandro Comeni**[18] and **Sabina Zagari**[19], advocacy organisations **Intersexioni**[20] and **Intersex Esiste,**[21] researchers **Michela Balocchi**[22] and **Daniela Crocetti**[23].

Methodology

This thematic NGO report is an updated, abridged and localised version of the **2016 thematic CEDAW NGO Report** for **France**[24] by partly the same rapporteurs.

This Report includes an Annexe with **4 anonymised personal testimonies of intersex persons**. The first person narratives have been collected with aid of the peer support group AISIA from submissions and interviews for this NGO Report (Case No. 1) or from interviews for the doctoral thesis and book of Daniela Crocetti (Cases No. 2-4). Each first-person narrative is preceded by a standardised abstract composed by the Rapporteurs. The identity of all persons concerned is known to AISIA and the Rapporteurs.

The small number of case studies is due to the fact that many patients, their families, and parents find it hard to speak about what happened to them, and do not wish their story to become public, even anonymously. These cases, however, show in an exemplary manner the **severe physical and mental pain and suffering** as a result of IGM practices in Italy.

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[12] http://www.certidiritti.org/x-congresso/

[13] http://www.npwj.org/sites/default/files/ressources/EN_BanFGMProgram_asdelivered_0.pdf

[14] http://intersex.shadowreport.org/

[15] http://www.aisia.org

[16] http://www.nascereklinefelter.it/

[17] http://www.animrkhs-onlus.org/

[18] http://www.intersexioni.it/intervista-ad-alessandro-comeni/
http://www.pagina99.it/2016/11/05/storia-alessandro-comeni-intersessuale-intersex-no-gender/

[19] http://www.barinedita.it/storie-e-curiosita/n2865---intersex---nascere-sia-maschi-che-femmine--%C2%ABcostretti-a-mutilazioni-genitali%C2%BB
http://intersexday.org/en/discussion-evening-varese-italy/

[20] http://www.intersexioni.it/

[21] http://www.intersexesiste.com/

[22] http://www.intersexioni.it/social-mutilations-scalpel-increasingly-popular-to-homologate-atypicalities/

[23] Crocetti, Daniela (2011), Medicalizing gender: from intersex to DSD, from the laboratory to patient groups , [Dissertation thesis], Alma Mater Studiorum Università di Bologna. Dottorato di ricerca in Science, technology, and humanities, 23 Ciclo, http://amsdottorato.unibo.it/3282/1/Crocetti_Daniela_tesi.pdf
Crocetti D, 2013 L'Invisibile Intersex: Storie di Corpi Medicalizzati [Invisible Intersex: Histories of Medicalized Bodies], Pisa: Edizioni ETS, pp. 192, http://www.edizioniets.com/scheda.asp?n=9788846737328

[24] http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

A. Intersex Genital Mutilations in Italy as a violation of CEDAW

1. IGM Practices: Involuntary, unnecessary medical interventions based on prejudice

IGM practices include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other similar medical treatments, including imposition of hormones, performed on children with variations of sex anatomy,[25] without evidence of benefit for the children concerned, but justified by *"psychosocial indications [...] shaped by the clinician's own values"*, the latter informed by societal and cultural norms and beliefs, enabling clinicians to withhold crucial information from both patients and parents, and to submit healthy intersex children to risky and harmful invasive procedures that would not be considered for "normal" children, *"simply because their bodies did not fit social norms"*.[26]

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) abortions and denial of needed health care, causing lifelong severe physical and mental **pain and suffering.**[27]

Individual doctors, national and international medical bodies, public and private healthcare providers have traditionally been **framing and "treating" intersex variations as a form of illness or disability** in need to be "cured" surgically, often **with racist, eugenic and supremacist undertones**,[28] [29] [30] [31] describing intersex people as *"inferior"*, *"abnormal"*, *"deformed"*.

In a response to international IGM doctors advocating involuntary non-urgent surgeries on intersex children in a 2016 medical publication,[32] two bioethicists underlined the **prejudice** informing the current medical practice (our emphasis):

"The implicit logic of [the doctors'] paper reflects what bioethicist George Annas has called a 'monster ethics' [6], which can be summed up this way: ***babies with atypical sex are not yet fully human, and so not entitled to human rights.*** *Surgeons make them human by making them recognizably male or female, and only then may they be regarded as entitled to the sexual and*

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[25] See "What is Intersex?", 2016 CEDAW NGO Report France, p. 39-44. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[26] For references, see "What are Intersex Genital Mutilations (IGM)?", 2016 CEDAW NGO Report France, p. 45. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[27] See "Most Frequent Surgical and Other Harmful Medical Interventions", 2016 CEDAW NGO Report France, p. 47-50. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[28] 2014 CRC NGO Report, p. 52, 69, 84, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

[29] 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

[30] "The Racist Roots of Intersex Genital Mutilations" http://stop.genitalmutilation.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM

[31] 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

[32] Pierre Mouriquand et al, "Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?", Journal of Pediatric Urology (2016), http://www.jpurol.com/article/S1477-5131(16)30012-2/

medical rights and protections guaranteed to everyone else by current ethical guidelines and laws."[33]

UN Treaty bodies and other human rights experts have consistently recognized IGM practices as a serious breach of international law.[34] **UN Treaty bodies have issued 23 Concluding Observations condemning IGM practices.**[35]

2. Intersex is NOT THE SAME as LGBT or SOGI

Unfortunately, there are several **harmful misconceptions about intersex** still prevailing in public, including 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,[36] or as a form of sexual preference.

The underlying reasons for these 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,[37] maintaining that Intersex Genital Mutilations 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"*,[38] and State parties referring to e.g. transgender guidelines,[39] *"Gender Identity Law"* [40] or *"Civil Status Act"* [41] when asked about IGM by Treaty bodies.

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[33] Ellen Feder and Alice Dreger, **"Still ignoring human rights in intersex care"**, Journal of Pediatric Urology (2016), http://www.jpurol.com/article/S1477-5131(16)30099-7/

[34] **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), "End violence and harmful medical practices on intersex children and adults, UN and regional experts urge", http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

[35] http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

[36] E.g. the **Swiss Federal Government** in 2011 in answers to parliamentary questions consistently described intersex as ***"True and Untrue Transsexualism"***, e.g. 11.3286, http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20113286

[37] For references, see 2016 CEDAW NGO Report France, p. 40, fn 49. http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

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

[39] CAT56 Austria, see http://stop.genitalmutilation.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations

[40] 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

[41] 7th and 8th Periodic Report of Germany on CEDAW, para 202, see 2016 CEDAW PSWG NGO Report, p. 2, http://intersex.shadowreport.org/public/2016-CEDAW-Germany-NGO-Zwischengeschlecht-Intersex-IGM.pdf

3. IGM practices in Italy: Pervasive and unchallenged

In **Italy** (see CRPD/C/ITA/CO/1 paras 45-46), same as in the **neighbouring states** of *France* (CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f; CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32–33), *Switzerland* (CEDAW/C/CHE/CO/4-5 paras 38-39; CRC/C/CHE/CO/2-4 paras 42-43; CAT/C/CHE/CO/7 para 20) and *Austria* (CAT/C/AUT/CO/6, paras 44-45) , and in **many more State parties**,[42], there are

- **no legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent** non-consensual, medically unnecessary, irreversible surgery and other harmful treatments a.k.a. **IGM practices**
- no measures in place to ensure data collection and monitoring of IGM practices
- **no legal or other measures** in place to ensure the **accountability** of IGM perpetrators
- no legal or other measures in place to ensure access to redress and justice for adult IGM survivors

To this day, the **Italian government** simply refuses to recognise the human rights violations and suffering caused by IGM practices, let alone to *"take effective legislative, administrative, judicial or other measures"* to protect intersex children, in spite of longstanding criticism and appeals, including by CRPD, intersex persons and their organisations, experts and Italy's own National Bioethics Committee (Comitato Nazionale per la Bioetica, CNB) (see below p. 14).

As substantiated in Annexe 2 (p. 23), **to this day in Italy all forms of IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and public Children's Hospitals, **advocated and paid for by the State** via the **Italian National Health Service** (Servizio Sanitario Nazionale, SSN), with public clinics publicly boasting in the media: ***"Boom in Surgeries on Babies with 'Indeterminate' Sex, in Rome 50% Increase during the Last 5 Years, 25% Increase on National Level".***[43]

Currently practiced forms of IGM in Italy include (see also **Cases No. 1-4,** p. 17)

- **IGM 3 – Sterilising Procedures:** Castration / "Gonadectomy" / Hysterectomy / Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation / Imposition of Hormones (p. 23)
- **IGM 2 – "Feminising Procedures":** Clitoris Amputation/"Reduction", "Vaginoplasty", "Labioplasty", Dilation (p. 24)
- **IGM 1 – "Masculinising Surgery":** Hypospadias "Repair" (p. 26)

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[42] Currently we count **23 Concluding observations on IGM practices for 15 State parties in Europe, South America, Asia and Oceania**, see http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations

[43] according to Aldo Morrone, Director General of the Ospedale San Camillo-Forlanini di Roma, quoted in: "Boom di bimbi con sesso 'incerto', a Roma un aumento del 50 per cento", see http://roma.repubblica.it/cronaca/2013/06/20/news/san_camillo-forlanini_boom_degli_interventi_infantili_sul_sesso_incerto-61524659/
full article: leggo.it 20.06.2013, http://web.archive.org/web/20140307005840/http://www.leggo.it/NEWS/ITALIA/boom_di_bimbi_con_sesso_quot_incerto_quot_a_roma_aumentano_del_50_per_cento/notizie/294638.shtml

- **Prenatal “Therapy”** (p. 27)
- **Other Unnecessary and Harmful Medical Interventions and Treatments** (p. 27)

4. IGM in Italy as a harmful practice and gender based violence

a) Article 5 in conjunction with General recommendation No. 31

Article 5 (a) of the Convention stipulates “To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women”.

This Committee has repeatedly recognised IGM practices to constitute a harmful practice under the Convention during previous Sessions (CEDAW/C/FRA/CO/7-8, paras 17e-f+18e-f; CEDAW/C/CHE/CO/4-5 paras 38-39; CEDAW/C/NLD/CO/6 paras 21-22, 23-24).

In addition, the Committee on the Rights of the Child (**CRC**) has already recognised IGM practices in **Italy** to constitute a **harmful practice** in CRC/C/IRL/CO/3-4, paras 39-40, as well as in other countries, referring to the CEDAW-CRC Joint general comment No. 31/18 on harmful practices (2014), in CRC/C/CHE/CO/2-4, paras 42-43; CRC/C/CHL/CO/4-5 paras 48-49; CRC/C/FRA/CO/5 paras 47-48; CRC/C/GBR/CO/5 paras 45-46; CRC/C/ZAF/CO/2 paras 37-38.

JGR No. 31/18 clearly stipulates the right of victims of IGM practices to **“equal access to legal remedies and appropriate reparations”** (para 55 (q)), and specifically to ensure that “children subjected to harmful practices have equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the **limitation period**” (para 55 (o)).

Also the Committee against Torture (**CAT**) consistently recognises IGM practices to constitute at least **ill-treatment**, urging States *“to undertake legislative, administrative and other necessary measures to ensure the bodily integrity of intersex people”*, and *“to investigate cases of medical or surgical treatments of intersex persons without their informed consent, and to undertake legislative measures to ensure redress for victims, including adequate compensation”*, for example in CAT/C/DEU/CO/5 para 20; CAT/C/CHE/CO/7 para 20; CAT/C/DNK/6-7 paras 42-43; CAT/C/CHN-HKG/CO/4-5 paras 28-29; CAT/C/FRA/CO/7 paras 32-33.

To this day, UN treaty bodies issued **23 Concluding Observations on IGM practices**, considering them as harmful practice (CRC art. 24 para 3 in conjunction with JGR No. 31/18, CEDAW art. 5 (a)), ill-treatment (CAT art. 2, 12 and 16), or a violation of physical and mental integrity (CRPD art. 7). [44]

Clearly, due to their nature, IGM practices in Italy also fall within the scope of article 5 (a) CEDAW and JGR No. 31/18.

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[44] CAT/C/DEU/CO/5, para 20; CRC/C/CHE/CO/2-4, paras 42-43; CRPD/C/DEU/CO/1, paras 37-38; CAT/C/CHE/CO/7, para 20, CRC/C/CHL/CO/4-5, paras 48–49; CAT/C/AUT/CO/6, paras 44-45; CAT/C/DNK/CO/6-7, paras 42-43; CAT/C/CHN-HKG/CO/4-5, paras 28-29; CRC/C/IRL/CO/3-4, paras 39-40; CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 32-33; CRPD/C/CHL/CO/1 paras 41-42; CRC/C/GBR/CO/5, paras 45–46; CRC/C/NPL/CO/3-5 p. 10–11, paras 41–42, CEDAW/C/FRA/CO/7-8, paras 17e-f+18e-f; CRPD/C/ITA/CO/1, paras 45-46; CRPD/C/URY/CO/1, paras 43-44; CRC/C/ZAF/CO/2 paras 37-38; CRC/C/NZL/CO/5 paras 25 + 15; CEDAW/C/CHE/CO/4-5 paras 38-39; CEDAW/C/NLD/CO/6 paras 21-22, 23-24; CEDAW/C/DEU/CO/7-8, paras 23-24; CEDAW/C/IRL/CO/6-7, paras 24-25

b) Article 1 in conjunction with General recommendation No. 19

In addition, due to their nature, IGM practices clearly also constitute a form of **gender-based violence**, and thus also article 1 of the convention in conjunction with the Committee's **General recommendation No. 19** applies, which further underline the right to life (para 7 (a)) and the right to protection from ill-treatment (CIDT) (para 7 (b)). In CEDAW/C/NLD/CO/6 paras 22-23 this Committee considered art. 1 and GR 19 as applicable for intersex women.

Regarding ill-treatment (GR 19 para 7 (b)), since 2011 the Committee against Torture (**CAT**) has repeatedly examined IGM practices, and consistently considered them as constituting **at least ill-treatment**.[45]

Thus, also art. 1 CEDAW in conjunction with GR 19 apply.

c) Article 12 in conjunction with General recommendation No. 19

States parties are required by article 12 to take measures to ensure equal access to health care, and GR 19 particularly underlines the right to the highest standard attainable of physical and mental health (para 7 (g)).

IGM practices per se are detrimental to the health of survivors. Additionally, one specific form of IGM practices is **denial of needed health care**.[46]

In addition, the **Special Rapporteur on Health** has identified intersex children as a *"vulnerable group"* and IGM practices as a *"painful and high-risk procedure with no proven medical benefits"*,[47] and IGM 2 "clitoral reduction" as constituting *"a form of female genital mutilation"*.[48]

Thus, also art. 12 CEDAW in conjunction with GR 19 applies.

5. 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".[49]

Also in Italy, there are no statistics on intersex birth and on IGM practices available.

However, the Joint general recommendation No. 31 CEDAW / Joint general comment No. 18 CRC "on harmful practices" (2014) clearly **stipulates comprehensive data collection and monitoring** (paras 37-39).

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[45] CAT/C/FRA/CO/7, paras 32–33; CAT/C/CHE/CO/7, para 20; CAT/C/DEU/CO/5; para 20; CAT/C/AUT/CO/6, paras 44–45; CAT/C/CHN-HKG/CO/5, paras 28–29; CAT/C/DNK/CO/6-7, paras 42–43

[46] see 2014 CRC NGO Report, p. 75, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

[47] A/64/472, para 49 incl. fn 67

[48] A/HRC/32/33, para 56

[49] Personal communication by journalist SRF (Swiss National Radio and TV), 2013

6. Lack of legislative provisions, impunity of the perpetrators

Article 5 (a) of the Convention in conjunction with the Joint general recommendation No. 31 CEDAW / Joint general comment No. 18 CRC "on harmful practices" (2014) underline state parties' obligations to *"**explicitly prohibit by law and adequately sanction or criminalize** harmful practices"* (JGR 31/18, para 13), as well as to *"**adopt or amend legislation** with a view to effectively addressing and eliminating harmful practices"* JGR 31/18, para 55), and specifically to ensure *"that the **perpetrators and those who aid or condone such practices are held accountable"*** (JGR 31/18, para 55 (o)).

Also the Committee's **General recommendation No. 19** obliges State parties, inter alia, to "take appropriate and effective measures to overcome all forms of gender-based violence" (para 24 (a)), to "encourage the compilation of statistics and research on the extent, causes and effects of violence, and on the effectiveness of measures to prevent and deal with violence" (para 24 (c)), to provide "Effective complaints procedures and remedies, including compensation" (para 24 (I)), "take all legal and other measures that are necessary to provide effective protection of women against gender-based violence" (para 24 (t)).

Accordingly, with regards to IGM practices, **this Committee** as well as the **Committee on the Rights of the Child (CRC)**, referring to Article 24 para 3 CRC and the Joint general recommendation No. 31 CEDAW / Joint general comment No. 18 CRC, already explicitly recognised the obligation for State parties to *"Ensure that […] no child is subjected to unnecessary medical or surgical treatment during infancy or childhood; adopt legislation to protect the bodily integrity, autonomy and self-determination of intersex persons and provide families with intersex children with adequate counselling and support"*, as well as to *"Adopt legal provisions in order to provide redress to intersex persons affected by cases of surgical or other medical treatment without free, prior and informed consent by the intersex person or his/her parents under the guidance of the court"*.[50]

Also in **Italy** there are still **no legal or other protections** in place to ensure the protection of intersex children from IGM practices, nor to ensure the **accountability of perpetrators** and accessories.

What's worse, this comes after the State party had already been reprimanded by CRPD for IGM practices.

7. Obstacles to redress, fair and adequate compensation

Article 5 (a) of the Convention in conjunction with the CRC/CEDAW Joint General Comment No. 18/31 "on harmful practices" clearly stipulates the right of victims of IGM practices to ***"equal access to legal remedies and appropriate reparations"***, and specifically to ensure that *"children subjected to harmful practices have **equal access to justice,** including by **addressing legal and practical barriers** to initiating legal proceedings, **such as the limitation period"***.

However, also in **Italy** the **statutes of limitation** prohibit survivors of early childhood IGM practices to call a court, because persons concerned often **do not find out** about their medical history until much later in life, and **severe trauma** caused by IGM Practices often prohibits them

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[50] CEDAW/C/CHE/CO/4-5, para 25.

to act in time once they do.[51] So far, in Italy there was no case of a victim of IGM practices succeeding in going to court (see **Cases No. 3, 4**).

The **Italian government** so far refuses to ensure that non-consensual unnecessary IGM surgeries on minors are recognised as a form of **genital mutilation**, which would formally prohibit parents from giving "consent". In addition, the state party **refuses to initiate impartial investigations**, as well as data collection, monitoring, and disinterested research.[52] In addition, hospitals are often **unwilling to provide full access to patient's files**.

This situation is clearly not in line with **Italy's** obligations under the Convention.

8. Italian Doctors and Government consciously dismissing Intersex Human Rights

The persistence of IGM practices in Italian public clinics is a **matter of public record**, with clinics boasting in the media about ***"Boom in Surgeries on Babies with 'Indeterminate' Sex, in Rome 50% Increase during the Last 5 Years, 25% Increase on National Level",***[53] or about the *"exceptional success"* of **removing the uterus and vagina of a two years hold intersex child** plus performing a *"reconstruction of the penis and the urethra [at the request of the parents]"* at the Department for Mother and Child of the **Policlinico Universitario Paolo Giaccone di Palermo.**[54]

Also the **criticism of persons concerned and their organisations** of involuntary surgeries and other medical treatment is **publicly known**,[55] [56] [57] [58] [59] [60] [61] [62] [63] and also in **government bodies**

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[51] 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.

[52] For more on this topic see 2016 CEDAW NGO Report France, p. 55: http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf

[53] according to Aldo Morrone, Director General of the Ospedale San Camillo-Forlanini di Roma, quoted in: "Boom di bimbi con sesso 'incerto', a Roma un aumento del 50 per cento", see http://roma.repubblica.it/cronaca/2013/06/20/news/san_camillo-forlanini_boom_degli_interventi_infantili_sul_sesso_incerto-61524659/
full article: leggo.it 20.06.2013,
http://web.archive.org/web/20140307005840/http://www.leggo.it/NEWS/ITALIA/boom_di_bimbi_con_sesso_quot_incerto_quot_a_roma_aumentano_del_50_per_cento/notizie/294638.shtml

[54] "Nasce femmina, ma è maschio: operato per cambiare sesso bimbo di 2 anni", Palermo Today 27.09.2016, http://www.palermotoday.it/cronaca/policlinico-cambio-sesso-bambino-2-anni.html

[55] Open Letter of Concern to the 9th Joint Meeting of Paediatric Endocrinology Societies by Persons Concerned, Partners, Families, Friends and Allies, Milano, 19.09.2013, http://zwischengeschlecht.org/public/Open_Letter_9th-Joint-Meeting_2013.pdf

[56] 'Noi intersex chiediamo rispetto', L'Espresso, 19.09.203, http://espresso.repubblica.it/attualita/cronaca/2013/09/19/news/noi-intersex-chiediamo-rispetto-1.134087

[57] http://www.altrapsicologia.it/wp-content/uploads/2016/04/InterSex-Padova.pdf

[58] http://www.certidiritti.org/x-congresso/

[59] Ministry of Foreign Affairs and International Cooperation - Italian Senate, "BanFGM Conference on the global ban on female genital mutilation", Rome, 30 January – 1 February 2017, see Parallel Session IV, p. 5, http://www.npwj.org/sites/default/files/ressources/EN_BanFGMProgram_asdelivered_0.pdf

[60] Alessandro Comeni: «Vi racconto cosa significa essere intersessuale», Pagina99, 15.11.2016, http://www.pagina99.it/2016/11/05/storia-alessandro-comeni-intersessuale-intersex-no-gender/

[61] "Intersex", nascere sia maschi che femmine: "Costretti a mutilazioni genitali", Barinedita, 28.04.2017, http://www.barinedita.it/storie-e-curiosita/n2865---intersex---nascere-sia-maschi-che-femmine--%C2%ABcostretti-a-mutilazioni-genitali%C2%BB

including the **Italian Senate**.[64]

Already in 2010 the **Italian National Committee of Bioethics** (Comitato Nazionale per la Bioetica, CNB) published an opinion “Disorders of Sexual Differentiation in Minors: Bioethical Aspects”, stating (p. 23):[65]

*“Following these clinical, ethical and legal considerations, **the CNB hopes** […] **that any eventual surgical interventions do not cause the child unnecessary mutilation** and do not involve, as far as possible, the loss of potential fertility and the terms for possible satisfactory sexual activity; that the scrupulous evaluation of the entire clinical situation is ensured by the doctors; which should take into account, but not be constrained by, environmental, social and cultural factors.”*

In 2012 also the **Ministry of Health** admitted to the **controversy regarding involuntary intersex surgery** in their guidelines “Promotion and care for the health of the child and the adolescent” (p. 151-152, own translation)**:**[66]

*“The current **intense debate** on the treatment of patients with intersexual disorder and associated conditions concerns four main issues:*
- the etiological diagnosis,
- the assignment of sexual identity (gender),
- genital surgery indications and the time of treatment,
- the dissemination of medical information to the patient and family members.”

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62 Crocetti, Daniela (2011), Medicalizing gender: from intersex to DSD, from the laboratory to patient groups , [Dissertation thesis], Alma Mater Studiorum Università di Bologna. Dottorato di ricerca in Science, technology, and humanities, 23 Ciclo, http://amsdottorato.unibo.it/3282/1/Crocetti_Daniela_tesi.pdf

63 Crocetti D, 2013 L’Invisibile Intersex: Storie di Corpi Medicalizzati [Invisible Intersex: Histories of Medicalized Bodies], Pisa: Edizioni ETS, pp. 192, http://www.edizioniets.com/scheda.asp?n=9788846737328

64 Parliamentary question dated 12.10.2016, asking the Minister of Health:

- *“Whether the Minister addressed has collected information on the incident and whether the person concerned has undergone surgery because of an imminent and serious danger to his health;*
- ***If the Minister intends to launch a monitoring and data collection initiative on intersex cases in Italy;***
- *If the Minister would not consider it appropriate to launch information campaigns for affected families so that they are aware of the risks that may arise from these operations and may consider alternative options such as raising their son or daughter without submitting them to invasive interventions and leaving them the choice regarding their own body for when are able to choose for themselves;*
- *If it has not considered the possibility of bringing together regions for a comparison of diagnostic, therapeutic and care pathways (PDTAs) together with organizations that address intersex variations and the human rights of people with intersex traits, and on any guidelines specific to the Treatment of minors with variations of sex development;*
- ***If it intends to initiate a direct collaboration with organisations of Intersex or DSD individuals.”***

Legislatura 17 Atto di Sindacato Ispettivo n° 4-06490Atto n. 4-06490, Pubblicato il 12 ottobre 2016, nella seduta n. 698, Lo Giudice, Albano, Amati, Bignami, Capacchione, Cirinna', Dalla Zuanna, Idem, Lo Moro, Mastrangeli, Orellana, Pagliari, Pegorer, Puppato, Spilabotte, Zanoni, http://www.senato.it/japp/bgt/showdoc/frame.jsp?tipodoc=Sindisp&leg=17&id=991855

65 Comitato Nazionale per la Bioetica (2010), “I disturbi della differenziazione sessuale nei minori: aspetti bioetici”, http://bioetica.governo.it/media/170698/p86_2010_disturbi_differenziazione-sessuale-minori_it.pdf

66 Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, tecnological and structural criteria of appropriateness, Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

In 2012 AISIA published an **Italian translation of the "DSD Guidelines"** written by a consortium of clinicians, adults intersex persons, family members and parents of intersex children, published by the Intersex Society of North America, calling for *"delaying elective surgeries until the patients themselves can participate in decision-making […] Healthy, functioning gonadal tissue should remain in place unless the patient, fully advised of risks and options, requests it be removed."* (p. 31-32) In the AISIA edition **46 Italian doctors, psychologists and healthcare professionals signed a pledge stating, *"As a professional, but above all as a person, I share the principles of this manual."*** (p. 4-5)[67]

Nonetheless, government bodies refuse to take any action, but continue to ignore intersex human rights, and doctors continue practicing IGM claiming they would simply follow the *"Italian law"* (see p. 24).

What's worse, this comes after the **Italian State party has already been reprimanded by CRPD** for IGM practices, urging Italy to

"ensure that no one is subjected to scientific undocumented medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to the children concerned, and provide families with intersex children with adequate counselling and support."[68]

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[67] http://www.aisia.org/document/nov_2012/pdf/9.pdf

[68] CRPD/C/ITA/CO/1, paras 45-46

B. Recommendations

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

Harmful practices: Intersex persons

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

In the light of its joint general comment No. 31 (2014) and No. 18 of the Committee on the Rights of the Child on harmful practices, the Committee recommends that the State party:

(a) Ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, adopt legislation with a view to guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support;

(b) Undertake investigation of incidents of surgical and other medical treatment of intersex persons without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;

(c) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;

(d) Educate and train medical professionals on the harmful impact of unnecessary surgical or other medical interventions for intersex children, and ensure that the views of intersex persons are fully considered by the interdisciplinary working groups established to review these procedures.

C. Annexe 1 – “Case Studies”

The first person narratives have been collected with aid of the peer support group AISIA. The abstracts were composed by the Rapporteurs. The identity of all persons concerned is known to AISIA and the Rapporteurs.

Case Study No. 1

The person concerned was born 1960 in Termini Imerese and raised as a girl. Later the mother noticed that the labia majora were swollen. In 1962 the person concerned underwent an exploratory laparotomy at the Children's Hospital Bambino Gesù in Rome which revealed testes in the abdomen. After showing more and more signs of virilisation during puberty, in 1971 the person concerned was taken to the private clinic Paideia in Rome, were the testes were removed and the enlarged clitoris was shortened.

When turning 25, the person concerned found out that sexual intercourse was not possible, due to a short vaginal depth, something the doctors hadn't told her. With the help of a gynaecologist and a psychologist she then tried to get information from her former doctors, but was denied them because of “professional secrecy”.

The person concerned was finally diagnosed with 5-alpha-reductase deficiency.

The person concerned tells their story:

I was born in 1960 in Termini Imerese in the province of Palermo, in a Catholic family. My father was a lawyer, my mother a teacher. When I was born the pediatrician and the midwife said I was a female, but after a year my mother noticed that my labia majora were swollen.

In 1962, after a consultation, Dr Musumeci from Catania made a hypothesis: vulviforme hypospadias (perineal hypospadias with a bifid (unfused) scrotum resembling labia majora). After consulting another paediatrician, Dr Piero Vignetti, in 1964 my father took me to a private clinic and paid for the treatment himself. Accompanied by my maternal grandmother I was submitted to a large exploratory laparotomy at the Children's Hospital Bambino Gesù in Rome by Professor Romualdi, from whom my father received yet another diagnosis: male pseudo-hermaphroditism with normal testes, which the Professor wanted to remove immediately. My father objected, accepting instead Dr Vignetti's advice to wait for my development, and only to remove my testes if I would develop male characteristics. My mother only received generic information.

For a short time I had a relatively carefree childhood, protected by my mother a little bit, not by my grandmother or my father. But then I developed a more and more masculine appearance, so much that I was considered strange: boys rejected me because I was girl; girls and my sister rejected me because I was not as feminine as they were.

So in 1971, I was promised a nice trip to Rome with my mother, where I was submitted to gonadectomy and clitorectomy at the private clinic Paideia, performed by the surgeon Francesco Minervini and advised by the paediatrician Dr Vignetti, again paid for by my father. My mother was present, convinced that it was my ovaries that would be removed because they had "malignant cysts"; lies always repeated to me and her again and again.

I saw that my body was no longer what it had been before. I remembered my clitoris before the surgery. After the surgery I saw immediately, that my clitoris was gone. My mother said that it was better this way because it wasn't a good thing.

Due to the removal of parts of my clitoris and scaring, it is really hard for me to achieve orgasm.

I had to start oestrogen hormone therapy immediately. Only when I was 26 I found out with the help of an endocrinologist that the dose was much too high, which explained the liver pain and rheumatism I suffered from. The other doctors had never asked how I felt with the hormone therapy. I also had oscillating anxious, hyperactive and/or depressed states, but they were considered manifestations of my character and growth.

After the surgery and the start of the hormonal treatment, I was subjected to follow-up medical exams for four years. Every time they took photos of my genitals. After four years the visits were suspended.

Even though the surgery was "successful" I was neglected and ignored at home and in the family because I was "strange and stupid", unlike my sister who was considered to be perfect. At school I was teased and marginalised because my body was not feminine enough.

As I learned later, Dr Vignetti had advised I should receive psychological assistance, but my family refused because that was considered as a sign of imbalance. Not being able to know what really happened and not having anybody to talk to kept me in a state of constant solitude and agitation.

At university, meeting many different kinds of people made me feel a little better and more independent. But I couldn’t talk to anybody about my "issues," not even with my sister. I felt alone. I was always considered strange and to keep under control. I was the family secret. Only my father's brother knew my history, and he mocked me until the last day of his life.

In 1985, when I was 25, I tried to make love, but it was impossible to penetrate me even with a finger: I was shocked and frightened, but my parents gave me the usual answers, that they had to remove the ovaries because of “malignant cysts”.

A visit with the gynaecologist Dr Aristide Vaccario helped me discover the truth: a blood test revealed that I had "partial androgen insensitivity" and a pseudo vagina of 1 cm.

I trustingly turned to the doctors Vignetti and Minervini who had cared for me to receive more in-depth explanations and detailed medical charts for myself and my gynaecologist Dr Vaccario, but received vague and poorly documented information: I was not heard or respected when I asked for information about my surgery in 1971, because of "professional secrecy". Also my gynaecologist did not receive any more information.

In 1986, I started a vaginal dilation therapy, but it was very painful and on top my father used to pass through my room indiscriminately.

I went to see a psychologist, Tiziana Montan, to help me deal with what had been done to me up to that point. To better understand the situation, she met both my parents, but without receiving any useful information.

From then on I paid for everything out of my own pocket (consultations, examinations, medical and psychological treatments).

In 1998, due to an inguinal neoplasm (later revealed to be benign), I requested another meeting with the doctors Piero Vignettia (then Professore ordinario Clinica Pediatrica, Università degli Studi “La Sapienza” di Roma) and Minervini to obtain information about any findings regarding my internal anatomy, but I received only disinterested replies and "I do not remember". On that occasion I also asked if I could meet other people like me, but the two doctors just joked and changed topic. The psychologist Montan was there and also witnessed this.

In 2007 I had a chromosomal analysis that finally revealed my definitive diagnosis of "5-alpha-reductase deficiency". In the same year I came into possession of some of my father’s documents after he had died, which revealed, that in 1964 Dr Vignetti had diagnosed me with male pseudo hermaphroditism and indicated to continue to raise me as a girl, and in case I developed a male appearance to remove my gonads, to widen my vagina first with a nasal speculum and then with a gynaecological one, to provide me with psychological support, and to have a surgical vaginoplasty in adolescence. The documents also revealed that in 1986 my father still asked Vignetti and Minervini to continue to lie to me and to my gynaecologist, when the doctors told my father that my right to know the truth should be respected – although in the end they denied me any information.

Today, I am still seeing the psychologist Tiziana Montan. She helps me to deal with the consequences of those traumas, the coercion, abuses, and lies. Since 1971 not a day passes when I do not wonder if I became who I am because of myself or as a consequence of surgery, hormones and neglect. And I wonder how long this practice will continue, so as not to disturb the peace and beliefs of men like my father.

Case Study No. 2

The person concerned was born in a small town outside of Rome in 1972. As a small child she was diagnosed with a heart condition, and an inguinal hernia at the Hospital Bambino Gesù in Rome. At 17 she again had an inguinal hernia and the doctors then decided to remove her testes, but did not inform her about the surgery, her diagnosis or the hormones she would need to take for the rest of her life. The parents weren’t informed completely either, and so she did not take hormones for the ten years after the gonadectomy until she learned about her diagnosis CAIS by accident from a textbook, and thereafter was prescribed oestrogens.

She suffered osteoporosis, depression and other health problems due to the lack of hormones.

When she eventually learned about her diagnosis and asked doctors for information, she was told she shouldn’t have sex because her body wasn’t fully formed, making her feel ashamed of her body and afraid to have relationships.

Once she learned of her medical history she confronted her parents and felt betrayed by them for many years.

She was monitored once a year for her heart condition, but didn’t get any care regarding the hormone therapy, and continued to have health problems. At 37 years old she learned of other persons with CAIS who also had their testes removed but used androgens instead of estrogens *with positive results. Seeing as there were no doctors who would try this in Italy, she had androgens prescribed to her father and began taking them without any medical support. She died of a heart attack 6 months later.*

The person concerned tells their story:

I don’t think of it as a disease, because I didn’t have anything at all until I was 17 years old. Then at 17 they operated on me and I still didn’t know anything because my parents didn’t tell me anything. Now I've begun to learn something on the internet.

At 17, when I went in for a hernia but they removed my gonads, and then my parents refused to follow any therapy, I never took any hormone therapy. Later by myself I got a DNA test, to see my chromosomes, and I found out I had this syndrome.

I used to be skinny, but after the operation I got fat.

I didn’t choose it [the gonadectomy], my parents told me it was a hernia, they didn’t tell me anything. My dad is very impatient, tends to remove things, to hurry up. He wants problems to be resolved quickly.

I wouldn’t have ever had the surgery, because now I have osteoporosis.

The doctors were the ones who really gave me hang-ups, because they told me "you can’t have sex, got it?" I froze up, I was even engaged, so now I have left him, because they told me that my vagina was too small, so I froze up.

But maybe it would have worked, because my aunts [who also had CAIS] didn’t do anything [didn’t have any surgery], they are married and have normal sexual intercourse.

Doctors ruin you, some doctors ruin patients. Before the operation I was fine. After the operation without hormones, for a long time I had no hormones, I had the classic menopause, so heat flashes, depression.

If I could talk to the doctor who did this to me, I would be very angry, I would say that he was superficial, that he didn’t inform my parents, but above all he didn’t inform me, because I also had rights that were not respected. He only thought about removing my gonads and didn’t give me any hormone therapy.

Case Study No. 3

The person concerned was born in a small town outside of Milano in 1979. She was first diagnosed with AIS and later with Leydig Cell Hypoplasia. At 15 her abdominal testes were removed and she was prescribed oestrogens, but was not informed about her medical history or the purpose of the surgery. She was told she had cancer and her uterus removed, and for ten years lived in fear of the cancer coming back. She suffered severe depression and other negative health repercussions due to the unmonitored hormone therapy. Only at 25 she learned about her diagnosis and the removal of the testes, which she says she would not have chosen.

She also felt hurt by the numerous medical exams she was subjected to without any explanation.

The person concerned tells their story:

I went to the hospital thinking I was being operated on for an inguinal hernia and instead they gave me a gonadectomy, and I was not told. My parents knew but the doctors told them not to tell me anything, because I would not understand, to say nothing to anyone because it wasn't a normal thing, it was something that would make me feel ashamed, that I couldn't accept, and that no one could accept.

I tried many times to ask why, but they never gave me an answer. I had problems when I got a serious boyfriend. We went together to Professor Chinello who operated on me, and he explained that I had had a tumor and they had removed my uterus, therefore I could not have children. I was always afraid that the cancer cells would re-grow and that they could destroy my future.

[Later] I saw a[nother] doctor and told him that I had been operated on at 15 years, that I had had uterine cancer. He looked at the medical records and asked me why had they told me that I had had a tumour? I told him that they had only told me at 19 years old because they thought it was too strong a blow for me at 15. The doctor wanted to know how old I was then and I told him 24, 25. And he said "old enough to know you didn't have a tumour, you are a pseudo-hermaphrodite." Just like that, abruptly, I knew the truth. I laughed in his face, because I had already seen a documentary, I already knew something.

Nobody explained anything to me, the internet and the documentary explained something to me. I got no explanation from the doctors. I'm angry with the doctors, very angry. I would have liked them to leave me the chance to decide later, when I would have had the maturity to do so. I would have liked to choose myself whether to operate or not. And honestly I wouldn't have had the operation, I would have kept the testes. Absolutely.

I would like to sue. To be examined continuously, medical visits without explanation. All those exams hurt me and I didn't even know anything yet. I didn't know, it was traumatic.

Case Study No. 4

The person concerned was born in small town outside of Milano in 1987 but was treated in Bologna at Sant'Orsola University Hospital. The lead pediatric surgeon advised her parents to subject her to a vaginal lengthening surgery, which they initially declined. The hospital sent numerous letters to her parents insisting that this was an essential operation that needed to be performed in childhood, until her parents folded to the medical pressure when she was ten years old.

She received a vaginal lengthening surgery that entails taking a piece of the intestine and attaching it to the end of the existent short vaginal entrance. This procedure often leads to tight scar tissue at the point where the intestinal tissue has been attached, must be maintained through dilation, and the intestinal tissue often produces malodorous fluids as it would in the intestine.

The person concerned remembers the period in the hospital as intensely traumatic, fully of invasive examinations, but without any explanations as her parents were instructed to tell her nothing.

Her first attempts at sexual intercourse as an adult were traumatic and painful, involving tearing and bleeding due to the scar tissues that had developed at the joint of the tissues. Instead of being pliable as her short vaginal entrance would have been, the operation created rigid tissue prone to tearing. It took her more than ten years to be able to have remotely comfortable or pleasurable intercourse or sexual intimacy.

The person concerned expressed interest in suing the doctors who had forced her parents to agree to the surgery, but Italian law was too ambiguous regarding consent laws and statutes of limitations for her to be able to find a lawyer who would take the case and she eventually lost interest in pursuing the case.

D. Annexe 2 – IGM Practices in Italy: Most Common Forms

a) IGM 3 – Sterilising Procedures: Castration / “Gonadectomy” / Hysterectomy / Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation Plus arbitrary imposition of hormones [69]

“I wouldn’t have ever had the surgery [gonadectomy], because now I have osteoporosis.”

(**Case No. 2**, see also **Cases No. 1, 3, 4**)

As advocated in the **“2016 Global Disorders of Sex Development Consensus Statement”**,[70] with Italian contributors Massimo Di Grazia (Department of Paediatric Surgery, **IRCCS Ospedale Infantile Burlo Garofolo**, Triest), Arianna Lesma (Director Urology, **IRCCS San Raffaele**, Milan), Gianantonio Manzoni (Director of Paediatric Urology, **Fondazione IRCCS Cà Granda dell'Ospedale Maggiore Policlinico**, Milan), Giacinto Marrocco (Director Paediatric Surgery and Urology, **Azienda Ospedaliera San Camillo-Forlanini**, Rome, currently Centre of Paediatric Surgery**, Salvator Mundi international Hospital**), Emilio Merlini (Director Paediatric Urology, **Azienda Ospedaliero Universitaria Torino**, Turin), Waifro Rigamonti (currently Professor of Paediatric Surgery, **Università degli studi di Trieste**, former Director Paediatric Urology, **Ospedale Infantile Burlo Garofolo**, Triest) – even when admitting *“low”* cancer risk (*“GCC risk”*) e.g. for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)[71]:

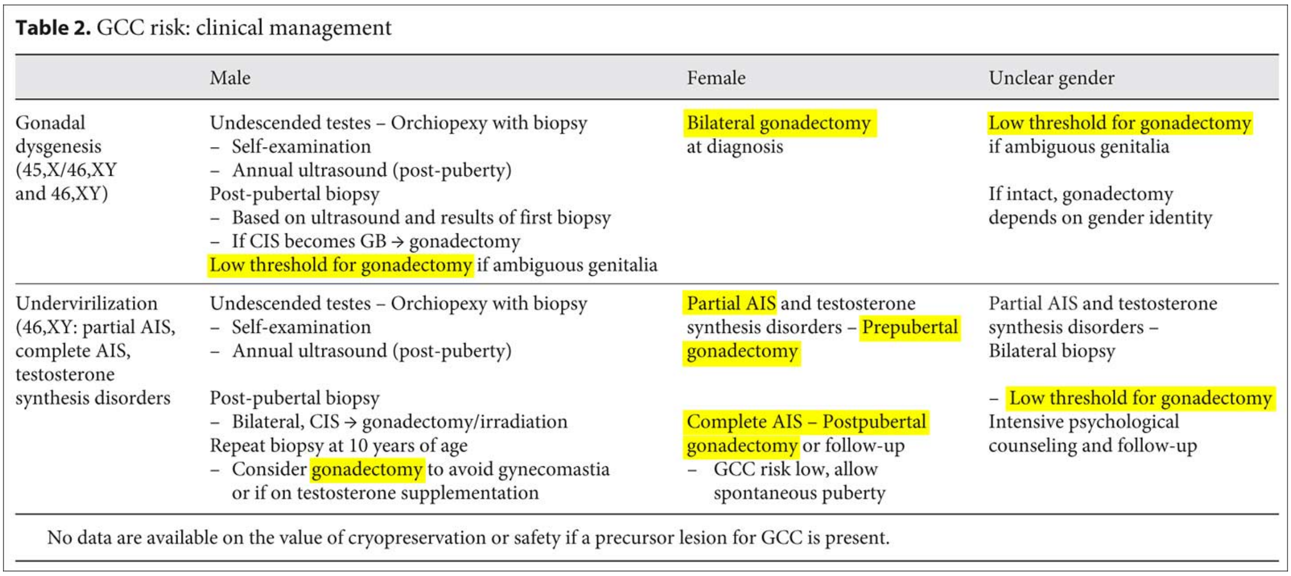

Table 2. GCC risk: clinical management

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Based on ultrasound and results of first biopsy – If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectomy Intensive psychological counseling and follow-up

No data are available on the value of cryopreservation or safety if a precursor lesion for GCC is present.

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174 (see fn 43)

Similarly a 2013 publication by paediatricians of the **University of Messina** and the **Campus Bio-Medico in Rome** describes **practicing gonadectomy** on a person with CAIS, justified by an alleged *“high”* cancer risk, without even telling the person concerned[72]:

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

[70] Lee et al., “Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care”, Horm Res Paediatr 2016;85:158–180, https://www.karger.com/Article/Pdf/442975

[71] ibid, at 180 (fn 111)

[72] Pizzo A, Laganà AS, Borrielli I, Dugo N. Complete androgen insensitivity syndrome: a rare case of disorder of sex development. Case Reports in Obstetrics and Gynecology. 2013,

"After communicating the results to the parents (who preferred not to inform the patient), we decide to perform laparoscopy […] [C]onsidering the high incidence of malignant degeneration of the gonads held in the abdominal cavity, we addressed the patient to a bilateral gonadectomy. […] Parents preferred not to disclose the diagnosis to the daughter, to whom it was explained that, due to the absence of the uterus and ovaries, hormone therapy was needed but could not resolve nor amenorrhea nor infertility. This news was so devastating for a young psychologically female, who hoped to solve her problems in other ways."

In addition, after public criticism by colleagues,[73] above paediatricians defended the involuntary unnecessary gonadectomy as having just followed *"Italian law"*:[74] (see also **Cases No. 3, 4**)

"Moreover, all the authors of the paper "Complete androgen insensitivity syndrome: a rare case of disorder of sex development" [2] currently ***work in Italy and operate under the Italian law****, as Balsamo et al. [1] do. According to the Italian law, the decision regarding disclosure of the diagnosis and medical/surgical treatment in minor patients must be demanded from their parents, unless there is a different decision from a judge.* ***So we just followed the law of the country in which we live and operate as MD, without applying any personal opinion about it."***

Also the **IRCCS San Raffaele**, Milan, openly advocates "*Eventual removal of altered gonads*" on its homepage under "*ambiguous genitalia*".[75]

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labioplasty", Dilation[76]

"Due to the removal of parts of my clitoris and scaring,
it is really hard for me to achieve orgasm." (**Case No. 1**)

As advocated by the **Ministry of Health** in their guidelines regarding "Promotion and care for the health of the child and the adolescent" (p. 153, own translation)**:**[77]

*"****Feminizing surgery*** *has three main goals:* ***reduce the size of the protruding masculinized clitoris,*** *reconstruct the large and small labia, increase the opening and, if possible, the length of the vagina.* ***Early surgery*** *should only be considered in cases of severe virilisation and, whenever possible, should be performed at the same time as the repair of the urogenital sinus."*

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https://www.hindawi.com/journals/criog/2013/232696/

[73] Balsamo, Antonio et al. "Comment on 'Complete Androgen Insensitivity Syndrome: Optimizing Diagnosis and Management.'" Case Reports in Obstetrics and Gynecology 2014, https://www.hindawi.com/journals/criog/2014/285715/

[74] Laganà Antonio Simone and Pizzo Alfonsa: Response to: Comment on "Complete Androgen Insensitivity Syndrome: Optimizing Diagnosis and Management". Case Reports in Obstetrics and Gynecology, Volume 2014, https://www.hindawi.com/journals/criog/2014/808270/

[75] http://www.hsr.it/clinica/specialita-cliniche/urologia/urologia-san-raffaele/patologie-e-trattamenti/ambiguita-genitali/

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

[77] Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, tecnological and structural criteria of appropriateness (Promozione e tutela della salute del bambino e dell'adolescente: criteri di appropriatezza clinica, tecnologica e strutturale). Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

As advocated in a brochure published by the **IRCCS Ospedale San Raffaele Milano** and **Università degli Studi di Padova, Dipartimenti di Salute della Donna e del Bambino,**[78] and online by the doctor-supported parent's association **"Associazione Interregionale Iperplasia Surrenalica Congenita ONLUS (AIRISC)"**[79] and **"Associazione I.S.C. ONLUS Lombardia"**[80] promoting early surgery:

"Surgical Therapy

Hormonal therapy is not enough to correct the external genital anomalies caused in the female by excess of androgens in utero. ***It is therefore necessary to intervene surgically to reduce the excessive size of the clitoris and to correct the appearance of the vagina****, separating the outlet of the urinary tract from the vaginal opening.* ***Generally, surgery is done early in the first year of life*** *to prevent the baby from being psychologically disturbed by the genital alteration.* ***Most often the interventions are performed as a single surgery****, with a possible "revision" during puberty. The purpose is twofold: correct the anatomical alteration (aesthetic aspect) and allow for normal and satisfying adult sexual relations (functional aspect)."*

Accordingly, a publication out of the **IRCCS Ospedale San Raffaele Milano** and **Università Vita-Salute San Raffaele** reports 82 patients being submitted to "clitoral reduction surgery" between 1998 and 2005 performed by a single surgeon, **Arianna Lesma**.[81] From the same clinic, a later study reports **95 patients** with CAH having been submitted to clitoral reduction surgery between 1980 and 2010, concluding:[82]

"Although clitoral sensitivity *in sexually active patients with congenital adrenal hyperplasia treated with Passerini-Glazel feminizing genitoplasty* ***is significantly reduced*** *compared to controls, sexual function in those patients is not statistically or clinically significantly different from their healthy counterparts. Finally,* ***1-stage Passerini-Glazel feminizing genitoplasty seems to allow normal adult sexual function."***

Similarly, a 2016 publication out of the **Università degli Studi di Bologna** and **Unità Operative di Chirurgia Pediatrica del Policlinico S. Orsola-Malphigi Bologna**[83] lists *"99 patients with type III vaginal malformations were treated from 1980 to 2014"*, and promotes vaginal dilation during the first years of life:

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[78] Gianni Russo, Maria Pia Guarneri, Paola Peroni, Paola Sgaramella (IRCCS Ospedale San Raffaele Milano), Nella Augusta Greggio (Università degli Studi di Padova, Dipartimenti di Salute della Donna e del Bambino) (2014), opuscolo "Iperplasia Surrenale Congenita".

[79] http://airisc.it/iperplasia_terapia.html

[80] iperplasia.it ➔ Iperplasia, http://manuel241069.wixsite.com/adrenogenital/about

[81] Arianna Lesma, Aldo Bocciardi, Francesco Montorsi, Patrizio Rigatti, Passerini-Glazel Feminizing Genitoplasty: Modifications in 17 Years of Experience with 82 Cases, european urology 52 (2007) 1638–1644, http://www.europeanurology.com/article/S0302-2838(07)00346-6/pdf

[82] Arianna Lesma, Aldo Bocciardi, Stefano Corti, , Giuseppe Chiumello, Patrizio Rigatti, Francesco Montorsi, Sexual Function in Adult Life Following Passerini-Glazel Feminizing Genitoplasty in Patients with Congenital Adrenal Hyperplasia, THE JOURNAL OF UROLOGY Vol. 191, 211, 2013, http://www.jurology.com/article/S0022-5347(13)05090-8/fulltext

[83] Lima, M., Destro, F., Cantone, N., Shalaby, M. M. A. E.-A., & Ruggeri, G. (2016). Anterior Sagittal Approach and Total Urogenital Mobilization for the Treatment of Persistent Urogenital Sinus in a 2-Year-Old Girl. European Journal of Pediatric Surgery Reports, 4(1), 13–16, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5177548/

"Persistent urogenital sinus (UGS) is a ***complex, challenging, and controversial pathology for the pediatric surgeon.*** *[…] Two-step surgery was recently introduced in our center for young patients to avoid lengthy operations in the case of long UGS* ***(genital reconstruction in the first months of life and delayed urogenital mobilization within the 1st year).*** *[…] After 2 weeks of the surgery,* ***vaginal dilatations were initiated by the patient's mother once a day for the 1st week and then twice a week for a total of 3 months,*** *increasing the size of the dilator to avoid postoperative vaginal stenosis […]* ***[T]he mother was satisfied with the cosmetic results.*** *[…] In all cases, surgery has three main goals: (1) to separate the urinary and genital tract, (2) to correct urinary continence, and (3) to* ***prepare for normal reproductive and sexual life*** *through reconstruction of the vagina and external genitalia. […]"*

Also the **IRCCS San Raffaele**, Milan, openly advocates *"Genitoplasty is a surgical procedure performed to correct the external genitals in a female way"* including "clitoral reduction", "vaginoplasty" and "labioplasty" *"with a single intervention, performed at the age of about 6 months"* on its homepage under *"ambiguous genitalia"*.[84]

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"[85]

As advocated by the **Ministry of Health** in their guidelines regarding "Promotion and care for the health of the child and the adolescent" (p. 153, own translation)**:**[86]

"In children with male gonadal sex, ***hypospadias, if present, requires early surgical correction.****"*

As advocated by doctors of the "Paediatric Surgery Unit" of the **Azienda Ospedaliera San Camillo-Forlanini, Rome**[87]**,** while at the same time admitting to having performed "hypospadias repair" on 693 children over 10 years, all operated by the same surgeon, Giacinto Marrocco:

"Our experience shows that the ***ideal age for surgery is 8–12 months.*** *Several considerations support our choice: the penile growth curve [6],* ***minor impact on the child psychologically*** *(genital area knowledge and stranger anxiety begin after 12 months of age) and* ***easier management when the patient is still in diapers.****"*

As currently advocated by the **IRCCS Ospedale Pediatrico Bambino Gesù** in Rome on its homepage (own translation):[88]

"Current guidelines agree to ***correct all forms of hypospadias****, including atypical forms,* ***within the second year of life, preferably in a single procedure****. This replaces all the recommendations only to correct the most severe forms, which underestimated the psychological impact of the*

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[84] http://www.hsr.it/clinica/specialita-cliniche/urologia/urologia-san-raffaele/patologie-e-trattamenti/ambiguita-genitali/

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

[86] Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, tecnological and structural criteria of appropriateness (Promozione e tutela della salute del bambino e dell'adolescente: criteri di appropriatezza clinica, tecnologica e strutturale). Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

[87] G. Marrocco, S. Vallasciani, G. Fiocca, A. Calisti (2004), Hypospadias surgery: a 10-year review. Pediatric surgery international, 20:200–203, at 202, https://www.researchgate.net/publication/8620545_Hypospadias_surgery_A_10-year_review

[88] http://www.ospedalebambinogesu.it/ipospadia?inheritRedirect=true

aesthetic problem. Reconstruction should also provide an aesthetic appearance as normal as possible, in order to ***prevent psychological problems****.”*

d) Prenatal “Therapy”

As advocated by the **Ministry of Health** (p. 149, own translation)**:**[89]

“The consequences of the enzymatic deficit due to fetal hyperandrogenization ***may be prevented by administering, precociously, dexamethasone to the mother.****”*

As advocated by the Italian **Associazione Culturale Pediatri** and several Italian paediatricians of the **Università di Bologna, Policlinico S. Orsola-Malphigi**:[90]

“Prenatal diagnosis and treatment ***should be performed*** *in families at risk for classical form, underlining them that long term results in dexamethasone treated subjects have however lacking.”*

As in 2016 again advocated **despite known risks** by Italian paediatricians of **IRCCS Ospedale San Raffaele** and **Università Vita-Salute San Raffaele**, Milan (own translation):[91]

“In families with a child affected by the classic form, and in which were identified two pathogenic variants, one can ***offer prenatal diagnosis and dexamethasone therapy*** *[…] More recently, some studies on the long-term effects on children treated with dexamethasone do not indicate general* ***problems*** *except for* ***long-term cognitive effects*** *[…]. The authors conclude that these data* ***should be verified by further studies****.”*

e) Other Unnecessary and Harmful Medical Interventions and Treatments

Other common harmful treatments include:

- **Forced Mastectomy**[92]
- **Imposition of Hormones**[93]
- **Forced Excessive Genital Exams, Medical Display and (Genital) Photography**[94]
- **Human Experimentation**[95]
- **Denial of Needed Health Care**[96]

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[89] Ministry of Health (2012), Promotion and care for the health of the child and the adolescent: clinical, tecnological and structural criteria of appropriateness (Promozione e tutela della salute del bambino e dell’adolescente: criteri di appropriatezza clinica, tecnologica e strutturale). Quaderni del Ministero della Salute, n. 16, luglio-agosto 2012, http://www.salute.gov.it/imgs/C_17_pubblicazioni_2573_allegato.pdf

[90] A. Balsamo, A. Cicognani. SINDROME ADRENO-GENITALE CONGENITA DA DEFICIT DI 21-IDROSSILASI. Medico e Bambino 2005;24:293-301, https://www.medicoebambino.com/?id=0505_293.pdf

[91] Carrera, Paola, Chiara Di Resta, and Maurizio Ferrari. 2016 "Sindrome adrenogenitale: più comune di quanto si pensi." Prospettive in Pediatria Societa Italiana di Pedatria • Vol. 46 • N. 181 • Pp. 83-84, https://www.sip.it/wp-content/uploads/2016/06/03_Frontiere.pdf

[92] see 2014 CRC NGO Report, p. 70, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

[93] see 2014 CRC NGO Report, p. 70

[94] see 2014 CRC NGO Report, p. 73

[95] see 2014 CRC NGO Report, p. 74

[96] see 2014 CRC NGO Report, p. 75

- **Selective (Late Term) Abortion**[97]
- **Preimplantation Genetic Diagnosis (PGD) to Eliminate Intersex Fetuses**[98]

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[97] see 2014 CRC NGO Report, p. 76

[98] see 2014 CRC NGO Report, p. 76

Intersex Genital Mutilations

Human Rights Violations Of Children
With Variations Of Sex Anatomy

NGO Report
to the 7th Report of Italy
on the Convention on the Elimination of
All Forms of Discrimination against Women (CEDAW)