

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). Consequently, 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,¹ 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 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. Human Rights Violations faced by intersex individuals in Germany

2.1. Harmful medical practices: Genital surgeries performed in Germany on intersex infants and children under the age of 10 (violating UDHR Art. 2, Art. 3, Art. 5, Art. 12, Art. 25.2 and ECHR Art. 3, Art. 8.1, Art. 13, Art. 14)

Since 2016 comprehensive and sound quantitative data on cosmetic genital surgeries performed on children throughout Germany is available: The study 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

¹ A gonadectomy is the removal of gonads, i.e. hormone producing tissue (e.g. testies and ovaries)

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

2005 and 2014.³ 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 between 2005 and 2014. In 2012 to 2014 the average number was still 91 per year. Most feminising surgeries were plastic operations on the vulva, others were clitoral surgery and vagina constructions. The average number of operations on the clitoris, which have clearly cosmetic reasons, was 12 procedures per year from 2012 to 2014, for neo-vaginas the average was 8.
- 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 (e.g. ‘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 an “unspecified malformation of the female genitalia” (Q52 in ICD) and 165 children were diagnosed with a specified intersex diagnosis. In 2014, though, “unspecified malformation of the female genitalia” surpassed specified intersex diagnoses by 40 diagnoses (Q52: n=140, specified intersex diagnoses n=100).

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):

- The number of masculinising surgeries (plastic surgeries of the scrotum, testicles, and penis, including ‘corrections’ of hypospadias⁴) increased from 2005 to 2014: 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

³ 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)

⁴ Hypospadias „correction“ or „repair“ is relocating the urethral opening on the top of the penis.

same time 10 to 16% of children diagnosed with hypospadias underwent plastic reconstructions of the penis.

- ***All in all, the relative frequency of masculinising surgeries remained almost constant over the period of investigation.***

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.

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.

In 2016 the Children's Commission of the German Parliament (Kinderkommission des Bundestages) stated that intersex children's bodies and their developing identities have to be accepted by society from the very beginning.⁵ It also emphasised 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.⁶

Recommendation:

- *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.*

⁵ “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.

⁶ “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

2.2) Lack of access to health for intersex people of all ages and discrimination and maltreatment in medical settings

(violating UDHR Art. 22, Art. 25.1 and EDHC Art. 3, Art. 13)

Access to general health care for intersex people in Germany is impaired by a 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. preventive check-ups, general health services) is related to the official sex of the individual seeking the service and is therefore not guaranteed.⁷ Mistreatment and violence expressed by healthcare personnel can lead intersex people to avoid seeking healthcare. Parents of intersex children report that doctors invite students to the examination of the child's inner or outer genitals, hence violating the child's right to privacy.⁸

In addition, 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. Due to small retention period for medical records, as adults, intersex people very often do not have access to their medical records. This hinders them not only to seek compensation for the harm done but also can make it difficult for them to know what specific surgeries and medical treatment they have undergone in the past. As a result, it can be difficult to obtain adequate medical care. Intersex issues are not mandatorily included neither in medical curricula nor in trainings in the field of care of the elderly or nursing education, which leaves intersex people in a very vulnerable position.

⁷ 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.

⁸ Testimonials can be found in: Amnesty International (2017): First do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany: „When our daughter was examined by a radiologist to determine what sex organs she had inside her body I was so angry. I simply wanted to come to terms with what I was being told. But the doctor had brought students to sit in on the consultation. It was me who had to tell him: I only want people here who need to be here as part of this conversation. Did he treat us as parents sensitively? No!“ (p. 30)

Recommendations:

- *Refund policies of health insurance companies should 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.*⁹ *The Ministry of Health should advise to the German Joint Government Committee (Gemeinsamer Bundesausschuss, G-BA) to include a respective paragraph in the catalogue of services covered by public health insurances.*¹⁰
- *To 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*
- *To provide compensation for intersex individuals who have suffered from genital surgeries, gonadectomies and hormonal treatment performed without their personal and fully informed consent.*
- *To change the law in order to extend the retention period for medical records from 10 to 30 years,*¹¹ *beginning with the age of maturity, in order to allow intersex people to access their records as capable adults*
- *To change the law in order to extent the statutes of limitation (according to § 197, § 199 Abs. 2 BGB)¹² so that they match with the recommended retention period of 30 years.*

⁹ This recommendation is based on the French model: 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.

¹⁰ The Federal Ministry of Health is the legal supervising body of the G-BA. The G-BA is the body who decides on the catalogue of services reimbursed by the public health insurances. Public health insurance is statutory unless one chooses a private health insurance instead. As a general rule, private health insurances usually cover more services than the public ones.

¹¹ As a general rules medical records are kept by law for 10 years; only some medical records, e.g. those that fall under federal radiation protection law, have to be kept for 30 years.

¹² § 197, § 199 Abs. 2 BGB extends the Statutes of limitation to 30 years for claims for damages based on intentional injury to life, body, health, freedom or sexual self-determination; the 30 years start when that injury occurred, which is very problematic for intersex adults that have been violated as infants or children.

2.3 Lack of access to Counselling (violating UDHR Art. 22, Art. 25.2 and EDHR Art. 14)

Parents and families of intersex infants and children as well as intersex people themselves face a huge lack of access to counselling. Parents often are only informed by medical personnel and are not presented with the variety of options available.¹³ Currently only three paid positions exist, that provide professional counselling for intersex people and their families from a non-medicalized, depathologizing and human rights based perspective.¹⁴

Recommendations:

- *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*
- *To ensure that intersex issues are included from a non-medicalized, depathologizing and human rights based approach in existing and future professional counselling centres*

2.4 Discrimination in educational settings (violating UDHR Art. 22, Art. 26.2 and EDHR Art. 14)

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.¹⁵ In addition, sex

¹³ A lot of testimonials can be found in: Amnesty International (2017): First do no harm. Ensuring the rights of children with variations of sex characteristics in Denmark and Germany: „Gerda Janssen-Schmidchen from Intersexuelle Menschen described the experiences many parents have of visiting the doctor, ‚for example, if I have a child and I go to the doctor with my child and they see that the genitals are different and the doctor asks me if I feel uneasy in a way that suggests I should actually feel uneasy. Even the way they talk – it’s about the wording that you use, it has an impact. Maybe the parent thought everything was OK and now they are worried’.“ (p. 31).

¹⁴ 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*)

¹⁵ 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->

education does not refer to their existence or their bodily experience. Instead, it tends to perpetuate the notion that only two sexes exist. These experiences can increase the feeling of shame, secrecy, not existing at all or being a fraud at a vulnerable age.

Recommendations:

- *Fund research on how to develop and implement measures that ensure the inclusion of intersex people and issues into all school and university curriculums, including medical curricula, in a positive, empowering and affirmative way.*¹⁶
- *Fund measures to ensure that teachers and other educational professionals know about the existence of intersex individuals and can have simple access to information about intersex from a human rights based perspective*

2.5 Discrimination on the basis of the blank civil status after the 2013 Civil Status Act, in force since 1st of November 2013 (violating UDHR Art. 16.1, Art. 22, Art. 29.2 and ECHR Art. 12, Art. 14)

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. Other forms, which only emerge at a later stage might be excluded. Adult intersex individuals, who were denied to amend their certificates on the basis of the 2013 Civil Status act, had to seek judicial clarification and were only in August 2016 granted to do so by a jurisdiction of Germany's Federal Court of Justice (Bundesgerichtshof).¹⁷ This privatization of legislative duties has to be seen very critical.

[schwule-lesben-trans-inter/ratgeber-praxishil-fe-und-studie/gleichstellungsorientierte-schulbuchanalyse/](#) (10.1.2017)

¹⁶ Education is part of the responsibility of the German Länder and not of the Federal government, therefore the State Party cannot directly influence e.g. school curricula or school books.

¹⁷ 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)

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 amendment lead to legal issues concerning family law, law of descent, rights of non-marital partnerships and registered partnerships.¹⁸ Those questions have not been addressed by the German government since 2013. Marriage equality, which was established in 2017, still only covers people of different or same sex, hence excluding people whose sex has not been registered or has been removed.¹⁹

Recommendations:

- *To ensure that sex or gender classifications are amenable 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.*

¹⁸ 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

¹⁹ *Gesetz zur Einführung des Rechts auf Eheschließung für Personen gleichen Geschlechts* (20.7.2017), Article 1: „Die Ehe wird von zwei Personen verschiedenen oder gleichen Geschlechts auf Lebenszeit geschlossen“ (Bundesgesetzblatt Jahrgang 2017 Teil I Nr. 52, ausgegeben zu Bonn am 28. Juli 2017 2787).