

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

justicia intersex



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

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April 2018

This NGO Report online:

http://intersex.shadowreport.org/public/2018-CRC-Argentina-Intersex-Justicia-Brujula-StopIGM_v2.pdf



Executive Summary

All typical forms of IGM practices are still practised in Argentina today, facilitated and paid for by the State party via the Universal Health Care System under the oversight of the Argentinian Ministry of Health. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and denied appropriate support.

Argentina is 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”.

This Committee has consistently recognised IGM practices to constitute a harmful practice under the Convention in Concluding Observations.

Also **CAT, CEDAW, CRPD, the HRCttee, the UN Special Rapporteur on Torture (SRT), the UN High Commissioner for Human Rights (UNHCHR), the World Health Organisation (WHO), the Inter-American Commission on Human Rights (IACHR), the African Commission on Human and Peoples’ Rights (ACHPR), the Council of Europe (COE)** and others have **consistently recognised** IGM as a breach of international law and have called for **legislation** to **(a)** end the practice, **(b)** ensure redress and compensation, and **(c)** to provide access to free counselling.

Intersex people are born with **Variations of Sex Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. While intersex people may face several problems, in the “developed world” the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations.

IGM practices include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures based on prejudice** that would not be considered for “normal” children, without evidence of benefit for the children concerned. **Typical forms** of IGM include “masculinising” and “feminising”, “corrective” genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, human experimentation and denial of needed health care.

IGM Practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, less sexual activity, dissatisfaction with functional and aesthetic results.

For 25 years, intersex people have publicly denounced IGM as **harmful** and **traumatising**, as a form of **genital mutilation** and **child sexual abuse**, as **torture or ill-treatment**, and called for legislation to prevent it and to ensure remedies.

This **Thematic NGO Report** has been compiled by the intersex NGOs **Justicia Intersex, Brújula Intersexual, Brújula Intersexual Argentina** and **StopIGM.org**.

It contains **Suggested Recommendations (p. 19)** and an Appendix with **6 Case Studies**.

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Introduction

1. Intersex, IGM Practices and Human Rights in Argentina

Argentina will be considered for its combined 5th and 6th periodic review by CRC. Unfortunately, so far **intersex children were not mentioned**, neither in the **State Report**, nor in the **List of Issues (LOI)**. Therefore we would like to again **urge the Committee to raise intersex and IGM** during the forthcoming Session.

This NGO Report demonstrates how doctors in **Argentinian public university clinics** are regularly performing **IGM practices**, which have been **described by survivors as genital mutilation and torture**. IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been **repeatedly recognised by CRC and other UN treaty bodies as constituting a harmful practice** as well as torture or ill-treatment.

Despite ongoing public criticism of the practice in Argentina by IGM survivors and legal experts, to this day the **State party not only fails to take effective legislative, administrative or other action to prevent the practice**, but in fact **directly finances it** via the Argentinian Universal Health Care System under the oversight of the Argentinian Ministry of Health, and via funding the public hospitals that practice IGM, including via the national research agency Consejo Nacional de la Carrera de Investigador (CONICET), thus **violating its duty to prevent harmful practices** (Art. 24(3) in conjunction with the CRC/CEDAW Joint general comment 18/31).

2. About the Rapporteurs

This thematic NGO report has been prepared by the intersex NGOs *Justicia Intersex*, *Brújula Intersexual*, *Brújula Intersexual Argentina* and *StopIGM.org*.

- **Justicia Intersex**, founded in 2013, is a national human rights NGO based in Argentina. It is led by intersex persons and works to prevent and denounce human rights violations against intersex people in the country and to promote their access to key human rights, including the rights to bodily integrity, to autonomy, to truth and to adequate reparations. Justicia Intersex has also worked at the regional and international human rights systems to report on intersex issues (including IAHRC, OHCHR and the Mandates of the Special Rapporteur on Torture and Health), as well as with the World Health Organization.^{1 2 3 4 5}
- **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, among others.⁶

1 <http://justiciaintersex.blogspot.com/>

2 <http://intersex.shadowreport.org/public/2017-CAT-Justicia-Intersex-Zwischengeschlecht-IGM.pdf>

3 <https://web.archive.org/web/20130719062125/http://ilga.org/ilga/en/article/61>

4 <https://intersexday.org/en/mauro-cabral-marks-bodies/>

5 <https://globaltransaction.files.wordpress.com/2015/10/intersex-issues-in-the-icd.pdf>

6 <https://brujulaintersexual.org/>

- **Brújula Intersexual Argentina** is a local affiliate organisation co-founded by Gaby González Ch and Laura Inter in 2017.⁷
- **StopIGM.org / Zwischengeschlecht.org**, founded in 2007, is an international Human Rights NGO based in Switzerland. It is led by intersex persons, their partners, families and friends, and works to represent the interests of intersex people and their relatives, raise awareness, and fight IGM practices and other human rights violations perpetrated on intersex people, according to its motto, “*Human Rights for Hermaphrodites, too!*”.⁸ According to its charter,⁹ Zwischengeschlecht.org works to support persons concerned seeking redress and justice. StopIGM.org regularly reports to UN treaty bodies.

3. Methodology

This thematic NGO report is a follow-up to the **2017 CRC PSWG NGO Report for Argentina**¹⁰ by StopIGM.org, and builds on the **2017 CAT NGO Report for Argentina**¹¹ by Justicia Intersex and StopIGM.org.

This Report includes **6 anonymised personal testimonies of IGM survivors and a mother of an intersex child in Argentina** collected by *Brújula Intersexual* for this Report (**Case No. 1**) and by *Justicia Intersex* originally for the 2017 CAT NGO Report (**Cases No. 2-6**), based on written submissions and interviews for this NGO report. They show in an exemplary manner how different forms IGM are practiced in Argentina without informed consent by the persons concerned and/or their parents, and cause **severe physical and mental pain and suffering**.

7 <https://www.facebook.com/brujulaintersexargentina/>

8 <http://Zwischengeschlecht.org/>, English pages: <http://StopIGM.org/>

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

10 <http://intersex.shadowreport.org/public/2017-CRC-PSWG-Argentina-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

11 <http://intersex.shadowreport.org/public/2017-CAT-Justicia-Intersex-Zwischengeschlecht-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, “*simply because their bodies did not fit social norms*”.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.

IGM practices are known to cause **lifelong severe physical and mental pain and suffering**,¹⁴ 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.

Individual doctors, national and international medical bodies, public and private healthcare providers have traditionally been **framing and “treating” intersex variations as a form of illness or disability** in need to be “cured” surgically, often **with racist, eugenic and supremacist undertones**,^{15 16 17 18} describing intersex people as “*inferior*”, “*abnormal*”, “*deformed*”.

12 See “What is Intersex?”, 2015 CRC Ireland NGO Report, p. 23–25, <http://intersex.shadowreport.org/public/2015-CRC-Ireland-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

13 For references, see “What are Intersex Genital Mutilations (IGM)?”, 2015 CRC Ireland Report, p. 29

14 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, 2015 CRC Ireland NGO Report, p. 29–34. See also below **Case Studies No. 1-6**.

15 2014 CRC NGO Report, p. 52, 69, 84, http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

16 In the WHO “World Atlas of Birth Defects (2nd Edition)”, many intersex diagnoses are listed, including “*indeterminate sex*” and “*hypospadias*”, <http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf>

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

18 See “**Intersex, IGM and Prejudice**”, in: 2018 CRPD New Zealand NGO Report, Annexe 1, p. 15-19, <http://intersex.shadowreport.org/public/2018-CRPD-New-Zealand-LOIPR-NGO-Intersex-StopIGM.pdf>
For **500 years of “scientific” prejudice** in a nutshell, see 2016 CEDAW France NGO Report, p. 7, <http://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

UN Treaty bodies and other human rights experts have consistently recognized IGM practices as a serious breach of international law.¹⁹ UN Treaty bodies have issued 31 Concluding Observations condemning IGM practices.²⁰

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**^{21 22} 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,²³ 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.²⁴

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*”,²⁵ and again IGM survivors as “*transgender children*”,²⁶ “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”²⁷.

19 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>

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

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

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

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

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

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

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

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

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

Particularly **State parties** are constantly **misrepresenting intersex and IGM as sexual 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*”,²⁸ “*a special provision on sexual orientation and gender identity*”, “*civil registry*” and “*sexual reassignment surgery*”²⁹, transgender guidelines³⁰ or “*Gender Identity*”^{31 32} 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.³³

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**^{34 35 36} – 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.**³⁷

28 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>

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

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

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

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

33 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>

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

35 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

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

37 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 Argentina: State-sponsored and pervasive, Gov fails to act

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

Allover Argentina, all forms of **IGM practices remain widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded University and Public Children's Clinics, as well as in some private clinics, and **paid for** by the Argentinian Universal Health Care System under the oversight of the **Argentinian Ministry of Health** – as the actors themselves publicly admit, as well as to the psycho-social justification of the surgeries, and to knowledge of the detrimental consequences of IGM for the persons concerned:

It is generally felt that surgery that is carried out for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents[.] The systematic evidence for this belief is lacking. [...] There are concerning reports on these patients about [...] anorgasmia or difficulty with orgasm, avoidance of sexual activity, and low scoring in many aspects of sexual life.

Is no surgery an option? From the surgeon's perspective is hard to "stay quiet" facing a chromosomally female patient with a treatable endocrinological disease with virilized genitalia feasible of changing to "normal looking female genitalia." [...] When counseling parents of these patients we should clearly state that we think rearing kids with sex-congruent looking external genitalia is more reasonable than leaving them untouched until puberty to avoid physiological trauma; but we have no clue if this is right. [...]

It is clear than [having] no surgery will be less damaging to any anatomical structure than the best possible operation performed in a center of excellence. But currently we have no choice other than surgery to correct the altered genitalia, no matter the sex of rearing or the age at the first operation.

– L. A. Piaggio, Professor of Paediatric Surgery and Urology, Universidad Nacional del Sur³⁸

On the side of **protections** as stipulated in **art. 24(3)** and **Joint general comment 18**, however, in **Argentina**, same as in the neighbouring state of *Chile* (see CRC/C/CHL/CO/4-5, paras 48–49; CRPD/C/CHL/CO/1, paras 41–42; CEDAW/C/CHL/CO/7, para 22-23) and in **many more State parties**,³⁹ there are

- **no effective legal or other protections** in place to ensure the rights of intersex children to physical and mental integrity, autonomy and self-determination, and **to prevent IGM**
- **no measures** in place to ensure **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 justice, redress and rehabilitation** for adult IGM survivors

38 Piaggio, L. A., "Congenital Adrena Hyperplasia: Review from a Surgeon's Perspective in the Beginning of the Twenty-First Century", in: *Front Pediatr.* 2013, 1:50. <https://www.ncbi.nlm.nih.gov/pmc/articles/pmc3877834/>

39 Currently we count **31 Concluding observations on IGM practices for 19 State parties in Europe, South America, Asia and Oceania**, see <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

The current situation can be summarised as follows:

- While Argentina has advanced legislation on children's rights,⁴⁰ patient's rights,⁴¹ right to identity⁴² and the prevention of torture,⁴³ **those provisions fail to be applied to intersex persons** in the country, particularly regarding IGM.
- While some official agencies, such as the Buenos Aires City Office of Public Defender for Children (AGT for the acronym in Spanish)⁴⁴ and the National Institute Against Discrimination (INADI)⁴⁵ have expressed their interest in protecting intersex people's human rights, **most relevant institutions remain indifferent or even support IGM.**
- While in some cases doctors are slowly reconsidering their approach to certain procedures, in most cases involuntary, non-urgent procedures continue to be performed.
- While some doctors recognize the need of reviewing current protocols, at the same time they dismiss survivor's experiences and expertise and refuse dialogue.
- Most intersex children are sent from their provinces to a few hospitals located in Buenos Aires city specialised in IGM. Most relevant institutions include **Hospital de Pediatría Garrahan, Hospital de Niños Dr. Ricardo Gutiérrez, Hospital Posadas and Hospital Pedro de Elizalde.** Hospital Garrahan is considered to be the key center of excellence for treating intersex children in Argentina. It also receives patients from other Latin American countries.
- Intersex people in Argentina find it **impossible to get access to justice, rehabilitation and reparations.**
- Intersex people in Argentina face **challenges in accessing their birth certificates,** and they find extremely difficult to have access to their **medical records,** and to accurate **information about procedures** performed during infancy and childhood.
- **Intersex advocacy in the country has been active since 1996.** It has played a key role in supporting survivors and their families, as well as getting support from official institutions on specific cases. Intersex advocates have also participated at meetings with doctors focused on intersex issues in Hospital Garrahan and Hospital Gutiérrez and conducted trainings at the National Ministry of Health, however, to little effect regarding the ongoing practice.

40 Ley de protección integral de los derechos de las niñas, niños y adolescentes. Ley 26.061, <http://servicios.infoleg.gob.ar/infolegInternet/anexos/110000-114999/110778/norma.htm>

41 Ley Derechos del Paciente en su Relación con los Profesionales e Instituciones de la Salud. Ley 26.529, <http://servicios.infoleg.gob.ar/infolegInternet/anexos/160000-164999/160432/norma.htm>

42 Ley de identidad de género. Ley 26.743, <http://servicios.infoleg.gob.ar/infolegInternet/anexos/195000-199999/197860/norma.htm> English translation: <https://globaltransaction.files.wordpress.com/2012/05/argentina-gender-identity-law.pdf>

43 Creación del Sistema Nacional de Prevención de la Tortura y Otros Tratos o Penas Crueles, Inhumanos o Degradantes. Ley 26.827, <http://servicios.infoleg.gob.ar/infolegInternet/anexos/205000-209999/207202/norma.htm>

44 Asesoría General Tutelar. *Aportes para el cumplimiento de los derechos humanos en la temática intersex,* <http://mptutelar.gob.ar/content/dt-n-22-feb-2014-aportes-para-cumplimiento-de-derechos-humanos-en-la-tem-tica-intersex.html>

45 Instituto Nacional contra la Discriminación. *Intersexualidad,* <http://201.216.243.171/biblioteca/wp-content/uploads/2016/03/intersexualidad.pdf>

2. IGM practices in Argentina: Pervasive and unchallenged (art. 24(3), GC 18)

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
and Arbitrary Imposition of Hormones⁴⁶**

Gonadectomies are a common practice in Argentina. They are usually justified by an alleged cancer risk, but they are routinely performed **even in those cases where the actual cancer risk is admittedly not clear**: “*until the issue can be clarified, gonadectomy should be recommended preventively*”.⁴⁷

Even for intersex persons with CAIS, a diagnose with a known low cancer risk, treatment “*must include gonadectomy and hormonal replacement and the creation of a functional vagina [...] in regard to gonadectomy, when it is delayed until adolescence or adulthood puberty occurs spontaneously. If gonadectomy is performed in infancy, puberty must be induced with estrogen replacement*”.⁴⁸

Doctors themselves admit that the actual cancer risk is “*very low*”, and early gonadectomy is also done for an alleged “*psychological benefit for parents*”: “*We program a laparoscopic approach, taking a biopsy and eventually performing gonadectomy and feminising genitoplasty simultaneously in patients assigned female. [...] Our current approach is early gonadectomy. The rationale is: the risk of neoplasia (although very low); the psychological benefit for parents of knowing that any tissue foreign to the sex of rearing has been removed; and avoiding reoperation.*”⁴⁹

b) IGM 2 – “Feminising Procedures”:

Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labioplasty”, Dilation⁵⁰

During the past years there has been a change in some doctors’ attitudes towards feminizing genital surgeries and, in particular, towards clitoridectomies.

Nonetheless, the **National Nomenclator for Pediatric Surgery** itself, published in September 2017, includes the performance of “*clitoridectomy for intersexual status*” (code .31.25).⁵¹

The Guide released by the **Ministry of Health** of the Province of Cordoba in 2012 recommends to perform genital surgery on girls with CAH “*after the first year*” of life.⁵² The website of the

46 For general information, see 2016 CEDAW NGO Report France, p. 47.

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

47 Copelli, Silvia, “Sindrome de Turner: el riesgo de tumores gonadales en pacientes con secuencias del cromosoma Y”. *Revista Argentina de Endocrinología y Metabolismo*, Vol 49, No 1. Diciembre 2012, http://www.scielo.org.ar/scielo.php?script=sci_arttext&pid=S1851-30342012000400005

48 Solana, Maria Laura; Paris, Analia, “Sindrome de insensibilidad completa a los andrógenos. Revista de la Sociedad Argentina de Endocrinología Ginecológica y Reproductiva. Volumen XX, Numero 1, Abril de 2013, <http://www.saegre.org.ar/revista/numeros/2013/n1/Saegre%20N1%20-%202013.pdf>

49 Bailez, M., “Rol de la cirugía en pacientes con anomalías de la diferenciación sexual (DSD). *Medicina Infantil*, Vol XVII, No. 2, Junio 2010, http://www.medicinainfantil.org.ar/images/stories/volumen/2010/xvii_2_210.pdf

50 For general information, see 2016 CEDAW NGO Report France, p. 48.

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

51 Asociación Civil Argentina de Cirugía Pediátrica. *Nomenclador Nacional de Cirugía Pediátrica*, http://www.acacip.org.ar/docs/NOMENCLADOR_CON_VALORES_SEPTIEMBRE_2017.pdf

52 *Guías de atención ambulatorial integral para el seguimiento de recién nacidos de riesgo*. Ministerio de Salud,

National Ministry of Health introduces CAH stating CAH girls' genitals are *“abnormal”*.⁵³

From a group of 42 adolescent patients investigated at Hospital Garrahan, **81% were operated**. Most common surgery performed was **vaginoplasty (57%)**. Only 31% received good information and 48% declared it to be bad.⁵⁴

Despite criticism and “controversy”, doctors continue to operate whenever, as much and as early as possible: *“Age for reconstruction is a controversial issue. Our current preference is that of early reconstruction during the first months of life, whenever it is possible [...] We prefer to perform it simultaneously with the plastic surgery of external genitalia in the first months of life, as long as there are no technical limitations for the procedure.”*⁵⁵

The negative consequences of IGM are wellknown to the perpetrators:

The Garrahan study concluded that 28,6% were depressed. Authors found that *“they are adolescents with less autonomy, major personal dissatisfaction, major anxiety and little adequacy between sex assigned at birth and gender identity”*. They also pointed out that *“25% of the population doesn't manifest sexual desire,”* and since most of them were individuals with CAH, they considered it *“a fact that makes us wonder if it is related with medical procedures (check ups, surgeries, treatments, etc.)”*⁵⁶

RAEM published a paper referring to a case managed at Hospital Gutiérrez, where the patient was subjected to a **clitoridectomy at 2 years old and to a vaginoplasty at 7 years old. She didn't return to the hospital until 16 years later, suffering the severe impact of lack of needed hormonal treatment during those years**. The paper doesn't relate the iatrogenic impact of early surgeries and the patient's abandonment of needed treatment.⁵⁷

Another study from Hospital Gutiérrez documents **16 “vaginoplasties”** performed at Hospital Gutiérrez between 1998 and 2005 on intersex children *“at a median age of 1.4 years (range 0.4-5.3). [...] Clitoroplasty and labioplasty were done simultaneously.”* The paper states that *“according to treating physicians and parents, aesthetic outcomes were highly satisfactory”*, but also says that one of the patients (6.4 years old) suffered **internal scarring and had to be operated** again while another patient (7.5 years old) suffered **urinary incontinence after surgery** and needed to be treated with endoscopic injections.⁵⁸

Gobierno de la Provincia de Cordoba, 2012, https://www.unicef.org/argentina/spanish/Prematuros_web.pdf

53 Ministerio de Salud, “Hiperplasia Suprarrenal Congenita”, <https://www.argentina.gob.ar/salud/glosario/hiperplasiasuprarrenal>

54 Di Martino, Marti; Ongaro, Liliana, “Aspectos psicoemocionales en el desarrollo de la identidad de gener en pacientes adolescentes con DSD, atendidos en el Hospital Garrahan”. Medicina Infantil XX, 2013, http://www.medicinainfantil.org.ar/images/stories/volumen/2013/xx_4_311.pdf

55 Bailez, M., “Rol de la cirugía en pacientes con anomalías de la diferenciación sexual (DSD). Medicina Infantil, Vol XVII, No2, Junio 2010, http://www.medicinainfantil.org.ar/images/stories/volumen/2010/xvii_2_210.pdf

56 Di Martino, Martin, Ongaro, Liliana, “Aspectos psicoemocionales en el desarrollo de la identidad de genero en pacientes adolescentes con DSD, atendidos en el Hospital Garrahan”. Medicina Infantil XX, 2013, http://www.medicinainfantil.org.ar/images/stories/volumen/2013/xx_4_311.pdf

57 Pardes, E; San Martin, P; Zunino A; Fuentes, A; Yampey, J; Kunzi G; Raya, S., “Hiperplasia adrenal congénita virilizante simple por déficit de 21-hidroxilasa. Complicación inusual en una paciente inadecuadamente tratada”. *Revista Argentina de Endocrinología y Metabolismo*, Volumen 45 #Sup, Buenos Aires, 2008.

58 Podesta, M, Mede, R, Castera, M, Herrera, M., Podesta, M (h), Galarza L., “Genitoplastia feminizante en pacientes con defectos de la diferenciación sexual, resultados actuales controversias. *Rev Hosp Niños*

The publication from Hospital IGA Dr. J. Penna in Bahía Blanca states: *“The available data suggests that re-operation for redo clitoral reduction, vaginoplasty, and introital stenosis are quite common and the greater the number of operations, the greater the chance of developing scars and jeopardizing sexual outcome with a denervated or dysfunctional clitoris and painful intercourse through a scarred vagina.”*⁵⁹

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”⁶⁰

Surgical interventions to “correct” hypospadias are very frequent in Argentina. The **National Nomenclator for Pediatric Surgery** itself, published in September 2017, includes different “hypospadias” surgeries (code .30.01, .30.04, .30.05, .30.06).⁶¹ A doctoral thesis from the National University of Cordoba reports 81 patients submitted to *“correction”* by a single surgeon in 7 years and claims the investigated method would pose *“no additional risks”*.⁶²

Hospital Italiano, one of the key private medical institutions in the country, informs on its website that *“nowadays, most urologists recommend repairs to be made before (the child is) 18 months old”* and would *“require to be performed in different stages”* (therefore anticipating the possibility of several surgeries). The Hospital claims that *“without treatment, challenges could arise when training the child to urinate in the bathroom”* which is clearly not a matter of medical necessity.⁶³

Doctors from Hospital Garrahan state, *“After a plastic surgery on the urethra, new operations are frequent due to fistulae (in some cases, multiple times). It is important to acknowledge that surgery for penile reconstruction is very difficult and success is scarce.”*⁶⁴ Other doctors recommend publicly *“to commence surgical treatment between the 1st and 2nd year of life”*⁶⁵ respectively *“to operate before 3 years”*, else there would be a risk for *“psychological damage”*.⁶⁶

BAires, vol 52 numero 238. Noviembre 2010,

<http://revistapediatria.com.ar/wp-content/uploads/2012/03/con351-462-471.Podesta.pdf>

59 Piaggio, L A., “Congenital Adrena Hyperplasia: Review from a Surgeon’s Perspective in the Beginning of the Twenty-First Century”, en *Front Pediatr.* 2013, 1:50, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3877834/>

60 For general information, see 2016 CEDAW NGO Report France, p. 48-49.

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

61 Asociacion Civil Argentina de Cirugia Pediatrica. *Nomenclador Nacional de Cirugia Pediatrica*,

http://www.acacip.org.ar/docs/NOMENCLADOR_CON_VALORES_SEPTIEMBRE_2017.pdf

62 Sentagne, Luis Miguel, *Meatobalansplastia asociada a movilización de uretra para corregir hipospadias distales*, http://lildbi.fcm.unc.edu.ar/lildbi/tesis/sentagne_luis_miguel.pdf

63 Hospital Italiano de Buenos Aires, “Cirugías de Hipospadias”,

<https://www.hospitalitaliano.org.ar/#!/home/isalud/noticia/6102>

64 Guercio, G; Constanzo, M; Belgorosy A; Rivarola M., “Anomalías de la diferenciación sexual (Disorders of Sex Development, DSD), Nuevos conceptos y manejo clínico”. Servicio de Endocrinología. Hospital de Pediatría Garrahan, <http://www.endopedonline.com.ar/img/n26/rev26.pdf>

65 Fiorentino, Jorge (jefe Departamento de Urgencias, Hospital Gutiérrez), “El paciente correcto, derivado al especialista correcto, en tiempo correcto”, en Paideia: web de medicina ambulatoria para el niño y el adolescente, <http://www.paideianet.com.ar/correcto.htm>

66 Urología Rosario Argentina, “Hipospadias”, <https://urologiarosario.wordpress.com/informacion-para-pacientes/patologias-urologicas/pene/hipospadia/>

d) IGM 4 – Other Unnecessary and Harmful Medical Procedures⁶⁷

- **Prenatal treatment:** The use of fetal dexamethasone started in Argentina more than a decade ago. For example, a paper published in 2008 affirmed that *“the goal of prenatal diagnosis and treatment of CAH is to avoid or mitigate the virilization of the affected female fetus”*.⁶⁸
- **Repeated genital exams and photography** are extremely frequent in Argentina. The Government of the Province of Tucuman sponsored the 50 Argentinian Congress of Pediatric Surgery, performing a **“live surgery”** on a child with hypospadias. The video of the surgery is easily available in their website.⁶⁹ **Case No. 5** clearly shows the impact of repeated genital exams and photography on an intersex child and the extreme negative consequences for his health and well-being. The study produced by doctors from Hospital Gutiérrez on 16 children says *“Postsurgical anatomic outcomes were assessed by the treating medical team every 4 months during the first year, annually after that, and through examination under general anesthesia 1, 3, 5 and 10 years after surgery to evaluate the vaginal caliber”*.⁷⁰
- **Lack of privacy:** The case of an intersex child was exposed on Argentinian media in 2013, including the face and name of the mother. **The child’s genitals were described to a journalist by an anonymous source from Hospital Garrahan and the description was published in a national newspaper.** The child was portrayed as having *“a penis with an opening wider than normal. Testicles were palpable. Information stating that the child is a girl was wrong”*.⁷¹
- **Challenges in access to legal registration:** Intersex infants and children in Argentina are frequently exposed to the **violation of their right to identity and to be recognized as a person before the law** when **doctors refuse to provide their parents with the necessary documentation** to legally register them. **Poor, rural and uneducated families** are more vulnerable, and an intersex child’s lack of proper birth certificate and national identity card will deprive the child and the family from State aid, which **increases their vulnerability** (see **Cases No. 4 and 6**). The INADI has had to intervene in different occasions to ensure an intersex child’s right to legal registration, including the case of an intersex child that spent two years without being legally registered.^{72 73}

67 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

68 Warman, M; Rivarola, M; Belgorosky, A., “Hiperplasia Suprarrenal Congenita (HSC) Deficit de la enzima 21-hidroxilasa. *Revista de Endocrinología Ginecológica y Reproductiva*, 2008

69 Tucuman es sede del 50o Congreso Argentino de Cirugía Pediátrica. Ministerio de Salud Pública. Gobierno de Tucuman. Noviembre de 2016, <http://msptucuman.gov.ar/tucuman-es-sede-del-50-congreso-argentino-de-cirugia-pediatria/>

70 Podesta, M, Mede, R, Castera, M, Herrera, M, Galarza L, “Genitoplastia feminizante en pacientes con defectos de la diferenciación sexual, resultados actuales controversias. *Rev Hosp Niños BAires*, vol 52 numero 238. Noviembre 2010, <http://revistapediatria.com.ar/wp-content/uploads/2012/03/con351-462-471.Podesta.pdf>

71 Hacher, S, “Sera lo que quiera ser”. Suplemento SOY Pagina12, 1 de marzo de 2013, <https://www.pagina12.com.ar/diario/suplementos/soy/1-2831-2013-03-01.html>

72 “Nacimiento intersex: el INADI pide cambiar la normativa”. *Misionescuatro.com*, 5 de setiembre de 2016, <http://misionescuatro.com/provinciales/nacimiento-intersex-inadi-pide-cambiar-la-normativa/>

73 “La niña intersex que vivió dos años anotada como varón”. *Agencia Presentes*,

3. State Actors Advocating and Financing IGM Practices (art. 24(3), GC 18)

Most medical institutions involved in treating intersex people in Argentina are **public hospitals**. Therefore, doctors involved in IGM practices are **state-employees**. Some of them are researchers **funded by the Consejo Nacional de la Carrera de Investigador (CONICET)**,⁷⁴ the national research agency in the country. All IGM procedures are paid for by the **Argentinian Universal Health Care System** under the oversight of the **Argentinian Ministry of Health**.

4. IGM Doctors Dismissing or Misrepresenting Survivor's Human Rights Claims

Argentinian doctors have an ambivalent position on human rights. They recognize the need of reviewing current protocols and procedures: *“there is consensus on the lack of scientifically demonstrated data, and according to what has been posed by groups of patients subjected to these surgeries, and who are clearly dissatisfied with the results, there is consensus on a moratorium”*.⁷⁵ At the same time they dismiss survivors' testimonies and misrepresent critical arguments, depicting them as based on resentment or radical perspectives. For example the web page on DSD at Hospital Gutiérrez **misrepresents criticism of IGM as a LGBT or transgender issue**: *“There are opinions that defend sexual diversity for those people at odds with the definitions of man or woman, that is to say, with so-called gender binary. They are against any kind of medical or surgical intervention.”*⁷⁶ Doctors themselves are **acknowledging and expecting future negative consequences** of current procedures: *“Taking into account that, eventually, the treatment chosen initially may be questioned in the future, it is recommended to implement the surgical treatment that is less aggressive [...], considering its future implications rather than the ease with which it can be carried out.”*⁷⁷ Nonetheless, the surgeries and other harmful treatments continue.

5. IGM Doctors Consciously Dismissing Law and Ethical Guidance

In 2011, city congresswoman Diana Maffia called doctors from key public pediatric hospitals in the city of Buenos Aires to three meetings to discuss intersex issues and, in particular, **human rights violations against intersex persons in medical settings**⁷⁸. Intersex advocates and other human rights institutions were also invited. Doctors only attended the first meeting, and refused to continue the process considering that the human rights focus was disrespectful to their

<http://agenciapresentes.org/2016/12/05/la-nina-intersex-vivio-dos-anos-anotada-varon/>

74 For example Prof Dr Miguel L Podestá, chief of the Urological Department at Hospital Gutiérrez, professor for Urology at the University of Buenos Aires (UBA), and clinical investigator of CONICET, see <http://guti.gob.ar/servicios-medicos/22-urologia.html#detalles>

75 <http://espanol.medscape.com/verarticulo/5900751>

76 Bergada, I; Podesta, M; Rey, R; Silberkasten, M, “Trastornos de la Diferenciación Sexual (Genitales ambiguos – Intersexualidad). Información sobre enfermedades. Hospital de Niños Dr. Ricardo Gutiérrez, <http://guti.gob.ar/pacientes-y-familias/informacion-sobre-enfermedades/3-trastornos-de-la-diferenciacion-sexual-genitales-ambiguos-intersexualidad.html>

77 Del Valle, M; Diaz Zorita, MA; Stepansky, N; et. al., Reflexiones del Comité de Bioética de un hospital pediátrico sobre las implicancias del diagnóstico y tratamiento de los trastornos del desarrollo sexual. *Arch. Argent. Pediatr.* Vol. 113 no3, Buenos Aires. Junio 2015, http://www.scielo.org.ar/scielo.php?script=sci_arttext&pid=S0325-00752015000300012

78 <http://dianamaffia.com.ar/?p=9356>

profession and reputation. One of the representatives from Hospital Gutiérrez claimed, *“when doctors are accused of performing torture it is not possible to continue the conversation”*.⁷⁹

In 2012 Argentina passed a gender identity law (Number 26.743) that **explicitly prohibits surgical interventions to be performed on children** with the purpose of modifying their sex characteristics **without informed consent from the child and permission from a judge** (art. 11, para 2). This law has been applied to transgender children but it is **failing to protect intersex infants**. On this regard, Dr. Maria Susana Ciruzzi, Hospital Garrahan’s legal advisor, acknowledged that, under Law 26.743, if *“according to the best judgment of the health professionals in a particular case, a child’s best interest would be protected by medical prescription of hormonal and surgical treatment, the parents and the child should be informed about it and, eventually, judicial authorisation should be requested for surgical cases.”* However, she has a different opinion on how to deal with these cases: *“a more adequate regulation could be found in the design and approval of protocols from scientific societies or institutions, which would allow the resolution of these cases within the specific, intimate and private framework of the clinical relationship”*.⁸⁰

The fact that **Law 26.743 fails intersex children** is also a matter of public record: *“[T]here is a clear omission of rules to limit abusive medical interventions [on intersex children]. This, we understand, is a direct consequence of the process of invisibility of the medicalization of intersexuality, which in the Argentine Republic is almost absolute, promoted by the discourse of ‘medical urgency’ [...].”*⁸¹

In 2014, the **child’s protection agency Asesoría General Tutelar (AGT)** released a public document establishing and expressing its concerns on human rights issues affecting intersex children. It affirms: *“If postponement does not pose a specific risk to health, then the time demanded by each decision must be respected, even if that means waiting for the person to reach maturity and sufficient age to provide autonomously their free and informed consent (or to deny it) in relation to treatment”*.⁸²

Finally, in its policy paper published in 2015, **INADI (National Institute against Discrimination)** explicitly recommended *“to stop medically unnecessary ‘normalizing’ treatments on intersex persons, including irreversible genital surgeries, without the person’s free and previous consent.”*⁸³ Nonetheless, the surgeries and other harmful treatments continue.

79 Verbatim Records distributed to participants and available on request from Justicia Intersex.

80 Ciruzzi, Maria S., “La intersexualidad en pediatría a la luz del ordenamiento jurídico argentino”. *Suplemento de Salud, Derecho y Bioética*, MJ-DOC-7412-AR | MJD7412. 24/9/15

81 Torroba, E. y Bertolé, C. (2017). “Análisis crítico sobre la condición de niñas y niños intersexuales en la ley 26.743 de identidad de género” *Revista Perspectivas de las Ciencias Económicas y Jurídicas*. Vol. 7, N° 2, <https://cerac.unlpam.edu.ar/index.php/perspectivas/article/view/2239/2200>

82 Aportes para el cumplimiento de derechos humanos en temática intersex. Documento de trabajo 22. Febrero de 2014, http://asesoria.jusbaires.gob.ar/sites/default/files/dtn22_intersex.pdf

83 INADI, *Intersexualidad*, <https://brujulaintersexual.wordpress.com/2016/08/04/documento-sobre-intersexualidad-del-inadi-argentina/>

6. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation

Article 24 para. 3 of the Convention in conjunction with the **CRC/CEDAW Joint General Comment 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 **Argentina** 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.⁸⁴ So far there was no case of a victim of IGM practices succeeding in going to a Argentinian court.

The 2015 *Civil and Commercial Code* of Argentina even **reduced the statute of limitation for medical liability from 10 to 3 years** (Article 2561). This happened while all the main human rights treaties (including CRC, CRPD and CAT) were in place in Argentina and, in some cases, given constitutional status. Considering that most human rights violations occur when the victims are minors, with regards to IGM **that time restriction is unacceptable and contrary to any human rights standards.**

The National System for the Prevention of Torture and other cruel, inhuman and degrading treatment (Law 26.827) is entirely dedicated to the monitoring of prisons and so far **disregards cases of human rights violations in medical settings.** Furthermore, **no agency working on children, disability, health or human rights is systematically safeguarding these human rights.**

While on the one hand IGM practices are financed by the **Argentinian Universal Health Care System** under the oversight of the **Argentinian Ministry of Health**, on the other hand **survivors of IGM practices find it impossible to obtain funding for rehabilitation** to mitigate the negative consequences and suffering caused by IGM, but have to **pay for rehabilitation by themselves** (see **Case No. 1**).

Conclusion: To this day, the **Argentinian government** fails to ensure that non-consensual unnecessary IGM surgeries on minors are recognised as a form of **genital mutilation**, which would formally prohibit parents from giving “consent”. In addition, the state party **refuses to initiate impartial investigations**, as well as data collection, monitoring, and disinterested research.

This situation is clearly not in line with article 24 para. 3 of the Convention and the CRC/CEDAW Joint General Comment No. 18/31 “on harmful practices”.

⁸⁴ Globally, no survivor of early surgeries **ever** managed to have their case heard in court. All relevant court cases (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

C. Suggested Recommendations

The Rapporteurs respectfully suggest that, with respect to the treatment of intersex persons in Argentina, the Committee includes the following measures in their recommendations to the Argentinian Government (in line with CRC's previous recommendations e.g. to South Africa, Denmark and Switzerland):

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, compensation and rehabilitation 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, the Committee recommends that the State party:

- (a) Ensure that the State party's legislation prohibits all forms of harmful practices, including intersex genital mutilation**
- (b) Explicitly prohibit unnecessary medical or surgical treatment during infancy or childhood to guarantee bodily integrity, autonomy and self-determination to children concerned, and provide families with intersex children with adequate counselling and support;**
- (c) Adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation and as full rehabilitation as possible, and undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent;**
- (d) Systematically collect disaggregated data on harmful practices in the State party and make information on the ways to combat these practices widely available;**
- (e) 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.**

D. Annexe “Case Studies”

The first-person narratives have been collected via *Brújula Intersexual* (Case No. 1) and *Justicia Intersex* (Cases No. 2-6). All abstracts have been composed by the Rapporteurs.

Case Study No. 1

*Born in 1979 with ambiguous genitalia, salt-losing Congenital Adrenal Hyperplasia (CAH) was diagnosed
Medication with hydrocortisone since birth to prevent salt loss*

Age 8 months clitoral reduction and labioplasty at Ricardo Gutiérrez Hospital, Buenos Aires, Argentina

Age 3 years further reduction of the clitoris at Ricardo Gutiérrez Hospital, Buenos Aires, Argentina

Age 12 years vaginoplasty at Humberto Notti Children's Hospital, Mendoza, Argentina

*Age 12-19 years vaginal dilation under anaesthesia every 6 months (third dilation without anaesthesia) at
Humberto Notti Children's Hospital, Mendoza, Argentina*

At the age of 19 the person concerned refused any further treatment.

*Age 36 doctor changes hydrocortisone medication to high doses of prednisone to prevent further
"masculinization" of the body, causing Cushing's Syndrome*

*The person concerned is currently undergoing psychological treatment to overcome the trauma caused by
her experiences in hospitals during her childhood and adolescence, which she has to pay by herself.*

I was born in 1979 in Mendoza, Argentina. The doctors explained to my parents that my genitals were “ambiguous” and that it was not possible to say if I was a boy or a girl. Through a genetic test it was determined that my chromosomes are XX and I was raised as a girl.

I was lucky to receive hydrocortisone and fludrocortisone treatment to counter my salt loss, as I already had an older sister that also was born with CAH with salt loss, but didn’t receive hydrocortisone treatment and died at 3 months. Therefore it is important to make a clear distinction between the medical treatment to prevent salt loss, which constitutes an actual medical issue, and the genital differences that one is born with, which is not a medical issue and should not be treated as a health problem in itself.

Nonetheless, the doctors soon told my parents that I would have to undergo some surgeries to “fix” my genitals to be able to lead a “normal” life. They didn’t explain to my mother why the surgeries had to take place, nor the possible consequences, they only told her that based on my karyotype XX they were going to perform clitorectomy, vaginoplasty and labioplasty. They only made her sign the consent form and told her that the surgeries were necessary. They did not inform her about the possibility to keep my body intact without health risks.

I don’t remember the first two surgeries, I was very young. My mother told me that the first surgery was at 8 months of age. The doctors reduced the size of my clitoris and fabricated labia majora. The second surgery at 3 years of age was done to further reduce the size of my clitoris. Only later I realised that these surgeries caused the partial loss of sensation in my genitals.

What I do remember with more clarity are the consultations that came later, during which one or several doctors looked at my genitals and touched them constantly, which made me feel very uncomfortable and very ashamed. Over time I learned to dissociate, leaving the doctor’s office emotionally and living in my thoughts during consultations, without taking into account what they were doing to me and my body, later leading to stigma and rejection of my own body. I didn’t have another option, being a little girl, it was the way I had to evade and escape.

At age 12, a new surgery called “vaginoplasty” was performed. The doctors only said: “It will make you more feminine.” They also didn’t explain to my mother exactly what this surgery consisted of, only that it would be necessary for me to be fine. When I came out of the surgery I remember that my body felt differently, it hurt, I was uncomfortable with the sutures. I remember that I felt a lot of pain in my genitals, a pain that I had not experienced before. Being so small I did not understand the reason for the surgery. I remember that I once asked but never got answers or explanations to what they did to me. This surgery, and the others that were done to reduce the size of the clitoris, caused me many problems to this day such as: pain and burning in my genitals and partial loss of sensation, as I later found out I don’t have sensations anymore where the scars are.

Later came more genital examinations during which the doctor touched my genitals and commented on things that I did not understand at all. I felt humiliated. Then they began with so called vaginal calibration therapies, i.e. vaginal dilations under general anaesthesia, where the doctor introduced tubes into the vagina that was created by surgery to make it bigger and prevent it from shrinking. These dilations were extremely uncomfortable and embarrassing, and I did not fully understand what was happening, because nobody explained to me anything. These dilations were performed every 6 months from the time I was 12 years old until I was 19 years old. At the third dilation, the doctor decided that it had to be without anesthesia. I was about 13 years old, I tried three times to insert the tube into my vagina, but I didn’t succeed. I was badly distressed, and felt very sore. Because of this traumatic experience, I insisted that the following calibrations should take place under general anesthesia like before or I would not allow them to do this again.

Only much later I understood that in fact I was raped under anesthesia, because that is what those calibrations are: rape.

All surgeries and other medical treatments were paid for by the Argentinian state.

When I was 19 years old, I decided that I did not want to be dilated anymore! I did not want those treatments anymore, they had been choosing for me for a long time! But now I was old enough to resist, I did not want that anymore!

All these surgical procedures and “treatments” also caused me serious emotional problems, especially depression, which I have suffered most of my life.

In 2010 I was diagnosed with Hodgkin's lymphoma (cancer). Fortunately, the chemotherapy worked and I was healed. I just have to go to the hospital for semiannual controls.

At 36, I began to notice that I had more body hair than before, especially on my face, in addition to acne. I went to the doctor and wanted to know why that happened to me. The doctor ordered a sequence of blood tests, and then with only a minimal explanation, she just changed my hydrocortisone medication to a higher dose of prednisone. I accepted but I didn’t really understand what was happening.

The high doses of prednisone, caused me to get fat in an almost monstrous way. I didn’t recognise myself in the mirror. This generated an effect of rejection towards myself, completely canceling my self-esteem. I suffer from Cushing’s syndrome and I learned later that it can be related to the high doses of prednisone they gave me.

In 2017 I found support and friendship when I met other intersex people in a self-help group.

I was able to recover part of my medical records in my mother's possession, but the extensive clinical file is apparently lost, so I started to ask my family and doctors questions to learn at least as much as possible.

For me, it is still very emotionally difficult to remember all these events, let alone talk about them. I am full of sadness, anger, uneasiness and helplessness, because the mutilations cannot be undone and today I am what they created of me. This is difficult for me to accept, as I was born without any health problems related to my urinary system and my genitals, they cut and modified them without my consent, and they also manipulated my body with high doses of hydrocortisone and prednisone, which caused me many health problems (obesity, insulinemia and high cholesterol). Because of these “treatments” and mutilations, today my body is not what it should have been. And the worst part is that they didn't let me choose what I wanted for my life!

In August 2017 I started a psychotherapy with a therapist who supports people from the self-help group. For the psychotherapy I have to pay out of my own pocket, although fortunately the therapist gives me some sessions for free since I otherwise I couldn't afford the treatment.

Thanks to the psychotherapy I realised that my feelings of anguish, sadness and anger are related to what happened to me as a child and young adult.

During therapy, for the first time I could also talk about my difficulty to interact with other people. I am still afraid of sexual contact and intimate relationships, and this is linked to the lack of the clitoris and the related inability to maintain adequate intimacy. I have experienced rejection because of this, which compounds my fear of establishing an intimate relationship with someone.

Case Study No. 2

*Born in 1983 with ambiguous genitalia, salt-losing Congenital Adrenal Hyperplasia (CAH) was diagnosed
Salt loss not treated in the first year of life*

*At 6 months clitoral reduction, relocation of urethra and construction of vulvar labia, performed by Dr
Cristobal Papendiek (because of life threatening bleeding the surgery couldn't be completed)*

At 1 ½ years surgery the former procedure was completed with another surgery

At 4 years further surgery to correct the labia which had fused again

Painful recurring urinary infections

Unable to establish loving or sexual relationships

I was born in December 1983 and was diagnosed with Congenital Adrenal Hyperplasia in its salt-losing form. Doctors wanted to fix my ambiguous genitals but didn't take in account the severe dehydration crises I suffered from during my first year of life as a severe life risk factor. My mother, a psychologist, was reluctant to exposing me to surgery, but doctors pressured her assuring that otherwise I would suffer from urinary infections. At 6 months of age I was operated by Dr Cristobal Papendiek. A reduction of the clitoris was performed, the urethra was relocated and the vulvar labia were constructed using tissue from the scrotum. The operation was not completed at that time because I almost died from bleeding. When I was 1 and a half years old the procedure was completed with another surgery. At 4 years old I had surgery again to “correct” the labia because they have fused again.

I had very painful and recurrent urinary tract infections throughout my childhood even though the surgeries were supposed to prevent them. I also had night terrors almost every night. I went through several painful studies and explorations during this time. Ever since I can recall, the pediatric endocrinologist who attended me, Dr. Pedro Eliseo Estévez, at each control, opened the vulva with his hands to make sure that everything was “okay.” It hurt me. When I was 6 my mother was told “pain forges a strong spirit” by a doctor, when I screamed in despair as he tried to do a study on my uterus. Fortunately, my mother shoved his hand away, the cannula went out and thus prevented my bladder from being perforated. When I was about 12 years old the same doctor asked me if I would show my genitals to a medical student. I agreed, because I had already learned to do what other expected from me, especially if they were doctors. I don’t remember what they talked about, but I do remember feeling embarrassed and powerless.

If during the years of my childhood the medical concern was centered on weight and height, during the years of my adolescence that concern was focused on the lack of menstruation. I did not menstruate during puberty as would be expected of a woman, and my family environment, especially my mother, were very disappointed. I felt broken, little woman, failed, horrible. I felt like a monster.

Later in life, when I attempted having sex with a man, I realized that it was no possible. The scar tissue does not have the same properties as the healthy tissue. It does not grow like it's supposed to, it's not flexible. At that moment, I had another surgery to be “fixed” but it resulted to be too traumatic and painful. Currently, my self-esteem is severely undermined and I find difficult studying or working. I have been unable to establish loving or sexual relationships for a long time. I live in fear and anguish. I'm struggling to overcome this feelings and difficulties with professional help.

Case Study No. 3

Born 1971 and raised as girl

Age 14 referred to gynecologist due to lack of menstruation, ultrasound showed no vagina or uterus

Painful physical explorations, endocrinologist recommends psychotherapy to “access femininity”

Age 17, under pressure of father, consents to vaginal surgery (with sigmoid = bowel tissue) performed by Dr. Hugo Vilarrodona

7 months after surgery: neovagina producing intestinal fluid and closing, causing massive infection and a double pneumonia, requiring emergency surgery

Forced to perform vaginal dilation, alledgedly to prevent another infection

Repeatedly mocked and laughed at by doctors and nurses when crying

Age 18 wrongly given intense psychiatric medication

Age 22 extreme anxiety due to ongoing dilations treated with more medication

7 years periodic dilations under general anaesthesia to prevent possible infections

Sexually harassed by surgeon

Today suffering from intense back pain because of destroyed abdominal muscles due to the surgeries, chronic pain where the sigmoid was cut, insensitive skin, massive scarring, nightmares, depression, suicidal ideations, and the pervasive and deep feeling of having been repeatedly raped

In 1985 I had an ultrasound in a pediatric clinic in Cordoba, Argentina. I had been referred to a gynecologist due to lack of menstruation, and he performed the ultrasound in his office. I was 14

years old and I was alone with him. He clearly said, “there is nothing there”. Without giving me another explanation, he called the clinic’s director, and both of them looked to the screen. I was told then that I had been born without a vagina and a uterus, and that I was sterile. They called my father and recommended him to take me to consult with an endocrinologist and a surgeon.

My father took me to see Dr Mirta Miras, a well-known endocrinologist in Cordoba. She criticized by gender expression, called me a rebel tomboy, and recommended my father to put me on psychotherapy to help me to access my femininity. I was referred to a psychoanalyst at the same clinic, called Mercedes Rimondino, and had to see her weekly. Dr. Miras was absolutely dismissive with me. She said that I felt pain during physical explorations because I was refusing to open my legs as a woman. I remember cuddling and crying on the examination table while she was leaving the room and slamming the door saying that she was sick and tired of me. I never received a diagnosis from her.

My father took me to see a surgeon, Dr. Hugo Vilarrodona. He said that I shouldn’t worry, that he was a body-maker, and that he would turn me into a real woman. I told him that I didn’t identify as a woman, but as a man. He said that I was too beautiful to be a man that once having a vagina and good sexual experiences I would start enjoying being a woman. A vaginoplasty was planned.

I consented the surgery under the pressure posed by my father, who threatened to send me to a psychiatric institution otherwise. He was a lawyer and a violent person and I was very afraid of him. I considered to run away from home and to kill myself but finally consented out of fear. In 1988 I was subjected to a vaginoplasty, made with sigmoid (a piece of bowel) as a way of treating not only the body but also my gender identity, in spite of being a surgery strictly recommended for people interested in vaginal sexual intercourse, which wasn’t my case.

Seven months after the surgery I had a massive infection. The surgically created vagina produced intestinal fluid. It has closed in the middle, which prevented the fluid to leak down. It concentrated there, got infected and ended up perforating the internal tissue. It caused an acute peritonitis and as the infection entered my blood it migrated to my lungs causing a double pneumonia. During surgery two liters of infected liquid were removed from my abdomen. I woke up with a tube on my nose, an oxygen mask, connected to different instruments, a catheter was on my urethra and a thick red rubber tube was opening the vaginal channel. A nurse said that it made me look as a dog. I spent a week on the intensive care unit. The combination of both surgeries cut my abdominal muscles vertically. After that I was told that the only way of preventing the same infectious episode to happen again was to have “therapeutic” vaginal intercourse or vaginal dilations. I was told that no one survives two episodes, and I was terrified, feeling that a time bomb has been placed inside my body. It was not possible for me to have vaginal intercourse. During some time I tried to perform dilations at home, or with a nurse’s help at the clinic. They didn’t work, as the entire procedure was too painful. However, Dr. Vilarrodona and his team told me several times that dilations don’t hurt, that I was closing my body because of my refusal to assume my life as a woman, or because I was trying to punish my father for giving me a malformed body. I was repeatedly mocked by doctors, who made fun of me when I cried, asking me what kind of man would cry like that. In 1989 and during 3 months was wrongly given intense psychiatric medication. In 1992, extreme anxiety due to dilations was treated with medication, but no attempt to recognize pain or humiliation was made. In 1993, after a dilation performed with

general anesthesia, a nurse hugged me and told me that I had woken up crying and screaming and that she and the other nurse in the room had finally understood that what I was saying was true.

During the following seven years, I had to have periodic dilations under general anesthesia, with bleeding during the next days, just to prevent possible infections. However, I had other infectious processes due to the same cause. They were extremely painful, as the liquid pressured to leak during days. I had very high fever during those episodes. I was hospitalized once during one of those episodes, due to pain and fever. It was not necessary to operate me to solve it. My psychiatrist came to visit me and when she saw the liquid leaking through my legs she was surprised because it was real. She said that she assumed that the pain, the fever and liquid and its horrible smell were just fantasies of me, as my male identity. When I was 22 one of the surgeons asked me out one night, and when he took me home in his car he said that he wanted to have sex with me. I refused, and he laughed and said that he was not attracted to me, but just curious to know if I was telling the truth about my male identity. Even when I told what happened to the chief surgeon, and explicitly asked him to be excluded from future dilations, I discovered that I had been lied to and he kept being part of the team. Finally, when I was 25, the neovaginal channel had been so hurt that it closed due to internal scarring. When I had the chance of asking my surgeon why he performed such a surgery in someone who was not interested in vaginal sex and who identified as a boy he said that he was following international protocols. My father has expressed his regrets many times for having consented what happened to me. He said that we had been misinformed by a respected surgeon, and that he truly believed that having a vagina I would become a happy woman, and not having one I would be mentally perturbed.

When I was 38 years old I had surgery to remove an ovarian cyst. Testicular tissue was discovered on the cyst wall. Surgery was very difficult due to the bowel being misplaced during previous interventions. Gonad removals have been recommended to prevent their malignisation, but bowels misplacement will make it a life-threatening procedure, which is delaying its occurrence. At 45 I am suffering from intense back pain due to lack of support from surgically destroyed abdominal muscles. I live with other consequences as well, in the form of chronic pain on my left side, where the sigmoid was cut, insensitive skin, massive scarring, nightmares, depression, suicidal ideations, and the pervasive and deep feeling of having been repeatedly raped. I still identify as a man.

Case Study No. 4

My son and I were referred to Hospital Gutiérrez from Tafi del Valle ten years ago. I had been told that my son was a hermaphrodite and that he will need a surgery to fix him. Once at the Hospital I was separated from my son, and told that he needed some urgent tests, and an immediate surgery, which was an emergency. I refused. I was told that without surgery my son was going to die. I asked several times what the connection was between genital surgery and living or dying, but doctors got really upset and stopped talking with me. They just ignored me. I said that I just wanted my son back and I leave, but they didn't respond. They said that by leaving I was going to be responsible for killing my son, and tried to make me sign a document which I couldn't understand. I was terrified. They brought my son back and at some moment, when they left us alone, I escaped. After that I consulted with a naturalist doctor who assured me that my son

was going to be fine. I lived with fear many years because of my decision, but also because of the possibility of my son being taken away from me and subjected to surgery without my consent. I only got a birth certificate for him when he was 8, I was terrified of him being medically tortured to be able to get one. I had to lie to a doctor to get the medical certificate that allows him to be legally registered. I am still so worried about him being mistreated that when I got in touch with a different medical team for him to get a checkup I went with a lawyer and an intersex advocate, but without my son. I wanted to make sure that his rights were going to be respected before taking him back to a hospital.

Case Study No. 5

Justicia Intersex was contacted by a citizen from another country living in Argentina. He is a male identified, 46XX person with CAH, the married father of three daughters, with kidney damage due to challenges in accessing treatment. He was repeatedly asked by his endocrinologist a public hospital in Buenos Aires to have surgery to remove his internal female organs, and he refused. His male identity was questioned. His wife was called to the hospital and asked if she knew his husband to have female internal organs, and asked if she was a lesbian. When he explained the doctor that he couldn't take time off to have surgery because of the need of working full time to support his wife and daughters, he was told that they were not they real daughters, provided that he is sterile. He stopped visiting the hospital after that, in spite of the serious suffering and risk posed by stopping renal treatment.

Case Study No. 6

Justicia intersex and its legal partner Abosex were contacted by a social worker who was concerned about the situation of a 13 years old boy without any legal registration. Parents had received a medical certificate stating that the child's sex was indeterminate at birth. They didn't receive any other information and after considering the medical certificate stigmatising they didn't register their child, who was therefore deprived from his birth certificate and national identity card. The family was referred to a national hospital located in Buenos Aires city, Hospital Elizalde. The child was taken there by his mother, who asked repeatedly for help to get his son's birth certificate. She was told that hospital staff could only help her only after the boy had genital surgery. She stopped taking him to medical checkups after realizing that the sole mention of going to the hospital triggered her son's incontrollable fear. After talking with advocates from Justicia Intersex and Abosex, the boy and his mother visited a different hospital to do a general checkup on the boy's health. Due to his previous experiences he explicitly requested not to be taken pictures or being naked with several adults in the room. Justicia Intersex and Abosex managed to get the boy legally registered through an administrative procedure.