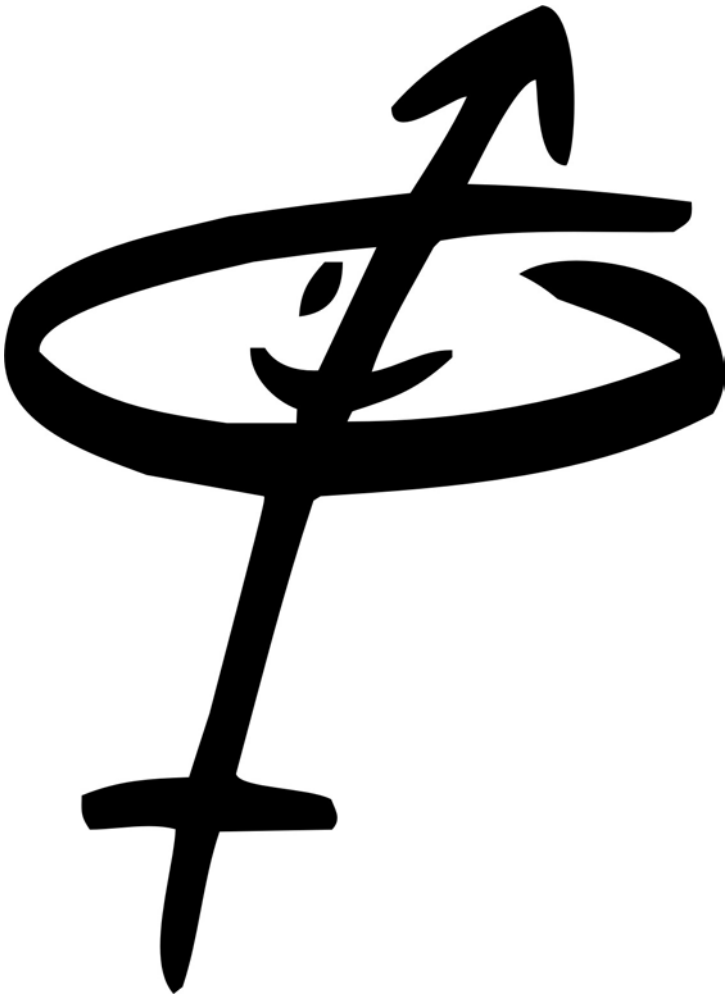

Parallel Report
to the 5th Periodic Report of the Federal Republic of Germany
on the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)

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Contents

Executive Summary

Intersexuals are people who do not fit into the medical and legal construct of two clearly distinguishable sexes, who can neither be defined as male nor as female. This is not always externally recognizable, sometimes chromosomes and inner sexual organs do not correspond with the dominant dichotomous gender norm (B.). **For the persons concerned, this is not a medical emergency calling for treatment, save in exceptional cases.** In most cases, there is no evidence for a clearly elevated risk of cancer. Rather, there is a societal pressure for „normalcy" (C.I. and C.III.). Still, under this pressure, intersexual children in Germany are routinely subjected to medical treatment which is to be considered torture or inhuman or degrading treatment. Even youths or adults who are later diagnosed with intersex variations can be victims to such treatment (C.II.).

The **medical treatment** usually consists of two elements based on the assignment of the, usually female, gender at birth: The child's gonads are removed which are responsible for the production of sexual hormones (C.II.1.), and their external genitals are surgically altered (C.II.2.). The **removal of the gonads** leads to infertility and a severe hormonal deprivation which remains untreated at early childhood and is later addressed with lifelong hormone substitution, using products not for developed for these patients. This leads to severe physical and psychological side effects. The **operative feminisation of the body** is effected by a reduction of the clitoris damaging erotic pleasure, as well as by constructing an artificial vagina which is then prepared for intercourse by traumatising and painful stretching. Patients and their parents or carers are often not properly informed about the procedure, especially not about the fact that they are medically unnecessary (C.IV.).

This treatment causes **severe physical and mental suffering** (D.II.1.) which is foreseeable for the medical staff, indicating **intentional** action (D.II.2.). The suffering is inflicted based on **discrimination on the grounds of sex and gender**, as it is based on the non-conformity of the individual's body and identity with dominant gender norms (D.II.3.). Since such treatment is inflicted in **public hospitals** with public insurance funding, while private treatment is not prevented despite being known to happen (D.II.4.), **Germany is violating its obligation to prevent torture and cruel, inhuman or degrading treatment** (Art. 1, 2, 16 CAT). Moreover, the obligation to train and inform medical staff on the prohibition of torture is not properly implemented (Art. 10 CAT).

Due to statutes of limitations and a restrictive practice of access to files in hospitals, victims encounter **severe obstacles to redress**. Their damages are also not adequately considered when assessing the degree of handicap (D.III.). This is contrary to the obligation under Articles 12, 13 and 14 CAT to establish a right to an impartial investigation and of an effective right to fair and adequate compensation and rehabilitation.

The Federal Republic of Germany thus violates the obligations under the UN Convention Against Torture and Cruel, Inhuman or Degrading Treatment (E.).

This Parallel Report to the 5th Periodic Report of the Federal Republic of Germany was compiled by the *Verein intersexueller Menschen e.V.* and Humboldt Law Clinic. It contains concluding **recommendations** (F.).

A. Introduction

The Federal Republic of Germany will be considered for its 5th periodic review by the Committee Against Torture in its 47th Session in 2011. This Parallel Report submitted to the Committee demonstrates that the medical treatment of intersexed people in Germany constitutes a breach of Germany's obligations under the Convention Against Torture. German doctors perform medical surgery on intersexed infants and adults and, as a consequence, subject intersexed persons to lifelong hormonal medication without medical reason and without the informed consent of those persons, thereby subjecting intersexed children and adults to torture and cruel, inhumane or degrading treatment. The German State does nothing to prevent this abuse and in fact provides public funds for these acts, thus violating its duty to prevent torture and inhuman or degrading treatment (Art. 2 and 16), and to provide adequate education and training of medical personnel on the prohibition of torture (Art. 10). Also, this Report shows severe obstacles to the right to an impartial investigation and to redress and compensation (Art. 12, 13, 14).

This report has been prepared by the German NGO *Verein Intersexueller Menschen e.V.* in collaboration with the *Humboldt Law Clinic*. The *Verein Intersexueller Menschen e.V.*, founded in 2004, is an organisation that consists of XY women with different intersex variations. The organisation works to represent the interests of German intersexed people and their relatives.[1] *Humboldt Law Clinic* is a clinical education project at the law faculty of Humboldt University Berlin, founded in 2010.[2]

This Report includes five recent case studies[3] of intersexed individuals, most of whom underwent medical treatment in the past ten years. The data were obtained from the clients or their parents by way of anonymised questionnaires in the summer of 2011, their identity being known to the *Verein intersexueller Menschen e.V.* The small number of case studies is due to the fact that many patients, and their families, parents find it hard to speak about what happened to them, and do not wish their story to become public, even anonymously. These cases, however, show in an exemplary manner that surgery on intersexed babies and children is not a thing of the past, but that it happens in German hospitals today, often without sufficient education both on the surgery and its alternatives, sometimes without consent, and often without an established diagnosis. Several patients report problems as a result of the procedures performed on them, both physical and psychological. In addition, this Report includes two case studies from the *Verein's* 2008 CEDAW and 2010 CESCR Shadow/Parallel Reports[4] which concern older patients and thus shed further light on the effects of gonadectomy and hormone therapy later in life.

B. What is 'Intersexuality'?

Babies are not always born with bodies which fit into the binary, culturally accepted definitions of male or female. There are different variations of X and Y chromosome combinations, or the sex indicated by the chromosomes may not match the exterior genitals; other bodies combine testicles (which can be inside the body) with a phenotype otherwise associated with females, or display what could either be a large clitoris or a small penis.[5] Such

[1] See also http://www.intersexuelle-menschen.net/.
[2] See also http://lawclinic.rewi.hu-berlin.de.
[3] See Annex, Cases No. 1-5.
[4] Verein intersexueller Menschen e.V. (2010), Parallel Report on CESCR; id. (2008), Shadow Report on CEDAW. For a summary of these cases, see Annex to this Report: *Christiane V.* and *M. Frances Maria K.*
[5] Overview from an NGO perspective at http://www.intersexualite.org/FAQ_English.html, and at http://www.isna.org/faq/what_is_intersex.

people are commonly pathologized as "intersexuals". In intersexed persons, the essential sexual characteristics, i.e., the chromosomes, the gonads (testicles, ovaries and mixed gonads), and the genitals (size, function, and location), do not make the person's sex clearly identifiable as either "male" or "female".

Experts use different definitions of "intersex" – the only thing that can be agreed on, however, is that there is no limit to the bodily variations people are born with. The *medical* definitions of intersex place the variation from the gender norm at the center of medical concern, thereby casting assimilation to one of two standard sexes as the "treatment" of a "pathology". This is evident in definitions such as "boys and girls with DSD" (DSD: disorders of sex development), the definition found by the Consensus Conference in 2005.[6]

The number of people born intersexual is unclear, also due to varying definitions. The German Government, based on a very narrow definition relating only to external genitals, estimates that 1 in 4,500 babies is born with "genital anomalies" that are actually subjected to medical "treatment", i.e. approximately 150 babies a year, corresponding with 8,000 to 10,000 people living in Germany today.[7] At the German medical conference in 2008, the estimate was far higher, amounting to several tens of thousands of individuals.[8] Other sources assume that 1 in 59 live births shows a "genital deformity".[9] Whichever definition is used, there is a sizeable number of people threatened with "treatment" in violation of the Convention living in Germany today, people whose rights are unprotected by the State.

C. Medical responses to intersexuality

I. Intersexuality as a medical construct

It is clear that a standardisation of the external genitals cannot be regarded as a surgical emergency: The vast majority of intersexed people *do not face any grave or life-threatening physical diseases* due to their specific sex characteristics at birth.[10]

Nevertheless, intersexuality is *regarded as a medical illness* and an abnormality that needs to be "corrected" by surgery and hormone replacement therapy.[11] In Germany, some 95 % of intersexed persons undergo genital surgery and various medical interventions following birth to change their fundamental and individual sexual characteristics.

This medicalization of sex variation derives from the scientifically unfounded medical experiments of John Money who posited that a child would be "successful in its gender role" if the child's ambiguous sex is surgically "clarified" and if the child never finds out about this

[6] International conference of medical experts convened in Chicago in October 2005 which developed a new, allegedly less offensive definition (DSD) and a new nomenclature for medical treatment (Consensus on 'DSD').
[7] BT-Drs. 16/4786, page 3, based on medical reports that employ the DSD definition, esp. Thyen et al. (2006), Epidemiology and initial management of ambiguous genitalia at birth in Germany, Horm. Res. 66:195-203, and Hiort (2007), Störungen der Geschlechtsentwicklung, ZfS 20 (2007):99-106, at 100.
[8] Intervention by Prof. Dr. Mau, verbatim transcripts at 304.
[9] Blackless et al. (2000), How sexually dimorphic are we?, Am. J. of Human Biology 12:151-166, at 159; Fausto-Sterling (1993), The five sexes: Why male and female are not enough, The Sciences 33:20-25.
[10] Guidelines on Gender Development Disorder (No. 027/022, last updated 10/2010) of the German Society of Pediatrics and Adolescent Medicine, at pp. 4 and 5: surgical therapy not indicated at birth ('Im Neugeborenenalter ist in der Regel keine chirurgische Therapie indiziert'); no surgical emergency ('Besonderheiten der Geschlechtsentwicklung ... stellen bei einem Neugeborenen keinen chirugischen, jedoch in der Regel einen psychosozialen Notfall dar.'); see also Chase (1998), Surgical progress is not the answer to intersexuality, J. Clin. Ethics 398.
[11] http://www.intersexualite.org/Intersex_FAQ.pdf.

medical history.[12] Money's model case ("John/Joan"), however, is said to have resulted in the suicide of the patient at adulthood. Nonetheless, this approach has dominated modern medicine for the last 60 years, with doctors seeking to operate on intersexed babies at a very early stage in their lives.[13]

There is also significant *social and political pressure* to assign an intersexed person a recognised gender. It is widely assumed that assignment to a clear sex is absolutely necessary in our society for legal, sociological and psychological reasons.[14] Due to this prevailing attitudes, operating upon intersexed children to "correct" their external genitals is socially accepted, despite a lack of scientific evidence to support this assumption, and despite the utter lack of reliable medical standards on this procedure.[15] It is also known that a non-intersexed body does not mean an individual will not suffer from psychological problems related to gender identity. Moreover, such irreversible interventions can also be performed later in life, at the mature person's wish, as in the case of transsexuals.

The classification as a disorder is already harmful, as the following statement of an intersexed person demonstrates: "If a person of my condition defines themselves as neuter, you're basically defining yourself by what you are not, and then you're less than. I don't feel that I'm less than. I don't feel that I'm a genetic mistake. I don't feel that I'm genetic junk. I don't feel that I'm a genetic failure; (I'm a) genetic variation."[16] But the medical procedures that intersexed individuals undergo with government funding mean that the harm is physical as well as psychological.

II. Gender Assignment and Surgery

In Germany, a child must be assigned a gender at birth, either male or female.[17] Where a child is diagnosed as intersexed, the gender assignment is usually based on the development of their external genitals.[18] In most cases (85-90 %)[19], the body will be turned into a externally female body: "it is easier to make a hole than to build a pole".[20] This is not only based on the feasibility of the surgery, it also corresponds with the sexist presumption that women can live without a fulfilling sex life more easily than men.[21] Even the ability to urinate standing up is rated higher than female sexual pleasure.[22] This guides the surgery: While feminisation surgery is aimed at readiness for traditional heterosexual intercourse by penetration, the more

[12] Preves (2003), Intersex and Identity, at 52-54. The John/Joan case involved a boy whose penis had been damaged at circumcision; the boy was surgically assimilated to the female sex and raised as a girl. David Reimer killed himself in 2004 at age 38.

[13] Money's theory and influence is described in more detail in the *Verein*'s Parallel Report to CESCR (2010).

[14] Hiort et al. (1999), Androgenresistenzsyndrome – Klinische und molekulare Grundlagen: Schlusswort, Deutsches Ärzteblatt 96(27): A-1846/B-1586/C-1470.

[15] Diamond/Beh (2000), An emerging ethical and medical dilemma: Should physicians perform sex assignment surgery on infants with ambiguous genitalia?, Mich. J. of Gender & L., vol. 7(1):1-63, at 12-27.

[16] Quoted in: Preves (2003), Intersex and Identity, at 127.

[17] § 21(1) no. 3 of the German law on civil status (*Personenstandsgesetz, PStG*): sex of the child needs to be listed in birth register; a new administrative regulation provides that this can only be either male or female: para. 21.4.3 of the *Allgemeine Verwaltungsvorschrift zum Personenstandsgesetz* (*PStG-VwV*) of 29 March 2010. Since 2009, it is possible to request that the sex not be listed in the birth certificate (§ 59(2) PStG). However, the presentation of a certified copy from the birth register is necessary for marriage, schooling or certain benefits.

[18] See Guidelines on Gender Development Disorder (No. 027/022, last updated 10/2010) of the German Society of Pediatrics and Adolescent Medicine (supra fn. 10), at p. 5: depending on anatomic findings ("abhängig vom anatomischen Befund").

[19] In a survey with 37 intersexed persons, all but three persons were assigned to the female gender: Brinkmann et al. (2007), Behandlungserfahrungen von Menschen mit Intersexualität – Ergebnisse der Hamburger Intersex-Studie, Gynäkologische Endokrinologie 4 2007, p. 241.

[20] Stark (2006), Authenticity and Intersexuality, in: Sytsma (ed.), 271-292, at 274.

[21] Heldmann (1998), Jenseits von Frau und Mann, in: Hauser-Schäublin (ed.), 54-77, at 59-60.

[22] Plattner (2008), Erfahrungen der Mutter eines intersexuellen Kindes, in: Groneberg/ Zehnder (eds.), 13-17, at 16.

rarely performed surgery towards a male body is guided by the doctor's concern for the size and function of the phallus.

There are three parts to most medical "treatment" of intersexed bodies: removal of the gonads (castration), genital surgery, and hormone replacement treatment. As a result of these invasions, most intersexuals are infertile, insensitive to sexual stimulus, and unable to produce vital hormones, resulting in severe secondary conditions, in addition to the psychological harm and the pain caused by the "treatment".

1. Gonadectomy (castration) and hormone replacement treatment

The gonad is the gland – testis or ovaries or a mix thereof – that produces gametes, thus sperm and eggs respectively. In addition to their procreative function, the gonads are the source of many vitally important hormones. These hormones in turn control secondary sexual characteristics which are associated with the female or the male sex, and influence bodily performance and general health.[23] These gonads do not always "correspond" with the respective external sexual organs, do not always find themselves in the "conventional" position, and are not always fully developed.

In intersexed people, the gonads are often **surgically removed** at infancy in order to maintain the original, feminine gender assignment and to stop virilisation of XY-intersexuals (XY women) through gonadal hormone production during puberty. Sometimes, gonadectomy only takes place after puberty, mainly as a result of an apparent girl failing to menstruate.[24] Most clients (XY-Women) are gonadectomised. The surgery consists of a surgical invasion of the body – scrotum or groin – and removal of the organs, and is irreversible. The client in Case No. 2 already reports regrets at age 16.

As the gonads are both responsible for gamete and for hormone production, gonadectomy invariably leads to **irreversible infertility**. Moreover, the intersexed person will most likely also have to undergo **lifelong regular hormone therapy** corresponding to the assigned gender, often counter-chromosomal – i.e. oestrogen therapy for XY individuals –, without knowing which hormone levels the body would have produced naturally. This paradox hormone therapy is not based on medical studies and thus not in line with medical standards; this also means that hormone preparations are administered off-label, i.e. not in line with their intended prescription.[25] The substitution also regularly exceeds by far the recommended duration of treatment.

For infants, there is a lack of age-appropriate hormone therapy, so that operated babies usually do not receive any hormone substitution up until puberty. This results in a pre-pubertal hormone deficiency during an important phase of their development with largely unexplored associated consequences. During puberty, girls and young women are then treated with non-age-appropriate hormone substitutes, e.g. contraceptive, or post- or menopausal hormones, which significantly alter the natural development their bodies would have taken.

In its recent decision on obligatory *surgical* sex change for *trans*sexuals, the German Federal Constitutional Court emphasised the health risk of surgery and ensuing lifelong hormonal treatment required for a full legal recognition of a sex change.[26] The Court especially highlighted the problematic **side effects** of counter-chromosomal hormone therapy, including

[23] http://www.faqs.org/health-encyc/Your-Body/The-Endocrine-Glands-The-gonads.html.
[24] Harper (2007), Intersex, at 107.
[25] The problems associated with off-label medication are explained in more detail in the *Verein*'s 2010 Parallel Report to CESCR.
[26] BVerfG, dec. of 11 Jan. 2011 – 1 BvR 3295/07, marginal note 32. Transsexuals are people born in one sex and wishing to live in another. This can, but does not have to, include the wish to change the body.

a higher risk of thrombosis, diabetes, chronic hepatitis, and liver damage.[27] As a result, the requirement was declared unconstitutional. (For these side effects, see Case studies M. Frances Maria K.; No. 2).

In addition to these lifelong effects, there is evidence to the point that the hormone deficiency resulting from gonadectomy causes osteoporosis. It also leads to constant kidney stress, as the kidneys overcompensate to make up for some of the functions of the missing gonads – as a result, intersexuals disproportionately suffer from kidney dysfunctions. Moreover, many XY women who have been subject to gonadectomy at an early age report lack of energy, caused by dysregulations of the metabolism (see Case studies M. Frances Maria K.; No. 1). Many psychological problems intersexuals report disappear once a hormone substitute is prescribed that corresponds with the chromosomal status.

2. Feminizing surgical procedures

The feminisation surgery on the outer genitals consists of the removal of healthy tissue from a penis considered too small or a clitoris considered too large.[28] This often results in the loss of sexual sensitivity.[29] At the same time, cruel operative methods aim at the construction of a vagina that will allow for traditional heterosexual intercourse by penetration. However, the psychological consequences of these methods make experience and enjoyment of sexual intercourse rather rare.[30]

Until about 1986, the clitoris/penis was often fully removed (*clitoridectomy*); today, **clitoris reduction** is preferred. In medical reports it is repeatedly stated that *clitoridectomy* treatment has been abandoned by German doctors.[31] However, the *Verein intersexueller Menschen e.V.* can report about members who are still suffering from these procedures performed in the past. The organisation moreover can provide strong evidence to demonstrate that despite the official prohibition, this inhumane treatment of genital mutilation is still performed on intersexed infants in Germany. However, *clitoris recession* also puts the sensitivity of the clitoris and the ability to have an orgasm at risk.[32] Both are thus highly invasive and equally degrading and take away female erotic pleasure.[33] Therefore, there is no value in the distinction.[34]

At the same time, a **vaginal opening** is produced that will allow for sexual intercourse by penetration. Some children have a short vagina, others have none. Where there is no opening, or the opening is too small for dilation, a small section of the colon or other parts of skin are used to build a neo-vagina. Vaginoplasty often necessitates further surgery due to complications such as fistulas, adhesions and inflammations, but also for further enlargement.[35]

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[27] Ibid; cf. Rauchfleisch (2006), Transsexualität – Transidentität, at 105.
[28] http://www.isna.org/faq/concealment; http://www.isna.org/faq/conditions/clitoromegaly.
[29] Richter-Appelt (2008), Medizinische und psychosoziale Aspekte bei Erwachsenen mit Intersexualität, in: Groneberg/ Zehnder (eds.), 53-81, at 58.
[30] Brinkmann et al. (2007), Geschlechtsidentität und psychische Belastung von erwachsenen Personen mit Intersexualität, ZfS 2007, 140: More than half of those having undergone surgery display insecurities in sexual social contacts and sexual interactions which impede their sexuality or have negative influence thereon.
[31] Richter-Appelt (2007), Intersexualität – Störungen der Geschlechtsentwicklung, Bundesgesundheitsbl – Gesundheitsforsch – Gesundheitsschutz 50:52-61, 57, for Great Britain: Minto, et al. (2003), The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study, The Lancet 2003, 361, 1252-1257, 1252.
[32] Richter-Appelt (2007), ibid., 57.
[33] Crouch, et al. (2004), Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study, BJU Int. 93:135-138.
[34] Harper, Intersex, 2007, at 78.
[35] Brinkmann (2007), Behandlungserfahrungen und Behandlungszufriedenheit von erwachsenen Menschen mit verschiedenen Formen der Intersexualität, at 51.

In order to produce a functionally "adequate" vaginal cavity at maturity, this opening will then be stretched out mechanically or manually (**dilation**) until regular intercourse takes place (twice a week).[36] "Pressure dilation" can as well be an alternative to surgery to expand the vagina. This procedure involves the insertion of a solid dilator into the vagina (for 15 minutes twice a day, over months or years). In many cases parents perform the dilation on their children. Children with surgically operated vaginas have to be dilated in hospitals once a year until they are considered penetrable, usually at the age of fourteen.[37]

III. No medical justification

In general terms, two reasons are often advanced to justify the medical manipulation of intersexed persons: Firstly, it is assumed that there are important physiological problems that can occur as a result of intersexuality that medical intervention will overcome. Secondly, it is argued that surgical and medical approaches that advance the goal of an externally "normal" clearly sexed body will serve the psycho-social well-being of the intersexed person. Both arguments are not viable.

1. No physiological justification of the medical 'treatment'

It is often argued that there is a pressing medical justification for surgical manipulation of intersexed persons. However, a closer analysis of the issue indicates that this is very often not the case.

The removal of gonads is often justified due to the **risk of cancer** developing in dysgenetic testicular tissue, i.e. unusual testicular tissue. However, German Medical Guidelines on 'DSD' point out that the literature on the definitive risk of a development of gonadal tumor is 'scant'.[38] The lack of available data is firstly owed to the fact that most intersexed people were gonadectomised as an infant preventing an assessment of the actual incidence of cancer, and secondly due to the lack of long-term studies.[39] The studies that do exist recommend gonadectomy only in limited cases[40] and often differ in their results and assessments.[41]

As it is usually also possible to conduct regular screenings, there is no need for a systematic gonadectomy of all intersexuals for prophylactic reasons. However, most intersexuals (up to 95 %) are gonadectomised following birth, although a medical justification exists only for a small group of patients.[42] Patients in Cases No. 1, 2, 4 and 5 were gonadectomized, sometimes without a full diagnosis and thus without full knowledge of the actual tumor risk.

Gonads are also removed **in order to "feminize"** an intersexed person. It is argued that leaving intact gonads which would produce testosterone would cause harm, as this would detain female development and obstruct the female gender assignment. Thus, for PAIS individuals[43] whose external organs appear feminine due to their androgen insensitivity, gonadectomy is specifically recommended to prevent virilisation at puberty.[44] This argument, however, cannot justify early gonadectomy, as this can still be achieved at the onset of

[36] http://surgery.med.umich.edu/pediatric/clinical/physician_content/a-m/ambiguous_genitalia.shtml.
[37] Kessler (2002), Lessons from the Intersexed, at 49.
[38] Guidelines on Gender Development Disorder (No. 027/022, last updated 10/2010) of the German Society of Pediatrics and Adolescent Medicine, p. 5.
[39] Kolbe (2010) Intersexualität, Zweigeschlechtlichkeit und Verfassungsrecht, at 166.
[40] Looijenga et al. (2007): Tumor risk in disorders of sexual development, Best Practice & Research Clinical Endocrinology & Metabolism, 21(3):480–495.
[41] Ibid.; Cools et al. (2006), Germ Cell Tumors in the Intersex Gonad: Old Paths, New Directions, Moving Frontiers, Endocrine Rev. 27(5):468–484, at 481.
[42] Richter-Appelt (2007), Intersexualität (fn. 33), at 59.
[43] PAIS: Partial Androgen Insensitivity Syndrome, the partial inability of the cell to respond to androgens, impeding the masculizing effect of androgens otherwise have on the development of the sex organs.
[44] *Ibid*.

puberty, when the child is old enough to consent. This would also be more adequate in view of the severe secondary conditions resulting from paradox hormone therapy, and it would respect the child's right to an open future in terms of its natural sexual development.

2. No psychological justification of the medical 'treatment'

Medical practitioners further claim that the interventions should be performed in order to **avoid future psychological disorders** within an intersexed person. Yet there is no proof that psychological disorders result from lack of surgical intervention. Moreover, there are even indications that that surgical intervention can actually have a negative psychological impact upon intersexed persons.

Vaginal surgery performed to "normalize" the external genitalia, as explained above, have the purported aim of guaranteeing a **stable gender identity** and a normal sexual development within the assigned gender. Yet, as recent studies have shown, a clear and unambiguous (external) sex will not necessarily guarantee an unambiguous gender identity.[45] On the contrary, as in the infamous "John/Joan case", *Christiane V.* (see Case study) grew to hate her artificial masculine genitals and attempted self-mutilation. Also, being labelled as a misfit by *medical* diagnosis and treatment can actually in itself challenge to one's identity development and stability.[46] Moreover, the fear that living with ambiguous genitalia can be the cause of psychological damage is also unfounded. In a study, only one of 80 adults with ambiguous genitalia suffered from psychosis, and most lived in sexual satisfactory relationships with their partners.[47]

Furthermore, the psychological problems and trauma an intersexed child might suffer from **bullying** have apparently been overstated, as surgically unmanipulated intersexed persons have reported from their own childhood experiences. There is no substantive evidence that an intersexed child with ambiguous genitalia is exposed to a higher risk of coping with psychosocial challenges than any other child living in our society.[48]

IV. Problems with informed consent to medical procedures

Under German law, a patient needs to give consent to any medical treatment; otherwise, the doctor will be liable under criminal law (e.g. battery) and tort law (e.g. damages).[49] It is the doctor's duty to inform the patient about the *reasons* for medical treatment, the *nature and purpose* of the treatment, *consequences and risks* (including chances of success), as well as possible other low-risk treatments (*alternatives*).[50] Insufficient or inaccurate information provided by the doctor can lead to the invalidation of the consent given. The standard of information needed for informed consent depend on the gravity and on the necessity of the medical procedure.[51] For purely cosmetic surgery without medical justification, such as that performed on the external genitals of intersexuals, the standard is especially high, and even remote risks must be explained.[52]

1. Adults are often not fully informed

Even if an adult consents to surgery, such consent may be voidable, if the patient has not been fully explained the full range of potential issues and risks associated with the treatment, of if

[45] Brinkmann et al. (2007), Geschlechtsidentität (Fn. 30), 141. See also Kolbe (2010), ibid., at 167.
[46] Preves (2003), Intersex and Identity, at 4.
[47] Fausto-Sterling (2000), Sexing the Body: Gender Politics and the Construction of Sexuality, at 94 et seq.
[48] Kolbe (2010), Intersexualität, Zweigeschlechtlichkeit und Verfassungsrecht, at 167.
[49] The threshold for criminal liability is, however, higher than for damages.
[50] Schöch, in: Roxin (2010), Handbuch des Medizinstrafrechts, at 66; on alternative treatment, see ibid. 70-71.
[51] BGH NJW 2006, 2108: The less urgent the treatment, the higher the standard of information, both on chances of success and risks.
[52] BGH MedR 1991, 85-86.

the patient has not been told that there is insufficient medical evidence about the necessity and effects of a treatment. This principle was confirmed by the case of *Christiane V.* (see Case study), in which the court held that the surgery performed by the doctor was illegitimate because of the lack of proper information prior to giving consent.[53] The *Verein intersexueller Menschen e.V.* can report several cases where the **conditions for informed consent were not met**.

First of all, doctors tend to explain the diagnosis of intersexuality as an illness or dysfunction which requires treatment, failing to mention that there is no medical evidence that 'treatment' by surgery is actually necessary or even that it is successful in terms of a stable gender identity. Often, no mention is also made of intersexual persons being able to live happily with the 'condition'. Patients report they are made to feel like they are the only ones with such 'problems', so that they do not realize there may be advice from support groups.

Second, contrary to medical standards,[54] information on surgery often does not include information on follow-up surgery that will be necessary, e.g. the need to regularly stretch a neo-vagina (dilation). Information on gonadectomy often does not mention that the removal of the gonads will result in the need for lifelong hormone therapy, a treatment that comes with its own risks and side-effects.

2. Parents consent to harmful practices without proper information

Most surgery is performed on intersexed children and therefore requires parental consent to proceed with the intervention. Art. 12 (1) of the Convention on the Rights of the Child requires that when such decisions are made, the views of the child are given due weight in accordance with the child's age and maturity. The older the child and the higher his or her capability to assess the medical implications, the more he or she will be able to consent to him- or herself. For very young children, medical consent is given by parents or guardians. Parents complain of the same type of lack of information as adults (see Cases No. 1, 3 and 4).

Under German civil law, any parental decisions must benefit the wellbeing of the child (§ 1627 BGB). Given that, outside of medical emergencies such as an established grave risk of tumors, the medical benefit of intersex surgery is unproven, and that the implications are severe, it clearly goes **against the benefit of the child**.[55] Parents can therefore not legally consent to the sterilization of their children (nor can the child itself), as this is an irreversible removal of intensely personal right of procreation (§ 1631c BGB). *Gonadectomy* also removes any procreative functions. It can therefore usually not legally be consented to.[56] Even the German law on castration of (male) sex offenders allows castration only after the age of 25, and only if the person himself consents (§§ 2(1), 3 KastrG). The only exception to these rules is a case of medical emergency, i.e. malignancy of the gonads. It follows from these rules that unnecessary, irreversible surgery can only be consented to in very limited cases. Given that *vaginal surgery* is to be regarded as cosmetic surgery and that it often causes insensitivity of the clitoris, it can therefore never be legally consented to by parents.

In terms of informed consent, surgeries performed on intersexed persons at a very young age (and subsequent hormone substitution) often have **consequences and associated risks that are not yet fully foreseeable**.[57] There is evidence to the fact that such interventions can have significant physiological as well as psychological consequences (*supra* II.). In such cases, doctors have to make clear that any 'treatment' has the character of a *medical experiment*, the

[53] OLG Köln, dec. of 3 Sept. 2008 – 5 U 51/08, MedR 2009, 343.
[54] OLG Köln, MedR 1996, 564 et seqq.; Schöch, in: Roxin (2010), Handbuch des Medizinstrafrechts, at 61.
[55] Kolbe (2010), Intersexualität, Zweigeschlechtlichkeit und Verfassungsrecht, at 178.
[56] Ibid., at 165, 171 and *passim*; Plett (2003), Intersexuelle – gefangen zwischen Recht und Medizin, in: Koha/Pühl (eds.), 21-41, at 34.
[57] Diamond/Beh (2000), ibid., at 56.

legal conditions for which are much stricter.[58] Parents also report that they are not informed that it will be necessary to regularly stretch the neo-vagina of their child, and that they themselves will have to participate in this abuse.

In accordance with the age and maturity of the child, the will of an older children or young adult must be taken into account in relation to decisions affecting it, including decisions on medical treatment. This is required by Article 12 of the Convention on the Rights of the Child and is also recognized in German supreme jurisprudence.[59] Due to the severity and intensity of medical treatments, it is often assumed that intersexual children are unable to sufficiently oversee the decision. Instead of waiting until the necessary maturity is reached for the child to decide on these grave and life-changing operations, this right is left to the parents. Indeed, many of the clients represented by *Verein intersexueller Menschen e.V.*, both parents and patients, state that they would never have consented to the treatment if they had known beforehand what harm to expect in their later life.

In conclusion, many adult patients are not fully informed about the necessity, nature and consequences of the medical procedures. This also applies to parents of intersexed children. However, parents cannot legally consent to irreversible medical procedures which are harmful to the child without serving a clear and proven medical purpose, such as gonadectomy and vaginoplasty.[60]

D. The Treatment of Intersexed Persons in Germany as a Violation of International Law

The following section will demonstrate that the genital "normalizing" surgeries and hormone "treatments", described above, that were not validly consented to by the intersexed patients, constitute torture or cruel, inhuman and degrading treatment under Articles 1(1) and 16 of the Convention.

I. Germany's Commitments to the Prevention of Torture and Cruel, Inhuman or Degrading Treatment

By ratifying the Convention Against Torture (CAT), Germany has committed itself to ensuring that no-one within its jurisdiction is subject to torture and other cruel, inhuman or degrading treatment or punishment (CIDT).[61] In addition, Germany has ratified the European Convention on Human Rights, which prohibits torture and "inhuman or degrading treatment or punishment" in its Art. 3,[62] and the International Covenant on Civil and Political Rights which in its Art. 7 contains a similar clause and explicitly includes freedom from forced medical experiments.[63] The prohibition of torture is absolute and non-derogable.[64] All of

[58] World Medical Association, Declaration of Helsinki on ethical principles for medical research involving human subjects (1964, 6th rev. 2008), para. 29 and *passim*; German laws on pharmaceuticals and medical products: § 40(4) AMG (*Arzneimittelgesetz*), § 20(4) MPG (*Medizinproduktegesetz*).

[59] BGHZ 29, 33-37 = NJW 1959, 811-811: A minor's consent to an invasion of the body (surgery) is valid if the minor, in view of his or her intellectual and moral maturity, is able to assess the severity and implications of the intervention and of the consent.

[60] Kolbe (2010), Intersexualität, Zweigeschlechtlichkeit und Verfassungsrecht, at 164-5.

[61] The former German Democratic Republic signed the Convention on 13 Oct. 1986. Reunified Germany ratified the Convention on 1 Oct. 1990; http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-9&chapter=4&lang=en#3 (last accessed 4 March 2011).

[62] Ratified 5 Dec. 1952.

[63] Ratified 17 Dec. 1973; Art. 7 ICCPR: 'No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.'

these Conventions are enforceable statutory law by virtue of their ratification. In addition, the prohibition of torture is part of German law as customary international law.[65] Freedom from torture is also constitutionally and statutorily protected.[66]

II. Treatment of Intersexuals in Germany as Torture

In Article 1 of CAT, torture is defined as:

> 'any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.'

Although many cases of torture happen in detention, torture is no longer understood to constitute solely interrogation, punishment or intimidation of a captive.[67] Rather, the definition includes any setting. The UN Special Rapporteur on Torture pointed out: "Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an *intrusive and irreversible nature*, when they *lack a therapeutic purpose*, or aim at correcting or alleviating a disability, *may constitute torture and ill-treatment if enforced or administered without the free and informed consent* of the person concerned."[68]

In light of this definition, medically unnecessary genital "normalizing" surgeries and hormone treatments that were not legally consented to by the patient constitute torture in violation of Article 1(1) of the Convention. That is, that such surgeries constitute acts that cause severe pain or suffering (1), they are intentional (2), they serve a specific purpose (3), there is a sufficient nexus with a public official (4) and they are not lawfully sanctioned (5).

1. Infliction of Severe Pain or Suffering

The infliction of severe pain or suffering on a person can be physical or mental. **Mental suffering** has been defined as the infliction of pain through the creation of a state of *anguish and stress* by means other than bodily assault.[69] Each circumstance of torture needs to be considered individually, in the context and circumstances, and there is no definitive list of what constitutes a tortuous act.[70]

The **severity** of pain and suffering is relative and therefore has to be evaluated in the specific context. Therefore, the severity of an act that might constitute torture needs to be assessed from an objective perspective that looks at each specific situation and each particular victim and his/her vulnerability.[71] Thereby one needs to take into account different factors, such as

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[64] Art. 2(2) CAT; Nowak/McArthur (2008), Convention Against Torture, Art. 3 para. 200; CAT, General Comment No. 2, CAT/C/GC/2, para. 5-6.
[65] Art. 25 of the German Constitution, or Basic Law (*Grundgesetz, GG*).
[66] Art. 2(2) and 1(1) of the Basic Law protect the dignity of man from interference through torture. This protection is still held to be absolute: Herdegen, in: Maunz/Dürig (2011), GG Art. 1 para. 95-99. Art. 104(1) of the Basic Law specifically prohibits physical and psychological abuse in detention, a provision which is implemented in § 136a of the German Code of Criminal Procedure (*Strafprozessordnung, StPO*).
[67] Sifris (2010), Conceptualising involuntary sterilisation as 'severe pain or suffering' for the purposes of torture discourse, Neth. Qu. HR 28(4), 523-547, at 526.
[68] Interim report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment, UN Doc. A/63/175, of 28 July 2008, para. 47.
[69] Eur. Com. Hum. Rts., *Greek case*, Op. Com., 15 Nov. 1969, Ybk. XII (1969), at 461.
[70] Association for the Prevention of Torture (2001), The Definition of Torture, at 28.
[71] Ibid., p. 28.

the duration of the treatment, its physical / mental effects and the sex, age, state of health of the victim.[72] Thus, the UN Special Rapporteur on Torture has pointed out that **children** are more vulnerable to the effects of torture as they are in the critical stages of physical and psychological development where they may suffer graver consequences than similarly ill-treated adults.[73] The effects of torture/ill-treatment will also differ according to the age of the child, depending on the readiness of mind. Torture inflicted on a child might leave more long-lasting effects than on an adult.[74] As with children undergoing female genital mutilation (FGM), intersexed children undergoing surgery at an early age are in a situation of **powerlessness**, as they are under the complete control of their parents and have no means of resistance.[75]

While the surgery performed on intersexuals will normally involve adequate pain management (anaesthesia), gonadectomy (a.) and vaginoplasty (b.) have severe effects on the intersexed person's physical and psychological wellbeing which constitute an infliction of severe pain or suffering. This also includes suffering from being assigned the wrong gender.

a. Gonadectomy

The removal of gonads leads to **permanent, irreversible infertility which causes severe mental suffering**. While a small number of intersexed people may be born infertile, this is not at all the case for all patients. Also, assisted reproduction aside, individuals diagnosed infertile sometimes turn out to be able to beget a child.[76] The pain caused by the inability to have children is linked with society's construction of firstly female identity as being bound up with reproductive capacity[77] and of male identity as being the strong protector of the family. Society's values and expectations significantly contribute to the severity of the pain and suffering. This has been explicitly recognized by the CEDAW Committee. In its General Recommendation No. 19, the CEDAW Committee notes that compulsory sterilisation adversely affects women's mental health, and likewise will it affects a man's mental health.[78] Moreover, in a recent case involving the sterilization of a Hungarian Romani woman without her knowledge or informed consent, the Committee noted the profound impact that the sterilization had on her life, resulting in her and her partner being treated medically for depression and psychological trauma.[79] The Special Rapporteur on Torture has also taken up the subject in strong words.[80] The sterilization of women without their consent has been recognized as a breach of the prohibition on torture.[81] Such a procedure is documented in the Case study *Christiane V.*

Gonadectomy also causes the **end of natural hormone production, which also causes mental suffering**. The gonads produce vital hormones without which no natural puberal development can occur, such that the body does not change the way it naturally would have during puberty. Moreover, as these hormones crucially contribute to bone mineralisation[82],

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[72] ECtHR, *Ireland v UK* (1978) 2 EHRR 25, para. 162.
[73] Report of the Special Rapporteur on Torture, E/CN. 4/1996/35, para. 10.
[74] Association for the Prevention of Torture (2001), The Definition of Torture, at 81.
[75] Report of the Special Rapporteur on Torture, UN Doc. A/HRC/7/3, para. 53.
[76] The second-instance civil court of Cologne adds that it should not be excluded that medical interventions to this effect may be developed during the lifetime of an intersexed infant: OLG Köln, dec. of 30 Nov. 2009 – 16 Wx 94/09, StAZ 2010, 45.
[77] Sifris (2010), Conceptualising involuntary sterilisation, Neth. Qu. HR 28(4), 523-547, at 542.
[78] CEDAW, General Recommendation No. 19 (1992): Violence against Women.
[79] CEDAW, *Andrea Szijjarto vs. Hungary*, Communication No. 4/2004, UN Doc. A/61/38, 14 Aug. 2006.
[80] Report of the Special Rapporteur on Torture, UN Doc. A/HRC/7/3, para. 39.
[81] CCPR General Comment No. 28 (2000) on article 3 (The equality of right between men and women), para. 20. See also Concluding Observations on Slovakia, CCPR/CO/78/SVK, para. 12; on Japan, CCPR/C/79/ADD.102, para. 31; and on Peru, CCPR/CO/70/PER, para. 21. See also CAT, Concluding Observations on Peru, CAT/C/PER/CO/4, para. 23.
[82] Kolbe (2010), Intersexualität, Zweigeschlechtlichkeit und Verfassungsrecht, at 166.

severe osteoporosis results (lack of bone formation). Stress hormones, thyroid function, the pituary as well as blood sugar and the lipometabolism are affected. Consequently, the patient is not able to develop his/her bodily natural identity. The suffering thereof consist of never "feeling home" in your own body: see Case No. 5. Moreover, the *Verein intersexueller Menschen e.V.* can testify to depressive effects of gonadectomy from its support group work (see also Case study M. Fances Maria K.).

Gonadectomized patients therefore require **life-long hormone substitution which results in severe physical suffering**. Even if an adequate hormone substitution is administered, these patients often display *atypical health disorders* such as disorders of the immune system and deregulations of the metabolism. For castrated genetically male people, other physical side effects typically include anaemia, diabetic diseases and disorders of the functions of the kidney and of the adrenal body. These conditions, which are atypical for younger people, can seriously impact not only the physical body, but also affect psychological, and social capability. *Paradox hormone therapy* – e.g. the administration of female sex hormones to surgically feminized XY individuals – furthermore alters the outer physical sex characteristics, particularly the secondary sex characteristics. While these may look like the those of the other sex, they often do not correspond to their natural model, concerning their development, structure and function. The affected person is often scared that the artificially altered sex characteristics cannot fulfil the expectations of society. This factor can easily cause a physical depression within the person concerned. The impact of the hormone therapy therefore can have a major impact on a patient's identity and profoundly disrupts the senses, therefore amount to mental suffering.

b. Feminising surgical procedures

The procedure of cutting away healthy genital tissue of what could be considered a small penis or a large clitoris is still taking place on children with ambiguous genitals, even though their development is not yet complete.

The **removal or recession of the clitoris** has been considered in international law as part of Female Genital Mutilation (FGM).[83] The UN Special Rapporteur on Torture, the UN Special Rapporteur on Violence against Women and the Human Rights Committee have made it clear that FGM constitutes torture[84] and that, from a human rights perspective, the medicalization of FGM – its performance in clinical surroundings – does not make this practice more acceptable.[85] This also holds for the mutilation of the clitoris of intersexed children or adults as part of unnecessary feminizing cosmetic surgery which, like FGM, is performed for purely cultural reasons.

According to medical studies[86], **genital sensitivity is impaired** in areas where feminizing genitoplasty was performed. Impairment to sensitivity is linearly related to difficulties in sexual function. Consequently, an intersexed person having a genitoplasty must fear sexual dysfunction. This is especially evident for vaginal penetration difficulties and decrease in intercourse frequency.

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[83] This procedure is also called Female Genital Cutting (FGC). The World Health Organization defines FGM as "all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons" and classifies it into four types, one of which is clitoridectomy.

[84] Report of the Special Rapporteur on Torture, UN Doc. A/HCR/7/3, paras. 53, 54; Report of the Special Rapporteur on Violence against Women, UN Doc. E/CN.4/2002/83, para. 6 (severe pain and suffering element of CAT) definition); see also UN Doc. A/HRC/4/34, para. 56. Breach of Art. 7 ICCPR: see CCPR general comment No. 28 (2000) on article 3 (The equality of rights between men and women), para. 11; see also Concluding Observations on Uganda, CCPR/CO/80/UGA, para. 10; Mali, CCPR/CO/77/MLI, para. 11; Sweden, CCPR/CO/74/SWE, para. 8; Yemen, CCPR/CO/84/YEM, para. 11.

[85] Report of the Special Rapporteur on Torture, ibid., paras. 53, 54.

[86] Crouch, et al. (2004), Genital sensation after feminizing genitoplasty: a pilot study, BJU Int. 93:135-138.

Genital dilation is described as a very a painful experience. Other than the listed treatments which are performed under anaesthesia, intersexed persons are dilated repeatedly to prevent the downsizing of the tissue. The insertion of a solid object into a young person's vagina does not only pain the aggrieved persons, but it is also highly traumatic. Such invasions of the body, performed without the acquiescence of the victim, constitute rape. The ICTR in its *Akayesu* judgement, has established that in international law, rape is not limited to the penetration of the vagina with a penis but encompasses other bodily invasions, including with objects of with other parts of the body.[87] The Inter-American Court of Human Rights thus considered a 'finger vaginal "examination" … sexual rape that due to its effects constituted torture', an invasion similar to what is endured during dilation.[88] As rape 'leaves deep psychological scars on the victims which do not respond to the passage of time as quickly as other forms of physical and mental violence'[89], it has been found to constitute torture in many international settings.[90] Intersexed people who have endured dilation as children often report to reject any kind of penetration at adulthood, and to experience any kind of physicality as torment.

The most severe mental suffering regardless of what form of operation was performed results in **suicidal tendencies**. In a study conducted in Hamburg, Germany, 50 % of those that had been subjected to irreversible surgical interventions were found to contemplate suicide.[91] Another study found the elevated rates of self-harming behaviour and suicidal tendencies among "DSD" individuals[92] comparable to those among women traumatised with physical or sexual abuse.[93] A concerned person concluded as to the most severe consequence of the operation: "The right to determine what is done to one's body is extremely important. I am not alone in having had suicidal thoughts that stemmed from the feelings of helplessness that my treatment as an intersexed person brought on. Such thoughts of suicide seem to be unusually common among those of us who have had the surgery that was supposed to make us feel normal".[94]

2. Intention

The intention must be directed to both the conduct of infliction of severe pain or suffering as well as the purpose to be achieved by this conduct.[95] This excludes purely negligent

[87] ICTR, *Prosecutor v. Akayesu*, ICTR-96-4, 13 Feb. 1996, amended 17 June 1997; see also ICC, Elements of Crimes, article 8(2)(b)(xxii)-1.
[88] IACHR, *Miguel Castro-Castro Prison v. Peru*, 25 Nov. 2006, para. 312.
[89] ECtHR, *Aydin v. Turkey*, Application no. 57/1996/676/866, 25 Sept. 1997.
[90] Special Rapporteur on Torture, UN Doc. E/CN.4/1992/SR.21, para. 35, E/CN.4/1995/34, para. 19, A/HRC/7/3, para. 35 CAT, *C.T. and K.M. v. Sweden*, CAT/C/37/D/279/2005; *V.L. v. Switzerland*, CAT/C/37/D/262/2005; implicit (in line with *X, Y, Z v. Sweden,* No. 61/1996): *T.A. v. Sweden*, CAT/C/34/D/226/2003, and *Mrs. Pauline Muzonzo Paku Kisoki v. Sweden*, CAT/C/16/D/41/1996. For the Inter-American Convention to Prevent and Punish Torture: IACHR, *Raquel Martí de Mejía v. Perú*, Case 10.970, Rep. No. 5/96, OEA/Ser.L/V/II.91 Doc. 7 at 157 (1996), 1 March 1996; *Dianna Ortiz v. Guatemala,* Case 10.526, Rep. No. 31/96, OEA/Ser.L/V/II.95 Doc. 7 rev. at 332 (1997), 16 Oct. 1996; for international humanitarian law: ICTY, *Prosecutor v. Anto Furundzija* (Trial Judgment), IT-95-17/1-T, 10.12.1998, para. 266f.; *Prosecutor v. Mucic, Delic, Landzo, Delalic* (Trial Judgment), IT-96-21-T, 16.11.1998, para. 940-943. ICTR, *Prosecutor v. Akayesu* (Trial Judgement), ICTR-96-4-T, 02.09.1998, para. 597.
[91] "Hamburg IS Study", quoted in the response of the Hamburg Senate to a formal parliamentary question: Antwort des Hamburger Senats auf die Grosse Anfrage von DIE LINKE, Drucksache 19/1993, 13 Feb. 2009.
[92] DSD: Disorders of sex development, as defined by the Consensus on DSD (2005).
[93] Schützmann et al. (2009), Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality, Arch Sex Behav. 2009 Feb;38(1):16-33.
[94] Joan Whelan, Presentation in January, 2002 at the Intersex Panel for Sex Week at the Robert Wood Johnson Medical School.
[95] Nowak/McArthur (2008), UN Convention against Torture, Comment Art.1, para. 107.

conduct.[96] It is however sufficient if the intention covers the act from which severe pain or suffering arise, even if this suffering itself is not intentionally inflicted.[97]

The Special Rapporteur on Torture points out that intent can be implied where the act had a specific purpose,[98] namely where a person has been discriminated against on the basis of disability.[99] Intent and purpose do not require a subjective inquiry into the motivation of the perpetrators, but rather an objective determinations under the circumstances.[100] The Rapporteur emphasises this in the context of medical treatment, where such discriminations are often 'masked as "good intentions" on the part of health professionals'.[101] Where individuals are discriminated against on the basis of bodily features pathologized as "disorders of sex development" (DSD) in medical terms, this discrimination will thus imply intent.

Clearly, surgery on intersexuals is always **intentionally** performed and not merely the result of negligence. Doctors are also aware that there is usually no medical indication for such surgery but nonetheless approve of the irreversibility of the treatments and the heavy consequential physical and psychological damages of their patients. Below, it will also be established that the treatment is inflicted in a discriminatory manner (see *infra* D.II.3.). The physical and mental suffering caused by clitoridectomy, clitoris reduction, vaginal dilation, loss of fertility, and dependency on hormone substitution is well-established in medical literature (see *supra* C.II.). It is thus **foreseeable** to those intentionally inflicting the treatment that severe pain and suffering will ensue.

It does not detract from the intention that doctors perform surgery **for *well-meant* purposes.** This has been established in a case where a medical team discriminated against a person with disabilities.[102] The same is true for intersexuals where doctors believe to prevent cancer or social ostracism. The fact that there is no medical justification for the ill-treatment (supra C.III.) means that good intentions cannot prevent the treatment from constituting torture.

3. Purpose of discrimination

Article 1 of CAT requires that the pain or suffering be inflicted for one of the enumerated purposes, i.e. for the extraction of information or confession, punishment, intimidation and coercion, "or for any reason based on discrimination of any kind".

The Committee against Torture emphasised that the protection of certain minority or marginalized individuals or populations especially at risk of torture is part of the State obligation to prevent torture. State parties must make sure that with respect to the Convention, their laws are in practice applied to all persons, 'regardless of … **gender, sexual orientation, transgender identity, mental or other disability, health status,** …'. This includes fully prosecuting and punishing all acts of violence and abuse against these individuals and implementing positive prevention and protection measures.[103]

The medical manipulations of intersexed persons are performed for reasons of **sex and gender-based discrimination**. Intersexed individuals of all ages are subject to violations of

[96] Interim report of the Special Rapporteur Torture, UN Doc. A/63/175, para. 49; Boulesbaa (1999), The U.N. Convention on Torture and the prospects for enforcement, p. 20; Burgers/Danelius (1988), The UN Convention against Torture, at 118; Nowak/McArthur (2008), UN Convention against Torture, Comment Art. 1, para. 106.
[97] Copelon (1994), Recognizing the Egregious in the Everyday: Domestic Violence as Torture, Col. HR L.R. 25:291-368, at 325. See also *Zubeda v. Ashcroft*, 333 F.3d 463, at 473 (3rd Cir 2003): 'the foreseeable consequence of deliberate conduct'.
[98] Interim report of the Special Rapporteur on the Torture, UN Doc. A/63/175, para. 30.
[99] Ibid. para. 49.
[100] CAT, General Comment No. 2 (2007), CA/C/GC/2, para. 9.
[101] Interim report of the Special Rapporteur on Torture, UN Doc. A/63/175, para. 49.
[102] Ibid., para. 50.
[103] CAT, General Comment No. 2 (2007), para. 21 (emphasis added).

the Convention on the basis of their actual or perceived non-conformity with the social norm for sex and gender. The Committee against Torture has pointed out that gender is a 'key factor' in subjection to torture, particularly involving reproductive decisions.[104] This is not only true for the female sex or gender, although sex or gender discrimination is usually raised in connection with discrimination against women, defined as 'any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.' (Art. 1 CEDAW) *Sex* refers to the genetic and anatomical characteristics that are used to distinguish between males and females. *Gender* describes the socially constructed roles, rights and responsibilities that communities and societies consider appropriate for those defined as men and women. However, a person's *gender identity* or self-identification as male, female or neither is not necessarily linked to his or her biological sex, or social gender. Today's society acknowledges only two sexes to exist. Hence, in order to gain valid membership and recognition within society's culture, a person must present oneself as male or female.[105] Yet, intersex people neither "fit" into this binary. Their bodies challenge this binary distinction, and some do not have a gender identity that is exclusively male or female. This challenge of the norm is considered highly problematic, not only by doctors but also by society. Intersexed children undergo plastic surgery so that their bodies conform to dominant ideas of what constitutes a 'male' or 'female' body. Gonads and ambiguous genitalia are removed or mutilated in order to produce a non-ambiguous person that complies with the gender and sex norm. This begins with the labelling of a new-born as either male or female. It is only once a certain sex is assigned that gender-specific socialization may begin.[106] Involuntary sterilization has been denounced as gender-based discrimination disproportionately affecting women.[107] Where this practice is based on the fact that a person does not clearly fit one or the other sex, this also constitutes sex- or gender-based discrimination.

By means of surgery, intersexed are penalised **compared to clearly defined infants**. Unlike intersexed children, children without "ambiguous" genitalia do not have to undergo surgery after birth. Apparently fitting into society, "normal" children are sent home to grow up within their natural sex and gender. Intersexed children who apparently do not fit into society have to grow up within their assigned gender and the associated physical and mental pain. Only for this group of people does this type of treatment appear to be permissible, in an effort to render this group invisible.

The surgery also **restricts intersexed people from living their natural sex** and thereby nullifies their recognition within society. The surgery deprives the victim of his/her sexual personality (see Case No. 5; *Christiane V.*). Sex and gender identity are widely considered important parts of a person's identity as it defines a person's sense of self and positions them in a social and political context. Every person has the right to have their sex and/or gender identity recognised and respected.[108] This also includes the right to an open future of sexual development.[109]

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[104] Ibid., para. 22.
[105] Preves (2003), Intersex and Identity, at 19.
[106] Ibid., at 15.
[107] Sifris (2010), Conceptualising involuntary sterilisation, Neth. Qu. HR 28(4), 523-547, at 529-531.
[108] Principles on the application of international human rights law in relation to sexual orientation and gender identity (2007); http://www.yogyakartaprinciples.org.
[109] For the right to an open future see, Matt (2006), Das Recht auf eine offene Zukunft, Juridikum 3/2006, 144-146; Vöneky/Wilms (2011), Rechtliche und rechtsethische Aspekte des Umgangs mit Intersexualität, , at 5.

Intersexuality as such is not a **disability**, on the contrary, many intersexed people become disabled as a result of their 'treatment'. However, the medical pathologisation of their bodies can be likened to the construction of a disability. This also constitutes the declaration of an inferior **health status**. Based on these diagnoses, intersexed people then undergo treatment that causes severe pain and suffering.

As mentioned above, many doctors proceed on the assumption that the abuse they commit is necessary to prevent future discrimination of children with bodies that challenge the norm. However, a, malignant intent is not necessary. It suffices that the ill-treatment is inflicted for a discriminatory reasons, even where the perpetrator has benign intentions.

Children, in the relation to these doctors, find themselves in a situation of **powerlessness**. They are under the total control of the doctor. The hospital scenario in which the great majority of all infants is born in Germany (2009: 96.7 %)[110] also contributes to a situation of powerlessness of the parents.

Upon birth, they are quickly confronted with an alleged need for quick medical intervention, by the very staff that was involved in the birth process. They are immediately put on the spot, threatened with scenarios of ostracism and cancer, pushed to make decisions that will affect their child forever, usually without proper information. This is apparent in Cases No. 4 and 5.

4. Involvement of a State official

As underlined by the Committee, the prohibition of torture must be enforced in all institutions, including hospitals that engage in the care of children.[111] The Special Rapporteur on Torture underlined that the obligation to prevent torture extends 'to doctors, health professionals and social workers, including those working in private hospitals [or] other institutions.'[112] The medical ill-treatment of intersexuals is attributable to the German State as it is committed by or at the instigation of or with the acquiescence of a person acting in an official capacity, either by way of involvement of public hospitals and insurances, or by the failure of the State to exercise due diligence to protect this group of citizens from torture.

a. Public hospitals and public health insurance companies as state actors

In Germany, over 96 % of all children are born in hospitals.[113] The clients in Cases no. 1, 2, 4, and 5 were treated in public hospitals, the client in case no. 3 was first treated in a private hospital. **State run hospitals** exist both in public and in private legal forms, and both on a federal or on a state level, or even run by public universities. Their legal form notwithstanding, these can be classified as public institutions engaging the responsibility of the State.[114] Doctors operating within these hospitals are thus **state employed medical practitioners**, 'acting in a public capacity'. This was confirmed by the CEDAW Committee in the case of *Andrea Szijjarto*, a case of involuntary sterilization of a Romani woman by medical staff at a public hospital.[115]

All citizen are obliged by German law to register for a public or private health insurance.[116] As of 2010, about 90% of all German citizens were members of a **public health insurance**,[117]

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[110] In 2009, 96.7 % of all children born alive or dead were born in a hospital: Gesundheitsberichterstattung des Bundes, statistics available at http://www.gbe-bund.de/.
[111] CAT, General Comment No. 2 (2007), CAT/C/GC/2, para. 15.
[112] Interim report of the Special Rapporteur on Torture, UN Doc. A/63/175, para. 51, referencing CAT General Comment No. 2 (2008), para. 17. See also A/HRC/7/3, para. 31.
[113] Above, fn. 110.
[114] Burgers/Danelius (1988), The UN Convention against Torture, at 120.
[115] CEDAW, *Andrea Szijjarto vs. Hungary*, Communication No. 4/2004, UN Doc. A/61/38, 14 Aug. 2006.
[116] § 5 *Sozialgesetzbuch V*, § 193 III *Versicherungsvertragsgesetz*.
[117] See www.gkv-spitzenverband.de (last visited on 7 March 2010).

as were Clients no. 2, 4 and 5. All public health insurances are statutory corporations. Any public health insurance pays for clinical treatment, as long the treatment is medically indicated. On the other hand, it would not pay for aesthetic surgery and it often explicitly excludes the payment for any treatments related to the surgery (for example if complications occur). However, surgeries performed on intersexed infants *are regarded* as urgent and medically necessary. So even if the health insurance would generally not pay for unnecessary surgeries (such as aesthetic ones), it takes over the costs. The conduct of paying for these medical treatments implies consenting to them.

The German State is thus directly responsible for the medically unjustified ill-treatment of intersexuals in public hospitals, funded by public health insurance, failing to protect intersexuals from severe suffering. This also points to a failure of the German State to ensure proper education and training on the prohibition of torture to all medical staff (Art. 10 CAT).

b. State consent or acquiescence of ill-treatment in private settings

The Special Rapporteur has made it clear that the concept of consent or acquiescence 'extends State obligations into the private sphere and should be interpreted to include State failure to protect persons within its jurisdiction from torture and ill-treatment committed by private individuals.'[118] The ECtHR supports this view.[119] The Committee has specifically emphasised this obligation to protect with respect to minority groups[120] and gender-based violence.[121] A failure to exercise due diligence to stop, sanction and provide remedies creates a climate of impunity, amounting to a form of encouragement and/or de-facto permission.[122] In the case of FGM, a procedure not dissimilar to the genital surgery endured by intersexuals, the Rapporteur specifically pointed out that where this is performed in private clinics and physicians carrying out the procedure are not being prosecuted, the State de facto consents to the practice and is therefore accountable.[123]

Where the ill-treatment is committed by **private hospitals or financed by private insurance companies**, the **German State fails to exercise due diligence** to intervene to stop, sanction and provide remedies to intersexed individuals victims of torture.

The German government (and the German judiciary) are **well aware** of the medical surgeries undertaken on intersexed bodies and of the pain arising from them, not only because of previous parallel reports (e.g. to the CEDAW Committee) and individual court cases. In fact, the topic has been raised at the highest instances. The situation of intersexuals has been the subject of parliamentary statements since 1996[124], e.g. in 2001 and 2007, which also raised the issue of torture.[125] On 23 June 2010, the Ethics Commission of Germany (*Deutscher Ethikrat*) conducted an official hearing on intersexuality and its consequences for the individual ('Life between the genders'). In January 2011, the German Federal Constitutional Court, addressing the requirement of sterilisation and modification of external genitalia for full recognition of transsexuals, emphasised the severity of such surgeries comparable to

[118] Report of the Special Rapporteur on Torture, UN Doc. A/HRC/7/3, para, 31.
[119] ECtHR, *Z and ors. v. United Kingdom*, Application no. 29392/95, judgment of 10 March 2001, para. 73, citing *Osman v UK*, judgment of 28 October 1998, Rep. 1998-VIII, pp. 3159-60, § 116: States must take measures designed to ensure that individuals within their jurisdiction are not subjected to torture or inhuman or degrading treatment, including such ill treatment administered by private individuals.
[120] CAT, General Comment No. 2 (2007), CAT/C/GC/2, para. 21 (emphasis added).
[121] Ibid., para. 18.
[122] Ibid.
[123] Report of the Special Rapporteur on Torture, UN Doc. A/HCR/7/3, 15 Jan. 2008, para. 53.
[124] Kleine Anfrage der PDS of 30 Sep. 1996: „Genitalanpassungen in der Bundesrepublik Deutschland", BT-Drs. 13/5757, response of 29 Oct. 1996, BT-Drs. 13/5916; see Plett (2010), Begrenzte Toleranz des Rechts gegenüber individueller sexueller Identität, in: Duttge et al. (eds.), 53-67, at 65.
[125] Statements issued in response to parliamentary requests, published as BT-Drs. 14/5627 and 16/4322.

those performed on intersexuals, citing a textbook on medical treatments for transsexed and intersexed people.[126] Despite this, the German State is **denying effective protection** to intersexuals by exercising due diligence to prevent such ill-treatment in private settings.

It is thus not enough that the procedures mentioned in this report oftentimes violate German law, including the law on castration (KastrG) and the laws on parental care in the Civil Act (BGB), as explained above (C.IV.2.). It is also not enough that some individuals manage to pursue their rights in front of German courts and manage to obtain damages, such as *Christiane V*. (see Case study).[127] Knowing that such surgery continues to be performed, to this date, Germany fails to adopt effective measures to prevent doctors from directly committing these surgeries.

5. Lawful Sanction

Surgery performed on an intersexed child or adult in Germany does not constitute a sanction. It is therefore not covered by the exception clause.

II. Treatment of Intersexuals in Germany as Cruel, inhuman or degrading treatment

Article 16 of the Convention commits each State Party to the prevention of:

> 'other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article 1, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.'

Acts which fall short of torture are thus still prohibited if they amount to cruel, inhuman or degrading treatment or punishment. This is the case if the treatment does not reach the requisite threshold of severity, or if the suffering was inflicted negligently[128] (see *supra* D.I.).

Thus, if it is considered that the treatment that intersexuals suffer does not meet the **severity** threshold of Article 1 of the Convention, it certainly meets the threshold of Article 16. If it is considered that this suffering is not foreseeable to the surgeons, the insurance companies or the State, this lack of consideration constitutes **negligence** sufficient for Art. 16. As to **State involvement** and due diligence, the same applies as above. A discriminatory or other purpose is not required for CIDT.

Thus, even if it is considered that the treatment of intersexuals does not constitute torture, it certainly constitutes cruel, inhuman and degrading treatment which is equally prohibited by the Convention in absolute and non-derogable terms.

III. Obstacles to redress, fair and adequate compensation

Articles 12 and 13 of the Convention require that the State provide the means for an impartial inquiry into allegations of torture or CIDT (Art. 16 CAT). Article 14 requires an enforceable right to redress, fair and adequate compensation, including the means for as full rehabilitation as possible. However, many patients encounter serious difficulties pursuing their rights.

The **statutory period for damages claims** was reduced from 30 to 3 years in 2002, counting from the damaging event and the knowledge of the tort.[129] However, many intersexuals **do not find out about their medical history until much later in life**, sometimes because they

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[126] BVerfG, decision of 11 Jan. 2011 – 1 BvR 3295/07, citing Sohn/Schäfer, in: Groß/Neuschaefer-Grube/ Steinmetzer (2008), Transsexualität und Intersexualität, at 135.
[127] OLG Köln, dec. of 3 Sept. 2008 – 5U/51/08.
[128] Interim report of the Special Rapporteur on Torture, UN Doc. A/63/175, of 28 July 2008, para. 59.
[129] § 195 BGB: General statute of limitations is three years; § 199(1) BGB: starting point is the end of the year in which the claim arises *and* the claimant obtains knowledge of the tort; the maximum statute of limitations (e.g. the claimant finds out about the tort much later) is 30 years for bodily harms or health claims, § 199(2) BGB.

fail to menstruate, or because their physical condition is revealed by accident during other medical procedures. For patients who were medically abused as children, claiming damages or pressing criminal charges in time is particularly difficult, especially where doctors follow John Money's theory that a healthy gender development requires that the patient never finds out about the surgery. Moreover, proof is difficult as **many hospitals are unwilling to provide access to a patient's files**, even to the patient herself.[130] In the famous case of *Christiane V.* whose uterus and ovaries were removed for no medical reason in 1977 (see Case study), even the old 30-year period was only just met.[131] The 3-year statute of limitations in torts law can therefore be an obstacle to justice. For criminal offenses, limitation periods (max. 10 years) are now suspended until the child turns 18.[132]

Moreover, intersexuals encounter severe **problems in claiming disability benefits** which are dependent on the degree of disability. Many health disorders caused by paradox hormone substitution are ignored in the assessment. The regulation for the disability degree assessment[133] also discriminates on the basis of sex, ranking the impairments from castration lower for women than for men. This assessment is based on the assigned sex, usually female, not the chromosomes or gender identity. *Intersexuelle Menschen e.V.* is supporting clients suing for their full entitlement, also under the **law on compensation of victims** (*Opferentschädigungsgesetz, OEG*) – so far, without success.

This situation is not in line with Germany's obligations under Articles 12-14 of the Convention.

E. Conclusion: Germany is failing its obligations towards intersexuals under the Convention against Torture

The surgery intersexed people endure in Germany causes severe mental and physical pain. Doctors perform the surgery for the discriminatory purpose of making a child fit into the binary gender system, although there is plenty of evidence on the suffering this causes. The German State is responsible for these acts of torture committed by publicly funded doctors relying on public health insurance. Although this procedure is common knowledge, Germany fails to prevent these acts of torture from happening both in public and in private settings.

Germany is thus in breach of its obligation to take effective legislative, administrative, judicial or other measures to **prevent acts of torture** (Art. 2 CAT). It is also in breach of its obligation to prevent **other forms of cruel, inhuman or degrading treatment** (Art. 16 CAT).

It appears that Germany's efforts on **education and information regarding the prohibition against torture in the training of medical personnel** are grossly insufficient with respect to the treatment of intersexuals (Art. 10 CAT).

While torture is a punishable offense in German law, although not specifically (Art. 4 CAT), victims of such acts of torture encounter severe obstacles in the pursuit of their **right to an impartial investigation** (Art. 12, 13 CAT), and to **redress, fair and adequate compensation, including the means for as full rehabilitation as possible** (Art. 14 CAT).

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[130] Süddeutsche Zeitung of 25 June 2011, http://www.sueddeutsche.de/wissen/aerzte-verweigern-einsicht-in-krankenakte-heiler-und-heimlichtuer-1.1112243 (last accessed 2 July 2011).

[131] OLG Köln (fn. 127). 100,000 € in damages were awarded. As the case arose before the reform, the old statute of limitations applied.

[132] § 78b StGB suspends the limitation period until the victim turns 18 in case of sexual offenses or grave forms battery, if at least one of the perpetrators committed gross abuse in violation of a special protection relationship (*Misshandlung Schutzbefohlener*), such as parent/child, or doctor/underaged patient. This clause was introduced to benefit victims of female genital mutilation/cutting, the abuse of whom is very similar to that of intersexuals.

[133] *Verordnung zur Durchführung des § 1 Abs. 1 und 3, des § 30 Abs. 1 und des § 35 Abs. 1 des Bundesversorgungsgesetzes* (*Versorgungsmedizin-Verordnung – VersMedV*).

F. Recommendations

The Rapporteurs respectfully suggest that the Committee recommend the following measures to the German Government with respect to the treatment of intersexual people:

1. Prevent torture and cruel, inhuman or degrading treatment (Art. 1, 2, 16 CAT):

   a. **Cease all gonadectomies on children** unless there is clear and reliable medical evidence of a severe risk of tumor development, both in public and in private settings.

   b. **Cease all cosmetic surgery on children's genitals**, both in public and in private settings.

   c. **Provide for truly informed consent** of parents, young and adult patients, both in public and in private settings: Provide full information, orally and in writing, on the quantity and quality of the evidence suggesting the treatment; on the alternatives to the suggested intervention, including non-intervention, and their likely effects; on necessary follow-up treatment such as hormone substitution for gonadectomy or dilation for vaginoplasty, including physical and psychological side-effects and long-term effects; on the legal situation regarding parental consent including the child's right to an open future; on the existence of support groups.

   d. **Avoid situations of powerlessness** in hospitals, both public and private: Make sure parents know that there is no time pressure on a decision except in cases of true medical emergency; allow for parents to adapt to the condition of their child; provide financial and structural support for intersexual self-help groups and outreach activities to young parents in hospitals.

2. Ensure that education and information regarding the prohibition against torture are fully included in the training of medical personnel (Art. 10 CAT):

   a. Include **specific vocational training** of medical professionals on intersexuality in all medical disciplines.

   b. **Ensure that all medical professionals know that medically unjustified gonadectomy and feminising surgery amount to the infliction of torture or CIDT** and constitute a punishable offense.

3. Ensure that any intersexual who alleges they have been subjected to torture has the right to complain to, and to have their case promptly and impartially examined by, Germany's competent authorities (Art. 13 CAT) and ensure in the legal system that an intersexual victim of an act of torture obtains redress and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible (Art. 14 CAT):

   a. Ensure each individual's **full access to the entirety of their medical files** in practice.

   b. Review the specific problems encountered by intersexuals in the pursuit of their rights with respect to the **statute of limitations**.

   c. Establish an **aid and compensation fund** for affected persons, provide access to the Act on Victim Compensation (*Opferentschädigungsgesetz*).

   d. Provide for special **educational and vocational training measures** viz. **increased pension levels** for intersexuals whose professional advancement is being or has been impaired due to traumatisation and side effects of hormone treatment.

   e. Provide **access to medical supply without discrimination**, including hormone substitution corresponding with the individual's gender identity.

   f. Establish an **adequate specific index for the assessment of the degree of disability** through treatment, non-treatment and wrong treatment of intersexuals.

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Annex: Case studies

Cases No. 1 through 5 have been assembled by way of questionnaires in the Summer of 2011 among clients of the *Verein intersexueller Menschen e.V.* By way of anonymisation, the accounts were numbered. The other cases – Christiane V. and M. Frances Maria K – have already appeared as first-person narratives in the *Verein*'s Parallel Reports to CEDAW (2008) and CESCR (2010). They were condensed for the purposes of this report. The identity of all persons concerned is known to the *Verein*. The information ist stored in a safe.

Case No. 1

The client was born in 2001. The intersexed child is XY-chromosomal and registed as female. Further diagnostification gets no results. In 2007, the client's gonads were removed, although the parents haven't consented to a sterilization (*Frauenklinik Heidelberg*). The parents report they were only educated in relation to the anaesthesia and did not consent to the procedure. They acted on the assumption of another intervention (biopsy). The client was on a private insurance scheme. The client now suffers from numerous bone fractures and rashes, although the parents say that a connection with the gonadectomy is not proven. Moreover, the child suffers from a postramatic disorder as a result of the gonadectomy.

Case No. 2

The client was born in December 1994 and was diagnosed with testicular feminisation. This is also known as CAIS (complete androgen insensitivity syndrome) where cells do not respond to the androgenic hormones produced in the testicles, preventing these hormones from influencing the development of the sexual organs. As a result of this, the body did not masculinize. The child is registed as female. While the parents were informed of the diagnosis right away, the client only found out from the parents at age 8 or 9. In November 1995 a biopsy of the genital skin was performed, as well as a test for hCG (human chorionic gonadotropin, a hormone produced during pregnancy but also an indicator of tumors). The diagnosis of CAIS was confirmed. The client also underwent a molecular-genetic analysis as well as a sonography of the abdomen, no tumors were found. In March 1996, the gonads were removed on both sides without prior education of the parents (*Eberhard-Karls-Universität Tübingen*). The client was insured through the statutory insurer *Techniker Krankenkasse*. The client, now aged 16, has to take paradox hormone substitutes, i.e. contrary to the chromosomal sex, and not adequate for childen and young people. The client reports bad haemogram laboratory values and regrets the gonadectomy. The client also displays all signs of a castrate, including a medical anaemia.

Case No. 3

The client was born in July 2007, displaying intersexed genitals. At first, it was assumed that the child had AGS/CAH (adrenogenital syndrome/ congenital adrenal hyperplasia). This means that the adrenal cortex produces a high amount of testosterone instead of aldosterone and cortisol, leading to ambiguous external genitals and, more importantly, a lack of vital salts. Based on this assumption, the child was registered as female and given a female first name. It then became clear that the child had XY chromosomes and testes which had not descended into the scrotum which was present. The child was now diagnosed with hermaphroditism/ DSD with unclear syndrome. The parents had the registered sex changed to male and changed the child's first name. The doctors at the *Klinikum Essen* referred the parents to the *Krankenhaus Maria Hilf Krefeld* (run by *Alexianer Krefeld GmbH*) to obtain further advice from a specialised doctor. This doctor conducted a general counselling interview and advised an orchiopexy, i.e. the surgical attachment of the undescended testicles to the scrotum, in order to save the testes from damage caused by the heat in the groin. Also,

she mentioned that it was possible to straighten the penis. The parents decided that both testicles should be moved into the scrotum. They decided not to consent to the cosmetic surgery straightening the penis, as they did not agree on this matter and wanted to spare the child unnecessary pain.

In July 2009, the two-year-old underwent surgery in Krefeld. Instead of the orchipexy, a hypospadia had been performed, i.e. a straightening of the penis, despite a lack of consent. The attending physician falsely claimed that this operation had been necessary. The operation caused severe ulcerations, a complication which is common for this operation according to many experts, a fact which the attending physician claimed not to be aware of. The child suffered from a severe infection for months. In December 2009, the testicles were finally lowered into the scrotum. However, the infection caused by the first surgery persisted, and in February 2010 the right testicle had to be removed due to a severe inflammation.

The parents then transferred to another physician due to the mismanagement at Krefeld. Eight further surgeries were necessary in the aftermath of the hypospadia. In total, the small child underwent 11 surgeries with general anaesthesia within a year. Today, the child is without his right testicle, the left testicle is now probably sterile, the prostate is damaged. The child is traumatised and panics at each visit to the doctor. The parents suffer with their child.

The insurance company was a private insurer (*AXA Versicherungs AG*).

Case No. 4

The client was born in January 2001. The client was diagnosed with mixed gonadal dysgenesis. This diagnosis covers a number of different phenomena, usually it means that the gonads are asymmetrical and/or develop in an unusual way. Just over two weeks after birth, an MRI (magnetic resonance imaging) was performed under general anaesthesia. Two to three weeks after birth, XY chromosomes were established, as well as two uteri and intra-abdominal testicles. The child was registered as female. A year after the screening, the gonads were removed (*Städtisches Klinikum Karlsruhe gGmbH*). The parents report that they had to read up themselves, constantly ask the doctors lots of questions and become experts themselves, as doctors only explained what was absolutely necessary. The client was insured through the father (*BKK Hochrhein-Wiesenthal*), and later transferred to a private insurance with retroactive effect.

Case No. 5

The client was born in February 2000 and was diagnosed with hypospadia scrotalis four weeks after birth. This means that the urethra opening was located at the scrotum. Surgery was performed in January 2001, in Nuremberg (*Klinikum Nürnberg*). The client's male sexual organs were removed. The baby's clitoris was reduced, and the vagina was surgically altered by introitusplasty (alteration of the vaginal entrance). Both parents consented. The insurance was a statutory health insurance (*IKK Waiblingen*). The client was registered as female at birth, despite the establishment of XY chromosomes. The client today has adjustment problems to the assigned gender and reports some problems with doctors in general. The child is bullied at school on account of being different and suffers from the assigned gender role.

Case study Christiane V.[134]

Christiane V. was born in the 1950s. Her internal organs as well as her XX chromosomes corresponded with those typically found in females. However, due to a condition called congenital adrenal hyperplasia (CAH), her external sexual organs had virilized during pregnancy. Her hydroxylase deficiency results in a deficiency of the essential hormones

[134] A first-person account from Christiane V. can be found in the 2010 Shadow Report to the CESCR Committee, pp 40-44, as well as in the 2008 Shadow Report to the CEDAW Committee, pp 26-29 ("Christiane T.").

cortison and aldosterone, causing an exceeding production of androgens. Upon birth, there was no apparent vagina, the merged labia were taken for an undersized empty scrotum with the undescended testicles inside the body, and the clitoris was taken to be a micropenis with a malformed urethra. Christiane V. was thus pronouced a boy and raised as a boy. At the age of three or four, her CAH condition caused an early puberty, further virilizing her body including the growth of pubic hair. Christiane V. grew to hate her external genitals and attempted self-mutilation, claiming to be a girl even as a small child.

At age 16, during an appendectomy, her female inner organs were discovered by the family physician who referred her to a urologist without informing either Christiane V. or her parents of what he called 'inguinal testicles'. The urologists, upon surgery, discovered an ovary-like structure with fimbriae and took a tissue sample. For an explanation of the results of the surgery, they referred her to the family doctor who, in turn, scorned her as a 'freak, a monstrosity' and explained she was an incurable 'hermaphrodite'. As a result, Christiane V. experienced depression and suicidal feelings.

At age 17, Christiane V. went to the University Hospital in Cologne asking for help. The hospital performed a series of tests which were not explained to Christiane V., including an intelligence test and intrusive questions on her sexual orientation and behaviour, and coerced her to undress for photographs and presentation in front of medical students. Christiane V. reports that the fact that her intimate and physical data including photos can possibly be found in diverse publications and internet fora has led her to isolate from people.

It was discovered that Christiane V. had the typical chromosomes and complete inner sexual organs of a female, a fact which revealed her CAH disposition. Christiane V., however, was told she had 'testovare', a mixture of male and female tissue in her abdomen which could cause cancer. Under the impression that she had cancerous or possibly cancerous tissue in her abdomen, Christiane V. underwent surgery at age 18 in the Clinic of Cologne-Merheim. During the surgery, only female internal sexual organs were found, all of which were removed. Christiane V. was led to believe that the doctors had removed degenerate gonadal tissue, a type of tumor. Without her knowledge, the senior physician at the hospital wrote to the army recruiting office in Krefeld: 'The patient is female and the genotypically normal female internal organs were removed during the operation. I ask for the unconditional consideration of the fact that Mr. V. is not fully informed about his disease. The above-mentioned diagnosis should not be told to him in any way.'

Following this abuse, Christiane V. had to undergo further surgery to construct a masculine external genitals (urethra construction) and was put on a high-dose testosterone therapy causing virilization, including beard growth and hair loss typical of males. Her voice masculinised, and her body developed so-called eunuchoid fat. Her actual dysfunction, CAH, was not treated until years later, with cortisone.

She says: 'With complete and correct education and with reasonable therapeutic treatment of the congenital adrenal hyperplasia, … I would have been able to experience a fulfilled female sexuality, the life of a woman and mother. All this destroyed to me by the genital mutilation respectively by the provenly enforced castration.'

In 2009, Christiane V. claimed her disabled person's file. She received an incomplete file but was told it was complete. The same happened when she claimed her medical file from the Clinic Cologne-Merheim. When Christiane V. finally obtained all her files, she discovered that the social office had been fully informed about her medical history when she first claimed disability status in 1987. Despite knowledge of her female physis and identity, the office determined her status on behalf of a male, not taking into account her mutilation and castration, establishing the low status of 50 %.

Christiane V. went to court in April 2010, claiming a higher disability status. She won her case in the second instance and was awarded 100,000 € in damages.

She says: 'I, as a woman, have been forced to live a false life, namely the life of a man. This way, a fulfilled partnership, fulfilled sexuality, my right to motherhood, and the possibility to build up a family, have been taken away from me and been destroyed. … From now on, at age 48, I am beginning to be the woman, I have always been by nature. This cannot bring me back the lost youth and the life of a woman at the age of 20 or 30. It can also never be compensated, what I have suffered at the hospital at the age of 17 and 18.'

Case study M. Frances Maria K.[135]

M. Frances Maria K. was born in Southern Germany in 1957 and raised as a girl. Frances Maria K. refused to wear skirts to primary school and was allowed to wear trousers. In 1972, at age 15, Frances Maria K. had not menstruated and was her to a human genetic examination. The diagnosis was XY gonadal dysgenesis / male pseudo-hermaphroditism, a condition of which Frances Maria K. was informed in the family. In 1973, both testes were removed in a so-called bikini cut, leaving the other internal and external genitals intact. The performing doctor was Dr. Overzier whose 1961 book on intersexuality was considered a standard work on which many other doctors based their diagnosis and treatment. He wrote: 'We are in the process of chromosomal testing. However, I did not want to delay the surgery to wait for the results, because the results would not have influenced the surgery anyhow and the patient might have changed her mind.' A life-long estrogen treatment was prescribed.

Frances Maria K.'s performance in school deteriorated following the surgery and beginning of the hormone therapy. Following university studies, Frances Maria K. was never able to keep jobs for more than two years, reporting lack of energy and suffering from the secret.

Hormonal treatment continued from 1973 until 2004, during which time the medication had to be changed several times due to increasing health problems associated with the treatment. Contraceptives were exchanged for menopausal resp. post-menopausal estrogen preparations. Despite this, health problems increased. In 2000, Frances Maria K. was told by the family doctor that due to metabolic symptoms (increased blood sugar and cholesterol levels) as well as an increasing body weight, life expectancy was about 4-5 years. Told by doctors to be „a normal woman", Frances Maria K. reports: „I felt rather unsettled and I could not be the woman I was supposed to be." In 1996, K. had already dropped the female first name Margaret and had assumed the middle names Frances Maria.

Repeated requests for insight into the medical files was denied on the basis that they were not available, a formal request equally failed. It was not until 2002 that Frances Maria K. joined a support group and started to speak about the condition and health problems. In 2005, Frances Maria K., then married to an intersex activist identified as male, started a trial to gain insight into the medical files. Frances Maria K. also decided that the paradox hormone treatment was responsible for all the health problems in the past. Finally, the endocrinologist was convinced to prescribe testosterone under his supervision.

In 2010, Frances Maria K. was adjudged a disability status (GdB) of 70 % for 1977-2000 and for 2006-07, of 90 % for 2001-2006, and unlimited since 2007. This assessment was based on the following health damages:

1. XY gonadal dysgenesis (deletion of SRY on the Y chromosome) with severe penis dysplasia (WHAT IS THIS?), loss of both testes before completion of puberty, long-term paradoxical hormone therapy resulting in severe gynecomastia (feminine breast

[135] A first-person account from M. Frances Maria K. can be found in the 2010 Shadow Report to the CESCR Committee, pp 45-49.

development of a male), multiple metabolic disorders, osteopenia (low bone minerals, a precursor of osteoporosis), and psycho-reactive symptoms (single GdB 90)

2. Hypophysis adenoma (benign tumor) with low prolactiemia (lack or the hormone prolactin) (single GdB 20)
3. Spinal disease (single GdB 20)
4. Recidivating erysipelas (infection of the skin with streptococcus bacteria) on the left foot and degree IV varicosis of the deep veins in both legs (single GdB 10)
5. Metabolic syndrome with diabetes mellitus (single GdB 10).