

# Intersex children and the violation of their right to privacy

OII Europe submission to the UN Special Rapporteur on  
the Right to Privacy

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## Who are intersex children?

Intersex children 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.<sup>1</sup>

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. Sex characteristics are set out from birth, whether we are intersex or not. However, the fact that someone has an intersex body can become apparent at different times in their life: at birth, during childhood, in puberty or even in adulthood. Depending on the specific life circumstances and the degree of taboo in their environment, a person might learn that they have an intersex body at a very early age or later in life. Some intersex people never find out at all.

The United Nations Human Rights Office has pointed out that in «many countries, intersex children are subjected to repeated surgery and treatment to try to change their sex characteristics and appearance, causing terrible physical, psychological and emotional pain – and violating their rights. Intersex children don’t need to be “fixed”; they are perfect just as they are!».<sup>2</sup>

Up to 1,7 % of the global population are intersex, i.e. have a variation of sex characteristics,<sup>3</sup> which equals, of this date, 132 million intersex people globally. UN treaty bodies have been calling on governments to protect intersex children from harm since 2009.

## Who is OII Europe?

OII Europe is the European intersex umbrella organisation with intersex-led member organisations in 20 Council of Europe member states. 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. 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. Since 2020 OII Europe is registered as an expert on sexual orientation, gender identity and gendered characteristics with the SOGI Unit of the Council of Europe. The NGO OII Europe was created in 2015, as an extension of a network of the same name set up in

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<sup>1</sup> See <https://www.unfe.org/intersex-awareness/>

<sup>2</sup> See <https://www.unfe.org/intersex-awareness/>

<sup>3</sup> See <https://www.unfe.org/wp-content/uploads/2018/10/Intersex-English.pdf>

2012, and is based in Berlin. For more information, please visit our websites [oiieurope.org](http://oiieurope.org) and [intervisibility.eu](http://intervisibility.eu).

## Intersex children experience severe breaches of their right to privacy

The right to privacy includes a wide range of overlapping and interrelated rights protecting the individual's freedom as long as their actions do not interfere with the rights and freedoms of others. The ICCPR, Article 17, defines several components that apply to breaches of rights intersex children experience, such as 'family' and 'home' and 'correspondence'. Provided that the definition of private life cannot be an exhaustive one,<sup>4</sup> the Human Rights Committee has defined several components, including that the notion of privacy refers to «the sphere of a person's life in which he or she can *freely express his or her identity, be it by entering into relationships with others or alone*».<sup>5</sup> Similarly the European Court of Human Rights has defined private life as "*multiple aspects of the person's physical and social identity*"<sup>6</sup>. According to the ECtHR, *personal autonomy and self-determination* fall under the rights protected by Article 8 of the European Convention on Human Rights, "Right to respect for private and family life, home and correspondence".<sup>7</sup> It also found that *physical and moral integrity* of the person are covered<sup>8</sup> and that States have the obligation to actively secure those rights.<sup>9</sup>

The Convention on the Rights of the Child guarantees all of the above named aspects in various provisions, namely:

- Article 6 (Right of the child to life, survival and development)
- Article 8 (Right of the child to preserve their identity)
- Article 12 (Right of the child to express their own views and have them given due weight)
- Article 16 (Right of the child to respect and protection of their privacy)
- Article 19 (Right of the child to be protected from physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation)

In our current world, however, intersex children experience a wide range of breaches of these rights, including but not limited to

- their bodily integrity and self-determination,
- the development of their autonomy,
- the development of their personal identity, including their identity as being a healthy human being and not a person with a medical disorder, their gender identity and gender expression,
- their family life,
- their right to education and personal growth,

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<sup>4</sup> See ECtHR *Niemietz v. Germany*, § 29; *Pretty v. the United Kingdom*, § 61; *Peck v. the United Kingdom*, § 57

<sup>5</sup> See *Coeriel and Aurik v. The Netherlands* (Communication No. 453/1991, Views of 31 October 1994), para. 10.2

<sup>6</sup> See e.g. *S. and Marper v. the United Kingdom* [GC], § 66

<sup>7</sup> See e.g., *Glass v. The United Kingdom*; *Trocellier v. France*; *Juhnke v. Turkey*; *Codarcea v. Roumania*

<sup>8</sup> See e.g. *X and Y v. the Netherlands*, § 22

<sup>9</sup> See e.g. *Odièvre v. France* [GC], § 42; *Glass v. the United Kingdom*, §§ 74-83; *Pentiacova and Others v. Moldova*)

- their social life,
- official recognition, including, if needed, legal gender recognition

The following submission aims to highlight some of these violations with a specific focus on the breaches to the right of privacy that they encompass.

## How is the privacy of intersex children violated?

### Medical interventions

Non-vital surgical and hormonal intervention, aiming to alter intersex children's sex characteristics, without the child's consent are still performed all over the world. The physical and psychological harm triggered by these interventions include trauma, sterilisation, painful scar-tissue and reduction or loss of (general and/or erotic) sensation, 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>10</sup>

Similar to Female Genital Mutilation (FGM), Intersex Genital Mutilation (IGM) aims to alter the body of a healthy child to make it appear more in line with social and cultural standards, in fact making these standards prevail over the dignity and the freedoms of the person concerned. Non-vital surgical interventions on intersex children have therefore been equaled with FGM by Equality bodies like the *24th Conference of Equality and Women Ministers and Senators of the German Länder (GFMK)*.<sup>11</sup> In 2017, the *BanFGM Conference* on the worldwide ban on female genital mutilation decided to include victims of intersex genital mutilation in their supporting structure through the provision of essential services (medical, psychological and legal).<sup>12</sup>

While invasive treatments have been traditionally justified with the need to ensure a regular gender development, to avoid discrimination and stigma and to increase the chance of healing and success, scientific evidence tells a different story and available research shows that none of these assumptions are evidence-based.<sup>13</sup>

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<sup>10</sup> Dan Christian Ghattas (2019): Protecting Intersex People in Europe: A toolkit for law and policymakers. Ed. by ILGA-Europe and OII Europe, p.15 <https://oiieurope.org/tag/legal-toolkit/>

<sup>11</sup> See: 24. Konferenz der Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GFMK) (2014): Tagesordnungspunkt 8.1: Rechte intersexueller Menschen wahren und Diskriminierung beenden – insbesondere Schutz der körperlichen Unversehrtheit [https://www.gleichstellungsministerkonferenz.de/documents/2014\\_10\\_13\\_beschluesse\\_gesamt\\_extern\\_2\\_15102\\_27377.pdf](https://www.gleichstellungsministerkonferenz.de/documents/2014_10_13_beschluesse_gesamt_extern_2_15102_27377.pdf)

<sup>12</sup> [http://www.npwj.org/sites/default/files/ressources/Declaration%20in%20EN\\_rev.pdf](http://www.npwj.org/sites/default/files/ressources/Declaration%20in%20EN_rev.pdf)

<sup>13</sup> S. Creighton, S.D. Chernausek, R. Romao, P. Ransley, J. Pippi Salle (2012): Timing and nature of reconstructive surgery for disorders of sex development – Introduction, in *Journal of Pediatric Urology*, 8(6), pp. 602-610; J. Schober, A. Nordenström, P. Hoebeke, P. Lee, C. Houk, L. Looijenga, G. Manzoni, W. Reiner, C. Woodhous (2012): Disorders of sex development: summaries of long-term outcome studies, in *Journal of Pediatric Urology*, 8(6), pp. 616-623.

Apart from exceptional cases in which intervention is necessary to urgently avoid serious physical harm or save the life of the child, non-vital surgeries and other medical treatments are harmful manipulation of otherwise healthy variations of sexual characteristics. These non-vital, “cosmetic” interventions have been defined on several instances by UN treaty bodies and other human rights bodies as harmful medical practices.<sup>14</sup>

According to FRA findings from 2015 non-vital medical surgeries were performed in at least 21 EU Member States.<sup>15</sup> This includes countries with guidelines that indicate to refrain from such interventions, where numbers have stayed relatively constant.<sup>16</sup> Recent reports of parents of intersex children received by OII Europe from across Europe, as well as two recent surveys on the amount of surgeries performed on intersex children, age 0 to 10 from 2005 to 2016 in Germany, show that the number of surgical interventions on children have not decreased despite other claims.<sup>17</sup>

Moreover, the 2019/2020 LGBTI Survey conducted by the European Union Agency for Fundamental Rights (FRA)<sup>18</sup> revealed that most intersex survey respondents that were subjected to surgery said they did not provide – and were not asked for – their own or their parents’ fully informed consent before their first surgical intervention to modify their sex characteristics (62 %). Almost half of those intersex respondents (49 %) said that fully informed consent was not provided for hormonal treatment, or for any other type of medical treatment.

Article 12 of the Convention on the Rights of the Child requires the States parties to ensure that the child is free to express their views. Article 12 goes not as far as requiring personal fully informed consent of the mature child. However, making **deferrable** decisions on behalf of the child, which include **far-reaching consequences** not only for the physical and mental health and bodily integrity of not only the child but also for the future adult is not reconcilable with the concept of **autonomy**, which is grounded in the Convention<sup>19</sup>, since the decisions can be safely postponed.<sup>20</sup>

The same line of reasoning is adopted by the Committee on the Rights of the Child, whose recommendations have evolved from ensuring that intersex «children are involved, to the

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<sup>14</sup> See Appendix 2: International recognition - Recommendations by the CRC; for a more comprehensive list of all treaty bodies recommendations: <https://oii-europe.org/wp-content/uploads/2018/05/International-intersex-human-rights-movement-Links-to-human-rights-documents-addressing-intersex-and-important-events-June-2020.pdf>

<sup>15</sup> European Union Agency for Fundamental Rights (2015): The Fundamental Rights Situation of Intersex People. FRA Focus, 4/2015, p. 6.

<sup>16</sup> See J. Hoenes, E. Januschke, U. Klöppel (2019): Häufigkeit normangleichender Operationen „uneindeutiger“ Genitalien im Kindesalter. Follow Up- Studie. Bochum.

<https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-2>; U. Klöppel (2016): Zur Aktualität kosmetischer Operationen „un-eindeutiger“ Genitalien im Kindesalter. Hg. von der Geschäftsstelle des Zentrums für transdisziplinäre Geschlechterstudien der Humboldt-Universität zu Berlin. Berlin [https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/bulletin-texte/texte-42/kloepfel-2016\\_zur-aktualitaet-kosmetischer-genitaloperationen](https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/bulletin-texte/texte-42/kloepfel-2016_zur-aktualitaet-kosmetischer-genitaloperationen); see also: Robert Koch Institut (2020): The health of lesbian, gay, bisexual, transgender and intersex people, in Journal of Health Monitoring, March 2020 Special Issue, p. 15.

<sup>17</sup> See footnote 16: J. Hoenes, E. Januschke, U. Klöppel (2019); U. Klöppel (2016)

<sup>18</sup> European Union Agency for Fundamental Rights (2020): A long way to go for LGBTI equality <https://fra.europa.eu/en/publication/2020/eu-lgbti-survey-results>

<sup>19</sup> See above paragraph “What are privacy and autonomy?”

<sup>20</sup> Sandberg, Kirsten (2018): Intersex children and the UN Convention on the Rights of the Child. In: Jens M. Scherpe; Anatol Dutta & Tobias Helms (ed.): The Legal Status of Intersex Persons. Intersentia, p. 528.

largest extent, in decision-making about their treatment and care»<sup>21</sup> to «[p]rohibit the performance of unnecessary medical or surgical treatment on intersex children where those procedures may be safely deferred until children are able to provide their informed consent»<sup>22</sup>.

*Therefore we consider the current medical practices to produce severe violations of intersex children's right to privacy and its multifaceted expressions including bodily integrity, personal autonomy and self-determination (Articles 6, 8, 12, 16, 19 CRC)<sup>23</sup>. Moreover, additional provisions are infringed at the same time, namely CRC Article 3.1 ( best interests of the child as primary considerations), Article 24.1 (right to the highest attainable standard of health), Article 24.3 (abolishing traditional practices prejudicial to the health of the children) and Article 37 (prohibition of torture or other cruel, inhuman or degrading treatment).*

## Access to health and counselling

Unconsented interventions and other mistreatments in healthcare settings have long lasting effects on intersex children/future adults, and on their relationship with the medical system.

A 2008 study found that well over half of the intersex participants (62%) showed clinically relevant psychological stress, 47% had suicidal thoughts, and 13.5% reported past self-harm. Ten years later, a 2018 study showed similar findings: 38% of the intersex respondents had tried to access mental health services in the preceding 12 months, and 13% of those attempts were unsuccessful. Prevalence rates of self-harming behaviour and suicidal tendencies in intersex people that were subjected to “normalising” surgeries have been found to be “twice as high as in a community based comparison group of non-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse”.<sup>24</sup>

As the 2017 PACE report points out, severe lack of knowledge about intersex people, the human rights violations they face and the specific needs that follow from these experiences exists among medical practitioners.<sup>25</sup> This lack is 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. 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. The lack of training for medical practitioners and other healthcare professionals severely hinders intersex people in accessing their right to health.

Furthermore, adequate psycho-social counselling for intersex people is still missing 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

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<sup>21</sup> CRC/C/FRA/CO/5

<sup>22</sup> CRC/C/AUT/CO/5-6; see paragraph “International recognition” for a broader overview.

<sup>23</sup> See above paragraph “What are privacy and autonomy?”

<sup>24</sup> See: K. Schützmann, L. Brinkmann, M. Schacht, H. Richter-Appelt (2007): Psychological distress, self-harming behavior, and suicidal tendencies in adults with disorders of sex development, Archives of Sexual Behavior, Vol 38, No. 1, p. 16-33.

<sup>25</sup> Parliamentary Assembly of the Council of Europe (PACE, 2017): Promoting the human rights of and eliminating discrimination against intersex people, Report 14404, Articles 49-50.

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, and many participating parents wished for a better support and guidance on how to best address the variation of the child with the child and their family and friends.<sup>26</sup> A lack of psycho-social counselling options for parents can be extremely harmful or even fatal for the child: 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>27</sup> Almost all participants considered comprehensive counselling services important in order to “avoid premature decisions”<sup>28</sup>.

*The findings show that appropriate training of healthcare professionals and educated psycho-social counselling, both based on a non-pathologising perspective on intersex bodies, are key to protect intersex children’s right to bodily integrity and autonomy. In addition, only comprehensive, transparent, detailed and depathologising information given to the intersex person and their family ensures that the child and future adult will be capable of taking informed decisions about their bodies and thereby exercise their right to self-determination over their body and their right to develop their identity on the basis of a preserved bodily integrity.*

## Discrimination and violence

At global level, violence is spread in various forms in multiple regions, including, but not limited to, infanticide, abandonment, mutilation and domestic and societal violence against intersex children. At European level, discrimination against intersex people in general, and intersex children in particular, remains high. Statistical evidence has recently been provided by the 2019/20 FRA LGBTI survey, which included LGBTI children aged 15 - 17 years old. Of the 15 - 17 year old intersex respondents 62% answered “yes” to the question: «In the past 12 months have you personally felt discriminated against due to being LGBTI in 8 areas of life?».<sup>29</sup>

What is deeply worrying is the fact that the vast majority of the intersex children participating in the survey affirmed that neither they nor someone else reported the last incident when they

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<sup>26</sup> See Bundesministerium für Familie, Senioren, Frauen und Jugend (2016): 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, p. 13  
<https://www.bmfsfj.de/blob/123144/40905d00b0bc5d9722523bb6f9e29824/imag-band-3-beratung-und-unterstuetzung-fuer-intersexuelle-menschen-data.pdf>

<sup>27</sup> J. C. Streuli, E. Vayena, Y. Cavicchia-Balmer & J. Huber (2013): 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, pp. 1953–1960

<sup>28</sup> See footnote 25: Bundesministerium für Familie, Senioren, Frauen und Jugend (2016), p. 13

<sup>29</sup> See findings retrieved from the European Union Agency for Fundamental Rights LGBTI Survey Data Explorer <https://fra.europa.eu/en/data-and-maps/2020/lgbti-survey-data-explorer> and OII Europe’s infographics based on these findings: <https://oiieurope.org/intersex-youth/>

felt discriminated against (83%). They further provided information on the reasons for not reporting the incident: The majority, 54%, chose the answer “nothing would happen or change”.<sup>30</sup>

Moreover, hate and violence continue to heavily affect the life of intersex children. According to the survey, 22% of them had experiences of physical or sexual attacks due to being LGBTI in the previous 5 years. In the time span, 27% of them experienced cyber harassment.<sup>31</sup>

*Violence and discrimination heavily limit intersex children’s life and freedoms, particularly their rights to survival and development, identity, privacy and freedom from violence (Articles 6, 8, 16, 19 CRC).*

## Identity documents

Globally many intersex people face severe barriers in having their births registered, in changing sex/gender markers on official documents, and some also report being forced into unwanted sex/gender categories.<sup>32</sup>

This situation amounts to severe violation of intersex children’s privacy, especially their right to develop their identity (Article 8 CRC). In General Comment No. 14 on the best interests of the child,<sup>33</sup> the Committee mentions identity as one of the elements to be taken into account in assessing the child’s best interests under Article 3. It is interpreted broadly to encompass characteristics ranging from sex to sexual orientation and personality.

As long as gender markers are registered at birth,<sup>34</sup> States should ensure that the existing diversity of sexes is reflected in options available to register the child’s sex/gender. They should also assure that all the people have the right to change their markers throughout their lives, so that they correspond to their identity.<sup>35</sup>

According to the 2019/20 FRA LGBTI survey, in the European Union one in five intersex survey respondents (19 %) faced obstacles when registering their civil status or gender in a public document. These include bureaucratic obstacles (58%), denials of service or ridicule by staff (41 %), and violations of privacy - personal or sensitive data was exposed or not protected (44 %).<sup>36</sup>

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<sup>30</sup> *ibid.*

<sup>31</sup> *ibid.*

<sup>32</sup> Office of the High Commissioner for Human Rights, Background Note on Human Rights Violations against Intersex People, p. 26

<https://www.ohchr.org/EN/Issues/Discrimination/Pages/BackgroundViolationsIntersexPeople.aspx>

<sup>33</sup> UN Committee on the Rights of the Child (CRC), General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1), 29 May 2013, CRC /C/GC/14 [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f14&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f14&Lang=en)

<sup>34</sup> The Yogyakarta Principles plus 10 clearly indicate that the registration of sex or gender by States should eventually cease. See Principle 31

[http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5\\_yogyakartaWEB-2.pdf](http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf)

<sup>35</sup> See the demands formulated at the 3rd International Intersex Forum and laid down in the Malta Declaration (2013), <https://oieurope.org/malta-declaration/>

<sup>36</sup> See footnote 26: European Union Agency for Fundamental Rights LGBTI Survey Data Explorer (2020)

A substantial number of intersex people reject the sex that they were registered with at birth. A 2012 clinical review paper found that between 8.5% and 20% of intersex people, regardless of whether their body was subjected to medical interventions or not, developed a gender identity that did not match the sex or gender that was assigned to them at birth.<sup>37</sup>

Parents of some intersex children, who talk openly with their child about the child's variation of sex characteristics, have reported to OII Europe and its national member organisations that their children are very aware of, e.g. being "a girl, but also a little boy" or declare that their gender identity does not match with the gender assigned to them at birth.

Research has shown that giving the possibility to a child to express and live, including officially if wanted, their personal gender identity is important for a healthy development of a child. A gender marker in official documents (including but not limited to birth certificates, identity documents, school certificates or any other documents, where a child's gender is being recorded), which reflects and recognises the child's gender identity has a positive impact on an individual's mental and emotional health.<sup>38</sup> Legal gender recognition also reportedly improves a person's life in regards to social inclusion and reduces the risk of structural and other discrimination.<sup>39</sup>

*It is therefore key to allow mature intersex children to adjust their gender marker by a low-threshold procedure, based on self-determination. This will allow them to guarantee the enjoyment of their right to develop and express their personal identity and exercise their right to social life by being recognized and having the gender which reflects their gender identity.*

## Education

Intersex children suffer at school from discrimination and violence in many different ways.

Intersex people from all over Europe have reported facing discrimination and bullying at school and in further education, including the use of derogatory language and psychological and physical violence, if their gender expression, stature or other parts of their appearance do not conform to the female or male norms.

The 2019/2020 FRA LGBTI survey<sup>40</sup> corroborates this information with alarming data. 36% of the intersex respondents declared that in the previous 12 months they have felt discriminated against due to being LGBTI by school/university personnel. Moreover, when

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<sup>37</sup> See: P.S. Furtado et al. (2012): Gender dysphoria associated with disorders of sex development, in: Nat. Rev. Urol. 9 (11): 620–627.

<sup>38</sup> See: European Court of Human Rights (2002): Christine Goodwin vs. United Kingdom, n° 28957/95; see also: Russell, S., Pollitt, A., Li, G. & Grossman, A. (2018): Chosen name is linked to reduced depressive symptoms, suicidal ideation, and suicidal behavior among transgender youth. Journal of Adolescent Health. DOI: 10.1016/j.jadohealth.2018.02.003; Strauss, P., Cook, A., Winter, S., Watson, V., Wright Toussaint, D., Lin, A. (2017): Trans Pathways: the mental health experiences and care pathways of trans young people. Summary of results. Telethon Kids Institute, Perth, Australia

<https://www.telethonkids.org.au/globalassets/media/documents/brain-behaviour/trans-pathways-report.pdf>

<sup>39</sup> See: Global Commission on HIV and the Law. HIV and the law: risks, rights and health; New York, NY: UNDP; 2012.

<sup>40</sup> See footnote 26: European Union Agency for Fundamental Rights LGBTI Survey Data Explorer (2020)

asked whether they experienced negative comments or conduct during their time at school, the 29% answered “often” and the 15% even “always”. Additionally, the 54% said that they have been ridiculed, teased, insulted or threatened at school.

In addition, no positive representation of people with variations of sex characteristics is available, if any at all: OII Europe’s member organisations report that intersex people do not appear in educational curricula at all<sup>41</sup> or only as an imaginative product of mythology (e.g. hermaphrodites), as an example of “abnormality”, or are presented in a pathological way (in biology texts, medical handbooks or encyclopaedias). Sex education does not take into account that bodies other than the so-called “male” or “female” bodies exist, and thus increases the feeling of shame, secrecy, not existing at all or being a fraud at a vulnerable age.

*Violence and bullying offend and destroy a child's physical and psychological integrity. In addition, poor education on sex and body diversity is an obstacle to the child's self-acceptance and thus limits their rights to identity and self-determination.*

## What are the effects on the development of intersex children’s autonomy?

The sections above discuss violations of the right to privacy that intersex children face in their everyday lives and assess how these experiences impact on their autonomy and self-determination.

Such violations clearly interfere with the human rights of the child, and, in addition also with their future rights to autonomy and self-determination as adults. This is especially true for two following aspects: non-vital, deferrable medical interventions, that are performed on intersex infants and children without their personal, prior and fully informed consent and the irreversible consequences they carry for their life and the health; and the arbitrary imposition of a gender marker. Both practices significantly limit the child’s future choices.

Every child should enjoy the right to an open future, which is grounded on the right to bodily integrity and self-determination.<sup>42</sup> This right entails the State obligation to protect the child against having important life choices determined by others before they have the ability to make them for themselves. It is about protecting the child not only as a human being, but also as a human becoming.<sup>43</sup>

We envision a world where every child enjoys the right to development (Article 6 CRC) and is free to determine their own future.

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<sup>41</sup> The few national research that exists on the matter, confirms this, see M. Bittner (2011): *Geschlechterkonstruktionen und die Darstellung von Lesben, Schwulen, Bisexuellen, Trans\* und Inter\* (LSBTI) in Schulbüchern. Eine gleichstellungsorientierte Analyse von im Auftrag der Max-Traeger-Stiftung.*

<sup>42</sup> Ouellette, A. (2010): ‘Shaping Parental Authority over Children’s Bodies’, *Indiana Law Journal*, 85(3), 956-1001.

<sup>43</sup> Kehrer, I. (2019): ‘Cuts into Children’s Future: a Comparative Analysis between FGM, Male Circumcision and Intersex Genital Surgeries’, *Peace Human Rights Governance*, 3(3), p. 350.

## Appendix 1: Testimonials

*Additional testimonials can be found in OII Europe (2019): #MyIntersexStory. Personal accounts by intersex people living in Europe. With a text by intersex scholar Janik Bastien-Charlebois "On our own terms and in our own words": The value of first person accounts of intersex experience.*

*The testimonials were added to this submission with approval of the concerned individuals, including the concerned child. Age references at the end of testimonials reflect age of the contributors at publication date (1st of November 2019).*

*As a result of taboo, secrecy and shame as well as the still prevailing high level of silence around the existence of intersex people, it is extremely difficult to obtain any approval for testimonies from intersex minors or parents' of intersex minors. However, many intersex youth report that they still experience the same medical malpractice and societal discrimination intersex adults have experienced for 6 decades up to date. Being well aware that the Special Rapporteur seeks information on children up to the age of 18 we have therefore decided to include, in addition of the testimonial of a parent and a 13 year old intersex child, 3 testimonies which describe the experience of young intersex individuals (23, 25 and 26 years old), whose childhood has not been over for long, in order to exemplify the impact of the still ongoing breach of intersex children's autonomy, bodily integrity and self-determination on intersex youth.*

### 1) BEING BORN INTERSEX IN GREECE 2009

The difficulties, the struggles and the violations for a family with an intersex child and for the child itself.

This is our family story. At 2008, while five months pregnant, I was asked to do an amniotic karyotype testing, due to our age (I was 43 and my husband was 40). The test revealed that everything was normal, except that the baby had an extra X in the sex chromosome, that is a 47,XXY (intersex) karyotype. As this was something new to us, we went online and gathered every possible, updated information about it, so we would be prepared properly. We also met through the internet with many XXY people around the globe, happy to share their personal XXY stories with us and very willing to support us psychologically. 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 fetus, 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. So, even before T was born, we had to struggle with medical ignorance for his safety and his profound right to be born. As I am hearing from other local hospitals, this "standard procedure" (to terminate healthy intersex fetuses) is still valid... So we can't say how many XXY's have already been "terminated" before

being even born. This is an ignorant and racist genocide that has to be stopped, in Greece and globally.

Next (3,5 years later) T was denied attending the local public nursery school, cause again they thought “he is not normal”, out of plain ignorance (before they even met him physically). After we strongly insisted to his right to attend, they accepted him and he went without any further problem.

But in primary school things got nasty: As many intersex children are, T is also a gender creative child, that since 3-4 years old he steadily identifies as “mostly I’m a boy, but I am a little girl too”, he loves Lego, ballet dancing, long hair, dresses and skirts and prefers to play with girls. Because in Greek schools the norm is “There are only boys and girls and that’s all”, the kids found it very strange for a boy to have ballet classes, to have long hair, to like girl-playing and have soft manners and high-pitched voice. So they gave him a hard time teasing and bullying him to the extend he cut his hair in tears and refuse to go to school. With a lot of work with the teachers and the psychologist there were created a little acceptance and space for him, so he made it to the end of the year.

As T entered elementary school in Sept. 2016, we as parents provided every possible and valid info about intersex traits (social and physical) to all his school teachers and the headmaster, to create awareness and acceptance. But in fact, the teachers are refusing (or declare themselves unable, “unqualified”) to accept his gender fluidity and create positive awareness to his co-students, by just telling them that “it’s ok to be a pink-boy, or a tomboy girl. Its ok to be different than distinct male/female, cause gender is a colourful spectrum that everybody can fit in”. They are refusing this scientific valid info to the kids, because (as they told us) 1) they don’t have such orders and guidelines from the Greek Ministry of Education and 2) they are very afraid of the possible bad reactions of other homophobic/transphobic or religious parents, who don’t want this info to reach their kids.

So my kid is being teased and bullied (again) because educators deny to offer kids valid and updated scientific info, and deny him acceptance and support for freely express his gender, like every other kid. He is just in first grade and already wants to quit school if things don’t change to the better.

These problems we face, that probably will be harder in years to come, this social and educational ignorance and rights violations, it would all be stopped if the Greek Government makes the right step now to INCLUDE intersex (and trans) children in the new legislation (May 2017) about gender identity.

Gender is a spectrum. Gender-fluid children do exist. Intersex and trans children do exist. They are all perfectly normal human children that deserve respect. Either intersex in their physiology/ anatomy/hormonal & chromosome profiling, or not, they do exist and have human rights and they need us to support their rights to develop safe and free to create their true, unique gender. They have to have the right to decide/create their gender at their own pace as they grow and not be pushed to identify strictly as males/females only. This social pushing towards the only-two-accepted-as-“normal” gender stereotypes, while excluding in shame and harm all the others, is adding a lot of social and inner stress to these kids and compromises their physical and psychological health, due to a lot of well-documented dangers (as gender bullying, harassment, personality assaulting, physical violence, depression, school quitting and even youth suicides).

For our child and all of these children we ask the Greek Government to include them in the new legislation. Also it is urgently needed for them to be included in the

Greek Educational System, through clear inclusive guide lines to all school-levels educators, from the nursery schools to universities.

## 2) I AS A PARENT MADE CHOICES THAT SHOULD NOT HAVE BEEN MINE TO MAKE

*Please note: the testimonial is about two intersex individuals that were born 14 years apart, with the second one being now 23 years old.*

In 1982 I gave birth to a beautiful healthy baby girl in Landsspítalinn Reykjavík. I took the baby home but few weeks later it was discovered that she had a hernia and an operation was scheduled. I was told that the operation would not take long but after about three hours

I started to ask questions but nobody seemed to know anything, the information I got was that she had been sent into surgery at scheduled time and the staff seemed surprised that the operation took so long. When I finally got to see her I asked why the operation took so long, I did not really get any answer.

I had a very strange meeting with the surgeon before we went home, but put it down to bad people skills. The only thing he said was the operation went well, that the stitches would dissolve and I did not need to bring her in for a checkup.

The stitches did not dissolve, the wound got infected and I had regular visits to the children's ward. During those visits I started to get strange feeling that something was wrong. Finally one doctor sat me down told me that my baby had a very rare chromosomal disorder, they did not really know much about it but there was a doctor that had been specialising in USA arriving shortly and he would explain everything. I went home and waited.

Finally the doctor came, and as kindly as he could, he explained this so called chromosomal disorder, told me she had undeveloped gonads that would need to be removed due to cancer risk and they advised to do it before the age of 2. He stressed at all times that she was a girl in any respect, she would get a hormonal treatment to help her through puberty and could live a healthy live with a hormonal treatment and the only thing she could not do was give a birth to a child. But he also stressed that I should keep this a secret, not to tell my daughter till she started her treatment as the information would be too much and she would not be able to keep the secret when she was young. He also stressed that I should not even tell my closest family.

My daughter had a reoccurring hernia, at three months she had another operation and during that the so-called undeveloped gonads were removed.

2005, years later when we went to a meeting in a support group in the UK, I found out that what was removed were functional testes that would have given her all the hormones to lead a healthy live, and the cancer risk was based on research that was not applicable to her condition. I also found out that the statement of my baby living a healthy live with substitute hormones was not true.

So, the operation that I had allowed in the belief that it would be the only choice to secure a healthy live for my daughter, actually ruined her health. On top of that I had kept this a secret from my daughter, and her trust in me was completely broken when I finally told her. I learned that secrecy is the mother of shame.

I am not saying that the health profession were doing this out of anything but with the best intentions at the time. But 1996 when my niece was born with the same condition, the same procedures started, nothing had changed, operation at the age of a few weeks, no problem they said, artificial hormonal treatment will ensure healthy living.

At that time a change had started in treatment and the advice was to leave the removal of testes or what was always referred to as undeveloped gonads till after puberty. If that had been done then we would have had the knowledge when my niece reached puberty that there is absolutely no reason for this operation.

We as a family had at least learned from my mistake in keeping secrets and my niece knew from a very young age that she was intersex.

We went to an another support group meeting in the UK in 2012, at that meeting we spoke to a doctor from University College London Hospital, and got confirmation that the health problems both my daughter and niece were having were due to early medical intervention and mismanagement of hormonal treatments.

When we started to ask questions and criticize the medical care we hit a brick wall and at that time there was no good intentions or compassion. Finally, we complained to the Directorate of Health, just to get a doctor assigned to my niece as she, at the age of 18, had been diagnosed with osteopenia.

We are still fighting, both for better health care but also for the future intersex children.

I as a parent made choices that should not have been mine to make and most definitely not the doctors to make, I firmly believe that the intersex individual should be the only one allowed to make choices regarding their own body, there must be an end to unnecessary medical treatment and surgery of intersex individuals without their consent. We as parents should not have the right to give this consent.

### 3) 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.

I remember the taste of the gallon of laxative I was forced to drink for my intestine to be clean, the smell of the strawberry balm they put under my nose before anesthesia and I remember the burning pain when I went to the toilet.

The question I have asked my worried father did not need an answer. Missing school on the regular for weekly check-ups and a never-ending burning sensation when I would go to the toilet.

As I was a rare case, I had to see different doctors who wanted to see parts I did not want to show, know things I did not want to tell any grown-up man (or woman for that matter...) and I saw fear and questioning in the loving, sometimes teary, eyes of my parents. I had a malformation in my tummy, was I told.

I grew up believing I was the only one living this and that no one would ever understand... I came to believe I was lucky because my disorder was not visible, no one would ever have to know. It could be worse, I could have had only one leg...

With lots of self-reinforcement, I came to forget what happened and believing these were "just" nightmares. Until the day I met the first intersex person. It was love at first sight. Their words were like mirrors to my soul. We became friends, with high levels of complicity, care and attention.

Yet, at first, it was scary. I was in a vulnerable situation, taking lifelong secrecy and shame away, peel after peel... Like an onion. 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.

It is important to create a movement, today, so that next generations do not have to go through the same “intersex adventure”. For past, present and future generation to express themselves and make our existence as worthy as anyone else’s’.

*Age: 25*

*Country: Switzerland*

#### 4) BEING INTERSEX IN RUSSIA

At 14 years old I still hadn’t experienced puberty except for some signs of very high testosterone levels. During my first ultrasound my doctors at the time in Ukraine found that both my gonads (or “ovaries” as they perceived them) looked not like they expected, both gonads were missing the follicular apparatus and my right gonad was “in a thick capsule”. Despite my gonads not looking like typical ovaries and instead of doing more tests and guring out what my gonads exactly were, doctors just kept perceiving my gonads as ovaries and said that they would make them work. And of course I never actually had ovaries.

I was sent to these sessions where they would put electrodes on my belly and I would lie there for 30 minutes while the electrodes warmed up my “ovaries” to stimulate them. I have never heard of anybody else undergoing such procedure, it must’ve been some local “invention”. After a couple of months of these session there were no results and still no puberty, but later that year I ended up with appendicitis and had to have surgery for it, and I suspect it was triggered by these sessions.

Since doctors in Ukraine couldn’t gure out what was happening to me, I went to doctors in Moscow, who did all the tests but never told me the results, they never talked to me at all. I was always left waiting in the corridor while my father was invited into their office to speak with them. He never told me the truth either, I was given a typical “ovary cancer scare” explanation and told I need to have one or several surgeries.

I had my gonadectomy at the age of 15, while having very little understanding on what surgery I’m getting, nobody told me they would remove my gonads completely. By Russian law a child has to give full informed consent to any medical intervention since the age of 15. I was 15 and nobody asked for my consent. Now, years since my surgeries I’m still sometimes experiencing pain because of abdominal adhesions caused by my surgeries.

Not knowing the truth about my body and treatment I received impacted me heavily over the years, with me developing lots of shame and self-hatred caused by me feeling “not female enough” and me not understanding why my body’s different. I still have to deal with a lot of issues I developed during those years, and I always will.

Over the years I was never given an explanation on why my breasts didn’t grow even after years of taking estrogen, the only advice I was given was to “eat more”.

Because of my intersex variation I was born with a chest deformity called pectus excavatum. None of the doctors I’ve visited through the years connected it to my intersex variation, I found out that connection years later by myself on the internet.

My doctors were always very scared that I wouldn't identify as a heterosexual female, for them it was the most important thing. I never understood that fear since I didn't know that I was intersex. When once during a checkup I told my doctors that I felt self-conscious and "not a girl enough" because of lack of breasts growth, and it really scared the doctors, who started interrogating me about my sexual orientation and gender identity, implying that liking boys automatically meant identifying as female. The therapist I was seeing when I was 20 ignored me saying that I was questioning my SOGI (sexual orientation and gender identity), always implying that I'm a girl who eventually will get a boyfriend.

When I finally discovered that my father purposefully kept the truth about my body from me for 7 years, he said that he was following advice given to him by two different child psychologists, who both told him not to tell me the truth.

Discovering the truth about my body was the best thing in my life, the most empowering thing. For the first time in my life I knew I wasn't alone, I finally felt normal, I finally felt confident. But still I'll never be the person that I could've been if I would've known the truth from the very beginning.

Recently my doctor for some reason decided to send me to another doctor, who turned out to be one of the doctors that treated me back when I was 15. When I said that I won't go to them because they ruined my life by keeping everything secret from me, she started defending them and their actions. But now I know my rights and I didn't back down, I kept arguing with her until she had no arguments. Now I would have to find a new doctor myself, and it's not an easy task.

*Age: 26*

*Country: Russia*

## Appendix 2: International recognition - Recommendations by the CRC

Since 2015, the Committee on the Rights of the Child has repeatedly acknowledged the multiple violations of human rights that intersex children are subjected to. It has addressed intersex specific recommendations to the States parties 19 times and even more counting all applicable recommendations (e.g. LGBTI specific).<sup>44</sup>

### Medical interventions

The Committee urged States parties to:

**Prohibit** the performance of unnecessary medical or surgical treatment on intersex children where those procedures may be safely **deferred until children are able to provide their informed consent** (CRC/C/AUT/CO/5-6);

**Gather data** with a view to understanding the extent of instances of unnecessary medical or surgical treatment performed on intersex children, which constitute a harmful practice, so that children at **risk** can be more easily **identified** and their **abuse prevented** (CRC/C/AUT/CO/5-6);

**Investigate** effectively incidents of surgical and other medical treatment of intersex children without informed consent and provide **redress** to victims of such treatment, including **adequate compensation and rehabilitation** (CRC/C/MLT/CO/3-6);

[E]nsure that intersex children and their families have access to adequate **counselling and support** and to **effective remedies**, including by **lifting the relevant statute of limitations** (CRC/C/BEL/CO/5-6);

Develop and implement a **child rights-based health-care protocol** for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, **guarantee bodily integrity, autonomy and self-determination** to children concerned [...] (CRC/C/ITA/CO/5-6);

**Educate and train** medical and psychological professionals on the range of sexual, and related biological and physical, diversity and on the consequences of unnecessary surgical and other medical interventions for intersex children (CRC/C/ITA/CO/5-6);

Continue and strengthen **preventive and protection measures** to address the issue of harmful practices, including the collection of data, the training of relevant professionals, awareness-raising programmes, the provision of protection and care to the child victims and the **prosecution** of those found guilty of perpetrating such acts (CRC/C/GBR/CO/5).

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<sup>44</sup> For recommendations by other UN treaty bodies please visit <https://oiiurope.org/international-intersex-human-rights-movement-resource-list/>

On the same topic, see also: CRC/C/PRT/CO/5-6; CRC/C/AUS/CO/5-6; CRC/C/MLT/CO/3-6; CRC/C/ARG/CO/5-6; CRC/C/ESP/CP/5-6; CRC/C/DNK/CO/5; CRC/C/ZAF/CO/2; CRC/C/NZL/CO/5; CRC/NPL/CO/3-5; CRC/C/IRL/CO/3-4; CRC/C/FRA/CO/5; CRC/C/CHL/CO/4-5; CRC/C/CHE/CO/2-4.

## Health

The Committee urged States parties to:

[P]rioritize **mental health service** delivery to children in vulnerable situations, in particular [...] lesbian, gay, bisexual, transgender and intersex children (CRC/C/AUS/CO/5-6);

Develop and adopt a **comprehensive sexual and reproductive health policy** for adolescents, with particular attention to reducing inequalities and with participation of adolescents (CRC/C/GBR/CO/5).

## Violence and bullying

The Committee urged States parties to:

Encourage **community-based programmes to address violence** in all its forms against children in remote areas, children with culturally and linguistically diverse backgrounds and lesbian, gay, bisexual, transgender and intersex children (CRC/C/AUS/CO/5-6);

Intensify its efforts to **tackle bullying and violence in schools**, including by teaching human rights, building the capacities of students and staff members to respect diversity at school, improving students' conflict-resolution skills, monitoring regularly the incidences of bullying at school and involving children in the initiatives and monitoring aimed at eliminating bullying (CRC/C/GBR/CO/5);

In the light of the recommendations resulting from the day of general discussion on digital media and children's rights, **train** children, teachers and families on the safe use of information and communication technologies, **raise awareness** among children on the severe effects that **online bullying** can have on their peers and increase the involvement of social media outlets in the efforts to combat cyberbullying (CRC/C/GBR/CO/5);

**Prevent intimidation and threats** directed towards lesbian, gay, bisexual, transgender and intersex children (CRC/NPL/CO/3-5).

## Non-discrimination

The Committee urged States parties to:

Strengthening other **preventive activities** against discrimination and, if necessary, taking **affirmative action** for the benefit of children and in particular children in marginalized and

disadvantaged situations, such as [...] intersex children; children with disabilities; and children in street situations (CRC/C/ITA/CO/5-6);

Ensure **full implementation** of relevant existing laws prohibiting discrimination, including by strengthening public education campaigns to address negative social attitudes towards indigenous children, children with disabilities, minority children, children from migrant backgrounds, and lesbian, gay, bisexual, transgender and intersex children (CRC/C/ARG/CO/5-6);

[E]nsure that all cases of discrimination against children are **addressed effectively**, including by disseminating accessible information about what constitutes discrimination, establishing disciplinary, administrative or, if necessary, penal sanctions, and guaranteeing children's access to psychosocial and legal counselling in cases of discrimination (CRC/C/ARG/CO/5-6);

Consider the possibility of **expanding legislation** to provide protection of all children under 18 years of age against discrimination on the grounds of their age (CRC/C/GBR/CO/5).

On the same topic, see also: CRC/C/DNK/CO/5; CRC/C/ZAF/CO/2; CRC/C/NZL/CO/5; CRC/NPL/CO/3-5; CRC/C/MDV/CO/4-5; CRC/C/CHL/CO/4-5.

## Identity documents

The Committee urged the States parties to:

Ensure that intersex children have access to **identity documents that correspond** with the sex/gender identity of their choosing (CRC/NPL/CO/3-5);

Recognize the right to identity of lesbian, gay, bisexual, transgender and intersex children, including the gender identity of transgender children (CRC/C/CHL/CO/4-5).

## Education

The Committee urged the States parties to:

Ensure that meaningful **sexual and reproductive health education** is part of the **mandatory school curriculum** for all schools, including academies, special schools and youth detention centres, in all areas of the State party. Such education should provide age-appropriate information on: confidential sexual and reproductive health-care services; contraceptives; the prevention of sexual abuse or exploitation, including sexual bullying; the support available in cases of such abuse and exploitation; and sexuality, including that of lesbian, gay, bisexual, transgender and intersex children (CRC/C/GBR/CO/5).

## Appendix 3: Recommendations of OII Europe and the European Intersex Community

The Committee on the Rights of the Child has taken a clear stand for the protection of the rights of intersex children and recommended targeted actions to various countries to that aim. In addition to those action points, please find detailed recommendations for measures on how to protect intersex individuals, including intersex children. The list builds on the demands of the European and international intersex community, as laid down in the Malta Declaration (2013), the Vienna Statement (2017) and the OII Europe/ ILGA-Europe toolkit: Protecting Intersex People in Europe.

### Medical interventions

In order to ensure intersex people's right to health, self-determination and bodily integrity, States should create laws that explicitly:

- prohibit medical practitioners and other professionals from conducting any irreversible, non-emergency sex-“normalising”, sex-“assigning” or sex-altering surgical or other interventions on a person's sex characteristics unless the intersex person has provided personal, free and fully informed consent.
- establish adequate legal sanctions conducting any irreversible, non-emergency sex-“normalising”, sex- “assigning” or sex-altering surgical 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 parts of human rights experts, intersex peer experts, psycho-social professionals and medical experts, to review and revise current treatment protocols to bring them in line with current medical best practice and human rights standards within a limited period of time laid down in the law.
- establish the right to expert-sensitive and individually tailored psycho-social counselling and support for all concerned individuals and their families, from the time of diagnosis or self-referral, for as long as necessary.
- extend the retention period for medical records of surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or hormonal set-up, including consultation minutes, to a minimum of 40 years in order to allow intersex people access to their medical records at a mature age.
- extend the statutes of limitations for surgical and/or other interventions that aim to alter the genitals, gonads, reproductive organs or hormonal set-up of a person 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 to be conducted on a mature minor's sex characteristics, if explicitly wished for by the mature minor and provided the mature minor gives personal and fully informed consent. In the case of a mature minor seeking treatment to alter their sex characteristics, establish the presence of an independent third party, who is neither a parent nor legal guardian nor a medical professional treating the minor; the independent party shall take part in the process, in order to guarantee that the consent of the minor is giving freely, and with fully informed consent.
- establish the legal obligation for medical professionals in regards to all surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or any

hormonal set-up: to inform the mature 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; to provide detailed minutes of the consultation, including all of the above information, which is provided to the patient and in addition, in case of a minor, to their parent(s) or legal guardian(s).

- end the coverage of intersex genital mutilation by the public and private health systems.
- ensure that regulations and practices in public and private sectors, e.g. in international competitive sport, do not bypass national protection and anti-discrimination legislation and provisions.

## Health

In order to ensure intersex people's enjoyment of their right to health, States should take measures to:

- protect people with variations of sex characteristics from non-emergency, invasive and irreversible "normalising" surgeries and other medical practices without the intersex individual's personal and fully informed consent (see previous section) as well as establish:
- the right to obtain treatment, including preventive check-ups and needed medication, which are based on the individual's physical needs and are 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 to coverage that is not limited by the sex/gender marker in the person's official documents, for any treatments.
- the right to expert-sensitive and individually tailored psychological and psycho-social counselling and support for all concerned individuals and their families, from the time of self-referral or diagnosis for as long as necessary.
- the right of survivors of intersex genital mutilation (IGM) to access reparative treatments on the same coverage terms as those provided for survivors of female genital mutilation (FGM).
- the right of access to one's own complete medical records, including for minors.

as well as taking measures to:

- include human rights-based information about the existence of intersex people and about intersex issues in all medical curricula and other curricula in the area of health.
- establish obligatory training for medical professionals, such as doctors, midwives, psychologists and other professionals working in the health sector (e.g. reception desk staff), in order to ensure that intersex individuals and their families have access to adequate healthcare and are protected from discrimination. The training should include information about the vulnerability and special needs of intersex people in medical settings.
- establish obligatory, human rights-based training about the existence of intersex people and about the specific needs of intersex seniors for professionals working in

elderly care to ensure that intersex seniors have access to adequate and respectful support and care without discrimination.

- invest in funding intersex groups and organisations so that they can engage in projects offering trainings for medical professionals, midwives, psychologists and other professionals working in the field of physical and mental health.

With good support systems, parents and families of intersex children can support their children and face possible challenges that lie in their way. To this aim, measures should be taken to:

- establish professional intersex peer counselling.
- ensure access for intersex people and their families to non-pathologising psycho-social counselling and peer support within close proximity.
- add human rights-based information about the existence of intersex people and intersex issues to curricula for all students in the areas of counselling and social work.
- invest in funding intersex peer support groups, preferably those who work from a de-pathologising and human rights perspective.
- increase the knowledge of general counselling services (e.g. family counselling services) about the existence and needs of intersex individuals and their families.
- raise awareness with future parents that intersex people exist, e.g. by including this information in an expert-sensitive manner in material directed to individuals and couples expecting children.
- invest in funding intersex groups and organisations so that they can engage in projects which offer trainings for psychologists, social workers and other professionals working in the field of psycho-social counselling.

## Discrimination and violence

In order to protect intersex people from discrimination and other violations of their human rights, OII Europe recommends the inclusion of “sex characteristics” as a protective ground in all existing and upcoming anti-discrimination legislation and provisions as well as in hate crime and hate speech legislation and provisions.

The ground “sex characteristics” should

- be explicitly included in all equal treatment and anti-discrimination provisions and legislation.
- ensure explicit protection in the fields of employment, access to goods and services including housing, and bias-motivated violence.
- ensure explicit protection against discrimination in the areas of social protection, including social security and healthcare, and social advantages and membership of and involvement in organisations of workers and employers.
- ensure that the statutes of limitation take into account the length of time a victim of discrimination needs to recover from discrimination; intersex people are especially vulnerable as a result of continuing invisibility, taboo and shame, and need recovery time before they are able to file a claim; the statute of limitations should reflect this need in order to allow the victim to access justice.

In addition, we recommend establishing comprehensive awareness raising measures for the general public as well as obligatory training about the existence of intersex people and human

rights violations intersex people face for professionals working in the area of health, education and law enforcement.

It is also important to:

- prohibit intersexphobic speech in the media, including on the Internet and social media.
- include intersex people as a vulnerable group in provisions and measures concerning the rights, support and protections of victims of crime.
- monitor intersexphobic hate speech and hate crimes
- create and evaluate protective measures to prevent intersexphobic hate speech and hate crimes.
- evaluate existing measures in regards to intersex inclusion.

## Identity documents

As long as gender markers are registered at birth, States should ensure that the existing diversity of sexes is reflected in options available to register the child's sex/gender. States should:

- statutorily and before the child is born, provide parents with information about the legal options for registering their child.
- make three (male, female, non-binary or equivalent) or more gender markers available when registering a child, and allow parents to choose their intersex child's legal gender (including leaving the gender marker blank, if available) without any medical statement/diagnosis.
- allow for gender-neutral names, with no obligation to add another, gendered middle name.
- allow for gender neutral family names.
- allow for postponing gender registration on the birth certificate until the child is mature enough to participate in the decision making process.
- allow for birth certificates without a gender marker entry for all, regardless of the infant's sex characteristics; in general, the absence of a marker should not indicate the sex characteristics of an individual.
- allow for parents and legal caretakers to choose M, F, or X for a child's passport when the child is registered as non-binary (or equivalent), non-specified or without a gender marker (entry left blank or registered as "not specified").
- establish a low-threshold procedure should the gender identity of the child not match the assigned gender, which allows the child to change their legal gender and name.

## Education

Key measures to protect intersex students from structural and verbal discrimination and harassment should include:

- explicitly including the protective ground "sex characteristics" in anti-discrimination provisions in the area of education.
- establishing mandatory training to prepare teachers for diversity in the classroom.
- establishing systems of support for vulnerable students that specifically include intersex students and their needs.

- establishing disaggregated data collection on bullying and harassment in school environments.
- establishing monitoring and evaluating tools and measurements for school inclusiveness.
- including intersex people and the existence of more than two biological sexes in a positive and empowering way in school curricula, text books and education materials in order to increase the understanding of the general public on the quality of sex as a spectrum and the existence of intersex people and to improve the self-confidence of intersex children and adolescents.
- establishing school policies that create a framework that is appropriate for protecting intersex students, and which
  - explicitly protect intersex students/students with variations of sex characteristics.
  - include basic facts about intersex students, e.g. that they can have all possible gender identities, that they may or may not transition, or that they may or may not be subjected to surgery or other medical interventions.
  - explicitly respect the right of all students to discuss and express their gender identity and expression as well as their sex characteristics openly or not and to decide with whom, when and how much private information they share.
  - explicitly include derogatory language in the scope of bullying; include derogatory language behaviour that takes place in the school, on school property, at school-sponsored functions and activities, as well as usage of electronic technology and electronic communication that occurs in the school, on school property, at school sponsored functions and activities, on school computers, networks, fora and mailing lists.
  - establish mandatory training about the existence of intersex people and about discrimination and human rights violations intersex students may face at school and in their everyday life for teachers, social workers, school psychologists and other professionals and staff working at schools.
  - establish low-threshold psychological and social support mechanisms for intersex students.
  - explicitly establish the entitlement of the intersex student to be provided with, on request, specific arrangements in relation to gender-specific facilities such as toilets and changing rooms, by providing them with a safe and non-stigmatising alternative.
  - encourage schools to designate facilities designed for use by one person at a time as accessible to all students regardless of their sex or gender, and to incorporate such single-user facilities into new construction or renovation.
  - allow for all students to participate in physical education classes and sports activities, including competition sports, in a manner consistent with their gender identity.
  - encourage schools to evaluate all gender-based facilities, activities, rules, policies, and practices in order to ensure that they meet equal treatment requirements and ensure non-discrimination for all students regardless of their sex, gender, or sex characteristics.
  - explicitly obligate school staff to use the name and pronoun based on the student's request, regardless of whether these have been changed in official documents.

- confirm or establish the school's obligation to change a student's official records to reflect a change in legal name and/or gender upon receipt of documentation that such change has been authorised, including reissuing or exchanging any social document or certificate relative to them according to their new name and/or gender.

## Access to justice

In order to allow intersex people to access justice, 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.
- explicitly establish the legal obligation for medical professionals with regards to all surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or any hormonal set-up:
  - to inform the mature 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;
  - in case of urgent, non-deferrable treatment on a child, which is not driven by social factors or a desire for legal certainty, inform the child's parent(s) or legal guardian(s) 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 including all of the above information, which are handed out to the patient or their parent(s) or legal guardian(s);
  - include these minutes in the intersex person's medical records.
- encourage the inclusion of legal cases about the human rights of intersex people in medical legal curricula and exams.

The harm that has been and is still being inflicted on intersex people is, in effect, a societal problem and as such, it is society's responsibility.

The 2013 Malta Declaration, which contains the joint demands of the international intersex community, calls on States to:

- recognise that medicalisation and stigmatisation of intersex people result in significant trauma and mental health concerns.
- provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past.
- provide adequate redress, reparation, access to justice and the right to truth.

The 2017 Yogyakarta Principles Plus 10 elaborate in detail on how to establish these rights for victims of violations on the basis of sexual orientation, gender identity, gender expression and sex characteristics<sup>45</sup>. The 2014 interagency statement Eliminating forced, coercive and otherwise involuntary sterilization by OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO includes a list of recommendations to States on how to best provide remedies and redress.<sup>46</sup>

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<sup>45</sup> See: The Yogyakarta Principles plus 10, Principle 37: The Right to Truth - A, p. 14-15, available at [http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5\\_yogyakartaWEB-2.pdf](http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf)

<sup>46</sup> OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014): Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement, p. 15-16.