

OII Germany: CEDAW Shadow Report. With reference to the combined Seventh and Eighth Periodic Report from the Federal Republic of Germany on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). Compiled by Organisation Intersex International Germany. 2017.

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0. Preface and demands

OII Germany is submitting this alternative report as a complementary report to the CEDAW Alliance Alternative Report¹ in order to notify the Committee about recent and very worrying findings in regards to the number of feminizing surgeries performed on intersex individuals in Germany. OII Germany also aims to highlight some consequences of these findings in regards to specific CEDAW Alliances recommendations.

OII Germany calls on the German government to

1. *legally ban all non-life saving and normalizing practices – including genital surgeries and other medical treatment – which are performed to alter variations of sex characteristics, unless these procedures are wished for and consented to by the mature intersex individual themselves.*

OII Germany calls on the German Government and the German Länder to

2. ensure that refund policies of health insurance companies cover access to health care and preventive check-ups for everyone and *that for all people health insurance coverage is mandatorily connected to the actual body part and not to the person's legal gender/sex marker.*
3. include intersex as a healthy variation of the human body in all medical curricula and further training
4. fund human rights based medical research about the actual health needs of intersex people of all ages, taking into account the needs that come with different bodily variations
5. provide compensation for intersex individuals who have suffered from genital surgeries, gonadectomies and hormonal treatment performed without their personal and fully informed consent.

¹ CEDAW Alliance: *CEDAW Alternative Report. With reference to the combined Seventh and Eighth Periodic Report from the Federal Republic of Germany on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). Drafted and compiled by the CEDAW Alliance of civil society organizations in Germany.* 2016. https://www.frauenrat.de/fileadmin/user_upload/aktionen/cedaw-allianz/CEDAW_Alternative_Report_2016_long_engl.pdf (10.1.2017)

6. extend the retention period for medical records from 10 to 30 years, beginning with the age of maturity, in order to allow intersex people to access their records as capable adults
7. extent the statutes of limitation so that they match with the retention period.
8. fund the infrastructure for further professional peer-counselling options for intersex people and their families throughout the country, including training, networking and creating spaces for counselling opportunities
9. ensure that intersex issues are included from a non-medicalized, depathologizing and human rights based perspective in existing and future professional counselling centres
10. include intersex into all school curriculums in a positive, empowering and affirmative way
11. ensure that intersex children and adolescence, like girls and boys, find themselves reflected as healthy human beings in schoolbooks
12. take measures to ensure that teachers and other educational professionals know about the existence of intersex individuals and can have low threshold access to information about intersex from a human rights based perspective
13. use intersex as a chance of rethinking gender-differentiated legal norms towards a more equal legal system
14. analyse the 2013 amendment critically and to establish a clear and just system of civil status law. At present, it is up to the individual to address the many legal issues that resulted from the amendment, which constitutes a privatization of legislative duties
15. to ensure that sex or gender classifications are amendable for everyone through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.

1. Who are intersex individuals?

Intersex people are individuals whose sex characteristics do not conform to the normative male or female sex. Intersex variations are usually referred to by the medical establishment and by society as disorder/differences of sex development (DSD). Consequentially, intersex people are subjected to irreversible medical treatment to align their bodies with the societal expectation in regard to appearance and body function. These procedures include, but are not limited to: genital surgery performed without any pressing medical need, gonadectomies, which lead to a lifelong need for Hormone Replacement Therapy (HRT) and constitute forced or coercive sterilization, hormonal treatment to emphasize the assigned sex and long-term psychological intervention. Those who have endured prenatal, surgical and hormonal treatment without their fully informed, free and prior consent, often face a lifetime of health issues as a result of these violations of their bodily integrity, including physical and psychological impairment. Intersex bodies can have health issues - as can male and female bodies-, but in general they are healthy bodies in and of themselves.²

2. Who are intersex women?

Many intersex people are legally assigned female at birth, hence intersex girls, intersex female adolescents and intersex women live in Germany. They experience the same discrimination as non-intersex women and, in addition, they face specific human rights violations and discrimination due to their intersex bodies.

CEDAW prohibits every form of discrimination on the basis of gender: “*the term ‘discrimination against women’ shall mean any distinction, exclusion or restriction made on the basis of sex*” (Article 1). In 2009 the Committee supported a broad interpretation of its mandate by including intersex persons for the first time ever in the concluding observations of an UN treaty body.³ In 2016 the *General Comment Nr. 3 (2016)* by the *Committee on the*

² See also: UNOHCHR: *Fact Sheet Intersex*, https://www.unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf (10.1.2017)

³ Committee on the Rights of Persons with Disabilities (2016): General comment No. 3. Article 6: Women and girls with disabilities, CRPD/C/GC/3: “5. Women with disabilities are not a homogenous group. They include: [...] lesbian, bi-sexual, transgender women, and intersex persons”, p.2, <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> (10.1.2017)

Rights of Persons with Disabilities on Article 6: Women and girls with disabilities, followed by explicitly including “intersex persons” in the list of Women with disabilities.

We would like to thank the Committee for creating this precedence and for including intersex people explicitly in the concluding observations on France, Netherlands and Switzerland in 2016.⁴ As of now UN treaty bodies have followed the CEDAW’s 2009 lead more than 20 times and have pointed in their concluding observations to the human rights violations intersex people face all over the world⁵ - including in Germany.

3. Who is OII Germany

OII Germany was founded in 2008 and has worked on a national, regional and international level to end discrimination against intersex people and to ensure the right of bodily integrity and self-determination ever since. OII Germany was one of the driving forces behind establishing the International Intersex Forum in 2011 and co-formulated the charter of intersex human rights that was formulated by 30 intersex organizations at the 3rd International Intersex Forum in Malta, 2013 (*Malta Declaration*, for the full list of demands please see: <http://oiieurope.org/public-statement-by-the-third-international-intersex-forum/>).

OII Germany is regularly consulted by the German Institute for Human Rights, the Federal Antidiscrimination Agency and the Interministerial Working Group on Intersexuality and Transsexuality (IMAG). In 2015 OII Germany organised a briefing for the CRPD Committee on intersex (Geneva, 27th of March 2015). OII Germany is also part of an international intersex expert group working on the ICD revision.

⁴ CEDAW/C/FRA/CO/7-8; CEDAW/C/NLD/CO/6; CEDAW/C/CHE/CO/4-5

⁵ An overview of intersex related human rights documents, including the UN concluding observations, can be found on <https://oiieurope.org/wp-content/uploads/2016/03/International-intersex-human-rights-movement-Links-to-human-rights-documents-addressing-intersex-and-important-events.pdf> (10.1.2017)

4. Human Rights Violations faced by intersex individuals

4.1. Health

a) Genital surgeries performed in Germany on intersex girls under the age of 10

For the first time, comprehensive and sound quantitative data on cosmetic genital surgeries performed on children throughout Germany is available: The study, published in December 2016, is a retrospective statistical data assessment from the DRG-statistics (hospital statistics based on case flat rates) on feminising and masculinising genital surgeries carried out in German hospitals between 2005 and 2014.⁶ The study focuses on children under the age of 10. The most important findings are:

- On average, 99 feminising surgeries (plastic surgeries on vulva, vagina, clitoris, and perineum) *per year* were carried out in the period of investigation. In 2012 to 2014 the average number was still 91 procedures per year. Most feminising surgeries were plastic operations on the vulva (including perineum), the other procedures were clitoral surgery and vagina constructions. The average number of operations on the clitoris, which have clearly cosmetic reasons, was still 12 procedures per year in the period 2012 to 2014, for neo-vaginas the average was 8.
- The development of the relative frequency of feminising genital surgeries - total number of procedures analysed in relation to the number of diagnoses - in the period of investigation showed no clear tendency, in any case no significant decline.

All in all, the relative *frequency of feminising genital surgeries in childhood did not drop between 2005 and 2014*. But in the same period a significant change of underlying diagnoses took place: Whereas the relative frequency of ‘classic’ intersex diagnoses such as ‘pseudo-hermaphroditism’ decreased, the frequency of other diagnoses that make up the spectrum of variations of sex characteristics and which are summed up in the category ‘unspecified malformation of the female/male genitalia’ remained constant or even increased. In 2005, for example, 127 children were diagnosed with a “unspecified malformation of the female

⁶ Ulrike Klöppel: Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter. Berlin 2016, https://www.gender.hu-berlin.de/de/publikationen/gender-bulletins/texte-42/kloepfel-2016_zur-aktualitaet-kosmetischer-genitaloperationen (10.1.2017)

genitalia” (Q52 in ICD) and 165 children were diagnosed with a specified intersex diagnose. In 2014 though “unspecified malformation of the female genitalia” surpass specified intersex diagnoses by 40 diagnoses (Q52: n=140, specified intersex diagnoses n=100).

As it can be taken for granted that the biological phenomena themselves have not changed the question arises whether the shift of diagnoses is related to a change of diagnostic practices on the one hand and/or to an increase of medical abortions on the other hand.

The results of the study are worrying, especially in the light of recent statements of medical practitioners who declared that surgeries on intersex children have significantly decreased in the past years: In reality the number of genital operations has not dropped.

Masculinizing surgeries are very often performed to prevent so-called gender identity disorder and to allow for “masculine” instead of “feminine” behaviour (e.g. urinating in a standing instead a sitting position). These surgeries show the inherent misogyny that still affects all genders in Germany:

- The number of masculinising surgeries (plastic surgeries of the scrotum, testicles, and penis, including ‘corrections’ of hypospadias, that is relocating the urethral opening on the top of the penis) were rising in the period under study: from an average of 1601 *per year* in the period 2005 to 2007 it ascended to 1617 in 2012 to 2014. Most of these procedures were relocations of the urethral opening, but at the same time 10 to 16 % of children diagnosed with hypospadias underwent plastic reconstructions of the penis.
- The relative frequency of masculinising surgeries remained almost constant over the period of investigation.

Despite these alarming results the German government does not acknowledge the need for a comprehensive ban of non-life saving, genital surgeries on intersex infants and children. Instead, in the recently issued status report of the Interministerial Working Group on Intersexuality and Transsexuality (IMAG), the German government refers to an alleged change of mind of medical practitioners in regards to cosmetic surgery and trust their claim that surgeries on intersex children have decreased in the past years. The above figures clearly show, that what is happening is only a veiling shift of diagnostics and not a change of the actual surgical practice.

The position of the German government is even more incomprehensible considering the fact that in its 2016 report on the implementation of the rights of the child in Germany the Children's Commission of the German Bundestag has made very clear that intersex children's individual bodies and their developing individual identities have to be accepted by society from the very beginning.⁷ In its report the Commission emphasises the necessity to legally ban all non-life saving genital and sex altering surgeries on children, unless they are able to give their free and personal consent. Non-clinical, independent counselling should be mandatory for intersex children and adolescents and their families.⁸

b) Sterilisation

OII Germany agrees with the CEDAW Alliance on calling for a ban of sterilisation on intersex infants and children.⁹ However we want to strongly point out that ***banning sterilisation will not ban other feminizing surgeries on intersex infants and intersex children (see above)***. The CEDAW Alliance also calls for "the protection of intersex children against damaging surgical interventions done with the aim of removing gender ambiguity [...]".¹⁰ Again, ***banning surgical interventions that aim to prevent gender ambiguity will not ban all of the surgeries mentioned in the above findings***.

One of the DSD-diagnoses that results in one of the highest numbers of feminizing surgeries is a diagnose called CAH. Intersex girls with CAH and XX chromosomes are considered by medical specialist to have a clearly female gender identity. The rational for the non-consented sex altering surgery is therefore three-fold:

⁷ "Die Körperlichkeit und individuelle Identitätsentwicklung ist von Anfang an zu akzeptieren. Wichtig ist, unsere Sprache sowie die gelebte Praxis im medizinischen wie auch gesellschaftlichen Umfeld zu entpathologisieren und nicht nur auf die weibliche und männliche Form zu beschränken.", Deutscher Bundestag. Kommission zur Wahrnehmung der Belange der Kinder (Kinderkommission): Stellungnahme der Kinderkommission des Deutschen Bundestages zur Umsetzung der Kinderrechte in Deutschland. Kommissionsdrucksache 18. Wahlperiode 18/13. Berlin, 22. Juni 2016, p. 6.

⁸ "Irreversible Entscheidungen, welche die Selbstbestimmung des Kindes sein Leben lang beschränken und beeinträchtigen können, entziehen sich der Entscheidungsbefugnis von Eltern und medizinischem Personal. Genitale und geschlechtsangleichende Operationen an nicht einwilligungsfähigen Kindern müssen, außer das Kind schwebt in Lebensgefahr, verboten und die Betroffenen vor Kastration geschützt werden. An das Verbot von Operationen sollte eine außerklinische Beratung und Begleitung von Kindern und Jugendlichen und ihrer Familie verbindlich gekoppelt sein", *ibid.*, p. 6-7

⁹ CEDAW Alliance (2016): CEDAW Alternative Report, p. XIV

¹⁰ *ibid.*, p. 29.

- a) to support an allegedly female gender identity by removing sex characteristics (e.g. by clitoral recession/reduction) that are assumed to disturb the girl when she grows up, and
- b) to support the girl to socially integrate in their family and their social environment;¹¹
- c) to prepare for penetrative intercourse of the future woman (e.g. vaginoplasty in infancy and early childhood in case of intersex people diagnosed with CAH)¹²

All these surgeries are high risk surgeries, that often result in follow-up surgeries and can cause severe health problems.¹³

When performed on infants and girls they are clearly performed without the intersex person's free and fully informed consent and violate the right to sexual and reproductive self-determination of the intersex girl as well as of the future intersex woman.

OII Germany therefore calls on the German government to

- *legally ban all non-life saving and normalizing practices – including genital surgeries and other medical treatment – which are performed to alter variations of sex characteristics, unless these procedures are wished for and consented to by the mature intersex individual themselves.*

c) Access to health for intersex women of all ages

Intersex individuals are still not part of the general medical curriculum. There is a substantial lack of follow-up research and long-term evaluation on health implications of surgeries and hormonal treatment that have been and are performed on intersex individuals. This is

¹¹ Olaf Hiort et al., “Management of Disorders of Sex Development,” *Nature Reviews Endocrinology* 10, no. 9 (July 15, 2014): 520–29, doi:10.1038/nrendo.2014.108; see also: Vickie Pasterski et al., “Predictors of Posttraumatic Stress in Parents of Children Diagnosed with a Disorder of Sex Development,” *Archives of Sexual Behavior* 43, no. 2 (February 2014): 369–75, doi:10.1007/s10508-013-0196-8.

¹² Intersex Issues in the International Classification of Diseases: a revision (2015), p. 7 <https://globaltransaction.files.wordpress.com/2015/10/intersex-issues-in-the-icd.pdf> (10.1.2017)

¹³ Callens N.: *The past, the present, the future: Genital treatment practices in Disorders of Sex Development under scrutiny*. Gent, Belgium: Universiteit Gent; 2014 p. 56

worrying for intersex people of all ages and especially for elderly intersex people. As the first wave of intersex individuals that have been subjected to “normalizing” medical treatment since the 1960ties is now reaching retirement age. So far intersex issues are not mandatorily included in trainings in the field of care of the elderly or nursing education, which leaves intersex people in a very vulnerable position.

In general, access to general healthcare for intersex women in Germany is impaired by a huge lack of knowledge, by prejudices of healthcare professionals and the refund policies of health insurance companies or where the medical history of a person matters (e.g. private health insurance, own-occupation disability insurance). The accessibility to particular services (e.g. availability of preventive check-ups for certain conditions or general health services) is related to the sex/gender of the individual seeking the service is not guaranteed: Intersex individuals, for example, who are assigned female but have body parts that are considered to be male (e.g. prostate) will often not be able to obtain a preventive check-up for the respective body part (see also § 4.1.d). Disbelief, lack of knowledge, mistreatment, and violence expressed by health care personnel can lead intersex people to avoid seeking healthcare (for testimonies please see Appendix).

d) “Intersex” as sex category in health related documents

The CEDAW Alliance calls on “intersex to be recognized and introduced as a sex category in vital records”.¹⁴ These call affects different areas of live, including intersex person’s access to health. Therefore, OII Germany would like to point out some possible and unfortunate consequences of an “intersex” sex marker in regards to health insurance coverage. (OII Germany’s recommendations about sex markers in official documents can be found in § 4.4.) *Background information:* Currently health insurance coverage is tied to a person’s legal gender in Germany. As a result, the possibility to get medical examination of body parts that are not considered to belong to the respective gender can be limited or impossible.¹⁵

Challenges:

¹⁴ CEDAW Alliance (2016): CEDAW Alternative Report, p. 17.

¹⁵ Dan Christian Ghattas (2013): *Human Rights between the sexes. A preliminary study on the life situations of inter* individuals*. Ed. By Heinrich Böll Foundation. Berlin 2013, p. 23 and 33.

a) Since the *2013 Civil Status Act* the sex marker on the birth certificate mandatorily needs to be left blank if the sex of the child cannot be determined as male or female. There is a danger that an “intersex” sex entry will follow the same legal pattern.

b) In addition, the implementation regulations of the *2013 Civil Status Act* leave the decision about the child’s sex to the medical practitioner. It is likely that an implementation directive for an “intersex” sex entry in vital documents will be handled similarly. In regards to the current diagnostic shift from specified intersex diagnoses towards “unspecified malformation” diagnoses (see above § 4.1.a) there is the danger that an entry like “intersex”, even if available for people with a specified intersex diagnosis, will hence only be available for some intersex people - intersex people with an “unspecified malformation” diagnosis, or those who are considered to have a clear sex, or those who have no diagnose at all, might be left in the same vulnerable position as they are now.

In regards to intersex individuals’ access to health OII Germany therefore recommends another approach, which is based on the French model.¹⁶

OII Germany calls on the German Government and the German Länder to

- ensure that refund policies of health insurance companies cover access to health care and preventive check-ups for everyone and *that for all people health insurance coverage is mandatorily connected to the actual body part and not to the person’s legal gender/sex marker.*
- include intersex as a healthy variation of the human body in all medical curricula and further training
- fund human rights based medical research about the actual health needs of intersex people of all ages, taking into account the needs that come with different bodily variations
- provide compensation for intersex individuals who have suffered from genital surgeries, gonadectomies and hormonal treatment performed without their personal and fully informed consent.

¹⁶ The comparative analysis “Human Rights between the sexes” published in 2013, found that of the 4 included EU countries only French intersex people had no difficulties to obtain coverage for examination and treatment of non-normative body parts; see *ibid.*, p. 23 and 32.

- extend the retention period for medical records from 10 to 30 years, beginning with the age of maturity, in order to allow intersex people to access their records as capable adults
- extent the statutes of limitation so that they match with the retention period.

4.2 Access to Counselling

Currently only three (part-time) paid positions exist, that provide professional counselling for intersex people and their families from a non-medicalized, depathologizing and human rights based perspective. Two of them are based in Berlin (*Inter* und Trans* Beratung Queer Leben*, Schwulenberatung e.V.; *Trans*- und Inter*-Beratung*, TransInterQueer e.V.) and one in Emden, in the North of Germany (*Inter* Beratungsstelle*).

OII Germany therefore calls on the German Government and the German Länder to

- fund the infrastructure for further professional peer-counselling options for intersex people and their families throughout the country, including training, networking and creating spaces for counselling opportunities
- ensure that intersex issues are included from a non-medicalized, depathologizing and human rights based perspective in existing and future professional counselling centres

4.3 Education

As the concept of binary gender is a social norm that is deeply embedded in institutions, regulations and everyday practices, bodies and behavioural patterns that do not meet the norms are constantly threatened to be sanctioned - in subtle discriminatory and openly violent ways.

Problems can exist for intersex people in educational settings from the very outset. Intersex people are not constructively included in any educational curriculum and, other than as examples for physical malformation, they do not appear in school books.¹⁷ In addition, sex education does not refer to their existence or their bodily experience. Instead, it tends to perpetuate the notion that only two sexes exist.

In addition, as there is no accessible information that would prepare children and adolescents for the fact that bodies can develop in variations of female and male the intersex person will usually be in charge of educating their peers, which places that individual in a very vulnerable position. These experiences can increase the feeling of shame, secrecy, not existing at all or being a fraud at a vulnerable age.

OII Germany therefore calls on the German Government and the German Länder to

- include intersex into all school curriculums in a positive, empowering and affirmative way
- ensure that intersex children and adolescence, like girls and boys, find themselves reflected as healthy human beings in schoolbooks
- take measures to ensure that teachers and other educational professionals know about the existence of intersex individuals and can have low threshold access to information about intersex from a human rights based perspective

¹⁷ Melanie Bittner (2011): Geschlechterkonstruktionen und die Darstellung von Lesben, Schwulen, Bisexuellen, Trans* und Inter* in Schulbüchern, <https://www.gew.de/ausschuesse-arbeitsgruppen/weitere-gruppen/ag-schwule-lesben-trans-inter/ratgeber-praxishil-fe-und-studie/gleichstellungsorientierte-schulbuchanalyse/> (10.1.2017)

4.4 Discrimination on the basis of the blank civil status after the 2013 Civil Status Act (in force since 1st of November 2013)

Since the 2013 Civil Status Act, it is mandatory for the sex marker on the birth certificate to be left blank if the sex of a child cannot be determined as male or female. The prerogative of interpretation about whether or not a child is intersex lies with the medical experts right after birth. This procedure results in a risk of recognizing only certain forms of intersex variations. Other forms, which only emerge at a later stage might be excluded. Neither the handling of those cases nor the question of the possibility to subsequently modify a birth certificate - including the birth certificates of intersex people who were born after the amendment of the Civil Status Act and had wrongfully been assigned a male or female sex – has been regulated so far. Thus, individuals, who were denied a claim to amend their certificates, had to seek judicial clarification and were only in August 2016 granted a right to do so by a jurisdiction of Germany’s Federal Court of Justice (Bundesgerichtshof).¹⁸ This privatization of legislative duties has to be seen very critical.

Furthermore, a blank civil status does not necessarily lower the pressure on parents to consent to genital surgeries, since it does not guarantee an equal civil status with the other sexes and might instead lead to further discrimination.

The German legal system is based on the idea of the binarity of sexes. Therefore, the amendment lead to numerous legal issues concerning family law, law of descent, rights of non-marital partnerships and registered partnerships.¹⁹ Those questions concern fundamental rights but have nonetheless not been addressed by the German government since 2013.

OII Germany therefore calls on the German Government and the German Länder to

¹⁸ BGH XII ZB 52/15 22. Juni 2016, 23, p. 8, <http://juris.bundesgerichtshof.de/cgi-bin/rechtsprechung/document.py?Gericht=bgh&Art=en&nr=75539&pos=0&anz=1> (10.1.2017)

¹⁹ Konstanze Plett: *Diskriminierungspotentiale gegenüber trans- und intergeschlechtlichen Menschen im deutschen Recht sowie Skizzierung von Lösungswegen zu deren Abbau und zur Stärkung der Selbstbestimmungs- und der Gleichbehandlungsrechte trans- und intergeschlechtlicher Menschen. Eine Expertise im Auftrag der Landesstelle für Gleichbehandlung – gegen Diskriminierung (Landesantidiskriminierungsstelle) der Senatsverwaltung für Arbeit, Integration und Frauen Berlin, Fachbereich für die Belange von Lesben, Schwulen, Bisexuellen, trans- und intergeschlechtlichen Menschen (LSBTI)*. Berlin 2016

- use intersex as a chance of rethinking gender-differentiated legal norms towards a more equal legal system
- analyse the 2013 amendment critically and to establish a clear and just system of civil status law. At present, it is up to the individual to address the many legal issues that resulted from the amendment, which constitutes a privatization of legislative duties
- to ensure that sex or gender classifications are amendable for everyone through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.^{Remark}

***Remark:** OII Germany recommends not to use the term “intersex” for such a gender marker. “Intersex” as a term should be reserved to address bodily variations of sex characteristics that people can be born with regardless of their gender identity. Establishing “intersex” as a third gender marker, as called for by the CEDAW Alliance, carries two dangers: (1.) either this gender marker will, like the current blank marker, be restricted to those people with medically specified intersex diagnoses; those may become less and less in the future according to the diagnostic shift (see above § 4.1.a); (2.) or, if the gender marker entry would be optional on request for everybody, then using the term “intersex” as place-holder for a non-binary gender identity will make the specific human rights violations invisible that intersex people face due to their non-normative body. Therefor our demand (as stated above) is in line with the Malta Declaration of the Third International Intersex Forum.*

Appendix: Testimonials on access to health

(1)

An intersex woman from Germany reported to OII Germany that she was regularly scolded since the beginning of puberty by different gynaecologists for not “allowing” them to insert their speculum in her vagina. Some of them went as far as to tell her that she should seek psychiatric help, implying that she was frigid. This intersex person has an intersex body and a variation that can cause a very narrow vagina. As a result, these kinds of bodies make it impossible to even use the smallest speculum (designed for girls), without causing substantial pain. As a result of these traumatizing experiences the intersex woman refuses to visit gynaecologists and has not had a preventive check-up in 8 years.

(2)

The intersex person represented in the following case was not detected as intersex at birth but was considered to be a girl and was assigned as such. As they grew up their body started to show more signs of its intersex variation. At the age of 32, still being legally a woman but having developed a male gender identity, they finally tried to get a medical explanation of their bodily variation and to learn more about possible health implications of an aging intersex body with this variation. At first their general practitioner refused to transfer them to a specialist for lack of “intersex symptoms”. Finally, the intersex person went to see three different endocrinologists, two of which were located in the person’s home town, one of Germany’s major cities. Both had been recommended as experts on intersex by different practitioners. The third one is a known German DSD/intersex specialist, but was based more than 400 km from the intersex person’s home town.

The first endocrinologist performed a blood test, checking the testosterone level and those chromosomes that are considered to determine a person’s sex as well as other chromosomes. The latter clearly showed a variation that occurs with certain intersex bodies. When the intersex person asked the endocrinologist for an explanation the doctor became very angry and said: “Basically they show that you should not exist”.

The second endocrinologist on the other hand flatly denied that the findings showed any intersex specific chromosomal variation – although they clearly did – and claimed that many women had a higher level of testosterone, that therefore there was no need to legally change

gender and that she, the endocrinologist, being also a gynaecologist, would have to perform an examination of the intersex person's genitals in order to verify that the intersex person was really intersex. When the intersex person refused this and asked again for an explanation of the findings, the doctor basically threw him out.

The third endocrinologist, one of the German DSD/intersex specialists, refused any further examination of the intersex person's case and actual physical needs. This refusal was given after the intersex person had been very decisive about the fact that he had no wish for the feminizing hormonal treatment, which the endocrinologist considered to be medically indicated for this kind of intersex variation. As a result of these and other traumatizing experiences the intersex person has since abstained from contacting any endocrinologist about possible health issues known to be in some cases related to the intersex variation they have.

(3)

The intersex person represented in the following case was not detected as intersex at birth but was considered to be a girl and was assigned as such. With the beginning of puberty bodily changes began to develop in a masculine way. The intersex person began to grow taller than the other girls (183cm when 14 years old), the voice dropped, body hair appeared, including beard growth which the intersex person tried to hide under their long hair, but eventually began to secretly shave every morning before school. The clitoris grew and could arouse. There was almost no breast development. At first these changes seemed interesting to the intersex person until they came to realise that no other girl underwent such changes and was often called or mistaken for a „boy“ in public. Also bullying began in school due to looking different from the other youths. The intersex person was trying to hide those changes (wearing long sleeves and trousers during summer time to cover up arms and legs, wearing sport clothing underneath to prevent to undress in changing rooms).

They waited for a menstruation that never appeared, then with the age of 17 decided to consult a gynaecologist. The doctor told the intersex person that they should have become a boy and that they could never become pregnant due to a missing uterus, and referred to specialists for further check-up.

At the Humangenetic Institute the intersex person was informed by the specialists with what later in life turned out to be deliberate misleading and false information about „cancerous

ovaries“ to persuade the intersex person to the removal of the gonads (gonadectomy). Without much explanation the intersex person was then asked to undress and stand in front of a medical grid for medical photos, arms spread out to the sides, the insides of the hands facing the camera. At this point the intersex person felt overwhelmed with the information of being seriously ill and therefore was unable to refuse this request. The shame and helplessness of being naked and photographed forced the intersex person to imagine themselves out of their body, hiding in a small space behind the eyes.

The evening before the surgery to remove the „inflamed ovaries“ the doctor and chief of the department of the hospital examined the intersex person on a gynaecologist chair, recommending to also remove the „enlarged“ clitoris, which was bothersome to being a woman. The intersex person declined. The doctor insisted, so the intersex person asked if there was a cancer risk if the clitoris is not removed to which the doctor replied „no“. The intersex person declined a second time which then was accepted with a mention that this can also be done a later date (at that time the intersex person was 18 years old which is the age of majority in Germany).

Hormone replacement therapy (HRT) with oestrogen began after the surgery, it was not clearly explained to the intersex person that this would now be required for the rest of their life because of health risks. Due to the HRT the intersex person's body began to develop more feminine features and they tried to live and pass as a woman. Each time at the yearly check-up with the gynaecologist they were offered to have the clitoris removed or reduced, which the intersex person always declined.

Rather by chance the intersex person found out about the term intersex and personal testimonials of similar experiences through the internet and began to research what really happened, twelve years after the surgery, now age 29. They ordered copies of their medical records which clearly stated findings of a 46-XY („male“) karyotype, of benign and healthy abdominal testes and further medical but also other details, for example in conversation to the transferring doctor the instruction to never tell the person the truth about their intersex status in order to protect them from psychological distress.

The same year the intersex person stopped their HRT and a few years later switched to the HRT with testosterone to simulate the original hormonal balance. The process to come to terms with the experiences and facts took many years, and when the intersex person considered to seek legal measures to sue the hospital and doctors for their mistreatment, the

possibility of filing a court case had already expired. In 2015 they requested to have the gender marker of „female“ changed to „blank“ in their documents.

Because of these traumatic and violating experiences with doctors the intersex person is very reluctant to trust medical personal or seek medical assistance, even when needed.