

# Intersex Genital Mutilations

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



Vivir y Ser  
Intersex

**HUMAN  
RIGHTS FOR  
HERM  
APHRODITES  
TOO!**

[StopIGM.org](http://StopIGM.org)

NGO Report (for Session)  
to the 6<sup>th</sup> Periodic Report of Mexico on the  
International Covenant on Civil and Political Rights  
(CCPR)

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**September 2019**

**This NGO Report online:**

<http://intersex.shadowreport.org/public/2019-CCPR-Mexico-NGO-Intersex-Brujula-StopIGM.pdf>



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## Executive Summary

**All typical forms of IGM practices are still practised in Mexico today**, facilitated and paid for by the State party via the **public health care system operated by the Ministry of Health (Secretaría de Salud)**. Intersex persons are also **denied needed health care**, and children **prevented from attending school and unable to obtain official papers**. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and **denied appropriate support**.

In 2018, **CEDAW recognised IGM in Mexico as a harmful practice** and called for an **explicit prohibition** (CEDAW/C/MEX/CO/9, para 21-22). To this day, the **State party fails to act**.

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

**This Committee has repeatedly recognised IGM practices to constitute a serious violation** of the Covenant in Concluding Observations, invoking **Articles 3, 7, 9, 17, 24 and 26**.

In total, UN treaty bodies **CRC, CAT, CCPR, CEDAW and CRPD** have so far issued **42 Concluding Observations** recognising **IGM as a serious violation of non-derogable human rights**, typically obliging State parties to **enact legislation** to (a) end the practice and (b) ensure redress and compensation, plus (c) access to free counselling. Also, the UN Special Rapporteurs on Torture (**SRT**) and on Health (**SRH**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**), the Inter-American Commission on Human Rights (**IACHR**), the African Commission on Human and Peoples' Rights (**ACHPR**) and the Council of Europe (**COE**) recognise IGM as a **serious violation of non-derogable human rights**.

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

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

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

This **Thematic NGO Report** has been compiled by the intersex NGOs **Brújula Intersexual, Vivir y Ser Intersex** and **StopIGM.org / Zwischengeschlecht.org**.

It contains **Suggested Recommendations (p. 23)** and an Annexe with **5 Case Studies (p. 24)**.

## A. Introduction

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

IGM practices are known to cause severe, lifelong physical and psychological pain and suffering, and have been repeatedly **recognised by multiple UN treaty bodies<sup>1</sup> including CCPR** as constituting cruel, inhuman or degrading treatment, violence and a harmful practice.

In 2018, CEDAW (CEDAW/C/MEX/CO/9, para 21-22) already considered **IGM in Mexico** as a **harmful practice**, and recommended the State party to “[a]dopt necessary provisions *explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children*” and to “*provide families of intersex children with adequate counselling and support*”. However, to this day the **Mexican government fails to act** accordingly.

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Mexico** – advocated, facilitated and **paid for by the State party**, and perpetrated both by public university hospitals and private health-care providers – constitute a **serious breach** of Mexico’s obligations under the Covenant.

### 2. About the Rapporteurs

This **thematic NGO report** has been prepared by the Mexican intersex NGOs *Brújula Intersexual* and *Vivir y Ser Intersex* in collaboration with the international intersex NGO *StopIGM.org / Zwischengeschlecht.org*:

- **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, Peru, among others.<sup>2</sup>
- **Vivir y Ser Intersex** (English translation: Living and Being Intersex), founded in 2016, is an advocacy project for intersex human rights, led by Hana Aoi and based in Mexico. Its goal is to raise awareness of intersex issues, such as current medical practices violating intersex people’s human rights, among different members of society, and to promote a change by educating key stakeholders on how to design public policy that duly addresses said issues.
- **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*

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

2 <https://brujulaintersexual.org/>

*Hermaphrodites, too!*”<sup>3</sup> According to its charter,<sup>4</sup> *Zwischengeschlecht.org* works to support persons concerned seeking redress and justice. *StopIGM.org* regularly reports to UN treaty bodies.<sup>5</sup>

In addition, the Rapporteurs would like to **acknowledge** the work of intersex advocates **Intersex y andrógino**<sup>6 7</sup> and **Yo Intersexual**.<sup>8 9</sup> We would like to acknowledge the work of intersex visual artist **Adiós Al Futuro** of the **Proyecto Intersexual**.<sup>10 11 12</sup> And we would like to acknowledge the work of **Mara Cristina Toledo Silva**<sup>13</sup> and **Dra. Eva Alcántara**.<sup>14 15 16 17</sup>

### 3. Methodology

This thematic NGO report is an updated and localised version of the **2018 thematic CEDAW NGO Report for Mexico**,<sup>18</sup> and the **2019 thematic CCPR NGO Report for Spain**,<sup>19</sup> both by the same Rapporteurs.

This Report includes **5 anonymised personal testimonies of IGM survivors in Mexico** collected by *Brújula Intersexual*, 4 of them based on written submissions and interviews for the 2018 CEDAW Report, and the last testimony excerpted from the *Brújula Intersexual* homepage.<sup>20</sup> Each first-person narrative is preceded by a standardised abstract composed by the Rapporteurs. The identity of all persons concerned is known to *Brújula Intersexual*.

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

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3 <http://Zwischengeschlecht.org/> English pages: <http://stop.genitalmutilation.org/>

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

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

6 <https://intersexyandrogino.wordpress.com/>

7 Mar Is (2018), También soy humano: Experiencias de discriminación, Dfensor, Marzo 2018, p. 40-43, [https://cdhdf.org.mx/wp-content/uploads/2018/07/dfensor\\_03\\_2018.pdf](https://cdhdf.org.mx/wp-content/uploads/2018/07/dfensor_03_2018.pdf)

8 <https://yointersexual.blogspot.com/>

9 Carla Nuñez (2018), Yo Intersexual: testimonio de vida, Dfensor, Marzo 2018, p. 36-39, [https://cdhdf.org.mx/wp-content/uploads/2018/07/dfensor\\_03\\_2018.pdf](https://cdhdf.org.mx/wp-content/uploads/2018/07/dfensor_03_2018.pdf)

10 <https://www.facebook.com/intersexARTS/>

11 <https://brujulaintersexual.org/2019/01/15/biblioteca-el-libro-intersexual-adios-al-futuro-2018/>

12 <http://stop.genitalmutilation.org/post/Fragments-An-Intersex-Experience-by-Adios-Al-Futuro-02-07-2018-ApsaraArts-Geneva>

13 Mara Toledo (2018), De infortunios y esperanzas. Talleres sobre intersexualidad, Dfensor, Marzo 2018, p.17-23, [https://cdhdf.org.mx/wp-content/uploads/2018/07/dfensor\\_03\\_2018.pdf](https://cdhdf.org.mx/wp-content/uploads/2018/07/dfensor_03_2018.pdf)

14 Eva Alcántara (2008), Pobreza y condición intersexual en México: reflexiones y preguntas en torno al dispositivo médico. In: Mauro Cabral (ed.), Interdicciones: Escrituras de la Intersexualidad en castellano, p. 16–30, <https://brujulaintersexual.files.wordpress.com/2016/07/interdicciones2.pdf>

15 Laura Inter, Eva Alcántara (2015), Intersexualidad y derechos humanos, Dfensor, March 2015, p. 28-32

16 Eva Alcántara (2017), Intersexualidad y la pregunta por el sexo, in: Lo complejo y lo transparente.

Investigaciones transdisciplinarias en Ciencias Sociales, México: UAM-X / imagia comunicación, pp. 177-203

17 Eva Alcántara (2009), Rompiendo fronteras: activismo intersex y redes transnacionales, in: Nattie Golubov, Rodrigo Parrini (Ed.), Los Contornos del Mundo. globalización, subjetividad y cultura, p. 119-142

18 <http://intersex.shadowreport.org/public/2018-CEDAW-Mexico-NGO-Intersex-Brujula-StopIGM.pdf>

19 <http://intersex.shadowreport.org/public/2019-CCPR-LOIPR-Spain-Intersex-Brujula-StopIGM.pdf>

20 <https://brujulaintersexual.org/2016/08/30/vagina-mi-felicidad-por-guadalupe-chavez-persona-intersexual/>

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

### 1. Precedents: 2018 CEDAW Concluding Observations, State Report

#### a) 2018: CEDAW/C/MEX/CO/9, para 21-22

##### *Harmful practices*

21. *The Committee notes with concern:*

*The limited provisions prohibiting unnecessary medical procedures on intersex children and the inadequate support and lack of effective remedies for intersex persons, who have undergone medically unnecessary surgical procedures.*

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

*(a) Adopt necessary provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age when they can give their free, prior and informed consent; and provide families of intersex children with adequate counselling and support.*

#### b) State Report, para 50

In the State report, **intersex is mentioned and IGM alluded to twice** in para 50 under “*Other actions in favour of lesbian, gay, bisexual, transgender and intersex (LGBTI) persons*”:

In the **first bullet point**, the State report refers to “*a care protocol for LGBTI persons and specific guidelines for each group*” developed by the **Ministry of Health** (*Secretaría de Salud*) and aimed at combatting “*discrimination*” in the “*National Health System*”. The specific guidelines on intersex are examined in the next chapter (see p. 10-11), where we also explain how doctors **fail to implement** these guidelines, but instead continue to **rely on the older but still current**, conflicting **syndrome-specific guidelines** also issued by the **Ministry of Health**, which **continue to recommend early unnecessary surgeries** on intersex children.

The **fourth bullet point** refers to a “*glossary of sexual diversity, gender and sex characteristics, for use by the federal administration*” issued by the “*National Council for the Prevention of Discrimination*” (CONAPRED).<sup>21</sup> While some sections of CONAPRED have to be commended for having expressed their interest in protecting intersex people’s human rights and consulted with intersex NGOs in 2017 (see below p. 10), unfortunately, this 2016 **glossary was compiled without consultation with intersex NGOs**, and the entry on intersex **gravely misrepresents the human rights at stake**, as under “*human rights perspective*” it exclusively focuses on “*the right to identity and the free development of personality*”, i.e. **discrimination issues**, while completely **ignoring non-derogable frameworks** including inhuman treatment and harmful practices, and completely **fails to even mention** involuntary, unnecessary procedures a.k.a. IGM practices:

*“From a human rights perspective, which alludes to the right to identity and the free development of personality, and from the vindication of this concept promoted by intersex movements around the world, the term intersex is considered appropriate for its use, rejecting that of hermaphroditism or pseudohermaphroditism, used some years ago in medical fields.”*

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21 Consejo Nacional para Prevenir la Discrimination (CONAPRED) (2016), *Glosario de la diversidad sexual, de género y características sexuales*, entry on intersex, see p. 25, [https://www.conapred.org.mx/documentos\\_cedoc/Glosario\\_TDSyG\\_WEB.pdf](https://www.conapred.org.mx/documentos_cedoc/Glosario_TDSyG_WEB.pdf)

## 2. Lack of Protection for Intersex Persons, Violations state-sponsored

### a) The Health Care System and Intersex in Mexico

*“Before the age of two the first “reduction” of the clitoris was performed, followed by three more surgeries to “touch up the clitoris” and “enlarge the vagina” until age 12. All these surgeries and other treatments were paid for by the Instituto Mexicano del Seguro Social (IMSS) (Mexican Social Security Institute).” (Case No. 1)*

In Mexico, the **universal health care system** is a combination of **public social security** (*Seguro Popular*), **public health services** and **private medical practice**. The public health care institutions are operated by the **Ministry of Health** (*Secretaría de Salud*); additional hospitals for employed citizens and their dependents are operated by the federal **Mexican Social Security Institute** (*Instituto Mexicano del Seguro Social, IMSS*), as well as hospitals for publicly employed citizens and their dependants by the Mexican **Civil Service Social Security and Services Institute** (*Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado, ISSSTE*). Private health care institutions, which make up the majority of hospitals in Mexico, are only accessible to those who can afford them, and only a small minority of the population has private insurance coverage.

In theory, every person can choose between at least some of above options, but in reality a large part of the population **only goes to state institutions because they can’t afford otherwise** and yet they almost always have to pay pre-established fees depending on income. And even when provided by the same doctor, **health care services rendered to public patients are reportedly inferior and less diligent** as compared to private patients.<sup>22</sup>

Intersecting with the stark **social and economic inequality** in Mexico, this **unequal access to health services has a cumulated strong impact on intersex people**, because in the health care system intersex cases must be addressed at the second or third level, which is not easily accessed by most of the population, particularly by poor families and in rural areas without hospitals, where births occur at home. Other communities only have rudimentary clinics without the necessary resources or medical specialists. In these circumstances, after the birth of an intersex baby with no obvious health problems, the family is simply sent home, hoping for the best, without much explanation.<sup>23</sup>

As a consequence, on the one hand there are **many intersex people that weren’t submitted to IGM practices** according to the Mexican health protocols and so retained their physical integrity. On the other hand, due to this unequal access to health care services, **many intersex children and adults are denied needed health care**,<sup>24</sup> which also concerns IGM survivors, for example those in need of hormonal treatment due to involuntary removal of gonads.

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22 Eva Alcántara (2008), Pobreza y condición intersexual en México: reflexiones y preguntas en torno al dispositivo médico. In: Mauro Cabral (ed.), *Interdicciones: Escrituras de la Intersexualidad en castellano*, p. 16–30, <https://brujulaintersexual.files.wordpress.com/2016/07/interdicciones2.pdf>

23 Laura Inter (2016), *The situation of the intersex community in Mexico*, <https://intersexday.org/en/situation-mexico/>

24 Denial of needed (intersex-specific) health care can in itself constitute a form of IGM practices, see 2014 CRC NGO Report, p. 75, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)



In addition, intersex children that weren't submitted to IGM are **unable to attend school due to massive bullying** because of their intersex traits and the failure of school institutions to prevent it (in itself considered as a harmful practice by CRC).<sup>25</sup> Further, some intersex children who weren't submitted to IGM, when the notification of the sex in the medical certificate is delayed due to uncertainty, or the sex included in the medical certificate is different from the appearance of the person concerned, this can **prevent children from obtaining a birth certificate**, the lack of which in turn **prevents them from enrolling in school**.<sup>26</sup>

In contrast, **intersex children of parents with extended health care coverage** e.g. under the Mexican Social Security Institute (*Instituto Mexicano del Seguro Social*, IMSS) or the Civil Service Social Security and Services Institute (*Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado*, ISSSTE) are **routinely submitted to IGM practices**. To this day, in Mexico all forms of IGM practices remain **widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by state funded public Children's Hospitals, as well as in private clinics, **advocated and paid for by the State party** via the public health care system managed by the **Ministry of Health** (*Secretaría de Salud*), and **perpetrated by publicly-employed doctors with impunity**.

#### **b) Lack of Legal Protections, Insufficient Government Initiatives**

However, on the side of protections, in **Mexico** (CEDAW/C/MEX/CO/9, para 21-22), same as in the **Latin American states** of *Chile* (CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d); CRC/C/CHL/CO/4-5, paras 48-49; CRPD/C/CHL/CO/1, paras 41-42), *Uruguay* (CRPD/C/URY/CO, para 44) and *Argentina* (CRC/C/ARG/CO/5-6, para 26), and in **many more State parties**,<sup>27</sup> there are

- **no legal or other effective 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 Mexico can be summarised as follows:**

- While Mexico has advanced new legislation on the **prevention of torture or cruel, inhuman or degrading treatment**,<sup>28</sup> which explicitly includes “medical or scientific procedures on a person without their consent”, considers it an aggravating circumstance

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25 See CRC/C/NPL/CO/3-5, paras 41-42

26 See example reported in: Cruz, E. (2011), “Quitán escuela y médico a niño con ambos sexos”. La razón, <http://www.razon.com.mx/spip.php?article99823>

27 Currently we count **42 Concluding observations on IGM practices for 24 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>

28 General Law to prevent, investigate and punish torture and other cruel, inhuman or degrading treatment or punishment (26 June 2017), [http://www.diputados.gob.mx/LeyesBiblio/pdf/LGPIST\\_260617.pdf](http://www.diputados.gob.mx/LeyesBiblio/pdf/LGPIST_260617.pdf)

when the victim is a child or adolescent, and includes particularly strong obligations for public servants, nonetheless **those provisions fail to be applied to intersex persons** in the country, particularly regarding IGM (despite that IGM practices have been **repeatedly recognised** as constituting at least cruel, inhuman or degrading treatment, including by CAT).<sup>29</sup>

- While some **official agencies**, such as the Human Rights Commission of the Federal District (*Comisión de Derechos Humanos del Distrito Federal de la Ciudad de México*, CDHDF)<sup>30 31 32 33 34</sup> and the National Council for the Prevention of Discrimination (*Consejo Nacional para Prevenir la Discriminación*, CONAPRED)<sup>35</sup> have expressed their interest in protecting intersex people’s human rights, **most relevant institutions remain indifferent or even support IGM**. These institutions must maintain a sustained effort to prevent IGM in the medical care of intersex people in the local and federal health sector, including in official publications<sup>36</sup> and when reporting to Treaty bodies.<sup>37</sup>
- In contrast, many intersex people, particularly those from poorer families and in rural areas, encounter **severe obstacles** or find it **impossible to get access to needed (intersex or IGM survivor-specific) health care**.
- While a segment of the Mexican **Ministry of Health** (*Secretaría de Salud*) has shown interest in reviewing medical protocols constituting serious human rights violations of intersex people, for example by issuing the **“Guide of Recommendations for the Care of Intersexuality and Variations of Sexual Differentiation”** (*Guía de recomendaciones para la Atención de Intersexualidad y Variación en la Diferenciación Sexual*)<sup>38</sup> which

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29 CAT/C/DEU/CO/5, para 20; CAT/C/CHE/CO/7, para 20; CAT/C/AUT/CO/6, paras 44–45; CAT/C/CHN-HKG/CO/4-5, paras 28–29; CAT/C/DNK/CO/6-7, paras 42–43; CAT/C/FRA/CO/7, paras 34-35; CAT/C/GBR/CO/6, paras 64-65

30 “Foro Inter Visibilidad, Visibilidad Intersex” (2014), see p. 135,

<http://cdhdf.org.mx/wp-content/uploads/2015/03/informe-anual-2014-2.pdf>

31 Hana Aoi (2017), 2º Foro Inter Visibilidad en la CDHDF,

<https://vivirintersex.org/2017/12/01/2o-foro-inter-visibilidad-en-la-cdhdf/>

32 Mexico City: Second forum on intersex visibility (2017), <https://intersexday.org/en/intersex-visibility-mexico-2017/>

33 Mexico: CDHDF calls for recognition of intersex people’s rights (2016),

<https://intersexday.org/en/mexico-cdhdf-2016/>

34 See p. 118, 127, 169, <http://www.aldf.gob.mx/archivo-0ed6f04cdee6d13f219a903a904047f1.pdf>

35 Mexico City: “Intersex visibility, problems and opportunities in Mexico”,

<https://intersexday.org/en/mexico-city-conapred-2017/>

36 For example, the 2016 “*glossary of sexual diversity, gender and sex characteristics, for use by the federal administration*” issued by the National Council for the Prevention of Discrimination (CONAPRED) and referred to in the State report (para 50), contains harmful misrepresentations of intersex and was compiled without consultation of intersex persons and NGOs (see above p. 7)

37 For example, unfortunately, the 2019 NHRI report by CDHDF keeps silent about IGM, despite the 2018 CEDAW Concluding Observations and that the report covers medical violence and references the CEDAW session (see p. 3). In fact, the only time intersex is alluded to is under “LGBTTTIQA+” hate crimes (p. 2).

38 In: “Protocol for Access without Discrimination to the Provision of Medical Care Services for LGBTTT and Intersex Persons” (Protocolo para el Acceso sin Discriminación a la Prestación de Servicios de Atención Médica de las Personas LGBTTT e Intersexual) (2017), p. 36-42,

[https://www.gob.mx/cms/uploads/attachment/file/234684/210617Protocolo\\_Comunidad\\_LGBTTTI\\_DT\\_Versi\\_n\\_III\\_17\\_3.pdf](https://www.gob.mx/cms/uploads/attachment/file/234684/210617Protocolo_Comunidad_LGBTTTI_DT_Versi_n_III_17_3.pdf)

recommends postponing non-urgent surgery until the capable person concerned is able to give informed consent, and which was drafted with consultation of intersex advocates,<sup>39</sup> **most doctors fail to implement these guidelines**, but instead continue to rely on the older but still current, conflicting **syndrome-specific guidelines** also issued by the **Ministry of Health**, which **continue to recommend early unnecessary surgeries** on intersex children.<sup>40</sup>

- Intersex people in Mexico, particularly IGM survivors, find it **impossible to get access to justice, rehabilitation and reparations**.
- Intersex people in Mexico face **challenges in obtaining or accessing their birth certificates**, and they experience difficulties in accessing their **medical records**, and accurate **information about procedures** performed on them during infancy and childhood.
- Due to lack of protection from **massive bullying**, as well as due to **lack of access to their birth certificate**, many intersex people find it **impossible to attend or complete school**.
- **Intersex advocacy in the country has been active since 2013**. 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 in meetings** with the *Coordinación de Institutos Nacionales de Salud* and the public *Hospital Infantil de México “Federico Gómez”*, as well as with public bodies including the Human Rights Commission of the Federal District (*Comisión de Derechos Humanos del Distrito Federal de la Ciudad de México, CDHDF*), the National Council for the Prevention of Discrimination (*Consejo Nacional para Prevenir la Discriminación, CONAPRED*), as well as with the Ministry of Health (*Secretaría de Salud*), however, to **little effect regarding the ongoing practice**.

### c) Conclusion: Mexico fails to protect intersex children from inhuman treatment

To this day, the Mexican 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, inhuman or degrading treatment, **in spite of longstanding public criticism and appeals** by intersex persons and their organisations, experts and Mexico’s own Human Rights Commission of the Federal District (*Comisión de Derechos Humanos del Distrito Federal de la Ciudad de México, CDHDF*) and National Council for the Prevention of

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2019 version of the Protocol (no changes in the section on intersex):

[https://www.gob.mx/cms/uploads/attachment/file/462171/Protocolo\\_Comunidad\\_LGBTTI\\_DT\\_Versi\\_n\\_IV\\_19\\_1\\_.pdf\\_Versi\\_n\\_15\\_DE\\_MAYO\\_2019.pdf](https://www.gob.mx/cms/uploads/attachment/file/462171/Protocolo_Comunidad_LGBTTI_DT_Versi_n_IV_19_1_.pdf_Versi_n_15_DE_MAYO_2019.pdf)

39 Hana Aoi (Vivir y Ser Intersex), and Dr. Eva Alcántara (ally)

40 For example the guidelines “Screening, diagnosis and treatment of congenital adrenal hyperplasia due to 21-hydroxylase deficiency” (*Tamizaje, diagnóstico y tratamiento de la hiperplasia suprarrenal congénita por deficiencia de 21 hidroxilasa*) recommending IGM2 “feminising” cosmetic genital surgery “in infancy” (“between 2 and 6 months”), <http://www.cenetec-difusion.com/CMGPC/IMSS-715-14/ER.pdf>, <http://www.imss.gob.mx/sites/all/statics/guiasclinicas/715GER.pdf>; and the guidelines “Diagnostics and Treatment of Hypospadias” (*Diagnóstico y Tratamiento de Hipospadias*) recommending IGM1 “masculinising” cosmetic genital surgery “ideally between 6 and 18 months”, <http://www.cenetec-difusion.com/CMGPC/IMSS-467-11/ER.pdf>

Discrimination (*Consejo Nacional para Prevenir la Discriminación*, CONAPRED), as well as some segments of the Ministry of Health (*Secretaría de Salud*), and **in spite of the 2018 CEDAW Concluding Observations** which recognised IGM in Mexico to constitute a **harmful practice** and explicitly recommend the State party to “[a]dopt necessary provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age when they can give their free, prior and informed consent” (CEDAW/C/MEX/CO/9, para 21-22).

### 3. IGM practices in Mexico: Pervasive and unchallenged

#### a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /  
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation  
and Arbitrary Imposition of Hormones<sup>41</sup>**

**Gonadectomies remain a common practice in Mexico**, usually justified by an alleged cancer risk. Even for intersex persons with CAIS, a **diagnosis with a known low testicular cancer risk**, a 2014 medical article in the **Revista Mexicana de Urología**, the official organ of the Mexican Society of Urology, written by three urologists out of the ISSSTE Regional Hospital “Valentín Gómez Farías” in Zapopan and the IMMS Centro Médico Nacional de Occidente in Guadalajara recommends “**early removal**” of testes because of “*probable malignant transformation*”.<sup>42</sup>

And a 2016 article in *Cirugía y Cirujanos*, the official organ of the Mexican Academy of Surgery, written by three doctors of the Instituto Nacional de Cancerología recommends as well: “*The risk of malignant transformation of an undescended testicle increases with age, thus gonadectomy should be performed after puberty, and in some cases hormone replacement therapy.*”<sup>43</sup>

Accordingly, the **official tariff list** of the **Hospital Infantil de México Federico Gómez** (*Tabulador de Cuotas de Recuperación*)<sup>44</sup> includes “*Unilateral Orchidectomy*” (code 2300035), “*Bilateral Orchidectomy*” (code 2300036) and “*Laparoscopic Gonadectomy*” (code 2300071).

The homepage of a (former) Professor for paediatric surgery at the University of Monterrey (UDEM) and the private *Christus Muguerza Hospital Alta Especialidad*, **still practising in Monterrey**, recommends: “*Treatment: By means of laparoscopy or minimally invasive surgery, we can resect the gonads that do not correspond to the assigned sex, we can also internally reconstruct the associated anomalies (‘resection of pseudovaginas’) and lower the testicles in case they are intra-abdominal.*”<sup>45</sup>

See also **Case No. 2 and 3**.

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

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

42 J. D. Farias-Cortés, F. Minakata-Ochoa e I. Sedano-Portillo (2014), Síndrome de insensibilidad completa a los andrógenos: reporte de un caso, ilustración del manejo quirúrgico. *Rev Mex Urol* 2014;74(2):117-122, at 121, <https://www.elsevier.es/es-revista-revista-mexicana-urologia-302-articulo-sindrome-insensibilidad-completa-los-androgenos-S2007408515300239?referer=buscador>

43 Alvarado, Leny; Isla-Ortiz, David; Salcedo-Hernández, Rosa A.; Chanona-Vilchis, José (2017), Mujer con seminoma puro y neoplasia intratubular germinal contralateral. Informe de un caso, *Cirugía y Cirujanos*. 2017;85(3):245-249, at 246, <http://www.redalyc.org/pdf/662/66250860009.pdf>

44 [http://himfg.com.mx/descargas/documentos/transparencia/tripticos/TABULADOR\\_AUTORIZADO\\_2015.pdf](http://himfg.com.mx/descargas/documentos/transparencia/tripticos/TABULADOR_AUTORIZADO_2015.pdf)

45 [http://www.ciruroped.com/genitales\\_ambiguos.htm](http://www.ciruroped.com/genitales_ambiguos.htm)

## b) IGM 2 – “Feminising Procedures”:

### Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labioplasty”, Dilation<sup>46</sup>

The **official Mexican CAH guidelines** “Screening, diagnosis and treatment of congenital adrenal hyperplasia due to 21-hydroxylase deficiency” (*Tamizaje, diagnóstico y tratamiento de la hiperplasia suprarrenal congénita por deficiencia de 21 hidroxilasa*) issued by the Mexican **Ministry of Health** (*Secretaría de Salud*)<sup>47</sup> recommends “genital reconstruction”, namely “clitoroplasty”, “vaginoplasty” and “perineoplasty”, “usually between 2 and 6 months” or “in infancy” in order to “reduce parental anxiety” and to “avoid stigmatisation” and “psychological problems”, despite openly admitting to the lack of evidence supporting early surgery, as well as to the increased risk of vaginal stenosis requiring dilation in case of early “surgical correction”.

Accordingly, the **official tariff list** of the **Hospital Infantil de México Federico Gómez** (*Tabulador de Cuotas de Recuperación*)<sup>48</sup> includes “Vaginal Reconstruction with Plastic Mould” (code 2000049), “Minor or Subtotal Vaginal Reconstruction” (code 2000050), “Vagina Reconstruction with Skin” (code 2000071), “Vagina Reconstruction with Amnion” (code 2000072), “Urogenital Sinus” (code 2300056), “Vaginoplasty” (code 2300057) and “Vaginoplasty with Tissue Engineering” (code 2300079).

And a 2011 publication out of the **Hospital Infantil de México Federico Gómez** states: “As part of the aesthetic and functional treatment, *these patients* [diagnosed with CAH] *require corrective surgery for girls with male external genitalia between 1 and 3 months of age to correct the abnormal appearance.*”<sup>49</sup>

And a 2007 publication out of the **Hospital Infantil del Estado de Sonora** reports of patients diagnosed with CAH “treated by surgery: one underwent labia minoraplasty, cystoscopy and vaginoscopy; another underwent meatoplasty, another clitoroplasty and vaginal reconstruction”. And generally recommends: “Surgical correction of genital abnormalities is indicated in a number of cases and should be done after 6 to 8 months of age.”<sup>50</sup>

Last but not least, the **2018 Pre-Congress Course of the Mexican Society of Paediatric Surgery** (*Curso Precongreso de la Sociedad Mexicana de Cirugía Pediátrica*) offers a “Module 3, Disorders of Sex Development”, featuring presentations on the “Experience of the DSD Clinic of the Children's Hospital of Mexico”, “Laparoscopic Neovagina” and “Salvage vaginoplasty, use of oral mucosa”.<sup>51</sup>

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

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

47 Secretaría de Salud (2014), Tamizaje, diagnóstico y tratamiento de la hiperplasia suprarrenal congénita por deficiencia de 21 hidroxilasa, p. 31-32, <http://www.cenetec-difusion.com/CMGPC/IMSS-715-14/ER.pdf>, <http://www.imss.gob.mx/sites/all/statics/guiasclinicas/715GER.pdf>

48 [http://himfg.com.mx/descargas/documentos/transparencia/tripticos/TABULADOR\\_AUTORIZADO\\_2015.pdf](http://himfg.com.mx/descargas/documentos/transparencia/tripticos/TABULADOR_AUTORIZADO_2015.pdf)

49 Nitzia Ayared Díaz García, Verónica Ávalos, Rodolfo Frago Ríos, Vicente Cuairán Ruidíaz (2011), Hiperplasia suprarrenal congénita variedad perdedora de sal. Presentación de un caso clínico. Revista Odontológica Mexicana, Vol. 15, Núm. 3 Julio-Septiembre 2011, pp 169-174, at 170, <http://www.scielo.org.mx/pdf/rom/v15n3/v15n3a6.pdf>

50 Irma Rocío Cardoso Martens, Norberto Sotelo Cruz (2007), Hiperplasia suprarrenal congénita: diagnóstico y tratamiento en 20 casos. Revista Mexicana de Pediatría, Vol. 74, Núm. 6 • Nov.-Dic. 2007 pp 251-256, at 254, 255, <http://www.medigraphic.com/pdfs/pediat/sp-2007/sp076c.pdf>

51 <http://hospitalinfantildemexicofedericogomez.mx/wp-content/uploads/2018/02/32-Tri%CC%81ptico-urologi%CC%81a.pdf>

And the upcoming **VIII. Latinamerican Congress of Paediatric Surgery / LI. National Congress of Paediatric Surgery of the Mexican Society and Colleague of Paediatric Surgery** includes a “*Course on Paediatric Urology*” featuring a “*Module 4: Complex Malformations of the Urinary Tract*” with a presentation on “*DSD*”.<sup>52</sup>

See also **Cases No. 1–5**.

### **c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”<sup>53</sup>**

The **official Mexican Hypospadias guidelines** “*Diagnosis and Treatment of Hypospadias*” (*Diagnóstico y Tratamiento de Hipospadia*) issued by the Mexican **Ministry of Health** (*Secretaría de Salud*)<sup>54</sup> recommends “*that patients with hypospadias have surgery after 6 months of age, ideally between 6 and 18 months*” justified by “*advantages of early surgery*” including “*emotional, cognitive and psychosexual aspects*”, “*decreased patient anxiety when hypospadias was corrected before 18 months*” and “*fewer emotional disturbances and better parental control*”, despite openly admitting to frequent and serious complications in the Mexican public health system:

“*A descriptive study that reviewed the records of 75 children with hypospadias (glanular 68%, midshaft 16% and proximal 16%) treated at the Regional Hospital of Zone 33 of the IMSS, Monterrey, Nuevo Leon, indicated that complications occurred in 27 (36%) of the cases, the most frequent being: urethro-cutaneous fistula in 16 (21.3%), dehiscence in five (6.6%), meatus stenosis in four (5.3%), urethral diverticulum in one (1.3%) and surgical wound bleeding in another (1.3%).*” (p. 24)

The **official tariff list of the Hospital Infantil de México Federico Gómez** (*Tabulador de Cuotas de Recuperación*)<sup>55</sup> includes “*Hypospadias*” (code 2300046).

In **2018** alone, the **Pediatric Surgery Association of Jalisco** (Colegio de Cirugía Pediátrica de Jalisco) convenes an “*expert panel*” titled “*Hypospadias. A Therapeutic Challenge*”,<sup>56</sup> the **Pediatric Surgery Association of Nayarit** (Colegio de Cirugía Pediátrica de Nayarit) offers a “*Hypospadias*” lecture,<sup>57</sup> the **Pre-Congress Course of the Mexican Society of Paediatric Surgery** (*Curso Precongreso de la Sociedad Mexicana de Cirugía Pediátrica*) includes a presentation on “*Hypospadias Complications, Redo Surgery*”,<sup>58</sup> and the upcoming **VIII. Latinamerican Congress of Paediatric Surgery / LI. National Congress of Paediatric Surgery of the Mexican Society and Colleague of Paediatric Surgery** in its “*Course on Paediatric Urology*” features a “*Module 2: Hypospadias*”.<sup>59</sup>

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52 <https://socmexcirped.org/congreso/programafinalwebcongreso.pdf>, see p. 14-15

53 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>

54 Secretaría de Salud (2010), Diagnóstico y Tratamiento de Hipospadia, p. 13-14,

<http://www.cenetec-difusion.com/CMGPC/IMSS-467-11/ER.pdf>

55 [http://himfg.com.mx/descargas/documentos/transparencia/tripticos/TABULADOR\\_AUTORIZADO\\_2015.pdf](http://himfg.com.mx/descargas/documentos/transparencia/tripticos/TABULADOR_AUTORIZADO_2015.pdf)

56 Colegio Mexicano y Sociedad Mexicana de Cirugia Pediatrica (2017), Programa Académico 2017-2018, p. 14,

<https://socmexcirped.org/programas-academicos/nuevoprograma-academico.pdf>

57 Ibid., p. 17

58 <http://hospitalinfantildemexicofedericogomez.mx/wp-content/uploads/2018/02/32-Tri%CC%81ptico-urologi%CC%81a.pdf>

59 <https://socmexcirped.org/congreso/programafinalwebcongreso.pdf>, see p. 14-15

The homepage of a (former) Professor for paediatric surgery at the University of Monterrey (UDEM) and the private *Christus Muguerza Hospital Alta Especialidad*, **still practising in Monterrey**, explains: <sup>60</sup>

**“WHY MUST THE PATIENT WITH HYPOSPADIAS BE OPERATED ON?”**

- They are unable to urinate standing up.
- They have significant ventral curvature, which prevents future sexual intercourse.
- They have an incomplete erection.
- In adulthood they present dyspareunia.
- The psychological damage caused by the dysfunctions described is prevented.”

**“WHAT AGE IS RECOMMENDED TO REPAIR HYPOSPADIAS?”**

*The optimal age seems to be between 6 and 15 months, which is what most experts now recommend. If hypospadias is diagnosed at birth, surgery is suggested at 6 months of age. It is important to note that THE HYPOSPADIAS must be fully repaired by the time the child enters school.”*

**d) IGM 4:<sup>61</sup> Denial of Needed<sup>62</sup> Health Care**

*“Social Security only gave me the Prednisone [but not Fludrocortisone], so we asked for support from the government of the state of Jalisco, who got me the medication in the United States and provided it for the next year. With this new medication my health situation improved in general but the supply was very complicated, since the health system did not take care of it. Although they prescribed it [Fludrocortisone] as the only option and for life they did not include it in their basic coverage.” (Case No. 1)*

Some intersex persons need **regular, vital (hormonal) medication**, for example persons with the salt-losing form of Congenital Adrenal Hyperplasia (CAH), or other persons that don't naturally produce all or sufficient (sex) hormones, or IGM3 survivors whose hormone-producing organs have been involuntarily removed. **In some rare cases, notably relating to problems with voiding**, also some surgical procedures may be actually medically indicated (as opposed to psychosocial indications in the case of involuntary, non-urgent procedures).

In this context, and intersecting with the stark **social and economic inequality** in Mexico, the **known unequal access to health services**<sup>63</sup> has a **cumulative strong impact on intersex people**, because in the health care system intersex cases must be addressed at the second or third level, which is not easily accessed by most of the population.<sup>64</sup>

In addition, in the Mexican public health system, in some cases the **coverage of intersex-related treatments is subject to age limits**,<sup>65</sup> which then results in **intersex adolescents or adults being**

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60 [http://www.ciruroped.com/pat\\_hipoadias.htm](http://www.ciruroped.com/pat_hipoadias.htm)

61 IGM 4 – Other Unnecessary and Harmful Medical or Other Procedures. For general information, see 2014 CRC NGO Report, p. 70-76,

[http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

62 StopIGM.org (2017), Intersex: How to Distinguish Medical Crimes from Health Care,

<http://stop.genitalmutilation.org/post/Intersex-How-to-distinguish-Medical-Crimes-from-Health-Care>

63 Eva Alcántara (2008), Pobreza y condición intersexual en México: reflexiones y preguntas en torno al dispositivo médico. In: Mauro Cabral (ed.), Interdicciones: Escrituras de la Intersexualidad en castellano, p. 16–30, <https://brujulaintersexual.files.wordpress.com/2016/07/interdicciones2.pdf>

64 Laura Inter (2016), The situation of the intersex community in Mexico, <https://intersexday.org/en/situation-mexico/>

65 For example, 25 years for persons covered via an IMSS employee plan of their parents, see Case No. 1; or under 12 years according to a report in the journal *La Razón*: “[...] but in fact the social security doesn't cover any of this, allegedly because of his age, he's twelve. That's what the agent of social security from the [Hospital del] Niño Poblano told me, that there's no treatment covered anymore and that I should investigate

**denied of needed health care** – or in the case of non-urgent elective treatments increases pressure on parents or persons concerned to “**‘consent’ quickly** before the coverage runs out (and regret later)”.

**Denial of needed health care because of intersex traits in itself constitutes a form of IGM and a harmful practice.**<sup>66</sup>

#### **e) IGM 4: Expulsion from School because of Intersex Traits**

There are reports of intersex children that are **unable to attend or finish school due to massive bullying** because of their intersex traits and the **failure of school institutions to prevent bullying of intersex children**, and in particular of intersex children who weren't submitted to IGM. Further, in some cases intersex children are prevented from obtaining a **birth certificate** (see also below), the lack of which in turn **prevents them from enrolling in school**.

Excerpt from a public interview with the **mother of an intersex child**:<sup>67</sup>

*“I wanted to inscribe him, and **he went to school just for a month**. But there was the situation that he wasn't registered because of the problem he has, **I had no birth certificate. So he was expelled**. After, already with a birth certificate, I decided to register him this time as a boy, but the school denied him the inscription. I explained the problem he had, and the favour I was asking of them too: that anytime he needed to go to the restroom, he were allowed to be escorted by his older brother, so he wasn't bullied by the children (because he has to drop his pants to urinate), but the school didn't allow it in that moment, the school director and the teachers conferred about it and replied to me: “**your son cannot attend this school because he doesn't belong here, because of the problem he has**”, and I said that he had no mental illness or anything like it, that his problem was from the waist down [...] he was rejected, that same year I wanted him to attend to school, but due to the same issue of his age they don't let him in, so **he hasn't studied not even primary education**.”*

**Expulsion from school due to massive bullying because of intersex traits has in itself been considered as a harmful practice by CRC.**<sup>68</sup>

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*if the surgery can be covered, if not I would have to pay for it, it's forty thousand pesos, I'm a low-income person and I don't have the resources to cover the expenses”, Cruz, E. (2011), “Quitan escuela y médico a niño con ambos sexos”. La razón, <http://www.razon.com.mx/spip.php?article99823>*

66 See 2014 CRC NGO Report, p. 75,

[http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

67 See Cruz, E. (2011), “Quitan escuela y médico a niño con ambos sexos”. La razón,

<http://www.razon.com.mx/spip.php?article99823>

See also: Juan Carlos López Rojas (2011), “El drama de Javier: sin acceso a una escuela por nacer con dos sexos”, [https://web.archive.org/web/20111120011307/http://www.e-consulta.com/portal/index.php?option=com\\_k2&view=item&id=21540%253Ael-drama-de-javier-sin-acceso-a-una-escuela-por-nacer-con-dos-sexos&Itemid=332](https://web.archive.org/web/20111120011307/http://www.e-consulta.com/portal/index.php?option=com_k2&view=item&id=21540%253Ael-drama-de-javier-sin-acceso-a-una-escuela-por-nacer-con-dos-sexos&Itemid=332)

68 See CRC/C/NPL/CO/3-5, paras 41-42



## f) IGM 4: Repeated genital exams and photography

*“I felt ashamed, because the doctors touched and examined my genitals, and it was common that there were several doctors and students in the room who examined my naked body.” (Case No. 2)*

*“I was hospitalised and they took me to a room where they gave classes to medical students, there were probably more than 15 people. I was 4 or 5 years old, [...], they put me in front of all these medical students and they undressed me so that everyone could see me. [...] it was one of the most horrible experiences of my life.” (Case No. 2)*

*“I remember how during the vaginal dilations, the exams and when they took photographs of my genitals without my consent, I lay bent and with my legs spread apart, I covered my face with a sheet because I felt ashamed. Some of the doctors and nurses made fun of me, as if they were amazed by my shame and how I showed it.” (Case No. 4)*

Unnecessary, repeated genital exams and photography abusing intersex children as a “freak show” are frequent in Mexico. **Cases No. 1-5** clearly show the devastating impact of repeated genital exams and photography 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.**<sup>69</sup>

## g) Obstacles to access to legal registration

In some cases, for example when the notification of the sex in the medical certificate is delayed due to uncertainty, or the sex included in the medical certificate in the meantime is different from the appearance of the person concerned, this can **prevent intersex children from obtaining a birth certificate**<sup>70</sup> (and the lack of which in turn prevents them from enrolling in school, see above).

While 2015 in Mexico City the legislation regarding the registration of sex was amended and the entry can now be changed by administrative means, and while currently the civil registry is looking for alternative legal registration in cases of intersex babies facilitating later changes,<sup>71</sup> nonetheless **the vast majority of intersex infants and children in Mexico are frequently facing obstacles to legal registration**, particularly 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**.

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69 See 2014 CRC NGO Report, p. 73,

[http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

70 See example reported in: Cruz, E. (2011), “Quitán escuela y médico a niño con ambos sexos”. La razón, <http://www.razon.com.mx/spip.php?article99823>

See also: Juan Carlos López Rojas (2011), “El drama de Javier: sin acceso a una escuela por nacer con dos sexos”, [https://web.archive.org/web/20111120011307/http://www.e-consulta.com/portal/index.php?option=com\\_k2&view=item&id=21540%253Ael-drama-de-javier-sin-acceso-a-una-escuela-por-nacer-con-dos-sexos&Itemid=332](https://web.archive.org/web/20111120011307/http://www.e-consulta.com/portal/index.php?option=com_k2&view=item&id=21540%253Ael-drama-de-javier-sin-acceso-a-una-escuela-por-nacer-con-dos-sexos&Itemid=332)

71 Personal communication Dr Eva Alcántara who accompanied such a case

#### 4. IGM in Mexico as a Violation of the Covenant

This Committee has already **recognised IGM practices as a serious violation of Covenant,**<sup>72</sup> and **arts. 3, 7, 9, 17, 24, 26** as applicable.

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

**On the basis of their “indeterminate sex,”** intersex children are singled out for experimental harmful treatments, including surgical “genital corrections” and potentially sterilising procedures, that would be **“considered inhumane” on “normal” children,**<sup>73</sup> e.g. “normal” boys and girls, so that, according to a specialised surgeon, **“any cutting, no matter how incompetently executed, is a kindness.”**<sup>74</sup> Generally, medical justifications for IGM are often rooted in **gender-based stereotypes.** Clearly, IGM practices therefore also violate Article 3.

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

Like this Committee, the **Committee against Torture**<sup>75</sup> has repeatedly **considered IGM to constitute inhuman treatment** falling under the non-derogable prohibition of torture (same as FGM and gender-based violence). Intersex advocates consider harmful practices and inhuman treatment as the **most important human rights frameworks** to effectively combat IGM.<sup>76</sup>

Concerning **involuntary medical or scientific experimentation,** as generally there is **no evidence** of any benefit for the children submitted IGM practices, any such treatments are **experimental.** While due to the general avoidance of follow-up by doctors, IGM practices are mostly done as **uncontrolled field experiments** and so in many cases may not be considered as involuntary medical or scientific experimentation in a more strict definition. However, internationally there are **many examples proving also a strict definition to apply.**<sup>77</sup> For decades, intersex children have been regularly described and exploited by scientists as an **“experiment of nature”.**<sup>78 79 80</sup> Often **twins, siblings, mothers or other family members or**

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72 See CCPR/C/CHE/CO/4, paras 24-25; CCPR/C/AUS/CO/6, paras 25-26; CCPR/C/DEU/QPR/7, para 13

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

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

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

76 Daniela Truffer, Markus Bauer / *Zwischengeschlecht.org*: “Ending the Impunity of the Perpetrators!” Input at “Ending Human Rights Violations Against Intersex Persons.” OHCHR Expert Meeting, Geneva 16–17.09.2015, online: [http://StopIGM.org/public/S3\\_Zwischengeschlecht\\_UN-Expert-Meeting-2015\\_web.pdf](http://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf)

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

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

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

**relatives** of intersex children are used as controls.<sup>81 82</sup> Generally, intersex children, while being submitted to IGM practices or thereafter, are often used as **subjects in scientific research**, particularly in the field of genetics, also in **Mexico**.<sup>83 84</sup>

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

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

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

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

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

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

83 See for example: Canto P, Vilchis F, Chávez B, Mutchinick O, Imperato-McGinley J, Pérez-Palacios G, Ulloa-Aguirre A, Méndez JP (1997), Mutations of the 5 alpha-reductase type 2 gene in eight Mexican patients from six different pedigrees with 5 alpha-reductase-2 deficiency, Clin Endocrinol (Oxf). 1997 Feb;46(2):155-60, <https://www.ncbi.nlm.nih.gov/pubmed/9135696>

84 Ana Gonzalez, Rehotbevely Rios, Sara Vazquez, Jose Velazquez, Camilo Villarroel, Silvia Sanchez, Bertha Alvarez, Angelica Martinez, Lorena Orozco, Christian Alvarado, Adareli León, Alejandro Valderrama, Paul Gallardo, Raul Calzada, Leda Torres, Edmun Bonilla, Benilde Garcia, Jose Velazquez (2018), Translational Medicine Copy Number Variants CNV in the Regulatory Region of SHOX Gene and Bone Modeling in Girls with Turner Syndrome 45X TS45X Preliminary Results, in: Latin American Pediatric Endocrinology Society (SLEP) (2018), 27th Annual Meeting, Cusco, October, 2018: Abstracts, p. 25, <https://www.karger.com/Article/Pdf/493744>

*provide specific information on the remedies available to victims of maltreatment and the procedure that complainants must follow, and statistics on the number of complaints and how they have been dealt with.” (para 14)*

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

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

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

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

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

### **Art. 24: Child Protection**

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

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

Intersex children have the **same rights to effective protections** from IGM as for examples girls against FGM. However, if there are any legal protections against IGM at all, these are **regularly considerably weaker** than those against FGM or gender-based violence. Concerning gender-based violence, this is also the case in **Mexico** (regarding FGM there is no legislation either), and clearly not in line with article 26.

## **5. Lack of Independent Data Collection and Monitoring**

With **no statistics available** on intersex births, let alone surgeries and costs, and **perpetrators, governments and health departments colluding to keep it that way as long as anyhow possible**, persons concerned as well as civil society **lack possibilities to effectively highlight and monitor** the ongoing mutilations. What's more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists “on record”.

**Also in Mexico, there are no statistics on intersex births and on IGM practices available.**

## **6. Obstacles to redress, fair and adequate compensation**

Also, in **Mexico** 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

once they do.<sup>85</sup> So far, in **Mexico** we know of **no case** of a victim of IGM practices succeeding in going to court.

**This situation is clearly not in line with Mexico’s obligations under the Covenant.**

## **7. Mexican Doctors and Officials consciously dismissing Intersex Human Rights**

The persistence of IGM practices in Mexican public clinics is a **matter of public record**.<sup>86 87 88 89</sup>

Also the **criticism of persons concerned and their organisations** of involuntary surgeries and other medical treatment is **publicly known**,<sup>90 91 92 93 94 95 96 97</sup> and also in **government bodies** including the **Gobierno del Estado Libre y Soberano de México**,<sup>98</sup> the **Comisión Ejecutiva de**

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- 85 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.
- 86 Arena Pública (2018), “Cirugías a niños intersexuales violan derechos humanos, pero en México son la norma” (“*Surgeries on intersex children violate human rights, but in Mexico they are the norm*”), <https://www.arenapublica.com/politicas-publicas/cirugias-ninos-intersexuales-violan-derechos-humanos-pero-en-mexico-son-la-norma>
- 87 La Jornada (2009), Intersexuales: la notable excepción de la regla, <http://www.jornada.unam.mx/2009/05/07/ls-central.html> “According to Miguel Ángel Márquez Gutiérrez, head of the Genetics Department at the National Medical Center La Raza, of the Mexican Social Security Institute (IMSS), the frequency of “genital ambiguity” - a term used in medical jargon - is one in two thousand births in Mexico and the world. [...]” **These are diseases that are studied at the third level. The emerging intervention lasts about ten years. For the physician, it has historically been more practical to lead the little person to a woman because of the surgical and functional ease. In many cases, it is decided that a small penis will not work, and then the gonads are removed,**” he says. **Faced with the question “is surgery necessary?”, the official responds that in Mexico you can’t stop practicing. “The cultural level is very closed; either we are ‘A’ or we are ‘B’, there is no need for intermediate points. We’re in diapers, we’re not trained to understand it.”**”
- 88 Laura Inter (2017), La situación de la comunidad intersexual de México, presentation at hearing of Inter-American Commission on Human Rights (IACHR), <https://brujulaintersexual.org/2017/03/26/cidh-la-situacion-comunidad-intersexual-mexico/>
- 89 Eva Alcántara (2008), Pobreza y condición intersexual en México: reflexiones y preguntas en torno al dispositivo médico. In: Mauro Cabral (ed.), Interdicciones: Escrituras de la Intersexualidad en castellano, p. 16–30, <https://brujulaintersexual.files.wordpress.com/2016/07/interdicciones2.pdf>
- 90 <https://brujulaintersexual.org/>
- 91 <https://vivirintersex.org/>
- 92 El Big Data (2015), “Corregir” bebés intersexuales es una violación a los derechos humanos, <https://elbigdata.mx/2015/07/corregir-bebes-intersexuales-es-una-violacion-a-los-derechos-humanos/>
- 93 El Big Data (2015), Mutilación genital, una cirugía donde el paciente no tiene derecho a decidir, <https://elbigdata.mx/2015/07/mutilacion-genital-una-decision-que-toman-por-ti/>
- 94 Laura Inter (2016), Finding my Compass, p. 10-13 (PDF: 17-20), in: Normalizing Intersex, Voices. Personal Stories from the Pages of NIB, Issue 2/2016, [http://narrativebioethics.com/wp-content/uploads/2017/07/Voices\\_2016\\_INTERSEX\\_FINAL.pdf](http://narrativebioethics.com/wp-content/uploads/2017/07/Voices_2016_INTERSEX_FINAL.pdf)
- 95 Palabras claras (2017), Viola sector salud derechos de intersex, <https://palabrasclaras.mx/estatal/viola-sector-salud-derechos-intersex/>
- 96 japii (2017), Mutilación genital a bebés intersexuales, <http://japii.mx/mutilacion-genital-bebes-intersexuales/>
- 97 proceso (2017), La CIDH pide a los Estados respetar la autonomía de personas intersex, <https://www.proceso.com.mx/512224/la-cidh-pide-a-los-estados-respetar-la-autonomia-personas-intersex>
- 98 Periódico Oficial, Gaceta del Gobierno (2017), Tomo CCIV, No. 46, p. 132, <http://legislacion.edomex.gob.mx/sites/legislacion.edomex.gob.mx/files/files/pdf/gct/2017/sep047.pdf> **“Intersex children may undergo surgery and other interventions without their informed consent or that of their parents, and as adults are also vulnerable to violence and discrimination.”**

**Atención a Víctimas (CEAV),<sup>99</sup> the Human Rights Commission of the Federal District (Comisión de Derechos Humanos del Distrito Federal de la Ciudad de México, CDHDF)<sup>100 101 102 103 104</sup> and the National Council for the Prevention of Discrimination (Consejo Nacional para Prevenir la Discriminación, CONAPRED).<sup>105</sup>**

In 2017 also the Mexican **Ministry of Health** (*Secretaría de Salud*) criticised involuntary non-urgent genital surgeries and other harmful medical treatment on intersex children in its **“Guide of Recommendations for the Care of Intersexuality and Variations of Sexual Differentiation”** (*Guía de recomendaciones para la Atención de Intersexualidad y Variación en la Diferenciación Sexual*) (see above p. 10-11).

**Mexican paediatric surgeons, despite openly admitting to knowledge of relevant criticisms by human rights and ethics bodies, nonetheless continue to consciously refuse to stop advocating, practicing and participating in IGM practices.**

Nonetheless, **Mexican government bodies refuse to take any appropriate action, but continue to ignore the full human rights implications of IGM, and allow IGM doctors to continue practicing with impunity.**

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99 Comisión Ejecutiva de Atención a Víctimas (CEAV), Comité de Violencia Sexual (2015), Investigación sobre la atención de personas LGBT en México, p. 15,

<http://www.ceav.gob.mx/wp-content/uploads/2016/06/Investigaci%C3%83%C2%B3n-LGBT-Documento-Completo.pdf>

**“Medical violence against intersex people, as most treatments and interventions seek the normalization of their bodies.”**

100 “Foro Inter Visibilidad, Visibilidad Intersex” (2014), see p. 135,

<http://cdhdf.org.mx/wp-content/uploads/2015/03/informe-anual-2014-2.pdf>

101 Hana Aoi (2017), 2º Foro Inter Visibilidad en la CDHDF,

<https://vivirintersex.org/2017/12/01/2o-foro-inter-visibilidad-en-la-cdhdf/>

102 Mexico City: Second forum on intersex visibility (2017), <https://intersexday.org/en/intersex-visibility-mexico-2017/>

103 Mexico: CDHDF calls for recognition of intersex people’s rights (2016),

<https://intersexday.org/en/mexico-cdhdf-2016/>

104 See p. 118, 127, 169, <http://www.aldf.gob.mx/archivo-0ed6f04cdee6d13f219a903a904047f1.pdf>

105 Mexico City: “Intersex visibility, problems and opportunities in Mexico”,

<https://intersexday.org/en/mexico-city-conapred-2017/>

## C. Suggested Recommendations

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

### **Intersex genital mutilation**

The Committee is seriously concerned about cases of medically unnecessary and irreversible surgery and other treatment of intersex children and adults without their informed consent, which can cause severe suffering, and the lack of redress and compensation in such cases, and about reports of intersex persons being denied needed health care, and children prevented from attending school and unable to obtain official papers (arts. 3, 7, 9, 17, 24 and 26).

#### **The State party should:**

- (a) Adopt necessary provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children until they reach an age when they can give their free, prior and informed consent; and provide families of intersex children with adequate counselling and support.**
- (b) Undertake investigation of incidents of surgical and other medical treatment of intersex persons without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation;**
- (c) Systematically collect disaggregated data on IGM practices in the State party and make information on the ways to combat these practices widely available;**
- (d) Educate and train medical professionals on the harmful impact of unnecessary surgical or other medical interventions for intersex children, and ensure that the views of intersex persons are fully considered by the interdisciplinary working groups established to review these procedures;**
- (e) Ensure that all intersex children have access to legal documents including birth certificates.**

## D. Annexe 1 – “Case Studies”

The first-person narratives have been collected by Brújula Intersexual. The abstracts were composed by the Rapporteurs.

### Case Study No. 1

*1982 born with ambiguous genitalia, diagnosed with salt-losing Congenital Adrenal Hyperplasia (CAH)*

*Since birth treatment with corticoids and high sodium diet to control dehydration*

*Before age 2 years first clitoral reduction*

*Age 8 years second clitoral reduction and vaginoplasty performed by urologist José Manuel Garcia de León*

*Vaginal dilation without anaesthesia performed by mother for more than 1 year*

*Two more surgeries to touch up clitoris and enlarge vagina*

*Age 16 years treatment of depression with Prozac/Fluxetine*

*Age 28 years diagnosed with 40% osteoporosis, caused by high dosis of corticosteroids, later diagnosed with osteoarthritis*

*Age 31 years kidney problems, related to long use of corticosteroids*

*Homeopathic treatment improves physical health, bones and kidneys beginning to recover*

*The person concerned suffers from chronic depression, constant anxiety and panic attacks in situations of emotional stress*

*The person concerned was treated at the Hospital de Pediatría del Centro Medico Nacional de Occidente in Guadalajara*

*All treatments were paid for by the Mexican Social Security Institute (Instituto Mexicano del Seguro Social, IMSS).*

#### **The person concerned tells her story:**

Since the first month of life I was treated with corticoids and high sodium diet to control dehydration.

Before the age of two the first “reduction” of the clitoris was performed with the consent of my mother. She tells me that she was asked what her degree of studies was. She replied that she attended school until sixth grade of primary school. Then the doctors tried to explain, but she confessed that she had not understood much, but that she trusted the doctors and that she herself wanted to have the surgery because “she wasn’t happy with the way my genitals looked like”.

This surgery and all subsequent treatments were paid for by the Instituto Mexicano del Seguro Social (IMSS) (Mexican Social Security Institute) and I’ve been treated at the Hospital de Pediatría del Centro Medico Nacional de Occidente in the city of Guadalajara, Jalisco.

From when I was born until I was 16 years old, I went to monthly appointments with endocrinologist Rene Ocampo Campos. They did blood tests and checked my genitals at every consultation. During those examinations there was not only Dr Ocampo present, but there were always more people participating who would watch and even touch my genitals. No one ever asked my permission to do it. During some consultations they even took photographs. At the same time as the endocrinologist, I saw a urologist and a psychologist. I remember that they used to make me draw, but they never explained anything to me, they only talked to my mother and I stayed alone for a long time. I hated all these appointments.



In 1990, I was eight years old and underwent another clitoral “reduction” and a vaginoplasty. I guess my mother also approved them. I just knew they had to operate, because something was wrong, but I didn't understand what they would do to me. This is the first surgery I remember. I spent more than a week in the hospital. As it was a public hospital it was very overcrowded and the service was very bad. I remember that the nurses treated us badly, although we were only children. They didn't let us sleep, if they saw that I was sleeping, they came closer and abruptly moved my intravenous bag or a chair to make noise. When they took blood samples they moved the needle that was in my arm abruptly causing a lot of pain.

My mother slept on the floor and once a day my surgeon arrived, the urologist José Manuel García de León with a group of students. They were checking my genitals and for the first time they inserted a dilator in my vagina. When I was out of the hospital my mother had to do these “dilations”. At first, they were once a week, then every other week. She did them without any kind of anaesthesia. I don't remember for how long exactly this happened, but it was more than a year. It was humiliating and physically painful.

In the following years I had two more surgeries to “touch up my clitoris” and “enlarge my vagina”. I don't remember exactly when, since I couldn't get my medical records. After one of these surgeries I was discharged with a catheter to urinate. When I got home, I couldn't urinate and felt a lot of pain. I had to return to the hospital in an emergency. They had to remove the catheter that was blocked and had caused a bad infection. I was 12 years old. I also remember that the sensitivity of my genitals almost disappeared after these surgeries.

In addition to surgeries and the constant blood tests, I remember other very painful procedures, injections of substances for X-ray tests, or inserting things directly into my urethra or vagina, going through very long periods of fasting, or not allowing me to urinate after drinking many litres of water. They kept me naked in very cold rooms without understanding why I was there.

The first few years, approximately until I was 8 years old, I was medicated with Primocort Depot (Deoxycorticosterone Enanthate), it was an injection every 15 days, then it was monthly. I was very scared every time I had to take the injection and in the summer it didn't help me to stop the vomiting and dehydration. In 1990 this medication was no longer produced, and we had to get 0.1 mg Fludrocortisone and 5 mg Prednisone. Social Security only gave me the Prednisone, so we asked for support from the government of the state of Jalisco, who got me the medication in the United States and provided it for the next year. With this new medication my health situation improved in general but the supply was very complicated, since the health system did not take care of it. Although they prescribed it as the only option and for life they did not include it in their basic coverage.

When I was 16 years old I was discharged from Paediatrics and sent to the Clínica de Especialidades in the Centro Médico Nacional de Occidente in Guadalajara, where I continued to see an endocrinologist, a gynaecologist and was sent to psychiatry and given antidepressants for the first time (Prozac/Fluoxetine). Without checking me first, they told me that I had chronic depression due to the medications I took. I had problems interacting with other people. I started to use illegal drugs and to think about suicide. Fortunately, I didn't have to go to the hospital so often and my health was more stable, which allowed me to find healthier alternatives and to stop taking antidepressants.

At the age of 20 years, I requested a laparoscopy to know my reproductive possibilities. This was the only surgery for which I gave my consent and of which I received informed support. The result was negative, although all the internal organs were found to be in apparent good condition, the necessary hormonal production was not given. At this time I had another very strong depression and was sent to psychiatry, the doctor prescribed me “Anfebutamona”, an antidepressant and norepinephrine–dopamine reuptake inhibitor (NDRI), a very strong drug that in less than a week caused me many problems due to the side effects: insomnia, tremors, auditory hallucinations, anorexia. At first the doctor didn't believe me and didn't want to change my medication until Dr González, my endocrinologist at the time, asked him to. To fight the effects of the first medication I was given high doses of Diazepam and then Sertraline, all this medication caused me more depression and my desire to commit suicide came back.

In Mexico, only workers who are also registered in the public health system for employees have access to specialised health services provided by the state, and can insure their children up to the age of 25, as long as their children are studying. Because I work as an independent artist, I am not registered for employee insurance, and at the age of 25 I was left without any type of health insurance. So, when I turned 25, I was without access to social security. Although I was a student and my case was considered to need lifelong treatment, the institution denied me the service. At first I was seen by private doctors, but I couldn't afford it and I just kept the medication that the endocrinologists always recommended: 0.1 mg of Fludrocortisone in the morning and 7.5 mg of Prednisone distributed in two doses a day for the rest of my life.

When I was 28 years old, I fell and broke my wrist. Dr Polanco from the Hospital Civil de Guadalajara, who was treating me at that time, diagnosed me with a 40% loss of bone mass (Osteoporosis), caused by corticosteroids. I was given Calcitriol, vitamin D and calcium supplement, at the Civil Hospital of Guadalajara. I underwent the treatment for a year and then I stopped it because of the stomach problems it was causing me. After a year my Osteoporosis level remained exactly the same: 40%, and my joints were calcified by the medication that was not being properly absorbed and that ended in osteoarthritis.

At the age of 31, in addition to the problems mentioned above (aforementioned), chronic depression and constant anxiety, I began to have kidney problems, also related to the long use of corticosteroids, according to a private doctor I was seeing at that time.

Fortunately I found a homeopath who helped me to stop this treatment and now at the age of 36 I have a better physical health, my bones and kidneys begin to recover, although my mental health is still fragile, I continue to suffer from depression, anxiety and panic attacks in situations of emotional stress, I have problems sleeping, fluctuating mood and aversion towards sexual relationships.

## Case Study No. 2

*Born in 1979, diagnosed with “clitomegaly” and “genital ambiguity”, a test showed karyotype 46XY*

*Age 6 years surgery to reduce the clitoris, it is determined that the duct of the urethra is separated from the vaginal canal, at the Hospital Infantil de México Federico Gómez, Mexico City*

*Age 7 years surgery to remove both gonads, Hospital Infantil de México Federico Gómez, Mexico City*

*Analysis of gonads results in diagnose 46XY Pure Gonadal Dysgenesis*

*Age 11-22 years Hormone Replacement Therapy*

*Age 22 years the person concerned stops taking the HRT and avoids doctors and hospitals*

*The person concerned refuses vaginal surgery proposed by doctors.*

*Consequence of these surgeries: depression, trauma, partial loss of sensitivity, scars*

### **The person concerned tells her story:**

I was born in Mexico City in a private clinic, and although I was born with genital differences, none of the doctors mentioned to my mother that there was something different, they only told her that I was a healthy little girl. Nevertheless, one of the doctors at the clinic said to my mother to take me to the Hospital Infantil de México Federico Gómez in Mexico City. As I didn't have any health problems, my mother ignored that recommendation, but since an early age, it was obvious that my body was different from the other girls. It was not until I was four years old that my mother took me to the doctor to find out why I was so different. The doctor transferred me to the Hospital Infantil de México Federico Gómez, where the first diagnosis was “clitomegaly” and “genital ambiguity”. I underwent a karyotype test and the result was 46XY.

The doctors informed my mother that I had a genital “malformation” and that it should be corrected by surgery. So, at 6 years old they performed the first surgery that consisted in reducing the size of my clitoris. During that surgery it was determined that my urethra and vagina were separated. A year later, a second surgery was performed in which my two gonads were removed and then they were analysed, so I was diagnosed with “Pure gonadal dysgenesis”, as stated in the summary of my medical file, which is the only one I have been able to obtain.

From that time my memories are very vague. I have blocked most of them. I only remember the anguish I felt before surgeries, and the physical pain that caused me, especially the second surgery.

For several years, my life was a coming and going to the children's hospital, between consultations and genital exams, that were very uncomfortable for me and I felt ashamed, because the doctors touched and examined my genitals, and it was common that there were several doctors and students in the room who examined my naked body.

In particular, I remember an experience that marked my life forever, it was when I was hospitalised and they took me to a room where they gave classes to medical students, there were probably more than 15 people. I was 4 or 5 years old, they took me in a hospital gown, they put me in front of all these medical students and they undressed me so that everyone could see me. I don't remember what the doctor said about me, but it was one of the most horrible experiences of my life. I think that's why, to this day, I find it difficult to speak in public, because it reminds me of this moment.

Between 4 and 7 years old, I was also in psychological treatment as a result of the diagnosis, but I don't remember that the doctors gave me information about what was happening to me. The treatment only consisted of sessions of "play therapy", they gave me different "girl" and "boy" toys and observed which ones I chose to play.

At 11 years, the doctors decided that it was time to start the "hormone replacement therapy", since my healthy gonads had been removed. This treatment consisted of taking a pill for twenty-one days each month, and when I turned 13 years old, estrogen was added to the treatment. The doctors said that I had to take these medications so that my body would start to develop and take a more feminine appearance and that I had to take it for life; Despite what the doctors had told me, there came a time when I didn't like to take the pills and many times I forgot about to take it. I stopped taking the pills definitively when I was about 21 or 22 years old. I know that this may cause me different health problems in the future, but I don't want to have anything to do with doctors and hospitals anymore. So far I haven't done any medical studies to see how my health is.

When I was 15 years old, I went to the doctor for a genital examination, accompanied by my older sister. During this exam the doctor would take a vaginal sample, the examination was very uncomfortable and very painful. The doctor couldn't take the sample since my vagina was too narrow. Therefore, she concluded that I had to undergo a vaginoplasty. I remember perfectly the comment that she made to my sister while she was examining me, she said, "Surgery is needed, because imagine if she gets married, she couldn't take it ...", I understood that she meant that I could die If I had sex with my husband. This comment generated a fear of sexuality that accompanied me for a long time.

I tried to avoid any relationship that could reach the sexual level. That was the last time I visited that hospital, I didn't want to go back to the consultations, although I was still taking hormone treatment.

In the end I decided not to perform the vaginoplasty and continue with my life. I don't want to go back to hospitals, I have generated a very big rejection to it and, as far as possible, I avoid any contact with hospitals or doctors.

In 2015, I asked for my medical records at the Hospital Infantil de México Federico Gómez, but they only gave me clinical summaries of endocrinology, urology, and psychology. The only thing they told me was that "it was not possible to get my full medical records". And since I was living a deep depression at the time, I didn't have the energy to insist any more. It was very hard to go back to the hospital and imagine that maybe at that same moment there were children going through the same things that I went through or maybe worse. A doctor I knew told me that it was obvious that they wouldn't give me my full medical file because the hospital was protecting itself from a possible lawsuit for everything they had done to me.

All these situations I lived, caused me many problems. My body was healthy when I was born. During my first 3 years of life I didn't have any health problems, but the first clitoral reduction surgery left me with scars and genital insensibility, and due to the second surgery in which my gonads were removed, I was made dependent on a hormone replacement therapy, which I have stopped taking and I don't know what consequences it may bring to my health in the future. Also, all the humiliating situations I lived in the hospitals, such as the genital examinations in the presence of several doctors, the medically unnecessary surgeries, the postoperative treatments and

the constant visits to the hospital as a child, left me with a feeling of being inadequate.

Because of this, I have been in psychological treatment on several occasions to overcome this depression, but at the moment I haven't been able to resume my psychological therapy since I don't have enough money to pay for it.

For me, everything I experienced in hospitals is as if the Nazis were still among us, experimenting with our bodies. I don't know if the comparison is accurate but it's the way I see it. I still have nightmares about the terrible experiences I had to go through in the hospitals.

These times have been very difficult, because I have had to face my inner demons that had been asleep for a long time and one day all of them woke up together. I never thought that everything that happened to me could affect me so much in my physical and emotional health, above all, to the extent of ruining my plans to get an academic degree and get a job, because the moment came when I was paralysed and didn't have the strength or courage to do something.

I hope that my story can help other children not live what I lived, that is my greatest wish.

### **Case Study No. 3**

*Born 1981, mother notices ambiguity of genitals only later and takes baby to local hospital, referred to the hospital Centro Médico La Raza*

*Age 6 months biopsy, diagnosed with true hermaphroditism with bilateral ovotestes, a uterus and ambiguous genitalia*

*Age 4 gonadectomy at hospital Centro Médico La Raza*

*Age 11 clitoral reduction and vaginoplasty at hospital Centro Médico La Raza*

*The person concerned finds out about having a uterus only at age 29 during a medical screening for a job*

*Age 34 haemorrhages due to myoma on uterus, change of hormone therapy causes menstruation suppressed by former medication*

*Consequence of these surgeries: depression, trauma, partial loss of sensitivity, scars*

#### **The person concerned tells her story:**

I was born in Mexico City in 1981. I was not diagnosed at birth but only months later, when my mother took me to our local clinic (clínica familiar) because she had noticed something atypical about my genitals. I was then sent to Centro Médico La Raza, a third-level hospital managed by the Mexican Social Security Institute (IMSS by its acronym in Spanish). The IMSS is a public health service, but only affiliated people can have access, either paying by themselves or through their employers. I was affiliated through my father's job.

When I was six months old, I was scheduled for the first of three surgeries during infancy and childhood. This surgery consisted in a biopsy to confirm the presumed diagnosis, which in this case, to the best of my parents' recollection, was true hermaphroditism with bilateral ovotestes and ambiguous genitalia. My parents remember feeling appalled by the diagnosis, and a multidisciplinary team was assembled to assess my case.

The physician in charge spoke to them about "viability" of being raised either as male or female.

He made it clear that it was more feasible to surgically feminise my body and raise me as a girl. He also recommended this option because my parents had already two girls, so I would fit better. So, my parents consented to proceed as suggested.

When I was four years old, my gonads were removed in a second surgery. Being hospitalised and awake in the night in the shared room with other children at the paediatrics wing of the hospital Centro Médico La Raza is, in fact, one of my earliest memories.

The third and last surgery took place in mid-September of 1992, I remember this clearly because I just had turned eleven and I was admitted to the hospital a couple of days before Independence Day (September 16).

I also remember the medical exams before the surgery, the doctor's fingers covered by latex poking my urethra and my incipient vulva. I was uncomfortable, ashamed. But I endured it because if my mom had taken me there, this could only mean that it was all to my benefit, and if I was sent to those examinations and sample-takings, it was because something was wrong with me.

I was scheduled for a vaginoplasty. However, my family didn't inform me in detail about the planned surgery, they just assured me that I needed the surgery to fix a problem I had. My mother tried to explain more but I didn't quite get it, and I got the idea that the procedure was related to my urinary system. It was a nurse who, two days after the surgery, answered my question regarding the procedure in a way I could understand. She took my chart and plainly said to me: "You had a vaginoplasty".

After the surgery doctors said to my dad, "your daughter is ready for life".

I spent a whole week at the hospital. I remember that the day of the surgery I was really nervous. I wished I wasn't there, but bottom line was that I was certain that my body needed to be "fixed", and I never had any choice in the matter of deciding whether to undergo surgery or not – I simply wasn't asked.

I remember how the physician in charge would come in the mornings. Once he brought a group of students. I remember that he asked my permission to inspect my genitals, although he acted as if it was granted. When he came with the students, I felt ashamed but didn't have any other choice but to endure it. I lost five weeks of school in total because of the hospitalisation and the convalescence period after being discharged, and with limited mobility due to the stitches.

Only years later, my mother fully disclosed other details of this procedure: I was born with a vagina and an enlarged clitoris, and my vulva wasn't typically developed. So, in this procedure the surgeons significantly reduced my clitoris and cosmetically reshaped my vulva.

After the surgery I still had to go to the hospital for follow-ups. Although it was one of the best public health care facilities in Mexico, there was little privacy when the time came to being examined. The last time I met the physician in charge of my case, I remember he poked my genitals and hurt me, but what really stuck was the feeling of humiliation, of being exposed with almost no privacy, making me feel violated, even if the physician conducted himself professionally.

At age 13 I was prescribed conjugated equine estrogens (Premarin, which is usually used in menopausal hormone therapy) to induce female puberty. I didn't quite understand why I needed "extra" hormones (I wasn't aware that I had no gonads anymore). My mom told me it was for my body development. I was embarrassed to keep asking. I felt ashamed and had a deep-rooted notion that there was still something wrong with my body.

There was a new doctor in charge of my case, an endocrinologist. One time he asked if I had a boyfriend already. The question troubled me. A part of me wanted to reply, "No, and it's not your business anyway!" But my mother was there, so I politely said, "No, I don't".

I soon found out, that because of the clitoral reduction my sexual sensations are reduced. When I wanted to find what was supposed to be "the female organ of sexual pleasure" with my fingers, I only found discomfort and discontent. Wherever I touched I could barely feel anything pleasant beyond the mere pressure of my fingertips. [...] Since long I've come to terms with the fact that my genitals aren't able to provide me with pleasant sensations.

However, the main damages in my life have been of psychological order. Ever since the third surgery, I've been experiencing deep anxiety, low self-esteem and lack of confidence in myself, feeling as if I wasn't good enough, and I came to believe that it was ordinary to live like that, until I was diagnosed with depression by a psychiatrist at age twenty-four.

I grew up looking always for my parents' (and every authority figure's) approval on everything. I tried very hard to make up for the things that I knew or I felt I wasn't good enough. I wanted to please them so much that I picked the "easy" choice, and ended majoring in Computer Engineering, just because I would easily find a well-paid employment and be self-sufficient, although I never liked it.

When I turned 30 my life started to crumble, no psychotherapist could help me to cope with the findings of my own story, and I turned against my parents. I started to inflict me physical damage and became deeply depressed, until I eventually had a breakdown and couldn't work anymore.

So began the hardest year of my life: the year to learn to forgive, the year to learn to love myself, the year to learn who I really was and what I really wanted to do, the only thing I had never sat down to think through. And furthermore, the year to embrace my body as it was, not as it could've been.

I only visited a gynaecologist at the age of thirty-four in an emergency, after I developed a myoma and was experiencing unexpected haemorrhages. He changed my hormone therapy from tablets of conjugated estrogens (0.625 mg a day since age thirteen) norelgestromin and ethinyl estradiol transdermal patches usually used as a contraceptive (6 mg / 0.6 mg a week to this day).

Due to this new medication, the haemorrhage ceased, and the myoma also reduced its size. Instead, as the gynaecologist had warned me, I started to have a menstrual cycle. At first that angered me even more. Now that I had gotten used not to menstruate, the period came punctually every month! But as I came to terms with my body, I took it as a sign of me changing. Now I'm fine about it.

Finally, the relation with my family was strained because we never spoke openly, and when I found out on my own by "connecting the dots", with the scars of my belly and the memories of surgeries and the HRT I needed, I became confused and depressed because I learned that my body

hadn't been really sick nor had had any medical problem, and there was never evidence presented to my parents regarding malignancy of my gonads, even though doctors argued malignancy as a motive to remove them.

Today my parents acknowledge they were misled back then, because they know now that ovotestes in average have as much probability of develop cancer as ovaries in typical women, yet typical women don't have their ovaries removed for the mere fear of cancer.

In 2012, I requested to see my medical records, but the hospital refused. They only provided a single sheet with a recent event of an unrelated medical matter, but nothing else. They argued that since nobody had claimed the file in so many years, it had been destroyed. I insisted and went to the archives, but they said the same thing. In any case, it's clear that the hospital never provided my parents with a hard copy of my medical file, so if what the hospital staff said to me is true, I will never be able to learn the full account of the procedures done to me.

My family helped me to get over my worst moments. Psychological help has been key to achieve emotional stability and mental clarity on how to deal with these issues. I recognise the effort of my parents to rebuild the history of my early years and the physicians' recommendations and the order and timing of medical procedures I was submitted to, especially since my clinical file with the details of such events remains denied to me.

Nonetheless, I don't care for grudges. I'd rather want justice and the full truth. Maybe I will never have them for me anymore, but I wish them for everyone else in the present and the future.

#### **Case Study No. 4**

*1982 born with ambiguous genitalia, diagnosed with salt-losing Congenital Adrenal Hyperplasia (CAH)*

*Age 11 months treatment with glucocorticoids, captopril and Sodium Chloride (serum)*

*Age 1 year and 10 months, clitoral reduction*

*Age 9 years urogenital sinus correction surgery (vaginoplasty)*

*Age 9-18 years vaginal dilations*

*Age 12 years introitoplasty*

*Age 14 years Cushing's syndrome due to over-medication with cortisol*

*Age 15 years vaginal enlargement surgery*

*Consequence of these surgeries: depression, trauma, partial loss of sensitivity, scars*

*The person concerned was treated at the Hospital Infantil de México Federico Gomez, Mexico City*

#### **The person concerned tells her story:**

I was born with genital differences, with an enlarged clitoris and with a "urogenital sinus", in which the urethra and vagina join in the same duct. My mother says that I never suffered any health problem before the surgeries. I was not delivered to my mother immediately after birth. I stayed in a government hospital for two more weeks to be monitored. I was first diagnosed with hypospadias.

At five months of age, my mother couldn't continue to breastfeed me and I began to vomit the food she gave me instead. The doctor who treated me recommended my mother to take me to the



“Hospital Infantil de México Federico Gomez” in Mexico City, and there they transferred me to endocrinology.

At 11 months, after several studies, I was diagnosed with salt-losing Congenital Adrenal Hyperplasia (CAH), and they started treating me with glucocorticoids, captopril and serum.

The only thing they told my mother is that they had to perform surgeries to make sure I was well, they never gave me the option to live with my body as it was. When I was 1 year and 10 months old, I had surgery to reduce the size of my clitoris, which I don't remember because of my early age.

What I remember well is when they operated on me for the second time. I had a vaginoplasty. I was 9 years old. It was a very painful surgery. Then came more bad memories of a life in hospital, with a new surgery at age 12 called “introitoplasty”. What affected me most was that from 9 to 18 years old, I underwent vaginal dilations, which consisted of the doctors introducing metal tubes of different sizes into the vagina that they created, which caused me a lot of pain, shame, and a trauma similar to rape.

I remember how during the vaginal dilations, the exams and when they took photographs of my genitals without my consent, I lay bent and with my legs spread apart, I covered my face with a sheet because I felt ashamed. Some of the doctors and nurses made fun of me, as if they were amazed by my shame and how I showed it.

The doctors never explained anything to my mother. We just had to accept that following their procedures and doing everything they say would be to my benefit.

The fourth and last surgery was a vaginal enlargement so that I could have intercourse when I was older.

With menstruation there were always problems, it was very irregular, the doctors always assumed that I was not taking the medications for CAH (cortisol), and I was prescribed several doses that failed. However, with each dose during which I had my period, after a while it stopped again.

Due to the medication with high doses of corticosteroids I suffered from Cushing's syndrome at 14 years old. I had a round face, swollen and red cheeks, a hump and stretch marks on my body. Fortunately, this was controlled, after they started to reduce the dose of the medication.

Because of all these experiences, I always assumed that being born with a body like mine was an illness and that the doctors will going to correct me, as if it was a malformation. At that time there wasn't so much information, and I had never considered that my body had anything wrong. Later I began to do research and I realised that these surgical procedures are not medically necessary and could be postponed until the person concerned is capable to decide on their own body.

Today I live with the consequences of these procedures: trauma, depression, partial insensitivity and scars. I hope my testimony helps that these medically unnecessary surgical procedures are no longer performed on infants and young children and that intersex people are given the opportunity to choose whether they want to be subjected to these or not.

## Case Study No. 5

*1985 born with inconspicuous genitalia, raised as a girl*

*Age 17 years due to absence of menstruation consultation with family doctor*

*Thereafter visit at a gynaecologist, who performs a ultrasound and genital examination, detecting a small lump in the right side of genitals*

*Sent to a paediatrician which sets appointment with the Seguro Social*

*From there sent to third-level clinic “Clínica 25 de la ciudad de Monterrey”, more examinations in front of many doctors*

*Parents are desperate and in tears, but person concerned is left in the dark and sent to see a psychologist*

*Age 19 orchiectomy (removal of abdominal testes), followed by complications, can't urinate; after the castration the person concerned is prescribed estrogens*

*A few days later doctors propose vaginal surgery, which the person concerned first refuses, but in the end decides to undergo surgery, although parents say it isn't necessary*

*After surgery painful, slow recovery, regular check-ups: doctor insert fingers to see, how deep the vagina goes, the procedure is very painful and humiliating*

*Doctors want to perform another surgery, to enlarge vagina, but she refuses and gradually stops attending appointments*

*Age 23 last appointment with endocrinologist, which discharges her, because she refuses estrogens and progress was non-existent.*

### **The person concerned tells her story:**

In 2002, my mother, concerned because I hadn't menstruated, asked for the opinion of the family doctor, who suggested to wait a few months more; however, her anguish and instinct led us to consult to the paediatrician [...] She spoke with my mom and sent us to the gynaecologist's room, it was something totally new to me. I was 16 years old and I had never been asked questions so intimate ever before, much less my body been touched like that. The gynaecologist did an ultrasound [...] he said he had to examine my intimate parts, he put new gloves and started to poke and probe, it wasn't too long before he found a small lump in the right side of my genitals. Until that moment, I hadn't given much importance to that lump, I never told anyone about it, it never was cause of pain or discomfort.

The gynaecologist asked me to wait outside the examination room, after several minutes my mother came out crying, we went to the car and asked her: “What's wrong? What did he tell you?” Silence was all I got for answer and when I insisted, she replied: “Nothing”. It was painful to watch my mother weep like that, to see the anguish in her eyes, she was shaking and in shock, I was the same so I stopped asking. My mother was still like that when we arrived home, she spoke with dad and he had the same reaction. I asked again: “What's wrong? What did I do wrong?”

A couple of days later the paediatrician set us an appointment in the Seguro Social and I was immediately sent to a third-level clinic [Clínica 25 de la ciudad de Monterrey, Nuevo León]. Everything went so fast that I didn't realise when I became surrounded by men and women in white coats, who looked at me like a freak, or so they made me feel, then my self-esteem plummeted and my happiness vanished.

I had never been in a hospital for so long, much less like this. My routine with the medical services started early in the morning. I had to be at my hometown's clinic at 3:30 AM to make the trip, I arrived exhausted and scared to the third-level clinic around 7:00 AM in the company of my

parents. There I had to go to Nuclear Medicine and other department which name I cannot remember, so they drew me blood samples. At 9:00 AM started the endless consultations with Genetics, Surgery, Endocrinology, Psychology, Urology, Psychiatrics, among others. The white coats spoke with many medical terms and stuff I didn't get, sometimes I had to wait alone in the waiting room; meanwhile the physicians spoke with my parents. At the end of those meetings, my mom showed signs of tears and my dad tried to show strength, but at the end the three of us succumbed to desperation and uncertainty.

When I was at Genetics, the doctor asked me all the time questions like: "Why don't you wear make-up? Why don't you dress more feminine? Would you like to depilate the eyebrow?" To me, those were empty questions to which I only said yes or no.

Soon after that I was sent to a psychologist, I never trusted her. I only wanted to know what was happening to me and when would everything end. Instead, she put me to draw and to tell stories, she even gave me assignments like search what was "5 alpha-reductase". I looked up that word in Internet and it appeared in a great number of medical notes that I never understood. One day she asked questions that made me uncomfortable: "Would you like to change? To be a man?" And my answer was: "What for? I'm a woman".

I didn't find answers until one day, I read my file and the first annotations was precisely from the psychologist, which stated that my behaviour, appearance and way of thinking was male. That lump turned out to be an undescended testicle, while the other was inside my abdomen, I was said it had to be removed to avoid a tumour or cancer. When I checked my file, in the majority of the sheets, the doctors had labelled me as follows: "Patient with a condition of male pseudohermaphroditism due to 5-alpha-reductase deficiency".

[...]

My first surgery was in 2004: orchiectomy. I have vague memories, maybe a denial of what happened to me or simply my mind blocked this stage to try to forget, even so, certain episodes come to my mind. I entered the surgical room in the morning, I was shaking from fear and a nurse said: "Don't worry, everyone here is to help you". They laid me down on that cold table and administered me many shots, after that I saw nothing but white coats fading and I fell asleep.

[...]

In recovery I had several complications, one of them was that I couldn't urinate and was all swollen, it was night time and there was no doctor available, I screamed and cried in pain, desperate I made a big mistake (and I accept it), I was cruel with my father blaming him: "Why did you bring me dad, for this?" He didn't reply, he only lowered his gaze and tears came from his eyes; meanwhile he pulled his hair with both hands. I confess that I still haven't apologised for that bad moment, and as I write these lines a lump is in my throat. Fortunately, a practitioner arrived, took out my parents, asked me some questions and read my file, he had to put a catheter between my legs so that I could urinate.

[...]

A few days later I had an appointment with the surgeon – I was still in pain and tired for what I had been through –, he confirmed that everything was in order, but how surprised I was when I heard him saying: "Are you ready for the next surgery?" Only a few hours had passed, how could

I be ready for another surgery? My answer was a resounding: “No”. I wanted to go back to my daily life, being at home and going to school, instead I was back to square one.

[...]

Yes, they offered me a vagina. For them it’s a synonym of happiness in my future life, when the moment comes of marrying I’ll have “sexual relations with my husband, like any other woman” and that “will make me happy”. I was in shock, I didn’t care for my future, I only wanted to run from the hospital.

[...]

I was caught in the middle, everything was confusing and my head was stacked with questions: “Why is this happening to me? Why, God, what did I do wrong? Why am I a freak?” There were moments when I considered taking my life away to end once and for all with the agony, but I couldn’t. Weeks before the appointment at the hospital to settle the next surgery – vaginoplasty –, my parents raised the topic. My dad wisely said not to undergo surgery, that it wasn’t necessary, and my mom mentioned that she supported any decision I made. One day before the appointment I decided, and not very convincingly said: “Yes”. I did it in part to end all of it and finally have peace and be happy. After two years since the first surgery I underwent vaginoplasty, which according to my file, consisted in taking a piece of intestine to put it between my legs.

This surgery was another trauma in my life, it was painful and the recovery was slow, I had catheters all over my body and all I wanted was to go home. When I was discharged, I rested a couple of days and returned for a medical check-up, that moment marked my life. I laid down on the examination table, my parents were with me and that doctor put on his gloves, counted till two, inserted his finger in my “vagina” as deep as possible and remained in there for what felt like an eternity. I cried because of the intense pain I was experiencing, but most of all, because of the humiliation I was suffering. This was the happiness everyone had talked about? When his finger came out, he said that everything was fine and that it looked like a regular vagina, it seems that his words had the intention of comforting me for what he had done to me. Since then I felt repulsion and rejection about my “happiness”.

[...]

I came back to the third-level hospital with the white coats, who wished to perform another surgery, a simpler one this time –according to them–, to enlarge my “happiness” and make it “functional when having intercourse with a male”. Apart from following a strict treatment of conjugated equine estrogens that I started taking after my first surgery, such medicine would serve for my body to take the shape of a “regular woman”, This time I was old enough to be more conscious and broke that protecting bubble to answer: “Not anymore”. They tried to convince me and sell me again that idea of happiness, but their strategy didn’t work anymore, I refused since then on and gradually stopped attending to appointments. The last time I went was in late 2008 with the endocrinologist, who didn’t have any choice but to discharge me because I wouldn’t take the estrogens and the progress was non-existent.

## E. Annexe 2 – Intersex, IGM and Non-Derogable Human Rights

### 1. Intersex = variations of reproductive anatomy

**Intersex persons**, in the vernacular also known as hermaphrodites, or medically as persons with “Disorders” or “Differences of Sex Development (DSD)”,<sup>106</sup> are people born with **variations of reproductive anatomy**, or “atypical” reproductive organs, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**.

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, with **1 to 2 in 1000 newborns** at risk of being submitted to non-consensual “genital correction surgery”.

*For more information and references, see 2014 CRC Switzerland NGO Report, p. 7-12.*<sup>107</sup>

### 2. IGM = Involuntary, unnecessary and harmful interventions

In “**developed countries**” with universal access to paediatric health care **1 to 2 in 1000 newborns** are at risk of being submitted to medical **IGM practices**, i.e. non-consensual, unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments that **would not be considered for “normal” children**, practiced without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs, and often **directly financed by the state** via the public health system.<sup>108</sup>

In **regions without universal access to paediatric health care**, there are reports of **infanticide**<sup>109</sup> of intersex children, of **abandonment**,<sup>110</sup> of **expulsion**,<sup>111</sup> of **massive bullying** preventing the

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106 The currently still official medical terminology “Disorders of Sex Development” is strongly refused by persons concerned. See 2014 CRC NGO Report, p. 12 “Terminology”.

107 [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

108 For references and general information, see 2015 CAT NGO Report Austria, p. 30-35,

<http://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf>

109 For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, <http://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf>

For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12,

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

For South Africa, see also <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens>

For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

<http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda> ; for Uganda, see also 2015 CRC Briefing, slide 46,

[http://intersex.shadowreport.org/public/Zwischengeschlecht\\_2015-CRC-Briefing\\_Intersex-IGM\\_web.pdf](http://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf)

For Kenya, see also <http://www.bbc.com/news/world-africa-39780214>

For Mexico, see 2018 CEDAW NGO Joint Statement, <http://stop.genitalmutilation.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018>

110 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

<http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

For example in China, see 2015 Hong Kong, China NGO Report, p. 15,

<http://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf>

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),<sup>112</sup> and of **murder**.<sup>113</sup>

Governing State bodies, public and private healthcare providers, national and international medical bodies and individual doctors have traditionally been **framing and “treating”** healthy intersex children as **suffering from a form of disability in the medical definition**, and in need to be **“cured” surgically**, often **with openly racist, eugenic and supremacist implications**.<sup>114 115 116 117</sup>

Both in “developed” and “developing” countries, **harmful stereotypes and prejudice** framing intersex as **“inferior”, “deformed”, “disordered”, “degenerated” or a “bad omen”** remain widespread, and to this day inform the current harmful **western medical practice**, as well as other practices including **infanticide and child abandonment**.

**Typical forms of medical 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.

Medical IGM practices are known to cause **lifelong severe physical and mental pain and suffering**,<sup>118</sup> 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.

**UN Treaty bodies and other human rights experts have consistently recognised IGM practices as a serious violation of non-derogable human rights.**<sup>119</sup> **UN Treaty bodies have so far issued 42 Concluding Observations condemning IGM practices accordingly.**<sup>120</sup>

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111 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

<http://stop.genitalmutilation.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

112 For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see

<http://stop.genitalmutilation.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3>

113 For example in Kenya, see <https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/>

114 2014 CRC NGO Report, p. 52, 69, 84, [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf)

115 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>

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

117 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>

118 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, *ibid.*, p. 38–47

119 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>

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

### 3. Intersex is NOT THE SAME as LGBT or Transgender

Unfortunately, there are also other, often interrelated **harmful misconceptions and stereotypes 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 is misrepresented 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 misrepresentations include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**<sup>121 122</sup> 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**,<sup>123</sup> maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT 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.<sup>124</sup>

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*”,<sup>125</sup> and again IGM survivors as “*transgender children*”,<sup>126</sup> “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”<sup>127</sup> and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.<sup>128</sup>

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*”,<sup>129</sup> “*a special provision on sexual orientation and*

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

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

123 For references, see 2016 CEDAW France NGO Report, p. 45

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

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

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

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

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

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

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

129 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>

gender identity”, “civil registry” and “sexual reassignment surgery”<sup>130</sup>, transgender guidelines<sup>131</sup> or “Gender Identity”<sup>132 133</sup> 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**<sup>134</sup> and public **representation**.<sup>135</sup>

#### 4. IGM is NOT a “Discrimination” Issue

An interrelated diversionary tactic is the **increasing misrepresentation by State parties of IGM as “discrimination issue”** instead of a serious violation of non-derogable human rights, namely inhuman treatment and a harmful practice, often in combination with the **misrepresentation of intersex human rights defenders as “fringe elements”**, and their legitimate demands and criticism of such downgrading and trivialising of IGM as “*extreme views*”. The first misrepresentation is also evident in the **Mexican State report** (see p. 7).

#### 5. IGM is NOT a “Health” Issue

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as “health-care issue”** instead of a serious violation of non-derogable human rights, and the **promotion of “self-regulation” of IGM by the current perpetrators**<sup>136 137 138</sup> – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee). This is also evident in the **Mexican State report** (see p. 7).

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**.<sup>139</sup>

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

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

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

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

134 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>

135 See e.g. “Instrumentalizing intersex: ‘The fact that LGBTs in particular embrace intersex is due to an excess of projection’ - Georg Klaua (2002)”, <http://stop.genitalmutilation.org/post/Instrumentalizing-Intersex-Georg-Klaua-2002>

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

137 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](http://stop.genitalmutilation.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf)

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

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