

Intersex Genital Mutilations Human Rights Violations Of Persons With Variations Of Sex Anatomy



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NGO Report
to the 6th Report of Chile
on the Convention against Torture (CAT)

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June 2018

This NGO Report online:

<http://intersex.shadowreport.org/public/2018-CAT-Chile-NGO-Intersex-Brujula-StopIGM.pdf>



Executive Summary

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).

Chile is in breach of its obligations under CAT to (a) take effective legislative, administrative, judicial or other measures to **prevent involuntary, non-urgent surgery and other medical treatment on intersex persons** without the effective, informed consent of those concerned, causing severe mental and physical pain and suffering, and (b) **to ensure impartial investigation, access to redress, and the right to fair and adequate compensation and rehabilitation for victims** (arts. 2, 12, 14 and 16, General Comments 2 and 3).

This Committee has repeatedly recognised IGM practices to constitute ill-treatment, and called for legislation to (a) end the practice, (b) ensure redress and compensation, and (c) to provide access to free counselling (CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; 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; CAT/C/FRA/CO/7, paras 32-33).

In addition, **CRC** and **CEDAW** have already **considered IGM in Chile as a harmful practice** (CRC/C/CHL/CO/4-5, paras 48–49; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d)), and **CRPD** as a **violation of the integrity** (CRPD/C/CHL/CO/1, paras 41–42). Also **CCPR, SR Torture, SR Health, UNHCHR, the Council of Europe (COE), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples' Rights (ACHPR) and the World Health Organisation (WHO)** recognise IGM practices as a serious human rights violation, calling for **legislative remedy and access to redress and justice**.

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 treatments that would not be considered for “normal” children, without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs. **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** was compiled by the intersex NGOs **Brújula Intersexual Chile, Brújula Intersexual** and **StopIGM.org**. It contains **Suggested Recommendations (p. 19)**.

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Table of Contents

IGM Practices in Chile (p. 10–19)

Executive Summary	3
Introduction	5
Intersex, IGM and Human Rights in Chile and State Report.....	5
About the Rapporteurs	5
Methodology	6
A. Background: Intersex, IGM and Harmful Misrepresentations.....	7
1. IGM Practices: Involuntary, unnecessary medical interventions.....	7
2. Intersex is NOT THE SAME as LGBT or SOGI.....	8
3. Misrepresenting Genital Mutilation as “Health Care”	9
B. IGM in Chile: State-sponsored and pervasive, Gov fails to act	10
1. Overview: Lack of Protection for Intersex Persons, Violations state-sponsored	10
2. IGM practices in Chile: Pervasive and unchallenged (art. 2, 12, 14, 16; GC 2, 3)	12
a) IGM 3 – Sterilising Procedures: Castration / “Gonadectomy” / Hysterectomy / Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation	12
b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labioplasty”, Dilation	12
c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”	13
d) IGM 4 – Other Unnecessary and Harmful Medical Procedures.....	14
3. The treatment of intersex persons in Chile as Torture	15
a) Infliction of severe pain or suffering	15
b) Intention.....	15
c) Purpose of Discrimination	15
d) Involvement of a State Official.....	15
e) Lawful Sanction	15
4. Treatment of Intersex People in Chile as ill-treatment.....	15
5. Lack of Impartial Investigation, Independent Data Collection and Monitoring.....	15
6. Lack of Legislative Provisions, Impunity of perpetrators.....	16
7. Obstacles to redress, fair and adequate compensation.....	16
8. Chilean Doctors and Officials consciously dismissing Intersex Human Rights.....	17
C. Conclusion: Chile is Failing its Obligations.....	18
D. Suggested Recommendations	19
E. Annexe – “Case Study”	20

Introduction

Intersex, IGM and Human Rights in Chile 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 bodies¹ including CAT** as constituting **torture or ill-treatment**, a harmful practice and violence, however **weren't mentioned** in the 6th Chilean State Report.

This NGO Report demonstrates that the current **harmful medical practice on intersex persons in Chile** – advocated, facilitated and paid for by the State party via the public health care system including the Fondo Nacional de Salud (FONASA), and already considered in Concluding Observations by **CRC** and **CEDAW** as a harmful practice and by **CRPD** as a violation of the integrity of the person² – constitutes **at least ill-treatment** and a **serious breach** of Chile's obligations under the Convention.

About the Rapporteurs

This **thematic NGO report** has been prepared by the Chilean intersex NGO *Brújula Intersexual Chile* and the Mexican-based international intersex NGO *Brújula Intersexual* in collaboration with the international intersex NGO *StopIGM.org / Zwischengeschlecht.org*:

- **Brújula Intersexual Chile** (English translation: Intersex Compass Chile) is a Chilean-based NGO led by Ale/Gabriel Is, founded in 2016. Its main objectives are to inform, disseminate and make visible everything related to intersex in Chilean society.
- **Brújula Intersexual** (English translation: Intersex Compass) is a Mexican-based NGO founded by Laura Inter in 2013. Its main objectives are to inform, disseminate and make visible everything related to intersex, mainly for Spanish-speaking people. We give priority to the opinion of intersex people over medical opinion. It is also a space that offers help and guidance to Spanish-speaking intersex people and their families, from countries such as Mexico, Argentina, Spain, Chile, Colombia, among others.³
- **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!*"⁴ According to its charter,⁵ StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to UN treaty bodies on IGM practices.⁶

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 CRC/C/CHL/CO/4-5, paras 48–49; CRPD/C/CHL/CO/1, paras 41–42; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d)

3 <https://brujulaintersexual.org/>

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

5 <http://zwischengeschlecht.org/post/Statuten>

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

In addition, the Rapporteurs would like to **acknowledge** the work of **Camilo Godoy**.^{7 8 9 10}

Methodology

This thematic NGO report is a localised and updated **addition to the extensive 2016 thematic CAT NGO Report for France**¹¹ by partly the same rapporteurs, which also contains the additional **thematic supplements** “*What is Intersex?*” (p. 32–37), “*What are Intersex Genital Mutilations?*” (p. 38–47), “*IGM as a Breach of the Convention against Torture*” (p. 48–57) and “*IGM in Medical Textbooks: History + Current Practice*” (p. 59–69).

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

8 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), http://www.derechoshumanos.udp.cl/derechoshumanos/images/InformeAnual/2016/Godoy_ddhhpersonasintersex.pdf

9 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>

10 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

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

A. Background: Intersex, IGM and Harmful Misrepresentations

1. IGM Practices: Involuntary, unnecessary medical interventions

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,¹² 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.¹³

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.¹⁴

IGM practices are known to cause **lifelong severe physical and mental pain and suffering**,¹⁵ including loss or impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, incontinence, problems with passing urine (e.g. due to urethral stenosis after surgery), increased sexual anxieties, problems with desire, less sexual activity, dissatisfaction with functional and aesthetic results, lifelong trauma and mental suffering, elevated rates of self-harming behaviour and suicidal tendencies comparable to those among women who have experienced physical or (child) sexual abuse, impairment or loss of reproductive capabilities, lifelong dependency on daily doses of artificial hormones.

This Committee has repeatedly recognised IGM practices to constitute a harmful medical practice and ill-treatment under the Convention during previous Sessions (CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; 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; CAT/C/FRA/CO/7, paras 32-33), same as many more human rights bodies and experts.¹⁶

To this day, UN treaty bodies issued **32 Concluding Observations on IGM practices**, considering them as **inhuman treatment** (CAT art. 2, 12, 14 and 16), **genital mutilation** and a

12 See “What is Intersex?”, 2016 CAT NGO Report France, p. 32-37.

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

13 For references, see “What are Intersex Genital Mutilations (IGM)?”, 2016 CAT NGO Report France, p. 38-39.

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

14 See “Most Frequent Surgical and Other Harmful Medical Interventions”, 2016 CAT NGO Report France, p. 39-42. <http://intersex.shadowreport.org/public/2016-CAT-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

15 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, 2016 CAT France NGO Report, p. 38–47, <http://intersex.shadowreport.org/public/2016-CAT-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

16 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>

For a regularly updated list of all **Treaty body Concluding Observations condemning IGM as a serious violation of non-derogable human rights**, see

<http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

harmful practice (CRC art. 24 para 3 and CEDAW art. 5 (a) in conjunction with the CEDAW-CRC Joint General Recommendation/Comment No. 31/18 “on harmful practices”), **inhuman treatment and involuntary medical or scientific experimentation** (CCPR art. 3, 7, 24 and 26) and a **violation of physical and mental integrity** (CRPD art. 17).¹⁷

2. Intersex is NOT THE SAME as LGBT or SOGI

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

The underlying reasons for such harmful misconceptions include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**^{18 19} 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,²⁰ maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT or SOGI community, and thus need to be **adequately addressed in a separate section as specific intersex issues.**

Also **human rights experts** are increasingly warning of the **harmful conflation** of intersex and LGBT.²¹

Regrettably, **these harmful misrepresentations seem to be on the rise also at the UN**, for example in recent **UN press releases** and **Summary records** misrepresenting IGM as “*sex alignment surgeries*” (i.e. voluntary procedures on transsexual or transgender persons), IGM survivors as “*transsexual children*”, and intersex NGOs as “*a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination*”,²² and again IGM survivors as “*transgender children*”,²³ “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”²⁴ and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.²⁵

Particularly **State parties** are constantly **misrepresenting intersex and IGM as sexual**

17 For a regularly updated list of all **Treaty body Concluding Observations condemning IGM as a serious violation of non-derogable human rights**, see

<http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

18 CRC67 Denmark, <http://stop.genitalmutilation.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark>

19 CEDAW66 Ukraine, <http://stop.genitalmutilation.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics>

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

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

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

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

23 CRC77 Spain, <http://stop.genitalmutilation.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children>

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

25 CAT/C/DNK/QPR/8, para 32

orientation or gender identity issues in an attempt to **deflect from criticism** of the serious human rights violations resulting from IGM practices, instead referring to e.g. “*gender reassignment surgery*” (i.e. voluntary procedures on transsexual or transgender persons) and “*gender assignment surgery for children*”,²⁶ “*a special provision on sexual orientation and gender identity*”, “*civil registry*” and “*sexual reassignment surgery*”²⁷, transgender guidelines²⁸ or “*Gender Identity*”^{29 30} when asked about IGM by e.g. Treaty bodies.

What’s more, **LGBT organisations** (including “LGBTI” organisations without actual intersex representation or advocacy) are using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus depriving actual intersex organisations (which mostly have no significant funding, if any) of much needed resources.³¹

3. Misrepresenting Genital Mutilation as “Health Care”

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as “health-care issue”** instead of a serious human rights violation, and the **promotion of “self-regulation” of IGM by the current perpetrators**^{32 33 34} – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health ministries** construe UN Treaty body Concluding observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse for “self-regulation” promoting state-sponsored IGM practices to continue with impunity.**³⁵

26 CRC73 New Zealand, <http://stop.genitalmutilation.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child>

27 CCPR120 Switzerland, <http://stop.genitalmutilation.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120>

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

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

30 CRPD18 UK, <http://stop.genitalmutilation.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

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

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

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

33 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8,

http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

34 For example CEDAW Italy (2017), see <http://stop.genitalmutilation.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN>

35 See for example Ministry of Health Chile (2016), <http://stop.genitalmutilation.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile>

B. IGM in Chile: State-sponsored and pervasive, Gov fails to act

1. Overview: Lack of Protection for Intersex Persons, Violations state-sponsored

In **Chile** (see CRC/C/CHL/CO/4-5, paras 48–49; CRPD/C/CHL/CO/1, paras 41–42; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d)), same as in *Germany* (see CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24), *Switzerland* (see CAT/C/CHE/CO/7, para 20; CRC/C/CHE/CO/2-4, paras 42-43; CEDAW/C/CHE/CO/4-5, paras 38-39), *France* (see CAT/C/FRA/CO/7, paras 32–33; CRC/C/FRA/CO/5, paras 47-48; CEDAW/C/FRA/CO/7-8, paras 17e-f + 18e-f), *Hong Kong* (see CAT/C/CHN-HKG/CO/4-5, paras 28-29), *Denmark* (see CAT/C/DNK/CO/6-7, paras 42-43; CRC/C/DNK/CO/5, para 24), and in many more State parties,³⁶ there are

- **no effective legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM 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

The current situation in Chile can be summarised as follows:

- After the UN Committee on the Rights of the Child (CRC) criticised Chile for “*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 its October 2015 Concluding Observations, referring to CRC art. 24(3) and the CEDAW-CRC Joint General Recommendation/Comment No. 31/18 “on harmful practices” (see CRC/C/CHL/CO/4-5, paras 48–49), in December 2015 the **Chilean Ministry of Health** issued the “**Circular No. 18**”, which inter alia referred to the CRC Concluding Observations, and 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.*”³⁷

Unfortunately, as evidenced by the post-2015 sources for IGM 1-3 below, **nothing changed in the Chilean practice** after the publication of “Circular No. 18”.

What’s worse, after **massive pressure by Chilean IGM doctors and some parents**³⁸

36 See <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

37 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 http://stop.genitalmutilation.org/public/Chile_Circular-No-18_22-12-2015_Instruye-Ninos-y-Ninas-Intersex_OCR_web.pdf

38 “*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*

determined to continue with involuntary, non-urgent surgeries and other treatments on intersex children, in August 2016 the Ministry of Health in fact replaced “Circular No. 18” by a **newer “Circular No. 7”**,³⁹ 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 children**⁴⁰ (see also below under evidence for IGM 1-3).

- While some official agencies, such as the National Human Rights Institute (*Instituto Nacional de Derechos Humanos, INDH*)⁴¹ and the Centre for Human Rights of the Faculty of Law of the University of Diego Portales (*Centro de Derechos Humanos UDP*)⁴² have expressed their interest in protecting intersex people’s human rights and criticises the (re-instated) ongoing practice in Chile, **most relevant institutions remain indifferent or even support IGM.**
- While a segment of the Chilean **Ministry of Health** has shown interest in reviewing medical protocols constituting serious human rights violations of intersex people, for example by issuing the 2015 “Circular No. 18” aimed at stopping involuntary non-urgent procedures, the Ministry quickly caved in under pressure from IGM doctors and parents by **re-prescribing the full range of IGM practices** via the newer “**Circular No 7**” and thus abandoning its earlier human rights-based approach (see above).
- Intersex people in Chile, particularly IGM survivors, generally find it **impossible to get access to justice, rehabilitation and reparations.**
- Intersex people in Chile face **difficulties in accessing their medical records**, and accurate **information about procedures** performed on them during infancy and childhood.
- **Intersex advocacy in the country has been active since 2014**, starting with the work of Camilo Godoy and then, since 2016, with the foundation of *Brújula Intersexual Chile*. It has played a key role in supporting survivors and their families, as well as getting support from official institutions on specific cases. **Camilo Godoy** has been working between 2014 and 2017 as a human rights advisor on intersex issues for Chilean government bodies

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

39 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>

40 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>

41 Instituto Nacional de Derechos Humanos (INDH), Informe Anual Situación de los Derechos Humanos en Chile 2017, on intersex: p. 68, 71-74, https://www.indh.cl/bb/wp-content/uploads/2017/12/01_Informe-Anual-2017.pdf

42 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), http://www.derechoshumanos.udp.cl/derechoshumanos/images/InformeAnual/2016/Godoy_ddhhpersonasintersex.pdf

including the Ministry of Health and the National Council of Childhood,⁴³ and reported to UN Treaty bodies. **Ale/Gabriel Is**, coordinator of Brújula Intersexual Chile, participated in the 2017 hearing on the “Human Rights Situation of Intersex People in the Americas” before the Inter-American Commission on Human Rights (IACHR).⁴⁴ However, to **no effect regarding the ongoing practice.**

To this day, the Chilean government fails to recognise the serious human rights violations and severe suffering caused by IGM practices, let alone to “take effective legislative, administrative, judicial or other measures” to protect intersex children from genital mutilation and other harmful practices and cruel, degrading or inhuman treatment, in spite of longstanding public criticism and appeals by intersex persons and their organisations, experts and Chile’s own National Human Rights Institute (*Instituto Nacional de Derechos Humanos, INDH*) and the Centre for Human Rights of the Faculty of Law of the University of Diego Portales (*Centro de Derechos Humanos UDP*), as well as some segments of the Ministry of Health.

2. IGM practices in Chile: Pervasive and unchallenged (art. 2, 12, 14, 16; GC 2, 3)

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
and Arbitrary Imposition of Hormones⁴⁵**

The current intersex guideline issued by the Chilean Ministry of Health, “*Circular No. 7*”, 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:⁴⁶

“surgeries in these patients, such as gonadectomy and/or genital surgery, should be done by mutual agreement between parents and the multidisciplinary team;”

b) IGM 2 – “Feminising Procedures”:

Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labioplasty”, Dilation⁴⁷

The Pontifical Catholic University of Chile (“*Pontificia Universidad Católica de Chile*”) openly advocates non-urgent “surgery” to “correct ambiguous genitalia in girls” without the consent of the person concerned, describing the possibility “to postpone surgery until the child is old enough to participate in the decision” as a mere (secondary) option for “parents”.⁴⁸

43 <http://www.consejoinfancia.gob.cl/2015/11/04/consejo-se-capacita-en-el-ejercicio-de-derechos-de-ninos-ninas-y-adolescentes-intersexuales/>

44 Hearing “Human Rights Situation of Intersex People in the Americas”, 161 session, March 20th, 2017, <https://brujulaintersexual.org/2017/03/23/cidh-audiencia-situacion-intersex-americas-2017/>

45 For general information, see 2016 CAT NGO Report France, p. 39-40.

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

46 Ministry of Health (23.08.2016), Circular No. 7, p. 2,

<https://brujulaintersexual.files.wordpress.com/2017/07/circular-7-chile-ministry-of-health.pdf>

Original Spanish version: <https://brujulaintersexual.files.wordpress.com/2017/06/circular-7.pdf>

47 For general information, see 2016 CAT NGO Report France, p. 40-41.

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

48 “Surgery can correct ambiguous genitalia in girls. However, parents may choose to postpone surgery until the child is old enough to participate in the decision.”, see

<http://redsalud.uc.cl/ucchristus/VidaSaludable/Glosario/H/hiperplasia-suprarrenal-congenita.act>

Also the **current intersex guideline issued by the Chilean Ministry of Health, “Circular No. 7”**, explicitly advocates non-urgent “feminising” surgery on children diagnosed with CAH justified by psycho-social indications but without the consent of the person concerned:⁴⁹

“In cases of people with 46XX DSD with classical congenital adrenal hyperplasia, surgeries such as clitoroplasty, uro-genital sinus surgery, and genitoplasty, should be agreed between the specialist multidisciplinary team and the family;”

Again, the “*possibility [...] of deferring surgery*” is described as a mere (secondary) option for parents and doctors.⁵⁰

Accordingly, a 2009 study by doctors from the Department of Paediatric Urology of the **Hospital Exequiel Gonzalez Cortés - Clínica Alemana (Santiago)** reports for this clinic alone “25 patients” who “*underwent genitoplasty*” between 1996 and 2006, concluding, “In our practice, we prefer to carry out clitoroplasty at an early age, if possible before 6 months”.⁵¹

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”⁵²

The **current intersex guideline issued by the Chilean Ministry of Health, “Circular No. 7”**, explicitly allows “*unnecessary genital surgery*” for most cases of hypospadias.⁵³

Accordingly, the **Pontifical Catholic University of Chile** (“*Pontificia Universidad Católica de Chile*”) openly advocates non-urgent “*hypospadias repair surgery*” on babies.⁵⁴

“Babies with hypospadias shouldn’t be circumcised and the foreskin should be preserved for later surgical repair.

Surgery is usually done before the child begins his school life. Currently, most urologists recommend repair before the child turns 18 months old. The surgery can be done at four months. During surgery, the penis is straightened and hypospadias is corrected, using tissue grafts from the foreskin. The repair may require multiple surgeries.”

49 Ministry of Health (23.08.2016), Circular No. 7, p. 1,

<https://brujulaintersexual.files.wordpress.com/2017/07/circular-7-chile-ministry-of-health.pdf>

Original Spanish version: <https://brujulaintersexual.files.wordpress.com/2017/06/circular-7.pdf>

50 “*The possibility should be explained of deferring surgery to an age where the patient may manifest or demonstrate tendencies of a sexual identity.*”, *ibid.* Note that the Ministry of Health here not even mentions to postpone surgery until the person concerned can participate in any decision, ut merely long enough for parents and clinicians to take a guess at the child’s “*tendencies of a sexual identity*”.

51 Jose Manuel Escala, Yair Cadena, Pedro-Jose Lopez, Lorena Angel, Maria G. Retamal, Nelly Letelier, Ricardo Zubieta (2009), Feminizing genitoplasty in adrenal congenital hiperplasia: one or two surgical steps? Paediatric Urology Arch. Esp. Urol.; 62 (9): 724-730,

<https://pdfs.semanticscholar.org/3041/d227575e5199da85de42485cafb7842ea7f.pdf>

52 For general information, see 2016 CAT NGO Report France, p. 41.

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

53 “*The recommendation that refers to not performing unnecessary genital surgery, does not refer to pathologies in which there is a clearly defined sex, both genetically and/or somatically, such as: cryptorchidism, isolated hypospadias, cloacal malformations and exstrophies.*”, Ministry of Health (23.08.2016), Circular No. 7, p. 1,

<https://brujulaintersexual.files.wordpress.com/2017/07/circular-7-chile-ministry-of-health.pdf>

Original Spanish version: <https://brujulaintersexual.files.wordpress.com/2017/06/circular-7.pdf>

54 “*Surgery can correct ambiguous genitalia in girls. However, parents may choose to postpone surgery until the child is old enough to participate in the decision.*”, see

<http://redsalud.uc.cl/ucchristus/VidaSaludable/Glosario/H/hiperplasia-suprarrenal-congenita.act>

The 2016 “*X Curso Internacional de Urología Pediátrica*” organised by the **Hospital Exequiel Gonzalez Cortés (Santiago)** and held at the **Clínica Universidad de los Andes (Las Condes)** featured “*Live surgeries*”.⁵⁵

And a 2015 study by doctors from the **Hospital Exequiel Gonzalez Cortés - Clínica Alemana (Santiago)** reports for this clinic alone: “*340 patients underwent corrective surgery for hypospadias between 1990 and 2013.*”⁵⁶

d) IGM 4 – Other Unnecessary and Harmful Medical Procedures⁵⁷

- **Prenatal treatment:** The use of fetal dexamethasone to prevent “ambiguous genitalia” in “girls with Congenital Adrenal Hyperplasia (CAH)” is **practised in Chile since at least 2001**,⁵⁸ sometimes (but not always) openly admitting that “*This treatment is still experimental and must be carried out with consent*”,⁵⁹ and often **in association with involuntary “feminising” genital surgery**:⁶⁰

“This disease [CAH], in its classical form, produces different degrees of virilization of the female fetus, leading to the need to perform subsequent correction surgeries, and secondarily consequences in the psychological sphere and sexual function of these patients. Prenatal treatment with dexamethasone manages to prevent or reduce the degree of virilization of affected girls, reducing the need for surgical treatment and its consequences.”

- Unnecessary, repeated genital exams and photography abusing intersex children as a “freak show” are frequent in Chile. **Case No. 1** clearly shows the devastating impact of repeated genital exams on an intersex child and the extreme negative consequences for his health and wellbeing.

Forced excessive genital exams, medical display and (genital) photography because of intersex traits in itself constitute a form of IGM and a harmful practice.⁶¹

55 <https://www.clinicauandes.cl/shortcuts/novedades/x-curso-internacional-urologia-pediatria-workshop-hipospadias>

56 Dr. Ricardo Zubieta, Dr. Alejandra Lopez, Dr. Nelly Letelier, Dr. Francisco Reed, Dr. Danielle Reyes, Dr. Pedro José Lopez (2013), P29) Es el viejo mathieu modificado una alternativa para las hipospadias distales ?, Revista Chilena de Urología | Volumen 78 | No 3, p. 72, https://www.revistachilenadeurologia.cl/urologia/wp-content/uploads/2013/11/PO_III_SESION_DE_POSTER_III.pdf

57 For general information, see 2014 CRC Switzerland NGO Report, p. 70-76,

http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

58 Carlos Fardella B. (2001), Hiperplasia suprarrenal congénita, Revista chilena de pediatría, v.72 n.5 Santiago, https://scielo.conicyt.cl/scielo.php?script=sci_arttext&pid=S0370-41062001000500003

59 PM. Merino, E. Codner (2010), Hiperplasia suprarrenal congénita no-clásica: avances en la detección, diagnóstico, conducta y tratamiento, Revista Chilena de Endocrinología y Diabetes, http://www.revistasoched.cl/1_2010/8.html

60 Paulina Merino, Tania Bacheaga, Pablo Céspedes, León Trejo, Ana Elisa Billerbeck, Ethel Codner (2007), Utilidad del estudio molecular de CYP21A2 en el manejo prenatal de hiperplasia suprarrenal congénita: detección de dos nuevas mutaciones en Chile, Rev Méd Chile; 135, p. 1451, http://repositorio.uchile.cl/bitstream/handle/2250/128911/Merino_Paulina_Captura.pdf?sequence=1&isAllowed=y

61 See 2014 CRC NGO Report, p. 73, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

3. The treatment of intersex persons in Chile as Torture

a) Infliction of severe pain or suffering

It is well established that IGM practices generally inflicts lifelong, severe pain and suffering, both physical and mental.

b) Intention

It is generally established that surgery on intersex persons is always intentionally performed and not merely the result of negligence, and that it does not detract of the intention if doctors perform surgery for well-meant purposes. The integral **use of cruelty as a mean to obtain formal consent from parents or from intersex persons themselves** for surgeries and other procedures, including repeated unnecessary genital examinations, and vaginal dilations, is undoubtedly intentional.

c) Purpose of Discrimination

It is generally established that on the basis of their sex characteristics intersex **children are subjected to various procedures that would be considered inhumane when performed on children who are not intersex**. Even when perpetrators have benign intentions, medical abuses produce and justify a situation of structural discrimination, stigma and violence against intersex people in Chile.

d) Involvement of a State Official

Most medical institutions involved in treating intersex people in Chile are **public University and children's hospitals**, and the involuntary treatments are advocated and paid for by the **public health care system** via the **Fondo Nacional de Salud (FONASA)** and advocated by the **Ministry of Health**.

Despite already having been urged three times to prevent the ongoing practice and to protect intersex children in Concluding Observations by **CRC, CRPD and CEDAW**,⁶² **the State party keeps failing in exercising due diligence** to protect intersex people from torture and ill treatment.

e) Lawful Sanction

Non-consensual unnecessary surgery performed on an intersex child or adult does not constitute a sanction in Chile.

4. Treatment of Intersex People in Chile as ill-treatment

Even if it would be considered that the treatment of intersex people in Chile does not constitute torture, it certainly constitutes cruel, inhuman and degrading treatment (Article 16). Ill-treatment is equally prohibited by the Convention in absolute and non-derogable terms. According to the Committee's General Comment No. 3, also for CIDT also Article 14 applies.

5. Lack of Impartial Investigation, Independent Data Collection and Monitoring

Also in **Chile**, there are **no statistics on intersex births and on IGM practices available**, let alone **impartial investigation** of cases.

62 CRC/C/CHL/CO/4-5, paras 48–49; CRPD/C/CHL/CO/1, paras 41–42; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d)

With no statistics available on intersex births, treatments 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".

6. Lack of Legislative Provisions, Impunity of perpetrators

Art. 2 of the Convention obliges State parties to *"take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction."* General Comment No. 2 states, *"The obligation to prevent ill-treatment in practice overlaps with and is largely congruent with the obligation to prevent torture,"* and similarly obliges State parties to *"to eliminate any legal or other obstacles that impede the eradication of torture and ill-treatment; and to take positive effective measures to ensure that such conduct and any recurrences thereof are effectively prevented."*

Accordingly, with regards to IGM practices, this Committee already explicitly recognised the obligation for State parties to *"Take the necessary legislative, administrative and other measures to guarantee respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures"*,⁶³ and Chile has already been urged to act in this matter by **CRC, CRPD and CEDAW**.⁶⁴

However, the Chilean State party still **refuses to "take effective legislative, administrative, judicial or other measures"** to protect intersex children. What's worse, after a first step towards protecting intersex children from unnecessary harmful treatments via the 2015 *"Circular No. 18"*, less than a year later the Chilean Ministry of Health not only **took back these protections**, but actually **re-prescribed the full range of involuntary, non-urgent genital surgery, sterilising procedures and other harmful treatments on intersex children** via the 2016 *"Circular No. 7"* (which replaced *"Circular No. 18"*, see above).

7. Obstacles to redress, fair and adequate compensation

Also in **Chile** the **statutes of limitation** generally 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 once they do.⁶⁵

So far there was no case of an adult victim of early childhood IGM practices succeeding in going to court in Chile. However, there is **one case of a mother of a then 12 years old intersex child** publicly known only by his initials **"B.N.R."**, which had been submitted to gonadectomy (castration) as a two months old baby, **successfully suing the Maule Health Service** in 2005, and

63 CAT/C/CHE/CO/7, para 20; CAT/C/DEU/CO/5, para 20; 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; CAT/C/FRA/CO/7, paras 32-33

64 CRC/C/CHL/CO/4-5, paras 48-49; CRPD/C/CHL/CO/1, paras 41-42; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d)

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

with the **Supreme Court** on 14 November 2012 eventually sentencing the Maule Health Service to pay **100 million Chilean pesos in compensation** for the moral and psychological damage caused to the then 19 years old intersex person concerned, and **5 more millions for each of the parents**, with the court also criticising that the **parents weren't informed properly** by the doctors.⁶⁶

The **Chilean government** so far refuses to ensure that non-consensual unnecessary IGM surgeries on minors are recognised as a form as a form of **torture or ill-treatment**, or as a form of **genital mutilation** or **harmful medical practice** respectively, which would formally prohibit parents from giving “consent”. In addition, hospitals are often **unwilling to provide full access to patient's files**.

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

8. Chilean Doctors and Officials consciously dismissing Intersex Human Rights

The persistence of IGM practices in Chilean public clinics is a **matter of public record**.^{67 68 69 70 71}

Also the **criticism of persons concerned and their organisations** of involuntary surgeries and other medical treatment is **publicly known**,^{72 73 74} and also in **government bodies** including the National Council of Childhood,⁷⁵ the Ministry of Health Working Group on Intersex (2015-2017), and the National Human Rights Institute (*Instituto Nacional de Derechos Humanos, INDH*).⁷⁶

Nonetheless, government bodies refuse to take any appropriate action, but continue to ignore intersex human rights, and allow IGM doctors to continue practicing with impunity.

66 Gabriela García (2013), Forced identity, Paula 1124, 22.06.2013, <http://www.paula.cl/reportajes-y-entrevistas/identidad-forzada/#>

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

68 “Conferencia Regional Latinoamericana y del Caribe de personas Intersex” in San José, March 2018, <https://brujulaintersexual.org/2018/04/13/san-jose-de-costa-rica-statement/>

69 Hearing “Human Rights Situation of Intersex People in the Americas”, 161 session, March 20th, 2017, <https://brujulaintersexual.org/2017/03/23/cidh-audiencia-situacion-intersex-americas-2017/>

70 Gabriela García (2013), Forced identity, Paula 1124, 22.06.2013, <http://www.paula.cl/reportajes-y-entrevistas/identidad-forzada/#>

71 Godoy, Camilo (2015). Análisis del tratamiento de la intersexualidad a la luz del derecho internacional de los derechos humanos y su realidad en Chile. Capítulo 5 (pp. 117-136): "La situación intersex en Chile al año 2015. Realidad y recomendaciones", <http://bibliotecadigital.indh.cl/handle/123456789/1022>

72 <https://brujulaintersexual.org/2016/03/19/articulo-cambiados-de-sexo-al-nacer-revista-ya-de-el-mercurio-chile/>

73 <https://brujulaintersexual.org/2018/03/28/ale-gabriel-entrevista-chile/>

74 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), http://www.derechoshumanos.udp.cl/derechoshumanos/images/InformeAnual/2016/Godoy_ddhhpersonasintersex.pdf

75 <http://www.consejoinfancia.gob.cl/2015/11/04/consejo-se-capacita-en-el-ejercicio-de-derechos-de-ninos-ninas-y-adolescentes-intersexuales/>

76 Instituto Nacional de Derechos Humanos (INDH), Informe Anual Situación de los Derechos Humanos en Chile 2017, on intersex: p. 68, 71-74, https://www.indh.cl/bb/wp-content/uploads/2017/12/01_Informe-Anual-2017.pdf

C. Conclusion: Chile is Failing its Obligations towards Intersex People under the Convention against Torture

The surgeries and other harmful treatments intersex people endure cause severe physical and mental pain and suffering. Doctors perform the surgery for the discriminatory purpose of making a child fit into societal and cultural norms and beliefs, although there is plenty of evidence on the suffering this causes. The State party is responsible for these violations amounting to torture or at least ill-treatment, 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 IGM practices is common knowledge, and the State party has been made aware of the situation and urged to take action 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 unhindered.

Thus Chile is in breach of its obligation to take **effective legislative, administrative, judicial or other measures** to prevent acts of torture (Art. 2 CAT) or other forms of cruel, inhuman or degrading treatment (Art. 16 CAT, General Comment No. 2).

Also in Chile, victims of IGM practices encounter **severe obstacles** in the pursuit of their right to an **impartial investigation** (Arts. 12, 13 CAT), and to **redress** and fair and adequate compensation, including the means for as **full rehabilitation** as possible (Art. 14 CAT, General Comment No. 3).

Also the State party's efforts on **education and information regarding the prohibition against torture in the training of medical personnel** are grossly insufficient with respect to the treatment of intersex people (Art. 10 CAT).

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 (in line with this Committee's previous recommendations to Switzerland, Austria, Denmark and France, and with CRC's, CRPD's and CEDAW's previous recommendation to Chile):

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 that these procedures have not as yet given rise to any inquiry, sanction or reparation (arts. 2, 12, 14 and 16).

The Committee recommends that the State party:

- (a) Take the necessary legislative, administrative and other measures to guarantee the respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected to unnecessary medical or surgical procedures during infancy or childhood, but that all non-urgent medical interventions are postponed until a child is sufficiently mature to participate in decision-making and give full, free and informed consent;**
- (b) Guarantee impartial counselling services and psychosocial support for all intersex children and their parents, so as to inform them of the consequences of non-urgent, unnecessary surgery and other medical treatment and the possibility of postponing any decision on such treatment or surgery until the persons concerned are able to decide for themselves;**
- (c) Undertake investigation of reports of surgical and other medical treatment of intersex people without effective consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation.**

E. Annexe – “Case Study”

The first person narrative has been collected by Brújula Intersexual. The abstract was composed by the Rapporteurs.

Case Study No. 1

*1982 born with ambiguous genitalia, diagnosed with salt-losing Congenital Adrenal Hyperplasia (CAH)
Age 2 months clitoral reduction, Suzaeta*

Age 10 years surgery urogenital sinus correction surgery (separation of urethra and vaginal canal), Dr Luis Francisco Ossandon (currently working as paediatric surgeon at the Hospital Luis Calvo Mackenna)

Age 12 years removal of intestinal tissue for vaginoplasty (lengthen the vaginal canal), Dr Luis Francisco Ossandon

Vaginal dilatations with metal tubes of different sizes, for a few weeks in the hospital 3 times a week without anesthesia, doctor recommend to continue with dilation at home

After a year, the person concerned refused to continue with the dilations.

The person concerned was treated at the Hospital San Juan de Dios, in the district of Quinta Normal, Santiago, Chile

The person concerned tells their story:

I was born in 1978 with ambiguous genitalia. At first, I was assigned male and diagnosed with hypospadias. Later, I suffered severe decompensation and dehydration. My mother told me that the doctors didn't know what was happening. I spent a few weeks in hospital.

After several examinations, doctors discovered that my chromosomes are XX and they reassigned me as a girl. They also diagnosed me with salt wasting congenital adrenal hyperplasia (CAH). I was referred to endocrinology with Dr Vivanco, who began to medicate me to avoid dehydration due to the salt wasting.

My mother was very young, she was only 21 years old, doctors never explained to her exactly what my diagnosis was. She only remembers being told that I was actually a girl, but that I was born with a genital malformation, and that it required me to undergo surgeries to correct it.

At 2 months old, I underwent the first surgery, a clitoral reduction. This procedure was performed by Dr Suzaeta.

A few years passed, and my mother remembers that Dr Vivanco told her that there was a doctor (Dr Luis Francisco Ossandon) who had studied in England and learned some new surgical techniques to perform feminizing genital surgeries.

I remember that when I turned 10 years old, in the hospital they performed a very painful test that had as objective to know where my urethra was (I don't know the name of the procedure). Two nurses held me by the arms so that I wouldn't move, without any type of anesthesia they injected a liquid into my genital area, I felt a very intense pain and cried out in pain. After this exam, the pain continued for several days and intensified each time I urinated.

A few months later, Dr Luis Francisco Ossandon, performed surgery to separate the urethra and vaginal canal. After this surgery, I suffered a total decompensation due to the lack of cortisol and intensified and triggered by the surgery. I remember that I suffered intense pain when urinating, which I didn't experience before surgery. Before the surgery my body was healthy.

I was hospitalised for 1 or 2 weeks, in which Dr Ossandon daily checked my genitals, and sometimes this happened in the presence of several doctors, which made me feel very afraid and ashamed.

I also experienced abuse by the nurses, who got upset because I told them that I was suffering a lot of pain when urinating. They didn't believe me and didn't give me medication to relieve the pain. There were times when I couldn't urinate, and when I told them what was happening, they didn't believe me and left me for hours. Everytime I complained about some discomfort or pain, the nurses got upset, and they shouted at me saying that I was lying and that I was fine.

At 12 years old, I underwent a surgery to remove intestinal tissue which they used to lengthen the vaginal canal. This surgery was also performed by Dr Ossandon.

Doctors never explained to me the reason for the surgeries nor what the surgery consisted of, and I wasn't even allowed to ask questions. I was very afraid of the doctor and to ask questions.

After this surgery I was hospitalised for approximately 2 weeks. I suffered a strong decompensation. I remember that I was full of tubes in the nose, in the urethra. I felt very uncomfortable and was in a lot of pain.

Just 3 days after surgery, I remember that the doctor called me and another girl, put us in a hospital ward, and as usual for us, they asked us to undress and put us on an examination table with legs spread open, and without any anesthesia or explanation, they inserted a metallic tube covered with vaseline in my new vagina created by surgery. It was an extremely traumatising and painful experience. This procedure was repeated three times a week.

During the recovery from the surgery, I was in a hospital ward with other girls who had also undergone the same or similar procedures as I did. The treatment of the nurses towards the children was very inhuman. If we complained of any discomfort or pain, or if we wanted to go to the bathroom or we were hungry or thirsty and we asked for something, the nurses got upset, shouted at us, and told us to shut up.

I remember one day I vomited and the nurses got angry and left me dirty with wet clothes without cleaning me. They threatened to report me to the doctor, as if it was my fault that I had vomited.

Finally, I was discharged. I returned home, but after just 2 days I had to return to the hospital. Again, I had a severe decompensation: I was vomiting and couldn't eat. I went to the hospital to the emergency room. They determined that the decompensation was because I had lost a lot of blood during the surgery, I don't know why I didn't have a transfusion before. So, I had two blood transfusions and I started to feel better. I was again hospitalised for two weeks.

After the hospitalisation, the doctor recommended that I continue the vaginal dilations at home. I had to do them 3 times a week, but they were extremely painful, traumatising and humiliating. Sometimes I stopped doing them for weeks. I stopped doing them at all after 1 year, because I couldn't stand it anymore.

I remember that when I went to the appointments with Dr Ossandon, he scolded me because he realized that I wasn't dilating my vagina, but despite his scolding I didn't do it again.

These surgeries caused me many physical sequels that I still suffer from today: constant vaginal fluid discharge, recurrent vaginal and urinary infections, pain where surgery was performed to

remove intestinal tissue, indigestion, gastritis, ulcerations and irritation in the vaginal area (were the surgery never healed properly), intense genital pain, itching, burning, pain during sexual intercourse, partial loss of genital sensation, scars, among others.

I suffer from severe depression, anxiety attacks, nightmares, anguish, frustration, mood swings, suicidal thoughts.

The Chilean health service never gave me adequate psychological support to be able to go through all the experiences I had in hospitals. I had a psychologist who took care of me in the hospital, but she never explained my situation to me nor my diagnosis, nor the reason for the surgical procedures.

When I was 34 years old, I began to dig into my past. Looking for answers, I discovered that people who are born with bodies like mine are called intersex. I got in touch with other intersex people. At 35 I started to live as a man.

I still suffer from depression, nightmares, anxiety and anguish as a result of the experiences I suffered in hospitals, but I have been in contact with psychologists. Unfortunately, I have to pay for this psychological therapy. And many times, I don't have enough money to pay for the therapy, due to the fact that I have a delicate health condition, so I haven't been able to find a stable job, because I constantly get sick and I can't go to work.

I share my story so that other intersex children who are born with ambiguous genitalia, don't have to experience these terrible genital surgeries. My greatest wish is that they would have left my body intact. Intersex people were happy with the bodies they were born with, we didn't need to be mutilated.