

PROTECTING INTERSEX PEOPLE IN EUROPE:

A TOOLKIT FOR LAW AND POLICYMAKERS

WITH DIGITAL APPENDIX
AND CHECKLIST

Dan Christian Ghattas

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Design & layout: Silja Pogule, www.siljapo.com

Printer: Corelio Printing, www.corelio.be



This publication has been produced with the financial support of the European Union's Rights, Equality and Citizenship Programme 2014-2020. The content of this publication is the sole responsibility of ILGA-Europe and OII Europe and can in no way be taken to reflect the views of the European Commission.



ACKNOWLEDGEMENTS

This toolkit would not have been possible without the strength and resilience of the European Intersex Community and the hard and continuous work of intersex activists all over Europe, nationally and on EU and CoE level. This toolkit would also not have been possible without the 2013 Malta Declaration, the 2014 the Riga Statement and the 2017 Vienna Statement. The work that the European and global intersex community put into creating these documents has been key for developing this toolkit. I want to thank my fellow intersex activists for all the conversations we had in the past ten years and for the continuous support we give each other.

Last but certainly not least I want to thank ILGA-Europe for their ongoing support. Starting in 2009 this collaboration has been substantial in opening doors on the European level, in bringing intersex people together and supporting intersex-led intersex work. My special thanks go to Katrin Hugendubel, Sophie Aujean and Cianán Russell for creating this toolkit with me.

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FOREWORD

Bodily autonomy – making one’s own informed decisions about one’s body and what happens to it – is a fundamental human right, repeatedly enshrined throughout myriad human rights instruments globally. Each of us holds this right individually. However, it is not equally protected nor enforced for everyone.

Across Europe, as well as much of the world, the right to bodily autonomy is regularly and grievously violated on the basis of sex characteristics. These violations are increasingly documented, and today, people with variations of sex characteristics are internationally recognised as victims of harmful medical practice and other human rights violations. From 2009 to the present, United Nations Treaty Bodies have called on Member States to stop human rights violations against intersex people 49 times. Of these, Council of Europe Member States have received 26 UN Treaty Body recommendations, 15 of these in the past two years alone.¹ The Yogyakarta Principles plus 10 call for protection of intersex people under the ground of “sex characteristics” and for ending human rights violations on intersex people, including protecting their right to bodily and mental integrity.²

Additionally, European bodies such as the Parliamentary Assembly of the Council of Europe and the European Parliament have both passed resolutions (2017 and 2019, respectively) calling for, among other protections and policies, the prohibition of sex-“normalising” surgery and other treatments practised on intersex children without their informed consent in national law among their respective Member States.³

On a national level, so far only Malta (2015) and Portugal (2018) have established protections for intersex people from violations of their bodily integrity and, together with Greece (2016), protection against discrimination on the ground of “sex characteristics”⁴. Additionally, courts have begun to recognise and adjudicate on the human rights violations faced by intersex people, both with respect to bodily integrity and gender markers.⁵

Protecting intersex people does not only ensure that people with variations of sex characteristics can enjoy their human rights. It also protects intersex people’s families, as these often equally suffer from the invisibility, shame and taboo surrounding intersex people, and face structural and verbal discrimination. Protecting intersex people and their families by creating an environment that cherishes diversity and works towards inclusion of all parts of the population has an effect on society as a whole. By living and working with people with different experiences and backgrounds we are able to learn and broaden our viewpoints, and diverse views make for better decisions.

1 A comprehensive and regularly updated list of UN recommendations concerning intersex human rights violations can be found on the OII Europe website <https://oiieurope.org/international-intersex-human-rights-movement-resource-list/>

2 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. As adopted on 10 November 2017, Geneva http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf

3 See the 2017 Parliamentary Assembly of the Council of Europe resolution here: <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-en.asp?FileID=24232&lang=en>. See the 2019 European Parliament resolution here: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2019-0128+0+DOC+XML+V0//EN&language=EN>

4 Finland revised its Gender Equality Act in 2015, which now also covers “gender features of the body” in order to protect intersex people.

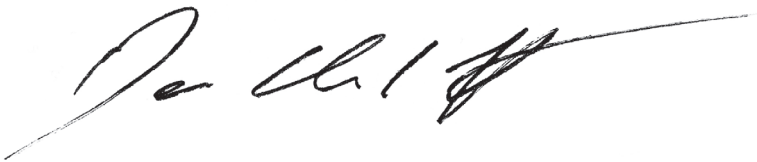
5 See Appendix.

Governments working against homophobia and transphobia should therefore also work against the human rights violations and discrimination intersex people face, as these are a direct result of the homophobia and transphobia that still prevails in society. However, as the human rights violations intersex people's face often differ significantly from those of LGBT people, they need to be protected on their own ground.

Protecting intersex people is not and cannot be treated as a matter of choice. It is instead inherent in the protection of the fundamental rights to which every human being is entitled.

We are delighted to present you with this toolkit and accompanying appendix and checklist so that we can work together to ensure the protection of all people on the basis of sex characteristics, including those most vulnerable to violations and abuses.

Dan Christian Ghattas



Evelyne Paradis



HOW TO USE THIS TOOLKIT

Protecting Intersex People in Europe:

A toolkit for law and policymakers comes in three parts:



This toolkit



Digital appendix



Digital checklist

These parts are intended to complement one another and to be used in concert with guidance and input from affected intersex people and communities. The toolkit describes the areas of life in which intersex people are most vulnerable to violations on the basis of their sex characteristics, and provides detailed guidance on what to do to minimise or eliminate these violations. The appendix serves to elaborate the existing legal landscape with references to and excerpts from statements, observations, and jurisprudence. Finally, the checklist is a simplified but complete list of the recommendations from the toolkit, designed as a quick reference guide for policymakers and public servants working to protect the rights of intersex people.

Throughout the main toolkit, references to specific legal instruments that exemplify the current best practice related to sex characteristics are highlighted. Additionally, central concepts such as *personal, prior, free, and fully-informed consent* and *expert-sensitive counselling* are explained. In some cases, common pitfalls in legal language that should be avoided are also detailed.

SOME BASIC FACTS

INTERSEX PEOPLE

Intersex individuals are born with sex characteristics (sexual anatomy, reproductive organs, hormonal structure and/or levels and/or chromosomal patterns) that do not fit the typical definition of male or female.

The term “intersex” is an umbrella term for the spectrum of variations of sex characteristics that naturally occur within the human species. The term intersex acknowledges the fact that physically, sex is a spectrum and that people with variations of sex characteristics other than male or female exist.

Sex characteristics are set out from birth, whether we are intersex or not. However, the fact that someone has an intersex body can become apparent at different times in

their life: at birth, during childhood, in puberty or even in adulthood. Depending on the specific life circumstances and the degree of taboo in their environment, a person might learn that they have an intersex body at a very early age or later in life. Some intersex people never find out at all.

MILLIONS OF INTERSEX PEOPLE EXIST

According to the United Nations at least 1.7% of the population, or, globally speaking, as of 2019, 131 million people have been born with intersex traits.⁶ This means that almost 1 person in 60 has a variation of sex characteristics and does not fit the typical medical and societal definition of male or female, and thus that at all ages they are at risk of being subjected to discrimination and other human rights violations on the basis of their variation of sex characteristics.

According to studies published in the Netherlands in 2014⁷ at least 1 in 200 people are at risk of being subjected to invasive surgeries and other medical interventions, like hormonal treatment, based on being diagnosed by medical professionals as having a “Disorder of Sex Development” (DSD⁸) or an “unspecified” diagnosis, such as “unspecified malformation

6 United Nations Office of the High Commissioner for Human Rights (2015): Fact Sheet. Intersex. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

7 The Netherlands Institute for Sociological Research (2014): Living with intersex/DSD. An exploratory study of the social situation of persons with intersex/DSD. Written by Jantine van Lisdonk. Appendix B Prevalence table for intersex/dsd. https://www.scp.nl/english/Publications/Publications_by_year/Publications_2014/Living_with_intersex_DSD

8 See: Dan Christian Ghattas (2015): Standing up for the human rights of intersex people – how can you help? Ed. by ILGA-Europe and OII Europe. Brussels, p. 20.

9 U. Klöppel (2016): Zur Aktualität kosmetischer Operationen ‚uneindeutiger‘ Genitalien im Kindesalter. Hg. von der Geschäftsstelle des Zentrums für transdisziplinäre Geschlechterstudien der Humboldt-Universität zu Berlin. Berlin https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/bulletin-texte/texte-42/kloepfel-2016_zur-aktualitaet-kosmetischer-genitaloperationen, p. 56-62.

10 See: Council of Europe Commissioner for Human Rights (2015): Human rights and intersex people. Issue Paper, p. 25 <https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original>; see also interview with Blaise Meyrat in the Documentary “Un Corps, Deux Sexes”, 20:50 – 21:49 <https://pages.rts.ch/emissions/36-9/4302693-un-corps-deux-sexes.html?anchor=4433097#4433097>; see also: Wiebren Tjalma (2017): The Blessings of Erectile Bodies. Journal of Pediatric and Adolescent Gynecology 30(4) (2017) : 514-515 [http://www.jpagonline.org/article/S1083-3188\(17\)30262-0/abstract](http://www.jpagonline.org/article/S1083-3188(17)30262-0/abstract). For more information on the danger of cosmetic, deferrable, and medically unnecessary interventions also see: J. Woweries (2012): Deutscher Ethikrat. Stellungnahme zur Situation von Menschen mit Intersexualität in Deutschland. Berlin. https://www.ethikrat.org/fileadmin/PDF-Dateien/Stellungnahmen_Sachverstaendige_Intersexualitaet/Woweries_-_Expertenbefragung.pdf

“Disorder of Sex Development (DSD)” is a medical umbrella term, which was introduced in 2006 by a Clinician Consensus Statement. Together with new categories of “syndromes”, it replaced the older medical terms. Some clinicians use DSD to stand for “differences of” or “diverse” sex development. However, in all its forms the term pathologises healthy variations of sex characteristics and refers to intersex sex characteristics as characteristics that are “deviant” from the norm of male and female bodies and thus need to be “disambiguated” or “fixed”. The term “DSD” does not align with human rights standards, and is only used in this document and the accompanying appendix in direct quotations or when referring to medical concepts that use the term.

of the male/female genitalia".⁹ Many of these interventions, especially but not limited to surgeries, are irreversible, deferrable, non-emergency interventions on healthy bodies¹⁰ and these interventions most often take place in infancy and childhood, without personal and fully informed consent.¹¹

11 See: page 16 and 17

12 S. Monroe, D. Crocetti, T. Yeaton-Lee, with F. Garland and M. Travis (2017): *Intersex, Variations of Sex Characteristics and DSD: The Need for Change*. University of Huddersfield, p. 19-20. <http://eprints.hud.ac.uk/id/eprint/33535/1/Intersex%20Variations%20of%20Sex%20Characteristics%20and%20DSD%20the%20Need%20for%20Change%20report%20Oct10.pdf>; Pressure by doctors to perform even late abortions of an (alleged) intersex foetus have been reported to OII Europe.

13 There are clear indications that foetal exposure to dexamethasone in preterm infants causes serious health issues in early adulthood, resulting in increased risks of heart disease and diabetes, see: Human rights and intersex people. Issue Paper published by the Council of Europe Commissioner for Human Rights (2015), p. 20. <https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper%282015%291&Language=lanEnglish&Ver=original>

14 A 2010 medical study found an increased frequency of symptoms attributable to hypercortisolism in the child-carrying person exposed to dexamethasone such as oedema and striae after a period of 1–5 years after the pregnancy, see: M. Merce Fernandez-Balsells, Kalpana Muthusamy, Galina Smushkin et. al. (2010): Prenatal dexamethasone use for the prevention of virilization in pregnancies at risk for classical congenital adrenal hyperplasia because of 21-hydroxylase (CYP21A2) deficiency: a systematic review and meta-analyses, in: *Clinical Endocrinology* (2010), 73, 436–444, here: 440.

15 Sweden is the only country that, since 1999, has a policy which, "restricts prenatal dexamethasone for CAH to women who agreed to participate in a continuous, prospective, long-term study of the intervention", see: A. Dreger et al (2012), p. 285. The long-term study showed impaired verbal working memory, correlating with the children's self-perception of difficulties in scholastic ability and an increased social anxiety, see: T. Hirvikoski, A. Nordenström, M. Ritzén, A. Wedell, S. Lajic (2012): Prenatal Dexamethasone Treatment of Children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint, in: *The Journal of Clinical Endocrinology & Metabolism* 2012 June; 97(6), p. 1881-3. For the 2016 version of the policy see also: Anna Nordenström, Martin Ritzén (2016): Vårdprogram för kongenital binjurebarkhyperplasi CAH (adrenogenitalt syndrom, AGS). Barnläkarföreningens sektion för endokrinologi och diabetes. http://endodiab.barnlakarforeningen.se/wp-content/uploads/sites/9/2015/02/VP_2016-CAH.pdf

16 Surya Monroe et al. (2017), p. 20-21; J. Woweries (2012), p. 7, 15-17, The Netherlands Institute for Social Research (2014), p. 44 and 76.

17 See: Amnesty International (2017): First, do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany, p. 32 <https://www.amnesty.org/download/Documents/EUR0160862017ENGLISH.PDF>

18 PACE (2017): Report, Article 41

19 J. Woweries (2012), p. 7-9; N.S. Crouch, C.L. Minto, L.M. Laio, C.R. Woodhouse, S.M. Creighton (2004): Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study. *BJU Int.* 2004 Jan; 93(1):135-8.

18 PACE (2017): Report, Article 41

19 J. Woweries (2012), p. 7-9; N.S. Crouch, C.L. Minto, L.M. Laio, C.R. Woodhouse, S.M. Creighton (2004): Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study. *BJU Int.* 2004 Jan; 93(1):135-8.

20 See: Netzwerk Intersexualität (2008): Erste Ergebnisse der Klinischen Evaluationsstudie im Netzwerk Störungen der Geschlechtsentwicklung/ Intersexualität in Deutschland, Österreich und Schweiz Januar 2005 bis Dezember 2007; a comprehensive summary can be found in J. Woweries (2012), p. 16-17.

PRE-NATAL INTERVENTIONS

Because being intersex in itself is still seen as a disorder, when pre-implantation diagnosis or pre-natal screening show a risk of variations of sex characteristics in embryos and foetuses, both may be prevented from further developing. In the UK for example, embryos determined to have intersex variations are on the termination list for pre-implantation and several parents from different countries in the Council of Europe region have reported to OII Europe that they were under huge pressure from doctors to abort their intersex child.¹²

In other cases, prenatal treatment with high-risk off-label use medication (dexamethasone) is prescribed. Dexamethasone has proven to be at high risk of long-term negative effects on the child's physical health and cognitive capacity,¹³ and also impacts the health of the parent carrying the child.¹⁴ However, to date only Sweden has discontinued the use of the drug for foetal treatment.¹⁵

MEDICAL INTERVENTIONS ON HEALTHY BODIES

Like anybody, intersex people can face health issues. However, in addition, many intersex people face health issues that they acquire as a result of human rights violations. After birth, as children, adolescents and adults, intersex people face violations of their physical integrity, including medical interventions without personal, prior, persistent and fully informed consent. This can cause psychological trauma.¹⁶ Resulting physical impairments include, but are not limited to, painful scar-tissue¹⁷ and lack of (general and/or erotic) sensation,¹⁸ osteoporosis and osteopenia already at a very young age after the removal of gonadal tissue, urinary impairments as a result of interventions on the urethral tract, including from so-called "hypospadias repair" and other genital surgeries, and infections.¹⁹

Intersex children face the risk of a disturbed family life due to medicalisation, which can include extended and/or multiple hospitalisations, multiple surgeries and/or procedures, invasive testing, administration of medication including hormone therapies, and clinical research practices.²⁰ They are also at risk of not being able to develop their full potential and of dropping out of school due to the effects of medicalisation and related

trauma, such as post-traumatic stress disorder, chronic illness or disability.²¹

INTERSEX GENITAL MUTILATION (IGM)

Intersex Genital Mutilation (IGM) is an intervention on a healthy intersex body. It is performed when, according to societal and medical notions, a person's external genitals do not look "normal" enough to pass as "male" or "female" genitals.

Performing IGM was not always the default practice. Before the middle of the twentieth century, as a 2016 article of three General Surgeons of the United States points out, "most children born with genitalia that did not fit the male-female

binary norm were not subjected to surgery". Beginning with the 1950s, however, in "an era when pressure to conform to social norms was often unyielding", the standard treatment protocol changed. Infants born with atypical genitalia were "increasingly subjected to surgical procedures such as clitoral reduction, vaginoplasty, gonadectomy, and hypospadias repair, primarily to 'normalize' gendered appearance, not to improve function".²²

MEDICAL INTERVENTIONS ON INTERSEX INFANTS AND CHILDREN ARE STILL THE RULE

Surgeries and medical interventions on intersex infants and children are still common.²³ According to a 2015 survey published by the EU Fundamental Rights Agency, so-called sex-"normalising" surgeries on intersex infants and children are carried out in at least 21 of the EU Member States.²⁴ Currently, only Malta and, with certain nuances, Portugal prohibit these harmful medical interventions. In 2017, the Parliamentary Assembly of the Council of Europe confirmed in its resolution *Promoting the human rights of and eliminating discrimination against intersex people* that it considers these kind of surgeries to be "serious breaches of physical integrity" and highlighted that they are performed "despite the fact that there is no evidence to support the long-term success of such treatments, no immediate danger to health and no genuine therapeutic purpose for the treatment".²⁵ In 2019, the European Parliament emphasised in its resolution *The rights of intersex people* that it "strongly condemns sex-normalising treatments and surgery" and that it encourages "Member States to adopt similar legislation as soon as possible."²⁶

Unfortunately, the international medical guidance and systems do not yet fully align with international human rights standards.²⁷ This is informed by much of the content covered in this introduction, including the biased and stereotyped cultural views that people, including doctors, continue to hold.

Fortunately, some clinicians have become more reluctant to perform certain surgeries at a very early age. This has been especially the case with hormone producing gonads, e.g. intraabdominal testes on infants, which were previously removed by default on the basis of an unverified cancer risk.²⁸ Some clinicians now opt for not operating and, instead, monitoring this tissue.²⁹

21 See also 2.2.2 Education.

22 M. J. Elders, David Satcher, R. Carmona (2017): Re-Thinking Genital Surgeries on Intersex Infants, p. 1. <https://www.palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf>. For a short summary of the development of the current practices see Amnesty International (2017), p. 17-19. A comprehensive historical overview is to be found in U. Klöppel (2010): *XXOXY ungelöst. Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zu Intersexualität*. Bielefeld: Transcript Verlag.

23 See: E. Feder, A. Dreger (2016): Still ignoring human rights in intersex care", *Journal of Pediatric Urology*, 4th of June 2016, p. 1 [http://www.jpuro.com/article/S1477-5131\(16\)30099-7/](http://www.jpuro.com/article/S1477-5131(16)30099-7/)

24 See: European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 1 <http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

25 Parliamentary Assembly of the Council of Europe (PACE) (2017): Resolution 2191 (2017). Promoting the human rights of and eliminating discrimination against intersex people. Article 2 <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232&lang=en>

26 European Parliament: Resolution 2018/2878(RSP). The rights of intersex people, Article 2 <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2019-0128+0+DOC+XML+V0//EN&language=EN>

27 The revised International Classification of Diseases, ICD-11, for example, still reaffirms the concept of "disorder" and "malformation" for healthy bodies that do not conform to social norms of male and female, hence perpetuating stigma and pathologisation. See: GATE (2017): Submission by GATE to the World Health Organization: Intersex codes in the International Classification of Diseases (ICD) 11 Beta Draft <https://transactivists.org/wp-content/uploads/2017/06/GATE-ICD-intersex-submission.pdf>; see also: GATE (2015): Intersex Issues in the International Classification of Diseases: a revision, p. 3-4 <https://globaltransaction.files.wordpress.com/2015/10/intersex-issues-in-the-icd.pdf>

28 See, e.g.: S2k-Leitlinie Varianten der Geschlechtsentwicklung 2016, p. 5; see also: 2007 AWMF-Leitlinien (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften) der Gesellschaft für Kinderheilkunde und Jugendmedizin: Störungen der Geschlechtsentwicklung (DSD); see also J. Woweries (2012), p. 12.

However, this thinking is mostly reserved for those children whose sex, according to medical professionals, is not determinable as male or female.³⁰ Other intersex children, whose sex is considered determinable,³¹ are still considered to “benefit” from early invasive cosmetic treatment.³² It is crucial to understand, however, that the surgeries performed on those children are the same deeply invasive interventions,³³ which reportedly lead to scar tissue, loss of sensation, multiple follow up surgeries, problems with hormonal balance, trauma and other physical and psychological impairments.

FGM AND IGM – COMMONALITIES TO CONSIDER

While many legal contexts do not explicitly address intersex genital mutilation (IGM), female genital mutilation (FGM) is widely addressed in the European legal landscape.³⁴ This legal differentiation, though, is largely arbitrary, and based in the same cultural assumptions and stereotypes that threaten the rights of intersex people to begin with.

QUICK GUIDE TO FGM AND IGM COMMONALITIES

FGM and IGM share many common characteristics, but vastly different explicit legal standards are in place. Here are explanations of some of the commonalities:

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

Motivated by beliefs about what is considered acceptable sexual behaviour; in the case of intersex people, the ultimate goal of those performing IGM is to allow for penetrative intercourse of the future adult and for an alleged ability to procreate. Neither the impossibility to foresee the future intersex adult’s gender identity, sexual orientation or sexual preference, nor the fact that the capacity for penetrative intercourse may be less important for the intersex adult than unharmed genitalia are taken into account.

Motivated by the notion that parts that are not considered female (or male) enough should be removed; in the case of intersex people this includes interventions on infants and children such as clitoris reduction/recession, removing the labia, moving the opening of the urethra to the tip of the penis, to name but a few.

Impactful on the person’s life and health; in the case of intersex people this includes impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, increased sexual anxieties, problems with desire, infertility issues and lifelong trauma, including feelings of child abuse and sexual abuse.

29 Amnesty International (2017), p. 28; see also: Creighton, S.M., L. Michala, I. Mushtaq, and M. Yaron (2014): Childhood surgery for ambiguous genitalia: Glimpses of practice changes or more of the same?, in: *Psychology and Sexuality* 5(1): 34–43; see also for mixed developments in the U.S.: Human Rights Watch, InterACT (2017): *A Changing Paradigm. US Medical Provider Discomfort with Intersex Care Practices*, p. 22-27 <https://www.hrw.org/report/2017/10/26/changing-paradigm/us-medical-provider-discomfort-intersex-care-practices>

30 E.g. intersex individuals diagnosed with CAIS (Complete Androgen Insensitivity Syndrome).

31 E.g. intersex children diagnosed with CAH (Congenital Adrenal Hyperplasia) and XX chromosomes

32 A 2016 German study on the number of genital surgeries performed in Germany on intersex children up to the age of ten found that the numbers of interventions stayed the same between 2005 and 2014, but that the underlying diagnoses had changed: the relative frequency of “classic” intersex diagnoses such as “pseudo-hermaphroditism” had decreased, while the frequency of unspecified diagnoses, like “unspecified malformation of the female/male genitalia” remained constant or even increased. U. Klöppel (2016), p. 34; OII Europe member organisations have found this diagnostic shift, through their peer and parent counselling, to be happening in their countries as well. A 2019 follow up study showed that the number of interventions did not go down in the subsequent years, see: J. Hoenes, E. Januschke, U. Klöppel (2019): Häufigkeit normangleichender Operationen „uneindeutiger“ Genitalien im Kindesalter. Follow Up-Studie. Bochum. <https://omp.ub.rub.de/index.php/RUB/catalog/view/113/99/604-2>.

33 See: U. Klöppel (2016), p. 4-5.

34 For examples, see: https://ec.europa.eu/info/policies/justice-and-fundamental-rights/gender-equality/gender-based-violence/eliminating-female-genital-mutilation_en

Social pressure to conform to gender roles and stereotypes about male and female bodies is common ground shared by FGM and IGM. Like FGM, intersex genital mutilation is carried out for cultural reasons, which, in the case of IGM, are based on the prevailing notion of the binary of human sexes.³⁵ In a binary society “being human” is strongly connected – in everyday life as well as legally – to “being male” or “being female”, to being a “man” or a “woman”. Within that cultural construct, the birth of an intersex child has been treated since the 1950s as a “psycho-social emergency” that needs to be “fixed” by medical means, in order to “prevent parental distress”, to “protect” the child from experiencing discrimination as a result of their “ambiguous” genitalia and/or to prevent “lesbianism”, “tomboyism” or a “gender identity disorder” in the child;³⁶ and while doing so, the intersex individual’s human rights to bodily autonomy and bodily integrity have been violated, often egregiously.

In 2014, the 24th Conference of Equality and Women Ministers and Senators of the German Länder (GFMK) pointed to the similarities between IGM and FGM and called for implementing a corresponding standard of protection for intersex children. The GFMK pointed out that “family law already prohibits guardians from consenting to the sterilisation of a child (§ 1631c BGB)” and that, “in the case of girls, parents cannot give effective consent to the removal or circumcision of the clitoris, as this is punishable as female genital mutilation (§ 226a StGB)”, but that intersex minors were “in fact often denied this protection by carrying out procedures that have a sterilizing effect or that alter the genitals of intersexual minors without their consent and without compelling medical indication”.³⁹

35 United Nations Office of the High Commissioner for Human Rights (2015), p. 1.

36 M.J. Elders et. al. (2017), p. 1; U. Klöppel (2010), p. 314-318, 479.

37 See: M. J. Elders et. al. (2017), p. 2.; see also: S2k-Leitlinie Varianten der Geschlechtsentwicklung 2016. Leitlinie der der Deutschen Gesellschaft für Urologie (DGU) e.V., der Deutschen Gesellschaft für Kinderchirurgie (DGKCH) e.V., der Deutschen Gesellschaft für Kinderendokrinologie und -diabetologie (DGKED) e.V., p. 5 https://www.awmf.org/uploads/tx_szleitlinien/174-001l_S2k_Geschlechtsentwicklung-Varianten_2016-08_01.pdf

38 See J. Woweries (2012), p. 7.

39 See: 24. Konferenz der Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GFMK) (2014): Tagesordnungspunkt 8.1: Rechte intersexueller Menschen wahren und Diskriminierung beenden – insbesondere Schutz der körperlichen Unversehrtheit https://www.gleichstellungsministerkonferenz.de/documents/2014_10_13_beschluesse_gesamt_extern_2_1510227377.pdf (translated from German by the author)

40 http://www.npwj.org/sites/default/files/ressources/Declaration%20in%20EN_rev.pdf

41 E. Feder, A. Dreger (2016): p. 1.

In 2017, the BanFGM Conference on the worldwide ban on female genital mutilation decided to include victims of intersex genital mutilation in their supporting structure through the provision of essential services (medical, psychological and legal).⁴⁰

SOCIAL NORMS CAUSE HUMAN RIGHTS VIOLATIONS

Most societies are structured along the supposed binary of sexes. These societal systems make those who do not fit into the male-female binary especially vulnerable to violations of their bodily integrity, discrimination, harassment, violence in medical settings, or bullying at school and in their job life.

The human rights violations intersex people face are rooted in what bioethicist George Annas has called “monster ethics”, as pointed to by a surgery-critical article published in 2016 in the Journal of Pediatric Urology:

“Babies with atypical sex are not [considered] yet fully human, and so not entitled to human rights. Surgeons make them human by making them recognizably male or female, and only then may they be regarded as entitled to the sexual and medical rights and protections guaranteed to everyone else by current ethical guidelines and laws.”⁴¹

INTERSEX PEOPLE ARE DISCRIMINATED AGAINST

At every age, intersex people can face stigma, structural discrimination, harassment, lack of adequate medical care, lack of access to needed medication, lack of access to justice, and the invisibility of their bodies in our society.⁴² Intersex people often face employment discrimination based on their appearance or gender expression. Due to hospitalisation or trauma-related mental health problems, intersex people may need to take time off. Gaps in their education or employment history might be difficult to explain to employers. There is a reportedly higher risk of poverty due to lack of education as a result of pathologisation and related trauma.

INTERSEXPHOBIA EXISTS

Intersexphobia, or interphobia, can be defined as a range of negative attitudes (e.g. emotional disgust, fear, violence,

anger, or discomfort) felt or expressed towards people whose sex characteristics do not conform with society's expectations of how the sex characteristics of a person, understood only as male or female, should look. Very often the same range of negative attitudes is also expressed towards the biological fact that sex is a spectrum, and that, therefore, variations of sex characteristics other than the male or female variations exist. The human rights violations intersex people face as a result of societal intersexphobia include, among others, pathologisation and genital mutilation (IGM).

42 Parliamentary Assembly of the Council of Europe (PACE) (2017): Resolution 2191 (2017). Promoting the human rights of and eliminating discrimination against intersex people. Doc. 14404 Report, Part C Articles 29, 49, 61, 68, 69 <https://bit.ly/2gfohnV>; Commissioner for Human Rights of the Council of Europe (2015), p. 29-51; see also: Swiss National Advisory Commission on Biomedical Ethics (2012): On the management of differences of sex development. Ethical issues relating to "intersexuality". Opinion No. 20/2012, p. 13-14 http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf; see also: Conseil d'Etat (2018): Revision de la loi bioéthique: quelles options pour demain? 2.4. Les enfants dits « intersexes » : la prise en charge médicale des enfants présentant des variations du développement génital, p. 132 https://www.dalloz-actualite.fr/sites/dalloz-actualite.fr/files/resources/2018/07/conseil_detat_sre_etude_pm_bioethique.pdf; Deutscher Ethikrat (2012): Intersexualität. Stellungnahme, p. 82, S. 49, 56-59, 82, 154-155, 165 https://www.ethikrat.org/fileadmin/Publikationen/Stellungnahmen/deutsch/DER_StnIntersex_Deu_Online.pdf; see also: S. Monroe et al. (2017), p. 21; The Netherlands Institute for Social Research (2014), p. 48-50; Dan Christian Ghattas (2013): Human Rights Between the Sexes. A preliminary study on the life situation of inter* individual. Ed. by the Heinrich Böll Foundation. Berlin, p. 22, 23 and 27 https://www.boell.de/sites/default/files/endf_human_rights_between_the_sexes.pdf

43 From the text of the 2017 Maltese law, "expert-sensitive" refers simultaneously to explicit expertise coupled with sensitivity through tailored education programmes.

44 See: A. Krämer, K. Sabisch (2017), p. 31-34; Amnesty International (2017), p. 24, 39-40.

45 Even parents who are medical practitioners themselves have reportedly not been able to follow the explanations given by the doctor in charge, see: A. Krämer, K. Sabisch (2017), p. 32.

46 A. Krämer, K. Sabisch (2017), p. 33; Amnesty International (2017), p. 23; Commissioner for Human Rights of the Council of Europe (2015), p. 23.

47 PACE (2017): Resolution 2191 (2017), Article 3.

48 Commissioner for Human Rights of the Council of Europe (2015), p. 37.

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

50 A. Krämer, K. Sabisch (2017), p. 33.

51 Amnesty International (2017), p. 26.

52 See: Bundesministerium für Familie, Senioren, Frauen und Jugend (2016.b), p. 14.

53 A. Krämer, K. Sabisch (2017), p. 28.

54 In order to reassure parents of an intersex child and give them low-threshold access to needed information, OII Europe has joined forces with IGLYO and EPA to create a parent's guide, see: OII Europe, IGLYO, EPA (2018): Supporting your intersex child <https://oii-europe.org/parents-guide/>

PROTECTION STARTS WITH SUPPORTING PARENTS

Having an intersex child is completely natural. However, this is not the information provided to many parents of intersex children. When a child is identified as intersex at birth, parents usually have to cope with the news without any independent expert-sensitive⁴³ psycho-social counselling.⁴⁴

Very often, parents are immediately confronted with complex medical explanations about the so-called "condition" of their new-born child.⁴⁵ These are often further accompanied by offers or even the pressure to proceed with medical treatments that will allegedly "fix" the child. The information delivered by medical practitioners often lacks clarity about the actual health status of the child.⁴⁶ As the 2017 PACE Resolution 2191 points out, this kind of medicalised counselling puts parents under pressure to make "life-changing decisions on behalf of their child, without having a full and genuine understanding of the long-term consequences for their children".⁴⁷

In everyday life, parents often feel lost about how to communicate to family members, friends or just people they meet on the street that the question "Is it a boy or a girl?" does not fit their child.⁴⁸ Of the parents participating in a 2015 German survey, 83% felt that there was a severe lack of counselling on how to handle the fact of having an intersex child within their social environment, i.e. in everyday life, with neighbours, teachers, or in kindergarten. 72% felt the need to be supported in how to speak about being intersex within their families.⁴⁹ Taboo and shame about variations of sex characteristics, still prevailing in society, can lead parents to believe that their child will not be able to lead a happy and fulfilled personal and family life in the future.⁵⁰ Their own beliefs about sex, gender and gender roles can also create feelings of guilt and shame.⁵¹ However, 80% of the participating parents wanted to acknowledge their child's physical sex development as it is, and wished for counselling on that matter.⁵²

The social pressure parents face, traumatising experiences in medical settings, lack of support in understanding the medicalised information they get from doctors, and lengthy examinations of their new-born child, can put parents at risk of high levels of stress, including the risk of developing post-traumatic stress syndromes.⁵³ Therefore, parents clearly need support as well.⁵⁴

PROTECTION: Putting an end to human rights violations of intersex people

PROTECTING INTERSEX PEOPLE AGAINST VIOLATIONS OF THEIR RIGHT TO BODILY INTEGRITY

After birth, as children, adolescents and adults, many intersex people face violations of their physical integrity, including medical interventions without personal, prior, persistent and fully informed consent. These interventions reportedly cause severe physical impairments, ranging from painful scar-tissue or lack of sensation to osteoporosis and urethral issues, as well as psychological trauma. In regards to psychological trauma, evidence and research have shown that infants and very young children already do experience physical as well as psychological trauma and that it impacts them later in life.⁵⁵

Invasive, irreversible and non-emergency medical interventions should only be performed on a mature individual who explicitly wishes for these interventions and has given their personal and fully informed consent. Infants

and children are future adults who will develop gender identities and sexual orientations specific to them, will take their own decisions, and will make their own choices in regards to their personal and professional lives. An intact body, which allows for a multiplicity of choices in the future adult's life, is key to ensuring the right to self-determination of not only the child but also the future adult.

*OII Europe and ILGA-Europe recommend the creation of a law that protects a person from any non-emergency interventions on the person's sex characteristics until the person is mature enough to express, if they want, their wish for surgical or other medical intervention and provide informed consent. **Such legislation is the only way to stop the violation of the bodily integrity of intersex people and ensure their right to self-determination.***

55 M.J. Elders et. al. (2017), p. 2; S. Monroe et. al. (2017), p. 2; GATE (2015), p. 4; The Netherlands Institute for Social Research (2014), p. 33-37; J. Woweries (2012), p. 7-8. See also: PACE (2017): Report. Part C Articles 25, 26; Commissioner for Human Rights of the Council of Europe (2015), p. 14; United Nations Office of the High Commissioner for Human Rights (2014), p. 1; Swiss National Advisory Commission on Biomedical Ethics (2012), p. 13. A study conducted for the German Ethic Counsel found that 25% of the intersex people participating in the study had been seeking psychological help and that this occurred twice as often after than before a medical intervention, see: Deutscher Ethikrat (2012): p. 71.

In its 2017 *Resolution Promoting the human rights of and eliminating discrimination against intersex people*, the Parliamentary Assembly of the Council of Europe has called on Member States to “prohibit medically unnecessary sex-‘normalising’ surgery, sterilisation and other treatments practised on intersex children without their informed consent”; and to ensure “that, except in cases where the life of the child is at immediate risk, any treatment that seeks to

alter the sex characteristics of the child, including their gonads, genitals or internal sex organs, is deferred until such time as the child is able to participate in the decision, based on the right to self-determination and on the principle of free and informed consent⁵⁶.

CURRENT BEST PRACTICES

The Maltese Gender Identity, *Gender Expression and Sex Characteristics Act*⁵⁷ is still to be considered a best practice example on how to put these recommendations into law. The Act, among other measures,

- provides clear and human rights-based definitions of terminology (e.g. sex characteristics).
- makes a distinction between treatments that address an actual health need of a person, and surgeries and other medical interventions that are cosmetic, deferrable and performed for social reasons.
- prohibits any sex-“normalising”, sex-“assigning” or sex-altering treatment and/or surgical intervention on the sex characteristics of a minor that could be deferred until a time when the minor is able to make their own decision and provide informed consent.
- allows for surgery and other medical treatment on an infant’s or child’s sex characteristics in cases where the infant’s or child’s life is at immediate risk, provided that any medical intervention which is driven by social factors without the consent of the minor is a violation of the law.
- provides for legal consequences in case the law is breached.

- allows a mature minor to seek a treatment aiming to alter their sex characteristics, which shall be conducted if the minor gives informed consent.
- establishes the right to expert-sensitive and individually tailored, life-long psychological and psycho-social support for intersex individuals, their parents and their families.

PERSONAL, PRIOR, FREE AND FULLY INFORMED CONSENT IS KEY

The 2013 Parliamentary Assembly of the Council of Europe (PACE) *Resolution 1945: Putting an end to coerced sterilisations and castrations* defines fully informed consent as follows:

Fully informed consent:

- includes, that the person has been informed comprehensively and without bias about all possible options.
- is not given if the person agrees to an intervention without having been fully informed, and
- is not given if the person has been pressured or (emotionally) coerced into agreeing. Especially in health settings this includes all pressure that diminishes a patient’s autonomy, as well as non-addressed power imbalances in the patient–care provider relationship “which may impede the exercise of free decision making, for example by those who are not accustomed to challenging people in positions of authority”.⁵⁸

56 PACE Resolution 2191 (2017), Article 7.1.1 and 7.1.2.

57 ACT XI of 2015, as amended by Acts XX of 2015 and LVI of 2016 and XIII of 2018 <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>

58 PACE Resolution 1945 (2013): Putting an end to coerced sterilisations and castrations, Article 2 <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=19984&lang=en>

In regards to intersex individuals, we often speak of the necessity of personal, prior, free and fully informed consent.

“Personal” emphasises that only the intersex individual themselves is able to consent to such an intervention and that parent or care-taker or medical professional cannot substitute for the intersex person’s consent.

“Prior” refers to the timing of the consent, such that specific consent must take place before the intervention for which it is sought. For example, there is a common experience such that although parental or individual consent was given for a specific intervention, additional surgeries or interventions were simultaneously performed without consent, then followed by an attempt to gather consent after the fact for the additional interventions.

“Free” refers to the impact of power dynamics that may diminish a person’s autonomy and pressure that may impact the individual’s ability to consent. For example, reportedly pressure from healthcare providers has led intersex adults to consent to an intervention that they did not want just to finally have that pressure cease.

“Fully informed” emphasises the need for the provision of the full variety of information and opinions on an intervention, including de-medicalised information.

WHAT TO DO?

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

- **prohibit** medical practitioners and other professionals from conducting any irreversible, non-emergency sex-“normalising”, sex-“assigning” or sex-altering surgical or other interventions on a person’s sex characteristics unless the intersex person has provided personal, free and fully informed consent.
- establish adequate **legal sanctions** conducting any irreversible, non-emergency sex-“normalising”, sex-“assigning” or sex-altering surgical or other interventions which can be deferred until the intersex person is mature enough to provide informed consent.
- establish an **independent working group**, composed in equal parts of human rights experts, intersex peer experts, psycho-social professionals and medical experts, to review and revise current treatment protocols to bring them in line with current medical best practice and human rights standards within a limited period of time laid down in the law.
- establish the right to expert-sensitive and individually tailored psycho-social **counselling** and support for all concerned individuals and their families, from the time of diagnosis or self-referral, for as long as necessary.
- extend the **retention period for medical records** of surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or hormonal set-up, including consultation minutes, to a minimum of 40 years in order to allow intersex people access to their medical records at a mature age.
- extend the **statutes of limitations** for surgical and/or other interventions that aim to alter the genitals, gonads, reproductive organs or hormonal set-up of a person to at least 20 years, and suspend them until the minimum age of 21 of the person concerned.
- allow for surgical and/or other reversible and irreversible interventions to be conducted on a **mature minor’s** sex characteristics, if explicitly wished for by the mature minor and provided the mature minor gives personal and fully informed consent.

Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act

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

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

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

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

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

European Parliament (2019): Intersex Resolution

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

- ♦ in the case of a mature minor seeking treatment to alter their sex characteristics, establish the presence of an **independent third party**, who is neither a parent nor legal guardian nor a medical professional treating the minor; the independent party shall take part in the process, in order to guarantee that the consent of the minor is giving freely, and with fully informed consent.

- establish the **legal obligation** for medical professionals in regards to all surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or any hormonal set-up:

- ♦ to **inform** the mature individual comprehensively about the treatment, including other possible medical options and details about risks and possible long-term consequences and effects, based on up-to-date medical information;

- ♦ to **provide detailed minutes** of the consultation, including all of the above information, which is provided to the patient and in addition, in case of a minor, to their parent(s) or legal guardian(s).

- **end the coverage of intersex genital mutilation** by the public and private health systems.

- ensure that regulations and practices in public and private sectors, e.g. in international competitive sport,⁵⁹

do not bypass national protection and anti-discrimination legislation and provisions.

59 In April 2018, IAAF introduced “Eligibility Regulations for Female Classification (Athlete with Differences of Sex Development)” for international events, including 400m, hurdles races, 800m, 1500m, one mile races and combined events over the same distances (‘Restricted Events’). All intersex women whose testosterone level exceeds 5 nmol/L will be forced to take drugs that suppress their natural testosterone level in order to be eligible; see: <https://www.iaaf.org/news/press-release/eligibility-regulations-for-female-classifica>. However, as the Office of the United Nations High Commissioner for Human Rights (OHCHR) has pointed out, “being intersex of itself does not entail better performance, whereas other physical variations that do affect performance [...] are not subjected to such scrutiny and restrictions”; see: United Nations (2015): Free & Equal. Fact Sheet Intersex, p. 2; https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf. The 2019 UN Human Rights Council resolution on the “Elimination of discrimination against women and girls in sport” notes with concern that the IAAF regulation “may not be compatible with international human rights norms and standards” and called upon States to “ensure that sporting associations and bodies implement policies and practices in accordance with international human rights norms and standards, and refrain from developing and enforcing policies and practices that force, coerce or otherwise pressure women and girl athletes into undergoing unnecessary, humiliating and harmful medical procedures in order to participate in women’s events in competitive sports”; see: A/HRC/40/L.10/Rev.1, p.2 and appendix for more details.

COMMON PITFALLS TO AVOID

In addition to highlighting best practices, it is also important to note when well-intentioned attempts at protecting intersex people have fallen short or created unexpected problems.

WHICH TERMINOLOGY CAN BE CHALLENGING IN REGARDS TO IMPLEMENTATION OF A LAW?

Some terminology, which may seem to be an obvious choice from the perspective of self-determination and trust in the existing healthcare system has proven to be rather problematic when it comes to ensuring effective protection of intersex people's bodily integrity. OII Europe and ILGA-Europe therefore recommend policy-makers to **not use** the following terms in order to avoid ambiguity and legal loopholes.

In cases where these terms have been included in legislation, specific caution should be paid to implementation in order to prevent undesired circumventions of the law and guarantee intersex people's access to justice.

“medically necessary” or “medically indicated”

Since the 1950s, medical interventions and treatments on intersex children have been considered to be “medically necessary” and “medically indicated” and have been covered by public and private health insurances.

Decisions as to whether a certain treatment is medically necessary mainly lie with the doctor as the medical expert.

However, there are few and relatively rare cases in which the intersex infant's life is at risk and immediate treatment is actually indicated/necessary.⁶⁰ All other interventions, despite being deferrable, are presented as equally “medically necessary”, based on a misconception of what constitutes a societal problem and what is medically indicated. Evidence shows that instead of increasing an intersex individual's health, interventions “too often lead to the opposite result”.⁶¹ Despite this contrary evidence as well as a lack of positive evidence, many medical guidelines still recommend invasive surgeries and other invasive medical treatments on intersex individuals as a medical necessity,⁶² thus reinforcing the medical indication as determined by doctors.

Any law aiming at preventing harmful practices performed on intersex people in medical settings should not use medical concepts like “medically indicated” and “medically necessary” as indicators of the lawfulness of an intervention, as the current definition of these concepts is flawed and continues to carry the high risk of depriving intersex individuals of the enjoyment of their human rights. If these terms are used, they should be clearly defined as referring to actual physical health needs⁶³ and life-saving treatments.

“manifestation of a child's gender identity”

There are two significant issues with this language. Firstly, it reinforces biological essentialism and its related assumptions that physical sex characteristics should be linked to gender identity (i.e. someone who identifies as male must have a penis, and when a penis is not present, one must be constructed to validate his “maleness”; someone who does not have a vagina cannot be a “woman”) – a concept heavily embedded into the social constructions of sex and gender and directly linked to violations of human rights such as coerced sterilisations and forced surgeries on the bases of gender identity, gender expression, and sex characteristics.

Furthermore, many deferrable interventions on intersex children are carried out at a very young age. Referring to treatments being postponed until “the child's gender identity manifests” carries the high risk that parents and/or doctors may believe or declare the child's gender identity to be “manifested” in order to carry out deferrable and irreversible interventions on the child's sex characteristics. Children depend on their caregivers and are especially vulnerable to pressure from adults. It is very

60 Two life-threatening conditions that can occur with some intersex variations (but are not limited to intersex individuals): salt-wasting syndrome and the closure of the urethra. Salt-wasting does not require surgery but only treatment. The closure of the urethra leads to self-poisoning and therefore must be opened by surgical means, see J. Woweries (2012), p. 4; however, these kind of surgeries have been used to do purely cosmetic surgery at the same time. See also: Swiss National Advisory Commission on Biomedical Ethics (2012), p. 14.

61 M. J. Elders et. al. (2017), p. 2.

62 Amnesty International (2017), p. 8, 18, 34, 50-51; Human Rights Watch, InterACT (2017), p. 8

63 For what “medically necessary” actually encompasses see: Conseil d'Etat (2018), p. 135-137, 140, see Appendix for a translation into English.

unlikely that a younger child, or even an older child, will have the capacity to defend themselves when pressure to “consent” is put on them, or be able to identify when the information provided to them is biased or incomplete.

EXISTING LEGISLATION (E.G. AGAINST STERILISATION OR FGM) IS NOT ENOUGH

Experience shows that legislation such as legislation prohibiting sterilisation, laws prohibiting (female) genital mutilation or patient rights legislation do not protect intersex people from violations of their bodily integrity. In 2015, the EU Fundamental Rights Agency (FRA) found that “sex (re)assignment or sex-related surgery seems to be performed on intersex children, and young people, in at least 21 EU Member States”.⁶⁴ Many of these countries have laws against (unconsented) sterilisation and/or sterilisation of minors⁶⁵ and against FGM.⁶⁶ The different treatment of IGM and FGM is even more striking when considering that many intersex individuals who experience IGM are registered as female, and, hence, have their genitalia operated on while legally registered as girls without their wish or consent.

In addition, only a portion of the surgeries performed on intersex individuals include sterilisation. With some variations of sex characteristics, medical interventions are performed to facilitate a presumed future capacity to

procreate and would thus not fall under legislation that prohibits sterilisation.⁶⁷

TREATMENT CODES ARE NOT LEGALLY SECURE

It is important to bear in mind that diagnostic processes and the way treatments are coded within the national health systems and health insurance coverage systems are not exact science and leave a lot of room to manoeuvre.

It is quite common to combine different interventions: sterilisation, for example, can be performed at the same time as a hernia operation, or a surgery on the urethra will be combined with a reduction of the clitoris. Depending on the way these treatments are coded in the national health system, the treatment necessary to maintain the person’s vital functions can be coded as the primary intervention and may cover up the second, purely cosmetic part of the surgery. In addition, how procedures are carried out and how they are referred to can and does change. Therefore, banning specific procedures through a list of codes does not offer adequate legal protection.

64 European Union Agency for Fundamental Rights: FRA Focus Paper. The Fundamental Rights Situation of Intersex People. Vienna 2015, p. 6 <http://fra.europa.eu/en/publication/2015/fundamental-rights-situation-intersex-people>

65 The findings of the German Family Ministry, however, showed that the German sterilisation legislation (§ 1631c BGB), is not impervious when it comes to intersex children, as their gonadal hormone producing tissue may not be considered equivalent to testes or ovaries, see also: Bundesministerium für Familie, Senioren, Frauen und Jugend (2016.a): Situation von trans- und intersexuellen Menschen im Fokus. Sachstandsinformation des BMFSFJ. Begleitmaterial zur Interministeriellen Arbeitsgruppe Inter- & Transsexualität – Band 5. Berlin, p. 19. <https://www.bmfsfj.de/blob/112092/f199e9c4b77f89d0a5aa825228384e08/imag-band-5-situation-von-trans-und-intersexuellen-menschen-data.pdf>

66 All EU Member States criminalise female genital mutilation, either by incorporating it in general criminal law or by explicitly mentioning it in a specific provision or law; 18 countries have a specific criminal law on female genital mutilation, see: European Institute for Gender Equality (EIGE, 2018): Estimation of girls at risk of female genital mutilation in the European Union Belgium, Greece, France, Italy, Cyprus and Malta, p. 16. <https://eige.europa.eu/rdc/eige-publications/estimation-girls-risk-female-genital-mutilation-european-union-report-0>

67 M. J. Elders et. al. (2017), p. 2; Swiss National Advisory Commission on Biomedical Ethics (2012), p. 13; J. Woweries (2012), p. 5.

PROTECTING INTERSEX PEOPLE FROM DISCRIMINATION IN ALL AREAS OF LIFE

Intersex people have the same human rights as everyone else. However, as with other minority groups, a specific ground on which they are protected helps to make sure they are acknowledged as having these rights and can access justice. This protective ground entails discrimination and other human rights violations that may be more specific to them than to other parts of the population.

INTERSEX PEOPLE MUST BE PROTECTED UNDER THE GROUND OF “SEX CHARACTERISTICS”

In the past few years, “sex characteristics” has been established as the adequate and human rights-based ground to protect intersex people/people with variations of sex characteristics. It has also been referred to in a number of human rights instruments and legislations.⁶⁸

OII Europe and ILGA-Europe advocate for protecting intersex people under the specific ground of “sex characteristics” for the following reasons:

- **Universality:** All human beings have sex characteristics. Therefore, as with “sexual orientation” or “gender identity”, the ground “sex characteristics” applies to all human beings. Intersex people are specifically vulnerable to facing violence, discrimination and harassment on the grounds of their physical sex characteristics. Different from “intersex” or “intersex status”, however, the ground of sex characteristics does not carry the risk of excluding some intersex people on the basis of a narrow definition of who is to be considered intersex or not.
- **Equality and equity:** All individuals, regardless of their sex characteristics, deserve to be treated equally and to be protected from discrimination and other human rights violations.

- **Recognition:** The ground of “sex characteristics” allows bodily diversity and the diversity of the human sexes to be acknowledged and legally recognised.
- **Visibility:** As long as the ground of “sex characteristics” does not exist, it is difficult for an intersex victim to be aware that they are legally protected against discrimination and harassment. The notion of the “binary of sexes” is widespread, which often leads to intersex people having to explain their existence and to educate lawyers and judges while being in a very vulnerable position.
- **Clarity:** The physical characteristics a person was born with may or may not be part of their gender identity or gender expression. Regardless of their conforming or non-conforming gender identity or gender expression, a person can face violence, discrimination and/or harassment on the basis of their sex characteristics. Situations like this can occur, for example, when a person needs to undress in locker rooms or in medical settings, or when they need medical examination and/or treatment of a body part that is not considered to “naturally” belong to the person’s assigned sex/gender. If, for example, an intersex person is not able to get a medical preventive check-up because of an alleged mismatch of the respective organ and the sex/gender on their ID or health insurance card, the discrimination happens regardless of whether the person’s gender identity or gender expression conforms to societal expectations or not. However, the discrimination is clearly related to the person’s sex characteristics.

⁶⁸ See, e.g.: PACE Resolution 2191 (2017), Article 7.4.

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

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

Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act

(2) The public service has the duty to ensure that unlawful sexual orientation, gender identity, gender expression and sex characteristics discrimination and harassment are eliminated, whilst its services must promote equality of opportunity to all, irrespective of sexual orientation, gender identity, gender expression and sex characteristics.

European Parliament (2019): Intersex Resolution

10. Deplores the lack of recognition of sex characteristics as a ground of discrimination across the EU, and therefore highlights the importance of this criterion in order to ensure access to justice for intersex people;

WHAT TO DO?

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

The ground “sex characteristics” should

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

In addition, we recommend establishing comprehensive awareness raising measures for the general public as well as obligatory training about the existence of intersex people and human rights violations intersex people face for professionals working in the area of health, education and law enforcement.

HEALTH

Intersex people's health is often jeopardised from an early age. Physical long-term effects of surgical and other medical interventions include, but are not limited to, genital insensitivity and impaired sexual function, sterility, massive internal and external scarring, chronic pain, chronic bleeding and chronic infections, osteopenia and osteoporosis at a very young age, as well as metabolic imbalances. Psychological long-term effects include post-surgical depression and trauma (in some cases associated with the experience of rape).⁶⁹ The complications and physical impairments related to these high-risk interventions are well known among surgeons and DSD⁷⁰ specialists and have been discussed in many medical articles over the past decades.⁷¹ However, this has not led to the rejection of these interventions by medical experts.⁷²

Despite the increased visibility of both intersex people and the human rights violations they face in recent years, intersex people still encounter taboo and stigma in their everyday lives. Many intersex people face severe trauma from the unconsented interventions they were subjected to: of the 439 participating intersex individuals of all ages in a 2007 German study, almost 50% reported psychological problems and a variety of problems related to physical well-being and sex life. Not only the adult respondents but also the children and adolescents

69 GATE (2015), p. 4.

70 This term does not align with human rights language. For more information, see textbox on p. 8.

71 See: J. Woweries (2012), p. 6-10.

72 Ibid.

73 81% of the participants had been subjected to one or multiple surgeries due to their DSD diagnosis (see textbox on p. XX). Two-thirds made a connection between those problems and the medical and surgical treatment they had been subjected to, see: Netzwerk Intersexualität (2008) and, for a comprehensive summary J. Woweries (2012), p. 16-17.

74 See: S. Monroe et. al. (2017), p. 18.

75 J. Woweries (2012), p. 15.

76 See: Equality Office (2018): UK National LGBT Survey. Summary report, p. 24. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/722314/GEO-LGBT-Survey-Report.pdf

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

reported significant disturbances, especially with their family life and in relation to their physical well-being.⁷³

When growing older, just like anyone else, intersex people rely more on the health sector. However, because they had to undergo traumatising treatments in the past, becoming dependent on health services can be uniquely challenging.⁷⁴ In addition, there is very little information on how their health may be affected by the treatments they took for most of their lives.

All these aspects lead to increased physical and mental health issues that are too often left unaddressed by the healthcare sector. A 2008 study found that well over half of the intersex participants (62%) showed clinically relevant psychological stress, 47% had suicidal thoughts, and 13.5% reported past self-harm.⁷⁵ Ten years later, a 2018 study showed similar findings: 38% of the intersex respondents had tried to access mental health services in the preceding 12 months, and 13% of those attempts were unsuccessful.⁷⁶ Prevalence rates of self-harming behaviour and suicidal tendencies in intersex people that were subjected to "normalising" surgeries have been found to be "twice as high as in a community based comparison group of non-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse".⁷⁷

IMPAIRED ACCESS TO HEALTH

Intersex people sorely need access to expert-sensitive health services. However, they often face severe obstacles when trying to access health and care services, such as ongoing discrimination and (re)traumatising experiences with healthcare professionals.

As the 2017 PACE report points out, a severe lack of knowledge about intersex people, the human rights violations they face and the specific needs that follow from these experiences exists among medical practitioners. This lack is matched with personal bias that can result in disbelief and insults, the refusal to perform needed examinations, and examinations being carried out in violent ways or without the intersex person's consent. Intersex people regularly speak in self-help groups and report to national intersex NGOs or to OII Europe that they are at risk of sexual harassment in medical settings.⁷⁸ The lack of training for medical practitioners and other healthcare professionals

severely hinders intersex people in accessing their right to health. Training modules have been developed, e.g. in the framework of the EU Health4LGBTI project,⁷⁹ but a lot remains to be done on national level to increase knowledge about and respect towards intersex people.

When seeking medical help for issues directly related to their sex characteristics, diagnosis or sexuality, intersex people often face highly insensitive and violent behaviour. For example, a 2014 Dutch study on the experience of intersex people in different areas of life emphasised that six out of seven spoke “with a great deal of emotion about poor information, insensitive communication and discourteous treatment”.⁸⁰

Also for health issues which are not related to their variation of sex characteristics, intersex people face challenges which the non-intersex population does not face: a 2018 study from the UK found that intersex respondents were more likely than

non-intersex respondents to say that their general practitioner was not supportive.⁸¹ Intersex respondents were also more likely than non-intersex respondents to say they were too worried, anxious or embarrassed to go to their general practitioner.⁸²

ACCESS TO NEEDED MEDICATION

Treatments and medications needed as a direct consequence of so-called “normalising” interventions are often not covered by health insurance. This can include, for example, life-long hormone substitution therapy after the removal of hormone-producing tissue in order to prevent osteopenia and osteoporosis.⁸³

COUNSELLING

Lack of adequate psycho-social counselling for intersex people is still commonplace in Europe: a 2015 German survey found that of 630 participants (intersex adults, parents of intersex children, counselling professionals and intersex experts), only 4% considered the existing counselling services to be sufficient. 90% of the participants found the existing counselling services insufficient for intersex adults and 95% pointed to the lack of offers for intersex children and adolescents. 95% found the counselling option for parents of intersex children to be insufficient. Almost all participants considered comprehensive counselling services important in order to “avoid premature decisions”.⁸⁴

The support must be accessible as well: 76% of the study’s participants wished for support offers in their immediate vicinities and 59% wished for a minimum of several contact points and advisory services per federal state.⁸⁵

The 2017 Amnesty report “First, do no harm” showed similar findings for Denmark, as did a 2018 survey in the UK.⁸⁶ OII Europe member organisations report the same situation for at least 14 more countries in the Council of Europe region.

A lack of psycho-social counselling options for parents can be extremely harmful or even fatal for the child as well: parents of intersex children who are provided with medicalised information are almost **three times more likely to consent to surgery** than those who receive de-medicalised information.⁸⁷

78 PACE (2017): Report, Part C Article 49-50.

79 Health4LGBTI is an EU-funded pilot project aiming at reducing health inequalities experienced by LGBTI people, see https://ec.europa.eu/health/social_determinants/projects/ep_funded_projects_en#fragment2

80 The Netherlands Institute for Social Research (2014), p. 54; for more testimonies about violence experienced in medical settings see: *ibid.* p. 54-55; as well as UN Shadow reports submitted from intersex NGOs: a comprehensive and regularly updated list for the Council of Europe region can be found on <https://oiiurope.org/wp-content/uploads/2018/09/List-of-intersex-specific-shadow-reports-to-UN-committees-OII-Europe.pdf>.

81 6% of intersex respondents compared with 2% of non-intersex respondents, or intersex people are three times as likely to express that their general practitioner is not supportive, see: Government Equality Office (2018): UK National LGBT Survey. Summary report, p. 24. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/722314/GEO-LGBT-Survey-Report.pdf

82 12% of intersex respondents and 7% of non-intersex respondents, or intersex people are nearly twice as likely to indicate worry, anxiety or embarrassment related to visiting their general practitioner, see: Government Equality Office (2018), p. 24.

83 See: D.C. Ghattas (2013), p. 22. Incidents like these are reported to OII Europe from member organisations on a regular basis.

84 See: Bundesministerium für Familie, Senioren, Frauen und Jugend (2016.b), p. 13.

85 See: Bundesministerium für Familie, Senioren, Frauen und Jugend: Dokumentation Fachaustausch (2016.b), p. 14.

86 See: Government Equality Office (2018), p. 24.

87 J. C. Streuli, E. Vayena, Y. Cavicchia-Balmer & J. Huber (2013), Shaping parents: impact of contrasting professional counseling on parents’ decision making for children with disorders of sex development, *Journal of Sexual Medicine*, Vol. 8 No. 3, pp. 1953–1960 <http://www.ncbi.nlm.nih.gov/pubmed/23742202>.

WHAT TO DO?

Right and access to health

National surveys as well as the UN shadow reports⁸⁸ clearly show that intersex people lack protection of their right to health. In order to ensure intersex people's enjoyment of their right to health, States should take measures to:

- protect people with variations of sex characteristics from non-emergency, invasive and irreversible “normalising” surgeries and other medical practices without the intersex individual's **personal and fully informed consent** (see Chapter 1) as well as establish:
 - the **right to obtain treatment**, including preventive check-ups and needed medication, which are based on the individual's physical needs and are not limited by the sex/gender marker in their official documents.
 - the **right to lifelong coverage** of any medication needed as a result of surgical and/or other interventions on the sex characteristics of a person by national health insurance reimbursement systems.
 - the right to access to coverage that is **not limited by the sex/gender marker** in the person's official documents, for any treatments.
 - the right to expert-sensitive and individually tailored psychological and psycho-social **counselling and support for all concerned individuals and their families**, from the time of self-referral or diagnosis for as long as necessary.
 - the right of survivors of intersex genital mutilation (IGM) to access **reparative treatments** on the same coverage terms as those provided for survivors of female genital mutilation (FGM).
 - the right of access to one's own **complete medical records**, including for minors.
- as well as taking measures to:
- include human rights-based information about the existence of intersex people and about intersex issues in all **medical curricula** and other curricula in the area of health.
 - establish **obligatory training for medical professionals**, such as doctors, midwives, psychologists and other professionals working in the health sector (e.g. reception desk staff), in order to ensure that intersex individuals and their families have access to adequate healthcare and are protected from discrimination. The

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

- 7.1.3. provide all intersex people with health care offered by a specialised, multidisciplinary team taking a holistic and patient-centred approach and comprising not only medical professionals but also other relevant professionals such as psychologists, social workers and ethicists, and based on guidelines developed together by intersex organisations and the professionals concerned;
- 7.1.4. ensure that intersex people have effective access to health care throughout their lives;
- 7.1.5. ensure that intersex people have full access to their medical records;
- 7.1.6. provide comprehensive and up-to-date training on these matters to all medical, psychological and other professionals concerned, including conveying a clear message that intersex bodies are the result of natural variations in sex development and do not as such need to be modified;

European Parliament (2019): Intersex Resolution

- 2. Stresses the need to provide adequate counselling and support to intersex children and intersex individuals with disabilities, as well as to their parents or guardians, and fully inform them of the consequences of sex-normalising treatments;

Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act 15

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

⁸⁸ As of January 2019, UN treaty bodies have issued 49 recommendations on intersex, 26 of which reprimand Council of Europe Member States.

training should include information about the vulnerability and special needs of intersex people in medical settings.

- establish obligatory, human rights-based training about the existence of intersex people and about the specific needs of intersex seniors for **professionals working in elderly** care to ensure that intersex seniors

have access to adequate and respectful support and care without discrimination.

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

COUNSELLING

In its Resolution 2191 (2017) *Promoting the human rights of and eliminating discrimination against intersex people*, the PACE called on Member States to ensure that “adequate psycho-social support mechanisms are available for intersex people and their families throughout their lives”.⁸⁹ It has also called on Member States to “support civil society organisations working to break the silence around the situation of intersex people and to create an environment in which intersex people feel safe to speak openly about their experiences”.⁹⁰

Providing independent, non-medicalised psycho-social counselling is a key factor for preventing invasive and irreversible surgeries and other medical treatments on intersex infants and children. It is also sorely needed to ease the burden on parents and families of intersex individuals. With good support systems, parents and families of intersex children can support their children and face possible challenges that lie in their way. To this aim, measures should be taken to:

- establish professional intersex **peer counselling**.
- ensure access for intersex people and their families to non-pathologising psycho-social **counselling and peer support** within close proximity.
- add human rights-based information about the existence of intersex people and intersex issues to **curricula** for all students in the areas of counselling and social work.

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

89 PACE (2017): Resolution 2191 (2017), Article 7.2.1.

90 PACE (2017): Resolution 2191 (2017), Article 7.2.2..

EDUCATION

Intersex students reportedly face discrimination in all areas of school life: they do not appear in educational curricula at all⁹¹ or only as an imaginative product of

91 See: M. Bittner (2011): Geschlechterkonstruktionen und die Darstellung von Lesben, Schwulen, Bisexuellen, Trans* und Inter* (LSBTI) in Schulbüchern. Eine gleichstellungsorientierte Analyse von im Auftrag der Max-Traeger-Stiftung.

92 See: Surya Monroe et. al. (2017), p. 49; see also: The Netherlands Institute for Social Research (2014), p. 48-49, 53. Statistical data are lacking for European countries to date. However, a 2015 UNESCO report on school bullying, violence and discrimination in the Asia-Pacific region found that of the participating 272 Australian intersex individuals, aged 16-85+, only a quarter of participants rated their overall experience at school positively. The overwhelming majority of participants (92%) did not attend a school with inclusive puberty/sex education. Overall, 18% of people with variations of sex characteristics had primary school education only (compared to 2% of the general Australian population). Many participants (66%) had experienced discrimination ranging from indirect to direct verbal, physical or other discriminatory abuse. Well-being risks were reportedly high, see: UNESCO TH/DOC/HP2/15/042, p. 38. <http://unesdoc.unesco.org/images/0023/002354/235414e.pdf>

93 See also: The Netherlands Institute for Social Research (2014), p. 49. A Russian study found that almost all (91%) participants experienced bullying related to their intersex variation at some point in their lives. Most often the bullying happened on the internet (73%), in school (64%) and in the company of friends (46%), see: Intersex Russia (2016): Intersex in Russia, p. 42-43 https://docs.wixstatic.com/ugd/8f2403_c9b4137f69d7482a9d8df2133d86f203.pdf

94 See: PACE (2017): Report. Part C, Article 17.

95 The World Bank, UNDP (2016): Investing in a Research Revolution for LGBTI Inclusion, p. 12.

96 A 2018 survey showed that “feminine boys” may face problems in being enrolled at school: “Feminine boys”, widely perceived as being gay, were at least three times more likely to be refused enrolment in primary schools (15%) compared to boys not perceived to be feminine (5%)” (World Bank Group, IPSOS, ERA, The Williams Institute (2018): Discrimination against sexual minorities in education and housing: evidence from two field experiments in Serbia, p. 8) <http://documents.worldbank.org/curated/en/509141526660806689/pdf/124587-SERBIAN-WP-P156209-DISCRIMINATION-AGAINST-SEXUAL-MINORITIES-IN-EDUCATION-AND-HOUSING-EVIDENCE-FROM-TWO-FIELD-EXPERIMENTS-IN-SERBIA-PUBLIC-SERBIAN.pdf>; some intersex people have a body that would be considered as ‘too feminine’ or ‘too masculine’ for the sex they were assigned to. It is very likely that these intersex children and adolescents face the risk reported in the 2016 survey.

97 This issue is also pertinent for trans youth; see: P. Dunne, C. Turraoin (2015): It’s Time to Hear Our Voices. National Trans Youth Forum Report 2015, p. 8-9 <http://www.teni.ie/attachments/f4fc5e54-f0c5-4f04-8a09-2703fdf264c2.PDF>

98 Incidents reported to OII Europe by intersex people from Germany and France.

99 See: The Netherlands Institute for Social Research (2014), p. 49.

100 See: J. Woweries (2012), p. 6-9; see also: Surya Monroe et al. (2017), p. 51.

101 Findings of unpublished interviews conducted in 2015 and 2017 by Dan Christian Ghattas with Vincent Guillot and other French intersex persons.

mythology (e.g. hermaphrodites), as an example of “abnormity”, or viewed in a pathological way (in biology texts, medical handbooks or encyclopaedias). Sex education does not take into account that bodies other than the so-called “male” or “female” bodies exist, and thus increases the feeling of shame, secrecy, not existing at all or being a fraud at a vulnerable age.⁹²

Intersex people from all over Europe have reported facing discrimination and bullying at school and in further education, including the use of derogatory language and psychological and physical violence, if their gender expression, stature or other parts of their appearance do not conform to the female or male norms.⁹³ Research has shown that bullying often leads students to drop out or experience significant mental health problems. Long and/or repeated periods of hospitalisation also can lead to early school drop-out⁹⁴ and act as a source of bullying against intersex students. These are harmful outcomes for both the individual as well as the larger community and society.⁹⁵ In addition, intersex students may face problems enrolling at school in the first place, because their physical appearance or gender expression do not fit normative expectations.⁹⁶

Places where the body becomes visible to others, such as toilets and changing rooms, are common areas of anxiety and reported harassment,⁹⁷ regardless of whether the intersex person has had a so-called “normalising” surgery performed on them or not.⁹⁸

On an even more alarming level, intersex individuals also face educational impairments directly linked to the violation of their bodily integrity and to the trauma related to insensitive communication and mistreatment by medical practitioners, as well as to the taboo and shame that is inflicted on them.⁹⁹ Most surgeries, which are performed at an early age, lead to several follow-up operations over the years.¹⁰⁰ Some children drop out of school as a result of this long-term recovery process. Unwanted hormonal treatment, in childhood or puberty, with the aim of altering the body towards the assigned sex has also been reported to coincide with a decrease in school grades.¹⁰¹

This physical and psychological strain often prevents intersex people from developing their full potential and leads to under-achievement at school.¹⁰² As a result, these children and young adults may face significant difficulties in obtaining a higher education degree and are at risk of

WHAT TO DO?

Every child's right to quality education on the basis of equal opportunity is firmly enshrined in the UN Convention on the Rights of the Child.¹⁰⁴ A child's enjoyment of this right, however, depends on different factors, one of them being the school's capacity to protect children from discrimination and harassment. Establishing school policies that oblige schools to create an inclusive and empowering environment is also key for protecting the rights of intersex children and adolescents to education.

The 2018 IGLYO *LGBTQI Inclusive Education Report* has shown that the main areas for improvement in regards to discrimination of LGBTQI students are compulsory education curricula, mandatory teacher training and data collection on bullying and harassment on grounds of actual or perceived sexual orientation, gender identity and expression or variation in sex characteristics. As of 2018, only two countries across Europe (Malta and Sweden) provide most of these measures with respect to sex characteristics specifically. Some regions in Spain have also developed inclusive laws and policies, but these have not been implemented nationally. By contrast, eleven countries have failed to implement any measures.¹⁰⁵

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

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

poverty when growing older. Intersex people who manage to achieve higher education still struggle with the combined impact of the human rights violations they experienced and the discrimination they still face in adulthood.¹⁰³

- establishing **disaggregated data** collection on bullying and harassment in school environments.
- establishing **monitoring and evaluating tools** and measurements for school inclusiveness.
- including intersex people and the existence of more than two biological sexes in a positive and empowering way in **school curricula, text books and education materials** in order to increase the understanding of the general public on the quality of sex as a spectrum and the existence of intersex people and to improve the self-confidence of intersex children and adolescents.
- establishing **school policies** that create a framework that is appropriate for protecting intersex students, and which,
 - ◆ explicitly **protect** intersex students/students with variations of sex characteristics.
 - ◆ include **basic facts** about intersex students, e.g. that they can have all possible gender identities, that they may or may not transition, or that they may or may not be subjected to surgery or other medical interventions.
 - ◆ explicitly respect the right of all students to **discuss and express their gender identity and expression** as well as their sex characteristics openly or not and to decide with whom, when and how much private information they share.
 - ◆ explicitly **include derogatory language** in the scope of bullying; include derogatory language behaviour that takes place in the school, on school property, at school-sponsored functions and activities, as well as

102 S. Monroe et al. (2017), p. 50.

103 See: The Netherlands Institute for Social Research (2014), p. 42.

104 UN Convention of the Right of the Child, Article 24.2.e <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

105 See: IGLYO (2018): LGBTQI Inclusive Education Report <http://www.iglyo.com/resources/lgbtqi-inclusive-education-report-2018>

usage of electronic technology and electronic communication that occurs in the school, on school property, at school sponsored functions and activities, on school computers, networks, fora and mailing lists.

- ♦ establish **mandatory training** about the existence of intersex people and about discrimination and human rights violations intersex students may face at school and in their everyday life for teachers, social workers, school psychologists and other professionals and staff working at schools.
- ♦ establish **low-threshold psychological and social support mechanisms** for intersex students.
- ♦ explicitly establish the entitlement of the intersex student to be provided with, on request, specific arrangements in relation to gender-specific facilities such as toilets and changing rooms, by providing them with a safe and non-stigmatising alternative.
- ♦ encourage schools to **designate facilities** designed for use by one person at a time as accessible to all students regardless of their sex or gender, and to incorporate such single-user facilities into new construction or renovation.
- ♦ allow for all students to participate in **physical education classes and sports activities**, including competition sports, in a manner consistent with their gender identity.
- ♦ encourage schools to evaluate all gender-based facilities, activities, rules, policies, and practices in order to ensure that they meet **equal treatment requirements** and ensure non-discrimination for all students regardless of their sex, gender, or sex characteristics.
- ♦ explicitly obligate school staff to **use the name and pronoun** based on the student's request, regardless of whether these have been changed in official documents.
- ♦ confirm or establish the school's obligation to change a **student's official records** to reflect a change in legal name and/or gender upon receipt of documentation that such change has been authorised, including reissuing or exchanging any social document or certificate relative to them according to their new name and/or gender.

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14. Calls on the Commission to take a holistic and rights-based approach to the rights of intersex people and to better coordinate the work of its Directorates-General for Justice and Consumers, for Education, Youth, Sport and Culture, and for Health and Food Safety, so as to ensure consistent policies and programmes supporting intersex people, including training of state officials and the medical profession;

Malta (2015) Trans, Gender Variant and Intersex Students in Schools Policy

This Policy aims to:

1. Foster a school environment that is inclusive, safe and free from harassment and discrimination for all members of the school community, students and adults, regardless of sex, sexual orientation, gender identity, gender expression and/or sex characteristics.
2. Promote the learning of human diversity that is inclusive of trans, gender variant and intersex students, thus promoting social awareness, acceptance and respect.
3. Ensure a school climate that is physically, emotionally and intellectually safe for all students to further their successful learning development and well-being, including that of trans, gender variant and intersex persons.

EMPLOYMENT

INTERSEX PEOPLE FACE DISCRIMINATION IN JOB SEARCH AND EMPLOYMENT

When it comes to job search and employment, intersex people are one of the most vulnerable groups within the LGBTQI spectrum. Challenges faced by intersex people in school often continue into their working life, perpetuating taboo, secrecy and shame. They can be victims of direct or indirect discrimination and harassment because of their physical appearance or gender expression.¹⁰⁶

When applying for a job, intersex people might need to explain gaps in their education or employment history, resulting from times when they were hospitalised or when they were not able to work due to depression or trauma.¹⁰⁷

Employee medical checks can be extremely difficult for intersex people, especially when the medical practitioner in charge is not educated about the existence of intersex individuals or considers intersex people to have a “disorder of sex development”.¹⁰⁸ This is often exacerbated by trauma associated with having to undergo a medical examination.¹⁰⁹

Once they secure employment, intersex people have reported intrusive curiosity about their bodies from their co-workers, or, when they opened up, disbelief and rejection. Just as in education, the strain of discrimination and stigmatisation may lead to higher absence rates, increasing the risk of intersex people losing their jobs.¹¹⁰

Some intersex people have obtained a disability status due to the physical impairments they have as a result of unconsented surgeries and other medical interventions. Depending on the country, this status can offer some protection; however, it can also come at the cost of additional discrimination and stigma as a persons with disabilities.¹¹¹

¹⁰⁶ Findings of unpublished qualitative interviews conducted with intersex people living in Berlin (Dan Christian Ghattas, Ins A Kromminga (2015)); see also: The Netherlands Institute for Social Research (2014), p. 49; see also testimonials of intersex people in the only existing employer’s guide to intersex inclusion in: M. Carpenter, D. Hough (2014): Employers’ Guide to Intersex Inclusion. Sydney: Pride in Diversity and Organisation Intersex International Australia, p. 16-17 <https://ihra.org.au/wp-content/uploads/key/Employer-Guide-Intersex-Inclusion.pdf>

¹⁰⁷ See: M. Carpenter, D. Hough (2014), p. 20.

¹⁰⁸ This term does not align with human rights language. For more information, see textbox on p. 8.

¹⁰⁹ See also chapter on Health, p. 23.

¹¹⁰ See: The Netherlands Institute for Social Research (2014), p. 56.

¹¹¹ See: OII Europe (2014): Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities, p. 12 https://oii-europe.org/wp-content/uploads/2015/05/CRPD_2015_Statement_OII_Europe.pdf; see also: Intersex Russia (2016), p. 41.

WHAT TO DO?

Important steps towards guaranteeing intersex people's full access to employment and protection from discrimination in work life are to:

- **add the ground of “sex characteristics”** to all anti-discrimination legislation and other equal treatment provisions in the area of job-search, training and employment.

However, these legal measures are not enough; as long as intersex people face human rights violations, invisibility, lack of education, taboo and shame, as well as structural and other discrimination in their everyday life, their capacity to work and develop their skills to their highest potential will still be significantly impaired. Therefore, legal measures in the area of employment must be accompanied by measures that increase the general capacity of intersex people to participate in work life as fully accepted members of society. Among these are:

- general **awareness-raising measures** with the general public.
 - informing **trade unions and work councils** about the existence of intersex people and establishing training measures on discrimination intersex people may face at the workplace.
 - informing **medical officers and company physicians** about the existence of intersex people and establishing obligatory, human rights-based trainings on specific needs intersex people may have, especially in regards to medical examinations.
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Parliamentary Assembly of the Council of Europe (2017): Resolution 2191 (2017). Promoting the human rights of and eliminating discrimination against intersex people

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

HATE CRIMES AND HATE SPEECH

INTERSEX PEOPLE ARE VICTIMS OF HATE CRIMES AND HATE SPEECH

Research has shown that intersex people are victims of intersex-related derogatory language on a regular basis throughout Europe.¹¹² In some languages, derogatory (or pathologising) language is the only language that exists to describe intersex people and their bodies, which requires intersex activists to create positive and empowering language from scratch.¹¹³ Derogatory language perpetuates the notion that intersex people do not have the same human rights as everyone else, adding to their vulnerability.

With regards to hate crimes and physical assault, intersex people with non-conforming physical appearances are especially vulnerable.¹¹⁴ Others face physical assault and/or (sexual) violence in their family, their social environment and medical settings as a direct result of their non-conforming sex characteristics. The taboo and shame, still often connected to having a variation of sex characteristic, and lack of knowledge, puts intersex people at additional risk when reporting such incidents to legal authorities.

As long as there exists no protection on the ground of sex characteristics, incidents of hate speech and hate crime may sometimes be dealt with on the grounds of sexual orientation, gender identity, gender expression or an open ground of “other”. However, a person who is attacked for their physical sex characteristics might not be aware of the possibility or may not want to seek justice through these protective grounds, especially if they are not part of the LGBTQ spectrum. In addition the use of the grounds sexual orientation, gender identity, gender expression and “other” are open to interpretation of legal and administrative staff and does not provide an explicit legal obligation to protect all intersex people.

WHAT TO DO?

In order to combat all forms of expressions that are likely to produce, spread or promote hatred and discrimination of intersex people, it is important to:

- include “sex characteristics” as a **protected ground** in existing hate speech and hate crime legislation and provisions, and thereby guarantee the principle of equal treatment between people irrespective of their sex characteristics. This allows and ensures intersex individuals are able to access justice on the basis of a ground that matches their specific area of vulnerability in society
- **prohibit intersexphobic speech** in the media, including on the Internet and social media.
- include intersex people as a **vulnerable group** in provisions and measures concerning the rights, support and protections of victims of crime.
- **monitor** intersexphobic hate speech and hate crimes
- create and evaluate **protective measures** to prevent intersexphobic hate speech and hate crimes.
- **evaluate existing measures** in regards to intersex inclusion.

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11. Calls on the Commission to enhance the exchange of good practices on the matter; calls on the Member States to adopt the necessary legislation to ensure the adequate protection, respect and promotion of the fundamental rights of intersex people, including intersex children, including full protection against discrimination;

112 See: D. C. Ghattas (2013), p. 58-59.

113 Unpublished interviews conducted by the author in 2017 with intersex activist Pol Naidenov (Bulgaria) and Kristian Randjelovic (Serbia, Balkan Countries)

114 Non-conforming gender expressions and/or appearances make individuals especially vulnerable in public, see, e.g.: Commissioner for Human Rights of the Council of Europe (2009): Human Rights and Gender Identity, p. 14 <https://rm.coe.int/16806da753>. The same is true for non-conforming intersex people, see D. C. Ghattas (2013), p. 15.

GENDER MARKER REGISTRATION AT BIRTH

THE THIRD OPTION

Like everyone else, intersex people may identify as male, female, non-binary or with any other gender. Providing a third option for sex/gender registration in addition to the sexes/genders “male” and “female” acknowledges diversity and strengthens the visibility and recognition of intersex people and people with non-binary gender identities, provided that some very important rules are followed:

- the third option must be used only on a **voluntary, personal basis**.
- the third option must be **available to all people**.
- parents must **not be obliged** to have their intersex child registered with the third option, as this leads to outing the child as intersex in a society where this may put the child and their family at risk; in addition, many intersex people do not identify as a third gender but as male or female.
- when deciding the name of the third option, all relevant members of **civil society**, including intersex human rights NGOs, should be consulted and involved in the development of the most suitable term. The term used to signify the third option must be a positive, respectful and inclusive term in the respective language.
- establishing a third option requires adapting all **legislation, implementation directives and administrative processes** to ensure that people registered as a third gender have **equal access and equal rights** to those registered as “female” or “male”, e.g. in regards to family rights, access to health, social security, etc.

A BLANK GENDER MARKER IS NOT THE SAME AS A GENDER MARKER

Next to a third gender marker, the option of leaving the gender or sex marker blank is also being discussed. However, this option carries several problems of which policymakers should be mindful.

First of all, a blank gender marker is not the same as a positive and respectful third gender marker and may not be considered a positive recognition of someone’s identity: “not having an entry is not the same for me as having a suitable entry.” (Vania, Dritte Option)¹¹⁵

Secondly, the blank option, like the third gender marker, must be registered as a free choice and open to all. In 2013, Germany established a non-entry in the birth registration, not as a free choice, but based on medical determination of an intersex variation of sex characteristics. The law established that if “the child can be assigned to neither the female nor the male sex, then the child is to be entered into the register of births without such a specification”.¹¹⁶ As a result, the law made leaving the sex marker blank in the birth certificate a legal requirement for all cases where, according to the implementation directives, a medical statement would confirm that the sex of the child was not determinable as male or female. As with an obligatory third option for intersex children, this law led to outing intersex children. In addition, the 2013 provision could further encourage the (potential) parents and doctors to avoid an “ambiguous” child at any cost (through abortion, prenatal “treatment” or so-called “disambiguating” or “normalising” surgical and/or hormonal interventions). Research has shown that very few children are assigned without a sex marker and that some children with a blank gender marker were assigned a sex after only a few months. The study also showed that many legal issues are still not

¹¹⁵ Vania and the strategic litigation group 3. Option filed the gender marker case for a third gender marker option that was decided positively by the German Federal Constitutional Court in 2018 <http://dritte-option.de/der-bgh-hat-entschieden-unsere-pressemittelung-dazu/> (translated from German by the author).

¹¹⁶ § 22 Absatz 3 PStG (translated from German by the author).

regulated for individuals with a blank gender marker, hence leaving them in a legal limbo.¹¹⁷

In the meantime, adult intersex people have successfully applied for a removal of the female or male gender marker in their birth certificates by providing medical records.¹¹⁸

This shows that there are mature intersex people who may choose this option. However, as long as medical records and other requirements are a prerequisite, this option is not available for intersex people who do not have access to their medical records or have medical records which are not considered as confirming that they are not of one of the two binary sexes. In addition, people who are not intersex have no access to a blank sex/gender registry. This situation creates inequality on many levels and should be considered discriminatory practice.

If a blank sex/gender marker is to be established, it should be obligatory for all children regardless of their sex characteristics up to the age of maturity. Beginning with the age of maturity the option should be given, if a person wishes so, to register a sex/gender out of multiple options or to leave the sex/gender marker blank. There should be no limit to how often a person can change their gender marker.

If this best practice is not currently an option, then the blank sex/gender marker should follow all the prerequisites as listed above for the third gender marker.

117 Between 2013 and 2015, only 12 blank entries were registered at birth, two of them were changed into male/female some months later, despite the fact that, according to estimates based on diagnostic prevalence, between 280 and 300 children were born during this time who fit the criteria from a medical perspective. The German Institute for Human Rights concluded that the law had in fact not been applied, see: Bundesministerium für Familie, Senioren, Frauen und Jugend (2017): Gutachten. Geschlechtervielfalt im Recht. Status Quo und Entwicklung von Regelungsmodellen zur Anerkennung und zum Schutz von Geschlechtervielfalt. Begleitmaterial zur Interministeriellen Arbeitsgruppe Inter- & Transsexualität – Band 8. Deutsches Institut für Menschenrechte Dr. Nina Althoff, Greta Schabram, Dr. Petra Follmar-Otto. Berlin, p. 17-18, 31-32 <https://www.bmfsfj.de/blob/114066/8a02a557eab695bf7179ff2e92d0ab28/imag-band-8-geschlechtervielfalt-im-recht-data.pdf>

118 Bundesministerium für Familie, Senioren, Frauen und Jugend (2017), p. 17.

119 The Yogyakarta Principles plus 10 clearly indicate that the registration of sex or gender by States should eventually cease. See Principle 31, http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf

WHAT TO DO?

As long as gender markers are registered at birth,¹¹⁹ States should ensure that the existing diversity of sexes is reflected in options available to register the child's sex/gender. States should:

- statutorily and before the child is born, **provide parents with information** about the legal options for registering their child.
 - make **three** (male, female, non-binary or equivalent) **or more** gender markers available when registering a child, and allow parents to choose their intersex child's legal gender (including leaving the gender marker blank, if available) without any medical statement/diagnosis.
 - allow for **gender-neutral names**, with no obligation to add another, gendered middle name.
 - allow for **gender neutral family names**.
 - allow for **postponing gender registration** on the birth certificate until the child is mature enough to participate in the decisionmaking process.
 - allow for **birth certificates without a gender marker entry for all**, regardless of the infant's sex characteristics; in general, the absence of a marker should not indicate the sex characteristics of an individual.
 - allow for parents and legal caretakers to **choose M, F, or X for a child's passport** when the child is registered as non-binary (or equivalent), non-specified or without a gender marker (entry left blank or registered as "not specified").
 - establish a **low-threshold procedure** should the gender identity of the child not match the assigned gender, which allows the child to change their legal gender and name (see Legal Gender Recognition, p. 36).
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7.3. with regard to civil status and legal gender recognition:

- 7.3.1. ensure that laws and practices governing the registration of births, in particular as regards the recording of a newborn's sex, duly respect the right to private life by allowing sufficient flexibility to deal with the situation of intersex children without forcing parents or medical professionals to reveal a child's intersex status unnecessarily;
- 7.3.3. ensure, wherever gender classifications are in use by public authorities, that a range of options are available for all people, including those intersex people who do not identify as either male or female;

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

Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act

4. (1) It shall be the right of every person who is a Maltese citizen to request the Director [for Public Registry] to change the recorded gender and, or first name, if the person so wishes to change the first name, in order to reflect that person's self-determined gender identity.

(2) The request shall be made by means of a note of registration published in accordance with article 5(3).

(3) The Director shall not require any other evidence other than the declaratory public deed published in accordance with article.

(4) The Director shall within fifteen days from the filing of the note of enrolment by the Notary at the public registry, enter a note in the act of birth of the applicant.

LEGAL GENDER RECOGNITION

The European Court of Human Rights (ECtHR)¹²⁰ and international human rights bodies¹²¹ have repeatedly made clear that procedures for legal gender recognition must respect the principles of self-determination and personal autonomy. This is also required by the right to privacy and family life, as laid down in Article 8 of the European Convention on Human Rights.

Research has shown that a gender marker in official documents that reflects and recognises the person's gender identity has a positive impact on an individual's mental and emotional health.¹²² Legal gender recognition also reportedly improves a person's life in regards to social inclusion and reduces the risk of structural and other discrimination.¹²³

A substantial number of intersex people reject the sex that they were registered with at birth. A 2012 clinical review paper found that between 8.5% and 20% of intersex people, regardless of whether their body was subjected to medical interventions or not, developed a gender identity that did not match the sex or gender that was assigned to them at birth.¹²⁴

120 See: EGMR A.P., Garçon and Nicot v. France, 06. April 2017, § 93.

121 See, e.g., Commissioner for Human Rights of the Council of Europe (2015); Fundamental Rights Agency of the European Union (2015); United Nations Office of the High Commissioner for Human Rights (2014).

122 See: European Court of Human Rights (2002): Christine Goodwin vs. United Kingdom, n° 28957/95.

123 Global Commission on HIV and the Law. HIV and the law: risks, rights and health; New York, NY: UNDP; 2012.

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

125 IGLYO (2018): LGBTQI Inclusive Education Report, p. 19 <http://www.iglyo.com/wp-content/uploads/2018/01/LGBTQI-Inclusive-Education-Report-Preview.pdf>

126 See also: Transgender Europe (2018): TGEU Position Paper on Gender Markers <https://tgeu.org/wp-content/uploads/2018/07/Gender-Marker-Position-Approved-13-June-2018-formatted.pdf>

127 Sunil Babu Pant et al. v. Prime Minister and Council of Ministers et al./ Case : Mandamus/070-WO-0287.

It is therefore crucial that intersex individuals have the option – like everyone else – to adjust their gender marker by a low-threshold procedure, based on self-determination so that it matches their gender identity.

INTERSEX CHILDREN AND ADOLESCENTS MUST BE ALLOWED TO CHANGE THEIR GENDER MARKERS IN OFFICIAL DOCUMENTS

Respect for a child's identity is crucial in the development of a positive self-image, and the child's right to identity is protected under Article 2 of the UN Convention on the Rights of the Child (UN CRC). Intersex children and adolescents are especially vulnerable to bullying and harassment at school. They face an increased risk of dropping out of school and lack of education, and poverty at an adult age as a result.¹²⁵ For an intersex child or adolescent whose gender identity does not match the sex/gender that was assigned to them at birth, legal gender recognition can be key to improving their standing related to their peers and/or school staff. With regards to the person's future employment, legal gender recognition before the legal age of maturity also allows school certificates to be issued with the correct gender, hence diminishing the risk of having to explain mismatches in the future. Therefore, mature children and adolescents should be able to change their gender markers by a low-threshold procedure, based on self-determination.

SOCIETAL REALITY MAKES MULTIPLE SEX/GENDER MARKER CHANGES INEVITABLE

A person's gender identity is a matter of self-determination and personal autonomy and can evolve over time.¹²⁶ In addition, when an individual first changes their gender marker, they may not yet know which gender marker would represent them best or the best possible marker might not be available. Furthermore, new options become available (such as a third gender marker), they must have the right to adjust their marker. For all of these reasons, allowing for changing a gender marker more than

once acknowledges and reflects these realities,¹²⁷ and therefore protects the rights to privacy and family life, as enshrined in Article 8 of the European Convention on Human Rights.

Intersex people who have been forcibly assigned a gender through surgical or other means often face trauma and may face severe obstacles in developing their own gender identity. Being able to change their gender marker several times while healing from the trauma and while developing their identity is important in order to prevent re-traumatisation as a result of the pressure that a ‘one time only’-chance would put on them. Limiting the number of times for changing the gender marker, therefore, is particularly problematic for intersex people.

REQUIRING MEDICAL RECORDS FOR LEGAL GENDER RECOGNITION IS A HUMAN RIGHTS VIOLATION

In 2017 a group of UN and international human rights bodies¹²⁸ 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.” The group explicitly pointed out that “coercive medical interventions/procedures should, therefore, never be employed”.

128 The group consisted of: the UN Committee on the Rights of the Child (CRC), UN Committee against Torture (CAT), UN independent experts, the UN Special Rapporteur on extreme poverty and human rights, the UN Special Rapporteur on the right to education, the UN Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, the UN Special Rapporteur on violence against women, its causes and consequences, the Inter-American Commission on Human Rights (IACHR), African Commission on Human and Peoples’ Rights (ACHPR), and the Council of Europe Commissioner for Human Rights.

129 PACE (2017): Report, Part C Article 52.

130 This term does not align with human rights language. For more information, see textbox on p. 8.

131 See: S2k-Leitlinie Varianten der Geschlechtsentwicklung 2016, p. 5.

132 See: The Universal Declaration of Human Rights, Article 16. <https://www.un.org/en/universal-declaration-human-rights/>

Requiring medical records confirming that a person is intersex as a baseline for a simple administrative procedure violates the person’s right to privacy and family life as protected under Article 8 of the Universal Declaration of Human Rights (UDHR).

In addition, many intersex people are not able to obtain their medical records¹²⁹ and will therefore not be able to access legal gender recognition. They would be forced to re-enter the medical setting, in order to receive an examination and a diagnosis, without discernible medical benefit for the individual and with a high probability of (re)traumatisation and stigmatisation.

Furthermore, recent medical opinions and guidelines have pointed out that a DSD¹³⁰ diagnosis does not allow any presumption on a person’s gender identity.¹³¹ Requiring medical records as a pre-requisite for legal gender recognition would therefore reintroduce outdated medical opinions and thus further consolidate the medicalisation and stigmatisation of intersex individuals.

REQUIRING DIVORCE FOR LEGAL GENDER RECOGNITION IS A HUMAN RIGHTS VIOLATION

The UDHR lays out the fundamental human right to found a family.¹³² Requirements that an individual be single or that a marriage be dissolved to undergo legal gender recognition violate this right. For intersex people, accessing the right to found a family can be made especially difficult due to arbitrary sex assignments at birth, administrative and legal hurdles to acquiring accurate identity documents, and social isolation and trauma. Further limitations in the form of forced divorce are especially punitive.

INTERSEX REFUGEES AND ASYLUM SEEKERS NEED TO BE PROTECTED

Intersex refugees and asylum seekers are especially vulnerable. Being able to change the gender marker in their documents can protect intersex and trans refugees and asylum seekers from the risk of structural and other discrimination and can ease the pressure that they are subjected to. Therefore, low threshold procedures for legal gender recognition based on self-determination should be established for refugees and asylum seekers who wish to have their gender identity reflected in their official documents.

Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act

(8) A person who was granted international protection in terms of the Refugees Act, and in terms of any other subsidiary legislation issued under the Refugees Act, and who wants to change the recorded gender and first name, if the person so wishes to change the first name, shall make a declaration confirmed on oath before the Commissioner for Refugees declaring the person's self-determined gender and first name. The Commissioner for Refugees shall record such amendment in their asylum application form and protection certificate within fifteen days.

133 See footnote 101, interview with Vincent Guillot.

134 See footnote 113, interview with Pol Naidenov.

135 See Appendix for details of this case law; in France another two cases were filed. The first case, by an intersex person who had been subjected to unconsented castration and "feminising" genital surgery as a child, on the basis of the article 222-10 of the Penal Code on the ground of aggravated violence resulting in mutilation or permanent disability. The case was rejected by the Court de Cassation (the highest court in France) on the 8th or March 2018 because the statutes of limitation had expired, see: B. Moron-Puech, « Rejet de l'action d'une personne intersexuée pour violences mutilantes. Une nouvelle « mutilation juridique » par la Cour de cassation ? », *La Revue des Juristes de Sciences Po*, juin 2018, p. 71-104 <https://sexandlaw.hypotheses.org/412/bmp-commentaire-6-mars-2018>. The second case is currently being processed. It was filed in 2016 on the grounds of mutilation and intentional violence against a minor under 15 years of age with seven so-called "masculinising" genital surgeries, beginning at the age of three, which left the claimant with severe pain; see <https://www.20minutes.fr/societe/2172971-20171126-personne-intersexe-depose-plainte-contre-medecins-operee-devenir-homme> (12.3.2019).

ACCESS TO JUSTICE AND REDRESS

Many intersex people, who have been subjected to surgeries and other medical treatments without their consent as infants, children or adolescents, were raised in an atmosphere of silence and taboo. Too often, they only find out as adults that they underwent treatment not because of health reasons but for societal reasons. Once they do find out, time to process and heal is needed before the person can start to think of seeking justice.

Intersex people seeking justice for the harm done by medical practices to their bodily integrity report challenges, such as difficulties in accessing their (full) medical records, sometimes because the retention period has expired, and sometimes because hospitals and doctors do not give them access, even in those countries where the right of patients to access their medical records is legally protected.¹³³ And even when intersex people do obtain their medical documents, the claim might be time-barred: too often, it is legally too late for intersex people to seek justice.

If a case is brought to court, lawyers and judges in most cases lack fundamental knowledge about the existence of intersex people. Intersex people seeking justice need to instead first educate them in a situation of increased vulnerability.¹³⁴ In addition, a doctor or hospital can claim that the medical interventions were in compliance with medical standards at the time. A court may be likely to base its ruling on this argumentation, especially as long as intersex people's bodily integrity is not protected by law. To this date, only two intersex people in Europe successfully went to court to get justice for the harmful medical practice they were subjected to. In one case, the petitioner won their suit against the surgeon in charge of the operation; in the other case, the petitioner won their case against the hospital where the surgery was performed in the first instance, but then settled in the second instance.¹³⁵

WHAT TO DO?

In order to allow intersex people to access justice, States should:

- extend the **retention period** for medical records of to at least 40 years in order to allow intersex people access to their medical records at a mature age.
 - extend the **statutes of limitations** to at least 20 years, and suspend them until the minimum age of 21 of the person concerned.
 - establish adequate **legal sanctions** for medical and other professionals who conduct any sex-“normalising”, sex-“assigning” or sex-altering surgical or other interventions which can be deferred until the person to be treated is mature enough to provide informed consent.
 - explicitly establish the **legal obligation** for medical professionals with regards to all surgical and other interventions that aim to alter the genitals, gonads, reproductive organs or any hormonal set-up:
 - ◆ to **inform** the mature individual comprehensively about the treatment, including other possible medical options and details about risks and possible long-term consequences and effects based on up-to-date medical information;
 - ◆ in case of urgent, non-deferrable treatment on a child, which is not driven by social factors or a desire for legal certainty, **inform the child’s parent(s) or legal guardian(s)** comprehensively about the treatment, including other possible medical options and details about risks and possible long-term consequences and effects based on up-to-date medical information;
 - ◆ provide **detailed minutes** of the consultation including all of the above information, which are handed out to the patient or their parent(s) or legal guardian(s);
 - ◆ include these minutes in the intersex person’s **medical records**.
 - encourage the inclusion of legal cases about the human rights of intersex people in **medical legal curricula and exams**
-

European Parliament (2019): Intersex Resolution

6. Calls on the Member States to improve access for intersex people to their medical records, and to ensure that no one is subjected to non-necessary medical or surgical treatment during infancy or childhood, guaranteeing bodily integrity, autonomy and self-determination for the children concerned;

Malta (2015) Gender Identity, Gender Expression and Sex Characteristics Act

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

REPARATION AND REDRESS ARE A MATTER OF TAKING RESPONSIBILITY

The harm that has been and is still being inflicted on intersex people is, in effect, a societal problem and as such, it is society's responsibility. As with the sterilisation of people with disabilities, the medical setting provides the space where societal norms and notions come into effect with devastating consequences for the individual. As long as their healthy bodies and sex characteristics are not recognised in their own right but instead as disordered male or female bodies, intersex people are and will continue to be victims of structural discrimination and violence. Access to redress remains limited as long as society and States wrongly consider the human rights violations of intersex people to be rightful or helpful treatments. As long as society and States do not acknowledge the existence of intersex people, their human rights will be disregarded and they face significant obstacles in seeking reparation and redress.

WHAT TO DO?

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

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

The *2017 Yogyakarta Principles Plus 10* elaborate in detail on how to establish these rights for victims of violations on the basis of sexual orientation, gender identity, gender expression and sex characteristics.¹³⁶ The 2014 interagency statement *Eliminating forced, coercive and otherwise involuntary sterilization* by OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO includes a list of recommendations to States on how to best provide remedies and redress.¹³⁷

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2. The Parliamentary Assembly considers that this approach involves serious breaches of physical integrity, in many cases concerning very young children or infants who are unable to give consent and whose gender identity is unknown. This is done despite the fact that there is no evidence to support the long-term success of such treatments, no immediate danger to health and no genuine therapeutic purpose for the treatment, which is intended to avoid or minimise (perceived) social problems rather than medical ones. It is often followed by lifelong hormonal treatments and medical complications, compounded by shame and secrecy.

¹³⁶ The Yogyakarta Principles plus 10 (2017): Principle 37: The Right to Truth - A, p. 14-15, see Appendix.

¹³⁷ OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014): *Eliminating forced, coercive and otherwise involuntary sterilization*. An interagency statement, p. 15-16, see Appendix.

DATA COLLECTION: Addressing research gaps

There has been a promising increase in sociological, non-medicalised studies regarding the situation of intersex people over the past few years, most of them conducted in collaboration with intersex organisations and intersex people, acknowledging and remunerating their expertise. However, there is still a substantial lack of data and surveys regarding the living situation of intersex individuals.¹³⁸

The most pressing research gaps include:

- Experiences of normalising practices.
- Ill-treatment and violence in medical settings.
- Statistical data on the number of intersex-related surgeries and other medical interventions in infancy and childhood.
- Statistical data on the long-term health effects (including impairments) of surgeries and other medical treatment in infancy and childhood.
- Trauma and mental health.
- Experiences with supportive environments and/or services in all areas of life (family, health-care, education, work etc.).
- School dropout and bullying.
- Facing stigma and harassment in every day life, at school and in employment.

But the challenge not only lies in gathering the data. Correct contextualisation is key for the validity of the findings, which cannot happen when intersex people are not meaningfully involved in all stages of research projects. In past studies which failed to adequately

involve intersex people, significant methodological flaws were the result, including biased sampling, failure to adequately account for or address researcher-participant power dynamics, poor instrument design, and misinterpretation of results. All of these issues can be addressed when intersex people are involved throughout the process.

¹³⁸ See: PACE (2017): Resolution 2191 (2017), Article 7.5., 7.5.1 and 7.5.2; see also: PACE (2013): Resolution 1952 (2013), Article 7.5.3.

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

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

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

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

European Parliament (2019): Intersex Resolution

12. Calls on all relevant stakeholders to carry out research concerning intersex people, taking a sociological and human rights perspective rather than a medical one;

WHAT TO DO?

There are some parameters, which, when taken into account, have proven to increase the usefulness of research findings on intersex people and foster the development of targeted research approaches:

- Research on the situation of intersex people must **ask about experiences**, not about identity.
 - Intersex people should not be researched only as a subgroup of LGBTI but as an **independent part of the population**; data **disaggregation** is key.
 - Working together with **intersex-led organisations and intersex-led peer support groups** is vital for increasing the reach of studies on intersex people.
 - **Consulting** with intersex activists and organisations is important.
 - when creating questionnaires to avoid pitfalls that lead to inaccurate data.
 - when analysing and contextualising the data to increase the accuracy of the analysis.
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FUNDING - CREATING SUSTAINABILITY

Despite the fact that intersex activism made its first steps in the mid 90s¹³⁹, it is only since 2015 that intersex-led human rights NGOs have started to receive some funding. However, intersex organisations in Europe (and world-wide) are still heavily underfunded and under-resourced.¹⁴⁰ To date, only a handful of NGOs in Europe receive enough funding to hire (part-time) staff.

According to the 2018 Global Resources Report for 2015/16, the total funding for work related to intersex people and intersex people's rights in Western Europe and Eastern Europe, Russia and Central Asia was \$0 USD (zero dollars) in 2013-2014 out of \$50,640,313 USD for the LGBTI movements overall in these two regions. This increased to \$161,711 USD for Eastern Europe, Russia and Central Asia and to \$607,042 USD for Western Europe for the time-period of 2015-2016 (out of \$19,336,445 USD and \$37,510,193 USD for the LGBTI movements overall for

these two regions, respectively).¹⁴¹ However, only a fraction of this already small amount went to intersex-led organisations.¹⁴²

Another 2017 funding report on the state of intersex organising found that many intersex-led human rights organisations had applied for funding unsuccessfully. About half (52.8%) of those organisations reported that donors told them that intersex people were not a key population for their work. Due to lack of opportunity and human resources, very few organisations and groups applied for or received any form of government funding.¹⁴³

The survey also found that intersex organisations play a key role in advancing the life situation of intersex people and that they work successfully in many different areas at the same time: more than eight in ten (85.4%) of the organisations or groups engaged in advocacy, community organising or health provider educational activities. Almost three-quarters (73.2%) provided peer support, social services or engaged in individual-level advocacy. When asked what work they would like to do but are precluded from doing for lack of resources, intersex groups most wanted to expand their work at local and national levels in the area of community organising (34.1%), campaigning (26.8%) and base-building activities (26.8%); however, they were hindered from pursuing these activities due to a lack of resources.¹⁴⁴

Volunteer work is the fragile pillar of all intersex organisations' activities so far. Volunteer activism leads key activists to burn out, requires them to accept financial insecurity and does not provide for enough human resources. This is not a sustainable situation, neither for intersex activism, nor for States who want to benefit from the knowledge and expertise, as well as the expert services (trainings, peer support, counselling, awareness raising), which only intersex organisations and groups can provide.

139 ISNA (Intersex Society of North America, U.S.A., founded in 1993) and the AGGPG (Arbeitsgemeinschaft gegen Gewalt in der Pädiatrie und Gynäkologie, Germany, founded in 1995).

140 See: Astraea – Lesbian Foundation for Justice, American Jewish World Service, Global Action for Trans Equality (2017): *The State of Intersex Organizing* (2nd edition). Understanding the Needs and Priorities of a Growing but Under-Resourced Movement <https://www.astraeafoundation.org/publication/state-intersex-organizing-2nd-edition/>

141 Funders for LGBTQ Issues, Global Philanthropy Project (2018): 2015/2016 Global Resources Report, Government and Philanthropic Support for Lesbian, Gay, Bisexual, Transgender, and Intersex Communities, p. 44 and 79 <https://lgbtfunders.org/research-item/2015-2016-global-resources-report/>

142 See: Astraea, GATE (2017), p. 6.

143 See: Astraea, GATE (2017), p. 7. When analysing the kind of grants the survey found that intersex groups are most likely to receive intersex or LGBT-specific funding from foundations and larger NGOs as sub-grants and that they did receive almost no government funding. Of the nearly two-thirds (64.3%) of intersex groups that received any external funding, a total of twenty-seven groups, the most common sources were foundation funding (55.6%) and sub-grants from larger NGOs (29.6%), see: *ibid.* p. 7 <https://www.astraeafoundation.org/publication/state-intersex-organizing-2nd-edition/>

144 Astraea, GATE (2017), p. 6.

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

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

European Parliament (2019): Intersex Resolution

5. Calls on the Commission and the Member States to increase funding for intersex civil society organisations;

WHAT TO DO?

OII Europe and ILGA-Europe, in conjunction with the key recommendations from the funding reports mentioned above, call on States to:

- fund work **led by intersex people**.
- provide **flexible and stable funding** to intersex organisations and groups.
- provide sufficient funding for **paid staff**, and invest in anti-trauma work and burnout prevention.
- invest in the **organisational strengthening** of intersex organisations and groups.
- support intersex activists to **build community and national-level work**, while they continue to advance work at the international level.
- **educate funding institutions and peers** about intersex people and the human rights violations they experience and challenges they face in society.
- **decrease the barriers** for intersex groups in finding and applying for funding, particularly by explicitly addressing calls for proposals to intersex organisations and groups and funding unregistered groups through intermediaries.

