# Protecting Intersex People in Europe A toolkit for policy and law makers

Dan Christian Ghattas

# **APPENDIX**





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## **Recommendations of UN Treaty Bodies<sup>1</sup> and other UN bodies**

### 1. Committee against Torture (CAT)

Since 2011, the Committee has expressed its concerns at "reports that unnecessary and irreversible surgery and other medical treatment are performed on intersex children without informed consent and impartial counselling". The Committee has also shown its concern in regards to the fact that "these procedures, which cause long-term physical and psychological suffering, have not been the object of any inquiry, sanction or reparation and that there are no specific legal provisions providing redress and rehabilitation to the victims".<sup>2</sup>

The Committee therefore has called on State parties to:

(a) Take the legislative, administrative and other measures necessary to guarantee the respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child without his or her informed consent;
(b) Guarantee impartial counselling services and psychological and social support for all intersex children and their parents, so as to inform them of the consequences of unnecessary and non-urgent surgery and other medical treatment to decide on the sex of the child and the possibility of postponing any decision on such treatment or surgery until the persons concerned can decide by themselves;

(c) Guarantee that full, free and informed consent is ensured in connection with medical and surgical treatments for intersex persons and that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to participate in decisionmaking and give effective consent;

(d) Undertake investigation of instances of surgical interventions or other medical procedures performed on intersex persons without effective consent and prosecute and, if found responsible, punish perpetrators. It should also ensure that the victims are provided with redress including adequate compensation.<sup>3</sup>

2. Committee for the Elimination of All Forms of Discrimination against Women (CEDAW) In 2009, the Committee was the first international human rights body to request a government to enter into dialogue with non-governmental organisations of intersex people "in order to better understand their claims and to take effective action to protect their human rights".<sup>4</sup>

<sup>&</sup>lt;sup>1</sup> For all links to the concluding observations of UN Treaty Bodies see the regularly updated PDF at: <u>https://oiieurope.org/international-intersex-human-rights-movement-resource-list/;</u> for a regularly updated list of List of intersex specific shadow reports to UN committees from CoE Region and from countries monitoring the CoE Region see: <u>https://oiieurope.org/list-of-intersex-specific-shadow-reports/</u>

<sup>&</sup>lt;sup>2</sup> CAT/C/NLD/CO/7, para. 52

<sup>&</sup>lt;sup>3</sup> CAT/C/NLD/CO/7, para. 53; for Council of Europe region see also: CAT/C/DNK/CO/6-7, CAT/C/AUT/CO/6, CAT/C/CHE/CO/7, CAT/C/DEU/CO/5, CAT/C/FRA/CO/7

<sup>&</sup>lt;sup>4</sup> CEDAW/C/DEU/CO/6, Article 62; for Council of Europe region see also: CEDAW/C/SVK/CO/5-6, CEDAW/C/FRA/CO/7-8, CEDAW/C/CHE/CO/4-5, CEDAW/C/NLD/CO/6, CEDAW/C/DEU/CO/7-8, CEDAW/C/IRL/CO/6-7, CEDAW/C/ITA/CO/7, CEDAW/C/LUX/CO/6-7, CEDAW/C/LIE/CO/5

Since then, the Committee has repeatedly shown strong concern about "the fact that intersex children are subjected to irreversible surgery for intersex variation and other medical treatment without their free and informed consent"<sup>5</sup> and that the "performance of medically irreversible sex reassignment surgery on intersex persons, a practice which is defined as non-consensual, unnecessary genital surgery and includes other comparable procedures that violate the physical integrity of such individuals"<sup>6</sup> is still taking place. In addition, the Committee has also emphasised the "lack of support for intersex persons who have undergone involuntary and medically unnecessary disfiguring surgical procedures when they were infants or children, often with irreversible consequences, resulting in significant physical and psychological suffering".<sup>7</sup>

The Committee has therefore called on State parties to:

(b) Specifically prohibit non-consensual sex reassignment surgery on intersex persons, develop and implement a rights-based health-care protocol for intersex children that requires medical doctors to inform intersex children about all available options and requires their involvement in decision-making about medical interventions and the full respect of their choices;
(c) Adopt legal provisions to provide redress to intersex persons who are victims of surgical or other medical interventions performed without their free, prior and informed consent or that of their parents.<sup>8</sup>

In regards to protecting intersex children and youth in education, the Committee has expressed concern about the "reports of bullying and violence towards migrant and lesbian, bisexual and transgender girls and adolescents and intersex children and adolescents in school settings"<sup>9</sup> and called on State parties to:

(e) Enable victims to confidentially report cases of bullying and expressions of discriminatory sentiments in educational institutions, including against migrant and lesbian, bisexual and transgender girls and adolescents and intersex children and adolescents, and ensure that those responsible receive adequate sanctions.<sup>10</sup>

#### 3. Committee for the Rights of the Child (CRC)

Since 2015 the Committee has expressed strong concern about "[c]ases of medically unnecessary surgical and other procedures on intersex children, which often entail irreversible consequences and can cause severe physical and psychological suffering, without their informed consent, and the lack of redress and compensation in such cases".<sup>11</sup>

The Committee urged State parties to:

(a) Ensure that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self- determination for the

<sup>&</sup>lt;sup>5</sup> CEDAW/C/ITA/CO/7, para. 41

<sup>&</sup>lt;sup>6</sup> CEDAW/C/LUX/CO/6-7, para. 27

<sup>&</sup>lt;sup>7</sup> ibid.

<sup>&</sup>lt;sup>8</sup> CEDAW/C/LUX/CO/6-7, para. 28

<sup>&</sup>lt;sup>9</sup> CEDAW/C/LUX/CO/6-7, para. 40

<sup>&</sup>lt;sup>10</sup> ibid.

<sup>&</sup>lt;sup>11</sup> CRC/C/CHE/CO/2-4, para. 42

children concerned and provide families with intersex children with adequate counselling and support;

(b) Develop and implement a child rights-based health-care protocol for intersex children, setting out the procedures and steps to be followed by health teams;

(c) Undertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the child victims of such treatment, including adequate compensation;

(d) 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.<sup>12</sup>

The Committee has also shown concern about the lack of explicit protection of intersex children by anti-discrimination legislation and has called on State parties to "continue taking awareness-raising measures to combat all forms of discrimination against children from ethnic minorities, asylum-seeking, refugee or Roma children, children with disabilities, and lesbian, gay, bisexual, transgender or intersex children".<sup>13</sup>

### 4. Committee for the Rights of People with Disabilities (CRPD)

Many intersex people have physical disabilities which they acquired as a result of unconsented medical treatments that they were subjected to. Furthermore, the human rights violations intersex people face match with the social definition of "disability", which defines a disability by the specific barriers individuals encounter in society, not by their impairment or difference.<sup>14</sup>

In 2015, the Committee expressed strong concerns about the "lack of implementation of the 2011 recommendations of the Committee against Torture (CAT/C/DEU/CO/5, para. 20) regarding upholding the bodily integrity of intersex children"<sup>15</sup> and about the fact that "children are subjected to irreversible surgery for intersex variation and other medical treatments without their free and informed consent".<sup>16</sup> It has also pointed to the abuse, ill-treatment and sexual violence intersex persons with disabilities face.<sup>17</sup>

The Committee urged State parties to "implement all the recommendations of the Committee against Torture relevant to intersex children" as well as to:

ensure that no one is subjected to scientific undocumented medical or surgical treatment during infancy or childhood; that it guarantee bodily integrity, autonomy and self-

<sup>&</sup>lt;sup>12</sup> CRC/C/DNK/CO/5, Article 24; for Council of Europe region see also: CRC/C/ESP/CO/5-6, CRC/C/GBR/CO/5, CRC/C/IRL/CO/3-4, CRC/C/FRA/CO/5, CRC/C/CHE/CO/2-4

<sup>&</sup>lt;sup>13</sup> CRC/C/DNK/CO/5, para. 12

<sup>&</sup>lt;sup>14</sup> For a more details on how intersex issues and the Convention for the Rights of People with Disabilities, see: OII Europe (2015): Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities <u>https://oiieurope.org/wp-content/uploads/2015/05/CRPD\_2015\_Statement\_OII\_Europe.pdf</u>

<sup>&</sup>lt;sup>15</sup> CRPD/C/DEU/CO/1, para. 37

<sup>&</sup>lt;sup>16</sup> CRPD/C/ITA/CO/1, para. 45

<sup>&</sup>lt;sup>17</sup> CRPD/C/GBR/CO/1, para. 38

determination to the children concerned; and that it provide families with intersex children with adequate counselling and support.<sup>18</sup>

It has also urged State parties to:

establish measures to ensure equal access to justice and to safeguard persons with disabilities, particularly women, children, intersex persons and elderly persons with disabilities from abuse, ill-treatment, sexual violence and exploitation.<sup>19</sup>

The Committee also has shown concern about the challenges faced by "organizations of persons with disabilities, including organizations representing women, children and intersex persons with disabilities, in accessing support and being consulted and actively involved in the implementation of the Convention".<sup>20</sup> It has reccommended to State parties to:

allocate financial resources to support organizations representing persons with disabilities, including women and children with disabilities, and develop mechanisms to ensure the inclusive, strategic and active involvement of organizations of persons with disabilities, including women, children and intersex persons, in the planning and implementation of all legislation and measures that affect the lives of persons with disabilities.<sup>21</sup>

#### 5. United Nations Human Rights Committee (CCPR)

Since 2017, the Committee has expressed concerns that "the performance of surgical procedures on intersex children, causing physical and mental suffering, is still not strictly regulated" and that "the conduct of surgery without consent has not yet given rise to any inquiry, sanction or reparation".<sup>22</sup>

It has called on State parties to:

(a) take all necessary measures to ensure that no child undergoes unnecessary surgery intended to assign sex;

(b) see to it that medical records are accessible and that inquiries are launched in cases where intersex persons are subjected to treatment or surgical procedures without their effective consent; and

(c) ensure that psychological assistance and reparation, including compensation, are provided for victims of needless surgical procedures.<sup>23</sup>

The Committee has also expressed concerns about the lack of adequate protection of intersex people from discrimination.<sup>24</sup>

<sup>&</sup>lt;sup>18</sup> CRPD/C/ITA/CO/1, para. 46

<sup>&</sup>lt;sup>19</sup> CRPD/C/GBR/CO/1, para. 39.a

<sup>&</sup>lt;sup>20</sup> ibid., para. 10.a

<sup>&</sup>lt;sup>21</sup> ibid., para. 11.a

<sup>&</sup>lt;sup>22</sup> CCPR/C/CHE/CO/4;

<sup>&</sup>lt;sup>23</sup> CCPR/C/CHE/CO/4; see also: CCPR/C/AUS/CO/6, para. 26

<sup>&</sup>lt;sup>24</sup> CCPR/C/PAK/CO/1, para.

#### 6. United Nations High Commissioner for Human Rights

In 2015, the UN High Commissioner for Human Rights Zeid Ra'ad Al Hussein addressed the human rights violations faced by intersex people in his opening speech for the 30th Human Rights Council, emphasising that intersex children and adults are "frequently subjected to forced sterilization and other unnecessary and irreversible surgery, and suffer discrimination in schools, workplaces and other settings" because their bodies don't comply with typical definitions of male or female.<sup>25</sup>

In 2014, the UN High Commissioner for Human Rights Navi Pillay stressed that "irreversible surgeries and sterilisations continue to be performed on intersex children without their informed consent, causing lifelong harm."<sup>26</sup>

# 7. United Nations Human Rights Council: Elimination of discrimination against women and girls in sport (A/HRC/40/L.10/Rev.1)<sup>27</sup>

In 2019 the Human Rights Council issued the first UN resolution that explicitly refers to the rights of intersex people. The Council noted with concern that the:

eligibility regulations for the female classification published by the International Association of Athletics Federations that came into effect on 1 November 2018 may not be compatible with international human rights norms and standards, including the rights of women with differences of sex development, and also concerned that there may have been a lack of legitimate and justifiable evidence for the regulations to the extent that they may not be reasonable and objective, and lack proportionality between the aim of the regulations and the proposed measures.<sup>28</sup>

It also expressed concern that regulations that require women and girl athletes with variations of sex characteristics to undergo medical treatment in order to compete:

may contravene international human rights norms and standards, including the right to equality and non-discrimination, the right to the highest attainable standard of physical and mental health, the right to sexual and reproductive health, the right to work and to the enjoyment of just and favourable conditions of work, the right to privacy, the right to freedom from torture or other cruel, inhuman or degrading treatment or punishment, and full respect for the dignity, bodily integrity and bodily autonomy of the person.<sup>29</sup>

The Council emphasised that these practices can lead to the "exclusion of women and girls from competing as such on the basis of their physical and biological traits, reinforce harmful gender stereotypes, racism, sexism and stigma, and infringe upon the dignity, privacy, bodily integrity and bodily autonomy of women and girls".<sup>30</sup> It therefore called upon States to:

<sup>&</sup>lt;sup>25</sup> <u>http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16414&LangID=E#sthash. q0 niwo.dpuf</u>

<sup>&</sup>lt;sup>26</sup> http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=14654&LangID=E

<sup>&</sup>lt;sup>27</sup> https://www.universal-rights.org/wp-content/uploads/2019/03/Elimination-of-discrimination-against-women-and-girlsin-sport.pdf

<sup>&</sup>lt;sup>28</sup> A/HRC/40/L.10/Rev.1, p. 2.

<sup>&</sup>lt;sup>29</sup> Ibid.

<sup>&</sup>lt;sup>30</sup> Ibid.

ensure that sporting associations and bodies implement policies and practices in accordance with international human rights norms and standards, and refrain from developing and enforcing policies and practices that force, coerce or otherwise pressure women and girl athletes into undergoing unnecessary, humiliating and harmful medical procedures in order to participate in women's events in competitive sports, and to repeal rules, policies and practices that negate their rights to bodily integrity and autonomy.<sup>31</sup>

## The United Nations Committee on Economic, Social and Cultural Rights: General Comment No. 23: Right to just and favorable conditions of work (E/C.12/GC/23)<sup>32</sup>

In 2016, following its 2009 General Comment,<sup>33</sup> the Committee confirmed the right of all individuals to equal opportunity for promotion through fair, merit-based and transparent processes that respect human rights and stated that the applicable criteria of seniority and competence should also include an assessment of individual circumstances in order to ensure equal opportunities for all. The Committee also emphasised that this is highly relevant for intersex workers, among others.<sup>34</sup>

In regards to physical and mental harassment, including sexual harassment, the Committee stated that "anti-discrimination laws, the penal code and labour legislation, should define harassment broadly, with explicit reference to sexual and other forms of harassment" and to include intersex people explicitly in the scope through their own protective ground.<sup>35</sup>

The Committee also underlined the "importance of consultation in formulating, implementing, reviewing and monitoring laws and policies related to the right to just and favourable conditions of work" and to include civil society organisations, including intersex organisations, into the process. <sup>36</sup>

Last but not least, the Committee emphasised that State parties have a "core obligation to ensure the satisfaction of, at the very least, minimum essential levels of the right to just and favourable conditions of work" and called on States to "guarantee through law the exercise of the right without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, disability, age, sexual orientation, gender identity, intersex status, health, nationality or any other status".<sup>37</sup>

<sup>&</sup>lt;sup>31</sup> Ibid.

<sup>&</sup>lt;sup>32</sup> http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2fGC %2f23&Lang=en

<sup>&</sup>lt;sup>33</sup> In 2009, the Committee pointed to the fact that intersex individuals "often face serious human rights violations" and included "harassment in schools or in the workplace" as discriminatory practices intersex people face, see: E/C.12/GC/20, Article 32

https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=E%2FC.12%2FGC%2F20&Lang=en <sup>34</sup> E/C.12/GC/23, Article 31

<sup>&</sup>lt;sup>35</sup> E/C.12/GC/23, Article 48

<sup>&</sup>lt;sup>36</sup> ibid., Article 56

<sup>&</sup>lt;sup>37</sup> ibid., Article 65 and 65a

# **9.** The United Nations Committee on Economic, Social and Cultural Rights: General Comment No. 22: Right to sexual and reproductive health (E/C.12/GC/22)<sup>38</sup>

In 2016, the Committee stated that due to "numerous legal, procedural, practical and social barriers, access to the full range of sexual and reproductive health facilities, services, goods and information is seriously restricted" and included intersex people in the scope of people who "experience multiple and intersecting forms of discrimination that exacerbate exclusion in both law and practice".<sup>39</sup>

The Committee therefore called on States to protect the right to sexual and reproductive health, combined with the right to work and just and favourable working conditions especially for workers in vulnerable situations, including intersex individuals.<sup>40</sup>

The Committee also reminded States of their obligation to take "effective steps to prevent third parties from undermining the enjoyment of the right to sexual and reproductive health". The Committee emphasised that States were not fullfilling this obligation when they failed to "prohibit and take measures to prevent all forms of violence and coercion committed by private individuals and entities", including violence targeting intersex persons, and "forced sterilization, forced abortion and forced pregnancy" as well as "medically unnecessary, irreversible and involuntary surgery and treatment performed on intersex infants or children".<sup>41</sup>

# **10.** OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO: Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement<sup>42</sup>

In 2014, several UN bodies, including the WHO, confirmed that "intersex persons, in particular, have been subjected to cosmetic and other non-medically necessary surgery in infancy [...] without informed consent of either the person in question or their parents or guardians" and that international human rights bodies and national courts had "regognized [such practices] as human rights violations".<sup>43</sup> The entire document is recommended reading for policymakers. For this appendix, please see five excerpts of specific relevance to intersex people below.

## (Excerpt 1)

Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved. As a result,

<sup>41</sup> ibid., Article 59

 <sup>&</sup>lt;sup>38</sup> <u>http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2fGC %2f22&Lang=en</u>
 <sup>39</sup> E/C.12/GC/22, Article 9

<sup>&</sup>lt;sup>40</sup> ibid., Article 30

<sup>42</sup> 

http://apps.who.int/iris/bitstream/handle/10665/112848/9789241507325\_eng.pdf;jsessionid=1839F90D7672C5D33EAAD8

<sup>&</sup>lt;sup>43</sup> OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014), p. 2

such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health.

Medical procedures that might result in sterility may sometimes be justified because of benefits to health, including the reduction of cancer risk. Such treatments may be recommended for transgender or intersex persons; however, they may be proposed on the basis of weak evidence, without discussing alternative solutions that would retain the ability to procreate. Parents often consent to surgery on behalf of their intersex children, including in circumstances where full information is lacking.

It has been recommended by human rights bodies, professional organizations and ethical bodies that full, free and informed consent should be ensured in connection with medical and surgical treatments for intersex persons and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent. It has also been recommended that health-care professionals should be educated and trained about bodily diversity as well as sexual and related biological and physical diversity, and that professionals should properly inform patients and their parents of the consequences of surgical and other medical interventions.

Discrimination on the basis of gender identity has been recognized by international human rights bodies as a human rights violation. Human rights bodies have condemned the serious human rights violations to which transgender and intersex persons are subjected and have recommended that transgender and intersex persons should be able to access health services, including contraceptive services such as sterilization, on the same basis as others: free from coercion, discrimination and violence. They have also recommended the revision of laws to remove any requirements for compulsory sterilization of transgender persons.<sup>44</sup>

#### (Excerpt 2)

International human rights standards require states to ensure effective accountability processes (including monitoring and evaluation), the availability of effective remedies, and the participation of a wide range of stakeholders in the development, implementation and monitoring of laws, policies and programmes. Individual, community and civil society participation – including of women living with HIV, persons with disabilities and transgender and intersex persons – in the development and monitoring of laws and policies, including budgets and use of public funds, is an important avenue for accountability.<sup>45</sup>

#### (Excerpt 3)

In the absence of medical necessity, when the physical well-being of a person with an intersex condition is in danger, if possible, postpone treatment that results in sterilization until the person is sufficiently mature to participate in informed decision- making and consent.<sup>46</sup>

<sup>&</sup>lt;sup>44</sup> ibid., p. 7-8

<sup>&</sup>lt;sup>45</sup> ibid., p. 12

<sup>&</sup>lt;sup>46</sup> ibid., p. 14

#### (Excerpt 4)

Provide support and information to parents who have intersex children, for example through psychological counselling and peer support or self-help groups, as well as support for intersex children.<sup>47</sup>

#### (Excerpt 5)

#### **Remedies and redress**

- Recognize past or present policies, patterns or practices of coercive sterilization, and issue statements of regret or apology to victims, as components of the right to remedy for these practices.
- Provide notification, through appropriate and humane means, to people who have been subjected to coercive sterilization, and who may be unaware of their situation, and provide information on the possibility of seeking administrative and judicial redress.
- Promptly, independently and impartially investigate all incidents of forced sterilization with due process guarantees for the alleged suspect, and ensure appropriate sanctions where responsibility has been established.
- Provide access, including through legal aid, to administrative and judicial redress mechanisms, remedies and reparations for all people who were subjected to forced, coercive or involuntary sterilization procedures, including compensation for the consequences and acknowledgement by governments and other responsible authorities of wrongs committed. Enable adults to seek redress for interventions to which they were subjected as children or infants.
- Guarantee access to reversal procedures, where possible, or assisted reproductive technologies for individuals who were subjected to forced, coercive or otherwise involuntary sterilization.

#### Monitoring and compliance

- Establish monitoring mechanisms for the prevention and documentation of forced, coercive and otherwise involuntary sterilization, and for the adoption of corrective policy and practice measures.
- Collect data regarding forced, coercive and otherwise involuntary sterilization, in order to assess the magnitude of the problem, identify which groups of people may be affected, and conduct a comprehensive situation and legal analysis.
- Providers of sterilization services should implement quality improvement programmes to ensure that recommendations aimed at preventing forced, coercive and otherwise involuntary sterilization are followed and procedures are properly documented.
- Establish mechanisms for obtaining patient feedback on the quality of services received, including from marginalized populations.<sup>48</sup>

<sup>&</sup>lt;sup>47</sup> ibid., p. 15

<sup>&</sup>lt;sup>48</sup> ibid., p. 15-16

## 11. United Nations General Assembly: Right of everyone to the enjoyment of the highest attainable standard of physical and mental health (A/64/272)<sup>49</sup>

Already in 2009, the United Nations General Assembly stated that "health-care providers must be cognizant of and adapt to the specific needs of [...] intersex persons".<sup>50</sup> It also call for "health-care providers [to] strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent" while explicitly pointing to the fact that this was "particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefit".<sup>51</sup>

 <sup>&</sup>lt;sup>49</sup> <u>http://www.refworld.org/pdfid/4aa762e30.pdf</u>
 <sup>50</sup> A/64/272, Article 46
 <sup>51</sup> ibid., Article 49 and footnote 67

## **Recommendations of Council of Europe Bodies**

Parliamentary Assembly of the Council of Europe (2017): Resolution 2191 (2017).
 Promoting the human rights of and eliminating discrimination against intersex people<sup>52</sup>

The resolution is a clear message to policymakers across Europe that they must take action to install legislative protections for intersex people, outlines the steps that need to be taken to protect the fundamental rights of intersex people and highlights the need to bring about rapid change within Council of Europe member states. Below is the text in its entirety.

#### Parliamentary Assembly

1. Intersex people are born with biological sex characteristics that do not fit societal norms or medical definitions of what makes a person male or female. Sometimes a person's intersex status is detected at birth; sometimes it only becomes apparent later in life, notably during puberty. Despite the wide variety of situations concerned, the majority of intersex people are physically healthy. Only a few suffer from medical conditions that put their health at risk. Yet the situation of intersex people has for a long time been treated as an essentially medical issue. The prevailing medical view has been that intersex children's bodies can and should be made to conform to either a male or a female paradigm, often through surgical and/or hormonal intervention; that this should be done as early as possible; and that the children should then be raised in the gender corresponding to the sex assigned to their body. 2. The Parliamentary Assembly considers that this approach involves serious breaches of physical integrity, in many cases concerning very young children or infants who are unable to give consent and whose gender identity is unknown. This is done despite the fact that there is no evidence to support the long-term success of such treatments, no immediate danger to health and no genuine therapeutic purpose for the treatment, which is intended to avoid or minimise (perceived) social problems rather than medical ones. It is often followed by lifelong hormonal treatments and medical complications, compounded by shame and secrecy. 3. Parents are often under pressure to make urgent, life-changing decisions on behalf of their

child, without having a full and genuine understanding of the long-term consequences for the child of the decisions made about their body during their infancy and early childhood. 4. Understanding of these issues is gradually increasing, but concerted efforts are still needed

to raise public awareness as to the situation and rights of intersex people so as to ensure that they are fully accepted in society, without stigmatisation or discrimination.

5. The Assembly emphasises that it is crucial to ensure that the law does not create or perpetuate barriers to equality for intersex people. This includes ensuring that intersex people who do not identify as male or female have access to legal recognition of their gender identity, and that where their gender has not been correctly recorded at birth, the procedure for rectifying this is simple and based on self-identification only, as set out in Assembly Resolution 2048 (2015) on discrimination against transgender people in Europe. Antidiscrimination laws may also need to be amended to ensure that the situation of intersex people is effectively covered.

<sup>&</sup>lt;sup>52</sup> http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-en.asp?FileID=24232&lang=en

6. The Assembly considers that the above may raise important issues under a number of provisions of the European Convention on Human Rights (ETS No. 5), notably Articles 3 and 8.
7. In the light of the above, and bearing in mind the provisions of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, "Oviedo Convention") and the relevant recommendations made in its Resolution 1952 (2013) on children's right to physical integrity, as well as those by the Council of Europe Commissioner for Human Rights and numerous treaty bodies of the United Nations, the Assembly calls on Council of Europe member States to:

7.1. with regard to effectively protecting children's right to physical integrity and bodily autonomy and to empowering intersex people as regards these rights:

7.1.1. prohibit medically unnecessary sex-"normalising" surgery, sterilisation and other treatments practised on intersex children without their informed consent;

7.1.2. ensure that, except in cases where the life of the child is at immediate risk, any treatment that seeks to alter the sex characteristics of the child, including their gonads, genitals or internal sex organs, is deferred until such time as the child is able to participate in the decision, based on the right to self-determination and on the principle of free and informed consent;

7.1.3. provide all intersex people with health care offered by a specialised, multidisciplinary team taking a holistic and patient-centred approach and comprising not only medical professionals but also other relevant professionals such as psychologists, social workers and ethicists, and based on guidelines developed together by intersex organisations and the professionals concerned;

- . 7.1.4. ensure that intersex people have effective access to health care throughout their lives;
- . 7.1.5. ensure that intersex people have full access to their medical records;
- . 7.1.6. provide comprehensive and up-to-date training on these matters to all medical,

psychological and other professionals concerned, including conveying a clear message that intersex bodies are the result of natural variations in sex development and do not as such need to be modified;

7.2. with a view to assisting intersex people, their parents and the people around them in dealing with the challenges posed, inter alia, by social attitudes towards variations in sex characteristics:

7.2.1. ensure that adequate psychosocial support mechanisms are available for intersex people and their families throughout their lives;

7.2.2. support civil society organisations working to break the silence around the situation of intersex people and to create an environment in which intersex people feel safe to speak openly about their experiences;

7.3. with regard to civil status and legal gender recognition:

7.3.1. ensure that laws and practices governing the registration of births, in particular as regards the recording of a newborn's sex, duly respect the right to private life by allowing sufficient flexibility to deal with the situation of intersex children without forcing parents or medical professionals to reveal a child's intersex status unnecessarily;

7.3.2. simplify legal gender recognition procedures in line with the recommendations adopted by the Assembly in Resolution 2048 (2015) and ensure in particular that these procedures are quick, transparent and accessible to all and based on self-determination;

7.3.3. ensure, wherever gender classifications are in use by public authorities, that a range of options are available for all people, including those intersex people who do not identify as either male or female;

7.3.4. consider making the registration of sex on birth certificates and other identity documents optional for everyone;

7.3.5. ensure that, in accordance with the right to respect for private life, intersex people are not prevented from entering into a civil partnership or marriage or from remaining in such a partnership or marriage as a result of the legal recognition of their gender;

7.4. with regard to combating discrimination against intersex people, ensure that antidiscrimination legislation effectively applies to and protects intersex people, either by inserting sex characteristics as a specific prohibited ground in all anti-discrimination legislation, and/or by raising awareness among lawyers, police, prosecutors, judges and all other relevant professionals, as well as intersex people, of the possibility of dealing with discrimination against them under the prohibited ground of sex, or as an "other" (unspecified) ground where the list of prohibited grounds in relevant national anti-discrimination provisions is non-exhaustive;

7.5. collect more data and carry out further research into the situation and rights of intersex people, including into the long-term impact of sex-"normalising" surgery, sterilisation and other treatments practised on intersex people without their free and informed consent, and in this context:

7.5.1. conduct an inquiry into the harm caused by past invasive and/or irreversible sex-"normalising" treatments practised on individuals without their consent and consider granting compensation, possibly through a specific fund, to individuals having suffered as a result of such treatment carried out on them;

7.5.2. in order to build a complete picture of current practice, keep a record of all interventions carried out on children's sex characteristics;

7.6. carry out campaigns to raise awareness among the professionals concerned and among the general public as regards the situation and rights of intersex people.

8. Finally, the Assembly invites national parliaments to work actively, with the participation of intersex people and their representative organisations, to raise public awareness about the situation of intersex people in their country and to give effect to the recommendations made above.

# 2. Commissioner for Human Rights of the Council of Europe (2015): Human Rights and Intersex People<sup>53</sup>

The Commissioner for Human Rights of the Council of Europe, Nils Muižnieks, recommended in his 2015 issue paper "Human Rights and Intersex People", to review "national equal treatment and hate

<sup>53</sup> https://rm.coe.int/16806da5d4

crime legislation" and to "ensure that it protects intersex people. Sex characteristics should be included as a specific ground in equal treatment and hate crime legislation or, at least, the ground of sex/gender should be authoritatively interpreted to include sex characteristics as prohibited grounds of discrimination".<sup>54</sup>

### (Excerpt)

#### The Commissioner's Reccommendations

- Member states should end medically unnecessary "normalising" treatment of intersex persons, including irreversible genital surgery and sterilisation, when it is enforced or administered without the free and fully informed consent of the person concerned. Sex assignment treatment should be available to intersex individuals at an age when they can express their free and fully informed con- sent. Intersex persons' right not to undergo sex assignment treatment must be respected.
- 2. Intersex persons and their families should be o ered interdisciplinary counsel- ling and support, including peer support. Intersex persons' access to medical records should be ensured.
- 3. National and international medical classi cations which pathologise variations in sex characteristics should be reviewed with a view to eliminating obstacles to the e ective enjoyment, by intersex persons, of human rights, including the right to the highest attainable standard of health.
- 4. Member states should facilitate the recognition of intersex individuals before the law through the expeditious provision of birth certi cates, civil registration documents, identity papers, passports and other o cial personal documen- tation while respecting intersex persons' right to self-determination. Flexible procedures should be observed in assigning and reassigning sex/gender in o cial documents while also providing for the possibility of not choosing a speci ed male or female gender marker. Member states should consider the proportionality of requiring gender markers in o cial documents.
- 5. National equal treatment and hate crime legislation should be reviewed to ensure that it protects intersex people. Sex characteristics should be included as a speci c ground in equal treatment and hate crime legislation or, at least, the ground of sex/gender should be authoritatively interpreted to include sex characteristics as prohibited grounds of discrimination.
- 6. National human rights structures such as ombudspersons, equality bodies, human rights commissions and children's ombudspersons should be active in their outreach towards intersex people, including children. They should be clearly mandated to work on issues related to intersex people and to provide victim-support services to them. There is a need to facilitate intersex persons' access to justice.
- 7. Member states should carry out research into the situation and human rights protection needs of intersex people in di erent settings. There is an urgent need to improve public awareness and professional training about the problems encountered by intersex persons. Intersex people and organisations representing them should be enabled to participate

<sup>&</sup>lt;sup>54</sup> See: Commissioner for Human Rights of the Council of Europe (2015), p. 9.

actively in research concerning them and in the development of measures improving their enjoyment of human rights.

8. The human rights violations intersex people have su ered in the past should be investigated, publicly acknowledged and remedied. Ethical and professional standards, legal safeguards and judicial control should be reinforced to ensure future human rights compliance.

# 3. Parliamentary Assembly of the Council of Europe (2013): Resolution 1952 (2013). Children's Right to Physical Intergrity<sup>55</sup>

The Parliamentary Assembly stated in 2013 that it was "particularly worried about a category of violation of the physical integrity of children, which supporters of the procedures tend to present as beneficial to the children themselves despite clear evidence to the contrary". The concern specifically included "early childhood medical interventions in the case of intersex children".<sup>56</sup> The Parliamentary Assembly, therefore, called on Members States to:

7.5.3. undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support.

<sup>&</sup>lt;sup>55</sup> http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174

<sup>&</sup>lt;sup>56</sup> See: PACE (2013), Article 2

## **Recommendations of European Union Bodies**

1. European Parliament (2019): The rights of intersex people. European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP))<sup>57</sup>

In 2018 the European adopted a landmark resolution on the rights of intersex people. By adopting this resolution, the European Parliament sets a clear standard within the European Union for the protection of intersex people's bodily integrity and human rights. The resolution complements the ground-breaking 2017 intersex resolution *Promoting the human rights of and eliminating discrimination against intersex people* adopted by the Parliamentary Assembly of the Council of Europe. In its resolution the European Parliament notes the urgent need to address violations of the human rights of intersex people, and calls on the Commission and the Member States to propose legislation to address these issues. Below is the text in its entirety.

#### The European Parliament,

- having regard to Article 2 of the Treaty on European Union,
- having regard to Articles 8 and 10 of the Treaty on the Functioning of the European Union,
- having regard to the Charter of Fundamental Rights of the European Union, and in particular Article 21 thereof,
- having regard to the European Social Charter, and in particular Article 11 thereof,
- having regard to Directive 2012/29/EU of the European Parliament and of the Council of 25 October 2012 establishing minimum standards on the rights, support and protection of victims of crime,
- having regard to the report published by the Commission in 2011 entitled 'Trans and intersex people',
- having regard to the final reports of the Commission-funded 'Health4LGBTI' pilot project on health inequalities experienced by LGBTI people,
- having regard to its resolution of 4 February 2014 on the EU Roadmap against homophobia and discrimination on grounds of sexual orientation and gender identity,
- having regard to its resolution of 13 December 2016 on the situation of fundamental rights in the European Union in 2015,
- having regard to the paper published in May 2015 by the European Union Agency for Fundamental Rights (FRA) entitled 'The fundamental rights situation of intersex people',
- having regard to the FRA's online publication of November 2017 entitled 'Mapping minimum age requirements concerning the rights of the child in the EU',
- having regard to the FRA Fundamental Rights Report 2018,
- having regard to the European Convention on Human Rights,
- having regard to the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment,
- having regard to Resolution 2191 of the Council of Europe Parliamentary Assembly, adopted in 2017, on promoting the human rights of and eliminating discrimination against intersex people,
- having regard to the 2015 report of the Council of Europe Commissioner for Human Rights on human rights and intersex people,
- having regard to the Universal Declaration of Human Rights,
- having regard to the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment,
- having regard to the UN Convention on the Rights of the Child,
- having regard to the UN Convention on the Rights of Persons with Disabilities,
- having regard to the 2013 report of the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment,

<sup>&</sup>lt;sup>57</sup> P8\_TA-PROV(2019)0128. The rights of intersex people. European Parliament resolution of 14 February 2019 on the rights of intersex people (2018/2878(RSP)) <u>http://www.europarl.europa.eu/doceo/document/TA-8-2019-0128\_EN.pdf</u>

- having regard to the Yogyakarta Principles ('Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics') adopted in November 2006, and the 10 complementary principles ('plus 10') adopted on 10 November 2017,
- having regard to the questions to the Council and to the Commission on the rights of intersex people (O-000132/2018 B8-0007/2019 and O-000133/2018 B8-0008/2019),
- having regard to the motion for a resolution of the Committee on Civil Liberties, Justice and Home Affairs,
- having regard to Rules 128(5) and 123(2) of its Rules of Procedure,
- A. whereas intersex individuals are born with physical sex characteristics that do not fit medical or social norms for female or male bodies, and these variations in sex characteristics may manifest themselves in primary characteristics (such as the inner and outer genitalia and the chromosomal and hormonal structure) and/or secondary characteristics (such as muscle mass, hair distribution and stature);
- B. whereas intersex people are exposed to multiple instances of violence and discrimination in the European Union and these human rights violations remain widely unknown to the general public and policymakers;
- C. whereas there is a high prevalence of surgeries and medical treatments carried out on intersex infants, although in most cases these treatments are not medically necessary; whereas cosmetic surgeries and urgent surgeries can be proposed as a package, preventing parents and intersex people from having full information on the impact of each;
- D. whereas surgeries and medical treatments are performed on intersex children without their prior, personal, full and informed consent; whereas intersex genital mutilation can have lifelong consequences, such as psychological trauma and physical impairments;
- E. whereas intersex individuals and intersex children who belong to other minority and marginalised groups are further marginalised and socially excluded and are at risk of violence and discrimination, because of their intersecting identities;
- F. whereas in most Member States surgery can be performed on an intersex child or an intersex individual with disabilities with the consent of their legal guardian, regardless of the capacity of the intersex person to decide for themselves;
- G. whereas in many cases parents and/or legal guardians are strongly pressured to make decisions without being fully informed of the lifelong consequences for their child;
- H. whereas many intersex people do not have full access to their medical records and therefore do not know that they are intersex or are not aware of the medical treatments they have been subjected to;
- I. whereas intersex variations continue to be classified as diseases, as in the World Health Organisation's International Classification of Diseases (ICD), in the absence of evidence supporting the long-term success of treatments;
- J. whereas some intersex people will not identify with the gender they are medically assigned at birth; whereas legal gender recognition based on self-determination is only possible in six Member States; whereas many Member States still require sterilisation for legal gender recognition;
- K. whereas anti-discrimination legislation at EU level, and in most Member States, does not include discrimination based on sex characteristics, whether as a standalone category or interpreted as a form of discrimination based on sex;
- L. whereas many intersex children face human rights violations and genital mutilation in the EU when undergoing sex-normalising treatments;
- 1. Notes the urgent need to address violations of the human rights of intersex people, and calls on the Commission and the Member States to propose legislation to address these issues;

#### Medicalisation and pathologisation

2. Strongly condemns sex-normalising treatments and surgery; welcomes laws that prohibit such surgery, as in Malta and Portugal, and encourages other Member States to adopt similar legislation as soon as possible;

- 3. Stresses the need to provide adequate counselling and support to intersex children and intersex individuals with disabilities, as well as to their parents or guardians, and fully inform them of the consequences of sex-normalising treatments;
- 4. Calls on the Commission and the Member States to support organisations that work to break the stigma against intersex people;
- 5. Calls on the Commission and the Member States to increase funding for intersex civil society organisations;
- 6. Calls on the Member States to improve access for intersex people to their medical records, and to ensure that no one is subjected to non-necessary medical or surgical treatment during infancy or childhood, guaranteeing bodily integrity, autonomy and selfdetermination for the children concerned;
- 7. Takes the view that pathologisation of intersex variations jeopardises the full enjoyment by intersex people of the right to the highest attainable standard of health as enshrined in the UN Convention on the Rights of the Child; calls on the Member States to ensure the depathologisation of intersex people;
- 8. Welcomes the depathologisation, however partial, of trans identities in the eleventh revision of the ICD (ICD-11); notes, however, that the category of 'gender incongruence' in childhood pathologises non-gender-normative behaviours in childhood; calls, therefore, on the Member States to pursue the removal of this category from the ICD-11, and to bring future ICD revision into line with their national health systems;

#### **Identity documents**

9. Stresses the importance of flexible birth registration procedures; welcomes the laws adopted in some Member States that allow legal gender recognition on the basis of selfdetermination; encourages other Member States to adopt similar legislation, including flexible procedures to change gender markers, as long as they continue to be registered, as well as names on birth certificates and identity documents (including the possibility of gender-neutral names);

#### Discrimination

- 10. Deplores the lack of recognition of sex characteristics as a ground of discrimination across the EU, and therefore highlights the importance of this criterion in order to ensure access to justice for intersex people;
- 11. Calls on the Commission to enhance the exchange of good practices on the matter; calls on the Member States to adopt the necessary legislation to ensure the adequate protection, respect and promotion of the fundamental rights of intersex people, including intersex children, including full protection against discrimination;

#### Public awareness

- 12. Calls on all relevant stakeholders to carry out research concerning intersex people, taking a sociological and human rights perspective rather than a medical one;
- 13. Calls on the Commission to make sure that EU funds do not support research or medical projects that further contribute to violating the human rights of intersex people, in the context of the European Reference Networks (ERNs); calls on the Commission and the

Member States to support and fund research on the human rights situation of intersex people;

- 14. Calls on the Commission to take a holistic and rights-based approach to the rights of intersex people and to better coordinate the work of its Directorates-General for Justice and Consumers, for Education, Youth, Sport and Culture, and for Health and Food Safety, so as to ensure consistent policies and programmes supporting intersex people, including training of state officials and the medical profession;
- 15. Calls on the Commission to reinforce the intersex dimension in its multiannual LGBTI list of actions for the current period, and to begin preparing as of now a renewal of this strategy for the next multiannual period (2019-2024);
- 16. Calls on the Commission to facilitate the sharing of best practices among Member States on protecting the human rights and bodily integrity of intersex people;

# 2. European Union Agency for Fundamental Rights (2015): FRA Focus Paper. The Fundamental Rights Situation of Intersex People<sup>58</sup>

In 2015 the EU Fundamental Rights Agency (FRA) pointed out in their report on the fundamental rights situation of intersex people, that "given that it concerns physical (sex) characteristics, intersex discrimination is better covered under sex discrimination than under discrimination on the basis of sexual orientation and/or gender identity".<sup>59</sup>

## (Excerpt)

## Key facts

- Many Member States legally require births to be certi ed and registered as either male or female.
- In at least 21 Member States, sex 'normalising' surgery is carried out on intersex children.
- In 8 Member States, a legal representative can consent to sex 'normalising' medical interventions independently of the child's ability to decide.
- 18 Member States require patient consent provided the child has the ability to decide.
- Intersex discrimination is better covered by sex discrimination rather than discrimination on the basis of sexual orientation and/or gender identity as it concerns physical (sex) characteristics.

## Key conclusions

• Legal and medical professionals should be better informed of the fundamental rights of intersex people, particularly children.

<sup>&</sup>lt;sup>58</sup> <u>http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people</u>

<sup>&</sup>lt;sup>59</sup> Key finding from the FRA comparative legal analysis 2015: Protection against discrimination on grounds of sexual orientation, gender identity and sex characteristics in the EU, p. 70

- Gender markers in identity documents and birth registries should be reviewed to better protect intersex people.
- Member States should avoid non-consensual 'sex-normalising' medical treatments on inter- sex people.

## **Recommendations of Non-Governmental bodies**

### 1. Yogyakarta Principles Plus 10 (2017)<sup>60</sup>

Since the Yogyakarta Principles were adopted in 2006, international human rights standards and law, as well as the understanding and recognition of violations affecting persons on the grounds of "sex characteristics" have developed significantly. Together, the original 29 Yogyakarta Principles and set of Additional Principles and State Obligations established by the Yogyakarta Principles plus 10 (YP+10), provide an expert exposition of international human rights law as it currently applies to the ground of sexual orientation, gender identity, gender expression and sex characteristics. The Yogyakarta Principles plus 10 call on States to respect each individual's human rights and therefore to, amongst others to:

- Recognise that forced, coercive and otherwise involuntary modification of a person's sex characteristics may amount to torture, or other cruel, inhuman or degrading treatment<sup>61</sup>
- Prohibit any practice, and repeal any laws and policies, allowing intrusive and irreversible treatments on the basis of sexual orientation, gender identity, gender expression or sex characteristics, including forced genital-normalising surgery, involuntary sterilisation, unethical experimentation, medical display, "reparative" or "conversion" therapies, when enforced or administered without the free, prior, and informed consent of the person concerned<sup>62</sup>
- Protect all persons from discrimination, violence and other harm on the basis of sexual orientation, gender identity, gender expression and sex characteristics in healthcare settings<sup>63</sup>

#### (Excerpt 1)

#### Principle 32 The Right to Bodily and Mental Integrity

Everyone has the right to bodily and mental integrity, autonomy and self- determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.

#### States shall

a. Guarantee and protect the rights of everyone, including all children, to bodily and mental integrity, autonomy and self-determination;

<sup>&</sup>lt;sup>60</sup> http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5\_yogyakartaWEB-2.pdf

<sup>&</sup>lt;sup>61</sup> ibid., Principle 10, D

<sup>&</sup>lt;sup>62</sup> ibid., Principle 10, E

<sup>&</sup>lt;sup>63</sup> ibid. Principle 17, J

- b. Ensure that legislation protects everyone, including all children, from all forms of forced, coercive or otherwise involuntary modification of their sex characteristics;
- c. Take measures to address stigma, discrimination and stereotypes based on sex and gender, and combat the use of such stereotypes, as well as marriage prospects and other social, religious and cultural rationales, to justify modifications to sex characteristics, including of children;
- d. Bearing in mind the child's right to life, non-discrimination, the best interests of the child, and respect for the child's views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity;
- e. Ensure that the concept of the best interest of the child is not manipulated to justify practices that confliict with the child's right to bodily integrity;
- f. Provide adequate, independent counselling and support to victims of violations, their families and communities, to enable victims to exercise and afm rights to bodily and mental integrity, autonomy and self-determination;

#### (Excerpt 2)

#### Principle 37 The Right to Truth

Every victim of a human rights violation on the basis of sexual orientation, gender identity, gender expression or sex characteristics has the right to know the truth about the facts, circumstances and reasons why the violation occurred. The right to truth includes effective, independent and impartial investigation to establish the facts, and includes all forms of reparation recognised by international law. The right to truth is not subject to statute of limitations and its application must bear in mind its dual nature as an individual right and the right of the society at large to know the truth about past events.

#### States shall:

- a. Adopt legal provisions to provide redress to victims of violations on the basis of sexual orientation, gender identity, gender expression and sex characteristics, including public apology, expungement of relevant criminal convictions and records, rehabilitation and recovery services, adequate compensation and guarantees of nonrecurrence;
- b. Ensure, in cases of violations of the right to mental and bodily integrity, effective access to remedies, redress, reparation and, where appropriate, psychological support and restorative treatments;
- c. Protect individuals' right to know the truth about their medical histories, including through full access to accurate medical records;
- d. Adopt and fully implement procedures to establish the truth concerning violations based on sexual orientation, gender identity, gender expression and sex characteristics;

- e. Establish a truth-seeking mechanism and process in regard to human rights violations based on sexual orientation, gender identity, gender expression and sex characteristics;
- f. Ensure that, in addition to individual victims and their families, communities and society at large can realise the right to the truth about systemic human rights violations based on sexual orientation, gender identity, gender expression and sex characteristics, while respecting and protecting the right to privacy of individuals;
- g. Preserve documentary evidence of human rights violations based on sexual orientation, gender identity, gender expression and sex characteristics, and ensure adequate access to archives with information on violations based on sexual orientation, gender identity, gender expression and sex characteristics;
- h. Ensure that the facts and truth of the history, causes, nature and consequences of discrimination and violence on grounds of sexual orientation, gender identity, gender expression and sex characteristics are disseminated and added to educational curricula with a view to achieving a comprehensive and objective awareness of past treatment of persons on grounds of sexual orientation, gender identity, gender expression and sex characteristics;
- i. Commemorate the suffering of victims of violations on the basis of sexual orientation, gender identity, gender expression and sex characteristics through public events, museums and other social and cultural activities.

## 2. The 2012 Helsinki Declaration on the Right to Genital Autonomy. 12th International Symposium on Law, Genital Autonomy & Children's Rights. Helsinki, Finland, 29 September to 3 October 2012<sup>64</sup>

The Helsinki Declaration confirms a person's fundamental right to have the full control over their genital and reproductive organs and to be protected from medically unnecessary genital modification and other irreversible interventions. Below is the text in its entirety.

The 2012 Helsinki Declaration on the Right to Genital Autonomy

<u>Whereas</u> it is the fundamental and inherent right of each human being to security of the person without regard to age, sex, gender, ethnicity or religion as articulated in the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of the Child.

## Now we declare

the existence of a fundamental right of each human being a Right of Genital Autonomy, that is the right to:

• personal control of their own genital and reproductive organs; and

<sup>&</sup>lt;sup>64</sup> http://www.genitalautonomy.org/wp-content/uploads/2013/07/Hel-Dec-Final\_WM.pdf

• protection from medically unnecessary genital modification and other irreversible reproductive interventions.

#### We declare

that consistent with the Right of Genital Autonomy the only person who may consent to medically unnecessary genital modification and other irreversible reproductive interventions is:

- in the case of a person who is competent to give free and informed consent, being fully informed about the nature, the risks and benefits of the intervention the person undergoing the intervention; and
- in the case of an incompetent person including a young child only a properly constituted public authority or tribunal appointed to balance the human rights and the best interests of the person after considering the views of family members, professionals and an independent advocate for the person.

### We recognise

the fundamental right of parents and guardians to freedom of thought, conscience and religion. Those rights of parents and guardians are not absolute, they are limited by the same fundamental human rights of others, in particular their children.

#### We declare

that healthy genital and reproductive organs are natural, normal, functional parts of the human body. Governments and healthcare providers have a duty to educate parents and children about non-invasive hygiene, care of genital and reproductive organs, and to explain their anatomical and physiological development and function.

#### We encourage and support

further research into the adverse consequences of such interventions.

#### We oppose

research and experimentation that involves the performance of medically unnecessary modification and other irreversible medical interventions affecting genital and reproductive organs upon non-consenting children and adults.

#### We call

on all governments to acknowledge the Right of Genital Autonomy for every child and adult, that is the right to:

- personal control of their own genital and reproductive organs; and
- protection from medically unnecessary genital modification and other irreversible reproductive interventions.

#### <u>We call</u>

on all States members to the Convention on the Rights of the Child to honor their commitments under that instrument in particular Articles 2, 12, 14, 19 and 24.

Done at Helsinki, Wednesday 3 October 2012

## **Opinions of national Ethic Councils and Governmental Bodies**

 Conseil d'Etat (2018): Revision de la loi bioéthique: quelles option pour demain? 2.4. Les enfants dits « intersexes » : la prise en charge médicale des enfants présentant des variations du développement genital (Revision of the bioethics law: what options for the future? 2.4. Intersex children: medical care for children with variations in genital development)<sup>65</sup>

The Statement of the Conseil d'Etat, which acts both as legal adviser of the executive branch of the French government and as the <u>supreme court</u> for <u>administrative justice</u>, has published this chapter as part of a larger document on the revision of the French bioéthique law. It outlines the very basis of what "medically necessary" means from an ethical and legal perspective and confirms that only interventions that are "<u>required to avoid jeopardizing the person's life or a physical suffering</u>" allow for medical interventions without the intersex persons personal, free and fully informed consent.

NOTE: The term "variations du développement génital" ("variations in genital development"), as used in the headline mixes human rights compliant language ("variation") with a reference to the pathologising terminology and concept "disorder of sex development" (DSD). Where ever possible these kind of combinations should be avoided and instead the human rights term "variations of sex characteristics" should be used.

#### (Excerpt 1)

The greater the damage to the integrity of the human body caused by the act, the greater the benefits of performing such an act or the risks of non-acting must be.

This is reflected in the provisions of article 41 of the Code of Medical Ethics, codified in article R. 4127-41 of the Public Health Code, which stipulates that "<u>no mutilating intervention may</u> <u>be carried out without very serious medical reasons and, unless urgent or impossible, without</u> <u>informing the person concerned and without his consent</u>". The comments of the Ordre des médecins specify that "the amputation of a limb, the removal of an organ, are serious consequences since they are irreversible. It goes without saying that the surgeon only decides when necessary, because the lesions impose it, because to do otherwise would be dangerous".<sup>66</sup>

#### (Excerpt 2)

The existence of a very serious medical reason must be assessed both in the light of the purpose of the proposed act and the time at which it is carried out.

<sup>&</sup>lt;sup>65</sup> Conseil d'Etat (2018): Revision of the bioethics law: what options for the future? 2.4. Children know as "intersex" children: medical care for children with variations in genital development [translated from French by the author]
<sup>66</sup> See: Conseil d'Etat (2018), p. 136-137: "Plus l'atteinte à l'intégrité du corps humain impliquée par l'acte sera importante,

See: Conseil d'Etat (2018), p. 136-137: "Plus l'atteinte à l'intégrité du corps numain impliquée par l'acté serà importante, plus les avantages liés à l'accomplissement d'un tel acte ou les risques associés à l'inaction devront s'avérer importants. C'est ce que traduisent les dispositions de l'article 41 du code de déontologie médicale, codifiées à l'article R. 4127-41 du code de la santé publique, qui prévoient qu'« <u>aucune intervention mutilante ne peut être pratiquée sans motif médical très</u> <u>sérieux et, sauf urgence ou impossibilité, sans information de l'intéressé et sans son consentement</u> ». Les commentaires de l'Ordre des médecins précisent en ce sens que « l'amputation d'un membre, l'ablation d'un organe, sont lourdes de conséquences puisque irréversibles. Il va de soi que le chirurgien ne s'y décide qu'en cas de nécessité, parce que les lésions l'imposent, parce qu'agir autrement serait périlleux »" [highlights in the original text]

First, according to the Conseil d'État, such a requirement refers, among the purposes of surgical procedures performed on infants with variations in genital development, <u>only to the interventions required to avoid jeopardizing the person's life or a physical suffering associated with these variations</u>. Performing treatments whose sole purpose is to promote the identity construction of the children on whom they are carried out, do not meet such a requirement; insofar as uncertainty remains as to the capacity of the envisaged acts to pursue such a goal.

Second, the requirement of a very serious medical reason implies that carrying out early surgical interventions, which are performed before before the child is able to participate in the decision and that do not strictly intended to avoid possible medical complications, must be justified by compelling and firmly established reasons. Two sets of reasons have been put forward to justify the early nature of such interventions: on one hand, reasons relating to surgical technique, which argue that the usability of tissue and the hormone level are better in an infant's body than when the person concerned reaches puberty. And, on the other hand, the lesser psychological impact of such interventions when the child is young. However, the hearings conducted by the Conseil d'État <u>enabled it to conclude that such grounds could</u> not, to the best of its knowledge, be established with certainty.

On one hand, opinions are divided on whether surgical procedures performed on infants are less risky than those performed on prepubescent children who have reached a degree of maturity that allows them to participate in medical decision-making. On the other hand, the supposedly lesser psychological impact of an intervention on an infant deserves to be qualified, on the same level of the child's psyche, in the light of the advantage of a later action allowing the person concerned to express their opinion and to adhere to the envisaged therapies.

<u>Ultimately, if the sole purpose of the medical procedure is to conform the aesthetic</u> <u>appearance of the genital organs to the representations of the male and female in order to</u> <u>promote the psychological and social development of the child, the procedure should not be</u> <u>conducted until the person concerned is able to express their wishes and participate in the</u> <u>decision-making process</u>.<sup>67</sup>

<sup>&</sup>lt;sup>67</sup> See: Ibid., p. 139-140 [translated into English by the author]: "L'existence d'un motif médical très sérieux doit s'apprécier à la fois au regard de la finalité poursuivie par l'acte envisagé et du moment auquel il intervient. Sur le premier point, une telle exigence renvoie selon le Conseil d'État, parmi les finalités des actes chirurgicaux effectués à l'égard de nourrissons présentant des variations du développement génital, aux seules interventions qui s'imposent afin d'éviter de mettre en jeu le pronostic vital de la personne ou les souffrances physiques associées à ces variations. Les traitements qui ont uniquement pour finalité de favoriser la construction identitaire des enfants sur lesquels ils sont mis en œuvre, dans la mesure où une incertitude demeure sur l'aptitude des actes envisagés à poursuivre un tel objet, ne répondent pas à une telle exigence. Sur le second point, l'exigence d'un motif médical très sérieux suppose que des raisons impérieuses et fermement établies justifient le caractère précoce d'interventions chirurgicales effectuées avant que l'enfant soit en mesure de participer à la décision et qui n'ont pas pour stricte finalité d'éviter d'éventuelles complications médicales. Deux séries de motifs sont aujourd'hui mises en avant pour justifier le caractère précoce de telles interventions : d'une part des raisons qui relèvent de la technique chirurgicale, tenant à la disponibilité des tissus et au climat hormonal des nourrissons qui seraient plus favorables que lorsque l'intéressé atteint l'âge de la puberté, d'autre part le moindre impact psychologique de ces interventions lorsque l'enfant est en bas âge. Or, les auditions réalisées par le Conseil d'État lui ont permis de constater que de tels motifs ne pouvaient pas, en l'état des connaissances, être établis avec certitude. D'une part, les avis sont partagés sur la question de savoir si les interventions chirurgicales pratiquées sur des nourrissons présentent plus de risques que celles effectuées sur des enfants prépubères ayant donc atteint un degré de maturité leur permettant de participer à la prise de décision médicale. D'autre part, l'impact psychologique supposé moindre d'une

2. 24th Conference of the Equality and Women Ministers and Senators of the German Länder (2014): Tagesordnungspunkt 8.1: Rechte intersexueller Menschen wahren und Diskriminierung beenden – insbesondere Schutz der körperlichen Unversehrtheit (Agenda item 8.1: Safeguarding the rights of intersex persons and ending discrimination – in particular the protection of physical integrity)<sup>68</sup>

In 2014 the 24th Conference Equality and Women Ministers and Senators of the German Länder (GMFK) called for a ban of cosmetic surgeries on intersex minors and pointed to the need to clearly regulate by law the conditions for surgeries and medical treatment on intersex minors.

The GMFK pointed out that "family law already prohibits guardians from consenting to the sterilisation of a child (§ 1631c BGB)" and that, "in the case of girls, parents cannot give effective consent to the removal or circumcision of the clitoris, as this is punishable as female genital mutilation (§ 226a StGB)",<sup>69</sup> but that intersex minors were "in fact often denied this protection by carrying out procedures that have a sterilizing effect or that alter the genitals of intersexual minors without their consent and without compelling medical indication".<sup>70</sup>

Therefore, the GMFK continued, a "corresponding standard of protection must also be implemented for intersex children who are equally worthy of protection, especially since the interventions usually concern the core area of identity, are predominantly irreversible and are justified as an supposedly preventive measure (in regards to a presumed later psychosocial burden and 'need for adaptation' to society) under the guise of the welfare of the child".<sup>71</sup>

intervention sur un nourrisson mérite d'être nuancé au regard de l'avantage, sur le même plan du psychisme de l'enfant, que présente une action plus tardive permettant à l'intéressé de faire part de son avis et d'adhérer aux thérapies envisagées. En définitive, l'acte médical ayant pour seule finalité de conformer l'apparence esthétique des organes génitaux aux représentations du masculin et du féminin afin de favoriser le développement psychologique et social de l'enfant ne devrait pas pouvoir être effectué tant que l'intéressé n'est pas en mesure d'exprimer sa volonté et de participer à la prise de décision." [highlights in the original text]

<sup>&</sup>lt;sup>68</sup>https://www.gleichstellungsministerkonferenz.de/documents/2014 10 13 beschluesse gesamt extern 2 1510227377.

<sup>&</sup>lt;u>pdf</u> <sup>69</sup> 24. Konferenz der Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GFMK) (2014), p. 53 (translated from German by the author): "Z.B. verbietet das Familienrecht den Sorgeberechtigten bereits, in die Sterilisation eines Kindes einzuwilligen (§ 1631c BGB). Bei Mädchen können die Eltern ferner keine wirksame Einwilligung zur Entfernung oder Beschneidung der Klitoris erteilen, da dies als Verstümmelung weiblicher Genitalien unter Strafe steht (§ 226a StGB)."

<sup>&</sup>lt;sup>70</sup> Ibid, p. 53 (translated from German by the author): "Intersexuellen Minderjährigen bleibt dieser Schutz aber faktisch häufig verwehrt, indem Eingriffe durchgeführt werden, die sterilisierende Wirkung haben oder Genitalien von intersexuellen Minderjährigen ohne deren Einwilligung und ohne zwingende medizinische Indikation verändert werden.

<sup>&</sup>lt;sup>71</sup> Ibid., p. 53 (translated from German by the author): "Ein entsprechender Schutzstandard ist auch für die ebenso schutzwürdigen intersexuellen Kinder zu implementieren, zumal die Eingriffe i.d.R. den Kernbereich der Identität betreffen, überwiegend irreversibel sind und vermeintlich präventiv (mit einer vermuteten späteren psychosozialen Belastung und "Anpassungsnotwendigkeit" in die Gesellschaft unter dem Deckmantel des Kindeswohls) begründet werden."

## **National Legislation**

On a national level Malta (2015), Greece (2016), the Netherlands (2018) and Portugal (2018) have established protection of intersex people against discrimination under the ground of "sex characteristics".<sup>72</sup>

Malta (2015) and, with some nuances, Portugal (2018) have also established protection of intersex individuals from non-emergency medical interventions that are performed without the free, personal and fully informed consent of the person.

## Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act (ACT XI of 2015 as amended by ACT XX of 2015, ACT LVI of 2016 and ACT XIII of 2018)<sup>73</sup>

The Maltese Act is the best practice example on how to legally ensure bodily integrity and selfdetermination of intersex people.

#### (Excerpt)

**14.** (1) It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and, or surgical intervention on the sex characteristics of a minor which treatment and, or intervention can be deferred until the person to be treated can provide informed consent:

Provided that such sex assignment treatment and, or surgical intervention on the sex characteristics of the minor shall be conducted if the minor gives informed consent through the person exercising parental authority or the tutor of the minor.

(2) Medical practitioners or other professionals in breach of this article shall, on conviction, be liable to the punishment of imprisonment not exceeding five years, or to a fine (multa) of not less than five thousand euro ( $\leq$ 5,000) and not more than twenty thousand euro ( $\leq$ 20,000).

(3) In exceptional circumstances treatment may 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:

Provided that medical intervention which is driven by social factors without the consent of the minor, will be in violation of this Act.

(4) The interdisciplinary team shall be appointed by the Minister for a period of three years which period may be renewed for another period of three years.

(5) The interdisciplinary team shall be composed of those professionals whom the Minister considers as appropriate.

(6) When the decision for treatment is being expressed by a minor with the consent of the persons exercising parental authority or the tutor of the minor, the medical professionals shall:

<sup>&</sup>lt;sup>72</sup> In addition, Finland revised its Gender Equality Act in 2015, which now also covers "gender features of the body" in order to protect intersex people.

<sup>&</sup>lt;sup>73</sup> http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1

(a) ensure that the best interests of the child as expressed in the Convention on the Rights of the Child be the paramount consideration; and

(b) give weight to the views of the minor having regard to the minor's age and maturity.

**15.** (1) All persons seeking psychosocial counselling, support and medical interventions relating to sex or gender should be given expert sensitive and individually tailored support by psychologists and medical practitioners or peer counselling. Such support should extend from the date of diagnosis or self-referral for as long as necessary.

(2) The pathologisation of any form of sexual orientation, gender identity and, or gender expression as may be classified under the International Classification of Diseases or any other similar internationally recognised classification, shall be null and void in Malta. The nullity of such classification shall not impact negatively the provision of any healthcare service related to sex and, or gender.

**16.** (1) The Minister, after consulting the Minister responsible for health, shall appoint a working group.

(2) The working group shall consist of a Chairperson and nine members.

(3) The Chairperson shall be a medical doctor with at least twelve years experience.

(4) The members shall be three experts in human rights issues, three psychosocial professionals and three medical experts.

(5) The Minister shall appoint the working group within three months of the entry into force of this Act.

(6) The members of the working group shall review the current medical treatment protocols in line with current medical best practices and human rights standards and shall, within one year from the date of their appointment, issue a report with recommendations for revision of the current medical treatment protocols.

## **National Policies**

### 1. Malta (2015): Trans, Gender Variant and Intersex Students in Schools Policy<sup>74</sup>

The Maltese school policy covers behaviour that takes place in the school, on school property, at school-sponsored functions and activities. It also applies to 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.

## (Excerpt 1)<sup>75</sup>

ISSUES faced by Trans, Gender Variant and Intersex Students

- Sex and gender stereotypes
- Culture and cultural expectations •
- Lack of well-being due to discrimination, bullying and other unfair treatment •
- Exclusion from sports and other gendered activities •
- Unease with gendered uniforms, toilets and other gendered spaces •
- Decreased attention during school time and failure to learn due to lack of safety in school and • lack of support services
- Minority stress and social isolation
- Absenteeism due to lack of safety in schools

#### NEEDS of Trans, Gender Variant and Intersex Students

- Privacy and confidentiality
- Persons to advocate for their wellbeing and rights: parents, teachers, psychologist, social • worker, counsellor, etc.
- Adequate facilities •
- Inclusive policies and regulations •
- Support from school and wider community •
- Possibility of amendments of gendered characteristics in documentation of child's file •
- Counselling when identity formation is proving difficult •
- Access to information

## (Excerpt 2)<sup>76</sup>

#### Intersex

Intersex is a form of bodily diversity, rather than a sexual orientation or gender identity. Intersex people typically discover their intersex variation when told by their parents or doctor. This is a different experience to the LGB (lesbian, gay, bisexual) concept of 'coming out' to family and

<sup>74</sup> 

https://education.gov.mt/en/resources/Documents/Policy%20Documents/Trans,%20Gender%20Variant%20and%20Interse x%20Students%20in%20Schools%20Policy.pdf <sup>75</sup> Malta (2015): Trans, Gender Variant and Intersex Students in Schools Policy, p. 12

<sup>&</sup>lt;sup>76</sup> ibid., p. 13

friends. Most intersex people identify as either a woman or man, while some may identify as neither exclusively a woman nor exclusively a man. This means that gender identity and gender expression issues that students face in schools still apply to intersex students. However advocacy and support for intersex students may take a different form from other work on issues related to sexual orientation, gender identity and gender expression since:

Intersex students may or may not:

- identify as male or female; identify as both, all, between, or neither gender/sex.
- connect with the LGBTIQ community.
- be post-diagnosis or have experienced medical intervention.
- be self-accepting.

#### Health issues faced by intersex people

Intersex bodies are most often healthy. While some health problems are associated with some forms of intersex, being intersex is not a health problem in and of itself. Intersex is not a medical condition.

## (Excerpt 3)<sup>77</sup>

#### Disclosure

It is not an intersex student's duty to discuss intersex at any time, nor should they be expected to discuss their experience.

### Intersex-specific Needs

1. In addition to the above, intersex students need:

- 1. clear messages that a service welcomes intersex people, and awareness of sex characteristics related to bodily variations, not gender identity or sexual orientation;
- 2. to know that confidentiality will be respected;
- 3. services that understand intersex health and well-being concerns.

#### Inclusive Language and Intersex

Terms to avoid include pathologising language such as 'disorders of sex development'. The word 'hermaphrodite' is also regarded as stigmatising by several intersex people. It is preferable to use the word 'intersex', or refer to sex traits, variations or characteristics. Most intersex people are not trans or gender variant either. Making assumptions that intersex people have, want to, or need to, transition should be avoided. Referring to intersex people using language that describes trans people, such as transgender, or 'gender diversity' should be avoided altogether. Questioning whether or not a person identifies with LGBT is unacceptable. 'All' or 'different' genders should be considered, without assuming that intersex people automatically have a non-binary gender identity or that having a non-binary gender identity means someone is intersex. Assumptions that people with a specific intersex variation identify with a specific gender should be avoided, as should assumptions that surface characteristics define an intersex student's gender.

<sup>&</sup>lt;sup>77</sup> ibid., p. 14

## Case law

This is primarily European case law. Three pieces of international case law (Colombia 1995 and 1999, and California 2017) were added because the cases do not have equivalents in Europe so far.

### 1. on bodily integrity and redress

### Anonymus (1995, Colombian Constitutional Court, Columbia)

In 1995, a young man whose penis was destroyed in a traumatic accident during infancy and who was then surgically and legally assigned as female, petitioned the Colombian Constitutional Court for redress. The Court ruled in his favour and held that parents cannot give consent on a child's behalf to surgeries intended to determine sexual identity. The Constitutional guarantee of free development of one's own personality implies a right to define one's own sexual identity.<sup>78</sup>

## Anonymus (1999, Colombian Constitutional Court, Columbia)

In 1999 the Constitutional Court of Colombia issued three decisions which established important protections of the human rights of intersex people and restricted the authority of parents and physicians to authorise medically unnecessary genital plastic surgery. The Court held that surgery may actually be a violation of autonomy and bodily integrity and be motivated by parents' intolerance of their own children's sexual difference. The Court also held that intersex people constitute a minority entitled to protection by the State against discrimination. This was an historic first.<sup>79</sup>

*Christiane Völling vs. her surgeon* (2008, Regional Court of Cologne, Germany) Christiane Völling from Germany is the first known person to have successfully sued a surgeon for surgeries performed on her without her consent. She filed her case only three months before the statutes of limitation had expired. The case was settled in 2008 and she was awarded 100,000€ by the Regional Court of Cologne. 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>80</sup>

*Michaela Raab vs. her surgeon* (2015, County Court Erlangen-Nürnberg, Germany) In 2015, the second case, again in Germany, was ruled positively in the first instance. Michaela "Micha" Raab had sued her surgeon from Germany for surgeries that were performed on her without her fully informed consent as a young adult. The Court found the hospital guilty of not fulfilling its duty to fully inform the claimant about her variation of sex characteristics and about the consequences and possible long-term effects of the surgeries and hormone therapy she was subjected to. This is the first time worldwide that a hospital was found guilty for breaching an intersex person's right to physical autonomy and self-determination.<sup>81</sup> However, the hospital filed an

http://www.justiz.nrw.de/nrwe/lgs/koeln/lg\_koeln/j2008/25\_0\_179\_07grundurteil20080206.html

<sup>&</sup>lt;sup>78</sup> Columbian Constitutional Court, Sentencia T-477/95, http://www.isna.org/book/print/515

 <sup>&</sup>lt;sup>79</sup> Columbian Constitutional Court Sentencia T-551/99 (Bogota, Aug 12, 1999) Sentencia SU-337/99 (Bogota, May 12, 1999)
 <u>http://www.isna.org/node/21</u>
 <sup>80</sup> Landgericht Köln, 25 O 179/07

<sup>&</sup>lt;sup>81</sup> LG Nürnberg-Fürth, Urteil v. 17.12.2015 – 4 O 7000/11

appeal and in 2019 the case was settled in the second instance. Raab was awareded 40,000€ by the Higher Regional Court of Erlangen-Nürnberg. According to the press, the Court hereby followed the argument of the University Hospital (yearly budget: 769,000,000€) that more than 40,000€ were not financable.<sup>82</sup> Litigation cost risks are high after such a decision and it is unlikey that Raab will appeal.

*M.C. Crawford vs. Medical University of South Carolina* (2017, Court of Common Pleas, State of South Carolina, County of Richland, United States)

In 2017 the family of 12-year-old M.C. Crawford settled with the hospital they sued for performing genital surgery on their adopted intersex son at the age of two, while he was in state custody. This was the first time worldwide that a case on surgery performed on an intersex infant was put forward.<sup>83</sup>

### 2. on a third gender marker

*Vanja/ Kampagnengruppe 3. Option vs. Germany* (2017, Bundesverfassungsgericht, Germany) In 2014, Vanja, an intersex person, submitted an application for registration as "inter/divers" to the registry office. The application was denied. As a result Vanja and the 3<sup>rd</sup> Option Campaign Group filed a case. Their case was dismissed by three courts before being decided positively by the German Constitutional Court in 2017. The Constitutional Court's decision obliges Germany to create a positive and respectful third gender marker.<sup>84</sup> According to legal interpretations of the ruling, the gender marker must be available for all people whose gender identity is not male or female.<sup>85</sup>

#### Alex Jürgen vs. Austria (2018, Verfassungsgerichtshof, Austria)

In 2018, the Austrian Constitutional Court followed suit and issued a similar decision in the case of an Austrian intersex person, who had filed a lawsuit for a third gender option.<sup>86</sup> By doing so, the Austrian Court confirmed the diversity of the human sexes and obliged the respective states to create a positive and empowering third legal gender based on self-determination.

http://www.gesetze-bayern.de/Content/Document/Y-300-Z-BECKRS-B-2015-N-

20775?hl=true & AspxAutoDetectCookieSupport=1

<sup>&</sup>lt;sup>82</sup> http://www.nordbayern.de/region/nuernberg/penis-amputation-intersexuelle-verklagt-uni-klinik-erlangen-1.8603872 (14.2.2019)

<sup>&</sup>lt;sup>83</sup> <u>https://www.buzzfeednews.com/article/azeenghorayshi/intersex-surgery-lawsuit-settles</u>

<sup>&</sup>lt;sup>84</sup> BVerfG 1BvR 2019/16, 10. Oktober 2017

<sup>&</sup>lt;sup>86</sup> VfGH G 77/2018-9, 15. Juni 2018 <u>https://www.vfgh.gv.at/downloads/VfGH\_Entscheidung\_G\_77-</u> 2018\_unbestimmtes\_Geschlecht\_anonym.pdf

#### **Demands of the European Intersex Community**

### 1. Malta Declaration (2013)<sup>87</sup>

Between 29 November and 1 December 2013, the Third International Intersex Forum, supported by ILGA and ILGA-Europe, took place in Valletta, Malta. This event brought together 34 activists representing 30 intersex organisations from all continents. Below is the text in its entirety.

### Malta Declaration (2013)

as issued on the 1. Dezember 2013

#### Preamble

We affirm that intersex people are real, and we exist in all regions and all countries around the world. Thus, intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

We reaffirm the principles of the First and Second International Intersex Fora<sup>88</sup> and extend the demands aiming to end discrimination against intersex people and to ensure the right of bodily integrity, physical autonomy and self-determination.

#### Demands

- To put an end to mutilating and "normalising" practices such as genital surgeries, psychological and other medical treatments through legislative and other means. Intersex people must be empowered to make their own decisions affecting own bodily integrity, physical autonomy and self-determination.
- To put an end to preimplantation genetic diagnosis, pre-natal screening and treatment, and selective abortion of intersex foetuses.
- To put an end to infanticide and killings of intersex people.
- To put an end to non-consensual sterilisation of intersex people.
- To depathologise variations in sex characteristics in medical guidelines, protocols and classifications, such as the World Health Organization's International Classification of Diseases.
- To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.
- To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.
- To raise awareness around intersex issues and the rights of intersex people in society at large.

<sup>&</sup>lt;sup>87</sup> <u>https://oiieurope.org/malta-declaration/</u>

<sup>&</sup>lt;sup>88</sup> For the statement of the Second International Intersex Forum see: <u>https://oiieurope.org/the-second-international-intersex-forum-has-just-concluded-in-stockholm-with-an-affirmation-of-seven-key-demands-and-priorities-for-intersex-people/</u>

- To create and facilitate supportive, safe and celebratory environments for intersex people, their families and surroundings.
- To ensure that intersex people have the right to full information and access to their own medical records and history.
- To ensure that all professionals and healthcare providers that have a specific role to play in intersex people's wellbeing are adequately trained to provide quality services.
- To provide adequate acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.
- To build intersex anti-discrimination legislation in addition to other grounds, and to ensure protection against intersectional discrimination.
- To ensure the provision of all human rights and citizenship rights to intersex people, including the right to marry and form a family.
- To ensure that intersex people are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.
- Recognition that medicalization and stigmatisation of intersex people result in significant trauma and mental health concerns.
- In view of ensuring the bodily integrity and well-being of intersex people, autonomous non-pathologising psycho-social and peer support be available to intersex people throughout their life (as self-required), as well as to parents and/or care providers.

## In view of the above the Forum calls on:

- 1. International, regional and national human rights institutions to take on board, and provide visibility to intersex issues in their work.
- 2. National governments to address the concerns raised by the Intersex Forum and draw adequate solutions in direct collaboration with intersex representatives and organisations.
- 3. Media agencies and sources to ensure intersex people's right to privacy, dignity, accurate and ethical representation.
- 4. Funders to engage with intersex organisations and support them in the struggle for visibility, increase their capacity, the building of knowledge and the affirmation of their human rights.
- 5. Human rights organisations to contribute to build bridges with intersex organisations and build a basis for mutual support. This should be done in a spirit of collaboration and no-one should instrumentalise intersex issues as a means for other ends.

### 2. Riga Statement (2014)<sup>89</sup>

Riga Statement (2014)

On Wednesday, the 8th of October 2014 the European Intersex Meeting took place in Riga. Under the umbrella of OII Europe and facilitated by ILGA Europe, this meeting gathered European intersex organisations working for intersex human rights. The goal of the meeting was to identify objectives and strategies to advocate for the full implementation of human rights and bodily integrity and self-determination for intersex individuals in Europe on the grounds of the Demands of the Malta Statement, formulated at the 3rd International Intersex Forum 2013.

#### The four objectives are:

- 1. To challenge the definition of sex as consisting of only male and female and promote the knowledge that sex is a continuum, as is gender.
- 2. To ensure that intersex people are fully protected against discrimination. To achieve this we recommend the adoption of anti-discrimination legislation on the ground of sex characteristics regardless of the specific appearance or configuration of these characteristics. Sex characteristics refer to the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and/or chromosomal structures and hormones; and secondary characteristics such as, but not limited to, muscle mass, hair distribution, breasts and/or stature.
- 3. To ensure that all stakeholders that have a specific role to play in intersex people's wellbeing such as, but not limited to, health care providers, parents and professionals working in the area of education, as well as society in general, are instructed on intersex issues from a human rights perspective.
- 4. To work towards making non-consensual medical and psychological treatment unlawful. Medical practitioners or other professionals should not conduct any treatment to the purpose of modifying sex characteristics which can be deferred until the person to be treated can provide informed consent.

In view of these objectives the European Intersex meeting calls on the European Union and the Council of Europe as well as national governments, to take on board intersex issues in their work and provide full protection for intersex people.

#### Background information:

Until now throughout Europe intersex individuals are being subjected to inhumane and degrading surgical, hormonal and other procedures, without consent. This is done at the discretion of doctors and outside legal regulation. The non-consensual sex modification of individuals is done disregarding the fact that sex is a continuum. This results in gross human rights violations and abuses of bodily integrity and personal dignity.

<sup>&</sup>lt;sup>89</sup> https://oiieurope.org/statement-of-riga/

### **3.** Vienna Statement (2017)<sup>90</sup>

STATEMENT of the 1st European Intersex Community Event (Vienna, 30st – 31st of March 2017)

On the 30th – 31st of March 2017 in Vienna, Austria the first OII Europe community event took place. During the community event 28 Intersex people from 16 Council of Europe member states, some activists and some not, came together to share their experiences, and their varied objectives and strategies for the full implementation of human rights, bodily integrity, self determination and societal acceptance of intersex people within Europe.

# We affirm that intersex people are real, and we exist in all regions and all countries around the world.

We reaffirm the Malta Declaration and its demands, formulated at the 3rd International Intersex Forum (2013), as well as the objectives formulated by the 1st European Intersex Meeting in the Riga Statement (2014).

We also stress the fact, that until this day more than 50 times UN bodies, regional and national human rights bodies have called on governments, policy makers and stakeholders to put an end to human rights violations faced by intersex people – including taking the necessary legislative, administrative and other measures to guarantee respect for the physical integrity and autonomy of intersex persons and to ensure that no one is subjected during infancy or childhood to non-urgent medical or surgical procedures intended to decide the sex of the child. Ensuring the right of intersex people of bodily integrity, physical autonomy and self-determination must be a priority in all action taken. Intersex people must be supported to be the drivers of social, political and legislative changes that concern them.

#### We therefore call on governments to:

• Recognise intersex people as a community that has specific and vital needs and that their human rights need protection.

#### To this aim governments should take decisive action to:

- Install legislative protections that ban medical interventions on children with variations of sex characteristics, on social, psychosocial, cultural or cosmetic grounds. A ban on Intersex genital mutilation is necessary as IGM is equatable with female genital mutilation that takes place within hospital settings. This may include installing legislative measures that penalise medical professionals that commit or assist in IGM.
- Ensure that medical practitioners or other professionals do not conduct any treatment to the purpose of modifying sex characteristics which can be deferred until the person to be treated can provide full, free and informed consent. Medical and psychological treatment that is performed without the intersex person's free, personal and fully informed consent, unless life-saving, should be made unlawful.

<sup>&</sup>lt;sup>90</sup> https://oiieurope.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/

Informed consent requires being informed of different options, including, but not limited to, medical, sociological and human rights based information. Peercounselling should be mandatorily included in the decision process.

- Ensure that intersex people are protected from discrimination. To this aim governments should install constitutional protection, anti-discrimination and hate crime and hate speech legislation on the grounds of sex characteristics. If adding a new ground is not an option "sex characteristics" should be included explicitly in the ground of "sex". Intersex people must benefit from the same rights and protections given to other citizens.
- Provide intersex people who endured medically unnecessary or degrading treatment with reparations.

#### In the field of education, we call on governments, universities and schools to take action to:

- Include intersex realities as a mandatory part of school curriculums, especially in biology and sex education.
- Inform professionals that play a role in intersex people's lives, including but not limited to future physicians, surgeons, midwives, nurses, healthcare assistants, teachers and administrative officers about the existence of people with variations of sex characteristics and intersex realities. All training should be provided from a depathologizing and human rights perspective.
- Install intersex inclusive anti-bullying policies in schools.
   Schools should take into account that gendered activities may be difficult and exclusionary for some intersex youth.

## In the field of healthcare we call on governments, doctors associations, health insurances and other decision and policy makers working in the area of healthcare, to

- Ensure intersex people's full access to medical records.
- Educate all healthcare professionals and providers about respectful behaviour towards intersex people and ensuring their privacy.
- Cover all health-related needs of intersex people, including those that were created by previous medical and psychological interventions.

#### In regards to support for intersex people and their families, we call on governments to

- Ensure that peer counselling, which approaches intersex issues in a depathologizing and human rights affirming manner, led by intersex adults is easily available for parents, families, intersex children and intersex adults.
- Ensure that professional counselling services that approach intersex issues in a depathologizing and human rights affirming manner are easily available for parents, families, intersex children and intersex adults.

# In the field of media, we call on all professionals working in this field as well as media ethics bodies to

• Increase positive representation in all fields of media, whether that be in films, tv shows, books, magazine articles and other areas.

- Discuss intersex issues without bias and without reproducing prejudices, stereotypes or assumptions.
- Ensure that people with variations of sex characteristics and intersex issues are not exoticised or "othered" by any means. Press councils and other media related ethic bodies should take action to ensure that intersex people are not discriminated against in the media and that their human rights are respected.

#### In regards to gender markers and gendered facilities we call on governments to

- Install an easy administrative process to facilitate gender/sex marker change on the basis of self-determination and self-declaration. A neutral marker should be made available.
- Make non-gendered facilities available for all people.
- Not permit educational institutions and businesses to require gendered dress codes. While sex and gender are two distinct facets of a person, the gender binary is harmful, especially for intersex people.

#### Allies should be aware that

- They must not instrumentalise intersex realities for their own purposes.
- Intersex activists need their support.
- They should under no circumstances exoticise intersex people, use intersex people in a tokenistic way or appropriate intersex issues or intersex funding.
- They must avoid exclusionary or pathologizing language.
- Safe spaces for intersex people need to be created.
- They must learn about intersex issues from intersex people, without pressuring intersex people to provide input unless they themselves want to. Seek out local or regional intersex organisations and the resources that they provide.
- They must promote intersex rights as human rights.
- Allyship manifests itself in actions, not identities, i.e., Identifying as an ally is not enough to be an ally, you must act like one.

Nothing about us - without us!