



# **Submission to the call for evidence for the initiative on the “Prevention of harmful practices against women and girls”**

Prepared by OII Europe (June – July 2022)

**OII Europe (Organisation Intersex International Europe)** is the European intersex umbrella organisation with intersex-led member organisations in 20 European countries. OII Europe advocates for the protection of intersex people’s human rights, raises awareness of intersex issues in society, e.g., through campaigns during Intersex Awareness Weeks, and supports the growth of the European intersex community together with its growing number of member organisations and allies through measures like the annual OII Europe Community Event & Conference.

OII Europe is a framework partner to the European Commission and holds expert status with the SOGI Unit of the Council of Europe. Since 2012 OII Europe has been regularly consulted on intersex issues by the Office of the United Nations High Commissioner for Human Rights, the Parliamentary Assembly of the Council of Europe, the Bioethics Committee of the Council of Europe, the European Parliament, the European Commission, the European Union Agency for Fundamental Rights, the European Network of Equality Bodies, the European Commission against Racism and Intolerance and national governments.

The NGO OII Europe was created in 2015, as an extension of a network of the same name set up in 2012, and is based in Berlin.

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***TRIGGER WARNING: description of harmful practices, including harmful medical interventions and (child) sexual abuse***

## Introduction

To this day, intersex individuals (also called: persons with a variation of sex characteristics), including but not limited to intersex women and girls experience severe fundamental rights violations across the EU. While intersex persons share the experience of structural and every day discrimination, as well as being targets of harassment, violence and hate speech with other highly vulnerable groups of the population, intersex persons are subjected to a form of harmful practice that is specific to them: intersex genital mutilation (IGM), i.e. non-vital, medical interventions to which persons born with a variation of sex characteristics are subjected to - often already in infancy or early childhood - without their free, personal and fully informed consent. These interventions aim to align their bodies with normative concepts of how a “female” or “male” body should look like. Intersex genital mutilation is flanked by other harmful practices, including but not limited to unconsented hormonal treatment, sterilisation or coerced and forced abortion of intersex fetuses on the grounds of their variation of sex characteristics. IGM has been identified by international human rights bodies, including the United Nations treaty bodies, as harmful practice, amounting to torture: Since 2009 UN committees, including the UN CEDAW, have issued 35 recommendations to 16 European Union member states, and called on them to end these and other violations of intersex persons’ fundamental rights.<sup>1</sup> The European Commission in its LGBTIQ Equality Strategy 2020-2025 has equally identified “non-vital surgery and medical intervention on intersex infants (intersex genital mutilation)” as “harmful practice”<sup>2</sup>.

Within the still existing binary framework, which recognizes only male and female, women

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<sup>1</sup> See OII Europe, *Intersex Resources*, available at <<https://oiieurope.org/wp-content/uploads/2021/08/International-intersex-human-rights-movement-Links-to-human-rights-documents-addressing-intersex-and-important-events-August-2021.pdf>> (it will be updated at the end of June 2022).

<sup>2</sup> European Commission LGBTIQ Equality Strategy 2020-2025, p. 15, available at <[https://ec.europa.eu/info/sites/default/files/lgbtiq\\_strategy\\_2020-2025\\_en.pdf](https://ec.europa.eu/info/sites/default/files/lgbtiq_strategy_2020-2025_en.pdf)>.

generally face far greater discrimination than men, as they are oppressed by power imbalances and harmful stereotypes that exert a strict control over their bodies and sexuality. This is equally evident in the medical establishment’s treatment of intersex people. In particular in the case of intersex women and girls, such practices are rooted in misogyny and a still prevalent understanding about the right of others to “fix” women who do not comply with societal norms. As a result of this entrenched notion, changing the genitalia of an intersex infant that has been identified as “female” to better align with “typical” female genitalia, is still a recommended and performed “treatment” across most EU countries. Such harmful practices, performed in infancy and early childhood, include, among others, operations on the vulva and the clitoris (including clitorrectomy and clitoris recession, i.e. the removal or retraction of the “too big” clitoris), and surgeries aiming to allowing for penetrative penis-into-vagina sexual intercourse in the future, as is the case with vaginoplasties. More importance is hence given to adhering to social expectations around sex and gender than to respecting the person’s bodily integrity and self-determination. Intersex children who are assigned as male, similarly experience “masculinizing” interventions. With an intersectional feminist approach, the intersex movement fights for the rights of all intersex persons, including but not limited to intersex women and girls.

In the following sections you will find more information about harmful practices against intersex women and girls, including evidence and testimonies as well as good practice examples and recommendations on how to protect intersex persons from harm. With this submission we would like to encourage the European Commission to explicitly include, in the framework of this specific initiative for prevention of harmful practices against women and girls, the protection of intersex women and girls against harmful practices in the scope of the recommendations. We would also like to encourage the European Commission to include all intersex persons in the scope of future recommendations against harmful practices.

## Evidence

### IGM

#### Definition and framework

**Intersex individuals** are born with sex characteristics (sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns) that do not fit the typical definition of male or female. The term “intersex” is an umbrella term for the spectrum of variations of sex characteristics that naturally occur within the human species. The term intersex acknowledges the fact that physically, sex is a spectrum and that people with variations of sex characteristics other than male or female exist.

The most severe harmful practice that affects intersex people is **Intersex Genital Mutilation (IGM)**, a non-vital intervention on a healthy intersex body. IGM is performed when, according to societal and medical notions, a person’s external genitals do not look or are considered not “normal” enough to pass as “male” or “female” genitals<sup>3</sup>: It alters the inner or outer genitalia of an intersex person’s body without the person’s own wish and without their personal, prior, free and fully informed consent.

Most often IGM is performed on infants and young children, including intersex girls, with follow-up surgeries when they grow up being common. IGM deprives those children of their human right to bodily integrity and self-determination. It sets them apart from non-intersex children who are not subjected to these interventions and carries multiple health risks for the child and the future adult.

**IGM breaches multiple fundamental rights** protected by regional and international Conventions and Charters including, among others, freedom from torture, human dignity, right

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<sup>3</sup> Dan Christian Ghattas, *Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist* (ILGA-Europe and OII Europe, 2019), p. 11, available at <<https://oiieurope.org/library-en/toolkit-cat/legal-toolkit/>>.

to bodily integrity, non-discrimination, best interest of the child, health protection<sup>4</sup>.

## Facts: effects and incidence

### *WHY DID THIS HAPPEN TO ME, DAD?*

*I remember asking this innocent question to my dad, sitting in a wheelchair in the parking lot of the hospital, after my first vaginoplasty. I was 8. My body was still sore from the operation and my mind and soul forever changed. I remember getting ready for an operation, which was barely ever done before. I was a rare case, was I told.*

*[...]*

*With the help of the intersex community, I then realized why this happened to me and the force of my question when I was 8. “Why did this happen to me?”*

*This happened to me because society wanted it to happen. Bodies that do not conform to societal standards of “normality” have to be corrected, surgically and/or hormonally. In order for this pseudo-normality to stay untouched, we all are rare cases. Keeping us apart, ashamed and in ignorance. Maybe ignorance is not bliss, after all<sup>5</sup>.*

### *MEDICAL REPORT*

*[...] At the time of the operation the new doctor examined me and found scars around my clitoris and labia, I talked to my parents and after month of fights they told me that it is true, that I had a genital operation when I was a baby and at that moment a lot of things where suddenly clear in my life, now I understood why I did not have any sexual feeling or could have an orgasm<sup>6</sup>.*

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<sup>4</sup> See: Charter of Fundamental Rights of the European Union, articles 1, 3, 4, 7, 21, 24, 35; European Convention on Human Rights, articles 3, 8, 14; European Social Charter, articles 11, 13; Convention on Human Rights and Biomedicine (Oviedo Convention), articles 5, 6, 8, 10; Universal Declaration of Human Rights, articles 1, 2, 5, 6, 7, 12; International Covenant on Civil and Political Rights, articles 2, 7, 16, 24, 26; Convention on the Rights of the Child, articles 3, 6, 8, 12, 16, 19, 24, 37; International Covenant on Economic, Social and Cultural Rights, article 12; Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, articles 1, 2, 4, 10, 14, 16; Convention on the Elimination of All Forms of Discrimination against Women, article 5.

<sup>5</sup> OII Europe, #MyIntersexStory. *Personal accounts by intersex people living in Europe* (November 2019), p. 59 available at <[https://oiieurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>. We include all of these testimonies and the additional information (e.g., country, age) as consented to by the respective intersex individuals.

<sup>6</sup> *Ibidem*, p. 8.

While none of the assumptions behind non-vital interventions on intersex bodies without the person's informed consent is evidence-based<sup>7</sup>, robust evidence exists as to their **harmful consequences**, namely: psychological trauma<sup>8</sup>, physical impairments including, but not limited to, painful scar-tissue<sup>9</sup> and lack of (general and/or erotic) sensation<sup>10</sup>, osteoporosis and osteopenia already at a very young age after the removal of gonadal tissue, urinary impairments as a result of interventions on the urethral tract, including from so-called “hypospadias repair” and other genital surgeries, and infections<sup>11 12</sup>.

Of the 439 participating intersex individuals of all ages in a 2007 German study, **almost 50% reported psychological problems and a variety of problems related to physical well-being and sex life**. Not only the adult respondents but also the children and adolescents reported significant disturbances, especially with their family life and in relation to their physical well-being. **81% of the participants had been subjected to one or multiple surgeries due to their “DSD” diagnosis**<sup>13</sup>. Two-thirds made a connection between those problems and the medical

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<sup>7</sup> See Kavot Zillén, Jameson Garland and Santa Slokenberga, *The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties*, Commissioned by the Committee on Bioethics for the Council of Europe (January 2017), p. 43, available at <<https://rm.coe.int/16806d8e2f>>.

<sup>8</sup> See: Surya Monro, Daniela Crocetti, Tracey Yeadon-Lee, Fae Garland and Mitch Travis, *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Research Report. University of Huddersfield (2017), available at <<https://pure.hud.ac.uk/en/publications/intersex-variations-of-sex-characteristics-and-dsd-the-need-for-c>>; The Netherlands Institute for Social Research: Jantine van Lisdonk, *Living with intersex/DSD: An exploratory study of the social situation of persons with intersex/DSD* (The Hague, August 2014), p. 44 and 76, available at <[https://www.researchgate.net/publication/290446986\\_Living\\_with\\_intersexDSD\\_An\\_exploratory\\_study\\_of\\_the\\_social\\_situation\\_of\\_persons\\_with\\_intersexDSD](https://www.researchgate.net/publication/290446986_Living_with_intersexDSD_An_exploratory_study_of_the_social_situation_of_persons_with_intersexDSD)>;

<sup>9</sup> Amnesty International, *First, do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany* (2017), p. 32, available at <<https://www.amnesty.org/en/documents/eur01/6086/2017/en/>>.

<sup>10</sup> Parliamentary Assembly, Promoting the human rights of and eliminating discrimination against intersex people. Report. Doc. 14404 (25 September 2017), part C, para. 25, available at <[https://pace.coe.int/en/files/24027/html#\\_TOC\\_d19e146](https://pace.coe.int/en/files/24027/html#_TOC_d19e146)>.

<sup>11</sup> N.S. Crouch, C.L. Minto, L.M. Laio, C.R. Woodhouse, S.M. Creighton (2004): Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study. *BJU Int.* 2004 Jan; 93(1):135-8.

<sup>12</sup> For personal testimonies of intersex people, see: OII Europe, *#MyIntersexStory. Personal accounts by intersex people living in Europe* (November 2019), available at <[https://oiieurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>. We include all of these testimonies and the additional information (e.g., country, age) as consented to by the respective intersex individuals.

<sup>13</sup> “Disorder of Sex Development (DSD)” is a medical umbrella term, which was introduced in 2006 by a Clinician Consensus Statement. Together with new categories of “syndromes”, it replaced the older medical terms. Some clinicians use DSD to stand for “differences of” or “diverse” sex development. However, in all its forms the term pathologises healthy variations of sex characteristics and refers to intersex sex characteristics



and surgical treatment they had been subjected to<sup>14</sup>.

A 2017 report confirm these findings: “The majority of individuals, in both Germany and Denmark, that Amnesty International spoke to who underwent medical interventions have experienced long-term negative physical or mental difficulties as consequences of the surgery, often compounded by a lack of information about what was done to them, as many have not been able to access their medical records”<sup>15</sup>.

As per the incidence of IGM, according to FRA findings from 2015, sex ‘normalising’ surgery is carried out on intersex children in **at least 21 EU Member States**<sup>16</sup>. Recent reports received by OII Europe from intersex organisations and intersex individuals show that **the number of interventions on children have not decreased** despite other claims, even in countries where guidelines exist that indicate to refrain from surgery.

More detailed statistical national surveys on the number of cases are still scarce. However, two full case studies on the frequency of feminising and masculinising operations on intersex children age 0-10 exist for Germany.<sup>17</sup>

The German study from 2019 had the objective to investigate “*whether there has been a decline in surgical "corrections" of "ambiguous" genitalia in children in Germany between*

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as characteristics that are “deviant” from the norm of male and female bodies and thus need to be “disambiguated” or “fixed”. The term “DSD” does not align with human rights standards.

<sup>14</sup> J. Woweries (2012): Deutscher Ethikrat. Stellungnahme zur Situation von Menschen mit Intersexualität in Deutschland. Berlin, p. 16-17, available at <[https://www.ethikrat.org/fileadmin/PDF-Dateien/Stellungnahmen\\_Sachverstaendige\\_Intersexualitaet/Woweries\\_-\\_Expertenbefragung.pdf](https://www.ethikrat.org/fileadmin/PDF-Dateien/Stellungnahmen_Sachverstaendige_Intersexualitaet/Woweries_-_Expertenbefragung.pdf)>.

<sup>15</sup> Amnesty International, *First, do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany* (2017), p. 9, available at <<https://www.amnesty.org/en/documents/eur01/6086/2017/en/>>.

<sup>16</sup> European Union Agency for Fundamental Rights, *The Fundamental Rights Situation of Intersex People. FRA Focus, 4/2015* (04/2015), p. 1 and 6, available at <<https://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>>.

<sup>17</sup> Josch Hoenes, Eugen Januschke, Ulrike Klöppel, *Häufigkeit normangleichender Operationen „uneindeutiger“ Genitalien im Kindesalter. Follow Up-Studie* (Bochum, 2019), available at <<https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-2>>; Ulrike Klöppel, *Zur Aktualität kosmetischer Operationen „un-eindeutiger“ Genitalien im Kindesalter*. Hg. von der Geschäftsstelle des Zentrums für transdisziplinäre Geschlechterstudien der Humboldt-Universität zu Berlin (Berlin, 2016), available at <[https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/bulletin-texte/texte-42/kloepffel-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen](https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/bulletin-texte/texte-42/kloepffel-2016_zur-aktualitaet-kosmetischer-genitaloperationen)>.

2005 and 2016”<sup>18</sup> To this aim, it analysed the relative frequency of “feminising” and “masculinising” interventions, i.e. the **frequency of such interventions** in relation to the **number of “variants of sex development” diagnoses**. The study concludes that “*The relative frequency of "masculinisation operations" on children under the age of ten with a main VSD [Variant of sex development, i.e. an intersex related] diagnosis remained relatively constant at 20 to 21 per cent in the study period from 2005 to 2016*” with “plastic reconstruction for male hypospadias” being the most frequently used procedure.<sup>19</sup>

As “feminizing operations” most frequently, “constructions and reconstructions of the vulva (and perineum)” were performed, followed by “operations on the clitoris” and “constructions and reconstructions of the vagina” and “other plastic reconstructions of the vagina”. However, the “*relative frequency of "feminisation operations" on children under ten years of age with a main VSD diagnosis*” ranged “*between 20 and 42 per cent in the years under review*”<sup>20</sup>. In other words, even though the number of registered interventions on children assigned male are substantial, the relative frequency of “**feminising**” interventions on female children have been **much higher (20-42% compared to 20-21%)** - that is: proportionally more female intersex persons were subjected to interventions on their genitalia than intersex persons assigned as male.<sup>21</sup> These findings match reports from OII Europe member organisations for other EU countries.

The 2019 FRA LGBTI II survey also shows high rates of incidence<sup>22</sup>. **62%** of the intersex survey respondents who were subjected to **surgery** say they did not provide – and were not

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<sup>18</sup> Josch Hoenes, Eugen Januschke, Ulrike Klöppel, *Häufigkeit normangleichender Operationen „uneindeutiger“ Genitalien im Kindesalter. Follow Up-Studie* (Bochum, 2019), p.4, available at <<https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-2>>

<sup>19</sup> *Ibidem*, p. 19

<sup>20</sup> *Ibidem*, p. 19

<sup>21</sup> As a sidenote, it is also important to know that hypospadias diagnoses and a so-called “hypospadias repair” intervention are usually simply coded as such, whereas the diverse interventions on female intersex children can often be hidden as secondary treatment under a primary code (e.g. the primary code registering a treatment for a urethral issue where at the same time, (unregistered) a clitoris recession is performed). Hence, it is much more difficult to get the proper numbers of interventions on female intersex children and therefore the numbers collected in the study need to be considered the minimum.

<sup>22</sup> European Union Agency for Fundamental Rights, *A long way to go for LGBTI equality* (14 May 2020), available at <<https://fra.europa.eu/en/publication/2020/eu-lgbti-survey-results>>

asked for – their own or their parents’ fully informed consent before their first surgical intervention to modify their sex characteristics. **Almost half (49%)** of those intersex respondents say that fully informed consent was not provided for **hormonal treatment**, or for any other type of medical treatment<sup>23</sup>.

Intersex people indeed are exposed to medical treatments other than (and often in combination with) surgery, in particular **hormonal treatment** which, if not administered based on their personal, prior, free and fully informed consent, equally amounts to a violation of their bodily integrity and self-determination. It is often reported that hormones are prescribed by physicians based on arbitrary binary “gender assignments” and assumptions about one’s gender identity<sup>24</sup>.

### IGM is a form of gender-based violence

Interventions performed on children assigned female present some **specificities** and evident **connections with other forms of violence against women and girls** such as FGM.<sup>25</sup> Similar to FGM, IGM against women and girls is aimed at **exerting social control over women’s physical appearance and over their sexuality**. Its unconcealed goals are “*to improve the cosmetic appearance of the genitals, to allow for vaginal-penile intercourse*”<sup>26</sup>. An intersex woman is expected to fulfil her role as a woman, which includes being able to have sexual intercourse, limited to penetrative heterosexual sex. An intersex woman must be put in the position to find a suitable partner, which allegedly will not be possible if her genitalia don’t align with the typical female body. What lies behind these assumptions is the same misogynist mindset that leads to intimate partner violence, rape and other forms of violence against women and girls. It is also worth noting that some intersex survivors have described the dilations that they had to experience to maintain the form of the vagina after the vaginoplasty as a form of

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<sup>23</sup> *Ibidem*, p. 53. See also OII Europe infographics, available at <<https://oiieurope.org/recent-survey-shows-high-rate-of-medical-interventions-on-intersex-people-lack-consent/>>.

<sup>24</sup> Amnesty International, *First, do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany* (2017), p. 37, available at <<https://www.amnesty.org/en/documents/eur01/6086/2017/en/>>

<sup>25</sup> For more details see below, p. 14

<sup>26</sup> Sarah Creighton, Steven D. Chernauseka, Rodrigo Romaode, Philip Ransley, Joao Pippi Sallef, “Timing and nature of reconstructive surgery for disorders of sex development – Introduction”, *Journal of Pediatric Urology*, 8 (2012), p. 603, available at <<https://www.sciencedirect.com/science/article/pii/S1477513112002367>>. Trigger warning: photos of interventions.

rape.<sup>27</sup>

Being a girl/woman (as such exposed to surveillance and control) and intersex (whose body does not conform with the typical female one) determines **increased vulnerability** and produces **multiple discriminations**, that result in the specific interventions of “feminisation” described above. It further results in other forms of violence, such as violence in medical settings, including **gynecological violence**. In the latter cases, again, harmful stereotypes around a “normal” body appearance (discrimination on the ground on sex characteristics) and around a “normal” woman’s (sexual) behaviour (discrimination on the ground of sex/gender) lead to episodes such as the following - accounted for by an intersex woman in Germany:

*“An intersex woman from Germany reported to OII Germany that she was regularly scolded since the beginning of puberty by different gynaecologists for not “allowing” them to insert their speculum in her vagina. Some of them went as far as to tell her that she should seek psychiatric help, implying that she was frigid. This intersex person has an intersex body and a variation that can cause a very narrow vagina. As a result, these kinds of bodies make it impossible to even use the smallest speculum (designed for girls), without causing substantial pain. As a result of these traumatizing experiences the intersex woman refuses to visit gynaecologists and has not had a preventive check-up in 8 years”<sup>28</sup>. Many other testimonies from various European countries can be found in national and regional organisations’ publications.<sup>29</sup>*

Another indication of how this practice affects women and girls specifically can be found in the misogynist attitudes towards female sexuality: Historically, a widespread notion among

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<sup>27</sup> See below, p. 16

<sup>28</sup> OII Germany: CEDAW Shadow Report. (20th of January 2017), Appendix, available at <[https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/DEU/INT\\_CEDAW\\_NGO\\_DEU\\_263\\_15\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/DEU/INT_CEDAW_NGO_DEU_263_15_E.pdf)>

<sup>29</sup> Intersex Greece, Shadow Report submitted to the Group of Experts on Action against Violence against Women and Domestic Violence (GREVIO) on 6 May 2022, pp. 3-5, available at <[https://rm.coe.int/greece-2022-shadow-report-grevio-cbr/1680a675f7?fbclid=IwAR1OiUovdT-NvgMG7R63\\_VX8Q5N9gYAPSIft0a6nQTdV8J6YAHKvEJ-g8iU](https://rm.coe.int/greece-2022-shadow-report-grevio-cbr/1680a675f7?fbclid=IwAR1OiUovdT-NvgMG7R63_VX8Q5N9gYAPSIft0a6nQTdV8J6YAHKvEJ-g8iU)>; OII Europe, #MyIntersexStory. *Personal accounts by intersex people living in Europe* (November 2019), p. 21, available at <[https://oiiurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiiurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>.

medical doctors was that “*it is easier to make a hole than to build a pole*”.<sup>30</sup> However, this notion was not just about lack of craftsmanship, but also very much rooted in a **misogynist** attitude: vaginas have been conceived as holes, places to put something in, that are not even required to be sensitive at all. That is precisely why it has been said that a “*functional*” vagina can be constructed in virtually everyone “because it is relatively easy to construct an insensitive hole surgically”.<sup>31</sup> While this claim will no longer be found in the latest medical literature and protocols, the sexist component continues to inform the contemporary techniques which, as stated above, still prioritise normative assumptions about a woman’s body and sexuality over protecting her dignity, bodily integrity and self-determination.

Among many other UN mechanisms repeatedly condemning IGM<sup>32</sup>, in 2013 Juan E. Mendés, the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, issued a strongly worded statement condemning non-consensual surgical intervention on intersex people as **a form of torture**. His report says: “Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex”<sup>33</sup>. He thus points out that behind this form of violence lies **socially constructed gender expectations**.

The **Committee on the Elimination of Discrimination against Women** repeatedly showed concern about reports of IGM cases and recommended that State parties “[a]dopt clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other

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<sup>30</sup> Jörg Woweries, “Who has a Disorder? Who gets to Decide?”, in the book *Normed Children* (December 2018), p. 99, <[https://www.researchgate.net/publication/355817435\\_Who\\_has\\_a\\_Disorder\\_Who\\_gets\\_to\\_Decide](https://www.researchgate.net/publication/355817435_Who_has_a_Disorder_Who_gets_to_Decide)>

<sup>31</sup> Alice Domurat Dreger, “Ambiguous Sex--or Ambivalent Medicine?”, *The Hastings Center Report* May/June 1998, Volume 28, Issue 3, pp. 24-35, <[https://isna.org/articles/ambivalent\\_medicine/](https://isna.org/articles/ambivalent_medicine/)>

<sup>32</sup> The Office of the High Commissioner for Human Rights, *Background Note on Human Rights Violations against Intersex People*, 8, available at <<https://www.ohchr.org/EN/Issues/Discrimination/Pages/BackgroundViolationsIntersexPeople.aspx>>. See also OII Europe’s Resource List – which includes all the intersex specific recommendations – at <<https://oiieurope.org/international-intersex-human-rights-movement-resource-list/>>.

<sup>33</sup> United Nations General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez (A/HRC/22/53), para. 77, available at <[https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf)>.

medical treatment on intersex children until they reach an age at which they can provide their free, prior and informed consent”<sup>34</sup>.

The **European Parliament**, in its 2021 resolution on identifying gender-based violence as a new area of crime, has identified **intersex genital mutilations as a form of gender-based violence and a form of femicide** and has called on Member States to ban female and intersex genital mutilation<sup>35</sup>.

Only a few countries – to a varying and limited extent – explicitly ban IGM<sup>36</sup>. The currently still prevailing differentiation between FGM and IGM in most EU Member States is largely arbitrary. **FGM and IGM share many common characteristics**, including but not limited to the desire to preserve and assert domination over women and girls and to exert social control over their sexuality. Individuals who are subjected to FGM or IGM experience gender-based violence. In particular, the two harmful practices are both:

- **Framed in terms of the need to be accepted socially**; however, for many intersex people, surgeries in their childhood and teenage years did not improve their situation concerning social inclusion or marginalisation.

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<sup>34</sup> CEDAW/C/DEU/CO/7-8. See also, among others, CEDAW/C/BGR/CO/8, CEDAW/C/AUT/CO/9, CEDAW/C/LUX/CO/6-7, CEDAW/C/ITA/CO/7, CEDAW/C/IRL/CO/6-7, CEDAW/C/NLD/CO/6, CEDAW/C/EST/CO/5-6, CEDAW/C/FRA/CO/7-8, CEDAW/C/SVK/CO/5-6. About the understanding of IGM as a form of GBV in the EU policy context, see OII Europe’s submissions to the European Commission: OII Europe, *Preventing and combatting gender-based violence and domestic violence against intersex individuals* (10.5.2021), available at <[https://oiieurope.org/wp-content/uploads/2021/05/2020\\_Submission-OII-Europe\\_Gender-based-and-domestic-violence\\_FINAL.pdf](https://oiieurope.org/wp-content/uploads/2021/05/2020_Submission-OII-Europe_Gender-based-and-domestic-violence_FINAL.pdf)> and OII Europe, *Towards an evaluation of the Victims’ Rights Directive* (22.10.2021), available at <[https://oiieurope.org/wp-content/uploads/2021/10/OII-Europe-Submission-Victims-Rights-Directive\\_FINAL.pdf](https://oiieurope.org/wp-content/uploads/2021/10/OII-Europe-Submission-Victims-Rights-Directive_FINAL.pdf)>.

<sup>35</sup> European Parliament resolution of 16 September 2021 with recommendations to the Commission on identifying gender-based violence as a new area of crime listed in Article 83(1) TFEU, Recital H and M, Article 28 (2021/2035(INL)).

<sup>36</sup> Malta: Gender Identity, Gender Expression And Sex Characteristics Act, 14th April 2015, art. 14, available at <<https://legislation.mt/eli/cap/540/eng/pdf>>; Portugal: Lei n.º 38/2018 de 7 de agosto. Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa, art. 5, available at <[https://www.pgdlisboa.pt/leis/lei\\_mostra\\_articulado.php?nid=2926&tabela=leis&ficha=1](https://www.pgdlisboa.pt/leis/lei_mostra_articulado.php?nid=2926&tabela=leis&ficha=1)>; Iceland: Lög nr. 154 29. desember 2020. Lög um breytingu á lögum um kynrænt sjálfræði, nr. 80/2019 (óðæmigerð kyneinkenni), available at <<https://www.althingi.is/lagas/nuna/2019080.html>> and <<https://www.althingi.is/altext/stjt/2020.154.html>>; Germany: Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung. Vom 12. Mai 2021, available at <[https://www.bgbl.de/xaver/bgbl/start.xav?start=//\[\\*\]@attr\\_id=%27bgbl121s1082.pdf%27#\\_bgbl\\_%2F%2F%27%5B%40attr\\_id%3D%27bgbl121s1082.pdf%27%5D\\_1642090566815](https://www.bgbl.de/xaver/bgbl/start.xav?start=//[*]@attr_id=%27bgbl121s1082.pdf%27#_bgbl_%2F%2F%27%5B%40attr_id%3D%27bgbl121s1082.pdf%27%5D_1642090566815)>.

- **Motivated by beliefs about what is considered acceptable sexual behaviour;** in the case of intersex people, the ultimate goal of those performing IGM is to allow for penetrative intercourse of the future adult and for an alleged ability to procreate. Neither the impossibility to foresee the future intersex adult's gender identity, sexual orientation or sexual preference, nor the fact that the capacity for penetrative intercourse may be less important for the intersex adult than unharmed genitalia are taken into account.
- **Motivated by the notion that parts that are not considered female (or male) enough should be removed;** in the case of intersex people this includes interventions on infants and children such as clitoris reduction/recession, removing the labia, moving the opening of the urethra to the tip of the penis, to name but a few.
- **Impactful on the person's life and health;** in the case of intersex people this includes impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, increased sexual anxieties, problems with desire, infertility issues and lifelong trauma, including feelings of child abuse and sexual abuse.

One of the clearest examples of the gendered component of this harmful practice is **vaginoplasty**, a so-called “feminising” intervention which is performed on children and even infants. Vaginoplasty requires manual maintenance in the form of penetrative **dilation** by either a physician or parent, and can require additional “corrective” interventions<sup>37</sup>. Many intersex survivors of this practice describe it as a form of rape<sup>38</sup>. When one considers that this surgery is performed solely for the purpose of creating a body that can have **penetrative heterosexual sex**, the gendered element of the practice becomes very apparent.

The same is true for the **operations on the vulva**, that among the “feminising” operations on intersex children registered in Germany annually, according to the above cited study, have been

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<sup>37</sup> Surya Monro, Daniela Crocetti, Tracey Yeadon-Lee, Fae Garland and Mitch Travis, *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Research Report. University of Huddersfield (2017), p. 9, available at <<https://pure.hud.ac.uk/en/publications/intersex-variations-of-sex-characteristics-and-dsd-the-need-for-c>>.

<sup>38</sup> *Ibidem*, p. 18.

the most frequent. Cosmetic reasons linked to beliefs about how “proper” female body and female genitalia should look are still allowed to prevail over the child’s bodily integrity and self-determination.

The above-mentioned German study registered a slight decrease only in **operations on the clitoris**, from about 10% (in relation to the number of diagnoses) per year in 2005-2014 to about 6% per year for 2015-2016<sup>39</sup>. In numbers however, this still means that in Germany alone 175 operations were performed from 2005 to 2016 (9 to 22 annually) on intersex girls whose clitoris was deemed “enlarged” or “malformed” based on stereotypical standards about femininity. In other words, institutionalised gender-based violence has continued to take place in medical settings, while the same cuts on non-intersex girls would have been prosecuted as a crime.

## Forced sterilisation

*I was sterilised while I was still relatively young. My parents were told that if they did not consent I would probably get cancer and that the organs were useless tissue anyway. Of course they said yes. What parent would not. If I were in the same situation without any real information I probably would. I only found out when I was older that it was healthy and functional gonadal tissue. That is what my medical records said. They did not need to take them. I have needed to be on hormones since I was a teenager<sup>40</sup>.*

Involuntary, coercive and forced **sterilisation** (= sterilisation without full, free and informed consent) infringes various fundamental rights, including the person’s dignity and self-determination and their right to be free from torture<sup>41</sup>. As part of so-called “normalising”

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<sup>39</sup> Josch Hoenes, Eugen Januschke, Ulrike Klöppel, *Häufigkeit normangleichender Operationen „uneindeutiger“ Genitalien im Kindesalter. Follow Up-Studie* (Bochum, 2019), p. 16, available at <<https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-2>>.

<sup>40</sup> OII Europe, #MyIntersexStory. *Personal accounts by intersex people living in Europe* (November 2019), p. 67 available at <[https://oiiurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiiurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>.

<sup>41</sup> WHO, *Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement* (2014), p. 1, available at <[https://apps.who.int/iris/bitstream/handle/10665/112848/9789241507325\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/112848/9789241507325_eng.pdf?sequence=1)>.



treatments, some intersex children and adolescents are subjected to gonadectomy, the surgical removal of the gonads, which is irreversible, results in sterilisation and requires lifelong **hormone treatment**<sup>42</sup>.

The removal of gonads has been justified with the aim - based on false beliefs and binary norms - of ensuring a proper gender development and preventing the emergence of traits considered to be undesirable, such as growth of facial hair in a child assigned female: alignment with **social expectations about gender** has been considered more important than respecting the person's own wishes and rights. In some cases, another aim has been found in preventing an **alleged cancer risk**, which is unsubstantiated by data<sup>43</sup>. On the contrary, removing gonads has been found to increase, among others, the risk of cardiovascular disease and osteoporosis<sup>44</sup>.

Some providers may refuse to acknowledge that the procedures they are performing are sterilisations when the child's capacity for fertility **does not match the gender assignment**. For example, if the child is assigned female, the doctor in charge may believe that they would not have any use for testes, even though their testes could produce viable sperm (or might gain that capacity through future medical advances). Involuntary sterilisation through non-consensual non-vital gonadectomy limits the child's and future adult's exercise of **reproductive freedom**<sup>45</sup>. However regardless of the potential for fertility, non-vital removal of gonads - unless is based on personal, prior, free and fully informed consent - is a  **mutilation** and can, as such, be considered a form of torture. In addition, removal of the hormone producing gonadal tissue leads to dependency of the future adult on hormone substitution with artificial hormones - if those are not covered by health insurance, or in times of drug supply

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<sup>42</sup> Amnesty International, *First, do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany* (2017), p. 34, available at <https://www.amnesty.org/en/documents/eur01/6086/2017/en/>.

<sup>43</sup> *Ibidem*, p. 28

<sup>44</sup> *Ibidem*.

<sup>45</sup> Tamar-Mattis, Anne, *Sterilization and Minors with Intersex Conditions in California Law* (2012). The Circuit. Paper 40, p. 132-133, available at <https://www.californialawreview.org/wp-content/uploads/2014/10/Sterilization-and-Minors-with-Intersex-Conditions-in-California-L.pdf>.

shortages<sup>46</sup> intersex persons whose hormone producing tissue was removed without their wish and free and fully informed consent are at high risk to suffer long-lasting health impairments, including osteopenia and osteoporosis at a very early age (as early as 18 years old, as reported to OII Europe) as a consequence of lack of hormones in their bodies (and, in some cases, despite hormonal substitution therapy).

As per the **incidence** of gonadectomies, available data is scarce. The above cited 2016 study from Germany reported that, in Germany alone, 19 gonadectomies were performed on intersex children younger than 10 between 2005 and 2009, 11 were executed between 2010 and 2014. The data do not show whether these were carried out because of an alleged cancer risk. On intersex children/adolescents aged 10 to 19 (mostly registered as **female**), 23 gonadectomies were performed in the first half of the study period and 21 in the second half<sup>47</sup>.

## Forced abortion and prenatal treatments

*[...] Unfortunately my first obstetric doctors in the local hospital were not that well-informed: they call us on a hospital counselling meeting (two of them) and insisted that the “standard procedure” was to terminate ANY XXY foetus, cause they will be “A freak! A monster! A nature’s fault! Someone like with Down syndrome, a dump person incapable of living on its own! A boy with a so small phallus, so better not to be at all” (these were their exact words...) Since we were informed that all these was false and outdated, we insisted on keeping the baby and they refuse to deliver it, so they made us sign papers that we continue on our own responsibility and they send me to an Athens central hospital to find new doctors to carry on.” (Greece, parent of an intersex child, born 2009)<sup>48</sup>.*

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<sup>46</sup> As happened in 2019, e.g. in Germany; drug supply shortages have become an increasingly common risk, see e.g. <<https://www.pharmaceutical-technology.com/pricing-and-market-access/drug-supply-shortages-in-germany-html/>>.

<sup>47</sup> Ulrike Klöppel, *Zur Aktualität kosmetischer Operationen ,un-eindeutiger‘ Genitalien im Kindesalter*. Hg. von der Geschäftsstelle des Zentrums für transdisziplinäre Geschlechterstudien der Humboldt-Universität zu Berlin (Berlin, 2016), p. 8 and 48-49, available at <[https://www.gender.hu-berlin.de/de/publikationen/gender-bulletin-broschueren/bulletin-texte/texte-42/kloepfel-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen/view](https://www.gender.hu-berlin.de/de/publikationen/gender-bulletin-broschueren/bulletin-texte/texte-42/kloepfel-2016_zur-aktualitaet-kosmetischer-genitaloperationen/view)>.

<sup>48</sup> OII Europe, #MyIntersexStory. *Personal accounts by intersex people living in Europe* (November 2019), p. 33 available at <[https://oiieurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>.

Because being intersex in itself is still seen as a disorder, when pre-implantation diagnosis or prenatal screening show a “risk” of variations of sex characteristics in embryos and fetuses, both may be prevented from further developing<sup>49</sup>. Several parents from different European countries have reported to OII Europe that they were under huge **pressure from doctors to abort** their intersex child.

Even when not amounting to explicit pressure, the lack of unbiased, evidence-based and non-pathologizing information to parents may equally prevent them from taking an **informed decision**. Access to safe abortion is a fundamental right, however it cannot be exercised if it is not based on correct, human rights based and updated information. Delivering such information should then be part of broader efforts to protect the right of pregnant persons to have access to sexual and reproductive health services<sup>50</sup>.

Another still very common intervention on female intersex persons starts already before the child is born: In order to prevent female fetuses, who are considered to possibly have a variation of sex characteristics diagnosed as CAH (“congenital adrenal hyperplasia”), from developing in a “sexually atypical fashion”, pregnant women are treated “at risk” for having an affected daughter with the steroid dexamethasone. As research shows this intervention aims at *“preventing development of ambiguous genitalia, the urogenital sinus, tomboyism, and lesbianism”* and starts *“as soon as pregnancy is confirmed”*. It continues *“throughout the pregnancy if the foetus is ultimately diagnosed as a CAH-affected female”*. However, if *“several weeks into the dosing the foetus is determined to be male or not CAH-affected, the*

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<sup>49</sup> Surya Monro, Daniela Crocetti, Tracey Yeadon-Lee, Fae Garland and Mitch Travis, *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Research Report. University of Huddersfield (2017), p. 19-20, available at <<https://pure.hud.ac.uk/en/publications/intersex-variations-of-sex-characteristics-and-dsd-the-need-for-c>>.

<sup>50</sup> Office of the High Commissioner for Human Rights, UNFPA, UNICEF, UN Women and World Health Organization, *Preventing Gender-Biased Sex Selection: An Interagency Statement* (World Health Organization (WHO), Geneva, 2011). The Statement calls to “Ensure women’s access to safe abortion and other services – efforts to manage or limit sex selection should also not hamper or limit access to safe abortion services. This should be part of broader efforts to protect the right of women to have access to legitimate sexual and reproductive health technologies and services”, p. 10, available at <[https://apps.who.int/iris/bitstream/handle/10665/44577/9789241501460\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/44577/9789241501460_eng.pdf)>.

*intervention is immediately stopped, because the intention is only to alter the course of development in CAH-affected females”.*<sup>51</sup> Sweden, since 1999, has discontinued the use of the drug for foetal treatment as a long-term study showed impaired verbal working memory, correlating with the children's self-perception of difficulties in scholastic ability and an increased social anxiety.<sup>52</sup>

Dexamethasone has also proven to impact the health of the parent carrying the child<sup>53</sup>.

## Insufficient prevention, protection, support and access to justice

*He put his hands on my butt and pulled me further down on the bench. He administered the hormones and they really hurt, a lot. I cried. It had never hurt before. He examined my genitals, his face was very close, I could feel his breathing on my genitals. My doctor never did that, even the one time I had needed a genital examination. I started panicking. I was frozen and could not move, it was hard to breathe and I started seeing black spots. Then he stuck his fingers inside of me and moved them back and forth. He asked me if I felt it, if I liked it... His smile was very creepy. I could not answer. I could not breathe. He stood up and told me to get up and get dressed. Then I had to pay him. It took me many years to realise that this was rape. No one ever talked about rape where I lived except about violent strangers that attacked women and forcibly and violently held them to rape them, rape always involved a penis. It was not until I met feminist groups later in my life that I realised that THIS WAS RAPE and I had paid someone after they raped me.*

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<sup>51</sup> Alice Dreger, Ellen K. Feder, Anne Tamar-Mattis, “Prenatal Dexamethasone for Congenital Adrenal Hyperplasia. An Ethics Canary in the Modern Medical Mine”, *Bioethical Inquiry* (2012) 9:277–294, available at <[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3416978/pdf/11673\\_2012\\_Article\\_9384.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3416978/pdf/11673_2012_Article_9384.pdf)>

<sup>52</sup> T. Hirvikoski, A. Nordenström, M. Ritzén, A. Wedell, S. Lajic (2012): Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint, in: *The Journal of Clinical Endocrinology & Metabolism* 2012 June; 97(6), p. 1881-3, available at <<https://doi.org/10.1210/jc.2012-1222>> ; Anna Nordenström, Martin Ritzén (2016): Vårdprogram för kongenital binjurebarkhyperplasi CAH (adrenogenitalt syndrom, AGS). Barnläkarföreningens sektion för endokrinologi och diabetes. [http://endodiab.barnlakarforeningen.se/wp-content/uploads/sites/9/2015/02/VP\\_2016-CAH.pdf](http://endodiab.barnlakarforeningen.se/wp-content/uploads/sites/9/2015/02/VP_2016-CAH.pdf)

<sup>53</sup> A 2010 medical study found an increased frequency of symptoms attributable to hypercortisolism in the child-carrying person exposed to dexamethasone such as oedema and striae after a period of 1–5 years after the pregnancy, see: M. Merce Fernandez-Balsells, Kalpana Muthusamy, Galina Smushkin et. al., *Prenatal dexamethasone use for the prevention of virilization in pregnancies at risk for classical congenital adrenal hyperplasia because of 21-hydroxylase (CYP21A2) deficiency: a systematic review and meta-analyses*, in: *Clinical Endocrinology* (2010), 73, 436–444.

*I still can not talk about it. I might never be able to*<sup>54</sup>.

There is still a long way to go until intersex persons can feel safe and respected and, when they are subjected to a fundamental rights violation, they can obtain a comprehensive response, including a judicial one. Unfortunately, most EU Member States continue to fail to ensure sufficient **prevention, protection, support and access to justice** to intersex people.

Intersex people regularly speak in self-help groups and report to national intersex NGOs or to OII Europe that they are at risk of **sexual harassment** in medical settings, including in some cases rape, and are exposed to degrading examinations, verbal violence and derogatory comments<sup>55</sup>. In addition, a severe **lack of knowledge** about intersex people, the fundamental rights violations they face and the specific needs that follow from these experiences still exists among medical practitioners<sup>56</sup>. It is often matched with personal bias that can result in disbelief and insults, the refusal to perform needed examinations, and examinations being carried out in violent ways or without the intersex person's consent.

When seeking medical help for issues directly related to their sex characteristics, diagnosis or sexuality, intersex people often face highly **insensitive and violent behaviour**. For example, a 2014 Dutch study on the experience of intersex people in different areas of life emphasised that six out of seven spoke “with a great deal of emotion about poor information, insensitive communication and discourteous treatment”<sup>57</sup>.

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<sup>54</sup> OII Europe, #MyIntersexStory. *Personal accounts by intersex people living in Europe* (November 2019), p. 68 available at <[https://oiieurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>.

<sup>55</sup> See the Shadow Report submitted to the Group of Experts on Action against Violence against Women and Domestic Violence (GREVIO) by Intersex Greece on 6 May 2022, p. 3-4 and 7, available at <[https://rm.coe.int/greece-2022-shadow-report-grevio-cbr/1680a675f7?fbclid=IwAR1OiUovdT-NvgMG7R63\\_VX8Q5N9gYAPSifT0a6nQTdV8J6YAHKvEJ-g8iU](https://rm.coe.int/greece-2022-shadow-report-grevio-cbr/1680a675f7?fbclid=IwAR1OiUovdT-NvgMG7R63_VX8Q5N9gYAPSifT0a6nQTdV8J6YAHKvEJ-g8iU)>. See also OII Germany: CEDAW Shadow Report. (20th of January 2017), available at <[https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/DEU/INT\\_CEDAW\\_NGO\\_DEU\\_26315\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/DEU/INT_CEDAW_NGO_DEU_26315_E.pdf)>.

<sup>56</sup> Parliamentary Assembly, Promoting the human rights of and eliminating discrimination against intersex people. Report. Doc. 14404 (25 September 2017), part C, paras. 49-50, available at <[https://pace.coe.int/en/files/24027/html#\\_TOC\\_d19e146](https://pace.coe.int/en/files/24027/html#_TOC_d19e146)>.

<sup>57</sup> The Netherlands Institute for Social Research: Jantine van Lisdonk, *Living with intersex/DSD: An exploratory study of the social situation of persons with intersex/DSD* (The Hague, August 2014), p. 54, available at <[https://www.researchgate.net/publication/290446986\\_Living\\_with\\_intersexDSD\\_An\\_exploratory\\_study\\_of\\_the\\_social\\_situation\\_of\\_persons\\_with\\_intersexDSD](https://www.researchgate.net/publication/290446986_Living_with_intersexDSD_An_exploratory_study_of_the_social_situation_of_persons_with_intersexDSD)>. For testimonies of rape in medical settings, see: OII Europe,

Treatments and medications needed as a direct consequence of so-called “normalising” interventions are often not covered by **health insurance**. This can include, for example, life-long hormone substitution therapy after the removal of hormone-producing tissue in order to prevent osteopenia and osteoporosis<sup>58</sup>.

Lack of adequate **psycho-social counselling** for intersex people is still commonplace in Europe: a 2015 German survey found that of 630 participants (intersex adults, parents of intersex children, counselling professionals and intersex experts), only 4% considered the existing counselling services to be sufficient. 90% of the participants found the existing counselling services insufficient for intersex adults and 95% pointed to the lack of offers for intersex children and adolescents. 95% found the counselling option for parents of intersex children to be insufficient. Almost all participants considered comprehensive counselling services important in order to “avoid premature decisions”<sup>59</sup>. These data confirm previous research who had demonstrated that parents of intersex children who are provided with medicalised information are almost three times more likely to consent to surgery than those who receive **de-medicalised information**<sup>60</sup>.

The **support must be accessible** as well: 76% of the study’s participants wished for support offers in their immediate vicinities and 59% wished for a minimum of several contact points

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#MyIntersexStory. *Personal accounts by intersex people living in Europe* (November 2019), p. 44-46, 69-70, available at <[https://oiieurope.org/wp-content/uploads/2019/11/testimonial\\_broch\\_21-21cm\\_for\\_web.pdf](https://oiieurope.org/wp-content/uploads/2019/11/testimonial_broch_21-21cm_for_web.pdf)>.

<sup>58</sup> Dan Christian Ghattas, *Human Rights Between the Sexes. A preliminary study on the life situation of inter\* individual* (Berlin: Heinrich Boll Foundation, 2013), p. 22, available at <[https://www.boell.de/sites/default/files/endl\\_human\\_rights\\_between\\_the\\_sexes.pdf](https://www.boell.de/sites/default/files/endl_human_rights_between_the_sexes.pdf)>.

<sup>59</sup> Bundesministerium für Familie, Senioren, Frauen und Jugend, *Dokumentation Fachaustausch: „Beratung und Unterstützung für intersexuelle Menschen (i. S. v. Menschen mit angeborenen Variationen der Geschlechtsmerkmale) und ihre Familien“ 4. November 2015. Begleitmaterial zur Interministeriellen Arbeitsgruppe Inter- & Transsexualität – Band 3* (Berlin, June 2016), p. 13, available at <<https://www.bmfsfj.de/blob/123144/40905d00b0bc5d9722523bb6f9e29824/imag-band-3-beratung-undunterstuetzung-fuer-intersexuelle-menschen-data.pdf>>.

<sup>60</sup> See Jürg C Streuli 1, Effy Vayena, Yvonne Cavicchia-Balmer, Johannes Huber, “Shaping parents: impact of contrasting professional counseling on parents’ decision making for children with disorders of sex development”, *Journal of Sexual Medicine*, Vol. 8 No. 3 (2013), pp. 1953–1960, available at <<http://www.ncbi.nlm.nih.gov/pubmed/23742202>>.

and advisory services per federal state<sup>61</sup>.

The **Covid crisis** has exacerbated an already dire situation. Among the intersex respondents to OII Europe 2020 Covid survey, 40% reported that their doctor appointments were postponed and 22% that they had their appointments cancelled during the crisis. 21% reported that they don't have access to a doctor who has the necessary expertise with their intersex body and 14% currently have no access to a doctor that they trust<sup>62</sup>.

Among the respondents, 40% stated that they follow a medicine taking regime on regular basis, which may include, but is not limited to, hormone substitution as a result of surgically induced loss of hormone-producing tissue. Of those, in July 2020 64% took their medicine as regularly as they did before the pandemic, but 28% who follow a regime on regular basis reported that they had to stop or will eventually **stop taking their medicine**<sup>63</sup>.

Finally, intersex people who want to **seek justice** for the harm inflicted on them by medical doctors face huge difficulties in accessing their (full) **medical records**, either because the retention period has expired or because of the stigma and secrecy surrounding their situation<sup>64</sup>. Even when they manage to get them, their claim may be time-barred. Retention periods and **statutes of limitations** are not designed to consider that intersex people often find out as adults that they underwent harmful treatment, because of the silence and taboo surrounding them, and once they find it out, they need time to process and heal before even thinking about going

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<sup>61</sup> Bundesministerium für Familie, Senioren, Frauen und Jugend, *Dokumentation Fachaustausch: „Beratung und Unterstützung für intersexuelle Menschen (i. S. v. Menschen mit angeborenen Variationen der Geschlechtsmerkmale) und ihre Familien“* 4. November 2015. Begleitmaterial zur Interministeriellen Arbeitsgruppe Inter- & Transsexualität – Band 3 (Berlin, June 2016), p. 14, available at <<https://www.bmfsfj.de/blob/123144/40905d00b0bc5d9722523bb6f9e29824/imag-band-3-beratung-undunterstuetzung-fuer-intersexuelle-menschen-data.pdf>>

<sup>62</sup> OII Europe, *COVID-19. A report on the situation of intersex people in Europe and Central Asia*. Authored by Dan Christian Ghattas, with Irene Kuzemko. Questionnaire developed by Irene Kuzemko (Berlin, 2020), p. 18, available at <<https://www.oiiurope.org/covid-19-survey-report/>>.

<sup>63</sup> *Ibidem*, p. 19.

<sup>64</sup> Parliamentary Assembly, Promoting the human rights of and eliminating discrimination against intersex people. Report. Doc. 14404 (25 September 2017), part C, para. 52, available at <[https://pace.coe.int/en/files/24027/html#\\_TOC\\_d19e146](https://pace.coe.int/en/files/24027/html#_TOC_d19e146)>.

before court<sup>65</sup>.

Due to these obstacles, limited case-law exists. Among **civil lawsuits**<sup>66</sup>, the first successful case was launched in Germany, filed only three months before the statutes of limitation expired. The claimant sued her surgeon for surgeries performed on her without her consent. The court ruled that "the defendant illegally, in a deliberate and culpable manner, injured the plaintiff's health by removing his [sic.] female sex organs" without full consent about the nature, content and extent of the surgery<sup>67</sup>. Another case was filed in Munich in 2012: the claimant agreed to a settlement as the person couldn't afford to continue a costly, lengthy civil lawsuit<sup>68</sup>. In 2015, another case in Germany was ruled positively. An intersex person sued their surgeon for surgeries that were performed on them without their fully informed consent as a young adult<sup>69</sup>. The Court found the hospital guilty of not fulfilling its duty to fully inform the claimant about their variation of sex characteristics and about the consequences and possible long-term effects of the surgeries and hormone therapy they were subjected to.

The first known **criminal lawsuit** on non-vital interventions on an intersex person was initiated in France. An intersex person, assigned to the female sex at birth, was subjected to several invasive operations during their childhood and adolescence. In their adulthood they filed a criminal complaint and constituted themselves as a civil party. They claimed that "these medical acts had been carried out not only without therapeutic interest, but also in the absence of her consent, as well as of prior information from which she and her parents should have benefited" and that they qualified as "aggravated violence resulting in permanent mutilation or disability". The investigating judge issued an order refusing to inform on the grounds of the

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<sup>65</sup> Dan Christian Ghattas, *Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist*. (ILGA-Europe and OII Europe, 2019), p. 38-39, available at <[https://oiieurope.org/wp-content/uploads/2020/09/OII-Europe\\_ILGA-Europe\\_Protecting-Intersex-People-in-Europe\\_Appendix.pdf](https://oiieurope.org/wp-content/uploads/2020/09/OII-Europe_ILGA-Europe_Protecting-Intersex-People-in-Europe_Appendix.pdf)>.

<sup>66</sup> See *Ibidem*, APPENDIX, p. 36.

<sup>67</sup> Regional Court of Cologne 25 O 179/07, available at <[http://www.justiz.nrw.de/nrwe/lgs/koeln/lg\\_koeln/j2008/25\\_O\\_179\\_07grundurteil20080206.html](http://www.justiz.nrw.de/nrwe/lgs/koeln/lg_koeln/j2008/25_O_179_07grundurteil20080206.html)>.

<sup>68</sup> See the NGO Report (for Session) to the 6th Report of Germany on the Convention against Torture (CAT), January 2019, compiled by StopIGM.org / Zwischengeschlecht.org, p. 28, available at <[https://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/DEU/INT\\_CAT\\_CSS\\_DEU\\_33753\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/DEU/INT_CAT_CSS_DEU_33753_E.pdf)>.

<sup>69</sup> LG Nürnberg-Fürth (Germany), Urteil v. 17.12.2015 – 4 O 7000/11, available at <<https://rewis.io/urteile/urteil/zqu-17-12-2015-4-o-700011/>>.



statute of limitations of the public action. The Court of Appeal confirmed the order. Lastly, the Court of Cassation dismissed the appeal. The Court did not accept the appellant's argument that “the weight of a dominant thought, which reflects the state of society at a given time, [...] when it leads to a person being kept in ignorance of the fact that they were subjected to acts likely to be classified as criminal, is such as to constitute an insurmountable obstacle to the prosecution of the offence, so as to suspend the running of the statute of limitations”<sup>70</sup>. The case was brought before the European Court of Human Rights, which recent decision finds the complaint inadmissible, but sets the basis for the qualification of IGM as torture<sup>71</sup>.

More precisely, the Court found the complaint under article 3 ECHR - which prohibits torture and inhuman and degrading treatment - inadmissible for failure to exhaust domestic remedies, i.e., because allegedly the applicant had failed to raise this complaint before the appropriate domestic court. However, despite leaving open the question whether non-vital medical interventions on intersex persons without their informed consent qualify as torture, the Court provided several arguments in support of a positive conclusion, which appears likely to be drawn the next time a similar case is examined. Notably, it stated that “the sterilisation of a person without a therapeutic purpose and without his or her informed consent is thus in principle incompatible with respect for human freedom and dignity and constitutes treatment contrary to Article 3 [...]. The same applies to **genital mutilation** [...] in particular when performed on a child” (para. 62).

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<sup>70</sup> French Court of Cassation, Criminal Division, 6 March 2018, Appeal No. 17-81.777, available at [https://www.courdecassation.fr/decision/5fca991b4320138e2ce45972?search\\_api\\_fulltext=&sort=&items\\_per\\_page=&judilibre\\_chambre=&judilibre\\_type=&judilibre\\_matiere=&judilibre\\_publication=&judilibre\\_solution=&op=&date\\_du=2018-03-06&date\\_au=2018-03-06&page=1](https://www.courdecassation.fr/decision/5fca991b4320138e2ce45972?search_api_fulltext=&sort=&items_per_page=&judilibre_chambre=&judilibre_type=&judilibre_matiere=&judilibre_publication=&judilibre_solution=&op=&date_du=2018-03-06&date_au=2018-03-06&page=1).

<sup>71</sup> See OII Europe press release (May 24, 2022) at <https://oiieurope.org/m-v-france-decision>.

## Good practice examples

Here follows a selection of good practice examples that help provide prevention, protection and support. More examples can be found in the section dedicated to all the annual Maps at OII Europe website<sup>72</sup>.

### Training

The Austrian intersex-led organisation VIMÖ held up to 60 workshops, consultations and speeches on the topic of intersex human rights, commissioned by private universities, companies and public institutions including: Public Employment Service Austria (AMS - Arbeitsmarktservice), UN-Globe, **Medical University Vienna**, Ärztekammer Oberösterreich (Austrian **Medical Chamber** of Upper Austria), **Health University** of Applied Sciences Tyrol, Österreichisches Hebammen-Gremium (Austrian **Midwives Board**), The (administrative) staff of Johannes Kepler University Linz, TU Wien (Vienna University of Technology), The University of Applied Sciences Campus Vienna, The executives of Österreichische Post AG (the Austrian postal service company).

This good practice example highlights that:

- Intersex-led organisations have the expertise and the capacity to give training to a wide range of entities
- It is crucial that training is provided by intersex experts that promote a depathologizing, destigmatising and empowering perspective
- Proper compensation for training is necessary to acknowledge that expertise and to ensure sustainability<sup>73</sup>.

Also OII Europe has provided extensive training for midwives, in collaboration with a German charity umbrella organisation.

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<sup>72</sup> See <<https://oiieurope.org/library-en/map/>>.

<sup>73</sup> See OII Europe 2020 Good Practice Map at <<https://oiieurope.org/good-practice-map-2021/#training>>.

Other positive examples exist also outside of the European Union. In Belgrade, a multidisciplinary team systematically refer parents of children with variations of sex characteristics to the intersex-led NGO XY Spectrum, which provides comprehensive human rights based information.

## Peer-counselling

VARGES is a project of the intersex-led organisation *VIMÖ/OII Austria*, providing services of education about sex and gender diversity and peer counselling in cooperation with the private funder *HIL Foundation*, with a part-time position to set up and coordinate the whole project. The team of VARGES, along with other intersex people who joined the team, acquire a peer-counselling certificate, which has been funded by ÖKUSS (Austrian Social Insurance Company)<sup>74</sup>.

This good practice example highlights that:

- intersex-led human rights-based organisations provide high quality, professional services and deserve more financial support to make them sustainable,
- peer-counselling is an essential service that draws from intersex people's unique expertise and lived experience,
- intersex-led human rights-based organisations need direct funding (both from the private and the public sector) and paid staff<sup>75</sup>.

Similar initiatives have been set up by other OII Europe member organisations, e.g. in France (Collectif Intersexe Activiste, CIA) or Switzerland (InterAction).

## Campaigns

In 2020 in France, the interministerial delegation against racism, antisemitism and anti-LGBT+ hatred funded the campaign „Intersex: Justice, now!“ created by the national intersex-led

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<sup>74</sup> Find out more about the project at <<https://varges.at>>.

<sup>75</sup> See OII Europe 2020 Good Practice Map at <<https://oiieurope.org/good-practice-map-2020/#fund>>.

organisation Collectif Intersexes et Allié.e.s-OII France. The campaign provides intersex people with information about their rights (especially regarding medical records), financially supports civil and penal complaints as well as psychological support. It has a dedicated website and new brochures and poster, and a training program for civil society organisations to help spreading awareness and support intersex people locally.

This good practice example highlights that:

- enabling intersex-led human rights-based organisations to take the lead on an awareness raising campaign allows for tailored and impactful activities and a dissemination of accurate and meaningful information
- financial support is key to allow these organisations to use their expertise to the full extent
- public funding sends the message to society that intersex people and their rights are valued, increases social acceptance of intersex people and intersex organisations in society
- intersex-led human rights-based organisations provide a wide range of services, on a local and national level, which need and deserve to be financially supported<sup>76</sup>.

## Awareness raising

The German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) provides an LGBTI portal including intersex issues, the *Regenbogenportal* (Rainbow Web Portal). It offers support to LGBTI people, as well as their friends and relatives and professionals working with people of diverse gender identities, sexual orientations and sex characteristics.

The articles

- are written in clear language
- give overviews on major intersex topics, e.g. what it means being intersex, having an intersex child, or the violation of intersex people in the health system.

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<sup>76</sup> See the French campaign at <<https://droits-intersexes.fr/>>. See OII Europe Good Practice Map 2020 at <<https://oiieurope.org/good-practice-map-2020/>>.

- are written or proof-read by intersex people
- offer information about the portal as well as a glossary in six languages, incl. Easy Language, and Sign Language<sup>77</sup>.

## Funding

Malta was the first government to fund a regional intersex organisation and one of the few governments that has funded intersex-led organisations at all. The grant was tailored to the intersex organisation's needs by

- being core/operational funding
- being a multi-annual grant allowing for flexibility and rapid-response reallocation of funds
- acknowledging and highlighting the importance of intersex human rights work in Europe.

The Dutch government has provided a national, intersex-led organisation with sustainable funding with grants of 5 and 3-year duration<sup>78</sup>.

## Research

The 2019 qualitative study “No information or options. Study on the rights and experiences of intersex persons”, commissioned by the Finnish Ministry of Justice and the Ministry for Foreign Affairs, brings to light life experiences of intersex people living in Finland. The study

- a. is a strongly participatory study
- b. was conducted with ongoing consultation of intersex-led groups and organisations
- c. bases its findings on an assessment of actual healthcare needs of intersex people and their families
- d. was conducted within a sociological instead of a medical framework
- e. has a human rights baseline and perspective

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<sup>77</sup> Find the portal at <<https://www.regenbogenportal.de>>.

<sup>78</sup> See OII Europe Good Practice Map 2019 at <<https://oiieurope.org/good-practice-map-2019/>>.

- f. includes and discusses good practices from other countries
- g. provides recommendations on how to implement intersex human rights in on national level<sup>79</sup>.

## Data collection

Since 2014 the German Family Ministry has funded several studies on the life situation of intersex people and their families, including on counselling or the situation of parents. It also funded the first-ever study on feminising and masculinising genital surgeries carried out on intersex children under the age of 10. The study is a best practice example of how to conduct a retrospective statistical data assessment of surgeries on people with variations of sex characteristics. It

- covers 10 years (2005-2014), hence allowing for a statistically valid analysis of changes
- uses the DRG hospital statistics, which is an annual complete survey of the hospitals obliged to transmit data and the services they provide; the statistics include, among other information like age, the diagnoses (via ICD-Codes) and the performed surgeries (via OPS-Codes, the German surgeries and procedures code)
- includes all relevant ICD-Codes
- is a full study, i.e. includes all relevant cases for the chosen time-frame
- was conducted by a sociologist with in-depth knowledge about the medicalisation of intersex people and statistical expertise
- included consultations with intersex human rights experts
- was followed by a second study, equally funded by the Ministry, covering the years 2015-16, to ensure continuous monitoring<sup>80</sup>.

## Policy action

In 2020 the French government launched an action plan on LGBTI-phobia, under the responsibility of the interministerial delegation against racism, antisemitism and anti-LGBT+

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<sup>79</sup> See the OII Europe 2019 OII Europe Good Practice Map at <https://oiieurope.org/good-practice-map-2019/>.

<sup>80</sup> See the OII Europe 2018 OII Europe Good Practice Map at [https://oiieurope.org/wp-content/uploads/2019/05/gpmap2018\\_web.pdf](https://oiieurope.org/wp-content/uploads/2019/05/gpmap2018_web.pdf).

hatred.

The implementation of this plan is monitored by a committee, with the intersex-led organisation Collectif Intersexes et Allié.e.s-OII France being one of its members. CIA-OII France has been working with the interministerial delegation on a summary sheet for public administrations in regard to the respect for intersex rights.

Who else: The Irish National LGBTI+ Inclusion Strategy addresses intersex-related issues. It includes commitment to fill data gaps and document current practice. The intersex-led organisation Intersex Ireland has a representative in the government appointed committee.

These good practice examples highlight that:

- independent monitoring of the activities conducted as part of any LGBTIQ\* strategy is key to ensure successful implementation,
- committees monitoring the implementation and results of activities that aim to increase protection of intersex individuals benefit greatly from the specific expertise of intersex-led human rights-based organisations as these have in-depth and long-term knowledge of the situation and of the challenges, including discrimination and other human rights violations intersex people face in their respective country<sup>81</sup>.

In October 2021, the Finnish government published the first implementation plan for the National Child Strategy, containing measures to secure the wellbeing of children.

The intersex organisation ISIO will have a seat on the panel in charge of developing a uniform model for the provision of first information to families, where it will spur a human rights based approach and accentuate psychosocial support.

This good practice example highlights that:

- Consulting intersex-led organisations is essential
- First steps can be taken from the government in any country to protect intersex people's rights<sup>82</sup>.

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<sup>81</sup> See OII Europe 2020 Good Practice Map at <<https://oiieurope.org/good-practice-map-2020/#fund>>.

<sup>82</sup> See OII Europe 2021 Good Practice Map at <<https://oiieurope.org/good-practice-map-2021/>>.

## IGM legislation

In the last years, new countries have started discussion on bills aimed at restricting non-vital interventions on intersex children and some have also adopted them<sup>83</sup>. This marks a **positive trend** towards putting an end to IGM in Europe, with the years of awareness raising and advocacy work done by intersex activists across European countries coming into fruition.

However, it is crucial that now that they are starting to pay attention to intersex voices and demands, national governments and parliaments are aware of the **pitfalls to avoid** and the gaps to fill in when they draft legislation, so that the objective of protecting the rights of intersex children can be fully achieved. The following paragraphs are meant to support Member States in the drafting process, provided that they also consult the national intersex organisation(s) which are the best placed to give expert advice based on knowledge of and tailored to the national context.

Please also refer to our recommendations about protection, in the chapter “Recommendations” above<sup>84</sup>.

## Malta

### What the law says

Article 14 of the Gender Identity, Gender Expression and Sex Characteristics Act<sup>85</sup> provides:

- Sex-assignment treatments or surgeries on the sex characteristics of the minor, if these can be deferred until the person can provide informed consent, are unlawful.

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<sup>83</sup> See section “In the making: put an end to IGM” in OII Europe 2021 Good Practice Map at <<https://oiieurope.org/good-practice-map-2021/#in-the-making-put-an-end-to-igm>>.

<sup>84</sup> The recommendations can also be found in Dan Christian Ghattas, *Protecting Intersex people in Europe. A toolkit for law and policy makers. With digital Appendix and Checklist* (ILGA-Europe and OII Europe, 2019), and especially the accompanying *Checklist*, available at <<https://oiieurope.org/library-en/toolkit-cat/legal-toolkit/>>

<sup>85</sup> Gender Identity, Gender Expression And Sex Characteristics Act, 14th April 2015, art. 14, available at <<https://legislation.mt/eli/cap/540/eng/pdf>>.



- These interventions/treatments may be carried out if the minor gives informed consent through the person exercising parental authority or the tutor.
- Medical interventions driven by social factors without the minor's consent are prohibited.
- Medical practitioners or other professionals in breach of this article shall, on conviction, be liable to the punishment of imprisonment or to a fine.
- In exceptional circumstances treatment can be effected once agreement is reached between the interdisciplinary team and the persons exercising parental authority or tutor of the minor who is still unable to provide consent.

### Comment

The Maltese Act is currently the best example among the existing laws regulating interventions on intersex children. The law:

- Provides clear and human rights-based definitions of terminology (e.g. sex characteristics)
- Comprehensively addresses all kinds of medical treatments (not only surgical)
- Ensures universality, in that the bodily integrity protection is universal to all persons, not limited to specific variations or diagnoses
- Prohibits treatments that can be deferred until the minor is able to make their own decisions and provide informed consent
- Allows for treatment on an infant's or child's sex characteristics in cases of emergency, provided that any medical intervention which is driven by social factors without the consent of the minor is a violation of the law.
- Provides for legal sanctions for medical and other professionals in case the law is breached.
- Establishes the right to expert-sensitive and individually tailored, life-long psychological and psychosocial support.

## Portugal

### What the law says

Lei n.º 38/2018<sup>86</sup> states (authors' translation):

#### *Article 4*

##### *Protection of sexual characteristics*

*All people have the right to maintain their primary and secondary sex characteristics.*

#### *Article 5*

##### *Changes to the body and to the sex characteristics of the intersex minor*

*Except in situations of proven risk to their health, surgical, pharmacological or other treatments or interventions that involve changes to the body and sex characteristics of the intersex minor shall not be performed until their gender identity is manifested.*

### Comment

The law fails in providing a comprehensive ban on non-vital interventions, namely:

- It allows interventions when there is a proven health risk, which may not be interpreted as restricted to emergency situations
- It allows interventions, regardless of a proven health risk, when the minor's gender identity has manifested even if they are not capable of providing informed consent.

## Germany

### What the law says

The law “on the protection of children with variants of sex development”<sup>87</sup>:

- makes treatments solely performed for aligning the intersex child's body to a more normative appearance and without their fully informed consent unlawful;
- requires the approval of the family court for surgical interventions that “cannot be

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<sup>86</sup> Lei n.º 38/2018 de 7 de agosto. Direito à autodeterminação da identidade de género e expressão de género e à proteção das características sexuais de cada pessoa, available at <[https://www.pgdlisboa.pt/leis/lei\\_mostra\\_articulado.php?nid=2926&tabela=leis&ficha=1](https://www.pgdlisboa.pt/leis/lei_mostra_articulado.php?nid=2926&tabela=leis&ficha=1)>.

<sup>87</sup> Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung. Vom 12. Mai 2021, available at <[https://www.bgb1.de/xaver/bgb1/start.xav?start=/\\*\[@attr\\_id=%27bgb1121s1082.pdf%27\]#\\_bgb1\\_%2F%2F\\*%5B%40attr\\_id%3D%27bgb1121s1082.pdf%27%5D\\_1642090566815](https://www.bgb1.de/xaver/bgb1/start.xav?start=/*[@attr_id=%27bgb1121s1082.pdf%27]#_bgb1_%2F%2F*%5B%40attr_id%3D%27bgb1121s1082.pdf%27%5D_1642090566815)>.

postponed” until the child can decide for themselves

- extends the retention period for medical records
- provides for an interdisciplinary commission to issue an opinion.

### Comment

On the positive side the law provides a first, yet non-comprehensive, framework towards protecting intersex children from non-vital, non-emergency medical interventions. There is room for improvement, due to the following:

- Lack of universality – pathologizing stance: The medical term ‘variants of sex development’ excludes from protection intersex children who, from a current medical perspective, do not fall under this definition. It also perpetuates a pathologizing perspective.
- Risk of interventions in the lack of health needs: Interventions that may be approved include those “necessary to cure or eliminate a functional disorder or to preserve the ability to reproduce, without there being any real risk to health at the present time, even if they have the effect of altering physical appearance”.
- The “consolidated wish” of the child, even if they are incapable of giving informed consent, may also justify an intervention; this carries the risk of misuse due to still existing social pressure.
- The law does not differentiate between physical and potential (presumed) mental health needs.
- Composition of the interdisciplinary commission: The majority can still consist of staff of the same health care facility. The involvement of a peer counsellor is not mandatory.

For a more in-depth analysis, please consult the Appendix below, which reproduces the content of our informative webpage on IGM legislation<sup>88</sup>.

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<sup>88</sup> See information at <<https://oiieurope.org/igm-legal/#germany>>.

## Iceland

### What the law says

The Act 80/2019, as amended by Act 154/2020<sup>89</sup>, regulates interventions on intersex minors. It stipulates that if the child is incapable of giving consent, an intervention can only be performed if health needs so require. It also sets up a ministerial committee in charge of approving interventions. A working group must be formed within the following three years to review the law.

### Comment

A major problem is the explicit exclusion of certain intersex variations from protection, that in the medical environment are designated as pathologies within the binary model i.e. “hypospadias” and “micropenis”. It is also regrettable that potentially any health needs – not limited to only urgent ones – are considered as reasons for intervening.

## France

### What the law says

Chapter I bis of Title III of Book I of the second part of the Public Health Code<sup>90</sup> stipulates that:

- Multidisciplinary teams of the centres of reference for specialised rare diseases are consulted, their consultation establishes the diagnosis as well as the possible therapeutic proposals, including therapeutic abstention, and their foreseeable consequences
- This information and the opinion resulting from the consultation shall be included in the child's medical file
- Full information and appropriate psychosocial support are provided to the child and their family
- Parents are informed of the existence of associations specialising in the support of

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<sup>89</sup> Lög nr. 154 29. desember 2020. Lög um breytingu á lögum um kynrænt sjálfræði, nr. 80/2019 (ódæmigerð kyneinkenni), available at <<https://www.althingi.is/lagas/nuna/2019080.html>> and <<https://www.althingi.is/altxt/stjt/2020.154.html>>.

<sup>90</sup> LOI n° 2021-1017 du 2 août 2021 relative à la bioéthique, article 30, available at <<https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000043884384>>.

intersex people.

- The consent of the minor must be systematically sought if they are capable of expressing their wishes and participating in the decision.
- The Government shall submit to the Parliament a report on the activity and functioning of the centres of reference, with the number of interventions performed.

### Comment

While steps forward are the inclusion of the possibility of therapeutic abstention, the stipulation that parents need to be informed about the existence of intersex associations and the reporting obligation, this law does **not** introduce any explicit ban on non-vital interventions before the person's free and fully informed consent. Other problematic points include:

- Use of a pathologising terminology (variation du développement génital)
- Introduction of a higher degree of institutionalisation, by reinforcing the power of the centres of reference, while not giving any indication about the composition of the multidisciplinary teams
- Lack of acknowledgement of past and ongoing harm<sup>91</sup>.

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<sup>91</sup> See Collectif Intersexe Activiste - OII France press release at <<https://cia-oiifrance.org/droits-intersexes-le-combat-continue/>>; OII Europe press release at <<https://oiieurope.org/france-lacks-understanding-of-intersex-human-rights-violations/>>.

## Recommendations

### Prevention

In order to prevent violations of intersex persons' fundamental rights, OII Europe we strongly encourage the Commission to recommend that Member States should:

- Establish comprehensive **awareness raising measures** for the general public
- Include intersex people and the existence of more than two biological sexes in a positive and empowering way in school curricula, textbooks and **education** materials
- Establish obligatory human rights-based **training** on intersex and intersex issues for professionals working in the areas of:
  - health including doctors, midwives, psychologists and other professionals working in the health sector (e.g. reception desk staff)
  - mental health and counselling professionals
  - education
  - law enforcement
  - elderly care
  - teachers, social workers, school psychologists and school staff
  - trade unions and work councils
  - medical officers and company physicians
- Improve **data collection** and address research gaps, by adhering to the following parameters:
  - Research on intersex must ask about experiences, not about identity
  - Intersex people should not be researched only as a subgroup of LGBTI but as an independent part of the population; data segregation is key
  - Work together with intersex-led organisations and intersex-led peer support groups
  - Consult with intersex activists and organisations when creating questionnaires AND when analysing and contextualising the data

## Protection

In order to ensure protection of intersex people's right to health, self-determination and bodily integrity, we strongly encourage the Commission to recommend that Member States should adopt laws that explicitly:

- **prohibit** any non-vital, non-emergency surgical or other interventions unless the intersex person has provided personal, free and fully informed consent
- establish adequate **legal sanctions** for medical professionals who conduct of any non-vital, non-emergency surgical and/or other interventions which can be deferred until the intersex person is mature enough to provide informed consent.
- establish an **independent working group** composed in equal measure of human rights experts, intersex peer experts, psychosocial professionals and medical experts, to review and revise treatment protocols
- establish the right to **expert-sensitive counselling** with providers trained to work with intersex people
- extend the **retention period** for medical records to at least 40 years
- extend the **statutes of limitations** for surgical and/or other interventions to at least 20 years, and suspend them until the minimum age of 21 of the person concerned
- allow for surgical and/or other reversible and irreversible interventions on a mature minor, if the mature minor gives **personal and fully informed consent**
  - establish the presence of an independent third party to take part in the process, in order to guarantee consent principles
- establish the **legal obligations for medical professionals** to:
  - to inform the individual comprehensively about the treatment, including other possible medical options and details about risks and possible long-term consequences and effects, based on up-to-date medical information
  - provide detailed minutes of the consultation to the patient and their parent(s) or legal guardian(s)
- **end the coverage** of Intersex Genital Mutilation by the public and private health system.
- ensure that regulations and practices in public and private sectors do not bypass national

protection and anti-discrimination legislation and provisions.

## Support

In order to provide adequate support to intersex people, we strongly encourage the Commission to recommend that Member States should:

Establish

- the right to obtain **treatment** which is based on the individual's physical needs and is not limited by the sex/gender marker in their official documents
- the right to **lifelong coverage** of any medication needed as a result of surgical and/or other interventions on the sex characteristics of a person, by national health insurance reimbursement systems
- the right to access coverage for any treatments that is **not limited by the sex/gender** marker in a person's documents
- the right to **counselling** and support for all concerned individuals and their families
- the right of survivors of intersex genital mutilation (IGM) to access **reparative treatment**
- the right of access to **medical records**.

Take measures to

- ensure intersex people's and their families' **psychosocial and peer support**
- establish professional intersex **peer counselling** (i.e. peer support by trained peer counsellors)
- ensure specialised **support services** are available to the victims of harmful practices, including intersex genital mutilation
- recognise intersex victims as victims with **specific needs**, by including, but not limited to, adequate training of professionals working in the area of victim support on how to support intersex victims
- include intersex and intersex issues in all **medical curricula** and curricula in the area of health
- include positive and empowering information about the existence of intersex people in **information material directed to future parents**.



## Access to justice

In order to allow intersex people to access justice, we strongly encourage the Commission to recommend that Member States should:

- extend the **retention period** for medical records of to at least 40 years in order to allow intersex people access to their medical records at a mature age.
- extend the **statutes of limitations** to at least 20 years, and suspend them until the minimum age of 21 of the person concerned.
- establish **adequate legal sanctions** for medical and other professionals who conduct any sex-“normalising”, sex-“assigning” or sex-altering surgical or other interventions which can be deferred until the person to be treated is mature enough to provide informed consent.

## Appendix - German IGM law

On 12th May 2021 in **Germany** a **law** was adopted “**on the protection of children with variants of sex development**”. It sets a yet non-comprehensive framework to preserve intersex children from non-vital, non-emergency medical interventions, while some obstacles persist in the way towards full protection<sup>92</sup>.

### What the law says

The law envisions **three possible situations**, in relation to intersex children who are **incapable of giving consent**:

- Interventions “carried out **solely with the intention of bringing the child’s physical appearance into line with that of the male or female sex**”  
→ *In this situation **interventions are unlawful and parental consent is not possible** as the law prohibits parents or legal guardians to “consent to treatment of a child who is incapable of giving consent and who has a ‘variants of sex development’<sup>93</sup> which, without any other reason for the treatment being added, is carried out solely with the intention of making the child’s physical appearance similar to that of the male or female sex”. (§ 1631e (1.1))*
- Surgical interventions that “**could result in an approximation** of the child’s physical appearance to that of the male or female sex”, if they are “**necessary to avert a danger to the child’s life or health** and cannot be postponed until approval has been granted”  
→ *In this case **parental consent is possible without any additional procedure**, as the justification of the law details: “If there is a danger to life or health and an operation must be performed quickly, it must be assumed that the child would give priority to*

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<sup>92</sup> See OII Europe informative webpage at <<https://oiieurope.org/igm-legal/#germany>>.

<sup>93</sup> The German law creates a new legal term, “Variante der Geschlechtsentwicklung” (“variant of sex development”). This terminology should not be confused with the human rights compliant term “variation of sex characteristics”. Instead it is equivalent with the diagnostic and pathologising term “disorder/difference of sex development” and used this way throughout the act..

*averting this danger if he or she had full capacity of understanding and judgement; such an operation is **therefore permitted without authorisation** under the narrow condition mentioned. [...] Subsequent authorisation by the family court is not provided for in such cases. However, the possibility of a later review under criminal or civil law remains open.”*

- Surgical interventions that “**could result in an approximation** of the child’s physical appearance to that of the male or female sex”, and in cases where “the procedure **cannot be postponed until the child has made a self-determined decision of his or her own**” → are lawful, provided that approval is granted by the **family court**, after having established that “the planned intervention is in the **best interests of the child**” (§ 1631e (1.3); however, exceptions to the family court procedure are granted to surgical interventions that are deemed urgently necessary in order to “avert danger to the child’s life or health and cannot be postponed until approval has been granted”. In order to prove that the planned procedure is in the best interest of the child the parents need to submit to the family court an opinion of an interdisciplinary commission, which consists of:
  - The attending medical doctor
  - Another medical doctor (from a different health care facility)
  - A psychologist, child psychotherapist or child psychiatrist
  - A person trained in ethics

## Positive points

The law:

- Is a first step towards comprehensive protection of intersex children from non-vital, non-emergency medical interventions
- makes surgeries solely performed for aligning the intersex child’s body to a more normative appearance and without the fully informed consent of the child unlawful
- Establishes a family court approval procedure for interventions which aim to eliminate a perceived functional disorder

- does *not* follow the proposal tabled by one party to explicitly exclude children with a CAH diagnosis – these children are one of the biggest groups suffering from non-vital medical interventions
- extends the retention period for medical records until the age of 48
- provides for an interdisciplinary commission to issue an opinion on whether the child’s best interest is being considered
- Provides examples of the most common non-vital surgical interventions that family courts should consider as falling under §1631e (1.1) and hence as prohibited, thereby providing additional guidance to courts
- exemplifies that the Federal Government is aware of and acknowledges some of the possible legal gaps of the current version of the law, and is committed to extend the protection in the future by providing for an evaluation of the law after 5 years. This evaluation will include an obligatory examination by the Federal Government about whether an extension of the provisions is appropriate in the following respects:
  - “extending the family court approval procedure to additional types of treatment or to additional groups of children,
  - introduction of a procedure for verifying the capacity of a child to give consent,
  - introduction of requirements for the treatment of children with have variants of sex developments and are capable of giving consent,
  - introduction of an obligation to seek independent advice on dealing with variants of sex development, and
  - inclusion of a provision on the costs of the opinion of the interdisciplinary commission.”

## Main obstacles towards full protection

While these articles, at first glance, seem to ensure a protection of intersex infants and children from non-vital medical interventions, the details show a much more complex picture, which includes loopholes and a risk of possible circumvention of its essential aim. Central obstacles are:

### ***# Lack of universality – pathologizing stance***

The medical term “variations in sex development” used in the law **only protects some intersex children**, thereby excluding intersex children who, from a current medical perspective do not fall under this definition, from the necessary comprehensive protection. Once these definitions and diagnoses change the affected children will no longer be covered under the law and will be left without protection. The law itself establishes these limits. By doing so it yet again defers its political responsibility to protect all intersex children to the medical profession. It also perpetuates a pathologizing perspective.

### ***# Risk of interventions in the lack of health needs***

Interventions that may be approved include those deemed “necessary to cure or eliminate a functional disorder or to preserve the ability to reproduce, **without there being any real risk to health at the present time**, even if they have the effect of altering physical appearance” (Explanatory report of the law)

*→ This means that (hetero)normative-compliant functions such as “penis-in-vagina” sexual intercourse and potential reproductive capacity may still be considered more important than the physical integrity and self-determination of the intersex person.*

Reports of intersex adults have shown that some of these interventions have a high risk of creating psychological trauma as well as physical health issues if they are performed at an early age and without the intersex individuals personal and fully informed consent.

One of the other reasons that can justify an intervention may be found in the “**consolidated wish**” of the child, even if they are incapable of giving informed consent (Explanatory report of the law)

*→ Considering the still high level of active social pressure put on intersex children to conform with the norm, such a “wish”, as separated from a fully informed consent, carries the high risk to be a result of medical and social pressure and should not be the basis for invasive and deferrable procedures.*

The law does not differentiate between physical and **potential (presumed) mental health needs**

→ *There is a risk that the concept of a psychosocial emergency, which served for decades as an indication for ‘normalising’ treatment, will become acceptable again.*

The law also **fails to provide a clear definition** of which interventions are to be considered **“too urgent”** and thus do not require following the family court procedure. This is even more problematic considering that family courts are used to processing urgent applications within weeks and even days and that the law does not provide for the obligation to seek the court’s consent at least *a posteriori*;

#### ***# Composition of the interdisciplinary commission***

The majority of the commission can still consist of staff of the **same health care facility** where the surgical procedure is to be performed

→ *There is a clear risk of bias and possible conflict of interest in particular considering the still prevailing medicalisation and pathologisation of intersex bodies in medical centres specialising in “DSD” related interventions.*

#### ***# Lack of provision of comprehensive information***

There is a lack of guarantee of comprehensive information provided to parents and children, seeing as the involvement of a **peer counselor** is not mandatory

→ *This precludes that full information, including non-medicalised information, is delivered to the child and their family – which is often not the case.*

Other **missing points** to address in order to strengthen protection include:

- The need to address the issues of prenatal treatments that aim to end pregnancies where it has been determined that the baby is intersex.
- The need to provide for a central register for medical records, which should be accessible through a low-threshold procedure, so that future intersex adults are able to access justice in the case that this law is breached. This can be ensured by creating a

central register for the storage of patient files. This will also ensure that monitoring activities can be successfully carried out.

- Including an ongoing and sustainable monitoring mechanism,
- The need to set out sanctions via the criminal and civil code, that explicitly account for the specific circumstances of vulnerability of the possible victim.
- Ensuring the training of professionals.
- The provision of long-term counselling for children subjected to such harmful procedures, and for parents who may wish to access such services
- Adequate provision for redress and reparation in the case that victims wish to seek legal remedy.
- The need to prohibit interventions carried out on intersex children who live in Germany, but who are subjected to surgeries performed in other countries without any repercussions.

**In its coalition contract, the current German government committed to improving the law and eliminating opportunities for circumvention.**