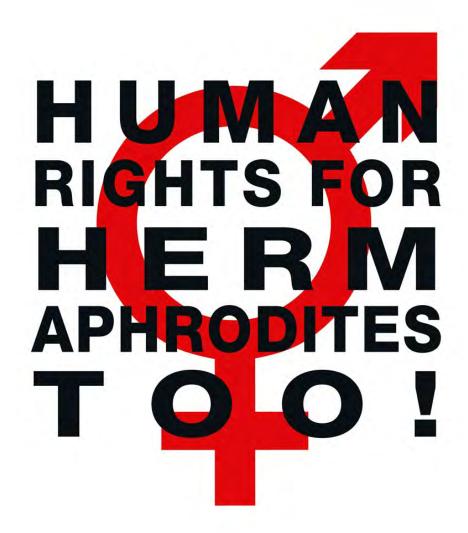
Intersex Genital Mutilation

Human Rights Violations Of Children With Variations Of Reproductive Anatomy



NGO Report (for Session)
to the 5th and 6th Report of Chile on the
Convention on the Rights of the Child (CRC)

Compiled by:

StopIGM.org / Zwischengeschlecht.org (International Intersex Human Rights NGO)

Markus Bauer Daniela Truffer

Zwischengeschlecht.org P.O.Box 1318 CH-8031 Zurich

info_at_zwischengeschlecht.org
https://Zwischengeschlecht.org/
https://StopIGM.org/

August 2021

This NGO Report online:

http://intersex.shadowreport.org/public/2021-CRC-Chile-NGO-Intersex-StopIGM.pdf



Executive Summary

Despite official denials, in Chile all typical forms of IGM practices persist with impunity, facilitated and paid for by the State party via the public health care system, including the Ministry of Health and the Fondo Nacional de Salud (FONASA).

Chile categorically fails to take appropriate action to effectively protect intersex children from harmful practices, in spite of repeated Concluding Observations not only by this Committee, but also by CRPD (CRPD/C/CHL/CO/1, paras 41–42) and CEDAW (CEDAW/C/CHL/CO/7, paras 22-23), and increasing public criticism by local persons concerned, legal experts and human rights bodies.

Chile remains thus in breach of its obligations under CRC to (a) take effective legislative, administrative, judicial or other measures to prevent harmful practices on intersex children causing severe mental and physical pain and suffering of the persons concerned, and (b) ensure access to redress and justice, including fair and adequate compensation and as full as possible rehabilitation for victims, as stipulated in CRC art. 24 para 3 in conjunction with the CRC-CEDAW Joint general comment No. 18/31 "on harmful practices".

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 rights.

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** 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.

This **Thematic NGO Report** was compiled by the intersex NGO **StopIGM.org**. It contains **Suggested Recommendations (p. 20).**

NGO Report to the 5th and 6th Report of Chile (for Session) on the Convention on the Rights of the Child (CRC)

Table of Contents

Update: IGM Practices in Chile (p. 11-20)

Executive Summary	3
Introduction	
IGM in Chile and State Report	
About the Rapporteurs	5
Methodology	6
A. Precedents: Concl Obs, Gov Regulations on IGM, LOIPR, State Report	5 6 R, State Report
1. Previous Concluding Observations, Gov Regulations on IGM	7
a) CRC 2015: Harmful Practices, CRC-CEDAW Joint General Comment No. 18/31	
(CRC/C/CHL/CO/4-5, paras 48-49)	
b) CRPD 2016: Integrity of the Person (CRPD/C/CHL/CO/1, paras 41-42)	8
c) CEDAW 2018: Harmful Practices, CRC-CEDAW Joint General Comment No. 18/31	
(CEDAW/C/CHL/CO/7, paras 22-23)	
2. Government Regulations on IGM	
a) Ministry of Health: Circular No. 18 (2015): Instruction to stop unnecessary genital surgery.	
b) Ministry of Health: Circular No. 7 (2016): Retracting Circular No. 18, re-prescribing IGM.	
3. Current 5 th and 6 th CRC Cycle: LOIPR and State Report	
a) CRC LOIPR: CRC/C/CHL/QPR/6-7, paras 15, 38(e)	
b) State Report: CRC/C/CHL/6-7, para 83	
B. IGM practices in Chile: Updates to NGO Report for LOIPR	
1. Overview: Still no protections, IGM persists with impunity despite denials	
2. Recent additional evidence of IGM practices in Chile	
 a) IGM 3 – Sterilising Procedures: Castration / "Gonadectomy" / Hysterectomy b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty" 	
c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair"	
3. Increasing public criticism of IGM since the NGO Report for LOIPR	
4. Fact-checking the State Report	
a) LOIPR, para 15: Harmful practices	
b) LOIPR, para 38(e): Statistical information and data on violence against children	
C. Conclusion: Chile is Failing its Obligations under the Convention	
D. Suggested Recommendations	
Annexe 1 – IGM Practices in Chile as a Violation of CRC	
1. The Treatment of Intersex Children in Chile as Harmful Practice and Violence	
b) Violence against Children (art. 19 and GC No. 13)	
2. Required Legislative Provisions to Ensure Protection from IGM Practices, Impunity	
3. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation	
Annexe 2 – "IGM in Medical Textbooks: Current Practice"	
IGM 1 – "Masculinising Surgery": "Hypospadias Repair"	
IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"	
IGM 3 – Sterilising Surgery: Castration / "Gonadectomy" / Hysterectomy	
"Bad results" / "Gonadectomy, Feminising Genitoplasty"	

Introduction

IGM in Chile and State Report

Chile fails to take appropriate action to protect intersex children from harmful practices, and to implement the repeated relevant Concluding Observations by this Committee, CRPD (CRPD/C/CHL/CO/1, paras 41–42) and CEDAW (CEDAW/C/CHL/CO/7, paras 22-23).

This is also evident in the **State Report** (para 83), which gives only a partial and misleading reply on (lack of) protections (LOIPR para 15), and no reply at all to the question on the number of intersex children submitted to IGM practices (LOIPR para 38(e)).

As this NGO Report on recent developments since the LOIPR demonstrates, in Chile all forms of IGM continue to be practiced with in impunity, advocated, facilitated and paid for by the State party via the public health care system – despite increasing public criticism by local persons concerned, legal experts and human rights bodies, and official denials by the State party.

Further, victims of IGM practices continue to face obstacles to access to justice, redress, compensation, and as full rehabilitation as possible, namely the statutes of limitation. Also, intersex people in Chile face difficulties in accessing their medical records, and accurate information about procedures performed on them during infancy and childhood.

About the Rapporteurs

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

• **StopIGM.org** / **Zwischengeschlecht.org**, founded in 2007, 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!*" ¹ According to its charter, ² 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 persons and organisations, ³ substantially contributing to the so far 54 Treaty body Concluding Observations recognising IGM as a serious human rights violation. ⁴ StopIGM.org has followed and reported on the situation in Chile since 2015, ⁵ and, in collaboration with Brújula Intersexual, has submitted NGO Reports to CAT in 2018 ⁶ and to this Committee in 2019. ⁷

^{1 &}lt;a href="https://Zwischengeschlecht.org/">https://Zwischengeschlecht.org/ English homepage: https://StopIGM.org

² https://zwischengeschlecht.org/post/Statuten

³ https://intersex.shadowreport.org

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

^{5 &}lt;u>https://stopigm.org/un-committee-on-the-rights-of-the-child-questions-chile-over-intersex-genital-mutilations/https://stopigm.org/un-crpd-reprimands-chile-for-intersex-genital-mutilations/</u>

https://stopigm.org/inter-american-commission-on-human-rights-condems-intersex-genital-mutilations/

^{6 &}lt;u>https://intersex.shadowreport.org/public/2018-CAT-Chile-NGO-Intersex-Brujula-StopIGM.pdf</u>

⁷ https://intersex.shadowreport.org/public/2019-CRC-LOIPR-Chile-NGO-Intersex-Brujula-StopIGM.pdf

The Rapporteurs would like to **acknowledge** the work of the local intersex NGO **Intersexuales Chile**⁸ (formerly Brújula Intersexual Chile) to raise awareness of intersex human rights in Chile.⁹ 10 11 12 13 14 We would like to acknowledge the work of international intersex NGO **Brújula Intersexual**. We would like to acknowledge the work of **Intersex Pacífico Sur**. And we would like to acknowledge the work of **Camilo Godoy**. The state of the local intersex NGO **Brújula Intersexual**.

Methodology

This thematic NGO report is an **update to the 2019 thematic CRC NGO Report for LOIPR** for **Chile**²¹ by Brújula Intersexual and StopIGM.org. Translations from Spanish texts are automatic translations revised by the Rapporteurs.

5

⁸ https://intersexualeschile.cl/

⁹ https://brujulaintersexual.org/2020/08/19/comunicado-intersexuales-chile-canal13/

¹⁰ http://www.invertidoediciones.cl/2021/04/14/dioses-sobre-nuestros-cuerpos-experiencia-intersexual-en-chile/ (see also below, p. 16)

¹¹ https://brujulaintersexual.org/2020/10/05/vivencia-intersexual-entrevista-intersexuales-chile/

^{12 &}quot;Do you know what it is? IGM Intersex Genital Mutilation", https://www.facebook.com/intersexchilenos/posts/2957565441166594

[&]quot;For Intersexualeschile this is an extremely important moment as a group [to participate in this course organised by the Medical College of Chile] because we are getting closer and closer that doctors and future doctors know that they should not be part of or complicit in surgeries on intersex babies that are only done as we know for aesthetic reasons and not for any health purposes.", https://www.facebook.com/intersexchilenos/posts/2933769156879556

¹⁴ https://brujulaintersexual.org/2021/08/26/intersexualeschile-convencion-constitucional/

^{15 &}lt;a href="https://brujulaintersexual.org/?s=chile">https://brujulaintersexual.org/?s=chile

^{16 &}lt;u>https://www.facebook.com/Intersex/Chile/photos/a.116820686326885/149218726420414</u>

¹⁷ Open Letter to the President of the Republic, https://intersexday.org/en/chile-letter-2015/

¹⁸ Centro de Derechos Humanos, Facultad de Derecho, Universidad Diego Portales (Tomás Vial Solar, editor general), Informe anual sobre Derechos Humanos en Chile 2016, chapter on intersex: Camilo Godoy, Derechos Humanos de las Personas Intersex en Chile (p. 321-355), https://derechoshumanos.udp.cl/cms/wp-content/uploads/2020/12/Godoy_ddhhpersonasintersex-1.pdf

Godoy, Camilo (2015). Análisis del tratamiento de la intersexualidad a la luz del derecho internacional de los derechos humanos y su realidad en Chile, http://bibliotecadigital.indh.cl/handle/123456789/1022

Instituto Nacional de Derechos Humanos (INDH), Informe Anual Situación de los Derechos Humanos en Chile 2017, chapter 3 on intersex, https://www.indh.cl/bb/wp-content/uploads/2017/12/01_Informe-Anual-2017.pdf

²¹ https://intersex.shadowreport.org/public/2019-CRC-LOIPR-Chile-NGO-Intersex-Brujula-StopIGM.pdf

- A. Precedents: Concluding Observations, Gov Regulations on IGM, LOIPR and State Report
- 1. Previous Concluding Observations, Gov Regulations on IGM
- a) CRC 2015: Harmful Practices, CRC-CEDAW Joint General Comment No. 18/31 (CRC/C/CHL/CO/4-5, paras 48-49)
- E. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39) [...]

Harmful practices

- 48. While noting the proposed development of a protocol on the health care of intersex babies and children, the Committee is seriously concerned about cases of medically unnecessary and irreversible surgery and other treatment on intersex children, without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases.
- 49. In the light of its general comment No. 18 (2014) on harmful practices, adopted jointly with the Committee on the Elimination of Discrimination against Women, the Committee recommends that the State party expedite the development and implementation of a rights-based health-care protocol for intersex children that sets the procedures and steps to be followed by health teams in order to ensure that no one is subjected to unnecessary surgery or treatment during infancy or childhood, protect the rights of the children concerned to physical and mental integrity, autonomy and self-determination, provide intersex children and their families with adequate counselling and support, including from peers, and ensure effective remedy for victims, including redress and compensation.

b) CRPD 2016: Integrity of the Person (CRPD/C/CHL/CO/1, paras 41-42) *Protecting the integrity of the person (art. 17)*

- 41. The Committee is concerned by the fact that sterilizations continue to be performed in the State party on persons with disabilities, especially women and girls, without their free and informed consent and at the mere request of their families or guardians, and by evidence that the procedure is commonly performed on persons with psychosocial disabilities admitted to psychiatric centres.
- 42. The Committee requests the State party to amend Act No. 20.584 and Decree No. 570 to require in all cases, without exception, the free and informed consent of persons with disabilities, including those whose legal capacity has been revoked, as an essential prerequisite for any surgery or medical treatment, especially those of an invasive nature and whose effects are irreversible, such as sterilization and procedures on intersex children.

c) CEDAW 2018: Harmful Practices, CRC-CEDAW Joint General Comment No. 18/31 (CEDAW/C/CHL/CO/7, paras 22-23)

Harmful practices

- 22. The Committee is concerned about:
- (a) The lack of clear legislation prohibiting the performance of unnecessary medical procedures on intersex infants and children until they reach an age when they are able to give their free, prior and informed consent;
- (b) The lack of support and effective remedies for intersex persons who have undergone medically unnecessary surgical procedures at a very early age, often with irreversible consequences and resulting in long-term physical and psychological suffering.
- 23. 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 of the Rights of the Child (2014) on harmful practices, the Committee recommends that the State party:
- (a) Adopt legislation to explicitly prohibit the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age when they are able to give their free, prior and informed consent, ensure that medical practitioners are informed about such legislation and provide families with intersex children with adequate counselling and support;
- (b) Ensure that intersex persons who have undergone unnecessary surgical or other medical treatment without their free, prior and informed consent have effective access to justice and consider establishing a State compensation fund for them.

2. Government Regulations on IGM

a) Ministry of Health: Circular No. 18 (2015): Instruction to stop unnecessary genital surgery

Referring to this Committee's Concluding Observations (CRC/C/CHL/CO/4-5, see above), in December 2015 the **Chilean Ministry of Health** issued the "Circular No. 18", which explicitly stated: "We instruct the stopping of unnecessary "normalization" treatment of intersex children, including irreversible genital surgeries, until they are old enough to decide about their bodies." ²² However, Chilean IGM doctors ignored "Circular No. 18" (see 2019 NGO Report for LOIPR, p. 10, 12-15).

b) Ministry of Health: Circular No. 7 (2016): Retracting Circular No. 18, re-prescribing IGM

After massive pressure by Chilean IGM doctors and some parents²³ determined to continue with involuntary, non-urgent surgery and other procedures on intersex children, in August 2016 the Ministry of Health in fact replaced "Circular No. 18" by a newer "Circular No. 7", ²⁴ which not only retracts the reservations of the former "Circular No. 18", but actually re-prescribes the full range of involuntary, non-urgent genital surgery, sterilising procedures and other harmful treatments on intersex children²⁵ (see 2019 NGO Report for LOIPR, p. 12-15).

Ministry of Health (2015), Circular No. 18: Instructions on aspects of health care to intersex children, p. 1, https://brujulaintersexual.files.wordpress.com/2017/07/circular-18-english.pdf
For a scan of the Spanish original, see https://stopigm.org/public/Chile_Circular-No-18_22-12-2015 Instruye-Ninos-y-Ninas-Intersex OCR web.pdf

[&]quot;The adoption of the new circular is explained because a group of doctors dedicated to the treatment of the so called "disorders of sex development" (DSD) objected to the adoption of Circular 18 arguing that it used the wrong language and because it interfered with the practice of irreversible genital surgeries. The main support to this group of doctors came from a group of parents of girls with congenital adrenal hyperplasia (CAH), who told the Ministry that their daughters didn't have gender ambiguity and that if they not intervened early, they could have physical and psychological problems."
Instituto Nacional de Derechos Humanos (INDH), Annual report on the human rights situation in Chile 2017 ("Informe anual sobre la situación de derechos humanos en Chile 2017"), p. 74, https://www.indh.cl/bb/wp-content/uploads/2017/12/01 Informe-Anual-2017.pdf

²⁴ Ministry of Health (2016), Circular No. 7: Complement to Circular No. 18 that instructs on certain aspects of the treatment of intersex children, https://brujulaintersexual.files.wordpress.com/2017/07/circular-7-chile-ministry-of-health.pdf
For a scan of the Spanish original, see https://brujulaintersexual.files.wordpress.com/2017/06/circular-7.pdf

For an detailed analysis of how Circular No. 7 re-instates and justifies IGM practices, see: Laura Inter and Hana Aoi (2017), Circular 7, 2016: A step back in the fight for the human rights of intersex people in Chile, https://brujulaintersexual.files.wordpress.com/2017/07/circular-7-english.pdf

- 3. Current 5th to 6th CRC Cycle: LOIPR and State Report
- a) CRC LOIPR: CRC/C/CHL/QPR/6-7, paras 15, 38(e)
- D. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39) [...]

Harmful practices

15. Please provide information on the measures taken to raise awareness of the negative consequences of child marriage with a view to ending this harmful practice. Please also provide information on the finalization and implementation of a rights-based health-care protocol for intersex children to ensure that no child is subjected to unnecessary surgery or treatment. [...]

III. Statistical information and data

- D. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39)
- 38. Please provide data, disaggregated as described in paragraph 33 above, on: [...]
- (e) The number of intersex children who have undergone surgery or treatment related to their sexual characteristics.
- b) State Report: CRC/C/CHL/6-7, para 83
- D. Violence against children (arts. 19, 24 (3), 28 (2), 34, 37 (a) and 39) [...]

Harmful practices

83. Circular No. 18 of 22 December 2015 of the Ministry of Health contains instructions on certain aspects of health care for intersex children and draws attention to their rights and the recommendations of the World Health Organization and the Committee. In this regard, it includes a directive for the cessation of any unnecessary treatment for the purpose of "normalizing" such children, including irreversible genital surgery, until they are old enough to make their own decisions about their bodies. Furthermore, each health service is instructed to set up a working group to review and analyse such cases.

B. IGM practices in Chile: Updates to NGO Report for LOIPR

1. Overview: Still no protections, IGM persists with impunity despite denials

Unfortunately, since our 2019 Joint Intersex NGO Report for LOIPR together with Brújula Intersexual, the situation in Chile remains unchanged:

On the side of violations, all typical forms of IGM practices are still practised in Chile today, facilitated and paid for by the State party via the public health care system, including the Ministry of Health and the Fondo Nacional de Salud (FONASA).

On the side of **protections**, there are still

- 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
 practices
- no measures in place to ensure data collection and monitoring of IGM practices
- **no measures** in place to ensure intersex persons' **access to their medical records**, and to accurate **information about procedures** performed on them during infancy and childhood
- 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

This is also evident in the **State Report** (para 83), which gives only **partial and misleading** answers on (lack of) protections (LOIPR para 15), and **conveniently ignores** the question on the number of intersex children submitted to IGM practices (LOIPR para 38(e)).

And it is further confirmed by reports of Government institutions, for example a 2021 publication of the Library of the National Congress of Chile (BCN): "In Chile there is no legislation regulating medical interventions on intersex persons." ²⁶

And it is also recalled by the NHRI Report for LOIPR of the **National Institute for Human Rights (INDH)** (para 29).

On the side of **positive developments**, there has been an **increase in public criticism** of the ongoing IGM practices and the lack of action by the State party, notably by the local intersex NGO **Intersexuales Chile**, as well in some **academic publications**, and sometimes, ironically, even by the **State party** itself, supporting statements to "protect [...] intersex adults and children [...] so that they live free from violence and harmful practices. Governments should investigate human rights violations and abuses against intersex people, ensure accountability, [...] and provide victims with access to remedy." ²⁷ (See also below, p. 16-17.)

Matías Meza-Lopehandía G. (2021), "Regulación de intervenciones médicas sobre niñas y niños intersex: Argentina, México y Uruguay", Biblioteca del Congreso Nacional de Chile / BCN, p. 1, https://obtienearchivo.bcn.cl/obtienearchivo?id=repositorio/10221/31995/1/BCN2021m Regulacion intervenciones intersexo.pdf

²⁷ Statement supported by Chile (and 35 other States) during the 45th Session of the Human Rights Council on 1 October 2020, see Session Report, p. 140, https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session45/Documents/AUV A HRC 45 2.doc Full statement, see https://www.permanentrepresentations.nl/permanent-representations/pr-ungeneva/documents/speeches/2020/10/1/united-nations-human-rights-council---45th-session

2. Recent additional evidence of IGM practices in Chile

a) IGM 3 – Sterilising Procedures:
 Castration / "Gonadectomy" / Hysterectomy /
 Removal of "Discordant Reproductive Structures" / (Secondary) Sterilisation and Arbitrary Imposition of Hormones²⁸

Note: Early "prophylactic" gonadectomies on intersex children diagnosed with Complete Androgen Insufficiency Syndrome (CAIS) are often performed under the pretext of an **alleged** "high cancer risk", however, the actual cancer risk is only 0,8%. ²⁹

The Chilean Society of Urology ("Sociedad Chilena de Urología SCHU") endorses the 2021 Guidelines of the European Association of Urology (EAU),³⁰ which include the current ESPU/EAU "*Paediatric Urology*" Guidelines 2021³¹ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:³²

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

Further, regarding "whether and when to pursue gonadal or genital surgery", ³³ the Guidelines refer to the "ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", ³⁴ which advocates "gonadectomies":

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

Also, the current "Manual of Paediatric Surgery from A to Z" of the Chilean Society of Paediatric Surgery ("Sociedad Chilena Cirugía Pediátrica SChCP") published in September 2019, prescribes "prophylactic gonadectomy" justified by an alleged "high" cancer risk for intersex children diagnosed with Androgen Insensitivity Syndrome (AIS): 35

"4. Risk of neoplasia: [...] For DSD patients carrying Y chromosome genetic material (or SRY segment) with varying degrees of gonadal dysgenesis and, also, cases of androgen insensitivity at post-pubertal ages are even more likely to have them. These children are likely to benefit from prophylactic gonadectomy given the high risk of developing gonadal neoplasia."

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

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

^{30 &}lt;a href="https://uroweb.org/guidelines/endorsement/">https://uroweb.org/guidelines/endorsement/

³¹ https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf

³² Ibid., p. 90

³³ Ibid., p. 89

P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebeke, "The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)", Journal of Pediatric Urology vol. 10, no. 1 (2014), p. 8-10, http://www.jpurol.com/article/S1477-5131(13)00313-6/pdf

³⁵ Sociedad Chilena Cirugía Pediátrica SChCP (2019), "Manual de Cirugía Pediátrica de la A a la Z", p. 372, https://www.schcp.cl/wp-content/uploads/2019/10/Manual-de-Cirug%C3%ADa-Pedi%C3%A1trica-de-la-A-a-la-Z-SChCP-2019.pdf

Accordingly, a **2021 Paper** by doctors of the **School of Medicine of the Pontifical Catholic University of Chile** in Santiago and the **Hospitals Dr. Sótero del Río** and **Dipreca** in Santiago prescribes unnecessary "gonadectomy":³⁶

"In female phenotypes, the **testes** are usually in an ectopic position and those located within the abdomen are at risk of malignancy, and therefore are **usually removed**. These are the most difficult cases to manage because apart from the **need for gonadectomy** followed by female hormonal therapy, there is a narrow vagina and a deep blind pouch that usually requires surgical correction to allow sexual activity."

Also, the current intersex guideline issued by the Chilean Ministry of Health, "Circular No. 7 (2016)", which explicitly advocates non-urgent surgical removal of testes ("gonadectomy") justified by psycho-social indications on children with "forms of DSD/intersex, with potential for both sex assignments" without the consent of the person concerned (see 2019 NGO Report for LOIPR, p. 12), remains in force.

b) IGM 2 – "Feminising Procedures": Clitoris Amputation/"Reduction", "Vaginoplasty", "Labioplasty", Dilation³⁷

The Chilean Society of Urology ("Sociedad Chilena de Urología SCHU") endorses the 2021 Guidelines of the European Association of Urology (EAU), 38 which include the current ESPU/EAU "Paediatric Urology" Guidelines 2021 9 of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.17 "Disorders of sex development", 40 despite admitting that "Surgery that alters appearance is not urgent" 41 and that "adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give inform consent", 42 the ESPU/EAU Guidelines nonetheless explicitly refuse to postpone non-emergency surgery, but in contrary insist to continue with non-emergency genital surgery (including partial clitoris amputation) on young children based on "social and emotional conditions" and substituted decision-making by "parents and caregivers implicitly act[ing] in the best interest of their children" and making "well-informed decisions [...] on their behalf", and further explicitly refusing "prohibition regulations" of unnecessary early surgery, 43 referring to the 2018 ESPU Open Letter to the Council of Europe (COE), 44 which further invokes parents' "social, and cultural considerations" as justifications for early surgery (p. 2).

Also, the current "Manual of Paediatric Surgery from A to Z" of the Chilean Society of Paediatric Surgery ("Sociedad Chilena Cirugía Pediátrica SChCP") published in September

José F. Delgado G., Javiera Pérez E., Dasha Delgado B., Felipe Valenzuela P., Alejandra Martínez G., Eugenio Arteaga U., José F. Delgado G., Javiera Pérez E., Dasha Delgado B., Felipe Valenzuela P., Alejandra Martínez G., Eugenio Arteaga U. (2021), "Síndrome de insensibilidad a andrógenos: Revisión bibliográfica a propósito de 5 casos" ("Androgen insensitivity syndrome: literature review of 5 cases"), Rev Chil Endo Diab 2021; 14(1): 21-28, p. 21 (p. 2 in PDF), http://revistasoched.cl/1 2021/4.pdf

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

^{38 &}lt;a href="https://uroweb.org/guidelines/endorsement/">https://uroweb.org/guidelines/endorsement/
39 https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf

⁴⁰ Ibid., p. 86

⁴¹ Ibid., p. 89

⁴² Ibid., p. 89

⁴³ Ibid., p. 90

⁴⁴ https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf

2019, prescribes "feminising surgery" justified by "psychosocial" indications: 45

"Sexual function: Although it is an issue that does not seem to be important in the newborn period, [...] a urologist familiar with the management of [...] 'feminising' surgery, among others, will be needed later."

Accordingly, a 2020 Presentation at the Congress of the Ibero-American Society of Paediatric Urology by a surgeon from the Department of Paediatric Urology of the Hospital Exequiel Gonzalez Cortés - Clínica Alemana (Santiago) cryptically asks "Where are we standing on posterior sagittal approach?" ⁴⁶ – notably, a **previous publication** including gruesome photos co-authored by the same surgeon reveals that said hospital in particular favours the "posterior sagittal approach" for the "more complex cases" of "feminizing genitoplasty in adrenal congenital hyperplasia", "if possible before 6 months" ⁴⁷ (see also 2019 NGO Report for LOIPR, p. 13).

And a 2021 Paper by doctors of the School of Medicine of the Pontifical Catholic University of Chile in Santiago and the Hospitals Dr. Sótero del Río and Dipreca in Santiago prescribes unnecessary "surgical correction to allow sexual activity": 48

"In female phenotypes, [...] [t]hese are the most difficult cases to manage because apart from the need for gonadectomy followed by female hormonal therapy, there is a narrow vagina and a deep blind pouch that usually requires surgical correction to allow sexual activity."

Also, the current intersex guideline issued by the Chilean Ministry of Health, "Circular No. 7 (2016)", which explicitly advocates non-urgent "feminising" surgery including "clitoroplasty, uro-genital sinus surgery, and genitoplasty" on children diagnosed with CAH justified by psycho-social indications but without the consent of the person concerned (see 2019 NGO Report for LOIPR, p. 13), remains in force.

c) IGM 1 – "Masculinising Surgery": Hypospadias "Repair" 49

The Chilean Society of Urology ("Sociedad Chilena de Urología SCHU") endorses the 2021 Guidelines of the European Association of Urology (EAU),50 which include the current ESPU/EAU "Paediatric Urology" Guidelines 2021⁵¹ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In chapter 3.6

Sociedad Chilena Cirugía Pediátrica SChCP (2019), "Manual de Cirugía Pediátrica de la A a la Z", p. 371, 45 $\underline{https://www.schcp.cl/wp-content/uploads/2019/10/Manual-de-Cirug\%C3\%ADa-Pedi\%C3\%A1trica-de-la-A-a-la-Z-SChCP-2019.pdf}$

Rocardo Zubieta (23.10.2020), "Abordaje sagital posterior, ¿dónde estamos? / Where are we standing on posterior sagittal approach?", presentation at the XXV Congress of the Ibero-American Society of Paediatric Urology, https://www.siupurologia.com/wp-content/uploads/2020/08/Programa XXV-Congreso-Virtual-SIUP_Edited-Aug-24-2020-FINAL-1.pdf

Jose Manuel Escala, Yair Cadena, Pedro-Jose Lopez, Lorena Angel, Maria G. Retamal, Nelly Letelier, Ricardo Zubieta (2009), "Genitoplastia feminizante en hyperplasia suprarenal congénita; ¿Una o dos etapas quirúrgicas?" ("Feminizing genitoplasty in adrenal congenital hyperplasia: one or two surgical steps?"), Paediatric Urology Arch. Esp. Urol.; 62 (9): 724-730, https://scielo.isciii.es/pdf/urol/v62n9/06.pdf

José F. Delgado G., Javiera Pérez E., Dasha Delgado B., Felipe Valenzuela P., Alejandra Martínez G., Eugenio Arteaga U., José F. Delgado G., Javiera Pérez E., Dasha Delgado B., Felipe Valenzuela P., Alejandra Martínez G., Eugenio Arteaga U. (2021), "Síndrome de insensibilidad a andrógenos: Revisión bibliográfica a propósito de 5 casos" ("Androgen insensitivity syndrome: literature review of 5 cases"), Rev Chil Endo Diab 2021; 14(1): 21-28, p. 21 (p. 2 in PDF), http://revistasoched.cl/1_2021/4.pdf

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

https://uroweb.org/guidelines/endorsement/ 50

https://uroweb.org/wp-content/uploads/EAU-Guidelines-on-Paediatric-Urology-2021-1.pdf 51

"Hypospadias",⁵² the ESPU/EAU Guidelines' section 3.6.5.3 "Age at surgery" nonetheless explicitly promotes, "The age at surgery for primary hypospadias repair is usually 6-18 (24) months." ⁵³ – despite admitting to the "risk of complications" ⁵⁴ and "aesthetic[...]" and "cosmetic" justifications. ⁵⁵

Accordingly, also in its current **2020 Manual of Urology** the **Chilean Society of Urology** ("**Sociedad Chilena de Urología SCHU**") in the chapter on "**Paediatric Urology**" prescribes early surgical "correction" for hypospadias: ⁵⁶

"Hypospadias is treated surgically, preferably between 6 and 18 months of age, after the hormonal surge that occurs in boys between 2 and 3 months of age (mini-puberty)."

And the current "Manual of Paediatric Surgery from A to Z" of the Chilean Society of Paediatric Surgery ("Sociedad Chilena Cirugía Pediátrica SChCP") published in September 2019, prescribes early "hypospadias repair" despite high rates of "complications":⁵⁷

"Hypospadias: [...]

Treatment

The treatment is surgical and is performed between 6 and 18 months of age."

"Complications

Thanks to technical advances and the use of fine suture materials and instruments, the complication rate has been significantly reduced (5 to 15 % for distal and 25 to 55 % for proximal sutures). On the other hand, the 'accumulation' of experience also reduces the complication rate."

Further, recent reports about hypospadias surgery in Chile stress the **psychosocial indications**, namely **relief of parental distress about "abnormal children"**, and the **stigma** associated with boys with hypospadias needing to sit to pee:

First, in a **2019 article** about hypospadias "repair" performed at the **Hospital de Curicó** (Servicio de Salud Maule), the local head paediatric surgeon states:⁵⁸

"The fundamental thing is that after the surgery, they can **lead a normal life**, that they are not limited or **discriminated against because of this condition**."

Second, in a **2021 article** about "complex" surgical "correction of pathologies including hypospadias" at the **Hospital Coquimbo** (Servicio de Salud Coquimbo), ⁵⁹ two mothers of children submitted to hypospadias surgery underline the psychosocial indications for surgery and the stigma associated with hypospadias:

53 Ibid., p. 28

⁵² Ibid., p. 26

⁵⁴ Ibid., p. 27

⁵⁵ Ibid., p. 27-28

Manual de Urología, Segunda Edición / Online (2020), Capítulo 36 - Urología pediátrica, p. 7, https://manualdeurologia.cl/capitulo-36-urologia-pediatrica/?print-posts=pdf

⁵⁷ Sociedad Chilena Cirugía Pediátrica SChCP (2019), "Manual de Cirugía Pediátrica de la A a la Z", p. 182-183, https://www.schcp.cl/wp-content/uploads/2019/10/Manual-de-Cirug%C3%ADa-Pedi%C3%A1trica-de-la-A-a-la-Z-SChCP-2019.pdf

⁵⁸ Savalnet.cl (2019), "Operativo quirúrgico de urología infantil", https://www.savalnet.cl/mundo-medico/noticias/operativo-quirurgico-de-urologia-infantil.html

Hospital de Coquimbo y Corporación MATER operan a niñas y niños de la región, https://www.hospitalcoquimbo.cl/archivos/6919

"I think it's good that they came, because the issue he had was very complex, because he didn't urinate like other people, but now he will be able to live a normal life. He was happy to have the surgery."

"He can't urinate normally and he wears nappies, so my concern was to operate on him before he went to school."

Also, the current intersex guideline issued by the Chilean Ministry of Health, "Circular No. 7 (2016)", which explicitly allows "unnecessary genital surgery" for most cases of hypospadias (see 2019 NGO Report for LOIPR, p. 13), remains in force.

3. Increasing public criticism of IGM since the NGO Report for LOIPR

Since the LOIPR, there has been an **increase in public criticism** of the ongoing IGM practices and the lack of action by the State party, notably by the local intersex NGO **Intersexuales Chile**, consistently calling for an end to unnecessary genital surgery and other treatment, ⁶⁰ notably by **demanding an explicit** "prohibition" ⁶¹ ⁶² of "intersex genital mutilation (IGM)": ⁶³ ⁶⁴ ⁶⁵

"Human rights violations against intersex people in Chile exist, and we don't know how long they will last; we don't know if one day they will stop mutilating bodies in hospitals, if doctors will stop feeling like gods over our bodies. What we can do is to help the Chilean population to learn about us, to let them know that we exist and that we suffer a great deal of abuse, without anyone looking out for our welfare. Those who should protect us from the first day of life abandon us: the government and the Ministry of Health."

"It is the obligation of the government, of the Ombudsman for Children, of human rights in Chile, to protect the lives of intersex children, to prohibit unnecessary surgeries and hormone treatments on their bodies." ⁶⁶

"A few months ago, it was said that in Africa in one country female genital mutilation had been abolished and that this was a great achievement. However, intersex genital mutilation continues, so while we are delighted that in Africa in some places the cutting of girls has ended, here in Chile it is still happening and it is also terrible because apart from the fact that there are many surgeries, the future consequences are terrible, since we have a lot of pain, urinary infection, and having a sexual relationship is going to be almost impossible and very complicated." ⁶⁷

Patinube de Intersexuales Chile (2021), "Dioses sobre nuestros cuerpos: experiencia intersexual en Chile" ("Gods over our bodies: intersex experience in Chile"), Invertido Ediciones, 15.04.2021, http://www.invertidoediciones.cl/2021/04/14/dioses-sobre-nuestros-cuerpos-experiencia-intersexual-en-chile/

⁶⁰ https://intersexualeschile.cl/quienes-somos/

Intersexuales Chile (2021), Statement at Hearing of 24.08.2021, Convención Constitucional, Comisión de Derechos Humanos, Subcomisión de Marco General de Derechos Humanos, Ambientales y de la Naturaleza, at 10:09, https://www.youtube.com/watch?v=732VtWvYfjI

^{63 &}quot;Do you know what it is? IGM Intersex Genital Mutilation", https://www.facebook.com/intersexchilenos/posts/2957565441166594

⁶⁴ Intersexuales Chile (2021), Statement at Hearing of 24.08.2021, Convención Constitucional, Comisión de Derechos Humanos, Subcomisión de Marco General de Derechos Humanos, Ambientales y de la Naturaleza, at 17:16, https://www.youtube.com/watch?v=732VtWvYfjI

Intersexuales Chile et al. (2020), Statement on on Canal 13 report, 19.08.2021, https://brujulaintersexual.org/2020/08/19/comunicado-intersexuales-chile-canal13/

Patinube de Intersexuales Chile (2021), "Dioses sobre nuestros cuerpos: experiencia intersexual en Chile" ("Gods over our bodies: intersex experience in Chile"), Invertido Ediciones, 15.04.2021, http://www.invertidoediciones.cl/2021/04/14/dioses-sobre-nuestros-cuerpos-experiencia-intersexual-en-chile/

⁶⁷ Intersexuales Chile (2021), Statement at Hearing of 24.08.2021, Convención Constitucional, Comisión de

Also, a **2020 Thesis**⁶⁸ from the **Faculty of Law** of the **University of Chile**, after discussing the "abrupt change" of "Circular No. 7 (2016)" retracting the previous "Circular No. 18 (2015)", and actually re-prescribing the full range of IGM practices (p. 55), concludes:

"Consequently, it is necessary for Chile to go a step further" by introducing a "legislative amendment", namely "The explicit prohibition of any surgery or hormonal treatment that affects the sexual characteristics of a minor that is motivated by purely aesthetic or psychosocial purposes, with the exception of those that address a concrete danger to the patient's health, also establishing a sanction for those who violate it and mechanisms of reparation for the victims." (p. 79)

Further, the **2019** "Manual of Paediatric Surgery from A to Z" of the Chilean Society of Paediatric Surgery ("Sociedad Chilena Cirugía Pediátrica SChCP"), ⁶⁹ despite continuing to proscribe IGM practices (see above, p. 12-15), at least vaguely anticipates a possible future where at least some intersex children may be allowed to grow up intact:

"Another challenge that is likely to be seen more frequently is the presentation of adolescent patients with DSD without genital surgeries during childhood. The trend towards minimal intervention or avoidance of non-functional (also called 'normalising') interventions is gaining increasing momentum internationally. The sense of human rights violations felt by some of the children who underwent non-reversible surgeries in childhood [...] raises the need to reconsider the need for early surgery [...].

[...] Today, many times adults come in who were diagnosed 20 or 30 years ago and are dissatisfied with the treatment they received at that time. This reality requires more and more study and research on the subject."

Last but not least, in 2020 on occasion of the 45th Session of the Human Rights Council, even the State party itself supported a public statement to "protect [...] intersex adults and children [...] so that they live free from violence and harmful practices. Governments should investigate human rights violations and abuses against intersex people, ensure accountability, [...] and provide victims with access to remedy." ⁷⁰ However, to this day the State party invariably fails to actually implement these declared noble intentions.

Derechos Humanos, Subcomisión de Marco General de Derechos Humanos, Ambientales y de la Naturaleza, at 17:06. https://www.voutube.com/watch?v=732VtWvYfiI

⁶⁸ Miguel Ángel Grez Catalán (2020), "LAS PERSONAS INTERSEXUALES FRENTE AL DERECHO: ESTUDIO EXPLORATORIO DE TRES PROBLEMAS JURÍDICOS." ("Intersex people and the law: An exploratory study of three legal problems"), Thesis, Universidad de Chile, Facultad de Derecho, Depto. de Derecho Público, http://repositorio.uchile.cl/bitstream/handle/2250/173871/Las-personas-intersexuales-frente-al-derecho-estudio-exploratorio-de-tres-problemas-jur%C3%ADdicos.pdf

Note: The Maltese and Portuguese intersex Laws, which the Thesis praises as "*examples to follow*", evidently fail to effectively protect intersex children from IGM (CRC/C/CO/MLT/3-6, paras 28-29; CRC/C/PRT/CO/5-6, para 28(b); CCPR/C/PRT/CO/5, paras 16-17).

⁶⁹ Sociedad Chilena Cirugía Pediátrica SChCP (2019), "Manual de Cirugía Pediátrica de la A a la Z", p. 372, https://www.schcp.cl/wp-content/uploads/2019/10/Manual-de-Cirug%C3%ADa-Pedi%C3%A1trica-de-la-A-a-la-Z-SChCP-2019.pdf

⁷⁰ Statement supported by Chile (and 35 other States) during the 45th Session of the Human Rights Council on 1 October 2020, see Session Report, p. 140, https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session45/Documents/AUV A HRC 45 2.doc Full statement, see https://www.permanentrepresentations.nl/permanent-representations/pr-ungeneva/documents/speeches/2020/10/1/united-nations-human-rights-council---45th-session

4. Fact-checking the State Report

a) LOIPR, para 15: Harmful practices

[...] Please also provide information on the finalization and implementation of a rights-based health-care protocol for intersex children to ensure that no child is subjected to unnecessary surgery or treatment. [...]

Fact: In its March 2021 reply in the State Report (para 83), the State party provided only a partial and ultimately misleading answer.

Namely, the State Report selectively referred only to the older "Circular No. 18 (2015)", which, as the State party correctly summarises, "includes a directive for the cessation of any unnecessary treatment for the purpose of 'normalizing' such children, including irreversible genital surgery, until they are old enough to make their own decisions about their bodies."

However, the State party **conveniently failed to mention** that said older "Circular No. 18 (2015)" in 2016 had been **replaced by the newer "Circular No. 7 (2016)"** which in fact **re-prescribed all forms of IGM**, see **2019 NGO Report for LOIPR (p. 10-11)** (see also above, p. 9). This is also corroborated in the **2020 NHRI Report for LOIPR (para 29, fn. 6)** of the National Institute for Human Rights (INDH), as well as in a **2020 Thesis**⁷¹ from the **Faculty of Law** of the **University of Chile**. And it was also reiterated by **Intersexuales Chile** at the August 2021 Hearing at the Subcommission for Human Rights of the Convención Constitucional, further referring to this Committee's 2015 Concluding Observations on intersex children in Chile.⁷²

b) LOIPR, para 38(e): Statistical information and data on violence against children *Please provide data, disaggregated as described in paragraph 33 above, on:* [...]

(e) The number of intersex children who have undergone surgery or treatment related to their sexual characteristics.

Fact: In its State Report, the State party conveniently failed to reply to this question at all.

-

Miguel Ángel Grez Catalán (2020), "LAS PERSONAS INTERSEXUALES FRENTE AL DERECHO: ESTUDIO EXPLORATORIO DE TRES PROBLEMAS JURÍDICOS." ("Intersex people and the law: An exploratory study of three legal problems"), Thesis, Universidad de Chile, Facultad de Derecho, Depto. de Derecho Público, p. 55, http://repositorio.uchile.cl/bitstream/handle/2250/173871/Las-personas-intersexuales-frente-al-derecho-estudio-exploratorio-de-tres-problemas-jur%C3%ADdicos.pdf

⁷² Intersexuales Chile (2021), Statement at Hearing of 24.08.2021, Convencíon Constitucional, Comisión de Derechos Humanos, Subcomisión de Marco General de Derechos Humanos, Ambientales y de la Naturaleza, at 03:25, https://www.youtube.com/watch?v=732VtWvYfjI

C. Conclusion: Chile is Failing its Obligations under the Convention

Intersex genital mutilation in Chile causes known severe physical and mental pain and suffering. Doctors continue to perform such unnecessary surgery and other treatment for the discriminatory purpose of making a child fit into societal and cultural norms and beliefs, although there is plenty of evidence of the suffering this causes. **The State party is responsible for these violations amounting to a harmful practice**, inhuman treatment and non-consensual medical or scientific experimentation, committed by publicly funded doctors, clinics, and universities, as well as in private clinics, advocated and **paid for by the public health care system** via the Fondo Nacional de Salud (FONASA).

Although meanwhile the pervasiveness of and severe harm caused by IGM practices is common knowledge, as well as the **increasing public criticism** by local persons concerned, their NGOs, legal and human rights experts and bodies, and the **State party has been made aware** of the situation and urged to take action also by CRC, CRPD and CEDAW, **Chile nonetheless fails to prevent these grave violations** both in public and in private settings, but allows the human rights violations of intersex children, adolescents and adults to continue with **impunity** – despite publicly claiming the opposite.

Also, victims of IGM practices encounter severe obstacles in the pursuit of their right to an impartial investigation, and to redress and fair and adequate compensation, including the means for as full rehabilitation as possible. Further, intersex people in Chile face difficulties in accessing their medical records, and accurate information about procedures performed on them during infancy and childhood.

Thus, Chile is in breach of its obligation to take effective legislative, administrative, judicial or other measures to prevent harmful practices and to ensure access to justice, redress and rehabilitation for IGM survivors, and to educate and train medical professionals on the harmful consequences of IGM (Art. 24(3) in conjunction with the CRC-CEDAW Joint General Comment No. 18/31).

D. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Chile, the Committee includes the following measures in their recommendations to the Chilean Government:

Harmful practices: Intersex genital mutilation

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

In the light of its joint general comment No. 18 (2014) and No. 31 of the Committee on the Elimination of Discrimination against Women on harmful practices and taking note of target 5.3 of the Sustainable Development Goals, the Committee urges the State party to:

- (a) Explicitly prohibit all forms of intersex genital mutilation in the criminal code, and provide families with intersex children with adequate counselling and support;
- (b) Repeal time-limits in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible;
- (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, psychological and education professionals on intersex as a natural bodily variation and on the consequences of unnecessary surgical and other medical interventions for intersex children.

Annexe 1 - IGM Practices in Chile as a Violation of CRC

- 1. The Treatment of Intersex Children in Chile as Harmful Practice and Violence
- a) Harmful Practice (art. 24(3) and JGC No. 18) 73

Article 24 para 3 CRC calls on states to abolish harmful "traditional practices prejudicial to the health of children". While the initial point of reference for the term was the example of Female Genital Mutilation/Cutting (FGM/C), the term consciously wasn't limited to FGM/C, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.⁷⁴

This Committee has repeatedly considered IGM as a harmful practice, and the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices as applicable.⁷⁵

Also **CEDAW** has repeatedly considered IGM as a **harmful practice**, and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 on harmful practices as applicable.⁷⁶

Harmful practices (and inhuman treatment) have been identified by intersex advocates as the **most effective, well established and applicable human rights frameworks** to eliminate IGM practices and to end the impunity of the perpetrators.⁷⁷

The CRC-CEDAW Joint General Comment/Recommendation No. 18/31 "on harmful practices" "call[s] upon States parties to explicitly prohibit by law and adequately sanction or criminalize harmful practices, in accordance with the gravity of the offence and harm caused, provide for means of prevention, protection, recovery, reintegration and redress for victims and combat impunity for harmful practices" (para 13).

Particularly, the Joint General Comment/Recommendation further underlines the need for a "Holistic framework for addressing harmful practices" (paras 31–36), including "legislative, policy and other appropriate measures that must be taken to ensure full compliance with [state parties'] obligations under the Conventions to eliminate harmful practices" (para 2), as well as

[&]quot;Data collection and monitoring" (paras 37–39)

[&]quot;Legislation and its enforcement" (paras 40–55), particularly:

[&]quot;adequate civil and/or administrative legislative provisions" (para 55 (d))

For a more extensive version, see 2017 CRC Spain NGO Report, p. 12-13, https://intersex.shadowreport.org/public/2017-CRC-Spain-NGO-Brujula-Zwischengeschlecht-Intersex-IGM.pdf

⁷⁴ UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 371

⁷⁵ 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/IRL/CO/3-4, paras 39-40; CRC/C/NPL/CO/3-5, paras 41-42; CRC/C/GBR/CO/5, paras 46-47; CRC/C/NZL/CO/5, paras 25+15; CRC/C/ZAF/CO/2, paras 39-40+23-24; CRC/C/DNK/CO/5, paras 24+12; CRC/C/ESP/CO/5-6, para 24; CRC/C/ARG/CO/5-6, para 26; CRC/C/ITA/CO/5-6, para 23; CRC/C/BEL/CO/5-6, paras 25(b)+26(e); CRC/C/MLT/CO/3-6, paras 28-29; CRC/C/AUS/CO/5-6, paras 25(b)+26(e); CRC/C/PRT/CO/5-6, paras 28(b); CRC/C/AUT/CO/5-6, para 27(a)-(b), CRC/C/LUX/CO/5-6, paras 13+19; CRC/C/TUN/CO/4-6, para 26, 14(c)+15(c)

⁷⁶ CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f; CEDAW/C/CHE/CO/4-5, paras 24-25, 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; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d); CEDAW/C/LUX/CO/6-7, paras 27b-c+28b-c; CEDAW/C/MEX/CO/9, para 21-22; CEDAW/C/NZL/CO/8, paras 23(c)-24(c); CEDAW/C/AUS/CO/8, paras 25(c)-26(c); CEDAW/C/LIE/CO/5, paras 35+36(c); CEDAW/C/NPL/CO/6, paras 18(c)-19(c)

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: https://StopIGM.org/public/S3 Zwischengeschlecht UN-Expert-Meeting-2015 web.pdf

Last but not least, the Joint General Comment explicitly stipulates: "Where medical professionals or government employees or civil servants are involved or complicit in carrying out harmful practices, their status and responsibility, including to report, should be seen as an aggravating circumstance in the determination of criminal sanctions or administrative sanctions such as loss of a professional licence or termination of contract, which should be preceded by the issuance of warnings. Systematic training for relevant professionals is considered to be an effective preventive measure in this regard." (para 50)

Conclusion, **IGM** practices in Chile – as well as the **failure** of the state party to enact effective **legislative**, administrative, social and educational measures to eliminate them and to ensure effective access to remedies and redress for IGM survivors – clearly violate Article 24 CRC, as well as the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices.

b) Violence against Children (art. 19 and GC No. 13)⁷⁸

Similarly, the Committee has also considered IGM practices as violence against children, and Art. 19 and the General Comment No. 13 also offer strong provisions to combat IGM practices.

2. Required Legislative Provisions to Ensure Protection from IGM Practices, Impunity of the Perpetrators (CRC art. 24(3) and JGC No. 18)

Article 24 para. 3 of the Convention in conjunction with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 "on harmful practices" (2014) underline state parties' obligations to "explicitly prohibit by law and adequately sanction or criminalize harmful practices" (JGC 18/31, para 13), as well as to "adopt or amend legislation with a view to effectively addressing and eliminating harmful practices" (JGC 18/31, para 55), and specifically to ensure "that the perpetrators and those who aid or condone such practices are held accountable" (JGC 18/31, para 55 (o)).

Accordingly, with regards to IGM practices, and referring to Article 24 para 3 and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31, CRC repeatedly recognised the obligation for State parties to "[e]nsure that the State party's legislation prohibits all forms of harmful practices [including intersex genital mutilation]", 79 as well as to "ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned", 80 and to "[u]ndertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation". 81

[&]quot;provisions on **regular evaluation and monitoring**, including in relation to implementation, enforcement and follow-up" (para 55 (n))

[&]quot;equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period, and that the perpetrators and those who aid or condone such practices are held accountable" (para 55 (0))

[&]quot;equal access to legal remedies and appropriate reparations in practice" (para 55 (q)).

For a more extensive version with sources, see 2016 CRC UK Thematic NGO Report, p. 57, https://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

⁷⁹ CRC/C/ZAF/CO/2, 27 October 2016 paras 39–40

⁸⁰ CRC/C/CHE/CO/2-4, 26 February 2015, para 43

⁸¹ CRC/C/DNK/CO5, 26 October 2017, para 24

3. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation (CRC art. 24(3) and JGC No. 18)

Article 24 para. 3 of the Convention in conjunction with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 "on harmful practices" clearly stipulate the right of victims of IGM practices to "equal access to legal remedies and appropriate reparations" (JGC 18/31, 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" (JGC 18/31, para 55 (o)).

However, also in **Chile** 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 to act in time even once they do. ⁸² So far there was no case of a victim of IGM practices succeeding in going to an Chilean court.

⁸² Globally, no survivor of early surgeries **ever** managed to have their case successfully heard in court. All relevant court cases resulting in damages or settlement (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

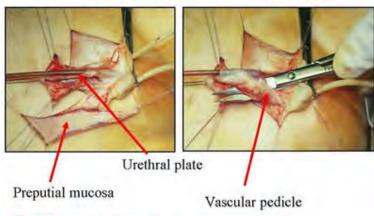
Annexe 2 - "IGM in Medical Textbooks: Current Practice"

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
- Suprapublic diversion ?
 Elbakry















infection



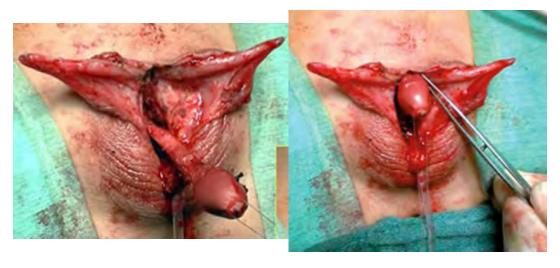
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: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

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

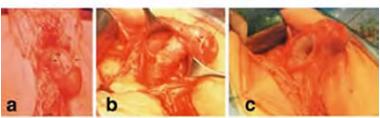
IGM 2 - "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

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").

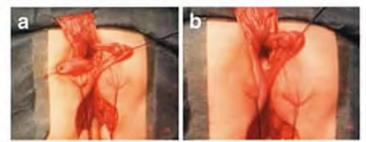
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "in the first 2 years of life", most commonly "between 6 and 12 months," and only 10.5% of surgeons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



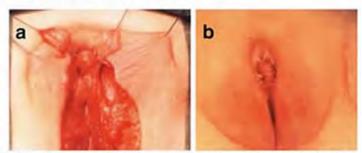
Source: Christian Radmayr: Molekulare Grundlagen und Diagnostik des Intersex, 2004



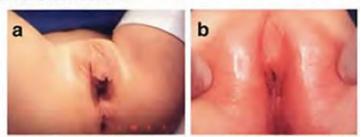
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



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).



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.),

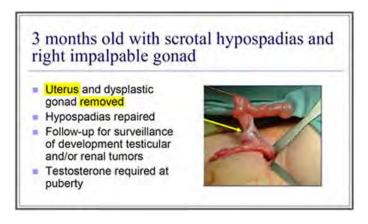
Pediatric Surgery: Diagnosis and Management, Berlin Heidelberg 2009.

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	?

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

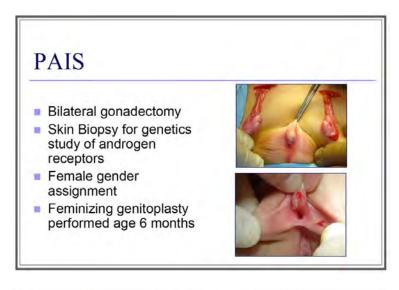
of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

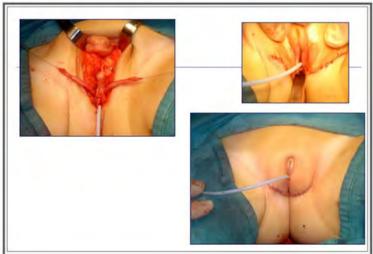
"Bad results" / "Gonadectomy, Feminising Genitoplasty"



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.