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Promoting the human rights of and eliminating discrimination against intersex people

Report[1]
Committee on Equality and Non-Discrimination
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Summary

Intersex people are born with sex characteristics that are not exclusively either male or female. In our societies, they face human rights violations and discrimination in all fields of life.

Invasive and irreversible sex-"normalising" surgery and hormonal treatments are carried out on intersex children without their free and informed consent and even though there is no medical need for such treatment. Member States should prohibit such interventions and defer treatments that seek to alter the sex characteristics of intersex children until they are able to participate in the decision. Health care should be multidisciplinary, holistic and patient-centred, and psychosocial support should be made available both to intersex people and their families.

To protect the right to private life, birth registration systems should allow sufficient flexibility to accommodate the needs of intersex people, and quick, transparent and accessible legal gender recognition procedures must also be available.

States should collect more data and carry out further research into these matters, and consider granting compensation to victims of past treatments. They should ensure that anti-discrimination legislation effectively protects intersex people and carry out campaigns to raise awareness among professionals and the general public as regards the situation and rights of intersex people.

1. Reference to committee: Doc. 14049, Reference 4219 of 20 June 2016.

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A. Draft resolution[2]

1. Intersex people are born with biological sex characteristics that do not fit societal norms or medical definitions of what makes a person male or female. Sometimes a person's intersex status is detected at birth; sometimes it only becomes apparent later in life, notably during puberty. Despite the wide variety of situations concerned, the majority of intersex people are physically healthy. Only a few suffer from medical conditions that put their health at risk. Yet the situation of intersex people has for a long time been treated as an essentially medical issue. The prevailing medical view has been that intersex children's bodies can and should be made to conform to either a male or a female paradigm, often through surgical and/or hormonal intervention; that this should be done as early as possible; and that the children should then be raised in the gender corresponding to the sex assigned to their body.

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

3. Parents are often under pressure to make urgent, life-changing decisions on behalf of their child, without having a full and genuine understanding of the long-term consequences for their children of the decisions made about their bodies during their infancy and early childhood.

4. Understanding of these issues is gradually increasing, but concerted efforts are still needed to raise public awareness as to the situation and rights of intersex people so as to ensure that they are fully accepted in society, without stigmatisation or discrimination.

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

6. The Assembly considers that the above may raise important issues under a number of provisions of the European Convention on Human Rights (ETS No. 5), notably its Articles 3 and 8.

7. In the light of the above, and bearing in mind the provisions of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, "Oviedo Convention") and the relevant recommendations made in its Resolution 1952 (2013) on children's right to physical integrity, as well as those by the Council of Europe Commissioner for Human Rights and numerous treaty bodies of the United Nations, the Assembly calls on Council of Europe member States to:

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

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

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

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

2. Draft resolution adopted unanimously by the committee on 18 September 2017.

7.1.4. ensure that intersex people have effective access to health care throughout their lives;

7.1.5. ensure that intersex people have full access to their medical records;

7.1.6. provide comprehensive and up-to-date training on these matters to all medical, psychological and other professionals concerned, including conveying a clear message that intersex bodies are the result of natural variations in sex development and do not as such need to be modified;

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

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

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

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

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

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

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

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

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

7.4. with regard to combating discrimination against intersex people, ensure that 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 amongst lawyers, police, prosecutors, judges and all other relevant professionals as well as intersex people of the possibility of dealing with discrimination against them under the prohibited ground of sex, or as an "other" (unspecified) ground where the list of prohibited grounds in relevant national anti-discrimination provisions is non-exhaustive;

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

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

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

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

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

B. Draft recommendation[3]

1. The Parliamentary Assembly refers to its Resolution … (2017) on promoting the human rights of and eliminating discrimination against intersex people, in which it calls on member States to take a number of measures to achieve these goals, *inter alia* in the field of children's rights and bioethics.

2. The Assembly believes it essential that rapid progress be achieved by member States and that Council of Europe standards be developed further in this field.

3. It therefore invites the Committee of Ministers to:

3.1. bring Resolution … (2017) to the attention of the governments of all member States;

3.2. instruct the Committee on Bioethics to continue its work on strengthening children's rights in biomedicine, in particular as regards the protection of intersex children's right to physical integrity and respect for the principle of free and informed consent, with a view to drawing up Council of Europe standards and guidelines in this field.

3. Draft recommendation adopted unanimously by the committee on 18 September 2017.

C. Explanatory memorandum by Mr Piet De Bruyn, rapporteur

1. Introduction

1. Every day, children are born with bodies whose sex characteristics are not exclusively either male or female. Intersex people are all too often taught to be ashamed of their bodies and to hide the reality of their biology. Intersex infants and children are frequently subjected to irreversible and highly intrusive surgery without their informed consent, and intersex people of all ages experience human rights violations and discrimination in many aspects of their daily lives. Legislation to combat discrimination and promote equality does not always cover the needs of intersex people effectively; intersex people face issues as regards their civil status and legal recognition of their gender; and where legislation designed to protect their rights does exist, the conditions for its effective implementation are not always met.

2. Estimates of the numbers of intersex people vary from 1/1 500-2 000 (a figure that includes only those people who can be identified as intersex at birth) to more than 1.7/100.[4] The situation of intersex people is however little known to the general public, and prejudice and ignorance exacerbate the inequalities they face.

3. I believe that it is crucial to take a holistic view of the issues faced by intersex people. We must look not only at the very important medical concerns at stake but also understand the full range of human rights issues affecting intersex persons – which unquestionably include the right to physical integrity and questions around informed consent, but also relate to legal gender recognition and civil registration, human dignity, and the right to be free of discrimination, for example.

4. Human rights are universal and their enjoyment must never depend on the sex characteristics of a person. The Parliamentary Assembly's decision to draw up a draft resolution on promoting the human rights of and eliminating discrimination against intersex people throughout Europe is therefore highly welcome. Through this report, I wish both to raise public awareness on the issues at stake and to help set member States on the path towards eliminating the human rights violations and discrimination experienced by intersex people.

5. In preparing this report, I carried out a fact-finding visit to Malta on 23 and 24 February 2017. I wish to thank the Maltese authorities for their assistance in ensuring that this visit was instructive and helpful. I also wish to thank the Council of Europe Commissioner for Human Rights, Nils Muižnieks, for his presentation to our committee on 28 January 2016 of his "Human rights and intersex people" issue paper, as well as the speakers who accepted our committee's invitation to participate in the hearings we held on 21 March 2017 in Paris and on 29 June 2017 in Strasbourg, and who generously gave of their time and experience in order to inform our work on this report. Finally, I wish to thank the medical professionals with whom I met to discuss my work and who provided careful and considered advice in the preparation of this report.

2. Terminology

6. Intersex people are people born with biological sex characteristics (including, for example, genital, hormonal or chromosomal characteristics) that do not fit societal norms or medical definitions of what makes a person male or female. Sometimes this is detected at birth; sometimes it only becomes apparent later in life, notably during puberty. While the variety of situations covered is broad, all of these variations or differences in sexual development are naturally occurring, and the majority of intersex people are physically healthy. Only a few suffer from medical conditions that put their health at risk.[5]

7. There is debate about the use of the term "intersex". Since the Chicago Consensus statement of 2006, medical professionals have mostly adopted the term "disorders of sex development", considering other terms then in use (including "intersex") to be too controversial and possibly pejorative.[6] However, many intersex activists reject this terminology, notably on the grounds that the term "disorders" may imply that their bodies have a problem that needs to be "fixed". Some sources have sought to find more neutral language, such as

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4. See *inter alia* "Fact Sheet: Intersex" published by United Nations Free & Equal; Blackless M. et al. (2000), "How sexually dimorphic are we? Review and synthesis", *Am J Hum Biol* No. 12(2), pp. 151-166.

5. See *inter alia* "Human rights and intersex people", Issue paper published by the Council of Europe Commissioner for Human Rights, April 2015, pp. 13-14; "The Fundamental rights situation of intersex people", Fundamental Rights Agency (FRA) of the European Union, Focus Paper, Vienna, April 2015, p. 2; "Fact Sheet: Intersex" published by United Nations Free & Equal; definition of intersex used by the Organisation Intersex International Europe (OII Europe).

6. Lee P. A. et al. (2006), Consensus Statement on the Management of Intersex Disorders, *Arch Dis Child*. No. 91(7), pp. 554–563.

"differences in sex development".[7] I have chosen to use the term "intersex" in this report, as it is the term currently in widest use amongst activists directly concerned by the issues at stake as well as at international level.[8] It is worth noting, however, that terminology is evolving all the time. A term now emerging, which I have also used in this report, is "variations in sex characteristics". This term, which is clear, neutral and purely descriptive, may in future become increasingly widely used.

3. Biology

8. Many different characteristics go into assigning a person to one sex or another. Primary sex characteristics are those that are present at birth – chromosomes, gonads (ovaries/testes, which produce both gametes (eggs or sperm) and the sex hormones that affect subsequent sexual development), hormones (oestrogens, progesterone, testosterone, etc.), outer genitalia (labia, clitoris, vagina, penis, scrotum) and inner genitalia (uterus). Secondary sex characteristics are those that develop at puberty, such as breasts, facial and pubic hair, the Adam's apple, muscle mass, stature and fat distribution.

9. Basic notions of biology teach us that people have 23 pairs of chromosomes, of which one pair – either XX or XY – will determine whether a person is female or male. Reality is however much more complex. First, chromosome patterns may vary, meaning that the genetic sex of a person is not always clear-cut. Second, chromosomes are not the only element that determines a person's biological sex. Until roughly the seventh week of pregnancy, the genitalia of the foetus are indistinguishable. The ways in which the outer and inner genitalia then develop *in utero*, and in which secondary sex characteristics develop during childhood and puberty, depend on the types and quantities of hormones that each person's body produces, and on the body's receptiveness to those hormones.

10. The term "intersex" thus covers a wide variety of situations and human experiences. An intersex person may thus, for example, have a genetic sex that differs from their other sex characteristics;[9] they may at birth have outer genitalia that are typically associated with the female sex, but develop secondary sex characteristics that are more often associated with the male sex (such as more pubic hair and/or a highly muscled body) as they grow;[10] they may have no gonadal tissue or undeveloped ("streak") gonads;[11] they may have genitalia that show some characteristics typically associated with the female sex and some with the male sex.[12]

11. Hypospadias (in which the opening of the urethra is not at the tip of the penis but on its underside) may also be associated with intersex conditions such as androgen insensitivity syndrome (AIS). There is discussion as to whether hypospadias should be considered an intersex condition in itself. I nonetheless consider it essential to include hypospadias in this report both because it can be part of the experience of intersex people and because it raises many identical medical and ethical issues (in particular, as I will discuss further below, whether or not non-life-saving surgery on the genitals of infants and children without their consent is acceptable).[13]

12. Finally, it must be underlined that being intersex is solely a question of biology, not of sexual orientation or gender identity: intersex people can have any gender identity (male, female, intersex, non-binary, neutral, undetermined, …) and any sexual orientation, as these are distinct from sex characteristics.

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7. 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, Berne, November 2012.
8. I am aware that some associations representing people who present differences in sex development nonetheless strongly reject this term. See for example the evidence given by the Surrénales association (representing people with congenital adrenal hyperplasia) to the French Senate on 19 October 2016. Sénat, rapport d'information No. 441 (2016-2017), Variations du développement sexuel: lever un tabou, lutter contre la stigmatisation et les exclusions, rapporteurs: Maryvonne Blondin et Corinne Bouchoux, sénatrices, Appendix 5 – Comptes rendus des auditions de la delegation.
9. This is for example the case of intersex people with complete androgen insensitivity syndrome (AIS), who have XY chromosomes but are resistant to male hormones such as testosterone and thus develop female outer genitalia.
10. This is for example the case of intersex people having some forms of congenital adrenal hyperplasia.
11. This is known as gonadal dysgenesis.
12. This is known as partial or mixed gonadal dysgenesis and may for example affect people with a mosaic karyotype, i.e. who have different combinations of X and Y chromosomes in different parts of their bodies.
13. See for example Carmack A., Notini L. and Earp B.D. (2016), "Should surgery for hypospadias be performed before an age of consent?", *Journal of Sex Research* No. 53, pp. 1047-1058.

4. Medical(ised) approaches to intersex people, their bodies and their rights

13. Because their bodies present biological differences from those that can be easily classified as either male or female, and because it is often medical professionals that first identify a person's intersex status, intersex people are frequently considered as having medical "problems" that need to be "fixed". Invasive and irreversible interventions, including hormonal treatments, are carried out on intersex children's bodies without their consent, in breach of the fundamental principle that interventions in the health field must not be carried out without the free and informed consent of the person concerned. Moreover, having their bodies "fixed" in such a way is not what many intersex people would wish.

4.1. Origins and development of current medical practice

14. Starting from roughly the middle of the 20th century, standard medical practice with respect to children born with external genitalia that do not neatly fit either the male or female stereotype has been to conduct so-called "sex-'normalising'" surgery on them, with the aim of making their genitals appear to conform to either the male or the female paradigm.[14] Surgery could include interventions such as clitoral reductions, vaginoplasties, gonadectomies, or repositioning the opening of the urethra at the tip of the penis.[15] Hormone treatments would later be administered in order to make secondary sex characteristics correspond to the surgically assigned gender. In parallel to such treatment, parents have been advised to raise the child as belonging to the surgically assigned gender.[16]

15. These protocols developed in the 20th century, as surgical techniques evolved to enable the alignment of an adult's physical characteristics with their gender identity. By the 1940s, such surgery was increasingly practised also on older intersex children, at their parents' request. Research in the 1950s however found signs of severe psychological trauma in intersex children who had been subjected to sex-"normalising" surgery at their parents' initiative after the age of three, in particular if the gender surgically assigned to them did not correspond to their gender identity. It was around this time that the paradigm became to perform such surgery on infants and very young children (under the age of three).

16. This practice was based on the assumption that if an intersex infant's "ambiguous" genitals were made to resemble "typical" male or female genitals, then the child would avoid stigmatisation based on their physique. It was further reasoned that parents could steer their child's gender development by raising them from infancy in accordance with the gender surgically assigned to them and mould the child into conforming with society's expectations of persons of their surgically assigned gender.[17] In this context, it came to be seen as crucial that gender assignment surgery be carried out at a very early age, and that the child not be informed of what had been done to their body. Combined with the parents' constant rearing of the child in accordance with his or her surgically assigned gender, this approach was supposed to ensure the child's healthy sexual development.[18] An additional goal of surgery (which could require multiple, risky interventions later in childhood) has been to enable penetrative penile-vaginal intercourse, which was presumed to be the individual's preference as regards sexual activity.[19]

17. The operations involved in such a process are life-changing and highly invasive. They may involve long and repeated periods of hospitalisation, including repeated surgery on the genital area, and may lead to severe and painful scarring. Such surgery also often involves sterilisation.[20] Moreover, when the gonads are removed, the body is no longer able to produce sex hormones. If this is done at a young age, puberty will not occur naturally and must be induced by hormonal treatment, involving frequent visits to doctors and regular

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14. See *inter alia* Kipnis K. and Diamond M. (1998), "Pediatric Ethics and the Surgical Assignment of Sex", *Journal of Clinical Ethics* No. 9(4), pp. 398-410; Zillén K., Garland J. and Slokenberga S. (2017), The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties, p. 40.
15. Statement of Kitty Anderson, OII Europe, at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris; see also for example McClintock J, "Growing up in the surgical maelstrom", www.isna.org/books/chrysalis/mcclintock.
16. See for example Sénat, rapport d'information n° 441 (2016-2017), footnote 8 above.
17. Zillén K., Garland J. and Slokenberga S. (2017), The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties, p. 41-42, and sources cited therein.
18. Colapinto J. (1997), "The True Story of John/Joan", *Rolling Stone*, 11 December 1997, pp. 54-97; Zillén K., Garland J. and Slokenberga S. (2017), op. cit., pp. 41-42.
19. Zillén K., Garland J. and Slokenberga S. (2017), op. cit, p. 42.
20. See *inter alia* "Human rights and intersex people", Issue paper published by the Council of Europe Commissioner for Human Rights, April 2015, pp. 13-14.

intrusive medical examinations.[21] In addition, finding the correct dosages of replacement sex hormones is complex, and blocking oestrogen or testosterone can lead to other serious consequences such as osteoporosis.

18. All of this is typically done from a very early age, when the child cannot be consulted, and often in the absence of any immediate danger to a child's life – in other words, these acts are carried out essentially for cosmetic and social reasons,[22] although they have no therapeutic purpose and are unnecessary.[23]

4.2. Past practices persist

19. Some medical teams today support the idea of postponing any form of sensitive and/or irreversible surgery until the individual is old enough to be actively involved in the decision – and implement this approach in practice. However, as was emphasised at the hearing held by our committee on 21 March 2017, even today, other medical practitioners stress that practices have changed but acknowledge that such operations are still carried out even when there is no danger to a child's life. Some medical practitioners draw a parallel with children born with a cleft lip, where therapeutic arguments are given for operating, but in fact the treatment responds to social norms rather than to any medical necessity. The objective may be legitimate but operations on intersex children are much more serious, have physical and psychological consequences throughout the person's life, often have to be repeated, and have never been proven to be of overall benefit.[24]

20. Many medical professionals explain that very little is taught about intersex people during medical training; although some research is being carried out and articles questioning the need for early surgery are now increasingly being published in medical journals, these elements are rarely taught in medical schools. This lack of full and up-to-date knowledge makes it easier for past paradigms to persist.

21. A study published in 2016 on current practices as regards cosmetic genital surgeries on children aged under 10 in Germany shows that on average, 99 feminising surgeries were carried out each year from 2005 to 2014, and that the overall number is not dropping. Masculinising surgeries (including "corrections" of hypospadias) remained almost constant at over 1 600 per year in the same period, even rising slightly at the end of this period. Diagnoses had changed from "classic" intersex categories such as "pseudo-hermaphroditism" to "unspecified malformation of the female/male genitalia", but the number of surgeries had not dropped – despite frequent declarations to the contrary by medical practitioners.[25]

22. A recent FRA study found that sex (re)assignment or sex-related surgery appeared to be performed on intersex children and young people in at least 21 European Union member States (Austria, Belgium, Bulgaria, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, the Netherlands, Poland, the Slovak Republic, Spain, Sweden and the United Kingdom). No indications could however be given as to the frequency of such surgery. There were considerable variations between States as regards the participation of children in giving consent.[26] In order to build a more complete understanding of current practice, all member States should in my view keep records of all interventions carried out on children's sex characteristics, whether or not these are understood as sex-"normalising" or sex-"aligning" interventions.

23. The protocols described above have thus continued to be applied, despite the absence of long-term data or follow-up confirming that they are safe and beneficial to patients. In essence, this means that medical practitioners have been experimenting on children for decades. The subsequent emergence of considerable

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21. Statement of Kitty Anderson, OII Europe, at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.

22. For example, in cases where children have streak gonads or undescended testes, gonadectomies are still sometimes carried out in infancy, on the grounds that there may be an increased risk of cancer. However, in many cases this risk does not increase substantially until after puberty or even adulthood – meaning that the decision whether or not to operate can safely be deferred until the child concerned is old enough to participate in it. See, for example, Cools, Martine et al., "Management of the gonads", http://dsdfamilies.org/mednote/manage_dsd_2.php.

23. See Moron-Puech B (2016), "Le droit des personnes intersexuées. Chantiers à venir", *La Revue des droits de homme* No. 11 (2016), mis en ligne le 23 décembre 2016, pp. 3-7.

24. Statement of Romain Blanchard, representative of the French *Défenseur des droits*, at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.

25. Klöppel U. (2016), Zur Aktualität kosmetischer Operationen "uneindeutiger" Genitalien im Kindesalter, Berlin, https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloeppel-2016_zur-aktualitaet-kosmetischer-genitaloperationen.

26. FRA (2015), Protection against discrimination on grounds of sexual orientation, gender identity and sex characteristics in the EU: Comparative legal analysis, Update 2015, Vienna, pp. 74-78. Note that this study was carried out prior to the changes to Maltese legislation discussed in section 5.3 below.

evidence of harm caused by these protocols has moreover still not led to radical change. Entrenched practices of performing early, irreversible genital surgery have continued, with only relatively minor changes in approach. Instead of ending such practices, the trend has generally been to seek to make more refined predictions as to the child's gender identity and to develop better surgical techniques.[27] Practitioners resistant to a fundamental change in approach have tended to reject arguments of principle based on respect for human rights and instead to highlight the diversity of situations arising and the need to leave medical practitioners leeway to deal with each case individually.[28]

4.3. Consequences of early sex-"normalising" surgery and treatments

24. One specific case (which has since become known as the "John/Joan" case) was pivotal in entrenching the practice of early genital surgery. In the late 1990s, follow-up research carried out into this case revealed that the long-term outcome had been very different from that claimed by psychologists and, furthermore, that there was no evidence to support immediate surgery as a best practice.[29] It is now clear that – whether they are biologically male, female or intersex – there is no way of knowing what a child's gender identity or sexual orientation will be, and that neither surgery nor rearing can determine these.

25. Accounts that have emerged since the late 1990s of intersex persons affected by early surgical and hormonal sex-assignment treatment show the devastating harm that these have caused in many people's lives. Physical harm typically includes various combinations of repeated surgery, irreversible scarring, incontinence, chronic urinary infections, the effects of castration, hormone imbalances, osteoporosis, loss of sensation, unwanted masculinisation or feminisation, vaginal narrowing and/or stenosis, dilation procedures. Psychological harm includes distress, depression, feelings of having been raped (in particular amongst persons having gone through vaginal dilation procedures), increased self-harming and suicidal behaviour.[30]

26. A small number of intersex people whose parents refused to agree to surgery have testified that they are grateful not to have been subjected to irreversible treatment without their consent.[31]

27. Medical practitioners continue to complain of a lack of long-term follow-up studies into the situation of both intersex people operated on in their infancy and/or childhood and those not subjected to surgery.Some practitioners suggest that since there is a mass of people who have never spoken out, it can be presumed that they are satisfied with the treatment administered and its outcomes. One obstacle to long-term studies is that intersex people are often lost to follow-up when they grow up, in particular when the transfer from paediatric to adult care is badly managed, or because they avoid contact with medical professionals.[32]

28. As regards prenatal treatment, the prenatal, off-label administration of dexamethasone to reduce virilisation in girls at risk of congenital adrenal hyperplasia (CAH) – which is initiated early in pregnancy, before prenatal testing for CAH is possible – has also been strongly criticised on ethical grounds[33] and this practice was discontinued in Sweden following a study demonstrating that it had adverse effects, notably impairing the verbal working memory of CAH-unaffected children exposed to the drug.[34] Other sources also point to increased risk of heart disease and diabetes as a result of prenatal exposure to dexamethasone.[35]

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27. Zillén K., Garland J. and Slokenberga S. (2017), op. cit., p. 42, and sources cited therein.
28. See for example Mouriquand P et al. (2014), "The ESPU/SPU standpoint on the surgical management of disorders of sex development (DSD)", *Journal of Pediatric Urology* No. 10(1), pp. 8-10.
29. Diamond M. and Sigmundson K. (1997), "Sex Reassignment at Birth: Long-Term Review and Clinical Implications", *Arch Pediatr Adolesc Med* No. 151(3), pp. 298-304.
30. See inter alia San Francisco Human Rights Commission (2005), A Human Rights Investigation into Medical "Normalisation" of Intersex People; New Zealand Human Rights Commission (2010), "To Be Who I Am": Intersex material from Report of the Enquiry into Discrimination Experienced by Transgender People; "Human rights and intersex people", Issue paper published by the Council of Europe Commissioner for Human Rights, April 2015 and sources cited therein; Sénat, rapport d'information n° 441 (2016-2017), footnote 8 above.
31. See, for example, the testimony of Hida Viloria, San Francisco Human Rights Commission (2005), A Human Rights Investigation into Medical "Normalisation" of Intersex People, and the statement of Dan Christian Ghattas at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.
32. Statement of Romain Blanchard, representative of the French *Défenseur des droits*, at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.
33. See *inter alia* Dreger A., Feder E.K. and Tamar-Mattis A. (2012), "Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine", *Bioethical Inquiry* No. 9(3), pp. 277-294.
34. Hirvikoski T. et al. (2012), "Prenatal Dexamethasone Treatment of children at Risk for Congenital Adrenal Hyperplasia: The Swedish Experience and Standpoint", *J Clin Endrocinol Metab* No. 97(6), pp. 1881-1883.
35. Council of Europe Commissioner for Human Rights (2015), "Human rights and intersex people", Issue paper, p. 20, and sources cited therein.

4.4. Shame, secrecy and pressure

29. Intersex people often face secrecy, stigma and shame. For the child, being inspected by and paraded in front of multiple doctors and medical students compounds their sense of difference and of shame.

30. Intersex children are often advised never to discuss their realities outside closed circles, and it can be extremely hard for intersex people to find a community. I was particularly moved by the accounts of Kitty Anderson and Dan Christian Ghattas during our hearing on 21 March 2017 as regards the impact on their well-being of long-term lying and secrecy (by both family and doctors), and of taboos and the sense of freakishness and hallucination created by the differences between others' denials and their own sensations. Yet all that would have been needed was acceptance and acknowledgement of the reality of their bodies.[36]

31. The way in which the medical profession announces an intersex variation can be crucial as far as the parents' bond with their child is concerned. When a variation in sex characteristics is presented as a pathology, abnormal, a problem, something that should be hidden or a crisis for the child and their parents, this isolates the child's parents and places pressure on them to "fix" the problem. If on the other hand being intersex is presented as a naturally occurring variation that is far more common than people realise, that can be talked about, and that is no hindrance to a healthy and happy life for the child, then there is no longer any reason for shame and secrecy for either the child or their parents.[37]

32. Providing non-judgmental and long-term support and counselling to intersex people and the parents of intersex children is crucial. In Malta, it is a legal requirement that all persons seeking psychosocial counselling, support and medical interventions relating to sex or gender should be given expert, sensitive, individually tailored support by psychologists and medical practitioners or peer counselling for as long as necessary.[38] Importantly in the context of intersex children, whose parents often feel lost and alone in the face of a complex situation for which they were unprepared, this means that not only the intersex person but also their parents and indeed any other concerned person are entitled to receive these services.

5. Human rights and ethical considerations as regards medical and surgical interventions on intersex children

33. In accordance with basic principles of bioethics, treatment should only be carried out if the expected benefits outweigh the risks, and with the free and informed consent of the patient.[39] There is growing acknowledgement that these principles have not been effectively applied in the past to the medical treatment of intersex people, including very young children, and that they urgently need to be applied now and in the future.

5.1. Positions taken at international level

34. There is now clear recognition at international level that performing unnecessary surgical procedures on intersex children that may have irreversible consequences, and administering other medical treatment having lifelong consequences, without the child being able to provide their consent, is contrary to international human rights standards.

35. In March 2007, a group of 29 eminent human rights experts from 25 countries and all continents across the globe adopted the now well-known Yogyakarta Principles, addressing the application of existing international human rights law to issues of sexual orientation and gender identity. Principle 18, on Protection from medical abuses, states that "no person may be forced to undergo any form of medical or psychological treatment, procedure, testing, or be confined to a medical facility, based on sexual orientation or gender identity. Notwithstanding any classifications to the contrary, a person's sexual orientation and gender identity are not, in and of themselves, medical conditions and are not to be treated, cured or suppressed". As regards measures that States should take to implement human rights in this field, it is recommended that they "take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered

36. Statements of Kitty Anderson and Dan Christian Ghattas, OII Europe, at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.
37. See Radio Télévision Suisse, "Un corps, deux sexes", 36.9°, programme broadcast on 14 November 2012.
38. Note, however, that so-called "conversion practices" that aim to change, repress or eliminate a person's sexual orientation, gender identity and/or gender expression are expressly prohibited under the Affirmation of Sexual Orientation, Gender Identity and Gender Expression Act, Cap. 567, 2016.
39. Principles of nonmaleficence and of double effect; principles of respect for autonomy and of informed consent.

by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration".[40]

36. In its Resolution 1952 (2013) on children's right to physical integrity, adopted in October 2013, the Assembly already recognised early childhood medical interventions on intersex children as belonging to a category of violations of the physical integrity of children, which supporters of the procedures tended to present as beneficial to the children themselves despite clear evidence to the contrary. It called on member States, *inter alia*, to ensure that "no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support".

37. In February 2013, the United Nations' Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment called on States to repeal any law allowing intrusive and irreversible treatments, including, *inter alia*, forced genital-normalising surgery or involuntary sterilisation, when enforced or administered without the free and informed consent of the person concerned.[41]

38. Numerous human rights treaty bodies of the United Nations, including the United Nations Committee against Torture and the United Nations Committee on the Rights of the Child, have in recent years also repeatedly voiced concern at unnecessary and irreversible surgical procedures being performed on intersex children, and other medical treatment having lifelong consequences being administered to them without their informed consent or that of their relatives, and without all options always having been explained to them. They have emphasised the failure to uphold the bodily integrity of children and the severe physical and psychological suffering entailed, and have expressed concern at the lack of inquiries into past practices and the lack of procedures for redress, rehabilitation, sanctions or reparation/compensation.[42] On the latter point, it is worth noting that the French Senate also recently recommended that the State consider granting compensation, possibly through a specific compensation fund, to individuals having suffered as a result of surgery or other irreversible treatment carried out on them due to a difference in sex development. I agree that the State has a duty to inquire into the harm caused to individuals by such practices and to grant compensation for such harm. Such an approach would moreover be more helpful to victims than requiring them to make individual claims for damages via the civil courts.

39. The World Health Organization and six other United Nations agencies have moreover called for stakeholders, "in the absence of medical necessity, when the physical well-being of a person with an intersex condition is in danger, if possible, [to] postpone treatment that results in sterilisation until the person is sufficiently mature to participate in informed decision-making and consent."[43]

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40. Yogyakarta Principles: Principles on the application of international human rights law in relation to sexual orientation and gender identity, March 2007.

41. Report of the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, 1 February 2013, A/HRC/22/53, paragraph 88.

42. See for example the most recent Concluding Observations of the United Nations Committee against Torture with respect to France (CAT/C/FRA/CO/7, 10 June 2016, paragraph 34), Denmark (CAT/C/DNK/CO/6-7, 4 February 2016, paragraph 42), Austria (CAT/C/AUT/CO/6, 27 January 2016, paragraph 44), Switzerland (CAT/C/CHE/CO/7, 7 September 2015, paragraph 20) and Germany (CAT/C/DEU/CO/5, 12 December 2011, paragraph 20), variously citing Articles 2, 12, 14 and 16 of the United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; the most recent Concluding Observations of the United Nations Committee on the Rights of the Child with respect to the United Kingdom (CRC/C/GBR/CO/5, 12 July 2016, paragraph 46(b)), Ireland (CRC/C/IRL/CO/3-4, 1 March 2016, paragraph 39), France (CRC/C/FRA/CO/5, 23 February 2016, paragraph 47) and Switzerland (CRC/C/CHE/CO/2-4, 26 February 2015, paragraph 42(b)), section dealing with Violence against children (articles 19, 24 (3), 28 (2), 34, 37 (a) and 39 of the UN Convention on the Rights of the Child); the Concluding Observations of the United Nations Committee on the Rights of Persons with Disabilities on the initial reports of Italy (CRPD/C/ITA/CO/1, 6 October 2016, paragraph 45) and of Germany (CRPD/C/DEU/CO/1, 13 May 2015, paragraph 37), citing article 17 of the United Nations Convention on the Rights of Persons with Disabilities.

43. World Health Organization (2014), Eliminating forced, coercive and otherwise involuntary sterilisation: An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Geneva, p. 14.

5.2. Ethics and informed consent

40. As noted above, very little data is available about long-term outcomes for intersex people, whether they were subjected to surgery in their infancy or not. Practices of operating on infants and young children continue despite this. From an ethical perspective, this is tantamount to conducting experiments on young children's bodies without their informed consent and without their parents being in a position to make an informed decision on behalf of their child.

41. Moreover, surgery and/or hormonal treatment that serves merely to "normalise" the appearance of genitalia (in other words, which has no therapeutic rationale) gives rise to substantial risks of harm – without there being evidence of benefits. Some argue that parents who choose not to have their children operated on are thereby forced to raise them as having a "third" gender, thereby creating social difficulties for their child. Yet this argument is spurious: first, social considerations should be clearly distinguished from medical matters, and questions of civil status can be regulated in non-discriminatory ways (see further below, on civil status). Second, parents who do authorise genital surgery usually do so based on their desire to prevent their child from facing stigmatisation based on their appearance during early childhood and up to adolescence. Yet adult intersex people frequently express the view that these decisions sacrifice their long-term sexual function, sensation and health. In essence, parents spontaneously tend to privilege appearance while their (adult) children would prefer to privilege function. This potential conflict of interests means that parents risk exceeding their parental authority in agreeing to medically unnecessary surgery on their intersex children. In short, even the informed authorisation of parents cannot make such surgery legitimate.[44]

42. The importance of free and informed consent is recognised by the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, "Oviedo Convention"), to which 29 member States are Parties. I welcome the fact that the Council of Europe's Committee on Bioethics is currently studying the challenges to children's rights in the field of biomedicine, including where issues of consent are concerned. An expert study recently commissioned by the Committee noted that "it is highly disputed whether gender modification techniques can be regarded as beneficial in the absence of a medical necessity" and that "as long as clinicians themselves do not agree on the advantages and disadvantages of these interventions, particularly if performed at a young age, the concept 'medical necessity' does not provide much certainty either". It found that some gender modification techniques used on intersex children (such as sterilisation or irreversible, involuntary and medically unnecessary procedures) could amount to a violation of their right to protection and physical integrity as well as of their right to preserve and maintain their identity, and that these matters fell within the responsibility of States. As far as participation in decision-making was concerned, it noted that "gender modification techniques on intersex children are generally conducted before the child is able to provide consent. Authorisation is provided by the parents who, even being well-intentioned, are often confused and under-informed". The study emphasised the need for concrete guidance, and possibly legally binding standards, on these matters.[45]

5.3. Recent developments in Council of Europe member States

43. The Swiss National Advisory Commission on Biomedical Ethics has found that all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself, except where a medical intervention is urgently required to prevent severe damage to the patient's body or health. It has emphasised that protection of the child's integrity is essential and that, given the uncertainties and imponderables involved, a psychosocial indication cannot in itself justify irreversible genital sex assignment surgery on a child who lacks capacity.[46]

44. In Germany, the Ethics Council has concluded that performing irreversible medical sex assignment procedures on persons of ambiguous gender infringes the right to physical integrity, to preservation of sexual and gender identity, to an open future and often also to procreative freedom. The Ethics Council has therefore recommended that such a decision should always be taken solely by the individual concerned. In the case of a minor, such measures should be adopted only after thorough consideration of all their advantages,

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44. Beh H.G. and Diamond M. (2005), "David Reimer's Legacy: Limiting parental discretion", *Cardozo Journal of Law and Gender* No. 12(1), pp. 5-30.

45. Liefaard T., Hendriks A. and Zlotnik D. (2017), From Law to Practice: Towards a roadmap to strengthen children's rights in the era of biomedicine, Leiden, 30 June 2017. This study is a counterpart to another study commissioned by the Committee on Bioethics and cited above: Zillén K., Garland J. and Slokenberga S. (2017), The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties.

46. 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, Berne, November 2012.

disadvantages and long-term consequences and for irrefutable reasons of child welfare. This is at any rate the case if the measure concerned serves to avert a serious concrete risk to the life or physical health of the affected individual.[47]

45. In France, it has been recognised that in the past, intersex situations were presented to parents as pathologies requiring treatment, but that parents were neither well informed nor in a position to decide on behalf of their children regarding such treatment – a situation that raises issues of medical liability that might be best addressed through collective compensation procedures.[48] The French Senate has since recommended that medical teams involve children with differences in sex development to the extent possible in any decision concerning them, based on the presumption that the child is capable of discernment; that the possibility of providing compensation to persons having suffered as a result of operations performed on them due to a difference in sex development be examined; and that questions concerning the situation of people with differences in sex development be referred to the national consultative committee on ethics. Bearing in mind the irreversible nature of gender assignment surgery, the Senate also expressed hope that a treatment protocol would shortly be established according to which the precautionary principle would be taken into account before conducting any surgery and the urgency and medical necessity of surgery would be evaluated, and families concerned would systematically be directed to specialised centres where their child could be supported by a multidisciplinary team.[49] The Interdepartmental Delegation on the fight against racism, antisemitism and anti-LGBT hate subsequently called for an end to operations on intersex children, characterising such operations, if conducted in the absence of imperative medical reasons, as mutilations.[50]

46. Malta is the first European State to have legislated specifically to protect the right to bodily integrity and physical autonomy of intersex people. The 2015 Gender Identity, Gender Expression and Sex Characteristics Act (GIGESC Act) (Article 14) makes it unlawful to conduct any sex assignment treatment or surgical intervention on the sex characteristics of a minor that can be deferred until the person concerned can provide informed consent. If the minor is able to give their informed consent through the person(s) exercising parental authority or the tutor of the minor, then such treatment or such an intervention can be carried out. To meet this condition, the minor has to understand what treatment is being proposed and to be able to express through their parents, in a way that can be documented, their wish to receive that treatment. My interlocutors at the Ministry explained that “sex assignment treatment” means both surgical and hormonal treatment and that, in essence, these provisions mean that any treatment or intervention that can be deferred until the child can provide informed consent should be deferred. Where a minor is expressing their consent through an adult, the paramount consideration shall be the best interests of the child as expressed in the United Nations Convention on the Rights of the Child.

47. The GIGESC Act further provides that in exceptional circumstances, treatment may be effected without the minor’s consent, where agreement is reached between an interdisciplinary team appointed by the Minister responsible for equality and the person(s) exercising parental authority or the tutor of the minor. Medical interventions driven by social factors without the minor’s consent are defined as being in violation of the Act.[51] It would only be in cases putting the child’s life in immediate danger or creating an immediate risk of grave harm to the health of the child that it would be possible to intervene without the informed consent of the child. The question whether cases of hypospadias are covered by the above prohibition may fall to be determined later by the courts.

48. Portugal is reported to be currently in the process of drafting a law similar to that of Malta.[52]

6. Long-term health-care needs of intersex people and access to medical records

49. Intersex people, like everyone else, have everyday health needs. Yet for many – treated like freaks, poked and prodded, paraded before medical students because their cases are relatively rare – trust in the medical profession is destroyed at a very young age. When secrets are kept from them about their bodies,

47. Deutsche Ethikrat, Intersexuality: Opinion, 23 February 2012.
48. Défenseur des droits, Opinion No. 17-04, 20 February 2017.
49. Sénat, rapport d’information n^{o} 441 (2016-2017), footnote 8 above, recommendations 3, 4, 5 and 8.
50. DILCRAH (Délégation interministérielle à la lutte contre le racisme, l’antisémitisme et la haine anti-LGBT), Plan de mobilisation contre la haine et les discriminations anti-LGBT: la République mobilisée contre la haine et les discriminations anti-LGBT, 2017, p. 25.
51. This is based on the above-mentioned opinion of the Swiss National Advisory Commission on Biomedical Ethics.
52. Information provided in a bilateral discussion with Portugal’s State Secretary for Citizenship and Equality, Catarina Marcelino, and at the seminar on Legal Gender Recognition that I attended on 31 March 2017 in Lisbon, organised by the Portuguese Commission for Citizenship and Gender Equality.

due to shame over their "abnormality", the sense of betrayal is multiplied. This lack of trust leads some adult intersex people to avoid medical consultations, even for matters that have nothing to do with their sex characteristics. More efforts are needed to ensure that intersex people have adequate access to health care that is patient-centred and based on the actual health needs of the individual.

50. Even where trust exists, transfer from paediatric to adult care can also, if badly handled, lead to a prolonged interruption in access to health care, or even to the person's being lost to follow-up.[53] This raises issues for the individual's access to health care generally.

51. It should also be of concern to medical professionals because it reduces the possibility of researching the long-term impact of treatment choices on intersex people.

52. Finally, it is crucial for intersex people to be able to have access to their medical records. Their situation having been surrounded for so long by stigma and shame, or considered as something to be "fixed" and then hushed up, they are frequently unable to obtain reliable information from any other source. The right of every person to know any information collected about their health is moreover recognised under Article 10 of the Oviedo Convention.

7. Civil status and legal gender recognition

53. As mentioned earlier, gender identity is distinct from a person's (biological) intersex status. Many intersex people identify as either male or female. However, others do not, and increasing numbers of intersex people have sought to be recognised as having another gender (non-binary, neutral, undetermined, unspecified, …).

54. A recent application by a French citizen to have their recorded gender changed to neutral was rejected by the Court of Cassation in April 2017, on the grounds that French law did not provide for gender markers other than male or female; although this was recognised to be an interference in the private life of the applicant, the Court of Cassation found that this was not disproportionate to the legitimate aim pursued.[54] In parallel, there has been some recent debate about possible changes to the law. Currently, parents have five days to declare the sex of their child, but a derogation for up to two years can be requested upon medical advice. The Senate has requested that this period be prolonged.[55] The *Défenseur des droits* has examined three options: removing all mention of a person's gender in their identity documents; creating a third gender category such as neutral; and making it easier to change one's legal gender. The last option was the position preferred by this institution, in line with procedures in place in Malta and Denmark. It should also be open to minors, on the basis of a request by their legal representatives and with a requirement that a judge verify that the child consented.

55. Today a number of States do provide for gender markers other than male or female. In Germany, since 1 November 2013, a newborn's gender marker must be left blank if the child cannot be identified as either male or female. In New Zealand, "indeterminate" birth certificates have been available since at least the 1950s.[56] In the United States, courts in Oregon and California have granted permission to at least seven individuals since mid-2016 to have their gender changed to non-binary.[57] In Australia, non-binary passports (using an "X" gender marker) have been issued since 2003. Initially issued only to persons holding a birth certificate that presents their sex as indeterminate, such passports have since 2011 been made available on the basis of a simple letter signed by a medical doctor.[58] In Australia, current government guidelines on the recognition of sex and gender note that "individuals may identify and be recognised within the community as a gender other than the sex they were assigned at birth or during infancy, or as a gender which is not exclusively male or female. This should be recognised and reflected in their personal records held by Australian Government departments and agencies". They expressly recognise that a person's sex and gender may not necessarily be the same and that intersex people may identify as male or female or neither. They provide that where sex and/or gender information is collected and recorded in a personal record, individuals

53. Crouch N.S. and Creighton S.M., "Transition of care for adolescents with disorders of sex development", *Nature Reviews Endocrinology* No. 10(7), pp. 436-442; statement of Dan Christian Ghattas at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.
54. Judgment No. 531 of 4 May 2017 (16-17.189) – Cour de cassation – Première chambre civile.
55. Sénat, rapport d'information n° 441 (2016-2017), footnote 8 above, recommendations 3, 4, 5 and 8.
56. Morgan, "Open birth sex assignments do not reduce surgical interventions", OII Australia, 4 November 2013.
57. O'Hara M, "Californian Becomes Second US Citizen Granted 'Non-Binary' Gender Status", NBC Out, 26 September 2016; "Court Rulings Raise Number of Legally Non-Binary Californians to Seven", NBC Out, 16 February 2017.
58. Morgan, "Ten years of 'X' passports, and no protection from discrimination", OII Australia, 12 January 2013.

should be given the option to select M (male), F (female) or X (Indeterminate/Intersex/Unspecified). The latter category refers to any person who does not identify as either male or female, i.e. who is of non-binary gender. A number of different terms may be used by these people to self-identify.[59]

56. The German legislation has been criticised by intersex activists as it is mandatory: the gender marker on a birth certificate is required to be left blank if the child's sex cannot be determined. This is problematic for several reasons. First, it is medical professionals who decide on this point. Second, it is not clear whom the child will be able to marry when they grow up – and, while it appears that the wording of the recently enacted legislation authorising same-sex marriage may have resolved this particular difficulty, questions remain about the possibility of adopting children. Third, when a child's gender marker is left blank it automatically outs them every time their birth certificate is presented anywhere (e.g. for enrolment in kindergarten or school). Germany is reportedly starting to consider whether gender markers should be included on birth certificates at all, since children do not actually have any need for them. Finally, leaving the gender marker blank or indeterminate provides no protection against surgical interventions on infants. The latter criticism has also been levelled against the New Zealand legislation.[60]

57. Malta's GIGESC Act simplifies the procedures that individuals need to follow in order to align their recorded gender with their gender identity. The State is also required to recognise gender markers other than male or female, or the absence thereof, that have been lawfully recognised by foreign courts or authorities. Malta's Civil Code provides that the sex of a minor is to be included in their act of birth, but that this may not be done until their gender identity is determined. This leaves scope, where necessary, for the gender marker included in a birth certificate to be left open until the age of 18. Malta has also been working in recent months to roll out non-binary X-gender passports and ID cards.[61]

58. As pointed out by Dr Benjamin Moron-Puech at the hearing held by our committee on 29 June 2017, the European Court of Human Rights has long since recognised that a person's sexual identity is one of the aspects of private life covered by Article 8 of the European Convention on Human Rights. This can be understood as implying both a "passive" (negative) obligation not to force an individual to reveal their sexual identity, and an "active" (positive) obligation, when recording or using a person's sexual identity, not to misrepresent it. Yet States frequently breach both of these obligations. They require individuals to reveal their sexual identity (on their birth certificate, passport, ID card, etc.) and take no issue with private parties requiring people to reveal their sexual identity in order to access a service. Moreover, intersex people who wish to avoid binary categorisation generally have no possibility of doing so. Even in Malta and Germany, the only option for intersex people other than identifying as male or female is to have no sexual identity recorded on their birth certificate or ID at all, effectively depriving them of the benefit of laws based on a person's sexual identity.

59. Dr Moron-Puech made four recommendations to overcome these human rights violations. First, every person should have the right not to disclose their sexual (or gender) identity, wherever revealing it does not correspond to any legitimate aim. This is a direct application of Article 8 to the case of intersex people. Second and in consequence, the mention of a person's sex on their ID documents must be optional for *everyone*. (If it is only optional for intersex people, they again risk being stigmatised.) States could of course go further, as indeed intersex people had called on them to do in their 2013 Malta Declaration.[62] Third, everyone should be recognised in the sexual (gender) identity of their choice – which must not be limited to masculine or feminine identities and for which some freedom must be left to the individual – in every rule or law of which the application depends on this identity. Of course, there must be no obligation on intersex people to identify as other than male or female, since some intersex people self-identify as men or women, and any other identity must be recognised only at the person's request. It must also be possible to change this identity, as intersex people's sexual (gender) identity may evolve over time. It must further be possible to identify differently in different circumstances (for example, as "X" in one's passport but as male in sporting

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59. Australian Government Guidelines on the Recognition of Sex and Gender, July 2013, updated November 2015. See paragraphs 1, 15, 19 and 20.

60. Ibid. and OII Europe, "Sham package for Intersex: Leaving sex entry open is not an option", 15 February 2013, and statement of Dan Christian Ghattas, at the hearing held by the Committee on Equality and Non-Discrimination on 21 March 2017 in Paris.

61. See Articles 4 and 9(2) of the GIGESC Act, Article 278(c) of the Civil Code and Press Release PR 170450 of 23 February 2017 of the Department of Information, Malta.

62. Technically speaking, making the mention of sex optional for all people could, for most documents, be achieved simply through issuing sub-statutory instruments or amending legislation. Removing the obligatory mention of a person's sex in their passport would however mean changing Doc 9303 of the International Civil Aviation Organisation (ICAO), which would require a decision adopted by a two-thirds majority of the ICAO Council. However, as most member States of the Council recognise the right to privacy under international law and/or in their Constitutions, such a change should be acceptable to them.

competitions). Fourth, all legal rules that rely on sex categories must be formulated in such a way as not to exclude persons with a non-binary sexual identity. This recommendation flows directly from the fact that Article 8 requires States to recognise non-binary sexual identities. This could be achieved in three ways: adding a third sex category (for example for rules on civil status, places of detention, or bathrooms/toilets); applying criteria other than sexual identity (for example, in sports); or removing sex categories from the relevant rules (e.g. on filiation). If the above four recommendations were implemented, intersex people's right to respect for their sexual identity would be upheld and the institutional discrimination described above would cease.

60. Bearing in mind that for the time being gender paradigms remain binary (our societies tend to categorise people as strictly either male or female), intersex organisations have called on governments to register all intersex children at birth as either female or male. However, they have emphasised that, like all people, intersex people may grow up to identify with a different sex or gender from the one registered. This means that sex or gender classifications need to be amendable through a simple administrative procedure at the request of the individuals concerned. Intersex organisations have further stressed, as regards gender markers, that all adults and capable minors should be able to choose between female, male, non-binary or multiple options. In the longer term, intersex organisations ask that sex or gender should in future not be a category on birth certificates or identification documents for anyone (as is already the case with respect to race or religion).[63]

8. Anti-discrimination measures and the promotion of equality

61. As was made clear to me during my fact-finding visit to Malta, a strong emphasis on anti-discrimination measures and the promotion of equality is needed in order to ensure that intersex people are able to fully enjoy their rights. However, few countries expressly cover the situation of intersex people in anti-discrimination law.

62. In 2013, Australia amended its anti-discrimination legislation in order to cover discrimination on grounds of sexual orientation, gender identity and intersex status.[64] "Intersex status" is defined in biological terms, as meaning "the status of having physical, hormonal or genetic features that are: a) neither wholly female nor wholly male; or b) a combination of female and male; or c) neither female nor male". Both direct and indirect discrimination are covered, as is discrimination by both private and public actors.

63. Malta has also legislated expressly to prohibit discrimination against intersex people.[65] In contrast with the Australian legislation, the word "intersex" is not used at all in the Maltese legislation. Rather, the GIGESC Act is consistently framed in terms of a person's "sex characteristics", which are defined as referring to "the chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and, or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and, or structure".[66] This is important for two reasons. First, it means that the Act is universal in scope – it is not addressed specifically to intersex people but to all people (as everyone has sex characteristics). The same rights are thus recognised for all people, making it clear that the Act does not create special rights for some people but equal rights for all. Second, my interlocutors explained that different actors may define the word "intersex" in different ways, and it was considered essential in the context of this Act to avoid restrictive interpretations that might deprive some intersex children of the protection against violations of physical integrity that the Act is intended to provide.

64. The Fundamental Rights Agency has emphasised that because being intersex is a question of bodily characteristics and is independent of a person's sexual orientation and gender identity, discrimination against intersex people is (in the absence of express grounds) better covered by sex discrimination than by discrimination on the grounds of sexual orientation or gender identity. Where a country's anti-discrimination law has an open list of grounds of discrimination, intersex people could be included in the category "other". However, this is unsatisfactory as it perpetuates the invisibility of intersex people and may lead to discrimination against them remaining unchallenged.[67]

63. Public Statement by the Third International Intersex Forum, Malta, 1 December 2013.
64. Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 (Cth).
65. See Article 13 of the GIGESC Act.
66. Article 2 (Interpretation) of the GIGESC Act.
67. FRA (2015), Protection against discrimination on grounds of sexual orientation, gender identity and sex characteristics in the EU: Comparative legal analysis, Update 2015, Vienna, p. 70-72.

65. I am of the opinion that anti-discrimination legislation will provide stronger protection to intersex people if it includes a clear and specific ground (such as discrimination on the basis of sex characteristics) that covers their situation. However, where such grounds have not been expressly included in legislation, the law must be interpreted broadly enough to cover discrimination against intersex people.

9. Public awareness-raising

66. Awareness of the situation of intersex people is growing, thanks to work at national level by the Maltese authorities and bodies such as the Swiss National Advisory Commission on Biomedical Ethics, the German Ethics Council, and the French Senate,[68] and of international bodies such as United Nations treaty bodies and the Council of Europe. Across Europe, the IDAHO Forum has also thrown an important spotlight on the situation of intersex people, notably in Budva (Montenegro) in 2015, where the Council of Europe Commissioner for Human Rights presented his issue paper on this subject, and in Brussels in 2017, where a full plenary session, which I had the honour of introducing, was devoted to this subject.[69]

67. Another key factor in improving public awareness of the crucial issues and rights at stake is the emergence of role models, such as internationally renowned Belgian model Hanne Gaby Odiele. Her decision to reveal in early 2017 that she is intersex sent a strong signal throughout the world that it is safe, comfortable and no barrier to success for intersex people to disclose their intersex status.

68. Nonetheless, and despite the fact that intersex people's biology shows this to be wrong, our societies continue to have a strongly binary vision of human beings as being male or female only. Media coverage is also rare and where it exists, tends to focus on "sensational" cases or on the field of sports, where intersex people are accused of cheating.

69. Public awareness-raising measures are crucial and urgently needed, not only in the context of support groups for intersex people, their parents and families, as discussed above, but also for the general public – including but not limited to teachers, social workers and members of the medical profession. For intersex people it is also extremely important to have the support of civil society organisations in which they can meet others with similar life stories: to know they are not alone, not freaks, and that someone understands them.

10. Conclusions

70. The term "intersex" is used to refer to a wide range of naturally occurring bodily variations. Intersex people are born with biological sex characteristics (including for example genital, hormonal or chromosomal characteristics) that do not fit societal norms or medical definitions of what makes a person male or female. Sometimes this is detected at birth; sometimes it only becomes apparent later in life, notably during puberty. While the variety of situations covered is broad, the majority of intersex people are physically healthy. Only a few suffer from medical conditions that put their health at risk.[70]

71. Intersex people's situation has nonetheless been treated for a long time as an essentially medical issue. The prevailing view since the middle of last century has been that intersex children's bodies can and should be made to conform to either a male or a female paradigm; that this should be done as early as possible; and that the children should then be raised in the gender corresponding to the sex assigned to their body. This has been seen as a guarantee that children will grow up healthy and will fit in easily in society.

72. Parents – who are the legal representatives of their children and authorise medical interventions on their behalf – often do not know how to react to the news that their newborn child is intersex. Often the only counselling that they receive is medical advice along the lines just described. This puts them under pressure to make urgent, life-changing decisions on behalf of their child.

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68. Outside the Council of Europe area, ground-breaking work has been done for example by the San Francisco Human Rights Commission (2005), the New Zealand Human Rights Commission (2010) and the Australian Human Rights Commission (2011) and government.

69. The IDAHO Forum has been organised annually in Europe since 2013 on the occasion of the International Day against Homophobia and Transphobia, as an event bringing together European ministers, government officials and civil society to discuss issues affecting LGBTI people. For the Issue paper of the Council of Europe Commissioner for Human Rights, see footnote 5 above.

70. See *inter alia* "Human rights and intersex people", Issue paper published by the Council of Europe Commissioner for Human Rights, Council of Europe, April 2015, pp. 13-14; "The fundamental rights situation of intersex people", FRA Focus Paper, Vienna, April 2015, p. 2; "Fact Sheet: Intersex" published by United Nations Free & Equal; definition of intersex used by OII Europe.

73. However, this approach often involves enormous breaches of physical integrity, including major surgical interventions such as castration and vaginoplasty, in many cases on 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 immediate danger to their health and no genuine therapeutic purpose for the treatment, which is intended to avoid or minimise social problems (which are outside the competence of medical professionals) rather than medical ones. It is often followed by life-long medical complications such as chronic urinary tract infections, debilitating pain, scarring and depression.

74. Such physical and emotional suffering is compounded by shame and secrecy when intersex children are told not to show their bodies and not to talk about their sex characteristics. Many parents and medical professionals hide from intersex children the fact that they have been subjected to medical interventions, including major surgical operations, or hide the nature of the operations, and intersex adults often have great difficulty accessing their full medical records later in life.

75. It is crucial to ensure that the law deals with these issues in a way that makes life easier for intersex people. This includes ensuring that intersex people who do not identify as male or female have access to the legal recognition of their gender identity, and that where their gender has not been correctly recorded at birth, rectifying this is simple. Anti-discrimination laws also need to be amended to ensure that the situation of intersex people is effectively covered.

76. While awareness of the situation of intersex people is gradually increasing, far more efforts are needed to continue raising public awareness as well as that of policy makers and medical professionals as to the situation and rights of intersex people, so as to ensure that they are fully accepted, whatever their sex characteristics.

77. States have a crucial role to play in eliminating human rights violations and discrimination against intersex people. I hope that this report will assist them on that path.