

# **Human Rights Violations Against Intersex People**



## **A Background Note**

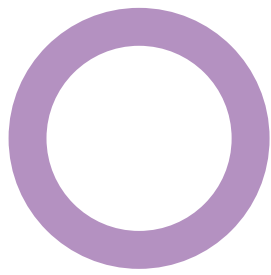


UNITED NATIONS  
**HUMAN RIGHTS**  
OFFICE OF THE HIGH COMMISSIONER



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**Introduction and methodology**

“Intersex” is an umbrella term used to describe a wide range of innate bodily variations in sex characteristics. “Intersex” people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns.

In recent years, awareness of intersex people, and recognition of the specific human rights abuses that they face, has grown, thanks to the work of intersex human rights defenders. These include risks of forced and coercive medical interventions, harmful practices and other forms of stigmatisation due to their physical traits. To date, only a handful of countries have implemented measures to prevent and address such abuses, and the effectiveness of existing measures remains to be fully documented.

In response, the United Nations Human Rights Office has undertaken a series of activities to raise public awareness of intersex human rights issues and deepen understanding of relevant international human rights law standards and recommendations and how they apply to the situation of intersex people. In September 2015, the United Nations Free and Equal campaign released a first fact-sheet on the rights of intersex people.<sup>1</sup> In the same month, UN and regional human rights mandate holders, intersex experts, UN agency staff, experts from national institutions and academia, civil society representatives and health professionals convened for the first UN Expert Meeting on ending human rights violations against intersex persons (see appendix 11.1). In October 2016, in part as a follow up to the Expert Meeting, a joint call by United Nations and regional human rights experts was published (see appendix 11.2), calling on Governments to prohibit forced and coercive surgeries and other medically unnecessary treatments on intersex children without their consent.<sup>2</sup> The United Nations Human Rights Office also launched the first UN public education campaign on the rights of intersex people, *United Nations for Intersex Awareness*, with a dedicated website and a video watched by more than a million people in its first week of release.<sup>3</sup>

This Background Note complements and builds on these initiatives, documenting the specific human rights abuses faced by intersex people and the corresponding human rights obligations of States, identifying gaps, challenges and positive developments, and charting the way forward to ensure that the human rights of intersex people are respected, protected and fulfilled.

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<sup>1</sup> Office of the High Commissioner for Human Rights, “Free & Equal Campaign Fact Sheet: Intersex” (2015), [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf) viewed 5 September 2015.

<sup>2</sup> Public statement of UN and regional human rights experts, “End Violence and Harmful Medical Practices on Intersex Children and Adults, UN and Regional Experts Urge”, <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E> viewed 24 October 2016.

<sup>3</sup> United Nations, “United Nations for Intersex Awareness”, <https://unfe.org/intersex-awareness> viewed 26 October 2016.



**Understanding intersex**

Intersex is an umbrella term used to describe a wide range of innate bodily variations of sex characteristics. According to experts, between 0.05 per cent and 1.7 per cent of the population is born with intersex traits.<sup>4</sup>

## WHO ARE INTERSEX PEOPLE?

Intersex people are born with physical sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit typical definitions for male or female bodies.

Intersex people have many different kinds of characteristics or traits. These traits may be evident prenatally or at birth, they may emerge at puberty, or become apparent later in life.

Intersex people are subjected to human rights violations because of their physical characteristics. Intersex children and adults are often stigmatized and subjected to multiple human rights violations, including violations of their rights to be free from torture and ill-treatment, to health and physical integrity, and to equality and non-discrimination.

Human rights violations include forced and coercive medical interventions; infanticide; restrictions on the exercise of legal capacity and in access to remedies and justice; discrimination in access to education, sport, employment and services. The root causes of human rights violations against intersex people include harmful stereotypes, stigma, taboos, and pathologization (i.e. treating intersex persons as necessarily ill or disordered).

## TERMINOLOGY

Intersex people use many different terms to describe themselves, their bodies, sex characteristics and identities. Some people consider themselves to *be* intersex, while others consider themselves individuals who *have* an “intersex variation”, an “intersex trait”, or are “born with a variation of sex characteristics”. Other terms such as “intersex condition”, and “differences of sex development” (abbreviated as DSD) are sometimes used, though some consider these terms to be medicalized.

Intersex persons, their parents and medical practitioners may make use of diagnostic terms. These change over time reflecting, in part, a shift from terms based on gonadal tissue<sup>5</sup> and observation, towards terms based on genetic information. In medical settings, the term “disorders of sex development” (also abbreviated as DSD) is frequently used by medical professionals and institutions, as well as by some parents of intersex persons and some intersex persons themselves. The term is widely rejected by many intersex people and human rights defenders as pathologizing, stigmatizing and as encouraging medically unnecessary interventions to modify the sex characteristics of intersex persons.<sup>6</sup>

<sup>4</sup> For an explanation of the upper estimate see Blackless M, Charuvastra A, Derryck A, Fausto-Sterling A, Lauzanne K and Lee E, “How Sexually Dimorphic Are We? Review and Synthesis” (2000) 12 Am. J. Hum. Biol. 151.

<sup>5</sup> i.e., ovaries, testes and ovotestes.

<sup>6</sup> Dreger A, “Twenty Years of Working toward Intersex Rights” in Baylis F and Dreger A (eds), *Bioethics in Action* (Cambridge University Press, 2018) pp 68–70.



Historical terms include “hermaphrodite”. This term has an ancient history associated with religious and civil jurisprudence that recognizes a diversity of intersex bodies, and facilitates marriage, inheritance and ordination depending on individuals’ predominant characteristics.<sup>7</sup> However, such old terms are often now considered pejorative by many intersex persons. In particular, the term hermaphrodite has taken on a narrow meaning in biological science<sup>8</sup> and so it can promote misleading and homogenizing ideas about the appearance and capabilities of intersex bodies. Some other intersex people use and reclaim the term.

It is important to always respect people’s choice of terms to refer to themselves.

## CONTEXTUALIZING THE RIGHTS OF INTERSEX PEOPLE

Human rights issues affecting intersex people share common features with human rights issues affecting other vulnerable populations, with the effect that multiple UN Treaties and frameworks are relevant to the situation of intersex people.

Intersex people are born with sex characteristics that vary from norms for female and male bodies. Because of this, intersex people are frequently subjected to so-called “normalizing” procedures to make them conform to sex and gender stereotypes. These include ideas that women must be able to have vaginal intercourse and men must be able to stand to urinate, and the idea that bodies need to be modified to make them socially acceptable. Gender stereotypes, including play and other behavioural preferences, can be used as rationales for medical interventions.<sup>9</sup>

Sexual health is understood as a state of physical, emotional, mental and social well-being in relation to sexuality that encompasses reproductive health – including being able to control one’s fertility, being free from sexual dysfunction, being free from sexual violence and female genital mutilation (and their consequences) having the freedom to decide what happens to one’s own body, including the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.<sup>10</sup> Sexual health and other rights may be violated due to stigma, institutional violence and forced medical interventions throughout intersex people’s lifetimes.<sup>11</sup> Harmful practices on intersex children – whether in medical or other settings – have lifelong consequences for physical and psychological health.

Parents of intersex children may be pressured into agreeing to “normalizing” and unnecessary medical interventions in order to obtain identification documents for their children.<sup>12</sup> Unnecessary medical interventions may take place deliberately before children are old enough to understand the nature of a

<sup>7</sup> Greenberg J, “Defining Male and Female: Intersexuality and the Collision Between Law and Biology” (1999) 41 *Arizona Law Review*, <http://ssrn.com/abstract=896307> viewed 31 March 2012; Uddin M, “Inheritance of Hermaphrodite (Khuntha) under the Muslim Law: An Overview” (2017) 08 *Beijing Law Review* 226.

<sup>8</sup> Carpenter M, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities” in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, England, 2018) pp 448–449.

<sup>9</sup> Feder EK and Dreger A, “Still Ignoring Human Rights in Intersex Care” (2016) 12 *Journal of Pediatric Urology* 436; Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8.

<sup>10</sup> World Health Organization, *Sexual Health, Human Rights and the Law* (World Health Organization, Geneva, 2015) p 1; Committee on Economic, Social and Cultural Rights, “General Comment No. 22 (2016) on the Right to Sexual and Reproductive Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)” (E/C.12/GC/22, 2 May 2016) at 1–5.

<sup>11</sup> Committee on Economic, Social and Cultural Rights, “General Comment No. 22 (2016) on the Right to Sexual and Reproductive Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)”, n 10 at 30 and 59; Monro S, Crocetti D, Yeadon-Lee T, Garland F and Travis M, “Intersex, Variations of Sex Characteristics, and DSD: The Need for Change” (Monograph, October 2017) at 8–10, <http://eprints.hud.ac.uk/id/eprint/33535/> viewed 15 October 2017.

<sup>12</sup> Justicia Intersex and *Zwischengeschlecht.org*, “Intersex Genital Mutilations Human Rights Violations of Children With Variations of Sex Anatomy: NGO Report to the 6th and 7th Periodic Report of Argentina on the Convention against Torture (CAT)” (INT/CAT/CSS/ARG/26985, March 2017) at 22.

procedure. In some jurisdictions, specific legal sex classifications may be designed for intersex children, singling them out for special attention and with deleterious consequences.<sup>13</sup>

The stigmatization of intersex bodies shares many commonalities with stigmatization faced by persons with disabilities. This is due to the historical dominance of the medical model of disability which seeks to “cure” or “correct” children and adults with disabilities. In this respect, both intersex people and persons with disabilities face forced and coercive medical interventions, sterilization and discrimination based on physical and genetic differences. Both groups are considered to be unhealthy on the basis that they do not conform to social and medical norms. Pregnant women may receive biased advice during pregnancy and efforts should be made to ensure elimination of discriminatory attitudes and prejudices, while also upholding women’s autonomy to make decisions about their lives and bodies, and sexual and reproductive health and rights. There are also overlaps between both populations as intersex individuals may have chronic conditions or impairments due either to their innate characteristics or as a consequence of medically unnecessary surgery and other treatment performed on them without their informed consent.

Many intersex organizations and experts have highlighted the relevance and applicability of the social model of disability to intersex people, which focuses on barriers within society as the source of disadvantage and discrimination, rather than on an individual’s particular characteristics.<sup>14</sup> A national inquiry in Australia in 2012-3 has recognized common experiences faced by persons with disabilities and intersex people;<sup>15</sup> and the German Institute for Human Rights has utilized the CRPD framework in relation to intersex people, as have disability representative organizations in Australia.<sup>16</sup> Some intersex organizations have expressed caution about positioning intersex issues mainly or solely within the framework of the rights of persons with disabilities, including fears about exacerbating stigma faced by intersex people.<sup>17</sup>

Intersex people share some common concerns with lesbian, gay, bisexual and transgender (LGBT) people due to shared experiences of harm arising from dominant societal sex and gender norms.<sup>18</sup> Human rights violations affecting intersex people may take place before they are able to develop or freely express an identity,<sup>19</sup> but stereotypes, fear and stigmatization of LGBT people provide rationales for forced and coercive medical interventions on children with intersex variations. Intersex people have

<sup>13</sup> Council of Europe Commissioner for Human Rights, “Human Rights and Intersex People, Issue Paper” (April 2015) at 38 to 40; Garland F and Travis M, “Legislating Intersex Equality: Building the Resilience of Intersex People through Law” (2018) *Legal Studies* 1 at 13–15; Althoff N, “Gender Diversity in Law: The German Perspective” in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, England, 2018) p 395; Cabral M, “Tercera posición en materia de género” (2014) 3 *Derechos Humanos* 199.

<sup>14</sup> Intersex Human Rights Australia, “Submission to the Australian Human Rights Commission: Protecting the Human Rights of People Born with Variations in Sex Characteristics” (30 September 2018), <https://ihra.org.au/32490/ahrc-submission-2018/> viewed 1 October 2018; Disabled People’s Organisations Australia, “Submission to the Australian Human Rights Commission: Protecting the Human Rights of People Born with Variations in Sex Characteristics” (30 September 2018), <http://dpoa.org.au/sub-ahrc-intersex/> viewed 3 October 2018; OII Europe, “Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities” (April 2015), [http://oiieurope.org/wp-content/uploads/2015/05/CRPD\\_2015\\_Statement\\_OII\\_Europe.pdf](http://oiieurope.org/wp-content/uploads/2015/05/CRPD_2015_Statement_OII_Europe.pdf) viewed 1 May 2015; Holmes MM, “Mind the Gaps: Intersex and (Re-Productive) Spaces in Disability Studies and Bioethics” (2008) 5 *Journal of Bioethical Inquiry* 169.

<sup>15</sup> Community Affairs References Committee, Senate of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (Community Affairs References Committee, Canberra, 2013), [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index) viewed 26 October 2013.

<sup>16</sup> Community Affairs References Committee, Senate and Australia, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013); German Institute for Human Rights, “Parallel Report to the UN Committee on the Rights of Persons with Disabilities” (Berlin, March 2015), [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNHS%2fDEU%2f19761&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNHS%2fDEU%2f19761&Lang=en) viewed 27 March 2015; OII Europe, “Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities”, n 14; Disabled People’s Organisations Australia, *Factsheet: Forced Sterilisation of People with Disability and People with Intersex Variations* (9 March 2018), <http://dpoa.org.au/factsheet-sterilisation/> viewed 19 February 2019; Disabled People’s Organisations Australia, n 14.

<sup>17</sup> OII Europe, “Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities”, n 14.

<sup>18</sup> Davis G, Dewey JM and Murphy EL, “Giving Sex: Deconstructing Intersex and Trans Medicalization Practices” (2015) *Gender & Society*.

<sup>19</sup> Carpenter M, “What Do Intersex People Need from Doctors?” (2018) 20 *O&G Magazine* 32 at 32, <https://www.ogmagazine.org.au/20/4-20/what-do-intersex-people-need-from-doctors/> viewed 29 November 2018.

diverse sexual orientations and gender identities,<sup>20</sup> and so intersex and LGBT populations overlap. Some intersex persons may identify with the sex marker assigned at birth, while others may not. Some may feel forced into legal sex and gender categories that they do not identify with, including binary (male or female) and third or non-binary categories.<sup>21</sup> Potential future LGBT identities in intersex children are frequently ignored by clinicians or presented as adverse outcomes,<sup>22</sup> and intersex people who are lesbian, gay, bisexual or transgender may face additional burdens of discrimination.<sup>23</sup>

At the same time, intersex persons have distinct lived experiences and human rights concerns. Attempts to include intersex within a framework around “sexual orientation and gender identity” (SOGI) have frequently lacked relevance or specific consideration of human rights issues affecting intersex persons.<sup>24</sup> As a result, a number of civil society organizations and human rights experts and institutions have expanded that framework to add issues relating to “sex characteristics” – notably in the recently updated *Yogyakarta Principles plus 10*.<sup>25</sup>

Some intersex advocates and organizations have identified concerns regarding representation, misrepresentation and resourcing,<sup>26</sup> and the extrapolation of data and policy frameworks on LGBT populations to an intersex population without clear evidence supporting that inclusion. Intersex-led and other organizations have expressed fears that this exacerbates stigma faced by intersex people. Kenyan research has found that the conflation of intersex with LGBT issues contributed to stigma and also impaired “an intersex person’s ability to receive a fair trial in a court of law”.<sup>27</sup> At the same time, a report on legal gender recognition in the Asia-Pacific region states that culturally-specific conflations of terms for intersex and transgender people “obscure the specific experiences and distinct human rights issues affecting each group”.<sup>28</sup> Some intersex organizations prefer to organize independently or align themselves with other movements.

Intersex human rights defenders call for the specific resourcing and leadership of intersex-led organizations. At the United Nations, the Office of the High Commissioner for Human Rights has highlighted the importance of a focus on specific human rights violations faced by intersex people.<sup>29</sup>

<sup>20</sup> An intersex person may be female, male, both, neither, or non-binary, and may be heterosexual, gay, lesbian, bisexual or asexual.

<sup>21</sup> Asia Pacific Forum of National Human Rights Institutions, *Promoting and Protecting Human Rights in Relation to Sexual Orientation, Gender Identity and Sex Characteristics* (Asia Pacific Forum of National Human Rights Institutions, Sydney, Australia, 2016) p 80 to 84, <http://www.asiapacificforum.net/resources/manual-sogi-and-sex-characteristics/> viewed 16 June 2016.

<sup>22</sup> Dreger A, Feder EK and Tamar-Mattis A, “Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine” (2012) 9 *Journal of Bioethical Inquiry* 277 at 282 to 283.

<sup>23</sup> Cabral M, “The Marks on Our Bodies” (2015) *Intersex Day*, <http://intersexday.org/en/mauro-cabral-marks-bodies/> viewed 25 October 2015.

<sup>24</sup> Koyama E and Weasel L, “From Social Construction to Social Justice: Transforming How We Teach about Intersexuality” (2002) 30 *Women’s Studies Quarterly* 169 at 173–174; Garland and Travis, n 13 at 12–13.

<sup>25</sup> Yogyakarta Principles, *The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics, to Complement the Yogyakarta Principles* (2017), <http://www.yogyakartaprinciples.org/principles-en/yp10/> viewed 21 November 2017.

<sup>26</sup> Davis et al, n 18; Koyama and Weasel, n 24.

<sup>27</sup> Kenya National Commission on Human Rights, *Equal in Dignity and Rights: Promoting The Rights of Intersex Persons In Kenya* (Kenya National Commission on Human Rights, Nairobi, 2018) p 18, <http://www.knchr.org/Publications/Thematic-Reports/Group-Rights/Rights-of-Sexual-Minorities> viewed 5 September 2018.

<sup>28</sup> Byrne J and Kismödi E, *Legal Gender Recognition: A Multi-Country Legal and Policy Review in Asia* (UNDP in Asia and the Pacific, 2017) p 2,20,22, [http://www.asia-pacific.undp.org/content/rbap/en/home/library/democratic\\_governance/hiv\\_aids/legal-gender-recognition--a-multi-country-legal-and-policy-revie.html](http://www.asia-pacific.undp.org/content/rbap/en/home/library/democratic_governance/hiv_aids/legal-gender-recognition--a-multi-country-legal-and-policy-revie.html) viewed 7 December 2017.

<sup>29</sup> Office of the High Commissioner for Human Rights, n 1; Office of the High Commissioner for Human Rights, “Living Free and Equal” (HR/PUB/16/3, 2016), <http://www.ohchr.org/Documents/Publications/LivingFreeAndEqual.pdf> viewed 23 November 2016; United Nations High Commissioner for Human Rights, “Opening Remarks by Zeid Ra’ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert Meeting on Ending Human Rights Violations against Intersex Persons”, <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E> viewed 16 September 2015; Centre for Human Rights and University of Pretoria, *Centre for Human Rights, Iranti-Org and SIPD-Uganda Host Panel Discussion on Intersex Human Rights in Africa* (7 November 2017), [http://www.up.ac.za/en/faculty-of-law/news/post\\_2592164-centre-for-human-rights-iranti-org-and-sipd-uganda-host-panel-discussion-on-intersex-human-rights-in-africa-](http://www.up.ac.za/en/faculty-of-law/news/post_2592164-centre-for-human-rights-iranti-org-and-sipd-uganda-host-panel-discussion-on-intersex-human-rights-in-africa-) viewed 26 November 2017.

## GROUNDS FOR DISCRIMINATION

In recent years, different legal grounds have been used to address human rights violations faced by intersex people and protect them from discrimination.

South Africa added protections for intersex people within existing protections from discrimination on grounds of **sex**, in 2005.<sup>30</sup> In 2013, Australia enacted explicit protections from discrimination on grounds of **intersex status**.<sup>31</sup> The Inter-American Commission on Human Rights considers violence and discrimination against intersex persons as violence and discrimination on the ground of **bodily diversity**.<sup>32</sup>

In 2015, Malta enacted legislation that protects all people, including intersex people, from discrimination and forced and coercive medical interventions on grounds of **sex characteristics**. This ground has since been adopted by multiple international institutions, including the Asia Pacific Forum of National Human Rights Institutions in 2016, and the European Parliament in 2019.<sup>33</sup> The 2017 *Yogyakarta Principles plus 10* define sex characteristics as “each person’s physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty”.<sup>34</sup>

UN bodies have taken a diversity of approaches, including attempts to address discrimination against intersex people within the framework of sexual orientation and gender identity. The attribute of “sex characteristics” is now an emerging standard.

## PROMOTING THE RIGHTS OF INTERSEX PEOPLE

The human rights of intersex people have historically been poorly addressed, perhaps due to societal taboos, and lack of public awareness, stigmatization, a lack of transparency about clinical practices, resistance to human rights norms in medical settings, and misconceptions. As a result, intersex people remain largely invisible. Awareness of the existence and rights of intersex people within human rights frameworks is growing thanks to the work of intersex human rights defenders in a largely volunteer-run movement.<sup>35</sup>

States have an obligation to tackle human rights violations against intersex people and their root causes. Only a handful of countries have so far taken concrete measures to uphold the rights of intersex people and protect them from abuses. Even in countries that have taken positive steps, there is a gap between legislation and policy, on the one hand, and the lived realities of intersex people, on the other.

<sup>30</sup> Republic of South Africa, “Government Gazette: No. 22 of 2005: Judicial Matters Amendment Act, 2005.” (28391st ed, Cape Town, 2006) vol 487.

<sup>31</sup> Australia. *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*.

<sup>32</sup> Inter-American Commission on Human Rights, “Violence against Lesbian, Gay, Bisexual, Trans and Intersex Persons in the Americas” (Inter-American Commission on Human Rights, 12 November 2015) at 11, <http://www.oas.org/en/iachr/reports/pdfs/violenceigbtipersons.pdf> viewed 30 July 2017.

<sup>33</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, p viii; European Parliament, *Motion for a Resolution on the Rights of Intersex People - B8-0101/2019* (8 February 2019), <http://www.europarl.europa.eu/sides/getDoc.do?type=MOTION&reference=B8-2019-0101&format=XML&language=EN> viewed 13 February 2019.

<sup>34</sup> Yogyakarta Principles, n 25, p 6.

<sup>35</sup> Howe E, Frazer S, Dumont M and Zomorodi G, *The State of Intersex Organizing (2nd Edition): Understanding the Needs and Priorities of a Growing but Under-Resourced Movement* (American Jewish World Service, Astraea Lesbian Foundation for Justice and Global Action for Trans Equality, New York, 2017).

This requires urgent action by States, national human rights institutions, United Nations and regional entities, civil society and other stakeholders.<sup>36</sup>

## UNITED NATIONS EXPERT MEETING

The Office of the United Nations High Commissioner for Human Rights convened a first expert meeting on ending human rights violations against intersex persons in September 2015.

In his opening remarks, then High Commissioner Zeid Ra'ad Al Hussein highlighted the seriousness of human rights violations faced by intersex people, combined with the stigma and taboo attached to being intersex, lack of investigation and prosecution of violations, impunity for perpetrators, absence of remedy, and a cycle of ignorance and abuse.

Experts unpacked different human rights standards, noting the applicability of multiple and complementary human rights frameworks, including those relating to torture and cruel, degrading and inhuman treatment; the rights of the child, of women, and of persons with disabilities; harmful practices including female genital mutilation (FGM)<sup>37</sup>; violations of physical and mental integrity, autonomy, free and informed consent; and discrimination.

Experts examined factors influencing forced and coercive medical practices, including surgeries, such as stigma and discriminatory prejudices or beliefs, heightened vulnerability and a generalized lack of a human rights approach within medical settings, absence of safeguards training on respecting fundamental human rights in healthcare, to nomenclature and medical classifications relating to intersex persons. Experts noted the continuous nature of harm, with lifelong health consequences and deep impacts on life trajectories.

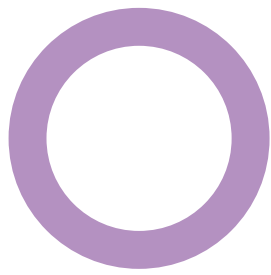
Experts reflected on some limited positive developments but noted that, in most places, these have not yet translated into significant or widespread evidenced improvements in protections of the rights of intersex people, nor in access to remedies.

Following the expert meeting, a number of United Nations treaty bodies, special procedures and regional human rights bodies adopted a joint statement calling for States to urgently adopt measures to end violence and harmful practices against intersex people.<sup>38</sup>

<sup>36</sup> Office of the High Commissioner for Human Rights, n 33; Monro et al, n 11.

<sup>37</sup> Joint CEDAW/CRC General Comment 31/18 on Harmful Practices

<sup>38</sup> Public statement of UN and regional human rights experts, n 2.





**Forced and coercive  
medical interventions**

- *Forced and coercive medical interventions violate rights to the security of person, right to bodily and mental integrity, freedom from torture and ill-treatment, and freedom from violence. The right to security of the person, including freedom from injury to the body and the mind, or bodily and mental integrity is protected by the first substantive right in the Universal Declaration of Human Rights, article 3,<sup>39</sup> as well as article 9 of the International Covenant on Civil and Political Rights, and article 17 of the Convention on the Rights of Persons with Disabilities.*
- *Forced and coercive medical interventions violate a right to health (including a right to free and informed consent), a right to legal capacity, and a right to non-discrimination.<sup>40</sup> The right to health includes the right to control one's health and body, including sexual and reproductive rights, freedom from interference, and the right to be free from torture, non-consensual medical intervention and experimentation.<sup>41</sup>*
- *All people have the right to privacy, including the right to private life, freedom from arbitrary or unlawful interference with privacy, and a right to the development and preservation of identity.<sup>42</sup>*
- *States have a legal obligation to protect all children from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.<sup>43</sup> Children have the right to freedom from violence, and freedom from torture and ill-treatment.<sup>44</sup>*
- *When medical procedures take place without personal informed consent, they violate the right to freedom from experimentation.<sup>45</sup>*
- *Poor, inadequate or partial information regarding the nature of a diagnosis, procedure or long-term outcomes, or the availability of peer support, violate the right to health and the right to accessible information and to free and informed consent.<sup>46</sup>*
- *States must take measures to abolish harmful practices and other traditional practices prejudicial to children's health,<sup>47</sup> including through rights-based strategies that adequately sanction or criminalize harmful practices, combat impunity and provide redress for victims.<sup>48</sup>*
- *The Committee on the Rights of the Child has cautioned that the requirement to give priority to the "best interests of the child" may be open to manipulation and should not be abused to justify discriminatory policies.<sup>49</sup> The Committee has stated that assessments of a child's best interests must*

<sup>39</sup> Committee on Civil and Political Rights, "General Comment No. 35: Article 9 (Liberty and Security of Person)" (CCPR/C/GC/35, 16 December 2014) at 2 to 3, and 9; Yogyakarta Principles, n 25, p 10.

<sup>40</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, "Sport and Healthy Lifestyles and the Right to Health" (A/HRC/32/33, 4 April 2016); United Nations, UNDP, OHCHR, UNAIDS, ILO, UNESCO, UNFPA, UNICEF, UNHCR, UN Women, UNODC, WFP and WHO, "Ending Violence and Discrimination against Lesbian, Gay, Bisexual, Transgender and Intersex People".

<sup>41</sup> Committee on Economic, Social and Cultural Rights, "General Comment No. 14 (2000) The Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)" (E/C.12/2000/4, 11 August 2000) at 8.

<sup>42</sup> United Nations, "Convention on the Rights of the Child" (1989) at article 16; United Nations, "International Covenant on Civil and Political Rights" (1966) at article 17; Zillén K, Garland J and Slokenberga S, "The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties" (Committee on Bioethics of the Council of Europe, 2017) at 44.

<sup>43</sup> United Nations, "Convention on the Rights of the Child", n 46 at article 19.

<sup>44</sup> United Nations, "Universal Declaration of Human Rights" at article 5; United Nations, "International Covenant on Civil and Political Rights", n 46 at article 7; United Nations, "Convention on the Rights of the Child", n 46 at article 37(a); United Nations, "Convention on the Rights of Persons with Disabilities" (2006) at article 15; Sandberg K, "Intersex Children and the UN Convention on the Rights of the Child" in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, England, 2018).

<sup>45</sup> United Nations, "International Covenant on Civil and Political Rights", n 46 at article 7; United Nations, "Convention on the Rights of Persons with Disabilities", n 48 at article 15; Zillén et al, n 46 at 44.

<sup>46</sup> International Covenant on Economic, Social and Cultural Rights, article 12; Committee on Economic, Social and Cultural Rights, General Comment 22 (E/C.12/GC/22), 2016, at paras 18-19.

<sup>47</sup> United Nations, "Convention on the Rights of the Child", n 46 at article 24(3); Committee on the Rights of the Child, "Concluding Observations on the Combined Second to Fourth Periodic Reports of Switzerland" (CRC/C/CHE/CO/2-4, United Nations, Geneva, 26 February 2015) at 42-43; Committee on the Rights of the Child, "Concluding Observations on the Second Periodic Report of South Africa" (CRC/C/ZAF/CO/2, United Nations, Geneva, 27 October 2016) at 39.

<sup>48</sup> United Nations, "Convention on the Rights of the Child", n 46 at article 24(3).

<sup>49</sup> Committee on the Rights of the Child, "General Comment No. 14 (2013) on the Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art. 3, Para. 1)" (CRC/C/GC/14, 29 May 2013) at 34.



*encompass the views of the child, and interpretations of a child's best interests cannot be used to justify practices that conflict with human dignity and the right to physical integrity.*<sup>50</sup>

- *States' obligation to eliminate forced, coercive, and unnecessary medical interventions to modify variations of sex characteristics, and violence against intersex persons includes investigating, prosecuting alleged perpetrators, providing victims with remedy, addressing patterns of violence, and tackling root causes.*
- *In order to prevent human rights violations, and linked with the right to health, states should develop and implement human rights-based health-care protocols for intersex children.*<sup>51</sup>

In countries around the world, intersex infants, children and adolescents are subjected to medically unnecessary surgeries, hormonal treatment and other procedures in an attempt to forcibly modify their appearance or physical development to be in line with societal expectations about female and male bodies.<sup>52</sup> As one intersex expert notes:

*Forced and coercive medically unnecessary interventions on the bodies of intersex children may sometimes be described critically or euphemistically as "normalization" surgeries, but also as "corrections," treatment for "malformations," genital "enhancement," "genital reconstruction," "sex assignment" or "gender assignment," or "gender reassignment." The procedures involved may include labiaplasties, vaginoplasties, clitoral "recession" and other forms of clitoral cutting or removal, gonadectomies, hypospadias "repairs," phalloplasties and other forms of penile augmentation surgeries, other forms of urogenital surgeries, and prenatal and postnatal hormone treatment. Associated practices may include dilation, repeated genital examinations, post-surgical sensitivity testing, and medical photography.*<sup>53</sup>

There is no clinical consensus about surgical timing, indications, necessity, procedure or outcome evaluation, and the quality of supporting clinical evidence is low.<sup>54</sup> These procedures violate the rights of persons subjected to such procedures when they occur without their full, free and informed consent.<sup>55</sup> When non-urgent interventions are invasive or irreversible, they are associated with high potential for, and evidence of, harm. These interventions can be distinguished from medical interventions essential for physical health, such as when an infant is unable to urinate, or unable to retain salt.

Testimonies have documented profound negative impacts of these often irreversible procedures, including permanent infertility/sterilization, incontinence, loss of sexual function and sensation, and experiences tantamount to rape (such as dilation, the repeated insertion of a device into a newly opened vaginal cavity), causing life-long pain and severe psychological suffering, including depression

<sup>50</sup> Committee on the Rights of the Child, "General Comment No. 14 (2013) on the Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art. 3, Para. 1)", n 53; Committee on the Rights of the Child, "General Comment 13: Article 19: The Right of the Child to Freedom from All Forms of Violence" (CRC/C/GC/13, 17 February 2011) at 61.

<sup>51</sup> Committee on the Elimination of Discrimination against Women, "Concluding Observations on the Seventh Periodic Report of Italy" (CEDAW/C/ITA/CO/7, 21 July 2017) at 42 (e); Committee on the Elimination of Discrimination against Women, "Concluding Observations on the Combined Seventh and Eighth Periodic Reports of France" (CEDAW/C/FRA/CO/7-8, 25 July 2016) at 19 (f); Committee on the Elimination of Discrimination against Women, "Concluding Observations on the Sixth Periodic Report of the Netherlands" (CEDAW/C/NLD/CO/6, 24 November 2016) at 22 (f); Committee on the Elimination of Discrimination against Women, "Concluding Observations on the Sixth Periodic Report of the Czech Republic" (CEDAW/C/CZE/CO/6, 14 March 2016) at 29; Committee on the Elimination of Discrimination against Women, "Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Slovakia" (CEDAW/C/SVK/CO/5-6, 25 November 2015) at 37.

<sup>52</sup> Ghattas DC, *Human Rights between the Sexes A Preliminary Study on the Life Situations of Inter\*individuals* (Heinrich-Böll-Stift., Berlin, 2013).

<sup>53</sup> Carpenter M, "Intersex Variations, Human Rights, and the International Classification of Diseases" (2018) 20 Health and Human Rights 205, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293350/> viewed 3 December 2018.

<sup>54</sup> Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, Baratz Dalke K, Liao L-M, Lin-Su K, Looijenga LHJ, Mazur T, Meyer-Bahlburg HFL, Mouriquand P, Quigley CA, Sandberg DE, Vilain E, Witchel S and the Global DSD Update Consortium, "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care" (2016) 85 Hormone Research in Paediatrics 158 at 176.

<sup>55</sup> Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, "Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment" (A.HRC.22.53, 1 February 2013) at 77; Sandberg, n 48.

and shame linked to attempts to hide and erase intersex traits.<sup>56</sup> In 2013, Juan Méndez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment remarked that such interventions result in “permanent, irreversible infertility and causing severe mental suffering”.<sup>57</sup> In 2018, Catalina Devandas-Aguilar, Special Rapporteur on the rights of persons with disabilities, remarked that there “are a growing number of treatments and interventions whose effectiveness is uncertain or deemed controversial” which “are invasive, painful and irreversible, and therefore may amount to torture or ill-treatment if applied involuntarily”.<sup>58</sup>

Intersex organizations have highlighted concerns that children are frequently subjected not to one but an ongoing series of surgeries, treatments, follow-up treatments, and treatments to address complications that frequently arise, all of which are reported as painful and deeply traumatising by many intersex persons who have undergone them.<sup>59</sup> In addition, repeated genital exams, photography and exposure, including in the context of training other medical professionals, have been experienced as deeply shaming, traumatic, and been described as a form of sexual abuse.<sup>60</sup>

In many cases the medical histories of intersex people have been concealed from them, or they have been denied access to their own medical records.<sup>61</sup> The Office of the Privacy Commissioner in New Zealand and the Kenya National Commission on Human Rights have identified variable progress in changing this clinical paradigm.<sup>62</sup>

## STERILIZATION, FERTILITY, AND SEXUAL AND REPRODUCTIVE RIGHTS

Forced or coercive sterilizations violate the sexual and reproductive rights of intersex people.<sup>63</sup> As with people with disabilities, laws protecting people from involuntary or coerced sterilization may not be enforced in relation to intersex people.<sup>64</sup> Sterilization may occur as a by-product of medical interventions justified on the basis of potential risks of cancer as well as by reference to gender stereotypes.

<sup>56</sup> Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, n 59 at 77; interACT, “Submission on United Nations Call for Information on Violence Against Women”.

<sup>57</sup> Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, n 59 at 77.

<sup>58</sup> Special Rapporteur on the rights of persons with disabilities, “Rights of Persons with Disabilities” (A/73/161, 16 July 2018) at 41.

<sup>59</sup> interACT, “Recommendations from InterACT: Advocates for Intersex Youth Regarding the List of Issues for the United States for the 59th Session of the Committee Against Torture” (INT/CAT/ICS/USA/24552, June 2016).

<sup>60</sup> Dreger AD, “Jarring Bodies: Thoughts on the Display of Unusual Anatomies” (2000) 43 *Perspectives in Biology and Medicine* 161; Creighton S, Alderson J, Brown S and Minto C, “Medical Photography: Ethics, Consent and the Intersex Patient” (2002) 89 *BJU International* 67; Karkazis K, *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (Duke University Press, 2008); Monro et al, n 11 at 37.

<sup>61</sup> Human Rights Watch, “*I Want to Be Like Nature Made Me*” (2017) pp 7, 34–36, <https://www.hrw.org/report/2017/07/25/i-want-to-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us> viewed 25 July 2017; Chase C, “Surgical Progress Is Not the Answer to Intersexuality” (1998) 9 *Journal of Clinical Ethics* 385.

<sup>62</sup> Office of the Privacy Commissioner, “Handling Health Information of Intersex Individuals”, <https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/> viewed 7 March 2018; Kenya National Commission on Human Rights, n 27, p 34.

<sup>63</sup> World Health Organization, OHCHR, UN Women, UNAIDS, UNDP, UNFPA and UNICEF, *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement* (2014); Tamar-Mattis A, “Sterilization and Minors with Intersex Conditions in California Law” (2012) 3 *California Law Review Circuit* 126; Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, “Re: American Academy of Pediatrics Considering a Policy Regarding Intersex People”; Committee on Economic, Social and Cultural Rights and United Nations, “Concluding Observations on the Fifth Periodic Report of Germany” (E/C.12/DEU/CO/5, 20 May 2011) at 26.

<sup>64</sup> Tamar-Mattis A, “Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment” in Center for Human Rights & Humanitarian Law and Washington College of Law (eds), *Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report* (Center for Human Rights & Humanitarian Law, Washington, DC, 2014) p 101, <http://antitorture.org/torture-in-healthcare-publication/> viewed 12 March 2014.

A history of preventative sterilizations and limited research on persons not subjected to sterilizations means that there is weak evidence associated with many intersex diagnoses, with insufficient data on cancer risks.<sup>65</sup> For example, risk levels associated with some intersex diagnoses may be lower or comparable to women's risk of breast cancer.

Insufficient regard may be given to the implications of treatment for the potential fertility of intersex people, especially where that potential is associated with a gender that does not match sex of rearing. For example, an assumption that a woman should not have testes may lead to surgery being performed, without her consent, and disregarding her future potential for fertility using novel technologies.<sup>66</sup>

Forced sterilization of intersex children and adults is recognized as a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and the right to be free from discrimination.<sup>67</sup> United Nations human rights bodies have also found that forced sterilization is a violation of the right to freedom from torture and ill-treatment.<sup>68</sup>

In other situations, deferrable medical interventions during infancy and early childhood may be intended to enable adult fertility, but necessity, timing, nature and evaluation of outcomes of such interventions lack clinical consensus. Potential for fertility aligned with sex of rearing may outweigh considerations of individuals' right to bodily integrity, and presume their future interests. Both situations seek to construct bodies that more closely fit narrowly-defined definitions of "normal" female or male bodies.

Medical interventions are often purported to be necessary in order to comply with gender stereotypes, and social and cultural norms for male and female bodies.<sup>69</sup> For example, an Australian court case in 2016 made reference to gender stereotypes including mention of a young intersex child's Barbie bedspread and Minnie Mouse underwear in justifying the child's sterilization.<sup>70</sup>

Some have tried to justify surgeries by highlighting the potential discrimination that individuals may face due to their intersex variations.<sup>71</sup> Alleged "psychosocial" rationales also include parental distress, fear of discrimination and stigmatization, potential so-called "confusion" around future gender identity,<sup>72</sup> stigma associated with having genitalia that does not match sex of rearing,<sup>73</sup> and marriage

<sup>65</sup> Tamar-Mattis, n 68, p 129.

<sup>66</sup> Tamar-Mattis, n 68, pp 132–133; Karkazis, n 64, p 56.

<sup>67</sup> World Health Organization et al, *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, n 67, p 1.

<sup>68</sup> World Health Organization et al, *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, n 67; Committee on the Elimination of Discrimination against Women, "CEDAW General Recommendation No. 24: Article 12 of the Convention (Women and Health)" (A/54/38/Rev.1, 1999) at 22.

<sup>69</sup> Karkazis, n 64, p 5; Garland J and Diamond M, "Evidence-Based Reviews of Medical Interventions Relative to the Gender Status of Children with Intersex Conditions and Differences of Sex Development" in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, England, 2018) p 475; Carpenter, "The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities", n 8.

<sup>70</sup> Carpenter, "The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities", n 8, p 475.

<sup>71</sup> Rossiter K and Diehl S, "Gender Reassignment in Children: Ethical Conflicts in Surrogate Decision Making" (1998) 24 *Pediatric Nursing* 59; O'Connor M, "The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children" (2016) 23 *J Law Med* 531 at 541–542; Kenya National Commission on Human Rights, n 27, pp 48–49.

<sup>72</sup> Garland and Diamond, n 73, p 86; Carpenter, "The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities", n 8, p 456.

<sup>73</sup> Carpenter, "The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities", n 8, p 457.

prospects.<sup>74</sup> In some countries, legislation prohibiting female genital mutilation may contain explicit exemptions permitting so called “normalizing” surgeries on intersex children, despite provisions stating that social, cultural and religious customs or practices cannot justify their necessity.<sup>75</sup> Fear of discrimination can never justify human rights abuses.<sup>76</sup> Attempts to resolve such fears through surgery have been described as a “circular argument”.<sup>77</sup> States have a responsibility to actively combat discrimination and stigma, including through education and awareness raising campaigns, as one of the root causes of these harmful practices.

Medical procedures may sometimes be justified on the basis of alleged health risks or benefits, but these may be proposed on the basis of weak evidence and without exploring alternative measures that protect physical integrity and respect autonomy.<sup>78</sup> Loose conceptions of medical necessity or therapeutic treatment may facilitate social and cultural rationales, and other rationales that lack evidence of urgent need.<sup>79</sup>

There is no clinical consensus on timing, however, surgeries are sometimes justified based on timing. Rationales alleging that early surgeries have better outcomes lack evidence. The idea that early surgery will remove a risk of trauma, and that children will be unable to recall surgery may not take into account the consequences of early surgery, including trauma, a need for follow-up and potential further surgery.<sup>80</sup> Early surgery also presumes children’s future interests. As stated by the Committee on Bioethics of the Council of Europe, there is no guarantee that early surgery “will be certain to coincide with the child’s actual identity, sexual interests, and desires for bodily appearance”.<sup>81</sup> There is evidence to suggest that, in some cases, surgical interventions may deliberately proceed early to preempt the legal capacity of a child.<sup>82</sup> Beliefs about a child’s best interests, including under the guise of medical necessity, must not outweigh their right to free and informed consent.<sup>83</sup>

Treatment may have a financial rationale, such that access to treatment may be subject to an age-dependent financial deadline that puts pressure on parents to agree to surgery earlier than it might otherwise occur. This includes a Canadian report where unwanted surgery took place in adolescence, prior to attaining an age of majority, as any further deferral would have ended access to subsidized treatment.<sup>84</sup> Financial rationales also include perceptions that surgery may be more cost-effective than ongoing psychosocial support and resourcing for peer support.<sup>85</sup>

Medical interventions may also in some cases have religious justifications. In 2019, the Congregation for Catholic Education called for acceptance of medical authority to determine sex assignment and “therapeutic” medical interventions on children with variations of sex characteristics to establish “the person’s constitutive identity”, stating that neither parents nor society should decide.<sup>86</sup> In pre-empting individuals’ natural

<sup>74</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, pp 71–73; “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, p 456.

<sup>75</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, p 74.

<sup>76</sup> Office of the High Commissioner for Human Rights, n 1 at 1.

<sup>77</sup> Community Affairs References Committee, Senate of Australia, n 15, p 74.

<sup>78</sup> Zillén et al, n 46 at 42–43.

<sup>79</sup> Ghattas DC, “Protecting Intersex People in Europe: A Toolkit for Law and Policy Makers” at 19; Intersex Human Rights Australia, “Submission to the Australian Human Rights Commission: Protecting the Human Rights of People Born with Variations in Sex Characteristics”, n 14 at 56–57; Sandberg, n 48, p 526.

<sup>80</sup> Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, n 59; Australian Human Rights Commission, *Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions Consultation Paper* (Australian Human Rights Commission, Sydney, 2018); Intersex Human Rights Australia, “Submission to the Australian Human Rights Commission: Protecting the Human Rights of People Born with Variations in Sex Characteristics”, n 14 at 56–66; Tamar-Mattis, n 68.

<sup>81</sup> Zillén et al, n 46 at 42.

<sup>82</sup> Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, p 476.

<sup>83</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, “Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health” (A/HRC/35/21, United Nations, 28 March 2017) at 63; Special Rapporteur on the rights of persons with disabilities, n 62 at 14, 41.

<sup>84</sup> Bastien-Charlebois J, “My Coming out: The Lingering Intersex Taboo” *Montreal Gazette*, 9 August 2015, <http://montrealgazette.com/life/my-coming-out-the-lingering-intersex-taboo> viewed 10 August 2015.

<sup>85</sup> Australian Human Rights Commission, n 84, p 20.

<sup>86</sup> Congregation for Catholic Education, n 32 at 13.

physical development, this appears to diverge from historical teachings on “hermaphrodites”.<sup>87</sup> Islamic teachings appear to endorse “corrective” interventions and individual choice.<sup>88</sup> Other religious bodies have sought to distance intersex people from LGBT people without comment on medical intervention.<sup>89</sup> Even in low income countries where access to medical treatment is challenging, parents and families face pressure to consent to medical interventions.<sup>90</sup> The Kenya National Commission on Human Rights has called on religious institutions to promote acceptance of intersex persons.<sup>91</sup>

## FEMALE GENITAL MUTILATION AND INTERSEX GENITAL MUTILATION

Female genital mutilation (FGM) refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons.<sup>92</sup> The practice persists due to normative ideas about women’s bodies, normative and unequal gender roles, and social control over women,<sup>93</sup> including the harmful notions that women must undergo the ritual in order to be eligible for marriage or as a rite of passage to adulthood.<sup>94</sup> In some cases, parents may be motivated to consent to female genital mutilation because they see other parents doing so; women subjected to the procedure may also exert pressures that promote conformity and ostracize others.<sup>95</sup> The World Health Organization and other UN bodies recognize that medicalization of FGM, for example as a form of harm reduction, does not justify a procedure or make it less severe.<sup>96</sup> FGM performed by health care professional without the free and informed consent of girls is a human rights violation, whether conducted or not by health care professionals.

Legal experts, policy-makers and advocates have drawn parallels between female genital mutilation and practices to modify the genitals of children with intersex variations.<sup>97</sup> In some cases, exemptions to legislation prohibiting female genital mutilation may contain exemptions permitting those practices on intersex infants and children.<sup>98</sup>

<sup>87</sup> Gratian, “Decretum Gratiani (Kirchenrechtssammlung) C III”, [http://geschichte.digitale-sammlungen.de/decretum-gratiani/kapitel/dc\\_chapter\\_1\\_1585](http://geschichte.digitale-sammlungen.de/decretum-gratiani/kapitel/dc_chapter_1_1585) viewed 4 July 2017; Finlay HA, “Sexual Identity and the Law of Nullity” (1980) 54 Australian Law Journal 115 at 120; Intersex Human Rights Australia and GATE, n 32.

<sup>88</sup> Sachedina, n 29, pp 192–193; Uddin, n 7.

<sup>89</sup> Sydney Diocesan Doctrine Commission, “A Theology Of Gender And Gender Identity” (June 2017), [http://portal.sds.asn.au/sites/default/files/ATheologyOfGenderAndGenderIdentity\(SydDoctrineCommission\).Aug2017.pdf?doc\\_id=NTQ3NjY%3D](http://portal.sds.asn.au/sites/default/files/ATheologyOfGenderAndGenderIdentity(SydDoctrineCommission).Aug2017.pdf?doc_id=NTQ3NjY%3D) viewed 5 October 2017; Coalition for a Biblical Sexuality, “Nashville Statement” at Article 6, <https://cbmw.org/nashville-statement> viewed 30 August 2017; Price C, *What About Intersexuality?* (24 March 2015) Focus on the Family, <http://www.focusonthefamily.com/socialissues/sexuality/transgenderism/what-about-intersexuality> viewed 29 December 2017; Simon L, “Intersex and the Nashville Statement”, <http://www.liannesimon.com/2017/09/03/intersex-and-the-nashville-statement/> viewed 4 September 2017; Simon L, “Barren Women and the Nashville Statement”, <http://www.liannesimon.com/2017/10/05/barren-women-and-the-nashville-statement/> viewed 9 February 2018.

<sup>90</sup> Thomson Reuters Foundation, “In Uganda, Parents Seek Controversial Genital Surgery for ‘intersex’ Babies” [news.trust.org](http://news.trust.org), 18 December 2016, <http://news.trust.org/item/20161218060443-tqfr4/> viewed 3 December 2017.

<sup>91</sup> Kenya National Commission on Human Rights, n 27, p 16.

<sup>92</sup> World Health Organization, Office of the High Commissioner for Human Rights, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCR and UNIFEM (eds), *Eliminating Female Genital Mutilation: An Interagency Statement* (World Health Organization, Geneva, 2008) p 1.

<sup>93</sup> World Health Organization et al, *Eliminating Female Genital Mutilation*, n 96, p 5.

<sup>94</sup> World Health Organization et al, *Eliminating Female Genital Mutilation*, n 96, p 6.

<sup>95</sup> Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child, “Joint General Recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/General Comment No. 18 of the Committee on the Rights of the Child on Harmful Practices” (CEDAW/C/GC/31-CRC/C/GC/18, 14 November 2014) at 57.

<sup>96</sup> Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child, n 99 at 12.

<sup>97</sup> Ehrenreich N and Barr M, “Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of ‘Cultural Practices’” (2005) 40 Harvard Civil Rights-Civil Liberties Law Review 71; Moron-Puech B, “The Legal Status of Intersex Persons in France” in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, UK, 2018) p 306; Jones M, “Intersex Genital Mutilation – A Western Version of FGM” (2017) 25 The International Journal of Children’s Rights 396; [Zwischengeschlecht.org](http://Zwischengeschlecht.org), “Intersex Genital Mutilations Human Rights Violations of Children With Variations of Sex Anatomy: NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC)” (Zurich, March 2014), [http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf) viewed 1 June 2014.

<sup>98</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, pp 74–75.

## FEMALE GENITAL MUTILATION AND INTERSEX GENITAL MUTILATION

Non-medical rationales are evident in decision-making about procedures that irreversibly modify the external genitalia of intersex children, including normative ideas about female and male bodies, claims regarding social, community and parental acceptance, social pressure, marriage prospects, and gender stereotyping.<sup>99</sup> Some experts describe such practices as “intersex genital mutilation”. This language reflects the parallels between the two practices, including parallels in justifications for procedures not based on urgent medical necessity. In concluding observations on South Africa, the Committee on the Rights of Child has called for the prohibition of harmful practices including intersex genital mutilation.<sup>100</sup>

Intersex-led organizations support access to affirmative treatments if and when individuals are able to provide informed consent.<sup>101</sup> This can be contrasted with female genital mutilation, where personal informed consent is not considered to be a valid rationale. Approaches towards female genital mutilation can also be contrasted with gender-affirming treatments for transgender people where irreversible interventions require personal informed consent as a minimum requirement.<sup>102</sup>

Societal beliefs and gender stereotypes are often reflected in the beliefs of doctors, as well as parents of intersex children, who may encourage and/or give their agreement to surgical and other procedures, even where such procedures may be medically unnecessary, irreversible, and violate human rights standards.<sup>103</sup> According to the Committee on Bioethics of the Council of Europe, parental consent or any desire for such interventions is inherently problematic due to the impact on children’s rights to autonomy and physical integrity.<sup>104</sup> Parents of children with intersex traits often face pressure to agree to such surgeries or treatments on their children, and sometimes receive partial information or misinformation,<sup>105</sup> without having information on alternatives or the potential negative and long-term consequences of these procedures.<sup>106</sup> Parents may lack contact with peers and intersex adults, and lack affirmative portrayals of intersex bodily diversity. Research shows that decision-making by potential parents on surgery is markedly different depending on the counselling approach and language adopted by healthcare practitioners,<sup>107</sup> and that, faced with uncertainty or the absence of pathways supporting non-surgical approaches, doctors may steer discussions with parents towards surgery.<sup>108</sup> In many countries, surgical interventions on children may be funded by insurance or the State, while psychological support for individuals and families, and access to reparative treatments, may be limited or unfunded.<sup>109</sup>

<sup>99</sup> Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, p 457 and 475; Human Rights Watch, n 65, pp 149–152; Ghattas, “Protecting Intersex People in Europe: A Toolkit for Law and Policy Makers”, n 83 at 13.

<sup>100</sup> Committee on the Rights of the Child, “Concluding Observations on the Second Periodic Report of South Africa”, n 51 at 39.

<sup>101</sup> Intersex Human Rights Australia, “Submission to the Australian Human Rights Commission: Protecting the Human Rights of People Born with Variations in Sex Characteristics”, n 14; Justicia Intersex and [Zwischengeschlecht.org](http://Zwischengeschlecht.org), n 12 at 18.

<sup>102</sup> Human Rights Watch, n 65, p 107.

<sup>103</sup> Karkazis, n 64, p 180; Davis G, “‘DSD Is a Perfectly Fine Term’: Reasserting Medical Authority through a Shift in Intersex Terminology” in McGann P and Hutson DJ (eds), *Advances in Medical Sociology* (Emerald Group Publishing, Bingley, 2011) vol 12.

<sup>104</sup> Zillén et al, n 46 at 44.

<sup>105</sup> Human Rights Watch, n 65, pp 10, 73–82; Davis, n 107; Timmermans S, Yang A, Gardner M, Keegan CE, Yashar BM, Fechner PY, Shnorhavorian M, Vilain E, Siminoff LA and Sandberg DE, “Does Patient-Centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics” (2018) *Journal of Health and Social Behavior* 002214651880246.

<sup>106</sup> Liao L-M, Wood D and Creighton SM, “Parental Choice on Normalising Cosmetic Genital Surgery” (2015) 351 *BMJ* h5124.

<sup>107</sup> Streuli JC, Vayena E, Cavicchia-Balmer Y and Huber J, “Shaping Parents: Impact of Contrasting Professional Counseling on Parents’ Decision Making for Children with Disorders of Sex Development: Parent Decision in Disorders of Sex Development” (2013) 10 *The Journal of Sexual Medicine* 1953.

<sup>108</sup> Timmermans et al, n 109.

<sup>109</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, pp 74–75.

Claims have been made about changes to clinical practices, including fewer surgical interventions, and improved surgical techniques.<sup>110</sup> In some cases, claims of technical obsolescence and technical improvements to surgical methods are made in support of claims that clinical practices have changed.<sup>111</sup> Claims of improved surgical techniques can never justify unnecessary or deferrable medical interventions on an individual without their consent.

There is little transparency about actual surgical practices, but available statistical data in recent years show no decrease in numbers of surgeries.<sup>112</sup> Some intersex human rights defenders state that clinical practices are underpinned by a lack of transparency.<sup>113</sup> In the United States, inconsistencies have been reported between perception and reality where surgeries and other medical treatments remain more prevalent in practice than some clinicians believe to be the case.<sup>114</sup> Evidence, for example from Australia, shows that human rights violations continue to take place despite clinical guidelines and statements that recommend against early interventions,<sup>115</sup> despite claims of “trends” away from early surgeries, and despite advice against a procedure “unless a condition poses a serious risk” to health.<sup>116</sup> The German Medical Association has identified that clinical guidelines are non-binding, no oversight exists, and adherence is uncertain; forced and coercive medical interventions persist.<sup>117</sup>

Intersex human rights defenders have challenged unnecessary medical interventions for more than twenty years.<sup>118</sup> Community statements include the Malta Declaration of the third International Intersex Forum in 2013,<sup>119</sup> and regional statements.<sup>120</sup> These make a range of calls, including for the prohibition of unnecessary or deferrable medical interventions, provision of effective oversight, and the development of standards of care. Civil society organizations have reported on the local situation in most regions of the world including, for example, by SIPD Uganda,<sup>121</sup> *Beyond the Boundary – Knowing*

<sup>110</sup> Timmermans et al, n 109; Karkazis, n 64; Sandberg D, “A Call for Clinical Research”, *Hermaphrodites With Attitude* (1995), <http://www.isna.org/files/hwa/winter1996.pdf> viewed 1 November 2014; Hendricks M, “Is It a Boy or a Girl?” (1993) 45 *Johns Hopkins Magazine* 10 at 14; Loeffler J, “These Children Aren’t Sick – But They Are Still Having Operations” *BuzzFeed News*, 31 August 2018, <https://www.buzzfeednews.com/article/julianeloeffler/intersex-operations-children-germany-netflix> viewed 4 September 2018.

<sup>111</sup> Karkazis, n 64, p 173; Cools M, Simmonds M, Elford S, Gorter J, Ahmed SE, D’Alborton F, Springer A and Hiort O, “Response to the Council of Europe Human Rights Commissioner’s Issue Paper on Human Rights and Intersex People” (2016) 70 *EurUro* 407.

<sup>112</sup> Creighton SM, Michala L, Mushtaq I and Yaron M, “Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?” (2014) 5 *Psychology and Sexuality* 34; Klöppel U, “Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter” (2016) *Gender Bulletin*; Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, pp 469–473; Moron-Puech, n 101, p 308; interACT, “Submission on United Nations Call for Information on Violence Against Women”, n 60.

<sup>113</sup> Carpenter M, “Intersex Human Rights: Clinical Self-Regulation Has Failed”, <http://www.srhm.org/news/intersex-human-rights-clinical-self-regulation-has-failed/> viewed 5 March 2019.

<sup>114</sup> Human Rights Watch, n 65, pp 48–53.

<sup>115</sup> Carpenter, “Intersex Human Rights”, n 117; Intersex Human Rights Australia, “Submission to the Australian Human Rights Commission: Protecting the Human Rights of People Born with Variations in Sex Characteristics”, n 14.

<sup>116</sup> Carpenter, “Intersex Variations, Human Rights, and the International Classification of Diseases”, n 57.

<sup>117</sup> Althoff, n 13, p 408; Loeffler, n 114.

<sup>118</sup> Chase C, “Intersexual Rights” (1993) 33 *The Sciences* 3; Chase C, “Rethinking Treatment for Ambiguous Genitalia” (1999) 25 *Pediatric Nursing* 451; Dreger, “Twenty Years of Working toward Intersex Rights”, n 6.

<sup>119</sup> Third international intersex forum, “Malta Declaration: Public Statement by the Third International Intersex Forum” (Floriana, Malta, 2 December 2013), <http://intersexday.org/en/third-international-intersex-forum/> viewed 24 March 2016.

<sup>120</sup> Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Black E, Bond K, Briffa T, Carpenter M, Cody C, David A, Driver B, Hannaford C, Harlow E, Hart B, Hart P, Leckey D, Lum S, Mitchell MB, Nyhuis E, O’Callaghan B, et al, “Darlington Statement” (Sydney, New South Wales, March 2017), <https://darlington.org.au/statement> viewed 10 April 2018; OII Europe, “STATEMENT of the 1st European Intersex Community Event (Vienna, 30st – 31st of March 2017)”, <https://oii-europe.org/statement-1st-european-intersex-community-event-vienna-30st-31st-march-2017/> viewed 4 July 2017; African Intersex Movement, “Public Statement by the African Intersex Movement”, <https://www.astraeafoundation.org/stories/public-statement-african-intersex-movement/> viewed 15 December 2017; Intersex Asia, “Statement of Intersex Asia and Asian Intersex Forum” (2018) Intersex Day, <https://intersexday.org/en/intersex-asia-2018/> viewed 16 April 2018; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, “San José de Costa Rica Statement”, <https://brujulaintersexual.org/2018/04/13/san-jose-de-costa-rica-statement/> viewed 19 May 2018.

<sup>121</sup> Support Initiative for Persons with Congenital Disorders, “Baseline Survey on Intersex Realities in East Africa – Specific Focus on Uganda, Kenya and Rwanda” (2016).

and Concerns Intersex in China and Hong Kong,<sup>122</sup> advocates in Nepal,<sup>123</sup> Brújula Intersexual and Vivir y Ser Intersex in Mexico,<sup>124</sup> Justicia Intersex in Argentina,<sup>125</sup> interACT and Human Rights Watch in the United States,<sup>126</sup> Intersex Human Rights Australia,<sup>127</sup> Amnesty International and partners in Denmark and Germany,<sup>128</sup> and in Iceland,<sup>129</sup> Intersexuelle Menschen<sup>130</sup> and OII Germany in Germany,<sup>131</sup> consortia in the United Kingdom<sup>132</sup> and France,<sup>133</sup> and [Zwischengeschlecht.org](http://Zwischengeschlecht.org) in Switzerland and multiple countries.<sup>134</sup>

In 2013 the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment called for States to end forced and coercive medical practices. The following year, a UN interagency statement called on States to end forced sterilizations, including the sterilization of intersex persons.<sup>135</sup> In 2015, the Office of the High Commissioner for Human Rights held a first expert meeting on ending human rights violations against intersex persons. Subsequently, UN human rights mechanisms, and Rapporteurs from the African Commission on Human and Peoples' Rights, Council of Europe and the Inter-American Commission on Human Rights published a joint statement on ending violence and harmful practices on intersex children and adults for Intersex Awareness Day in 2016.<sup>136</sup>

<sup>122</sup> Beyond the Boundary - Knowing and Concerns Intersex, "Intersex Report from Hong Kong China, and for the UN Committee Against Torture: The Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment" (INT/CAT/CSS/HKG/22156, 1 October 2015).

<sup>123</sup> Regmi E, *Stories of Intersex People from Nepal* (Kathmandu, 2016); [Zwischengeschlecht.org](http://Zwischengeschlecht.org), Regmi E and Ram Rai P, "NGO Report to the 6th Report of Nepal on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)" (Zurich, October 2018), <http://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf> viewed 6 December 2018.

<sup>124</sup> Brújula Intersexual, Vivir y Ser Intersex and [Zwischengeschlecht.org](http://Zwischengeschlecht.org), "NGO Report to the 9th Report of Mexico on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)" (Zurich, June 2018).

<sup>125</sup> Justicia Intersex and [Zwischengeschlecht.org](http://Zwischengeschlecht.org), n 12.

<sup>126</sup> interACT, "Recommendations from InterACT: Advocates for Intersex Youth Regarding the List of Issues for the United States for the 59th Session of the Committee Against Torture", n 63; Human Rights Watch, n 65.

<sup>127</sup> Intersex Human Rights Australia, "CEDAW Shadow Report on Australia" (11 June 2018), <https://ihra.org.au/32166/shadow-report-submission-cedaw/> viewed 12 June 2018; Organisation Intersex International Australia, "Shadow Report Submission to the Human Rights Committee on the Situation of Intersex People in Australia" (INT/CCPR/CSS/AUS/28771, 28 August 2017), <https://oii.org.au/31568/shadow-report-iccpr-2017/> viewed 29 August 2017.

<sup>128</sup> Amnesty International, "First, Do No Harm" (EUR 01/6086/2017, Amnesty International, London, May 2017).

<sup>129</sup> Amnesty International, "No Shame in Diversity: The Right to Health for People with Variations of Sex Characteristics in Iceland" (EUR 28/9498/2019, February 2019).

<sup>130</sup> Intersexuelle Menschen, "Shadow Report To the 6th National Report of the Federal Republic of Germany On the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)" (INT/CEDAW/NGO/DEU/43/8534, INT/CEDAW/NGO/DEU/43/8535, Hamburg, 2 July 2008), [http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/AIP\\_Germany43\\_en.pdf](http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/AIP_Germany43_en.pdf) viewed 1 January 2014; Intersexuelle Menschen and Veith L, "Parallel Report to the 5th Periodic Report of the Federal Republic of Germany on the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment" (Humboldt Law Clinic, 2011), [http://intersex.shadowreport.org/public/Association\\_of\\_Intersexed\\_People-Shadow\\_Report\\_CAT\\_2011.pdf](http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf) viewed 19 January 2014.

<sup>131</sup> OII Germany, "CEDAW Shadow Report. With Reference to the Combined Seventh and Eighth Periodic Report from the Federal Republic of Germany on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)" (INT/CEDAW/NGO/DEU/26315, 20 January 2017).

<sup>132</sup> [Zwischengeschlecht.org](http://Zwischengeschlecht.org), Intersex UK, OII-UK and The UK Intersex Association, "Intersex Genital Mutilations Human Rights Violations of Children with Variations of Sex Anatomy: NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC)" (INT/CRC/NGO/GBR/23792, Zurich, 15 April 2016), [http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM\\_v2.pdf](http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf) viewed 23 May 2016.

<sup>133</sup> [Zwischengeschlecht.org](http://Zwischengeschlecht.org) and Guillot V, "Intersex Genital Mutilations Human Rights Violations of Children With Variations of Sex Anatomy: NGO Report to the 7th Periodic Report of France on the Convention against Torture (CAT)" (Zurich, 28 March 2016).

<sup>134</sup> [Zwischengeschlecht.org](http://Zwischengeschlecht.org), "Intersex Genital Mutilations Human Rights Violations of Children With Variations of Sex Anatomy: NGO Report on the Answers to the List of Issues (LoI) in Relation to the Initial Periodic Report of Germany on the Convention on the Rights of Persons with Disabilities (CRPD)" (INT/CRPD/CSS/DEU/19781, Zurich, March 2015), [http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany-NGO-Report\\_Zwischengeschlecht-Intersex-IGM.pdf](http://intersex.shadowreport.org/public/2015-CRPD-LoI-Germany-NGO-Report_Zwischengeschlecht-Intersex-IGM.pdf) viewed 10 March 2015; [Zwischengeschlecht.org](http://Zwischengeschlecht.org), "Intersex Genital Mutilations Human Rights Violations of Children With Variations of Sex Anatomy: NGO Report to the 7th and 8th Report of France on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) + Supplement 'Intersex, IGM and Human Rights'" (Zurich, June 2016).

<sup>135</sup> World Health Organization et al, *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, n 67, pp 7–8.

<sup>136</sup> Public statement of UN and regional human rights experts, n 2.



In 1999, the Constitutional Court of Colombia determined that an eight-year old child should not undergo feminizing surgeries, on the basis that surgery was not urgent and that child's right to autonomy, increasing with age, should be respected after age five.<sup>137</sup> This judgment was confirmed in another case in 2008.<sup>138</sup> While considered progressive at the time, it has been criticized for expediting early surgeries.<sup>139</sup> The Chilean Ministry of Health introduced a prohibition in 2015 on early non-urgent surgeries without the consent of the person concerned.<sup>140</sup> However, this was rescinded some months later by a policy supporting substitute consent by parents, including for non-urgent genital surgeries.<sup>141</sup> The Madurai Bench of the Madras High Court has also called in 2019 for a prohibition of “sex reassignment” surgeries on intersex infants in India, stating that the “consent of the parent cannot be considered as the consent of the child”.<sup>142</sup> 2018 Portuguese legislation protects children until their gender identity is established; however, intersex organizations have expressed concern about a lack of attention to both the child's capacity and agency in determining gender identity, and to the legality of early necessary medical interventions.<sup>143</sup>

Only Malta has introduced protection from forced and coercive deferrable medical interventions, through recognition of the right to bodily autonomy. The law specifically prohibits “medical interventions driven by social factors without the consent of the minor”, with a later amendment enacting penalties commensurate with penalties for female genital mutilation.<sup>144</sup> The Act has also required the provision of oversight, and the development of medical standards that comply with human rights norms. While Maltese reforms are considered good practice, there are few reports on implementation of the law, and alleged cases of unnecessary medical intervention persist.<sup>145</sup>

Multiple regional and national reports have recommended an end to forced medical interventions and, in some cases, changes to medical classifications.<sup>146</sup> In 2015, the Commissioner for Human Rights of the Council of Europe recognized a right for intersex persons to not undergo sex assignment

<sup>137</sup> International Commission of Jurists, “Sentencia SU 337/99, Constitutional Court of Colombia (12 May 1999) | ICJ”, <https://www.icj.org/sogicasebook/sentencia-su-33799-constitutional-court-of-colombia-12-may-1999/> viewed 25 August 2017.

<sup>138</sup> International Commission of Jurists, “Sentencia T-912/08, Pedro v. Social Security et al., Constitutional Court of Colombia, Chamber of Revision (18 December 2008) | ICJ”, <https://www.icj.org/sogicasebook/sentencia-t-91208-pedro-v-social-security-et-al-constitutional-court-of-colombia-chamber-of-revision-18-december-2008/> viewed 6 September 2017.

<sup>139</sup> Holmes M, “Deciding Fate or Protecting a Developing Autonomy? Intersex Children and the Colombian Constitutional Court”, *Transgender Rights* (University of Minnesota Press, Minneapolis, Minnesota, 2006); International Commission of Jurists, “SOGI Casebook Chapter Six: Intersex”, <http://www.icj.org/sogi-casebook-introduction/chapter-six-intersex/> viewed 27 December 2015.

<sup>140</sup> Centro de Derechos Humanos UDP and Godoy Peña C, *Informe Anual Sobre Derechos Humanos En Chile 2016* (Ediciones Universidad Diego Portales, 2016), [http://www.derechoshumanos.udp.cl/derechoshumanos/images/InformeAnual/2016/Godoy\\_ddhhpersonasintersex.pdf](http://www.derechoshumanos.udp.cl/derechoshumanos/images/InformeAnual/2016/Godoy_ddhhpersonasintersex.pdf) viewed 9 December 2016.

<sup>141</sup> Inter L and Aoi H, “Circular 7 De 2016: Un Paso Atrás En La Lucha Por Los Derechos Humanos De Las Personas Intersexuales En Chile” (June 2017), <https://brujulaintersexual.files.wordpress.com/2017/06/circular-7-laura-y-hana11.pdf> viewed 10 July 2017.

<sup>142</sup> WP(MD) No4125 of 2019 and WMP(MD) No3220 of 2019 (Unreported, Madurai Bench of Madras High Court, Madurai Bench of Madras High Court, 22 April 2019) at 16–17.

<sup>143</sup> OII Europe, «PROTECTING INTERSEX PEOPLE IN EUROPE: A TOOLKIT FOR LAW AND POLICYMAKERS», [https://oiiurope.org/wp-content/uploads/2019/05/Protecting\\_intersex\\_in\\_Europe\\_toolkit.pdf](https://oiiurope.org/wp-content/uploads/2019/05/Protecting_intersex_in_Europe_toolkit.pdf) [Viewed 16 September 2021].

<sup>144</sup> *Gender Identity, Gender Expression and Sex Characteristics Act 2018* at 14.

<sup>145</sup> Committee on the Rights of the Child, “Concluding Observations on the Combined Third to Sixth Reports of Malta” (CRC/C/MLT/CO/3-6, United Nations, Geneva, 31 May 2019) at 28 to 29; [Zwischengeschlecht.org](http://www.zwischengeschlecht.org), “Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Reproductive Anatomy NGO Report to the 3rd to 6th Report of Malta on the Convention on the Rights of the Child (CRC)” (April 2019), <http://intersex.shadowreport.org/public/2019-CRC-Malta-NGO-Zwischengeschlecht-Intersex-IGM.pdf> viewed 7 June 2019.

<sup>146</sup> Human Rights Commission of the City and County of San Francisco, *A Human Rights Investigation Into The Medical “Normalization” Of Intersex People* (San Francisco, 2005); National Advisory Commission on Biomedical Ethics NEK-CNE and Switzerland, *On the Management of Differences of Sex Development. Ethical Issues Relating to “Intersexuality”*. Opinion No. 20/2012 (Berne, 2012), [http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf) viewed 29 November 2012; German Ethics Council, *Intersexuality, Opinion* (2012), <http://www.ethikrat.org/publications/opinions/intersexuality> viewed 8 November 2014; Community Affairs References Committee, Senate of Australia, n 15; Senate, *Variations du développement sexuel: lever un tabou, lutter contre la stigmatisation et les exclusions* (2017); World Health Organization et al, *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, n 67; European Union Agency for Fundamental Rights, *The Fundamental Rights Situation of Intersex People* (Vienna, 2015), <http://fra.europa.eu/sites/default/files/fra-2015-focus-04-intersex.pdf> viewed 12 May 2015; Inter-American Commission on Human Rights, n 36.

interventions.<sup>147</sup> In 2016, the Asia Pacific Forum of National Human Rights Institutions stated that “fear and discrimination can never justify human rights abuses, including forced medical treatment”.<sup>148</sup> The Committee on Bioethics of the Council of Europe (2017) issued a detailed critique of clinical protocols as part of a broader analysis on the rights of children in biomedicine, finding that current so-called “normalizing” practices lack evidence and necessity.<sup>149</sup> The European Parliament adopted a wide-ranging resolution on the rights of intersex people in 2019, including a condemnation of “sex-normalising treatments and surgery” and a call for EU-funded research projects to ensure that the human rights of intersex people are respected.<sup>150</sup>

National human rights institutions have also published reports on the situation of intersex people, including in Argentina,<sup>151</sup> Kenya<sup>152</sup> and New Zealand.<sup>153</sup> The Australian Human Rights Commission is currently conducting a study on protecting the rights of people born with variations of sex characteristics in the context of medical interventions.<sup>154</sup> A statement by the Conference of German Ministers for Women and Equalities in 2014 equated surgeries to modifying the appearance of intersex genitalia with Female Genital Mutilation. It criticized medical intervention on intersex children based on a perceived need to assimilate or conform, under the guise of the “best interests” of the child, noting that the concept can be manipulated. The Conference also adopted a resolution on the rights of intersex people that indicates that parental consent is not possible for surgeries on girls that involve removal or cutting of the clitoris due to criminal code provisions on female genital mutilation.<sup>155</sup>

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<sup>147</sup> Council of Europe Commissioner for Human Rights, n 13.

<sup>148</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, p 86.

<sup>149</sup> Zillén et al, n 46 at 78.

<sup>150</sup> European Parliament, n 37 at 4.

<sup>151</sup> Mouratin P and Instituto Nacional contra la Discriminación, la Xenofobia y el Racismo, *Documento temático INADI: Intersexualidad* (Instituto Nacional contra la Discriminación, la Xenofobia y el Racismo - INADI, Ciudad Autónoma de Buenos Aires, 2015), <http://inadi.gob.ar/wp-content/uploads/2015/07/intersexualidad.pdf> viewed 10 January 2016.

<sup>152</sup> Kenya National Commission on Human Rights, n 27.

<sup>153</sup> Human Rights Commission and New Zealand, “Intersex Roundtable Report 2017 Ending the Practice of Genital Normalisation on Intersex Children in Aotearoa New Zealand” (March 2018).

<sup>154</sup> Australian Human Rights Commission, n 84.

<sup>155</sup> Hessisches Ministerium für Soziales und Integration, “Beschlüsse 24. Konferenz der Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GFMK)” (2014) at 52–55.



**Violence and infanticide**

- *The right to security of the person, including freedom from injury to the body and the mind, or bodily and mental integrity is protected by the first substantive right in the Universal Declaration of Human Rights, article 3, as well as the International Covenant on Civil and Political Rights, article 9; and the Convention on the Rights of Persons with Disabilities, articles 16 and 17.*<sup>156</sup>
- *All persons have the right to freedom from violence, and freedom from torture and ill-treatment.*<sup>157</sup>
- *States have an obligation to investigate, prosecute alleged perpetrators, provide victims with remedy, address patterns of violence, and tackle root causes.*

Evidence suggests that intersex infants and children may be subjects of infanticide and mutilation in multiple regions of the world, with documented cases of infanticide in East and Southern Africa and South Asia, and of mutilation in East Africa.<sup>158</sup> As noted by intersex organization SIPD Uganda, the Kenyan national human rights institution and the Foundation for Human Rights in South Africa, intersex infants and their mothers may be considered witches, or victims of witchcraft; and children may be considered a curse or bad omen.<sup>159</sup>

Reports from South Africa and Kenya state that infanticide may traditionally occur at birth if an intersex variation is evident in the baby, performed by midwives in the belief that an infant with ambiguous genitalia is cursed or bewitched.<sup>160</sup> In East Africa, the appearance of an obviously intersex infant may be difficult to conceal due to traditional practices that celebrate a birth.<sup>161</sup> Research in Kenya by Disability Rights International suggests that beliefs in curses are also experienced by parents of children with disabilities, suggesting that these beliefs are associated with visible physical difference.<sup>162</sup> A report published on African children accused of witchcraft by UNICEF has identified that “abnormal births” are associated with infanticide and abandonment.<sup>163</sup>

Non-governmental organizations, academic and governmental institutions have collaborated in work in South Africa and in a side-event of a session of the African Commission on Human and Peoples’ Rights to identify and tackle these violence and infanticide of intersex children.<sup>164</sup>

<sup>156</sup> Committee on Civil and Political Rights, n 43 at 2–3, 9; Yogyakarta Principles, n 25, p 10.

<sup>157</sup> United Nations, “Universal Declaration of Human Rights”, n 48 at article 5; United Nations, “International Covenant on Civil and Political Rights”, n 46 at article 7; United Nations, “Convention on the Rights of the Child”, n 46 at article 37(a); Human Rights Committee, “Concluding Observations on the Sixth Periodic Report of Australia” (CCPR/C/AUS/CO/6, 1 December 2017) at 25–26.

<sup>158</sup> Support Initiative for Persons with Congenital Disorders, n 125; Kenya National Commission on Human Rights, n 27; Foundation for Human Rights, Department of Justice and Constitutional Development, South Africa, Intersex South Africa and Iranti, “National Dialogue on the Protection and Promotion of the Human Rights of Intersex People” (April 2018).

<sup>159</sup> Support Initiative for Persons with Congenital Disorders, 114 supra, pages 6 to 7; Foundation for Human Rights et al, 114 supra

<sup>160</sup> Grady H and Soy A, “The Midwife Who Saved Intersex Babies” (2017) BBC World Service, Kenya, <http://www.bbc.com/news/world-africa-39780214> viewed 4 July 2017; Collison C, “Intersex Babies Killed at Birth Because ‘They’re Bad Omens’” Mail & Guardian, 24 January 2018, <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens> viewed 25 January 2018; Botha K and Schoole J, *Intersex Rights in Rural Settings: The First Dialogue of Its Kind in South Africa* (October 2017) Intersexday Org, <https://intersexday.org/en/south-africa-rural-2017/> [Viewed 16 de September 2021].

<sup>161</sup> Support Initiative for Persons with Congenital Disorders, n 125; Kaggwa J, “A General Overview on Lived Realities of Being Intersex in Uganda and the East African Region” (at the Expert meeting on ending human rights violations against intersex persons, Geneva, Geneva, 16 September 2015).

<sup>162</sup> Soy A, “I Was Told to Kill My Disabled Baby” BBC News, 27 September 2018, <https://www.bbc.com/news/world-africa-45670750> viewed 8 April 2019.

<sup>163</sup> Cimpric A, “Children Accused of Witchcraft An Anthropological Study of Contemporary Practices in Africa” (UNICEF, April 2010), [https://www.unicef.org/wcaro/wcaro\\_children-accused-of-witchcraft-in-Africa.pdf](https://www.unicef.org/wcaro/wcaro_children-accused-of-witchcraft-in-Africa.pdf) viewed 3 April 2019.

<sup>164</sup> Botha and Schoole, n 165; Centre for Human Rights and University of Pretoria, n 33; Foundation for Human Rights et al, n 163.

In China, cases of abandonment and attempted infanticide have also been reported.<sup>165</sup> The intersex group “Beyond the Boundary” has expressed concern that this is associated with social norms favouring the birth of boys.<sup>166</sup>

Cases of murder, mutilation, harassment and stigmatization of adolescents and adults have been reported. In 2015, news of the murder and mutilation of an adolescent was reported in Kenya.<sup>167</sup> In 2017, disturbing video footage emerged of the assault and potential rape in Nigeria of an adolescent intersex boy, tagged as a witch.<sup>168</sup> In the case of *Richard Muasya v. the Hon. Attorney General and others* before the High Court of Kenya in 2010, Richard Muasya was found to have suffered inhuman and degrading treatment through humiliating and invasive body searches while in prison.<sup>169</sup>

Intersex organizations and the UNHCR report that intersex persons may flee persecution and violence due to their physical characteristics, and seek asylum.<sup>170</sup> Intersex organizations have also identified cases where individuals who speak up about intersex human rights issues have been forced to flee. Little evidence for this appears in literature on LGBTI refugees, which frequently assumes that individuals fit specific identity categories.<sup>171</sup> As with policies designed to protect individuals in places of detention, policies aimed at protecting people with particular identities may fail to protect individuals with particular physical characteristics.<sup>172</sup> Due to their physical characteristics, intersex asylum seekers may not face barriers associated with “proof” of identity.<sup>173</sup> However, they may fear disclosure, exposure and violence from diaspora communities.

Australian sociological research published in 2016 found that survey respondents whose intersex characteristics were visible to strangers were more likely to experience discrimination; these experiences including reporting of violence, insults and discrimination that associated such characteristics with being LGBT or having a disability.<sup>174</sup> Research on intersex persons in Kenya for a national taskforce inquiry found that a majority of respondents had a physical appearance that did not fit expectations associated with the sex recorded on their birth certificates.<sup>175</sup>

<sup>165</sup> Beyond the Boundary - Knowing and Concerns Intersex, n 126 at 6; Lau M, “Baby Born with Male and Female Genitals Found Abandoned in Chinese Park” South China Morning Post, 24 August 2015, <http://www.scmp.com/news/china/society/article/1851891/baby-born-male-and-female-genitals-found-abandoned-chinese-park> viewed 13 January 2016; Morgan J, “Father Tries to Kill Intersex Baby Three Times for Being a ‘Monster’” Gay Star News, 22 June 2016, <http://www.gaystarnews.com/article/father-tries-kill-intersex-baby-three-times-monster/> viewed 23 June 2016.

<sup>166</sup> Beyond the Boundary - Knowing and Concerns Intersex, n 126 at 6,17.

<sup>167</sup> Odero J, “Intersex in Kenya: Held Captive, Beaten, Hacked. Dead.”, <http://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/> viewed 28 December 2015.

<sup>168</sup> Makanjuola O, “Who Do We Blame When an Intersex Teenager Is Attacked?”, 20 September 2017, <https://guardian.ng/features/who-do-we-blame-when-an-intersex-teenager-is-attacked/> viewed 24 September 2017.

<sup>169</sup> Kenya National Commission on Human Rights, n 27, p 25 and 81; International Commission of Jurists, “Richard Muasya v. the Hon. Attorney General, High Court of Kenya (2 December 2010)” (International Commission of Jurists, 2010), <http://www.icj.org/sogicasebook/richard-muasya-v-the-hon-attorney-general-high-court-of-kenya-2-december-2010/> viewed 7 December 2014.

<sup>170</sup> n 125; International Commission of Jurists, “Refugee Status Claims Based on Sexual Orientation and Gender Identity” at 128, <http://icj.wpengine.netdna-cdn.com/wp-content/uploads/2016/02/Universal-PG-11-Asylum-Claims-SOGI-Publications-Practitioners-Guide-Series-2016-ENG.pdf>; UN High Commissioner for Refugees, “Guidelines on International Protection No. 9: Claims to Refugee Status Based on Sexual Orientation and/or Gender Identity within the Context of Article 1A(2) of the 1951 Convention and/or Its 1967 Protocol Relating to the Status of Refugees” (HCR/GIP/12/01, 23 October 2012) at 10.

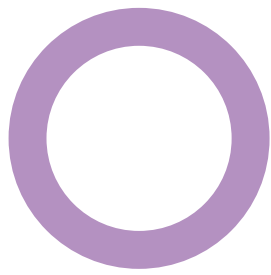
<sup>171</sup> International Commission of Jurists, “Refugee Status Claims Based on Sexual Orientation and Gender Identity”, n 175 at 24, 34–5, 128–132.

<sup>172</sup> Carpenter M, *Detention* (10 February 2019) Intersex Human Rights Australia, <https://ihra.org.au/detention/> viewed 28 March 2019.

<sup>173</sup> International Commission of Jurists, “Refugee Status Claims Based on Sexual Orientation and Gender Identity”, n 175 at 35.

<sup>174</sup> Jones T, Hart B, Carpenter M, Ansara G, Leonard W and Lucke J, *Intersex: Stories and Statistics from Australia* (Open Book Publishers, Cambridge, UK, 2016) pp 63–64, <https://researchers.mq.edu.au/en/publications/intersex-stories-and-statistics-from-australia> viewed 28 May 2019.

<sup>175</sup> Office of the Attorney General and Department of Justice, n 29 at 14.





**Stigma and discrimination  
in healthcare**

- *Everyone is entitled to enjoy the right to health. Children have the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.*
- *The right to sexual and reproductive health is an integral part of the right to health,<sup>176</sup> closely linked to enjoyment of rights to freedom from violence and coercion, to bodily integrity, to non-discrimination, and access to education, information and appropriate health services.<sup>177</sup>*
- *Discrimination in healthcare settings is widespread, and violates the most fundamental human rights. Users of healthcare services should be empowered to demand their rights and hold service providers accountable for discrimination-free healthcare. Access to effective mechanisms for redress and accountability must be guaranteed. Healthcare professionals must be provided with guidance and practical tools to raise awareness of human rights standards for non-discrimination in healthcare.<sup>178</sup>*

Because their bodies do not fit sex and gender norms, intersex people face stigma and discrimination in access to healthcare. The right to health of intersex persons is impacted by stigma and bias within healthcare systems,<sup>179</sup> poor quality healthcare,<sup>180</sup> institutional violence,<sup>181</sup> lack of access to medical records,<sup>182</sup> lack of training of medical professionals, lack of research on the long-term health outcomes and needs of intersex people,<sup>183</sup> and a lack of standards of care that are respectful of the rights of intersex people.<sup>184</sup>

Intersex organizations and human rights institutions have called for medical providers to defer decision-making on non-emergency invasive and irreversible interventions until children are old enough to determine themselves whether or not they wish to undergo a procedure.<sup>185</sup> In some important cases, early medical interventions may sometimes be necessary for the physical health of a child, and justified through clear evidence of medical necessity and urgency. The Committee on Bioethics of the Council of Europe states that these situations are:

*On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion.<sup>186</sup>*

<sup>176</sup> Committee on Economic, Social and Cultural Rights, “General Comment No. 22 (2016) on the Right to Sexual and Reproductive Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)”, n 10 at 1.

<sup>177</sup> World Health Organization, n 10, pp 1, 18 and 27.

<sup>178</sup> World Health Organization, UNAIDS, UNHCR, UNICEF, World Food Programme, United Nations Development Programme, UNFPA, UN Women, International Labor Organization, Office of the High Commissioner for Human Rights and International Organization for Migration, “Joint United Nations Statement on Ending Discrimination in Health Care Settings”.

<sup>179</sup> Justicia Intersex and [Zwischengeschlecht.org](http://Zwischengeschlecht.org), n 12 at 22.

<sup>180</sup> Support Initiative for Persons with Congenital Disorders, n 125.

<sup>181</sup> Jones et al, n 179, p 113.

<sup>182</sup> Human Rights Watch, n 65, pp 7, 34–36.

<sup>183</sup> Human Rights Watch, n 65, pp 83–87.

<sup>184</sup> Zillén et al, n 46 at 42; Garland and Diamond, n 73.

<sup>185</sup> Human Rights Watch, n 65, pp 154–158.

<sup>186</sup> Zillén et al, n 46 at 43.



Some individuals may require medical care when able to choose, for physical health or psychological well-being. In some cases, specific intersex variations may be associated with additional specific health needs, for example, congenital adrenal hyperplasia is associated with adrenal insufficiency, and sex chromosome variations may be associated with physical and cognitive issues.<sup>187</sup> The consequences of prior medical intervention may require ongoing medical treatments that are also associated with specific risks. For example, persons subjected to gonadectomies invariably require lifelong hormone replacement to maintain health.<sup>188</sup> Individuals subjected to forced and coercive interventions in childhood may lack support to remedy or manage the impact of those interventions in adulthood. Risks and costs associated with ongoing treatments may be underestimated or poorly disclosed when initial treatment is determined. Individuals may be obligated to pay for ongoing hormone replacement and associated health care, and any reparative treatments.<sup>189</sup>

These health needs may be overshadowed by a focus on individuals' identities or physical sex characteristics,<sup>190</sup> and a focus on "fixing" intersex traits in place of living with intersex bodies.<sup>191</sup> In all cases, intersex-led and medical organizations stress the importance of peer support, psychological support and counselling for individuals, families, and prospective parents.

Intersex adults have reported discrimination in access to care based on their intersex traits,<sup>192</sup> including lack of access to necessary screening and procedures, prejudice, and an absence of health professionals trained on the specific health needs they may have.<sup>193</sup> Medical practices focused on surgical interventions on infants and young children may be accompanied by a lack of resources or attention to the psychological needs of individuals and their families, and adolescent health needs.<sup>194</sup> Health services designed to meet the needs of adults who identify as LGBT, or transgender children do not, by virtue of that fact, have capacity or skills to manage the healthcare of infants, children, adolescents or adults with intersex variations and their families.<sup>195</sup>

In some contexts, access to healthcare may be financially prohibitive irrespective of age.<sup>196</sup> In others, financial rationales may mean that treatment is agreed by parents earlier than it should, without an individual's personal, informed consent.

<sup>187</sup> For example, Human Rights Watch, n 52, p 17; Skakkebak A, Wallentin M and Gravholt CH, "Neuropsychology and Socioeconomic Aspects of Klinefelter Syndrome: New Developments" (2015) 22 *Current Opinion in Endocrinology & Diabetes and Obesity* 209.

<sup>188</sup> Human Rights Watch, n 65, pp 6, 25 and 52.

<sup>189</sup> Jordan-Young RM, Sonksen PH and Karkazis K, "Sex, Health, and Athletes" (2014) 348 *BMJ* g2926 at 3.

<sup>190</sup> Koyama and Weasel, n 24 at 174; Carpenter M, *Intersex Intersectionalities with Disability* (29 October 2012) Intersex Human Rights Australia, <https://ihra.org.au/21214/intersex-and-disability/> viewed 29 October 2012.

<sup>191</sup> Morland I, "Intimate Violations: Intersex and the Ethics of Bodily Integrity" (2008) 18 *Feminism & Psychology* 425 at 425–6.

<sup>192</sup> "4th International Intersex Forum—Media Statement", <https://oiieurope.org/4th-international-intersex-forum-media-statement/> viewed 8 December 2018.

<sup>193</sup> Inter L, "The Situation of the Intersex Community in Mexico" (2016) *Intersex Day*, <http://intersexday.org/en/situation-mexico/> viewed 26 October 2016.

<sup>194</sup> Liao L-M and Simmonds M, "A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development" (2013) 5 *Psychology & Sexuality* 83 at 1; Liao et al, n 110 at 1; Human Rights Watch, n 65, p 154.

<sup>195</sup> Carpenter, "What Do Intersex People Need from Doctors?", n 19.

<sup>196</sup> Regmi, n 127.

Some intersex people have reported that prior experience of human rights violations in medical settings has hindered their later engagement with health services.<sup>197</sup> A 2016 clinical statement identifies that the “practice of withholding medical history details, along with the possibility of negative medical experiences likely contributes” to a disengagement with clinical services.<sup>198</sup> Many individuals also lack the information they need about their diagnosis and peer support to satisfactorily manage their health and well-being.<sup>199</sup> In some cases, there are reports of lack of access by intersex persons to certain procedures, treatments or screening deemed applicable only to one sex, because they are registered as another sex.<sup>200</sup> A 2017 study found that pathologizing language itself acted as a barrier to healthcare access.<sup>201</sup> Intersex organizations also highlight adverse consequences of medical classifications and diagnostic categories on perceptions of intersex bodies, where the labelling of intersex traits as disordered or abnormal contributes to discrimination and stigma, as well as the encouragement of surgeries and other interventions.<sup>202</sup>

UN and regional human rights bodies, intersex human rights defenders and researchers, and Physicians for Human Rights have expressed concern at the unnecessary pathologization of intersex variations. Human rights institutions, researchers and human rights defenders have identified a relationship between pathologization and disease classifications, on the one hand, and human rights violations against intersex people, on the other.<sup>203</sup> The World Health Organization has recognized the existence of human rights violations against intersex people within the contexts of forced sterilization<sup>204</sup> and sexual health.<sup>205</sup> The International Classification of Diseases 11 (ICD-11) introduces new language that regards intersex people as having “disorders of sex development” while retaining pejorative language such as “pseudo-hermaphrodite” in addition to clinical descriptions that promote or facilitate early irreversible surgeries.<sup>206</sup> Intersex organizations and researchers are advocating for changes to be made to these classifications.<sup>207</sup>

<sup>197</sup> Johnson EK, Rosoklija I, Finlayson C, Chen D, Yerkes EB, Madonna MB, Holl JL, Baratz AB, Davis G and Cheng EY, “Attitudes towards ‘Disorders of Sex Development’ Nomenclature among Affected Individuals” (2017) *Journal of Pediatric Urology*; Dreger, “Twenty Years of Working toward Intersex Rights”, n 6, pp 58–59.

<sup>198</sup> Lee et al, n 58 at 170.

<sup>199</sup> Kirkland F, “Intersex Patients ‘Routinely Lied to by Doctors’” BBC News, 22 May 2017, <http://www.bbc.com/news/health-39979186> viewed 18 July 2017; Dreger, “Twenty Years of Working toward Intersex Rights”, n 6, p 58.

<sup>200</sup> Dreger A, *Bye, Max. (We Already Miss You.)* (4 February 2008), <http://alicedreger.com/Max> viewed 8 December 2018.

<sup>201</sup> Johnson et al, n 202.

<sup>202</sup> M Cabral and M Carpenter (eds), *Intersex Issues in the International Classification of Diseases: A Revision* (2014) <https://globaltransaction.files.wordpress.com/2015/10/intersex-issues-in-the-icd.pdf>

<sup>203</sup> Public statement of UN and regional human rights experts, n 2; Inter-American Commission on Human Rights, n 36 at 192; Council of Europe Commissioner for Human Rights, n 13 at 9; Cabral M and Carpenter M (eds), *Intersex Issues in the International Classification of Diseases: A Revision* (2014), [http://intersexday.org/wp-content/uploads/2015/10/intersex\\_issues\\_in\\_the\\_international\\_classification\\_of\\_diseases-cabral-carpenter-2014.pdf](http://intersexday.org/wp-content/uploads/2015/10/intersex_issues_in_the_international_classification_of_diseases-cabral-carpenter-2014.pdf) viewed 25 October 2015; Holmes M, “The Intersex Enchiridion: Naming and Knowledge” (2011) 1 *Somatechnics* 388; Davis, n 107; Physicians for Human Rights, “Unnecessary Surgery on Intersex Children Must Stop”, <http://physiciansforhumanrights.org/press/press-releases/intersex-surgery-must-stop.html> viewed 21 October 2017.

<sup>204</sup> World Health Organization et al, *Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement*, n 67.

<sup>205</sup> World Health Organization, n 10.

<sup>206</sup> Carpenter, “Intersex Variations, Human Rights, and the International Classification of Diseases”, n 57; Carpenter M and Cabral M, “Submission by GATE to the World Health Organization: Intersex Codes in the International Classification of Diseases (ICD) 11 Beta Draft” (June 2017), <https://gate.ngo/wp-content/uploads/2020/03/GATE-ICD-intersex-submission.pdf> viewed 30 June 2017.

<sup>207</sup> Carpenter and Cabral, n 211; Intersex Human Rights Australia, “Joint Statement on the International Classification of Diseases 11 / Declaración Conjunta Sobre La Clasificación Internacional de Enfermedades 11 / Совместное Заявление о Международной Классификации Болезней 11 / Déclaration Commune Sur La Classification Internationale Des Maladies 11 / Dichiarazione Comune Sulla Classificazione Internazionale Delle Malattie 11 / 關於針對國際疾病分類第11版(ICD-11)的聯合聲明 / 关于针对国际疾病分类第11版(ICD-11)的联合声明”, <https://ihra.org.au/35299/joint-statement-icd-11/> viewed 24 May 2019.

## WHO ARE INTERSEX PEOPLE?

The pathologization of intersex variations as disorders has led to the use of prenatal interventions, and genetic testing and deselection for multiple intersex traits. Prenatal hormone treatments may be used – wrongfully – to reduce the physical and psychological manifestations of an intersex variation, including to try to modify physical characteristics, reduce “behavioural masculinization”<sup>208</sup> and change sexual orientation.<sup>209</sup> Such interventions are experimental and lack evidence of long-term outcomes, while there is also evidence of poor developmental outcomes.<sup>210</sup> Prenatal and *in vitro* tests to ensure that sex characteristics conform to stereotypical gender norms reinforce stereotypes and perpetuate discrimination against intersex people on the basis of their sex characteristics, and sex and gender norms.<sup>211</sup>

The Convention on the Elimination of Discrimination Against Women calls for the elimination of practices based on stereotyped roles for men and women.<sup>212</sup> A 2011 UN interagency statement urged States to combat gender-biased sex selection, describing the consequences of gender-biased sex selection as “an unacceptable manifestation of gender discrimination against girls and women and a violation of their human rights. The statement called for legal and policy measures and advocacy and awareness activities to combat sex selection, including communication and community mobilization that address root causes.<sup>213</sup> The statement also called for data collection on the phenomenon, in addition to research on causes and impact, and promotion of the responsible use of technologies.

The Council of Europe Commissioner for Human Rights has stated that prenatal hormone treatments and genetic testing intended to eliminate intersex embryos are “discriminatory ‘sex selection’” and incompatible with “human rights standards due to the discrimination perpetrated against intersex people on the basis of their sex characteristics”.<sup>214</sup>

<sup>208</sup> Nimkarn S and New MI, “Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency” (2010) 1192 *Annals of the New York Academy of Sciences* 5 at 9.

<sup>209</sup> Dreger et al, n 22; Nimkarn and New, n 213 at 9; Meyer-Bahlburg HFL, “Will Prenatal Hormone Treatment Prevent Homosexuality?” (1990) 1 *Journal of Child and Adolescent Psychopharmacology* 279.

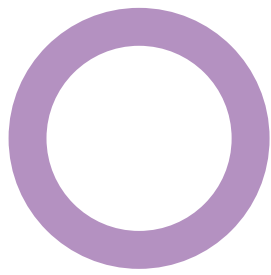
<sup>210</sup> Dreger et al, n 22; Hirvikoski T, Nordenström A, Wedell A, Ritzén M and Lajic S, “Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint” (2012) 97 *The Journal of Clinical Endocrinology & Metabolism* 1881.

<sup>211</sup> Sparrow R, “Gender Eugenics? The Ethics of PGD for Intersex Conditions” (2013) 13 *The American Journal of Bioethics* 29; Davis G, “The Social Costs of Preempting Intersex Traits” (2013) 13 *The American Journal of Bioethics* 51; Toebes B, “Sex Selection under International Human Rights Law” (2008) 9 *Medical Law International* 197; Carpenter M and Organisation Intersex International Australia, “Submission on the Review of Part B of the Ethical Guidelines for the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2007” (Organisation Intersex International Australia, Sydney, 30 April 2014), <http://oii.org.au/25621/submission-ethics-genetic-selection-intersex-traits/> viewed 30 April 2014.

<sup>212</sup> United Nations, “Convention on the Elimination of All Forms of Discrimination against Women” (3 September 1981) at article 5(a).

<sup>213</sup> Office of the High Commissioner for Human Rights, UNFPA, UNICEF, UN Women and World Health Organization, *Preventing Gender-Biased Sex Selection: An Interagency Statement* (World Health Organization (WHO), Geneva, 2011). The Statement also calls to “Ensure women’s access to safe abortion and other services – efforts to manage or limit sex selection should also not hamper or limit access to safe abortion services. This should be part of broader efforts to protect the right of women to have access to legitimate sexual and reproductive health technologies and services.”

<sup>214</sup> Council of Europe Commissioner for Human Rights, n 13 at 30.





**Legal recognition, including  
registration at birth**

- *The Convention on the Rights of the Child (article 7), the International Covenant on Civil and Political Rights (article 24) and Convention on the Rights of Persons with Disabilities (article 18(2)) require that children be registered immediately after birth, with a name and the right to acquire a nationality, but do not require States to register sex or gender.*<sup>215</sup>
- *The Yogyakarta Principles plus 10 recommend an end to the registration of the sex or gender of the person in identity documents and as part of their legal personality, while proposing interim arrangements that include a multiplicity of gender markers.*<sup>216</sup>

Intersex people face barriers in having their births registered, in changing sex or gender markers on official documents, and some also report being forced into unwanted sex or gender categories.

In some countries, parents and individuals have had difficulty in registering the birth of intersex persons, and in some cases registration has been made dependent on parental consent for a child to undergo unnecessary and irreversible surgeries, with such two cases reported in Argentina.<sup>217</sup> In the case of *Richard Muasya v. the Hon. Attorney General and others* before the High Court of Kenya, an intersex individual, Richard Muasya, had no identity documentation and did not complete schooling, but was found to be responsible for obtaining his own birth certificate, after a failure of his parents to obtain one at the time of his birth.<sup>218</sup> The same court later adjudicated in the case of a five-year old child and required authorities to issue a birth certificate.<sup>219</sup>

In some jurisdictions, such as France, birth registration processes may facilitate the late registration of an intersex child, for example, where sex of rearing may only be established after genetic and other testing.<sup>220</sup> Intersex organizations have identified risks and benefits associated with such regulations. While allowing more time to determine the most appropriate sex of rearing for an intersex child, or even involve a child in a decision about sex assignment, the imminent approach of a deadline may encourage surgical or hormonal procedures in an attempt to reinforce sex of rearing.<sup>221</sup> In Malta, determination of a female, male or non-binary gender marker can be delayed until age 18.<sup>222</sup>

No early medical intervention is certain to coincide with a child's future identity or desires.<sup>223</sup> Like others, intersex people may face barriers and discrimination if they wish to or need to amend sex markers on birth certificates and official documents. Processes in some countries allow for changes to initial birth registration if an initial sex of rearing is discovered to be incorrect or inappropriate. A 2018 Kenyan intersex taskforce report found that a majority of intersex persons surveyed had birth certificates, but recorded sex frequently conflicted with physical appearance, limiting access to ID cards.<sup>224</sup>

<sup>215</sup> United Nations, "Convention on the Rights of the Child", n 46 at article 7.

<sup>216</sup> Yogyakarta Principles, n 25, p 9.

<sup>217</sup> Justicia Intersex and [Zwischengeschlecht.org](http://Zwischengeschlecht.org), n 12 at 22.

<sup>218</sup> International Commission of Jurists, "*Richard Muasya v. the Hon. Attorney General, High Court of Kenya* (2 December 2010)", n 174.

<sup>219</sup> Migiyo K, "Kenya Takes Step toward Recognizing Intersex People in Landmark Ruling" Reuters, 5 December 2014, <http://mobile.reuters.com/article/idUSKCN0JJ1M120141205?irpc=932> viewed 6 December 2014.

<sup>220</sup> OII Francophonie, *Supposée reconnaissance d'un troisième sexe par l'État allemand: des risques à considérer* (20 August 2013) OII Francophonie, <https://oii francophonie.org/2013/08/20/communiquede-presse-de-loii-francophonie/> viewed 18 November 2017.

<sup>221</sup> OII Francophonie, n 225.

<sup>222</sup> Ni Mhuirthile T, "The Legal Status of Intersex Persons in Malta" in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, UK, 2018) p 364, <http://intersentia.com/en/the-legal-status-of-intersex-persons.html> viewed 15 March 2018; Pace Y, *Malta Introduces 'X' Marker on Passports, ID Cards and Work Permits* (5 September 2017) [MaltaToday.com.mt](http://www.maltatoday.com.mt), [http://www.maltatoday.com.mt/news/national/80228/malta\\_introduces\\_x\\_marker\\_on\\_passports\\_id\\_cards\\_and\\_work\\_permits](http://www.maltatoday.com.mt/news/national/80228/malta_introduces_x_marker_on_passports_id_cards_and_work_permits) viewed 4 December 2017.

<sup>223</sup> Zillén et al, n 46 at 42; Garland and Diamond, n 73, p 92.

<sup>224</sup> Office of the Attorney General and Department of Justice, n 29 at 14.

In some cases, courts have determined the ability of intersex persons to change sex classification. In 2008, the Supreme Court of the Philippines determined that an intersex man had the right to change the sex marked on his birth certificate from female to male. The decision was based on naturally occurring physical changes as his body matured; he “had allowed ‘nature to take its course’ and had not interfered with what ‘he was born with’”.<sup>225</sup> In this example, natural changes to sex characteristics from puberty aligned with his desired legal sex registration. In a different case, an Indonesian intersex man was acquitted on appeal to the country’s Supreme Court after an accusation of fraud in relation to his gender brought by his wife.<sup>226</sup>

In some jurisdictions, surgical or age requirements may be imposed, in violation of human rights norms. In Uganda, for example, the *Registration of Persons Act 2015* permits intersex children to be registered and have their sex registration changed through the recommendation of a medical practitioner following a surgical procedure.<sup>227</sup> The Act further refers to such children as “hermaphrodites”, a term that many intersex persons find stigmatizing and dehumanizing, and the provisions of the Act do not apply to persons who became adults prior to its commencement.

Imposing surgical requirements as a precondition of legal recognition amounts to coercive treatment, and so violates rights to bodily integrity, self-determination and freedom from torture and cruel, inhuman and degrading treatment. Surgical requirements are particularly harmful where an inappropriate initial sex assignment was itself imposed through unwanted and irreversible changes to sex characteristics.

Some intersex (and non-intersex) people feel that they were forced into binary sex and gender categories that do not fit them, and some individuals express a desire for legal recognition as intersex. Some countries permit at least some official documents to record a third or other sex or gender classifications.<sup>228</sup> In some cases, such as in the U.S. State of New York, this appears driven by demands that birth registration reflect a particular understanding of biology.<sup>229</sup> The German Government has enacted a new classification called “diverse”, available only to some intersex people with medical certification.<sup>230</sup> This approach has been criticized by intersex and transgender organizations, including for failing to address forced medical interventions, medicalizing access to legal documentation, and a failure to make the new classification available to non-intersex persons.<sup>231</sup> Australia has offered an X marker on passports for intersex people since 2003, and formally maintained a more broadly available “Indeterminate/ Intersex/Unspecified” classification since 2011.<sup>232</sup> Since 2015, intersex and transgender organizations in Australia have jointly called for that classification to be renamed “non-binary”.<sup>233</sup> A federal case of an intersex person who identifies as non-binary is pending in the US.<sup>234</sup>

<sup>225</sup> International Commission of Jurists, “Republic of the Philippines v. Jennifer Cagandahan, Supreme Court of the Philippines, Second Division (12 September 2008) | ICJ”, <https://www.icj.org/sogicasebook/republic-of-the-philippines-v-jennifer-cagandahan-supreme-court-of-the-philippines-second-division-12-september-2008/> viewed 25 August 2017.

<sup>226</sup> Asia Pacific Forum of National Human Rights Institutions, n 21, p 82.

<sup>227</sup> Support Initiative for Persons with Congenital Disorders, n 125 at 12–13.

<sup>228</sup> Examples include Australia, Bangladesh, Canada, India, Malta, Nepal, New Zealand, Pakistan.

<sup>229</sup> O’Hara ME, *Nation’s First Known Intersex Birth Certificate Issued in NYC* (29 December 2016) NBC, <http://www.nbcnews.com/feature/nbc-out/nation-s-first-known-intersex-birth-certificate-issued-nyc-n701186> viewed 31 December 2016.

<sup>230</sup> OII Europe, “New Draft Bill in Germany Fails to Protect Intersex People”, <https://oiieurope.org/new-draft-bill-in-germany-fails-to-protect-intersex-people/> viewed 2 September 2018.

<sup>231</sup> OII Europe, “New Draft Bill in Germany Fails to Protect Intersex People”, n 235.

<sup>232</sup> Garland and Travis, n 13 at 5.

<sup>233</sup> National LGBTI Health Alliance, A Gender Agenda, Organización Intersex International Australia, Trans Formative y Transgender Victoria, « Joint submission on recognition of non-binary gender in federal sex/gender guidelines », 24 October 2015. <https://ihra.org.au/30043/joint-submission-federal-sexgender-guidelines/> [Viewed 16 September 2021].

<sup>234</sup> Lambda Legal, *Victory! Court Denies Stay; State Department Must Issue Accurate Passport to Nonbinary Intersex Citizen* (21 February 2019) Lambda Legal, [https://www.lambdalegal.org/blog/20190221\\_victory-court-denies-stay-state-department-must-issue-accurate-passport-to-nonbinary-intersex-citizen](https://www.lambdalegal.org/blog/20190221_victory-court-denies-stay-state-department-must-issue-accurate-passport-to-nonbinary-intersex-citizen) viewed 23 February 2019.

Many intersex people feel forced into association with new, third or non-binary sex and gender categories.<sup>235</sup> Latin American and Caribbean, and Australia/New Zealand intersex community declarations reject the idea that intersex is a third sex.<sup>236</sup> The Darlington Statement (Australia/New Zealand) states that “attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self-determination” and have been harmful.<sup>237</sup>

Human rights defenders fear that, despite assertions that new categories offer parental choice and reduce risk of surgeries, stigma and fear of disclosure may drive surgical interventions to make children with intersex characteristics appear more typically male or female.<sup>238</sup> Some intersex and other human rights defenders call for the removal of all sex and gender markers from identification documents.<sup>239</sup> For so long as they remain, intersex organizations recommend that intersex people should never be automatically categorized into third or non-binary categories of sex or gender, and that such categories should be universally available.<sup>240</sup> They also recommend that, while legal sex or gender classifications continue to be assigned on a compulsory basis at birth, children receive a “best fit” assignment to either male or female, without medical intervention, acknowledging that the classification can later change if necessary or requested by the person concerned.<sup>241</sup> Intersex community declarations typically support access to non-binary and alternative sex or gender classifications for all individuals, whether they are intersex or not.<sup>242</sup>

In a statement on embracing diversity and protecting trans and gender diverse children and adolescents, UN Treaty Bodies, Independent Experts, and representatives of regional human rights institutions have called on States to “facilitate quick, transparent and accessible legal gender recognition and without abusive conditions, guaranteeing human rights for all persons, respectful of free/informed choice and bodily autonomy” without coercive requirements such as sterilization or mental health diagnoses.<sup>243</sup>

Argentina, Malta and an increasing number of other jurisdictions have introduced legislation and regulations enabling gender recognition through simple administrative processes. The Argentinian law, enacted in 2012, is low cost and requires no medical certification.<sup>244</sup> Maltese regulations, introduced in 2017 also allow for self-determination.<sup>245</sup>

<sup>235</sup> Androgen Insensitivity Syndrome Support Group Australia et al, n 124; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124; Garland and Travis, n 13 at 13–15; Althoff, n 13, p 395.

<sup>236</sup> Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124.

<sup>237</sup> Androgen Insensitivity Syndrome Support Group Australia et al, n 124 at 8.

<sup>238</sup> Council of Europe Commissioner for Human Rights, n 13 at 38; Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, pp 485–486; Garland and Travis, n 13 at 14.

<sup>239</sup> Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124 at 8; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124.

<sup>240</sup> Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124.

<sup>241</sup> Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124; Dreger, “Twenty Years of Working toward Intersex Rights”, n 6, p 61.

<sup>242</sup> Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124.

<sup>243</sup> Committee on the Rights of the Child, Committee Against Torture, Special Rapporteur on extreme poverty and human rights, Special Rapporteur on the right to education, Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, Special Rapporteur on the right to health, Special Rapporteur on violence against women, its causes and consequences, Working Group on the issue of discrimination against women in law and in practice, Inter-American Commission on Human Rights, African Commission Chairperson of, the Committee for the Prevention of Torture in Africa on Human and Peoples’ Rights, African Commission Chairperson of and Council of Europe Commissioner for Human Rights, “Embrace Diversity and Protect Trans and Gender Diverse Children and Adolescents”, <http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=21622&LangID=E> viewed 17 May 2017.

<sup>244</sup> Byrne J Open Society Foundation, Open Society Foundations and Open Society Institute, *License to Be Yourself Laws and Advocacy for Legal Gender Recognition of Trans People* (Open Society Foundations, New York, 2014) p 17 and 24, <http://www.opensocietyfoundations.org/reports/license-be-yourself> viewed 23 October 2014.

<sup>245</sup> Garland and Travis, n 13 at 6–7.





**Discrimination and stigmatization**

- *International human rights law contains guarantees of equal access to the law and equal protection before the law without discrimination of any kind, as well as to remedy for violations of rights.*<sup>246</sup>
- *UN mechanisms have recognized that discrimination may be, and commonly is, compounded by discrimination on multiple grounds, including sex, gender, gender identity, race, age, religion, disability, health, sexual orientation and economic status.*<sup>247</sup>
- *Where forced, coercive and unnecessary medical interventions arise from sex and gender stereotypes, stigma and social prejudice, or are justified using social and cultural rationales, they violate the right to non-discriminatory treatment.*<sup>248</sup>
- *The Convention on the Rights of Persons with Disabilities calls for the provision of reasonable accommodations, where necessary in order to promote equality and eliminate discrimination.*<sup>249</sup>

Intersex persons are often subjected to discrimination and abuse if it becomes known that they are intersex, or if they are perceived not to conform to sex and gender norms. Anti-discrimination laws do not typically ban discrimination against intersex persons, leaving them vulnerable to discriminatory practices in a range of settings, including access to education, public services and employment.<sup>250</sup> The available data show that intersex people may have high rates of poverty, associated with high rates of early school leaving, stigmatization and discrimination.

An East African baseline survey published in 2016 based on interviews with 120 participants, including intersex people, parents, medical practitioners and community leaders, found that, in Uganda and other East African countries, 90 per cent of the intersex youth interviewed reported that they were forced to drop out of school due to stigma and discrimination from students and staff associated with their physical development during puberty.<sup>251</sup> Students faced problems in accessing sanitation, including toilets, showers and changing rooms. A 2018 Kenyan intersex taskforce survey also found very high levels of early school leaving, “due to negative peer pressure and societal stereotyping”.<sup>252</sup>

A 2015 Australian sociological study with a convenience sample of 272 participants born with atypical sex characteristics found that 18 per cent only completed primary school.<sup>253</sup> Most early school leavers left between ages 12 to 16, during years associated with puberty, hormone treatments and, in some cases, genital surgeries and distress associated with medical treatment. School curricula were non-inclusive, and counselling services unaware. Experiences of bullying from students and staff, notably on the basis of atypical physical characteristics, developmental delays or medical leave were common and well-being risks were high. Few governments have addressed the needs of intersex youth in school

<sup>246</sup> See for example, United Nations, “Universal Declaration of Human Rights”, n 48 at articles 2 and 7; United Nations, “International Covenant on Civil and Political Rights”, n 46 at articles 26 and 2(3a); United Nations, “International Covenant on Economic, Social and Cultural Rights” (16 December 1966) at article 2; United Nations, “Convention on the Rights of the Child”, n 46 at article 2; Committee against Torture, “General Comment No. 2 Implementation of Article 2 by States Parties” (CAT/C/GC/2, United Nations, Geneva, 24 January 2008).

<sup>247</sup> United Nations High Commissioner for Human Rights, “Discrimination and Violence against Individuals Based on Their Sexual Orientation and Gender Identity” (A/HRC/29/23, 4 May 2015) at 42, viewed 2 June 2015; Committee on Economic, Social and Cultural Rights, “General Comment No. 22 (2016) on the Right to Sexual and Reproductive Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)”, n 10 at 2; Committee on the Elimination of Discrimination against Women, “General Recommendation No. 28 on the Core Obligations of States Parties under Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women” (CEDAW/C/GC/28, 16 December 2010) at 18.

<sup>248</sup> United Nations, “International Covenant on Civil and Political Rights”, n 46 at article 26; United Nations, “Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment” (10 December 1984) at article 1; United Nations, “Convention on the Rights of the Child”, n 46 at article 2; United Nations, “Convention on the Rights of Persons with Disabilities”, n 48 at articles 4-6; Human Rights Committee, n 162 at 25–26.

<sup>249</sup> United Nations, “Convention on the Rights of Persons with Disabilities”, n 48 at articles 5, 24 and 27.

<sup>250</sup> Office of the High Commissioner for Human Rights, n 33.

<sup>251</sup> Support Initiative for Persons with Congenital Disorders, n 125 at 16.

<sup>252</sup> Office of the Attorney General and Department of Justice, n 29 at 159–160.

<sup>253</sup> Jones T, “The Needs of Students with Intersex Variations” (2016) 16 Sex Education 602 at 9.

and other educational contexts. An example by the South Australian government focuses solely on issues of identity and gender transition.<sup>254</sup>

The Australian study found high levels of poverty amongst survey participants, and lower than typical levels of participation in the workforce. Multiple reports have found evidence of discriminatory treatment in workplaces and in social services, while the negative impacts of surgeries and other interventions, in addition to poor information provision on associated health risks, can have a severe impact on the work and professional trajectories of intersex people.

Multiple women athletes with variations of sex characteristics have been disqualified or humiliated due to their characteristics.<sup>255</sup> Many have had their lifelong legal and social status and identities as women questioned as a consequence of policies that single them out for exclusion.<sup>256</sup> In the recent past, women athletes have been subjected to chromosomal testing, in some cases revealing that they do not possess two X chromosomes.<sup>257</sup> Following criticism of the discriminatory nature of chromosome testing, these policies were later abandoned, but international and national sporting federations subsequently introduced policies restricting participation in women's sport by women with "hyperandrogenism" (testosterone levels exceeding a certain threshold). International sporting bodies have mandated that national bodies "actively investigate any perceived deviation in sex characteristics",<sup>258</sup> thus targeting women who fail to meet gender stereotypes.<sup>259</sup> Restrictions on participation by women with hyperandrogenism were suspended following the Court of Arbitration in Sport 2015 interim judgement in *Chand v. Athletics Federation of India* and the International Association of Athletics Federations,<sup>260</sup> but then reintroduced in certain athletics events in 2018.<sup>261</sup>

South African athlete Caster Semenya challenged the IAAF's 2018 "differences of sex development" regulations before the Court of Arbitration in Sport.<sup>262</sup> During the course of that challenge, the IAAF modified the regulations to focus on only on testosterone but also, in a return to earlier methods of sex verification, based on chromosomes.<sup>263</sup> CAS adjudicated a majority decision in favour of the IAAF.<sup>264</sup> At the time of writing, Semenya had appealed the decision.<sup>265</sup>

Hyperandrogenism and differences of sex development policies have led to suggestions that women athletes who are perceived not to conform to certain gender stereotypes- i.e. in particular stereotypes based on binary/biological sex characteristics- should or could be subjected to forced or coercive

<sup>254</sup> Department for Education and Child Development and South Australia, "Transgender and Intersex Student Support Procedure".

<sup>255</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 55–57.

<sup>256</sup> Martínez-Patiño MJ, "Personal Account A Woman Tried and Tested" (2005) *The Lancet* 366.

<sup>257</sup> Genel M, Simpson J and de la Chapelle A, "The Olympic Games and Athletic Sex Assignment" (2016) *JAMA*.

<sup>258</sup> Jordan-Young et al, n 194 at 1.

<sup>259</sup> Karkazis K, Jordan-Young R, Davis G and Camporesi S, "Out of Bounds? A Critique of the New Policies on Hyperandrogenism in Elite Female Athletes" (2012) 12 *The American Journal of Bioethics* 3 at 13.

<sup>260</sup> CAS 2014/A/3759 *Dutee Chand v Athletics Federation of India (AFI) & The International Association of Athletics Federations (IAAF)* [2015] Court of Arbitration for Sport 2014/A/3759 (July 2015).

<sup>261</sup> International Association of Athletics Federations, "Eligibility Regulations for Female Classification (Athletes with Differences of Sex Development)" (IAAF, 23 April 2018).

<sup>262</sup> Dainius Puras, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Nils Melzer, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Ivana Radacic and Chair-Rapporteur of the Working Group on the issue of discrimination against women in law and in practice, "Letter to Mr Coe", 18 September 2018, [https://www.ohchr.org/Documents/Issues/Health/Letter\\_IAAF\\_Sept2018.pdf](https://www.ohchr.org/Documents/Issues/Health/Letter_IAAF_Sept2018.pdf) viewed 21 September 2018; Court of Arbitration for Sport, "Caster Semenya Challenges the IAAF Eligibility Regulations for Female Classification at CAS" (Court of Arbitration for Sport, 19 June 2018), [http://www.tas-cas.org/fileadmin/user\\_upload/Media\\_Release\\_Semenya\\_IAAF.pdf](http://www.tas-cas.org/fileadmin/user_upload/Media_Release_Semenya_IAAF.pdf) viewed 12 December 2018.

<sup>263</sup> Athletics South Africa, "Press Release: ASA Not Amused of Agreement Breaches in Case Before CAS", 29 March 2019, <https://athletics.org.za/asa-not-amused-of-agreement-breaches-in-case-before-cas/> viewed 31 March 2019.

<sup>264</sup> CAS 2018/O/5794 *Mokgadi Caster Semenya v International Association of Athletics Federations & CAS 2018/O/5798 Athletics South Africa v International Association of Athletics Federations* [2019] (Unreported, Court of Arbitration for Sport, 30 April 2019) at 551–2.

<sup>265</sup> Karkazis RMJ-Y Katrina, "4 Myths about Testosterone", <https://blogs.scientificamerican.com/observations/4-myths-about-testosterone/> viewed 19 June 2019.

treatment in order to continue to compete.<sup>266</sup> Cases have already been recorded of coercive interventions for hyperandrogenism,<sup>267</sup> including athletes required to undergo a gonadectomy (the removal of their reproductive organs) and partial clitorectomies (a form of female genital mutilation) in the absence of symptoms or health issues warranting those procedures.<sup>268</sup>

There is insufficient scientific evidence to establish that women in such cases are afforded a “substantial performance advantage” warranting exclusion.<sup>269</sup> Having an intersex trait does not in itself entail better performance, whereas other physical variations that do affect performance, such as body mass,<sup>270</sup> height and muscle development, are not subjected to such scrutiny and restrictions. In the case of Caster Semenya, the Court of Arbitration for Sport determined in 2019 that its role was to determine whether the regulations set by the International Association of Athletics Federations (IAAF) were necessary, reasonable and proportionate and could not consider the adequacy of decision-making processes or consequential scientific integrity of the evidence put to it.<sup>271</sup>

In 2005, South Africa included intersex within a broad definition of sex, in the Promotion of Equality and Prevention of Unfair Discrimination Act, 2000.<sup>272</sup> In 2013, Australia included the attribute of “intersex status” within the Sex Discrimination Act; however, despite the legislation referring to individuals’ physical features, the attribute has frequently been imputed to refer to an identity group.<sup>273</sup> Intersex organizations in that country have called for effective protections from discrimination on the ground of “sex characteristics”.<sup>274</sup>

The Maltese Gender Identity, Gender Expression and Sex Characteristics Act that prohibits surgery and treatment on the sex characteristics of minors without their informed consent also prohibits discrimination on the ground of sex characteristics.<sup>275</sup> Malta has also implemented an anti-discrimination policy in schools.<sup>276</sup>

<sup>266</sup> Puras et al, n 267; Kelner M and Rudd J, “Caster Semenya Could Be Forced to Undertake Hormone Therapy for Future Olympics” *The Guardian*, 4 July 2017, <https://www.theguardian.com/sport/2017/jul/03/caster-semenya-could-be-forced-to-undertake-hormone-therapy-for-future-olympics> viewed 4 July 2017.

<sup>267</sup> Ha NQ, Dworkin SL, Martínez-Patiño MJ, Rogol AD, Rosario V, Sánchez FJ, Wrynn A and Vilain E, “Hurdling Over Sex? Sport, Science, and Equity” (2014) 43 *Archives of Sexual Behavior* 1035 at 1039.

<sup>268</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 55–57; Jordan-Young et al, n 194.

<sup>269</sup> Katrina Karkazis & Morgan Carpenter « Impossible “Choices”: The Inherent Harms of Regulating Women’s Testosterone in Sport», <http://www.cecileparkmedia.com/world-sports-advocate/hottopic.asp?id=1525> [Viewed 16 September 2021].

<sup>270</sup> Healy ML, Gibney J, Pentecost C, Wheeler MJ and Sonksen PH, “Endocrine Profiles in 693 Elite Athletes in the Postcompetition Setting” (2014) 81 *Clinical Endocrinology* 294.

<sup>271</sup> CAS 2018/O/5794 *Mokgadi Caster Semenya v International Association of Athletics Federations* & CAS 2018/O/5798 *Athletics South Africa v International Association of Athletics Federations* [2019] (Unreported, Court of Arbitration for Sport, 30 April 2019) 551–552.

<sup>272</sup> Republic of South Africa, n 34.

<sup>273</sup> Smith D, Revised Explanatory Memorandum: Marriage Amendment (Definition and Religious Freedoms) Bill 2017 2017 at 6.

<sup>274</sup> Androgen Insensitivity Syndrome Support Group Australia et al, n 124 at B and 9.

<sup>275</sup> *Gender Identity, Gender Expression and Sex Characteristics Act 2018*.

<sup>276</sup> Ministry for Education and Employment, Malta, “Trans, Gender Variant and Intersex Students in Schools: Policy”, <http://education.gov.mt/en/resources/Documents/Policy%20Documents/Trans,%20Gender%20Variant%20and%20Intersex%20Students%20in%20Schools%20Policy.pdf> viewed 16 June 2015.



**Access to justice and remedies**

- *The Convention against torture and other cruel, inhuman or degrading treatment or punishment requires that States ensure access to redress and compensation, including means for rehabilitation.<sup>277</sup> It has been recommended that States arrange for investigations of cases of surgical or other medical treatment reportedly carried out without individuals' informed consent.<sup>278</sup>*
- *The right to truth describes a set of principles for the protection and promotion of human rights through action to combat impunity.<sup>279</sup> General principles include the inalienable right to the truth, the duty to preserve memory, and the victim's right to know, supported by guarantees to give effect to the right to know.<sup>280</sup>*
- *The Yogyakarta Principles plus 10 recognizes a right to truth for victims of human rights violations on the basis of sex characteristics that should not be subject to statutes of limitations.<sup>281</sup>*

Intersex organizations have suggested that statutes of limitations unnecessarily limit access to redress for intersex individuals who have suffered unnecessary or inappropriate medical interventions without their consent during childhood or adolescence.<sup>282</sup> Precedents exist for the removal of such limits such as, in some jurisdictions, the removal of limitations in relation to child sexual abuse.<sup>283</sup> Access to justice also appears to have been limited by clinical assertions of consensus regarding medical practices, including the concept that procedures comprised the usual or best practices at the time.<sup>284</sup> To date, there are few successful instances of claims for redress. While clinical bodies have proposed, this century, that disclosure of intersex variations to individuals and their families must always take place, progress at changing historical practices of non-disclosure appears variable.<sup>285</sup> Non-disclosure can be expected to have a profound effect on individuals' capacities to access justice for unnecessary interventions.

Successful legal cases where redress has been sought have occurred in Germany and Chile, and the Court of Arbitration of Sport. In the case of *Re: Völling*, in the Regional Court Cologne, Germany, Christiane Völling was awarded damages in 2008 for what the International Commission of Jurists have described as “an example of an individual who was subjected to sex reassignment surgery without full knowledge or consent”.<sup>286</sup> A second case was awarded in 2015 to Michaela Raab, by the Nuremberg State Court. The court dismissed a case against the surgeon, but found his colleagues and institution liable for damages.<sup>287</sup>

<sup>277</sup> United Nations, “Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment”, n 253 at article 14.

<sup>278</sup> Committee against Torture, “Concluding Observations on the Seventh Periodic Report of France” (CAT/C/FRA/CO/7, United Nations, Geneva, 10 June 2016) at 35.

<sup>279</sup> Orentlicher D and Economic and Social Council, “Report of the Independent Expert to Update the Set of Principles to Combat Impunity, Diane Orentlicher Addendum Updated Set of Principles for the Protection and Promotion of Human Rights through Action to Combat Impunity” (E/CN.4/2005/102/Add.1, UN Commission on Human Rights, 8 February 2005).

<sup>280</sup> World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, “Durban Declaration and Programme of Action” at 98.

<sup>281</sup> Yogyakarta Principles, n 25, p 14.

<sup>282</sup> [Zwischengeschlecht.org](https://www.zwischengeschlecht.org) et al, n 136 at 47.

<sup>283</sup> Sweetland Edwards H, “Statute-of-Limitation Laws Can Leave Few Choices for Child Sex-Abuse Victims” *Time*, 13 September 2018, <https://time.com/5394927/statute-of-limitations-changes/> viewed 21 June 2019; Pakula M, “Time Limitations For Child Abuse Cases Abolished”, <https://www.premier.vic.gov.au/time-limitations-for-child-abuse-cases-abolished/> viewed 21 June 2019.

<sup>284</sup> interACT, “Update on M.C. s Case – The Road to Justice Can Be Long, but There Is More than One Path for M.C.”, <https://interactadvocates.org/intersex-in-the-courts/> / viewed 19 February 2017.

<sup>285</sup> Human Rights Watch, n 65, pp 7, 34–36; Chase, “Surgical Progress Is Not the Answer to Intersexuality”, n 65; Office of the Privacy Commissioner, n 66; Kenya National Commission on Human Rights, n 27, p 34.

<sup>286</sup> International Commission of Jurists, “In *Re Völling*, Regional Court Cologne, Germany (6 February 2008) | ICJ”, <http://www.icj.org/sogicasebook/in-re-volling-regional-court-cologne-germany-6-february-2008/> viewed 27 December 2015.

<sup>287</sup> Baller S, “Michaela Raab klagt gegen ‘Zwangstranssexualisierung’” (2015) *stern.de*, <http://www.stern.de/familie/leben/operation-an-intersexuellem-menschen-michaela-raab-klagt-gegen-zwangstranssexualisierung-2176273.html> viewed 25 August 2017.

In the case of Benjamín-Maricarmen, in Chile, a mother won a case before the country's Supreme Court for “lack of service” in relation to her son, Benjamín. He had been raised female, and subjected to a sterilization procedure including the unnecessary removal of a male reproductive system during a procedure to manage a hernia, without consent of either the child or his parents.<sup>288</sup> The applicant was awarded compensation for moral and psychological damages.

The 2015 interim judgement in *Chand v. Athletics Federation of India and the International Association of Athletics Federations* facilitated competition by women athletes in the related sporting events without the imposition of medical requirements.<sup>289</sup>

In the case of *M.C. v Aaronson*, a young boy born with ovotestes was subjected to “feminizing” surgeries while a ward of South Carolina in the United States. The defendant in the case had previously written that feminizing intervention would be “catastrophic” in a child who later identified as a boy,<sup>290</sup> however, clinical norms and the lack of regulation or prohibition of such surgeries led the claim to be later settled out of court.<sup>291</sup> The growing documentation of contention and lack of consensus about such practices within medicine may impact future cases.<sup>292</sup>

In many jurisdictions, intersex people lack access to justice and remedy for human rights violations. Cases also exist where courts have approved early interventions without safeguarding the rights of the child. In a 2016 decision, the Family Court of Australia found that parents could authorize the sterilization of their 5-year old child in the absence of evidence of medical necessity, and determined that this was better done before the child attained legal capacity. The judge described a prior clitorrectomy and labioplasty<sup>293</sup> as having “enhanced the appearance” of her genitalia; those prior procedures had not required court approval.<sup>294</sup> A subsequent case in 2017 recorded that an adolescent had been prescribed testosterone to kickstart puberty without her informed consent or oversight; the judge made no comment on the inappropriateness of that prescription.<sup>295</sup>

<sup>288</sup> Centro de Derechos Humanos UDP and Godoy Peña, n 144.

<sup>289</sup> CAS 2014/A/3759 *Dutee Chand v Athletics Federation of India (AFI) & The International Association of Athletics Federations (IAAF)* [2015] Court of Arbitration for Sport 2014/A/3759 (July 2015).

<sup>290</sup> Aaronson IA, “The Investigation and Management of the Infant with Ambiguous Genitalia: A Surgeon’s Perspective” (2001) 31 *Current Problems in Pediatrics* 168 at 189.

<sup>291</sup> interACT, “Update on M.C.’s Case – The Road to Justice Can Be Long, but There Is More than One Path for M.C.”, n 289; Ghorayshi A, “A Landmark Lawsuit About An Intersex Baby’s Genital Surgery Just Settled For \$440,000” BuzzFeed, 27 July 2017, <https://www.buzzfeed.com/azeenghorayshi/intersex-surgery-lawsuit-settles> viewed 27 July 2017.

<sup>292</sup> Physicians for Human Rights, n 208; Elders MJ, Satcher D and Carmona R, “Re-Thinking Genital Surgeries on Intersex Infants” (Palm Center, June 2017), <http://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf> viewed 30 June 2017; Lee et al, n 58.

<sup>293</sup> These procedures are generally considered to be forms of female genital mutilation. See the section on female genital mutilation.

<sup>294</sup> Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8; Kelly F and Smith MK, “Should Court Authorisation Be Required for Surgery on Intersex Children? A Critique of the Family Court Decision in *Re Carla*” (2017) 31 *Australian Journal of Family Law* 118.

<sup>295</sup> Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, pp 478–480.

Several countries have undertaken investigations of medical practices affecting intersex people, including Australia,<sup>296</sup> France,<sup>297</sup> Germany,<sup>298</sup> and Switzerland.<sup>299</sup> In a 2012 report, the German Ethics Council has recommended the establishment of a State compensation fund,<sup>300</sup> but this has not been implemented.<sup>301</sup> The French Human Rights Defender made a similar call, lacking implementation, in 2017.<sup>302</sup> No actions appear to have yet been taken to prosecute alleged perpetrators of human rights violations.

The Committee on the Rights of the Child has expressed concern about a lack of redress and compensation in cases of medically unnecessary procedures on intersex children.<sup>303</sup> Similarly, the Committee against Torture has expressed concern regarding a lack of adequate redress and compensation in cases of forced, involuntary or otherwise coercive or abusive treatments of intersex persons.<sup>304</sup> The Committee on the Elimination of Discrimination against Women has called on States to adopt specific measures aimed at providing victims of forced sterilization with assistance to access their medical records, and investigate past practices, prosecute and adequately publish perpetrators and compensate victims.<sup>305</sup>

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<sup>296</sup> Community Affairs References Committee, Senate of Australia, n 15; Australian Human Rights Commission, n 84.

<sup>297</sup> Senate, n 151.

<sup>298</sup> German Ethics Council, n 151.

<sup>299</sup> National Advisory Commission on Biomedical Ethics NEK-CNE and Switzerland, n 151.

<sup>300</sup> German Ethics Council, n 151, p 155.

<sup>301</sup> Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Combined Seventh and Eighth Periodic Reports of Germany” (CEDAW/C/DEU/CO/7-8, 9 March 2017) at 24(e).

<sup>302</sup> Moron-Puech, n 101, p 309.

<sup>303</sup> Committee on the Rights of the Child, “Concluding Observations on the Combined Third to Fourth Periodic Reports of Ireland” (CRC/C/IRL/CO/3-4, United Nations, Geneva, 1 March 2016) at 39.

<sup>304</sup> Committee against Torture, “Concluding Observations on the Fifth Periodic Report of Germany” (CAT/C/DEU/CO/5, United Nations, Geneva, 12 December 2011) at 20; Committee against Torture, “Concluding Observations on the Fifth Periodic Report of China” (CAT/C/CHN/CO/5, United Nations, Geneva, 3 February 2016) at 56.

<sup>305</sup> Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Combined Fourth and Fifth Periodic Reports of Namibia” (CEDAW/C/NAM/CO/4-5, 28 July 2015) at 37.





**Addressing root causes of  
human rights violations**

- *States have a duty to address the root causes of human rights violations. States have an obligation to challenge and modify social norms that underpin and justify harmful practices.*<sup>306</sup>

Lack of awareness, misconceptions, harmful social and religious attitudes, stigma and taboos perpetuate human rights violations, and prevent people from speaking out. Lack of visibility and misconceptions still impede access by intersex individuals and their families to information, peer support, legal services. Limited disclosure of historical and current medical practices also impacts on the credibility of victims of human rights violations.<sup>307</sup> Intersex advocates in Europe have also identified a lack of non-pathologizing information on intersex.<sup>308</sup> With a legacy of concealment of medical practices from individuals and from society, individuals have reported feelings of isolation, and a lack of words to describe their lived experiences and bodies.<sup>309</sup>

Intersex human rights organizations play a vital role in providing support to intersex people and their families, educating and addressing stigmatization and discrimination, and collecting evidence of human rights violations. Intersex human rights defenders have also filmed documentaries and published memoirs to raise greater awareness.<sup>310</sup> Eric Lohman, an interACT board member and parent of an intersex child, published *Raising Rosie* in 2018, describing his family's journey.<sup>311</sup> 26 October has been designated by intersex organizations as Intersex Awareness Day, and 8 November as Intersex Day of Remembrance or Intersex Day of Solidarity.<sup>312</sup> The European *InterVisibility* project has translated intersex-related material into 27 languages,<sup>313</sup> and interACT published a media guide in early 2017,<sup>314</sup> which accompanied news coverage of the model Hanne Gaby Odiele.

In 2016, the United Nations Human Rights Office launched a new webpage, *United Nations for Intersex Awareness*, as part of its ongoing UN Free & Equal campaign for the rights of LGBT and intersex people. The site highlighted key human rights issues affecting intersex people, and hosted an awareness raising video that was watched by more than a million people on social media. The United Nations Development Program and the World Bank are developing “LGBTI Indicators” that, over time, may provide disaggregated data on the circumstances of intersex people.<sup>315</sup>

<sup>306</sup> Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child, n 99 at 57.

<sup>307</sup> Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, pp 459–460.

<sup>308</sup> Ghattas DC, “Standing Up for the Human Rights of Intersex People” in Scherpe J, Dutta A and Helms T (eds), *The Legal Status of Intersex Persons* (Intersentia, Cambridge, England, 2018) p 433.

<sup>309</sup> Dreger, “Twenty Years of Working toward Intersex Rights”, n 6, p 58.

<sup>310</sup> Hart P, *Orchids: My Intersex Adventure* (2010), <http://www.hartflicker.com/orchids/index.html> viewed 1 January 2019; Lahood G, *Intersexions* (2012), <https://www.intersexionfilm.com> viewed 1 January 2019; Haynes S, “New Documentary Explores the Realities of Being an Intersex Person and Their Treatment By Society” *Time*, 19 June 2019, <https://time.com/5608917/no-box-for-me-intersex-documentary/> viewed 21 June 2019; Pagonis P and Bernier-Clarke A, “‘I Am Non-Binary in My Biology and My Gender’ – Intersex Activist Pidgeon Pagonis”, <https://www.britishcouncil.org/voices-magazine/non-binary-biology-gender-film-intersex-activist-pidgeon-pagonis> viewed 28 March 2019; Hillman T, *Intersex (For Lack of a Better Word)* (Manic D Press, Inc., 2008); Vilorio H, *Born Both: An Intersex Life* (Hachette Books, New York, 2017).

<sup>311</sup> Lohman E and Lohman S, *Raising Rosie Our Story of Parenting an Intersex Child*. (Jessica Kingsley Publishers, London, 2018).

<sup>312</sup> Intersex Day Project <<http://intersexday.org/>>

<sup>313</sup> OII Europe. ‘InterVisibility’ (2019) <<http://intervisibility.eu>>

<sup>314</sup> interACT, “Media Guide, Covering the Intersex Community”, <http://interactadvocates.org/wp-content/uploads/2017/01/INTERSEX-MEDIAGUIDE-interACT.pdf> viewed 24 January 2017.

<sup>315</sup> World Bank and UNDP, “Investing in a Research Revolution for LGBTI Inclusion” (November 2016), <http://documents.worldbank.org/curated/en/196241478752872781/pdf/110035-WP-InvestinginaResearchRevolutionforLGBTIInclusion-PUBLIC-ABSTRACT-SENT.pdf> viewed 10 August 2017.

## INTERSEX HUMAN RIGHTS ORGANIZATIONS

It is only within the last 25 years that intersex-led organizations have established themselves and grown to provide peer support and challenge human rights violations. Intersex human rights defenders and intersex-led human rights organizations play a vital role in tackling stigma, misconceptions, social taboos and discrimination, and in documenting rights violations. According to a 2017 survey, their work includes systemic advocacy, community organizing, education activities, and social services, peer support and individual advocacy.<sup>316</sup>

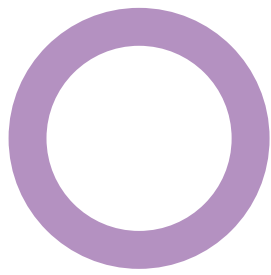
The movement remains hampered by a lack of resources,<sup>317</sup> subject to a reliance on volunteers, and systemic barriers to fundraising including a lack of funder awareness and misconceptions about the intersex population.<sup>318</sup> A 2013 study identified that intersex-led organizations had distinctly different priorities to organizations that included intersex within a broader remit.<sup>319</sup>

<sup>316</sup> Howe et al, n 39, pp 6–7.

<sup>317</sup> Eisfeld J, Gunther S and Shlasko D, *The State of Trans\* and Intersex Organizing: A Case for Increased Support for Growing but under-Funded Movements for Human Rights* (Global Action for Trans\* Equality and American Jewish World Service, New York, 2013) p 9; Howe et al, n 39.

<sup>318</sup> Astraea Lesbian Foundation for Justice, “We Are Real: The Growing Movement Advancing the Human Rights of Intersex People” at 3, <https://astraeafoundation.org/wearereal/wp-content/uploads/2016/07/AstraeaWeAreRealReport.pdf> viewed 21 July 2016.

<sup>319</sup> Eisfeld et al, n 322, p 9.





**Conclusions and way forward**

## CONCLUSIONS

Intersex people suffer violations of their rights to liberty, security, freedom from torture, harmful practices, experimentation, and discrimination. Few States have investigated human rights violations against intersex people. Stigma, societal taboos, lack of awareness have contributed to the invisibility of intersex people.

Intersex people face risks of unnecessary forced and coercive medical procedures from birth to adolescence and in adulthood, associated with limited or absent provision of information to the individuals concerned and their families, with terrible consequences. Medical practices are perpetuated through the unnecessary pathologization of intersex bodies, and limited disclosure of the impact of historic and current practices

Intersex people face stigmatization and discrimination in education, employment, access to services. Intersex persons' right to health is threatened by stigma and bias, lack of clinical training, and unnecessarily pathologizing clinical practices and classifications.

Some individuals have had difficulty obtaining legal identification documents because of a difficulty in establishing their legal status. Attempts to recognize intersex people in sex and gender classification systems have often failed to adequately recognize the diverse existing legal and social status of intersex people. In some cases, surgical requirements have been imposed on survivors of forced medical practices who seek a change to their legal status.

These violations continue to happen in a generalized climate of impunity. Few cases have succeeded where intersex people have sought redress. Reasons for this appear to include the impact of statutes of limitations, limited disclosure of medical information, and claims that medical norms that violate children's rights provide satisfactory benchmarks.

States have an obligation to investigate human rights violations and provide redress and remedies. States are also under an obligation to address the root causes of human rights violations, including by tackling stigma, pathologization, and harmful social and cultural norms. There have been some positive developments to protect the human rights of intersex people, however a lot remains to be done. Below are some steps on the way forward.

## WAY FORWARD

### **Bodily Integrity, freedom from torture, right to health, autonomy and self-determination**

Multiple institutions including the Office of the United Nations High Commissioner for Human Rights, and UN and regional human rights mechanisms, have advised that States should, as a matter of urgency, protect the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment.<sup>320</sup>

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<sup>320</sup> Human Rights Committee, "Concluding Observations on the Fourth Periodic Report of Switzerland" (CCPR/C/CHE/CO/4, 22 August 2017) at 24–25; Human Rights Committee, n 162 at 25–26.

UN treaty bodies have made reference to these rights in calls to protect the right to bodily integrity, and autonomy and self-determination of intersex children, and ensure that no-one is subjected to harmful practices or unnecessary medical treatment during infancy or childhood.<sup>321</sup> Treaty bodies have further called on States to ensure that all medical or surgical treatment during infancy or childhood are documented.<sup>322</sup> This may involve the repeal of legislation, regulations and practices allowing any form of forced intervention or surgery.<sup>323</sup> Treaty bodies further recommend the adoption of legislation to explicitly prohibit the performance of surgical or other medical treatment on intersex children unless such procedures constitute an absolute medical necessity, and until the children involved reach an age at which they can provide their free, prior and informed consent.<sup>324</sup>

In collaboration intersex-led organizations and medical bodies, States should ensure the development and implementation of rights-based, lifetime health-care protocols for intersex children,<sup>325</sup> and effective independent oversight. States should also ensure that individuals and their families have access to independent counselling and support.<sup>326</sup>

<sup>321</sup> Committee on the Rights of the Child, “Concluding Observations on the Combined Second to Fourth Periodic Reports of Switzerland”, n 51 at 43; Committee on the Rights of the Child, “Concluding Observations on the Third to Fifth Periodic Reports of Nepal” (CRC/C/NPL/CO/3-5, United Nations, Geneva, 3 June 2016) at 42; Committee on the Rights of the Child, “Concluding Observations on the Combined Fourth to Fifth Periodic Reports of Chile” (CRC/C/CHL/CO/4-5, United Nations, Geneva, 30 October 2015) at 48–49; Committee on the Rights of the Child, “Concluding Observations on the Combined Third to Fourth Periodic Reports of Ireland”, n 308 at 40; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of the United Kingdom of Great Britain and Northern Ireland” (CRC/C/GBR/CO/5, United Nations, Geneva, 12 July 2016) at 47; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of France” (CRC/C/FRA/CO/5, United Nations, Geneva, 23 February 2016) at 48; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of New Zealand” (CRC/C/NZL/CO/5, United Nations, Geneva, 21 October 2016) at 25; Committee on the Rights of the Child, “Concluding Observations on the Second Periodic Report of South Africa”, n 51 at 39–40; Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Germany” (CRPD/C/DEU/CO/1, United Nations, Geneva, 13 May 2015) at 37; Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Chile, Addendum Comments Received from Chile on the Concluding Observations” (CRPD/C/CHL/CO/1/Add.1, United Nations, Geneva, 13 April 2016) at 42; Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Uruguay” (CRPD/C/URY/CO/1, United Nations, Geneva, 31 August 2016) at 44; Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Italy” (CRPD/C/ITA/CO/1, United Nations, Geneva, 6 October 2016) at 46; Committee on the Rights of the Child, “Concluding Observations on the Combined Third to Sixth Reports of Malta”, n 150 at 28–29. Committee on the Rights of the Child, “Concluding Observations on the Second Periodic Report of South Africa”, n 51 at 39–40.

<sup>322</sup> Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of Italy”, n 328 at 46.

<sup>323</sup> Committee on the Rights of Persons with Disabilities, “Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland” (CRPD/C/GBR/CO/1, United Nations, Geneva, 3 October 2017) at 40–41.

<sup>324</sup> Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Eighth Periodic Report of Australia” (CEDAW/C/AUS/CO/8, 25 July 2018) at 25–26; Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Ninth Periodic Report of Mexico” (CEDAW/C/MEX/CO/9, 20 July 2018) at 21–22; Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Eighth Periodic Report of New Zealand” (CEDAW/C/NZL/CO/8, 20 July 2018) at 23–24; Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Sixth Periodic Report of Nepal” (CEDAW/C/NPL/CO/6, 9 November 2018) at 18–19; Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Combined Seventh and Eighth Periodic Reports of Germany”, n 306 at 24.

<sup>325</sup> Committee on the Rights of the Child, “Concluding Observations on the Combined Fourth to Fifth Periodic Reports of Chile”, n 328 at 49; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of France”, n 328 at 48; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of New Zealand”, n 328 at 25; Androgen Insensitivity Syndrome Support Group Australia et al, n 124. Committee on the Rights of the Child, “Concluding Observations on the Combined Fourth to Fifth Periodic Reports of Chile”, n 253 at 49; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of France”, n 253 at 48; Committee on the Rights of the Child, “Concluding Observations on the Fifth Periodic Report of New Zealand”, n 253 at 25.

<sup>326</sup> Committee on the Rights of the Child, “Concluding Observations on the Combined Second to Fourth Periodic Reports of Switzerland”, n 51 at 42–43; Committee on the Rights of the Child, “Concluding Observations on the Combined Fourth to Fifth Periodic Reports of Chile”, n 328 at 49; Committee on the Rights of the Child, “Concluding Observations on the Combined Third to Fourth Periodic Reports of Ireland”, n 308 at 40; Committee against Torture, “Concluding Observations on the Sixth Periodic Report of Austria” (CAT/C/AUT/CO/6, United Nations, Geneva, 27 January 2016) at 45; Committee against Torture, “Concluding Observations on the Combined Sixth and Seventh Periodic Report of Denmark” (CAT/C/DNK/CO/6-7, United Nations, Geneva, 4 February 2016) at 43; Committee against Torture, “Concluding Observations on the Fifth Periodic Report of China with Respect to the Hong Kong Special Administrative Region” (CAT/C/CHN-HKG/CO/5, United Nations, Geneva, 3 February 2016) at 29.

Regarding clinical classifications, multiple human rights institutions and experts have recommended that medical institutions review their policies and procedures on the pathologization of intersex characteristics.<sup>327</sup> Medical classifications that pathologize innate variations of sex characteristics should be reviewed and modified, to ensure effective enjoyment of the highest attainable standard of health and other human rights, including freedom from harmful practices.<sup>328</sup>

Medical institutions should formally end support for deferrable surgical and other procedures to modify the sex characteristics of children born with variations of sex characteristics. Research should meet ethical and legal standard for use of human research subjects, and respect the human rights of intersex persons.<sup>329</sup> Medical institutions should promote complete age-appropriate disclosure of information to children and youth, including details of independent peer support groups.

## Violence and discrimination

A joint statement by UN and regional experts urges States to take steps to prohibit discrimination on the basis of sex characteristics, including in education, healthcare, employment, sports, places of detention, and access to public services, and address such discrimination through relevant anti-discrimination initiatives.<sup>330</sup>

States should ensure that members of the judiciary, immigration officers, law enforcement, healthcare, education and other officials and personnel are trained to respect and provide equal treatment to intersex persons.<sup>331</sup>

General Comment 23 by the United Nations Committee on Economic, Social and Cultural Rights states that, like all workers, intersex workers have the right to equal opportunity in workplaces, including in hiring, promotion and termination.<sup>332</sup> Access to reasonable accommodations should be provided where necessary.

The UN special rapporteur on health has recommended that sporting authorities ensure that all individuals who wish to participate in sport are supported to do so, and should ensure that all individuals are able to play, without restriction, in line with their sex assigned at birth,<sup>333</sup> and subject only to reasonable, proportionate and non-arbitrary requirements to play in line with the gender with which they identify.<sup>334</sup>

Humanitarian protective mechanisms must acknowledge human rights violations including threats to life, torture, violence, stigmatization and discrimination faced by people born with variations of sex characteristics and their families, including intersex human rights defenders, and safeguard their right to refuge and asylum.

<sup>327</sup> Public statement of UN and regional human rights experts, n 2.

<sup>328</sup> Inter-American Commission on Human Rights, n 36; Council of Europe Commissioner for Human Rights, n 13; Cabral and Carpenter, n 208; Physicians for Human Rights, n 208.

<sup>329</sup> Human Rights Watch, n 65, pp 155–157; European Parliament, n 37 at 12–13.

<sup>330</sup> Public statement of UN and regional human rights experts, n 2.

<sup>331</sup> Public statement of UN and regional human rights experts, n 2.

<sup>332</sup> Committee on Economic, Social and Cultural Rights, “General Comment No. 23 (2016) on the Right to Just and Favourable Conditions of Work (Article 7 of the International Covenant on Economic, Social and Cultural Rights)” (E/C.12/GC/23, 27 April 2016) at 31–33.

<sup>333</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 55–57.

<sup>334</sup> Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 58–61.



## Legal recognition of sex and gender

International intersex community statements and the *Yogyakarta Principles plus 10* call for an end to the unnecessary registration of sex or gender in personal identification documents; for so long as such registration is required, all people should be able to access male, female, non-binary and alternative classifications.<sup>335</sup>

For so long as sex or gender classifications are used on personal identification documents, intersex organizations have called for registration of intersex children as male or female, and for sex/gender classifications to be amendable through simple administrative procedures, upon request.<sup>336</sup> Policy-makers should have regard to both the diversity of intersex people and the diversity of non-intersex people in making new sex/gender classifications available. Respect for self-determination requires respecting the right of intersex persons to be recognized as men and women, ensuring that new classifications are framed and named in a manner that does not adversely impact this population.<sup>337</sup>

## Access to justice

UN treaty bodies and a joint statement by UN and regional experts have repeatedly called on States to investigate human rights violations against intersex people, gather data on their incidence, hold those found guilty of perpetrating such violations accountable, and provide intersex people subjected to abuse with redress and compensation.<sup>338</sup> A UN interagency statement calls on States to recognize practices of coercive sterilization, and issue statements of regret or apology to victims as components of the right to remedy for these practices.<sup>339</sup> The *Yogyakarta Principles plus 10* calls on States to recognize the right of intersex people to truth, including the truth about their medical histories.<sup>340</sup>

Statutes of limitations should be amended to facilitate access to justice, and states should consider the establishment of compensation funds.<sup>341</sup>

## Addressing root causes

States must address root causes of human rights violations against intersex people- These include harmful social and cultural norms and stereotypes, including beliefs about attributes required of men and women. UN treaty bodies have called on States to educate and train medical and psychological professionals on the range of sexual and related biological and physical diversity and/or the human rights of intersex people.<sup>342</sup> The media should include the voices of intersex people and groups in newspaper, TV and radio coverage, and give an objective and balanced picture of intersex people and their human rights concerns.<sup>343</sup>

<sup>335</sup> Third international intersex forum, n 123. Yogyakarta Principles, n 23, p 9

<sup>336</sup> Third international intersex forum, n 123.

<sup>337</sup> Androgen Insensitivity Syndrome Support Group Australia et al, n 124.

<sup>338</sup> Public statement of UN and regional human rights experts, n 2.

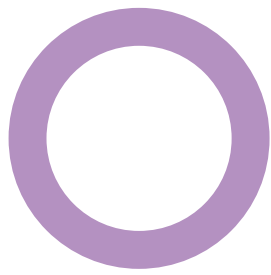
<sup>339</sup> World Health Organization and others, 86 supra, page 15

<sup>340</sup> Yogyakarta Principles, n 25, p 9.

<sup>341</sup> Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Combined Seventh and Eighth Periodic Reports of Germany”, n 306 at 24(e).

<sup>342</sup> Committee against Torture, “Concluding Observations on the Fifth Periodic Report of Germany”, n 309; Committee against Torture, “Concluding Observations on the Fifth Periodic Report of China”, n 309 at 56.

<sup>343</sup> Office of the High Commissioner for Human Rights, n 1 at 2.





**Annexes**

## EXPERT MEETING ON ENDING HUMAN RIGHTS VIOLATIONS AGAINST INTERSEX PERSONS

On 16 and 17 September 2015, the Office of the United Nations Human Rights Commissioner for Human Rights convened an expert group meeting in Geneva on ending human rights violations against intersex persons. The meeting brought together 35 experts from academia, civil society organizations, United Nations agencies and bodies, regional human rights mechanisms, national institutions

### Summary

In sessions on human rights norms, experts examined human rights standards and norms and their application to the situation of intersex people by UN, regional and national entities. Experts found that multiple and complementary human rights concepts and frameworks are applicable, including freedom from torture and cruel, degrading and inhuman treatment; violence; harmful practices including female genital mutilation; violations of bodily and mental integrity; autonomy; privacy; free and informed consent; and the right to non-discrimination. Experts identified multiple opportunities through each mechanism and institution to address violations, including in reporting, inquiries, recommendations, thematic reports, statements, letters, individual communications and complaints mechanisms. Participants identified multiple intersectionalities between the rights of intersex people, the rights of the child and the rights of women. The disability framework has powerful elements that resonate with the situation of intersex people and violations faced, though there are some nuances and different perspectives on its application.

Participants also looked at factors influencing harmful medical practice, including surgeries. These range from discriminatory stereotypes, taboos, prejudices and beliefs, and the vulnerable position of young children, to a generalized lack of a human rights approach and absence of safeguards training on respecting fundamental human rights in medical settings, and to nomenclature and medical classifications relating to intersex persons. Participants noted the continuous nature of harm – which can be lifelong, and have deep impact on trajectories over a lifetime, including physical and mental consequences, and also in terms of consequences for education and employment. The use of prenatal interventions and genetic selection was also noted.

In considering the implementation of human rights standards by different national stakeholders, experts examined legislation that protects physical integrity of minors, to anti-discrimination legislation and measures, policies to protect rights within the education system, and measures by national human rights institutions and by other national bodies, including ethics commissions.

Participants looked at work to increase public awareness and public debate, and recognition of violations, and to establish protocols for care and attention that protect the rights to physical integrity, dignity and autonomy of intersex children and adults.

In most places, progress to identify human rights violations has not yet translated into significant or widespread changes in practices in the treatment of intersex adults, children or infants. Indeed, some statistics show an increase in numbers of surgeries. Few court cases have provided remedies, while other court cases have facilitated violations.

All of this progress has been made possible by the work of intersex organizations, yet the meeting heard of the precarious and underfunded nature of this work, without which United Nations, regional and national human rights mechanisms could not address this issue.

## Proposals and priorities

### Legal guarantees and safeguards

Experts recommended the prohibition of medically-unnecessary non-consensual medical interventions. Legal safeguards were recommended to safeguard the right of children to be heard and protected and ensure that nobody, including parents of underage children, can consent to medically unnecessary cosmetic surgery and other unnecessary medical treatment. Experts recommended that civil and criminal frameworks recognize medically unnecessary non-consensual medical interventions as offences of violence against the person, such as grievous bodily harm. Statutes of limitations barring civil and criminal actions against perpetrators should be extended, as in other cases such as child sexual abuse and asbestosis.

UN, regional and national human rights mechanisms must address harm committed through medically unnecessary non-consensual intervention on intersex individuals under the respective provisions of each treaty and mandate.

Experts recommended capacity building for judicial systems to ensure that intersex people have effective access to justice. Victims of human rights violations are entitled to truth, justice, reparation, rehabilitation and other remedies. In some cases, access to treatment may be reparative.

Regarding birth registration systems, experts recommended that any new legal classifications (such as an X sex or gender marker) should be universally available, and not be specific to an intersex population.

### Standards of care and protection in medical settings

Experts recognized that there are objective medical needs associated with intersex bodies, and a need to distinguish bodily diversity from medical necessity (including distinguishing social, cultural and other related “psychosocial” rationales from urgent, physical rationales for medical intervention). Experts found similarities between intersex and other forms of bodily diversity, such as albinism.

Experts identified a need to depathologize intersex traits, and bodily diversity in general. It was recommended that the bodies of intersex persons (including reproductive and hormone producing capacities) must be valued in the same way as those capacities are valued in the bodies of non-intersex persons. Experts agreed that full, free and informed consent must be provided by affected individuals.

Experts identified a need to address a lack of clinical transparency, including secrecy attached to clinical data, practices and guidelines. Violations should be documented and monitored, including in health settings, to ensure that survivors are included and that intersex genital mutilations are adequately addressed.

Experts found it necessary to apply human rights principles to the implementation of medical protocols, and to ensure that children are recognized as subjects of rights, and not objects. It was recommended that human rights principles be applied to medical classification codes relating to intersex traits, including at the international level. Experts suggested that relevant bodies, including the World Health Organization, produce guidelines affirming a human rights approach to intersex issues in medical settings. The development of human rights-based training curricula for health professionals was also recommended.

Experts recommended that parents receive better information, support and counselling, including affirmative, independent peer support. Recognizing the existence of concerns regarding prenatal and genetic selection issues, as well as surgeries and hormonal interventions, experts recommended that standards of care start before birth though affirmative information during pregnancy, and through counselling, and access to peers. Experts agreed that greater transparency regarding clinical practices is required.

### Overcoming discrimination

Discrimination against intersex people must be prohibited, preferably as a standalone attribute (of sex characteristics), or, at a minimum, through a progressive interpretation of sex.

Experts identified a necessity to link anti-discrimination measures to legislation and medical classifications, and to support for intersex organizations. Experts noted that visibility requires standards, youth participation, role models, campaigns, language, and ownership. More data on employment is needed.

Experts recommended the creation of education guidelines for schools, healthcare and medical practitioners, including on training and bullying and possibly including human rights education in curricula. Diversity education should include bodily diversity, and intersex people need to be portrayed in schoolbooks in a positive manner that affirms human diversity.

### Research, data and implementation

Experts identified a need to address research issues, tackling issues of funding, a lack of research operating within human rights framework, and a lack of research with intersex leadership. Experts recognized issues of privacy, with examples of good (and poor) practices available, including pitfalls like adding intersex to a question on legal sex classifications.

Experts identified a need to disaggregate “LGBTI” data, with care to distinguish LGB and trans populations and issues from intersex populations and issues, while recognizing that there is overlap between these populations. Experts also identified a need to recognize commonalities with other populations, including people with disabilities, children’s rights, and the rights of women.

On all issues, experts identified a need to push implementation.

Participants included representatives of treaty bodies, special rapporteurs, the Office of the UN High Commissioner for Human Rights, World Health Organization and other UN institutions; regional human rights institutions; intersex, clinical, children’s rights and LGBT civil society organizations; national governments; and biomedical ethics institutions.

## UN AND REGIONAL EXPERTS STATEMENT, INTERSEX AWARENESS DAY, 26 OCTOBER 2016

The following statement was published on 24 October 2016, at <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

### Intersex Awareness Day – Wednesday 26 October

End violence and harmful medical practices on intersex children and adults, UN and regional experts urge.<sup>344</sup>

(24 October 2016) – Speaking ahead of Intersex Awareness Day on 26 October, a group of United Nations and international human rights experts is calling for an urgent end to human rights violations against intersex children and adults. They urge Governments to prohibit harmful medical practices on intersex children, including unnecessary surgery and treatment without their informed consent, and sterilization.

In countries around the world, intersex infants, children and adolescents are subjected to medically unnecessary surgeries, hormonal treatments and other procedures in an attempt to forcibly change their appearance to be in line with societal expectations about female and male bodies. When, as is frequently the case, these procedures are performed without the full, free and informed consent of the person concerned, they amount to violations of fundamental human rights.

Parents of children with intersex traits often face pressure to agree to such surgeries or treatments on their children. They are rarely informed about alternatives or about the potential negative consequences of the procedures, which are routinely performed despite a lack of medical indication, necessity or urgency. The rationale for these is frequently based on social prejudice, stigma associated with intersex bodies and administrative requirements to assign sex at the moment of birth registration.

Profound negative impacts of these often irreversible procedures have been reported, including permanent infertility, incontinence, loss of sexual sensation, causing life-long pain and severe psychological suffering, including depression and shame linked to attempts to hide and erase intersex traits. In many cases intersex people do not even have access to their own medical records or original birth certificates.

While awareness of the existence and rights of intersex people is slowly growing thanks to the work of intersex human rights defenders, only a handful of countries have taken concrete measures to uphold their rights and protect them from abuses.

States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers.

Intersex children and adults should be the only ones who decide whether they wish to modify the appearance of their own bodies – in the case of children, when they are old or mature enough to make an informed decision for themselves. They should have access to support as well as to medical services that respond to their specific health needs and that are based on non-discrimination, informed consent and respect for their fundamental rights. In this connection, it is critical to strengthen the integration of these human rights principles in standards and protocols issued by regulatory and professional bodies.

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<sup>344</sup> Public statement of UN and regional human rights experts, 2 supra

States should investigate human rights violations against intersex people, hold those found guilty of perpetrating such violations accountable and provide intersex people subjected to abuse with redress and compensation.

Ending these abuses will also require States to raise awareness of the rights of intersex people, to protect them from discrimination on ground of sex characteristics, including in access to health care, education, employment, sports and in obtaining official documents, as well as special protection when they are deprived of liberty. They should also combat the root causes of these violations such as harmful stereotypes, stigma and pathologization and provide training to health professionals and public officials, including legislators, the judiciary and policy-makers.

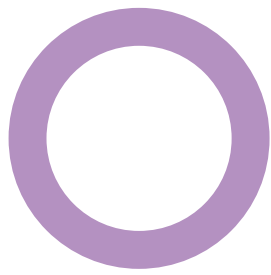


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