Deutscher Ethikrat

Intersexuality

OPINION

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Jaegerstrasse 22/23 · D-10117 Berlin
Phone: +49/30/20370-242 · Fax: +49/30/20370-252
Email: kontakt@ethikrat.org
www.ethikrat.org

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1 OUTLINE OF PROBLEM, INSTRUCTION AND PROCEDURE

In December 2010 the German Ethics Council received an instruction from the Federal Ministry of Education and Research and the Federal Ministry of Health to continue the dialogue with intersexed people and their support groups, to undertake a comprehensive review of their situation and the associated challenges with due consideration of the relevant medical, therapeutic, sociological and legal perspectives, and to distinguish the issues concerned clearly from those of transsexualism.

The background to this instruction is the demand by the UN Committee on the Elimination of Discrimination against Women (CEDAW)[1] that the Government of the Federal Republic of Germany enter into a dialogue with intersex people and adopt measures to protect their human rights.[2]

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1 Convention on the Elimination of All Forms of Discrimination against Women of 18 December 1979; effective in Germany from 9 August 1985 (BGBl. 1985 II, 648).

2 The Convention requires states to adopt measures to implement the Convention. For monitoring purposes, it requires states to submit regular reports on the implementation status of the Convention; non-governmental organizations may present "parallel reports" or "shadow reports" of their own on these reports. The Federal Government's Sixth State Report, dated 8 June 2007, which does not address the issue of intersexuality (*Deutscher Bundestag* 2007a), prompted the submission of a shadow report and a parallel report by the Association *Intersexuelle Menschen* (German Association of Intersex People) and its associated support group *XY-Frauen* (XY-Women) dated 2 July 2008. These reports describe the situation of intersex women in particular, illustrated by individual autobiographical accounts; contain a detailed critique of violations of fundamental requirements of the Convention; put a number of questions to the Federal Government on measures to eliminate these violations; and, lastly, recommend ways of avoiding and eliminating violations of the Convention (*Intersexuelle Menschen* 2008). In its concluding remarks of 10 February 2009, the CEDAW Committee regrets to note that the demand for dialogue expressed by intersex and transsexual persons has not met with a positive response from the Federal Government; it calls on the Federal Government to enter into a dialogue with non-governmental organizations of intersex and transsexual persons in order to arrive at a better understanding of their concerns so that it can adopt effective measures to protect their human rights (UN Committee on the Elimination of Discrimination against Women 2009). In its written report of 18 August 2011, the Federal Government gives a detailed account of the

In recent years the issue of intersexuality has become more visible than in the past, owing in particular to the activities of groups representing intersex people, as well as to media discussions in the field of sport; on the whole, however, it still seems to be subject to a powerful taboo, and such little public debate as there is on the matter is conducted on the basis of inadequate information.

With the formation of the Intersex Society of North America (ISNA) in 1990, which marked the beginning of the entry of intersex people on to the public stage, the fundamental problem of ambiguous sex in a society characterized by the existence of two sexes and the associated psychological and social consequences entered the consciousness of the public at large for the first time. This also led to critiques of the medical and legal treatment of intersex people.[3] An increasing number of organizations and support groups fighting for the recognition of intersex people and for more attention to be devoted to them were established throughout the world. These organizations also condemn the treatment of intersexuality in medicine and its classification as a disease; they see intersexuality as individual variation.[4] However, sex designation where the possibility of intersexuality exists has in the last few years also attracted attention in the field of sport in particular, on account of several high-profile cases such as those of Erika Schinegger[5] or Caster Semenya[6] (see Section 5.2).

That said, the term "intersexuality", as used in the public debate and on which the Federal Government's instruction

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activities of the Federal anti-discrimination centre on behalf of transsexuals (*Bundesministerium für Familie, Senioren, Frauen und Jugend* 2011). With regard to dialogue with intersex people, the Federal Government draws attention to its instruction to the German Ethics Council.

3 See Kolbe 2010, 18.

4 See Kolbe 2010, 144.

5 A former Austrian Alpine skier who won the gold medal for women's downhill skiing in 1968 but was disqualified after failing a sex test and had to give up the sport.

6 A South African middle-distance female runner who was suspected of not being a woman in the 2009 World Championships, but was readmitted by the International Association of Athletics Federations in 2010.

to the German Ethics Council is based, is neither unequivocal nor undisputed. It relates to persons who cannot be unambiguously categorized as male or female owing to physical particularities. The term is intended to supersede older designations such as "hermaphrodite" or the German word "Zwitter", which may be discriminatory in character. The word "intersexuality" leaves open the question of whether it relates to a third sex or whether the person's sex has merely not been, or cannot be, determined.

Transsexuals, on the other hand, have an unambiguous biological sex but feel that they belong psychologically to the other sex, so that they often choose to undergo medical interventions to align their body with their sexual identity and have their sex as recorded in the civil register amended in accordance with the provisions of the *Transsexuellengesetz* (Transsexuals Act).

The term "intersexuality" is also sometimes used for persons who can be unambiguously categorized as genetically female, but who exhibit virilization of the external sex organs owing to hormonal disorders, as in the case of girls and women with congenital adrenal hyperplasia (CAH).[7] Although persons in this group reject the ascription "intersex" for themselves, they nevertheless fall within the German Ethics Council's remit.

In addition, some of those affected identify themselves as "intersex" in order to make it clear that ambiguous sex is not a disease but a complex situation with not only biological but also psychological and social aspects. Others, however, reject the use of this term to identify themselves. The German Ethics Council employs the more generic, internationally accepted medical term DSD for the entire group forming the subject of its Opinion. Although the term originally stood for *disorders of sex development*, the Ethics Council uses it here, in accordance with the prevailing conception in the debate in Germany

7 See Section 4.3 for a detailed discussion.

today, to mean *differences of sex development*.[8] Understood as merely describing difference, the term DSD avoids the negative connotation of a disease or disorder, even if a small number of significantly pathological forms admittedly exist. The term is simply a biological and medical description of a bodily situation (see Section 2).

The present Opinion does not address all forms of DSD. For instance, it does not consider conditions characterized by numerical sex chromosome abnormalities such as Turner syndrome and Klinefelter syndrome. Although both of these syndromes involve differences of sex development that often need to be treated with sex hormones, the persons concerned are of unambiguous sex and their anatomy does not present any intersex features.[9]

The word "intersexuality" (or "intersex") is used in this Opinion to denote DSD with an intersex appearance with particular reference to the resulting ethical, social and legal issues.

To satisfy the requirements of the German Ethics Council's dual remit of both continuing the dialogue with affected people and compiling an Opinion, the Council undertook a number of interconnected steps.[10]

The first of these steps was the conduct, from 2 May to 19 June 2011, of an online survey on the situation of intersex people in Germany.[11] The aim of the survey was to record experience of medical treatments, subjective assessments of respondents' quality of life and attitudes to cultural and social issues.

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8 The recommendations of, for example, the *Netzwerk Intersexualität* (Network Intersexuality) are based on this conception (*Arbeitsgruppe Ethik im Netzwerk Intersexualität* 2008).

9 Female Turner syndrome individuals with mosaicism are the exception (see Sections 4.1c and 4.5).

10 All the data obtained by the German Ethics Council are recorded in the document "Intersexualität im Diskurs" (see *Deutscher Ethikrat* 2012).

11 The questionnaire for the online survey was drawn up by the German Ethics Council's working group on intersexuality. A project group at the University of Bielefeld headed by Alfons Bora, a member of the Ethics Council, drew up the electronic questionnaire, collected the data and evaluated the results (see Bora 2012).

Respondents were recruited in three ways. First, the Ethics Council gave notice of the planned survey on intersexuality on its website and sought large-scale participation. Second, information on the survey and hard copies of the questionnaire were disseminated via representative organizations and support groups. This assistance was a major factor in the success of the survey, a high proportion of the responses being obtained through these networks. Third, information on the survey was published on a number of occasions in the medical journals *Ärzte Zeitung* and *Deutsches Ärzteblatt*. In this way, it was hoped that more affected persons could be reached by using medical practitioners as multipliers.

The total number of participants in the survey was 201, of whom 78 responded by post and 123 by the online questionnaire. There were 199 evaluable responses.[12] The principal results are set out in Section 6.

In addition, opinions were obtained from experts in the relevant specialities. Academics in the fields of medicine, psychology, sociology and neighbouring disciplines were asked about recommended treatments and the practice of treatment, the evidential value of scientific results, indications, quality-of-life issues and cultural and social aspects. The legal experts were consulted on treatment and consent to treatment, the law of civil status and compensation. The German Ethics Council obtained 18 opinions from the fields of medicine, psychology, sociology and neighbouring disciplines[13] and 15 opinions from the legal sphere; together, these constitute one of the cornerstones of the present Opinion.[14]

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12 Two of the questionnaires received by post had to be disregarded because they each contained responses for two persons.

13 These comprise eight opinions from medical experts, three from psychologists, and one each from a sociologist, a philosopher, a biologist, a cultural studies expert, an educationalist, a medical ethicist and a historian of medicine.

14 The opinions received and the underlying problem statements can, subject to their authors' consent, be accessed online at http://www.ethikrat.org/sachverstaendigenbefragung-intersexualitaet [2012-02-07].

The second step in the compilation of the Opinion was a public hearing involving intersex persons, parents and academics, held in Berlin on 8 June 2011. It comprised two sets of topics, on which 12 experts – four affected individuals, two mothers of affected children, two lawyers, two psychologists, a doctor and a philosopher – were invited to speak. The first set of topics concerned "medical treatment/indication/consent" and the second "quality of life, social situation and perspectives" of intersex people. Following the experts' statements and questioning by the German Ethics Council, questions were invited from the floor, these being collected by appointed deputies and submitted in groups to the experts.[15]

As a follow-up to the hearing, the Ethics Council conducted an online discourse[16] on the subject of intersexuality. This enabled affected individuals, members of their families and experts from various disciplines to exchange views with a low access threshold. This approach was intended in particular to reach persons who were not members of organizations, did not possess relevant expertise or had for whatever reason not so far expressed a view and were unable to take part in the public hearing. The online discourse took the form of a weblog which encouraged users to debate various issues on the basis of articles presented several times a week by academics or compiled by the editorial team. The online discourse ran from 8 June to 7 August 2011 and was carried out in collaboration with *Kooperative Berlin*.[17] The 50 contributions posted gave rise to a total of 727 comments. The number of page views exceeded 34 000, while more than 8000 visitors viewed the pages for a significant length of time.[18]

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15 The hearing's contributions can be accessed online at http://www.ethikrat.org/veranstaltungen/anhoerungen/intersexualitaet [2012-02-07].

16 See http://diskurs.ethikrat.org [2012-02-07].

17 *Kooperative Berlin – Netzwerk für Kulturproduktion* has existed since 2006 and describes itself as a network offering editorial material and other productions. Its specific fields are contemporary history and current affairs, network and media, referral and advice, art and culture.

18 Average dwell time was 08:08 minutes. The evaluation yielded a total of 2574 "definite visitors" who visited the page several times a day.

In June 2010 – i.e. before receiving the instruction from the Federal Government – the German Ethics Council had already commenced dialogue with affected individuals and their support groups by means of a public meeting on the subject of "Intersexuality – life between the sexes". The Ethics Council was able to continue the process begun with this dialogue through the public hearing and the online discourse.

To obtain more complete information, the German Ethics Council in addition organized individual expert meetings with medical practitioners and invited written contributions from three parents who had come to the Ethics Council's attention as having brought up their children, born intersexed, without a sex designation.

In all these surveys, hearings and discussions, the main issues raised were the problems of medical interventions, their legitimacy and/or appropriateness both after and before the attainment of decision-making capacity, and aspects of the law of civil status that currently demand the registration by the state of every individual as *female* or *male*.

As to the legitimacy of medical interventions, the common conclusion of all discussion forums and surveys was that very clear distinctions had to be drawn between the forms of DSD existing in each individual case. Furthermore, in the last few years, not only have the methods of medical treatment improved, but there has also been a change of attitudes, whereby early sex assignment surgery is increasingly condemned (see Section 6). However, a number of now adult affected individuals underwent such operations, such as gonadectomy, while not yet competent to decide for themselves.

During the course of the dialogue and the drafting of the Opinion, the German Ethics Council became aware of some distressing vicissitudes suffered by affected individuals who are now adults. Impressions from the lives of some of those affected are included in our Opinion. They clearly illustrate the existential significance of the issues concerned for those persons; for this reason, the German Ethics Council supports

their demand to be recognized as they are and to be able to live a normal life free of discrimination with their individual particularities.

1.1 Subjective experiences of affected individuals

1.1.1 Autobiographical account: an extract from the CEDAW shadow report[19]

> I was born in 1965 with a bad heart defect and ambiguous genitalia. Due to the heart defect, I was given an emergency baptism only a few days after my birth, as the doctor said I would not survive much longer. Consequently, they kept me in the hospital and would not allow my parents to take me home. [...] The doctor justified all this with high risks of infections due to the heart defect. According to the medical file however, during these three months the various treatments took place due to my ambiguous genitals, whereas it was detected that I had abdominal testis and a male chromosome status. [...]
>
> In September 1965, being 2.5 months old, I was castrated despite to my life-threatening heart defect. This operation was incomprehensible for two reasons: first it was very risky because of my severe heart defect. Second it made no sense because of my presumed low life expectancy. [...] The performed castration was carried out without the informed consent of my parents, and was subsequently to be kept secret. However the doctors then made a different decision. [...] *"Discussion with the parents: Contrary to the earlier decision that was agreed upon, that the parents must indeed say that the child will be castrated and that there must be rigorous monitoring during puberty. The follow-up monitoring is not assured as the mother is [...], and it might be possible that she will run off to [...]."*

19 *Intersexuelle Menschen* 2008, 22 ff. [Translator's note: This autobiographical account is taken from the English version of the shadow report.]

Later the castration will be declared as a mistake: "*7. Further procedures: Directly after the cystoscopy, I discussed the case with Prof. [...] again. In his view a male gender with Hypospadias is given. Although he was present at the earlier discussion and castration, retrospectively he believed that a mistake had already been carried out. The situation is now forcing us to continue this way and the small patient must be made a girl. Concerning the vaginal prosthetic he meant that this should be carried out as soon as possible and as long as the child is not aware what happens to him.*"

The doctor did not tell my parents the truth about me but advised them how to educate me: "*The child is a girl and will stay one as the entire educational upbringing has been arranged. Only between parents and doctor [...] the question of gender should be discussed.*"

My parents had not been told that I have male chromosomes and that my testicles were removed. Of course they had not been informed about the mistakes. Continually wrong information was given to my parents: "*The parents certainly asked whether the girl would be able to have children, and they were told, that this was doubtful.*" With absurd frauds they were fobbed off: "*Both parents are incidentally well oriented about the situation. They know that D. is a girl and that she will remain being a girl. They know that the malformed ovaries had to be taken out, cause otherwise the danger of virilisation would have been given [...].*" (3.2.72)

First of all, I never had ovaries. Second of all, one cannot adopt male characteristics with ovaries! [...]

I would eventually get older than initially expected. At the age of seven the doctor decided to carry out the operation on my heart, whether the prognosis was good or not: "*The atrioventricular septal defect operation is still very difficult and shows a high rate of mortality i.e. from around 50% with the entire profile. In this case, survival in addition to the hypoplasia of the left side and the probability of the mitral stenosis, is what can still change the chances of operation to the worse. [...] The whole prognosis also considering the pseudohermaphroditism and the severe malformation doesn't look very good. Though from experience, no indication of continuity can be given. But we do not believe that the girl will reach adulthood.*"

In 1972 I was in the hospital for the heart operation pre-examination. Because of an infection however, the preexamination was not able to be conducted. Being there the chance was used to correct my genital. The following abstract was documented from my patient file: *"Due to the reoccurring cardio logical Streptococci infections, the scheduled intracardiac catheter must be delayed. We used the opportunity to carry out the genital correction originally planned in 1965."*

[...] Today I am 42 years old, still living (tenacious like a cat, my father always says) and so far I have had no specific health problems, compared to the experiences others had gone through. I am now starting to think about my chromosomes and the paradox hormone therapy including the possible damages caused thereby. The consequences of the wrongful treatment are beginning to show: For about two years I have increasingly joint pain (back, left hip, knee and foot) after an one hour walk with my dog (before long walks did not cause any problems). My legs often feel as heavy as lead and I feel dizzy nearly everyday. Increasingly having hot flashes and being fatigue. I also lost much weight. Two years ago early stages of osteoporosis had been diagnosed. Today I a[m] certain to have osteoporosis. I know I have to see a doctor!

I was able to clear most of my psychological problems in a psychoanalysis during the last seven years. I will however still suffer throughout my life, living with the torture of this inhuman treatment. I am neither a man nor a woman, but above all, I am no longer a hermaphrodite. I will remain the patchwork created by doctors, bruised and scarred. If I want to keep living, I must discover myself anew.

Today I am thankful that I have found my inner peace throughout psychoanalysis over the past few years. I am able now to allow closeness and love into my life. Nevertheless, it is still difficult. I feel like someone who has woken up from a 40-year coma, realizing how time has pas[sed] and how little life has had for me. My original body is irretrievably lost. My identity and my dignity were taken away from me. I am starting now to get it back once and for all!

1.1.2 Autobiographical account: an extract from the CESCR shadow report[20]

[...] I was born in February 1957 [...]. I have two younger sisters. [...] My parents brought us up as girls. When I moved to the former boys' grammar school in 1969, I refused to go to school in a skirt. [...] At the end of 1972 I underwent a genetic examination because I had not had any periods and the result was an XY gonadal dysgenesis/masculine hermaphroditism. My parents and later I myself were given the following information: I had an XY chromosome set, could most probably not have children of my own and had to undergo surgery owing to the risk of cancer. My mother asked to see the X-rays but was refused.

In March 1973 [...] both gonads were completely removed. [...] I was told that I would now have to take hormone tablets for the rest of my life. My academic performance deteriorated and I left the grammar school.

I subsequently followed every piece of medical advice. Yet I had to switch oestrogen preparations every few years as my state of health constantly worsened.

In 1976 I left the Fachoberschule [upper secondary level vocational school] with the Fachhochschulreife qualification [diploma qualifying the holder for entry to a university of applied sciences]. I studied agriculture at Witzenhausen Gesamthochschule [polytechnic] and graduated as an agricultural engineer in 1982. For health reasons I had to give up a job on an experimental farm using environmentally friendly techniques in the United Kingdom.

I moved to Berlin to join my boyfriend and studied international agricultural economics [...]. I had increasing health problems and, on medical advice, I was put on menopausal/post-menopausal hormone preparations. My state of health and general well-being continued to deteriorate. I thought the hormones could not be to blame because

20 *Intersexuelle Menschen* 2010, 46 ff. [Translator's note: This English translation by P. Slotkin of the second autobiographical account is given here instead of the wording from the English version of the parallel report because the latter does not correspond to the German text.]

the doctors treating me assured me that everything was all right with them. My relationship ended after my second course of study. I then moved several times and was unable to hold down a job. Another relationship failed because I was unable to have children.

I did not dare enter into a close relationship with female friends in case it was seen as lesbian.

After moving from place to place several times, I settled in Hamburg in 1996, where my then general practitioner revealed to me in 2000 that if we could not get my metabolic levels (cholesterol and sugar) right, I would only have four or five years to live. In 2002, after reading a newspaper article about a report entitled "The prescribed sex", I came into contact with other intersex people and the self-help group "xy-frauen". As a result I went to see a specialist in Lübeck, who told me that I was perfectly all right and referred me for talking therapy. Although my physical condition, well-being and participation in social and cultural life went on deteriorating, the psychologist told me: "You have a lot going for you; you are a perfectly normal woman." This did not help me in any way. I went on searching; the XY-Women group was very helpful to me. At a meeting on intersexuality in 2004, I met my present wife C.

After we met, we jointly set about demanding the documentation so as to gain a clear view of the situation. After I became aware that my nuclear sex was not female, I realized that the removal of my testes was the reason for the deterioration in my health and the associated collapse in my performance, and that the cross-sex hormone therapy had prevented me from living a fulfilled life for 32 years, so I switched my hormone therapy to testosterone under medical supervision.

Readers should always bear in mind what [...] Prof. Dr. Claus Overzier writes in the conclusion (p. 537) to his book "Die Intersexualität", published by Thieme Verlag in 1961 (he was the surgeon in charge when I was operated on in 1973): "Not uncommonly, a decision will be made 'contrary' to the nuclear sex diagnosis and the histological findings. These findings should then be kept secret from the patient and perhaps even from the general practitioner." [...]

In 2010, after more than two years of expert appraisals and contradictions, and having involved the Social Court, I was given a

disability rating [GdB] and awarded a severely disabled person's pass: GdB 70 from 1977 to 2000 and from 2006 to 2007, GdB 90 from 2001 to 2006, and this level applies indefinitely from September 2007.

The disability rating concerns the following situation, but involves only the main health-related reasons and causes:

1. XY gonadal dysgenesis with severe hypotrophy of the penis, loss of both testes before completion of bodily development, many years of cross-sex hormone therapy resulting in pronounced gynaecomastia, multiple metabolic disturbances, osteopaenia and psychoreactive disturbance (single GdB 90)
2. Pituitary adenoma with slight prolactinaemia (single GdB 20)
3. Spinal pathology (single GdB 10)
4. Relapsing erysipelas on the left foot and trunk varicosis, degree IV, in both legs (single GdB 10)
5. Metabolic syndrome with diabetes mellitus (single GdB 10)

[...] I now know how important my karyotype is: my metabolism is becoming normal before my very eyes with testosterone. For instance, I had the testosterone levels of a post-menopausal woman for 32 years. [...] But the consequences of the oestrogen therapy from 1973 to 2005 were switching from job to job with periods of unemployment, as well as several moves and failed relationships – all these were due solely to the ablative castration and the oestrogens, as well as to the incorrect social, legal, psychological and medical notion of "the two proper sexes" – so they never at any time had anything to do with my own person.

Here are some more absurdities and aspects from my life:

It is a statutory requirement for the sex recorded on one's health insurance card to be the same as one's official civil status. Without a change of civil status, I am refused a "male" health insurance card. As a result, because of "my female card", the laboratory levels measured are compared not with the male reference values but with the female ones because the process is automated. This gives rise to misdiagnoses and incorrect treatments. Although it would be simple for me to have my civil status amended in accordance with Section 47 PStG

[Act on Civil Status], I am married to a true hermaphrodite with a male civil status (not in a civil partnership). So our marriage could be at risk. It would not be a technical problem for the health insurance fund to issue an appropriate card, but I am discriminated against on the grounds of sex, disability and sexual identity – a case covered by the AGG [General Equal Treatment Act], the BGG [Act on Equal Opportunities for Disabled Persons] and the PStG.

In spite of my high educational level, including tertiary education, I have been unable to hold down a job because my capacity has been greatly restricted: I needed 80% of my energy just to mobilize 20% of my capacity. Although healthy people too have to overcome their negative inner voices, they then have more or less 100% of their capacity/energy at their disposal. Having reached the age of 54, I do not now consider myself capable of enduring a three-hour working day even on testosterone, however prepared and willing I am.

Whether it is oestrogen or testosterone, because all my vital parameters have to be monitored regularly, I have medical appointments almost every month, with my general practitioner, a radiologist, an endocrinologist, an andrologist, a urologist, a gynaecologist or whatever; and each time I go to a new doctor, I have to "explain everything all over again". (Civil status = sex on health insurance card.) The testosterone level is just as difficult to get right as the insulin dose in diabetes.

2 DISTINCTION BETWEEN INTERSEXUALITY AND TRANSSEXUALISM

A person's anatomical appearance is typically either unambiguously female or unambiguously male. It is paralleled by internal and external sex organs, all of which are either unambiguously female (ovaries, uterus, vagina, clitoris, etc.) or unambiguously male (testes, epididymis, vas deferens, prostate gland, penis, etc.). However, the medical literature includes an abundance of descriptions of particularities and malformations of the anatomical structure of the sex organs, all of which are subsumed in the concept of DSD (disorders or differences of sex development). The majority of these – e.g. cryptorchidism or vaginal atresia – do not impede sex designation. This Opinion deals only with the less common variants of anatomical appearance, in which the designation of an individual as male or female is doubtful because the internal and external sex organs of that individual include both typically female and typically male characteristics. This coexistence of organs of both sexes is not necessarily accompanied by a physical impairment; however, it may also result in the development of physical (in particular, hormonal) conditions that give rise to difficulties in those affected. Specifically, they may impair an individual's sexual development and sexual identity.

The word "intersexuality",[21] which is not universally accepted, is usually taken as a generic term for all cases of a DSD syndrome with ambiguous sexual anatomy. The emphasis with this term is on the practical and psychosexual consequences of the condition and its physical effects for the individual. The practical consequences relate to the administrative attribution to a sex for the child and adult-to-be (or its non-attribution), the child's sex of rearing and the individual's self-perception as

21 The term "intersexuality" was introduced in 1916 by the geneticist Richard Goldschmidt (1878–1958).

belonging to a given sex or as intersex (this is a matter of gender rather than physical sex). From the medical perspective, the consequences comprise diagnostic and therapeutic measures that may be indicated in childhood or adolescence or in some cases only later and may often significantly influence the self-perception of those concerned.

The term "intersexuality" leaves open the question of whether it denotes a third sex alongside the usual binary classification or, alternatively, whether no sex is designated. It is also used with a view to avoiding the often discriminatory interpretations associated with the older scientific term "hermaphroditism".[22]

This semantic controversy indicates that the medical or social categorization of a person as belonging to one of the two sexes or to neither does not constitute a neutral diagnosis (such as, for example, that of a "fractured elbow"), but affects the person's self-perception and identity. A conflict may arise if a person with an intersex phenotype is designated as belonging to a sex that this individual does not wish, or is unable, to accept. Conversely, a conflict is also possible if a person is classified as intersexed on the basis of physical features despite subjectively belonging unambiguously to a specific sex and not deeming the physical variation to be significant.

The term DSD is used in the following text in relation to genetic/anatomical/hormonal status, as well as to its diagnosis and therapy – that is, as a biological and/or medical description of a physical situation. However, the anatomical variation does not automatically imply that a situation deviating from the usual binary classification is pathological or requires correction.[23]

The concept of transsexualism must be clearly distinguished from those of DSD and intersexuality. Transsexual individuals

22 However, some intersex people are happy to describe themselves explicitly by this term and do not accept its pejorative character.

23 The attribute "intersex" is used purely descriptively to indicate the presence of both male and female anatomical sexual characteristics in a single individual.

typically consider that their physical sex is the opposite of their sexual identity or gender. Some aspire to transfer from their biological sex to what they perceive to be their correct sex or gender and in addition sometimes opt for surgical or hormonal harmonization therapy to align their bodies with that sex or gender. They do not as a rule have an intermediate bodily and/or psychological sex or gender status. They are concerned to possess an unequivocal male or female status, whereas intersex relates to an intermediate condition. Admittedly, however, there are also people (classified as transsexual) who describe themselves as intersexed although not diagnosed with DSD, attributing this to the hormonal situation of their body, and specifically of their brain. It should be noted in this connection that virtually no other concept in sex research gives rise to as many difficulties of definition as transsexualism.[24]

24 See Richter-Appelt/Schönbucher/Schweizer 2008.

3 DESIGNATED SEX AND SEXUAL IDENTITY

Sex is not a unidimensional attribute, but a complex label resulting from the combination of many heterogeneous properties on the genetic, hormonal and anatomical levels. Another element is individual self-perception – a person may feel that he or she belongs to one sex, to both sexes or to no sex – as well as one's social attribution to a particular gender or, in other words, how one is classified by others.

As a rule, a newborn individual is designated as belonging to a specific sex (male or female) on the basis of the appearance of the external genitalia. This gives rise to a concomitant administrative and social designation. In DSD, however, sex determination on this basis may be difficult or impossible, or subsequently prove to be wrong. In such cases, medical measures such as hormone treatment or surgery are sometimes adopted to make the individual's sex unambiguous or to permit designation as belonging to one or other sex.

- In the following, medical interventions will be described as directed towards *sex ambiguity correction* if their aim is to bring anatomical particularities of the external sex organs into line with the existing sex where the person otherwise belongs unambiguously to a given sex.
- Interventions will be said to have the aim of *sex assignment* where they are intended to put an end to the state of ambiguity where unequivocal categorization really is impossible, thus modifying a person's body – in particular, the internal sex organs – in the direction of a specific sex; that is to say, assigning a given sex to the person.

A systematic distinction of this kind between sex ambiguity correction and sex assignment measures has not hitherto been made in the general debate or in the legal literature, either on

the level of language or in medical descriptions, or indeed in legal and ethical assessments. The terms sex assignment, alignment and ambiguity correction are predominantly used as synonyms. Yet the distinction drawn here by the German Ethics Council is important for both legal and ethical purposes, as will be shown below.

The levels of description underlying the complex attribution "sex" (or "gender") will now be briefly addressed.

3.1 Biological sex

Sexual reproduction is an essential condition for high variability of genetic endowment and hence good adaptability to changing environmental conditions. Like all mammals, humans reproduce when a male individual and a different female individual unite their heterogeneous germ cells, or gametes, thus giving rise to a new organism. From this biological perspective, hermaphroditism is an uncommon variant; self-fertilizing hermaphrodites do not occur in the human species.

3.1.1 Chromosomes

The sex of the newly forming organism is initially decided by the chromosomes it receives from the parental gametes. Male gametes (sperm) include not only the 22 normal chromosomes (autosomes) but also an X or a Y chromosome. X and Y chromosomes are called sex chromosomes (or allosomes). A female egg typically includes an X chromosome in addition to the 22 autosomes. If, after egg and sperm unite, the result is an individual with a karyotype including an X and a Y chromosome in addition to the 44 autosomes, that individual is deemed to be male; if there are two X chromosomes, the individual is female. At least one X chromosome is necessary for an embryo to develop at all.

The microscopic karyotype that can be visualized in appropriately prepared nuclei from human cells is called a karyogram. This indicates whether the individual concerned has a typical karyotype or one that exhibits variations. A karyotype is described by the total number of autosomes and the set of gonosomes present – e.g. 46,XX.

The resulting embryo and all the millions and later billions of somatic cells that develop from the fertilized egg have either a 46,XX or a 46,XY chromosome set depending on the kind of sperm that fertilized the egg – that is to say, the "chromosomal sex" is either female (XX) or male (XY). All the remaining 22 chromosome pairs are structurally identical in their paired form and differ only in fine detail (genetic variants) in all human individuals, whether female or male.

Departures from these typical chromosomal distinctions sometimes occur.[25] In addition, some individuals' chromosomal sex is not identical in all cells or tissues of their organism. Such an individual is called a chromosomal mosaic. Variants of this kind may arise spontaneously as a result of errors of cell division in the early embryo. Their consequences for sexual development depend on which parts of the mixed karyotype contribute to sex organ formation.

Besides variations in karyotype, modifications of the fine structure of the chromosomes – that is, of the DNA sequence – that may influence development as male or female have been reported. These are termed mutations. Their presence cannot be detected by a karyotype examination, but only by precise genetic analyses of DNA sequences.

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25 Examples are the karyotypes 47,XXY (Klinefelter syndrome); 47,XXX (triple X syndrome); 45,Xo (i.e. only one X – Turner syndrome); and Y polysomies: 47,XYY, 48,XXYY, 48,XYYY (very rare) and 49,XYYYY (very rare). In these special cases, an embryo is as a rule classified as chromosomally male provided that there is at least one Y; otherwise it is deemed to be female. Individuals born with such atypical karyotypes often exhibit physical particularities in their organs, including their sex organs, or in the functions of those organs, but as a rule do not present intersexual characteristics.

3.1.2 Gonads

A person's "gonadal sex" is determined by the individual's gamete-producing organs, or gonads. Paired testes characterize the male sex and paired ovaries the female. In very rare cases, testicular and ovarian tissue is present in one and the same individual. This situation is described as true hermaphroditism.

The gonads form together with the uropoietic system of organs in the fifth to eighth week of embryonic development. Male and female primordia are practically indistinguishable up to the end of the sixth week. Spontaneous development in the case of absence or inhibition of a Y chromosome proceeds in the direction of female sex organ formation. It is only after the sixth week that the SRY gene on the Y chromosome is transcribed in a male embryo. It codes for a protein known as testis determining factor (TDF). If this factor is not present (no Y) or not functional (owing to a mutation in the SRY gene), the internal sex organs always develop in the female direction (paired ovaries, Fallopian tubes, uterus and vagina); the external sex organs form later. If, however, TDF is active, a conversion takes place into male internal sex organs (paired testes, epididymis, vas deferens, prostate and some other glands), with subsequent formation of the external sex organs.

The formation of the gonads from initially neutral precursors explains their binary character – i.e. the fact that an individual as a rule possesses either testes or ovaries.

3.1.3 External sex organs

Besides the internal sex organs, their external counterparts too are laid down in rudimentary form at a later stage of embryonic development; they will develop as either female (clitoris, mons veneris, labia and certain glands) or male (penis, scrotum and certain glands). These external sex organs, which belong to the

genitalia, determine the sex designation of a newborn individual. These physical characteristics are differentiated under the influence of sex hormones that regulate the structuring of the body (by means of complex regulation circuits controlled by the brain), commencing in the fetal phase and continuing until the end of puberty.

Like the gonads (see Section 3.1.2), the external sex organs form from initially undifferentiated common precursors. That is why an individual as a rule has either a penis or a clitoris. In the case of DSD, where the anatomical appearance is intersexed, it may be impossible to decide whether the organ should be seen as a clitoris or a penis and what form of surgical treatment, if any, should be applied.

3.1.4 Hormones

Hormones are genetically encoded messenger substances whose production in various endocrine organs is ultimately controlled via the part of the brain known as the diencephalon. They coordinate the biochemical and physiological functions of the body. Contrary to their usual characterization, the sex hormones (testosterone, dihydrotestosterone, oestradiol, oestriol and others) are not completely sex-specific. Nor are they formed only in the gonads. For this reason, they occur in both sexes. However, significant differences in their concentration characterize the male and female bodies. This is already the case in the prenatal phase, when certain sexual differences in physical status, psychology, temperament and behaviour begin to develop, paving the way for subsequent differentiation. These are further consolidated by the circumstances of life and upbringing, and are ultimately accepted by most adults as their sexual identity.

A complex network of interactions exists between all hormones – the sex hormones and the other hormones of the body alike – with characteristic differences in various organs,

including the sex organs. Unlike genetic sex, hormonal sex is not typologically binary (i.e. strictly male or female), but varies along a sliding scale on which individual status may sometimes lie between the two extremes.

The hormonal network comprises all the genetically encoded hormones of the body, including the steroid hormones. Steroid hormones comprise the following "classes":

- Glucocorticoids (vital "stress hormones" which influence carbohydrate metabolism – e.g. cortisol)
- Mineralocorticoids (vital regulators of the salt/water balance – e.g. aldosterone)
- Male sex hormones (androgens, such as testosterone and dihydrotestosterone, which influence the development of the male body and male sexual characteristics)
- Female sex hormones (progesterone and oestrogens [e.g. oestradiol], which influence the development of the female body and the regulation of the monthly cycle, pregnancy and lactation)

The production of steroid hormones is controlled by the diencephalon (specifically, the hypothalamus) via the pituitary gland. Disturbances of their interaction may have direct or indirect repercussions on the balance of the sexual system and at the same time on the rest of the body's metabolism. Natural variation, genetic defects or medicinal manipulation of the hormonal system can give rise to hormonally induced DSD. An example with non-genetic causation is the virilization of sportswomen by hormone doping to improve performance. On the other hand, hormone therapy can shift the physical characteristics of DSD in the direction of one or other of the binary sexes. The changes become irreversible in the event of long-term administration.

3.2 Sexual identity

Sexual identity is a generic term for people's self-categorization in accordance with their body, hormonal endowment, feelings and biography (including how they were brought up as children). Sexual identity does not necessarily correspond to a person's physical sex and may conflict with it. This self-definition must be distinguished conceptually from a person's sexual orientation in terms of preference for sexual partners of a given sex.

3.3 Gender

Gender is socially determined and is the outcome of the interaction of factors and processes that operate on a variety of biological and psychosexual levels. These include a person's anatomical and hormonal constitution, psychological development and resulting identity, and social biography (rearing).

Gender relates to an individual's role in society. As a rule it corresponds to one's biological sex, but sometimes conflicts with it. A child's sex of rearing describes that child's role in the family and society.

When an individual's sex is recorded in the civil register, the relevant gender is fixed administratively and used for other statutory purposes as a distinguishing feature. This has hitherto precluded the adoption of an intersexed position in many practical life situations.

4 MEDICALLY RELEVANT FORMS OF DSD

Forms of biological sex differing from the typical phenotype were deemed in the past, and are in some cases still deemed today, to call for medical treatment and, for this and other reasons, included in the International Statistical Classification of Diseases and Related Health Problems (ICD).[26] The syndromes usually subsumed in the concept of DSD are included in the 11th revision of the ICD (ICD-10 GM) in two main chapters, as follows:

Chapter IV: Endocrine, nutritional and metabolic disorders, including:

- E 25 adrenogenital disorders of various kinds (CAH)
- E 29.1 5-alpha-reductase deficiency
- E 34.5 Androgen insensitivity syndrome (AIS, Partial androgen insensitivity syndrome [PAIS]: E 34.50, Complete androgen insensitivity syndrome [CAIS]: E 34.51)

and:

Chapter XVII: Congenital malformations, deformations and chromosomal anomalies:

- Q 56.0 Hermaphroditism[27]
- Q 96 Turner syndrome (usually without intersex)
- Q 98 Klinefelter syndrome (usually without intersex)
- Q 99 Other chromosome abnormalities (true hermaphroditism)

26 The International Statistical Classification of Diseases and Related Health Problems is a classification system for diagnosis and coding in medicine issued by the World Health Organization and recognized throughout the world.

27 The term "true" hermaphroditism, as distinct from pseudohermaphroditism (all the other syndromes mentioned), is used in medicine if a functioning ovary and functioning testes are present in a single organism or if ovarian and testicular tissue are present together in a gonad (this condition is also known as ovotestis).

According to the emphasis of this chapter structure, hormonal disturbances (deficiency or excess of hormone-producing enzymes) are the principal causative factor in the conditions described in Chapter IV and malformations of certain organs for Chapter XVII.

Conversely, the paediatric endocrinologists' proposal in the Chicago Consensus Statement[28] subsumes intersex syndromes with other sex organ malformations in the generic term "disorders of sexual development" (DSD) and subdivides them according to chromosomal sex:

- DSD in the case of an atypical variant of chromosomal sex
- DSD in the case of 46,XY status (male chromosomal sex)
- DSD in the case of 46,XX status (female chromosomal sex)

These two medically based classification approaches subdivide DSD syndromes differently and are the subject of vigorous debate in specialist circles. For the descriptive purposes of this Opinion, a division into the following three classes of syndromes has been found to be most suitable:[29]

- DSD in the case of congenital atypical gonadal formation
- DSD in the case of congenital disturbances of hormonal balance with androgen hypofunction
- DSD in the case of congenital disturbances of hormonal balance with androgen hyperfunction

28 See Hughes et al. 2006.

29 A similar classification was used by a working group in the Netherlands to determine the tumour risk in malformed gonads; it comprises gonadal dysgenesis, undervirilization and hypervirilization (see Cools et al. 2006; Looijenga et al. 2007).

The first group includes cases of true biological intersexuality due to disturbances of embryonic development. In the other two groups, the anatomical appearance is attributable secondarily to a hormonal disturbance. In the case of androgen hypofunction, the intersexual anatomical appearance affects the internal sex organs and, owing to the unremarkable aspect of the external genitalia, often results in a change to the opposite (female) sex (XY women), whereas in the case of hyperfunction the intersexual status is less marked and essentially concerns the external genitalia (XX women with CAH). The consequences and therapeutic measures for people with each of these syndromes differ accordingly.

Since the biological manifestations and the physical and mental characteristics are extremely heterogeneous in the various forms of DSD, only a simplified description can be given in this Opinion.

4.1 DSD due to atypical gonadal development

The prenatal process of sex organ formation outlined above is a highly complex development "program" controlled by a network made up of a large number of interacting products of development genes. Important genes in this network are located on the sex chromosomes (X and Y). Disturbances of these development processes, often due to mutations in the development genes, may give rise to atypical gonad formation (gonadal dysgenesis). They may likewise occur in cases of atypical chromosome sets (Turner syndrome or chromosomal mosaic) as well as in people with normal 46,XX or 46,XY chromosome sets in the event of control gene mutations.

Since the formation of the internal and external sex organs depends on properly functioning control genes and intact hormonal functioning of the gonads, genetic variants often result in an intersexual anatomical phenotype.

The anatomical and hormonal manifestations of gonadal dysgenesis take a variety of forms, although such cases are on the whole rare. The network of development genes and hormones is currently the subject of intensive research in the field of molecular genetics, and a more precise medical differentiation is likely to be introduced in the relatively short term. This clarification is urgently necessary because a differentiated biological analysis would permit more accurate prediction and diagnosis of the formation of sex in all its variants as well as of the possible pathological consequences of malformations (e.g. a tendency to malignant degeneration). The following overview is based on the currently accepted subdivisions and can, in view of the ongoing process of research, be regarded as no more than a descriptive guide. The anatomical manifestations of conditions attributable to a chromosome anomaly such as Turner syndrome (45,X0; female with only one sex chromosome) and Klinefelter syndrome (47,XXY; male with an excess X chromosome) are not addressed in detail here because they do not present intersexual anatomical characteristics.[30]

a) Gonadal dysgenesis with a normal female chromosome set (46,XX). Prevalence: rare. For reasons which have not been explained in detail, functioning ovaries do not form. These individuals have a female anatomical appearance, but are sterile. The body's own androgens may cause virilization of the external sexual characteristics.
b) Gonadal dysgenesis with a normal male chromosome set (pure gonadal dysgenesis, Swyer syndrome). Disturbance of testicular development. Prevalence: approximately 1:30 000. The condition involves a genetic defect which prevents normal functioning of the Y chromosome. Testis determining factor (TDF) and other gene products partly responsible for conversion of the originally "female"

30 In the case of chromosomal mosaic, both anomalies may also be present in individuals with DSD (see Section 4.1 c: Mixed gonadal dysgenesis).

primordia to "male" at the early embryonic stage are then inactive. As a result, testes do not form, but instead only dysfunctional "streak gonads", which in addition present a not insignificant risk of cancer. Anatomical development of the internal and external sex organs tends to be female rather than male and newborns are designated female (XY female). The intersexual configuration takes the form of the absence of functional gonads. Sexual maturity is not observed in adolescence. Hormone treatment may modify the anatomical appearance.

c) Mixed gonadal dysgenesis. Prevalence: rare. This is an unusually heterogeneous syndrome,[31] characterized by the presence of ovary-like organs on one side and testis-like organs on the other, usually with rudimentary streak gonads conspicuous on one of the two sides. Such malformations often tend to degenerate into life-threatening tumours. The syndrome can occur with a normal chromosome set. In most cases, however, a chromosomal mosaic is present – that is to say, the organism consists of cells with differing sex chromosome endowments. Individuals with the following mosaics have been observed: (45,X0/46,XY), (45,X0/47,XXY) and (46,XX/47,XY). The anatomical appearance of these individuals is intersexual, more female than male, with a tendency to virilization of the external sex organs and secondary sexual characteristics (hair growth, vocal pitch, etc.).

d) Persistent Müllerian duct syndrome in a 46,XY karyotype. Prevalence: rare. Regression of the Müllerian duct[32] does not take place, so that male internal sex organs (not gonads) do not form, with the result that anatomical forms

31 For relevant case histories, see Donahoe/Crawford/Hendren 1979; Kim et al. 2002.

32 The Müllerian duct (paramesonephric duct), named after the German anatomist and physiologist Johannes Peter Müller (1801–1858), is an early embryonic, as yet sexually undifferentiated structure, from which the Fallopian tubes, uterus and vagina subsequently develop in the female embryo, but which regresses in the case of male sex development.

of both sexes exist alongside each other (anatomical intersexuality). Neonates have seemingly normal male genitals, but female internal sex organs. Adult individuals are infertile.

e) Ovotesticular DSD (formerly called true hermaphroditism). Prevalence: very rare. This syndrome occurs in both chromosomally female (46,XX) and chromosomally male (46,XY) individuals, as well as in chromosomal mosaicism (46,XX/46,XY). Its characteristic feature is that both testicular and ovarian tissue are found in one and the same organism. How the body develops depends on which organs are adopted by which component during the embryonic phase. The resulting intersexed organism may turn out to be more female or more male, the former being more common. If immature or rudimentary gonads are present, malignant tumours of the sexual system may arise. If both tissues are fully mature, the tumour risk is considered to be lower. The cases described to date have been extremely heterogeneous, so that each case must be examined and assessed individually.

4.2 DSD due to androgen hypofunction

a) Disturbances or inhibition of androgen synthesis due to Leydig cell agenesis or hypoplasia.[33] Prevalence: rare. The signal from the diencephalon for testicular differentiation and androgen production is not effectively decoded and androgen biosynthesis is disturbed. In the severe form, a female external phenotype develops, albeit with a foreshortened vagina and no uterus and ovaries. Testes are present in the groin area. In the milder form (partial disturbance of synthesis), the phenotype is intersexed to male, with an

33 Leydig cells are hormone-producing cells in the connective tissue of the testes.

excessively small penis and hypospadias (atypical urinary meatus). Testosterone treatment is indicated.

b) Steroid 5-alpha-reductase deficiency, a very rare hereditary enzyme defect which, however, is relatively frequent in the Caribbean. The function of the enzyme is to convert testosterone into dihydrotestosterone, which is more active. In its absence, the female genital phenotype persists, testes being present but concealed. The individuals concerned are usually brought up as girls. Testosterone becomes active at puberty and leads to virilization with penis formation (although with hypospadias).

c) 17-beta-hydroxysteroid dehydrogenase deficiency, a hereditary enzyme deficiency. Prevalence: rare. The enzyme catalyses a step in testosterone synthesis, so that, if it does not function correctly, the basic female model of the sex organs persists and the newborn is designated as female. Some individuals also have an intersexed appearance. Virilization occurs at puberty and in some cases the individuals concerned switch to the male sex.[34] According to the Chicago Consensus Statement,[35] there is an increased risk of malignant degeneration of the gonads.

d) Androgen insensitivity: inhibition of androgen action due to a mutation in the androgen receptor gene. Prevalence: 1:20 000. If androgen activity is completely inhibited (complete androgen insensitivity syndrome [CAIS]), the chromosomally male individual is born with female genitalia and therefore brought up as a girl. The intersex status becomes manifest at puberty (absence of menarche, no uterus, but instead testes, although these are usually in the abdominal cavity). The risk of malignant gonadal growth is not considered to be high in CAIS. If androgen activity is not completely inhibited (partial androgen insensitivity syndrome [PAIS] – prevalence: rare), the body may develop

34 See Jürgensen et al. 2010.
35 See Hughes et al. 2006, Table 4.

more in the male direction depending on the degree of the inhibition, so that the external appearance may be mixed male/female or predominantly male. The risk of malignant tumour formation is significantly increased in PAIS if the immature gonads remain in the abdominal cavity (on the tumour risk, see Section 4.5).

4.3 DSD due to androgen hyperfunction

a) Congenital adrenal hyperplasia in a 46,XX karyotype. Congenital adrenal hyperplasia (CAH) is the most frequent DSD configuration, with initially unclear sex designation in 46,XX individuals (approximately 1 in 10 000 births). It is as a rule due to a hereditary mutation in one of the genes whose gene product (21-alpha-hydroxylase, 11-beta-hydroxylase, 3-beta-hydroxysteroid dehydrogenase or 17-alpha-hydroxylase) is an enzyme necessary for the metabolic pathway of glucocorticoid or mineralocorticoid synthesis in the adrenal cortex. These hormones are produced in reduced quantities or not at all. This results in defective control by the pituitary gland, so that instead of cortisol there is increased production of the sex hormones that are normally less abundant in the female sex.[36] Androgens ultimately give rise, already during pregnancy, to virilization of the external sex organs (clitoral enlargement to quasi-penile form and scrotum-like development of the labia, sometimes with hypospadias). In the absence of hormone treatment, "male" secondary sexual characteristics – pubic hair and acne – develop precociously, so that the external

36 Of the enzyme defects mentioned, a deficiency of properly functioning 21-alpha-hydroxylase is the most frequent (90% of all cases). The enzyme's precursor, the steroid hormone 17-hydroxyprogesterone, then remains in that form and transfers to the blood plasma. A routine biochemical test detects an increased concentration of this substance in a drop of blood taken from a finger pad. However, the other, less common enzyme defects cannot be detected by this specific test.

sexual characteristics diverge from the chromosomal and gonadal sex in girls with CAH. Another typical manifestation in the absence of treatment is early-onset accelerated body growth which ends prematurely, so that the individuals concerned are taller in childhood and their bodies mature sooner, but they ultimately remain short in stature. The size of the enlarged clitoris is classified in accordance with a scale devised by the Swiss doctor Andrea Prader, ranging from Prader I (mild enlargement) to Prader V (substantial hypertrophy, penis-like). The vagina may be malformed in Prader V, usually calling for surgical correction.[37] In severe cases of this syndrome, the neonate's female sex cannot be unambiguously determined from the anatomical appearance. In milder cases it is only later – sometimes not until puberty – that manifestations of virilization become evident, owing to underdevelopment of female secondary sexual characteristics (lack of breast development and absence of menarche) and the unwanted formation of typically male characteristics (e.g. body hair type or acne).

CAH-related DSD is thus a developmental disorder due indirectly to a hereditary mutation in the steroid balance. The resulting virilization as a rule affects only the external sex organs. 46,XX individuals with DSD are chromosomally female, have ovaries, a uterus and other female internal sex organs, are fertile subject to appropriate therapy and usually accept their female sex. Cortisone treatment stabilizes the hormone balance in accordance with the child's chromosomal and gonadal sex, so that the virilization of the external genitalia may regress during the first year of life. The treatment must commence at birth and continue throughout life.

37 Prader V is characterized by substantial virilization of the external genitalia: clitoris and labial folds formed like a pseudo-phallus with a closed pseudo-scrotum; the urethra ends at the tip of this organ. There is also a malformed vagina, substantially combined with the urethra. Patients often suffer from urinary incontinence and infections of the urinary tract.

This syndrome, which is deemed to be the "classical form" of CAH, occurs in some 10% of the male and female individuals in whom the mutation is homozygotic (i.e. present on both copies of chromosome 6). In about 25% of these cases, the hormone aldosterone is also not produced owing to the genetic defect described above, so that life-threatening salt and water wastage already occurs in the newborn. Such cases of CAH must be treated throughout life not only with cortisone but also with other hormone preparations that supply the body with aldosterone.

Milder forms of CAH are much more common than the "classical" type and account for 90% of cases. They are usually of later onset and not typically associated with alterations of the external sex organs. Their manifestations are known as "non-classical CAH" (or "late-onset CAH"). References in the German Ethics Council's Opinion to CAH relate primarily to the "classical" form of CAH.

Since 1997, the directives of the *Arbeitsgemeinschaft für Pädiatrische Stoffwechselstörungen* (Working Group on Paediatric Metabolic Disorders) and the *Arbeitsgemeinschaft für Pädiatrische Endokrinologie* (Working Group on Paediatric Endocrinology) have recommended a test for the early diagnosis of CAH in newborn babies. The test has been carried out in all Federal States since 2002 and was incorporated in the directives of the *Gemeinsamer Bundesausschuss* (Federal Joint Committee) as a part of the neonatal screening programme in 2005.[38]

b) Congenital adrenal hyperplasia in a 46,XY karyotype. Prevalence: as with 46,XX, since the syndrome is autosomal recessive. The phenotype is not intersexed, but the hormonal effects are similar to those in the 46,XX karyotype. Appropriate hormone treatment is necessary.

38 See BAnz. No. 60 (p. 4833) of 31 March 2005.

4.4 Malformations of the urogenital system associated with DSD

In very rare cases, the embryonic development of the urogenital system with the formation of a separate rectum results in severe malformations which require treatment and in which the contrasexual characteristics of the genitalia are less prominent (hypospadias, persistent urogenital sinus[39] or cloacal exstrophy[40]).[41] Another type of malformation of the sex organs is vaginal atresia (occlusion of the connection between vagina and uterus). Prevalence: 1:4000. The individuals concerned are female; in a newborn, however, the malformation may give rise to doubt, sometimes resulting in designation as male.

4.5 Tumour risk

The various forms of malignant tumours of the gametic tissue are currently the subject of intensive research using the techniques of molecular genetics and cell biology.[42] More accurate assessment of the tumour risk is likely to be possible in the future on the basis of molecular-genetic criteria. A particular risk is considered to exist in the case of gonadal dysgenesis with complete or mosaic-like XY endowment and of PAIS with immature gonads present in the abdominal cavity (prevalence between 15 and 60% depending on the form of DSD). Turner syndrome mosaicism with partial presence of Y chromosomes, gonadal dysgenesis (scrotal gonads) and the

39 The urogenital sinus is the initially combined embryonic vagina/urethra primordium. Its persistence constitutes a malformation in which the vagina and urethra are not separated as normal.

40 Cloacal exstrophy is a severe malformation of the urogenital and rectal canal, sometimes with exposed abdominal organs.

41 Some authors consider the urogenital malformations described here as also falling within the field of DSD (see Hughes 2008). These anatomical malformations do not as a rule present an intersexed appearance.

42 See Hughes et al. 2006; Cools et al. 2006; Looijenga et al. 2007; Hersmus et al. 2008.

genetic defect 17-beta-hydroxysteroid dehydrogenase present a moderate risk (15%). In individuals with CAIS (a relatively frequent form of DSD), the prepubertal tumour risk is considered to be slight (less than 1%). Individuals with CAH are not at increased risk of gonadal tumours.

5 MEDICAL DIAGNOSIS AND THERAPY

5.1 History

In traditional European societies, hermaphrodites occupied a special position characterized by ambivalence. On the one hand, they were seen as fascinating "whims of nature", distinguished if only by their rarity, whereas, on the other, they were deemed to fall outside the normal realm of existence. Towards the end of the nineteenth century, hermaphrodites ceased to be regarded as whims of nature and came to be seen instead as cases for medical attention because they departed from the "norm" and did not fit into the binary sex system.

The term "intersexuality"[43] was coined at the beginning of the twentieth century, covering a large number of manifestations of ambiguous sex development, most of which were seen as pathological.[44] An approach based on the research of the psychologist John Money came to be accepted during the 1950s. Money assumed that a person's sexual identity was formed primarily by social factors. This was a popular position at the time: the malleability of human beings due to the effects of socialization was predominantly regarded as outweighing that due to biological factors. The feminist movement in particular drew on Money's writings, which were adduced as proof that the differences between men and women were reflections of social expectations and prejudices to a much greater extent than of biology. In this climate, Money became a feted scientist.

For a long time, Money's theory was a primary influence in the treatment of children born intersexed. With the aim of the development of a stable sexual identity,[45] Money postulated that a child born intersexed should be surgically aligned

43 See Kolbe 2010, 17.
44 See *Deutscher Bundestag* 2001a; Kolbe 2010, 150.
45 This is still regarded as important today; see Säfken 2008, 8; Wacke 1989, 889; Coester-Waltjen 2010, 855 with further references.

with the "optimum" sexual norm for the individual as early as possible. The operation should be carried out in the first years of life, because in his view sexual identity did not develop before the third year of life.[46] The external appearance should be matched to the sexual "norm", although sexual sensation was frequently destroyed in the process.[47] Owing to technical difficulties with the surgical construction of a penis, it was mostly feminizing operations that were carried out.[48] Gonads inconsistent with the sex as determined at birth were surgically removed, partly to prevent hormonal influences on the body at puberty.[49]

Another of Money's recommendations was that no mention should ever be made of the diagnosis and treatments, in order not to endanger the affected child's personality development.[50] The relevant diagnosis was often kept secret from affected people even as adults, and they were not granted access to their medical records.[51] However, the parents themselves were frequently left in ignorance of their children's particularities, the treatments to be carried out and in particular the eventual effects of these treatments.[52] They were left in the belief that their child was not fully developed and accordingly needed surgery in order to be able to lead a normal life.[53]

On this basis, parents would exercise their parental decision-making competence and consent to medical treatment for their intersexed children often without adequate information.

If the individual's real sex emerged only in later examinations during adulthood (for instance in the case of childlessness), testes were occasionally removed without the patient being asked, or else those affected were not informed of the

46 For a more detailed account see Kolbe 2010, 137.
47 See Kolbe 2010, 140.
48 See Kolbe 2010, 135.
49 See Kolbe 2010, 139.
50 See Beh/Diamond 2000; see also Kolbe 2010, 136.
51 See Kolbe 2010, 137 with further references; see also *Intersexuelle Menschen* 2008, 17, 24, 28.
52 See Beh/Diamond 2000.
53 See Beh/Diamond 2000.

diagnosis, in order not to burden them psychologically and to permit them to lead a "normal" life,[54] especially if they had already been content with life in their designated sex.

However, Money's theory had its critics even during its heyday, in particular in relation to his "showpiece" example, the case of David Reimer.[55] The most significant of these critics was surely Milton Diamond, a professor of anatomy and reproductive biology, who, unlike Money, assumed that individuals were born with a genetically and hormonally fixed psychosexual disposition and the propensity to develop specific sexual and gender-related models. In addition, Money's Gender Identity Clinic was closed as early as in 1979 after the new director of the Johns Hopkins Hospital commissioned a review of the prevailing treatments for intersex and transsexual individuals, the outcome of which differed greatly from Money's position.

The earlier recommendations concerning "optimum sex ascription" were abandoned in the final report of the 2005 Chicago Consensus Conference, sex assignment surgery being recommended subject to specific conditions only.[56]

However, the Chicago Consensus Statement has also met, and is still meeting, with increasing criticism not only from representative groups of intersex people but also within medicine and neighbouring disciplines, to the effect that insufficient account was and is taken of individual self-determination.

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54 See Kolbe 2010, 45, 82; Lang 2006, 105.

55 David Reimer (1965–2004) was born as Bruce, the identical twin brother of Brian Reimer. Owing to a botched circumcision, he lost his penis at the age of eight months. At Money's recommendation, his testes were removed at the age of 22 months and Bruce became Brenda. For Money, the twin experiment became the touchstone of his thesis on sexual identity. Although the raising of the male child as a girl failed, he published the case history of the Reimers as the "John/Joan case" and presented it as evidence of the correctness of his theory. For more information, see Colapinto 2000.

56 See Hughes et al. 2006. In addition to accurate diagnosis, these conditions include, for example, clitoral surgery only with effect from a specific size discrepancy, vaginal dilatation not to be conducted before puberty, plastic surgery such as vaginoplasty and penoplasty to be carried out only in adulthood, and prepubertal gonadectomy only in the case of specific diagnoses such as gonadal dysgenesis or partial androgen insensitivity (PAIS).

These critiques are paralleled by ongoing changes in the medical approach to DSD and intersexuality. For example, the *Arbeitsgruppe Ethik im Netzwerk Intersexualität* (Ethics Working Group within the Network Intersexuality) calls in its "Ethical principles and recommendations for DSD" for a "therapeutic attitude of openness and acceptance" and stresses that "measures for which no satisfactory scientific evidence exists and measures with potential irreversible consequences for sexual identity or possible adverse effects on sexuality or fertility [require] a compelling medical indication".[57]

Nowadays it is increasingly considered important to inform children of their particularity when they reach a suitable age and are sufficiently mature to understand it, and to support them in coming to terms with their particularity.[58] Restraint is urged specifically where sex assignment surgery is concerned.[59]

5.2 Medical diagnosis of DSD

Ambiguous sex is often evident immediately after birth, principally owing to the "combined" presence of male and female external sexual characteristics or their unclear formation. In addition, classical CAH is nowadays diagnosed predominantly in newborn screening or by virtue of a salt-wasting crisis.[60] In other cases of DSD, behaviour that suggests the opposite sex may not emerge until puberty. Medical diagnosis is as a rule

57 *Arbeitsgruppe Ethik im Netzwerk Intersexualität* 2008, 245. Gonadectomy in the case of specific forms of androgen insensitivity such as CAIS, which do not usually carry a tumour risk, is thus no longer considered by most authorities to be essential prior to the age of decision-making capacity and is therefore no longer performed.

58 See Kolbe 2010, 147.

59 See guidelines of the German Society of Pediatrics and Adolescent Medicine on disorders of sex development (*Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010, 5).

60 Only the most frequent variant of "classical" CAH (21-beta-hydroxylase deficiency) can be detected by screening, but not other genetic alterations or the milder variant of late-onset CAH – see Section 4.3a.

requested only at puberty, when the body undergoes changes due to hormone secretion under the control of the diencephalon and atypical secondary sex characters arise (beard growth, breaking voice, penile growth, male pubic hair, male muscle type etc., in a "girl"; breast growth, female pubic hair type, female body shape etc., in a "boy") or atypical body functions develop (regular spontaneous bleeding and/or non-formation of sperm and semen in a "boy"; absence of menarche in a "girl").

Medical examination is directed initially to determination of chromosomal, gonadal and hormonal sex status. This involves a large-scale, often prolonged and stressful programme of tests in the fields of cell biology, genetics, biochemistry/physiology and anatomy, as specified in detail in the recommendations of the relevant specialized medical societies (paediatrics, endocrinology, urology etc.).[61] Some tests are invasive and not without risk (e.g. testicular biopsy), so that careful consideration is required to decide whether it is appropriate to inflict them on affected individuals. Others, such as detailed examination of the genitalia, may violate a person's modesty and must be undertaken with a corresponding level of tact. An insensitive approach (e.g. involving demonstration to students) has in the past caused substantial and long-lasting offence to intersex individuals and harmed the reputation of medicine (see Section 7.2).

In the most favourable case, the outcome of the examination is unambiguous determination of the subject's physical sex. However, in less favourable cases the various aspects of biological sex (chromosomal, gonadal and hormonal) may yield contradictory results, so that unambiguous biological identification proves impossible. The dilemma in this situation is that the diagnostic process results in designation as female or male, whereas a logically consistent determination will often not be strictly possible.[62]

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61 See *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010.

62 For a detailed account of the complexity and contradictions involved see Lang 2006, 64–130.

This then influences the second aspect of diagnosis – namely, analysis of the psychosocial and psychological situation, which determines a person's self-perception or self-definition and is at the same time determined by these. Sex is then no longer necessarily identified on a dichotomous basis but instead on a sliding scale (*male, female, intersex*). This examination must involve psychological and medical expertise and take account not only of the affected individual's self-definition but also of the views of that individual's family and possibly also of representative groups which offer counselling to people in that situation. The outcome may conflict with that of a purely medical diagnosis.

A particular form of diagnosis is "gender verification" in sport. This includes physical and genetic tests for sex determination in sporting events open to female entrants only. Compulsory sex tests involving full-body examination were first introduced at the European Athletics Championships in 1966, but were replaced from 1967 on by chromosomal tests, which were felt to be less discriminatory. When well over 3000 female participants in the 1996 Summer Olympics in Atlanta were examined, four women were diagnosed with partial androgen insensitivity, three with complete androgen insensitivity and one with a steroid 5-alpha-reductase deficiency after gonadectomy (gonad removal). However, all eight athletes were allowed to take part. An increasingly critical debate on the practice of gender verification, initiated by the International Olympic Committee, has been ongoing since 1996. Demands have been repeatedly been voiced for the universal requirement to be abolished and replaced by testing only when considered necessary in an individual case. It is frequently also argued that the compulsory drug tests that have since been introduced are sufficient. However, evaluation of test results in each case appears still to be inconsistent. Whereas the athletes with DSD mentioned above were allowed to compete in Atlanta and, for example, the South African middle-distance runner Caster Semanya, having initially been deprived of the

gold medal she won in the 800-metre race at the Berlin World Athletics Championships in 2009, has been readmitted, the Indian middle-distance runner Santhi Soundarajan was stripped of her silver medal at the Asian Games in Qatar in 2006 when she was found to have a male chromosome set.

5.3 Medical therapy of DSD[63]

The traditional medical model applied to most cases of DSD is that of a genetic disorder characterized by the functional failure of one or more important gene products (hormones, enzymes or an embryonic transcription factor). Critics of this view, however, regard DSD as a biological variation of sex.

The medical model hitherto prevalent reveals an unusual situation:

- The existence of an indication for therapeutic intervention depends on the subject's sex attribution, although this may be contradictory in problematic cases.
- Many individuals with DSD – in particular, children – do not currently exhibit any physical functional disturbances that directly suggest the need for therapy. The indication must then be based on preventive considerations, or else the existence of a psychosocial emergency situation deemed to require treatment must be established.
- In many cases the aim of the therapeutic intervention is the "production", "alignment" or "clarification" of a specific sex. This may affect the core area of the patient's

63 The German Ethics Council consulted the following medical experts: Hartmut A.G. Bosinski , Annette Grüters-Kieslich, Olaf Hiort, Paul-Martin Holterhus, Ulrike Klöppel, Birgit Köhler, Susanne Krege, Ursula Kuhnle-Krahl, Hertha Richter-Appelt, Katinka Schweizer, Gernot H.G. Sinnecker, Knut Werner-Rosen, Martin Westenfelder, Peter Wieacker, Claudia Wiesemann, Jörg Woweries and Lutz Wünsch. See also the following online source: http://www.ethikrat.org/sachverstaendigenbefragung-intersexualitaet [2012-02-07].

identity – something that is very seldom the case with medical therapy in other disciplines (except sometimes in neuropsychiatry).

- In view of the effect on the core area of identity, substantially more stringent requirements apply concerning justification of the indication, information, counselling and informed consent, specifically when given by parents of children and adolescents, than are otherwise applicable in medicine.
- Many interventions are irreversible, with effects and side-effects that often emerge only after many years. Since all DSD syndromes are rare and take a very different course in each individual case, it is extremely difficult to assess therapeutic procedures reliably. It is not easy to find large enough homogeneous random samples of treated people compared with individuals who have remained untreated.
- Few accepted medical standards exist in this situation. An exception is cortisone or aldosterone replacement therapy in congenital adrenal hyperplasia (CAH) for hormone balance stabilization.

The possible treatments for DSD differ in character according to their objectives and urgency:

- The aim of a hormone treatment may be the elimination of a severe and possibly life-threatening hormonal disorder (e.g. salt-wastage syndrome in CAH). The subject's sex is relatively immaterial in this indication.
- Surgery is indicated for malformations of the urogenital system (hypospadias, bladder exstrophy etc.) if vital functions are severely impaired and/or infections of the lower abdomen or even of the abdominal cavity are likely or already present.
- Surgical removal of hormonally dysfunctional or non-functioning gonads that are useless for reproductive purposes (e.g. undescended testes or streak gonads) may be

indicated in the event of a risk of malignant degeneration. The urgency of preventive therapy greatly depends on the particular DSD syndrome. However, few data are available for reliable estimation of the associated risk of such malignancy. The functional findings also determine whether the surgery should be classified as removal of dysfunctional tissue carrying a tumour risk or as true castration.[64] For an accurate indication, the risk of degeneration must be weighed against the need for stressful lifelong hormone replacement therapy if functioning gonads are to be removed.

- Removal of wholly or partially functional contrasexual gonads (gonadectomy or castration – for instance, in the case of PAIS and inhibition of androgen synthesis) is sometimes recommended to make it easier for the body to live in the designated sex. Some also consider this to be indicated in order to preclude contrasexual fertility.[65] For this indication too, it is increasingly recommended that restraint be exercised in deciding on a gonadectomy, or at any rate that surgery should where possible be deferred until the decision can be made by the specific affected individual; it should also be borne in mind that people who have undergone a gonadectomy usually require very expensive and uncomfortable long-term hormone replacement therapy.
- Some procedures are directed towards removal of internal sex organs incompatible with the designated or chosen sex (removal of uterine or vaginal primordia in a "man" or of the relevant glands and other anatomical structures in a "woman"). Surgery of this kind has far-reaching physical and mental effects, but is not essential for the purpose of preserving life.
- The aim of a number of surgical interventions is to match the appearance of the external genitalia to the individual's

64 Castration is an intervention in which the gonads are removed or otherwise rendered non-functional.

65 "Paradoxical" contrasexual parenthood of this kind is possible with present-day techniques of reproductive medicine.

chromosomal and gonadal sex even where this is not necessary for medical reasons (vulvoplasty, vaginoplasty or clitoral reduction). One objection to the conduct of these procedures at an early age is that they deaden sexual sensation. Doctors argue that improved microsurgical techniques no longer present this risk and that such operations, if successful, help to enhance self-esteem and to avoid stigmatization in childhood.

- Experts disagree on the optimum timing of operations for bringing the genitalia into line with the subject's chromosomal and gonadal sex. Such surgery concerns in particular the relatively frequent case of 46,XX individuals with CAH. Given the importance of such operations for personality development, some experts recommend waiting until the subject can understand the nature of the intervention and is capable of giving consent. Other experts emphasize that these individuals are not intersexed but female and that the new surgical techniques achieve the best corrective results, in terms also of the preservation of sensation, if carried out precociously (during the first 12 months of life), while psychological pressures in the child can be avoided by operating at this early stage of life.
- Many affected individuals require treatment with sex hormones to replace those lost as a result of therapy, to achieve the desired effects in terms of the designated sex or to suppress unwanted side-effects. Sex hormone therapy must as a rule continue on a long-term basis and may have significant long-term physical and psychological side-effects (e.g. tendency to obesity, effects on the musculature and skeleton, breaking of the voice, breast growth, hair loss or depressive tendencies).

All the above forms of therapy have more or less drastic effects on the core area of personal identity and physical integrity. They must be carefully weighed against the intended physical changes and the possible unintended side-effects. If a given

therapeutic procedure calls for early intervention before the specific person can make the decision, it is necessary to establish whether the parents may give consent on behalf of that individual. For this purpose, not only anatomical and physiological aspects but also psychological, psychosocial and legal considerations must be taken into account. The collaboration of an interdisciplinary team is essential for the indication and conduct of the therapy.

Both in the current guidelines of the *Gesellschaft für Kinderheilkunde und Jugendmedizin* (German Society of Pediatrics and Adolescent Medicine) on disorders of sex development (027/022 of 12 May 2011) and in the Society's older guidelines, surgery is stated to be the correct treatment for DSD; however, more restraint than in the earlier guidelines is now advocated as regards drastic therapies in childhood.[66] The guidelines also recommend that parents be given comprehensive information by an interdisciplinary team and that a corresponding interdisciplinary therapy programme be drawn up.[67] According to the guidelines, operations should be carried out only at centres whose surgeons have adequate experience; in addition, controlled studies should be conducted. Between the twelfth month of life and adolescence, surgery – in particular, vaginal dilatation – should be avoided except in the case of medical complications. Owing to the dearth of available information on the tumour risk, early gonadectomy is recommended only in the case of gonadal dysgenesis in female designees. With regard to other syndromes (CAIS, PAIS and inhibition of androgen synthesis in a female designee), only a biopsy should be carried out, any further measures being as far as possible deferred until the child is competent to decide. A particularity of sex development is nevertheless regarded as a psychosocial

66 For instance, surgery for newborns is as a rule considered not to be indicated (see *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010, 4).

67 See *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010, 4 f.

emergency. In addition, provision should be made for parents to meet other parents in the same situation, so as to counteract any isolation and stigmatization of intersex people.[68]

68 See *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010, 5.

6 REALITY OF LIFE AND QUALITY OF LIFE

The factual background to this Opinion is the practical life situation of people with DSD in Germany, which is considered by many affected individuals and representative organizations to be wanting. A detailed knowledge of this situation is essential for the purposes of ethical and legal appraisal. To establish the present-day reality and quality of life of people with DSD in Germany, the German Ethics Council had at its disposal the opinions of the experts consulted by the Council,[69] the statements accruing from the online discourse organized by the Council[70] and, in particular, three empirical studies, which are considered in detail below.

6.1 Empirical studies of the current situation of people with DSD

1) The clinical evaluation study by the German Network of Disorders of Sex Development/Intersexuality (the "Network Study")[71] was conducted from 2005 to 2007 and has not yet

69 The following sociological and psychological experts were consulted on the complex of issues raised by the reality and quality of life of people with DSD: Nina Degele, Gabriele Dietze, Michael Groneberg, Christoph Rehmann-Sutter, Hertha Richter-Appelt, Katinka Schweizer, Jürg C. Streuli, Knut Werner-Rosen and Kathrin Zehnder. All their opinions can be accessed online at http://www.ethikrat.org/sachverstaendigenbefragung-intersexualitaet [2012-02-07].

70 The online discourse was conducted by the German Ethics Council together with *Kooperative Berlin* between 8 June and 7 August 2011. Author contributions from experts, affected individuals or the editorial team on the main points, which had also already been addressed at the hearing, were posted online. Any interested person could then register and comment anonymously on these posts. A total of 97 users registered, of whom 62 commented. The entire discourse can be accessed online at http://www.diskurs.ethikrat.org [2012-02-07].

71 A final report on the study as a whole has not yet been published. An overview of the participants and the principal results can be found in a guide for study participants and parents (see Kleinemeier/Jürgensen 2008); for a description of the design including a breakdown of the participants,

been published in its final form. The study is based on data from 439 participants, comprising 97 children under the age of four, 80 children between the ages of four and seven, 86 children between eight and twelve years old, 66 adolescents and 110 adults. According to the authors, the parents responded on behalf of the under-four-year-olds. In the group of children and adolescents between the ages of four and 16, the individuals responded together with their parents. Participants over the age of 16 answered for themselves. The data for the Network Study were gathered at four study centres in Germany, Switzerland and Austria and collated and evaluated at the *Universitätsklinik für Kinder- und Jugendmedizin Lübeck* (Lübeck University Clinic for Paediatrics and Adolescent Medicine).

2) The follow-up study of adults with various forms of intersexuality and of transsexuals (the "Hamburg Intersex Study")[72] was conducted in 2007 and 2008 at the *Universitätsklinikum Hamburg-Eppendorf* (University Medical Center Hamburg-Eppendorf). The study is based on data from 69 adults aged between 16 and 60 (average 33). Some two thirds of the respondents were aged between 28 and 38. The median age was 31.5 years. However, information on the exact age group distribution is not included in the material published so far.

3) The German Ethics Council's online survey on the situation of intersex people was conducted between 2 May and 19 June 2011.[73] It reflects the positions of those reached via the networks of representative organizations of affected individuals, the public hearing and the appeals in the medical press. The survey yielded a total of 199 evaluable response forms.

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see Lux et al. 2009; partial evaluations with more detailed results are contained in, for example, Kleinemeier et al. 2010; Jürgensen et al. 2010; Köhler et al. 2011.

72 See Richter-Appelt et al. 2008; see also Brinkmann/Schweizer/Richter-Appelt 2007a; Brinkmann/Schweizer/Richter-Appelt 2007b; Schweizer et al. 2012.

73 On this point, see Bora 2012.

People in every age group up to and including 67 years took part in the study. The median age was 24. Each of the first four decade cohorts (up to 9; 10 to 19; 20 to 29; 30 to 39 years) accounts for roughly a fifth of the study population. One in eight of the respondents is aged between 40 and 49, whereas only 6% of respondents are in the 50 to 59 bracket. The smallest group comprises the over-60s (about 3%). This survey too includes cases where parents responded for or together with their children.

The participants in the surveys were assigned to different subgroups according to diagnosis.

The following four groups were distinguished in the Network Study: (1) girls and women (46,XX) with CAH (178 participants); (2) girls and women (46,XY) in whom androgens were active prenatally and in some cases after birth (partial androgen insensitivity [PAIS], partial gonadal dysgenesis, disturbance of androgen biosynthesis, etc.; 96 participants); (3) boys and men (46,XY) with reduced androgen activity, including also people with PAIS or gonadal dysgenesis living with a male identity (121 participants); and (4) girls and women (46,XY) in whom androgens were not active during and immediately after pregnancy (complete androgen insensitivity [CAIS], complete gonadal dysgenesis, complete disturbance of androgen biosynthesis, etc.; 39 participants). Only the third group of participants were living with a male identity.

Those taking part in the Hamburg Intersex Study were classified in accordance with the ICD diagnoses: 21 participants with 46,XX CAH; 25 participants with androgen insensitivity (13 with CAIS and 12 with PAIS); 14 participants with gonadal dysgenesis; seven participants with disturbances of androgen biosynthesis; and two participants with other forms of DSD.

People with CAH and a male chromosome set did not take part in either of these two studies.[74] Hence the results for people

74 They have an increased level of male sex hormones (androgens) but none of the characteristics of DSD (see Section 4.3 b).

with CAH relate in both studies to girls and women living, with a few exceptions,[75] with a female identity.[76]

In the German Ethics Council's survey, 101 participants stated that they had been diagnosed with CAH and 65 other forms of DSD; significant groups among the latter were 21 people with androgen insensitivity and eight with gonadal dysgenesis. Some 15% of participants did not specify their form of DSD. The group of respondents with CAH has an average age of 19 (range 1 to 67 years). For half of those affected by CAH (53 people), an age of up to 14 was given. This compares with an average age of 37 for the group of people with a different diagnosis (range 1 to 64 years). Half of the members of this group are aged 38 or younger. Only eight of these people are under 20 years old (approximately 12%). The survey thus includes two groups of respondents – namely, one group with CAH, in which the parents sometimes responded on behalf of their still young children, and a second group with different DSD diagnoses, whose average age was higher.

It is impossible to say how representative all three studies are. The participants were recruited in each case following the announcement by the university institutes concerned or the Ethics Council, or when approached by the representative organizations of affected individuals and support groups or the attending medical practitioners and therapists.[77] Reliable data on the overall group of individuals with DSD in Germany

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75 According to the Network Study, all 173 of the CAH individuals are living with a female identity; of the 21 CAH individuals in the Hamburg Intersex Study, three are living with a male identity or were brought up as boys. They are now adults who would today be diagnosed differently and hence receive different treatment.

76 References to "people with CAH" or "CAH individuals" in the following paragraphs denote girls and women whose external genitalia exhibit more or less pronounced intersexual characteristics at birth owing to hormonal effects during pregnancy, but whose sex is otherwise unambiguous.

77 On the evidential value of the data in the Network Study, see Lux et al. 2009. See Bora 2012 on the German Ethics Council's survey, for which participants were reached firstly by a wide-ranging public appeal by the Council on its website and during the public hearing, and secondly by direct circulation of the questionnaire via representative organizations, networks and support groups. In addition, an appeal was published in the medical journals

as an indication of the representativeness of the respondents are lacking. However, given that the studies contain information on the physical, psychological and social circumstances of people affected by DSD, they constitute qualitative evidence of the legal and ethical situation notwithstanding these empirical deficiencies.

Again, the results of the three surveys are not exactly comparable in scientific terms. For that purpose, the data in all the studies would have had to be recorded in accordance with the same criteria and by the same methods. Furthermore, for a meta-analysis the raw data of all the surveys would need to be available. For this reason, where the findings are compared below, the aim is to identify common features and differences, even if the evidential value of a given individual study cannot be assessed here.

For the purposes of the following account of the reality of affected individuals' lives, other sources available to the German Ethics Council were the opinions of the experts consulted, the evaluation of the online discourse and three informal responses based on a subsequent survey of affected people or of parents whose children were not reared in a specific sex or gender. These sources too are included in the following account in so far as they reflect the reality and quality of the lives of people with DSD.

6.2 Experience of treatment

The majority of the participants in these studies have experienced medical treatments.

Deutsches Ärzteblatt and *Ärzte Zeitung*, in which attending physicians in particular were asked to draw their patients' attention to the survey.

The Hamburg Intersex Study records information not only on hormone replacement therapy[78] but also on the various types of surgery; its conclusions are described below.

Almost all respondents (96% for all forms of DSD combined) underwent hormone replacement therapy. 64% of respondents had a gonadectomy,[79] although considerable differences emerged between individuals with CAH (2 out of 21 cases) and the other people affected by DSD (41 out of 43). 38% of the respondents had undergone clitoral reduction, 42% of these operations being accounted for by the CAH group. 33% of the respondents had vaginal surgery, the proportion of these interventions in CAH individuals being significantly higher (11 out of 21) than in the other people with DSD (12 out of 43). Urethral correction surgery was performed in 13%. Operations such as mastectomy (breast removal) are also reported. Surgery of this kind was carried out in four out of five cases of partial androgen insensitivity (PAIS) in people living with a masculine gender role.[80]

According to the results of the Hamburg Intersex Study, hormone treatments commenced in most CAH individuals before the age of 10,[81] whereas with the other forms of DSD they began only after age 10. Genital surgery in CAH individuals and gonadectomies in people with other forms of DSD were carried out in some of the study participants in early childhood.[82]

In the Network Study, 81% of respondents report that they have undergone surgery. However, the detailed results are not

78 References to hormone replacement therapies or hormone treatments in both this study and the other two studies relate firstly to replacement therapies with sex hormones and secondly (in the case of CAH) to therapy with the hormone cortisone for stabilization of the sex hormone balance and prevention of severe developmental disorders and adverse effects on health; in the case of aldosterone, such therapy may constitute a life-preserving measure (to avoid salt wastage crises) – see Sections 4.3 a and 8.3.4.

79 See Richter-Appelt et al. 2008, 23.

80 See Richter-Appelt et al. 2008, 24.

81 Treatment with cortisone and where applicable aldosterone for people with CAH must commence at birth and continue throughout life.

82 See Richter-Appelt et al. 2008, 25.

strictly comparable with those of the Hamburg Intersex Study because in the former case no data are available on the specific operations concerned and on the frequency of hormone treatments – although specific information is given on the timing and frequency of medical interventions. Whereas just over a fifth of babies up to 6 months old had had surgery, this was already the case in as many as 68% of children between the ages of 6 months and 3 years and indeed 86% in children up to the age of 7. In the 8–12 age group, the proportion of those undergoing surgery increases to 87%, and among adolescents (age 13 to 18) to 91%. No major differences are observed between the various groups in this connection. It is only in girls with complete androgen insensitivity (CAIS) that the proportion of those undergoing surgery, at 65%, is lower than in the other groups. However, this difference too tends to disappear in adulthood, thus indicating that people with CAIS are nowadays less likely to undergo gonadectomy before they are able to decide for themselves. The authors of the Network Study conclude from the data that a high proportion of the operations in all diagnostic groups are carried out before the individuals reach school age. 18% of the study participants had not had surgery up to the time of the survey, but an operation was then planned in 7.6%.[83]

Half of those who had undergone surgery had had one operation, a quarter had had two operations, 12% three and 10% four or more operations. Post-operative complications, such as fistulization, stenoses, infections of the urinary tract and micturition difficulties were reported in 25% of cases.[84]

In the German Ethics Council's survey, 68% of respondents state that they have had surgical treatment and 74% hormone treatment. More than half the participants report both hormone treatment and surgery. Only 13% have undergone

83 See Kleinemeier/Jürgensen 2008, 16.
84 See Kleinemeier/Jürgensen 2008, 17.

neither hormone treatment nor surgery.[85] If individuals with CAH are distinguished from those diagnosed with other forms of DSD, the following picture emerges: 73% of the CAH respondents report hormone treatment and 57% surgery; the figures for other DSD diagnoses are 84% hormone treatment and 93% surgery.

Ninety-five questionnaires report functional plastic surgery – predominantly, ambiguity correction operations for alignment with the female sex, such as clitoridectomy, neovagina and penectomy. Gonadectomies were carried out in 37 cases. Just under 70% of the individuals underwent surgery at preschool age.

The German Ethics Council's survey reveals the following results for hormone treatment: 24% of respondents state that they are taking female hormones, 3% male hormones, 54% hormones typically used to treat CAH (e.g. hydrocortisone) and 16% other hormones; 3% are undergoing hormone replacement therapy.

The Hamburg Intersex Study does not include quantitative data on issues of information and consent, which are addressed in the form of individual reports. For instance, study participants are reported to have complained of inadequate information on their diagnosis and treatment measures, lack of consent for interventions in childhood and adolescence, and the use of inappropriate language and an inappropriate professional approach in communication of their diagnosis. Specific critiques were also directed at certain concomitants of medical treatment, such as medical photography and repeated genital examinations in the presence of often quite large groups of doctors and students.[86]

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85 In this regard, the German Ethics Council is in possession of two reports by adult individuals who did not undergo treatment. One states that she is living as a woman with untreated CAH (detected only late on) but sees herself neither as a woman nor as a man. The other individual has untreated gonadal dysgenesis, lives predominantly in a masculine role and is subjectively androgynous.

86 See Schweizer et al. 2012, [7].

The Network Study reports that parents were often dissatisfied with "diagnosis and information management", with regard to the time required to arrive at a diagnosis, concern for their feelings and inadequate information on the available treatments and drugs. It is emphasized that parents of girls with CAH are, however, significantly more content with diagnosis and information management and coordination. The number of operations performed had no effect on satisfaction in this respect.[87]

In the online discourse, affected people state that adequate and relevant information is not forthcoming from medical practitioners, this also being one reason for prompt consent by the parents of children who are not yet competent to decide for themselves on surgery.[88] This being the case, some participants in the online discourse describe the fear and distrust of doctors and the apparatus of medicine that they have experienced ever since. They report incorrect treatments due to wrong diagnoses or prognoses and complications not allowed for in the doctors' recommendations or not previously mentioned. Those concerned are often critical of the whole field of medicine, deplore the fact that intersexuality is still seen in medicine as a defect and demand that intersexuality should not be regarded as a disorder.[89]

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87 See Kleinemeier/Jürgensen 2008, 18.

88 For instance, Claudia Kreuzer reports in the online discourse: "As a part of my work for the Federal Association of Intersex People, I have been able to inspect a large number of medical records. None of these documents – not a single one – included even the slightest indication that minimally sufficient information or information for the purpose of self-determination had been given."

89 One of the two untreated DSD individuals (the one with gonadal dysgenesis) who furnished a detailed report to the German Ethics Council comments that the medicalization of the condition made it difficult for it to be simply "left alone": "The fact that I have not undergone treatment is [...] due to a chain of fortunate circumstances and to ignorance pure and simple [...] – nowadays it would surely be much more difficult to slip through the medical net. Given an androgynous appearance and certain phenomena in puberty, an immediate presumption of intersex would nowadays be more likely [...] – the increasing knowledge of sexual ambiguity affords no protection here. If anything it is the other way round. Certain things are now automatically presumed to require treatment, whereas in the past they would have been left alone or simply ignored."

The following results on the issue of consent or involvement in the decision on surgery emerge from the German Ethics Council's survey. Two thirds of respondents state that they were involved in the decision on surgery. Fifty-one respondents took the decision themselves; 34 were included in consultations; 23 were merely informed. However, 60 respondents state that they were neither informed nor involved; on this point there were no significant differences between CAH individuals and people with other forms of DSD.

As to consent to or involvement in the decision on hormone treatment, more than a third of the respondents in the German Ethics Council's survey report feeling informed about their medication. Another third feel insufficiently informed or completely uninformed, while the remaining third give other responses. Individuals with CAH tend to answer this question indirectly and to describe their drug treatment as essential for their survival, thus leaving them no alternative.

In the Hamburg Intersex Study, 45% of respondents state that they have consulted psychotherapists or psychologists.[90] In the German Ethics Council's survey, about a quarter of respondents state that they have undertaken such treatment, the frequency being twice as high after than before a medical intervention. A quarter of those treated in this way received psychopharmacological treatment or a combination of psychopharmacological treatment and psychotherapy; three quarters of cases had psychotherapy.

The experts consulted by the German Ethics Council also report that changes are currently taking place in this respect. Greater care is now stated to be taken with diagnosis and its communication. More consideration is in their view currently shown to those concerned than in the past; they receive better information and measures are no longer taken against their will.

90 See Schweizer et al. 2012, [9].

6.3 Quality of life and life satisfaction

To assess the actual situation of people living with DSD in German society, subjective appraisal of their quality of life is an important factor. Although each of the three studies considered here has its own individual methodology, their conclusions are similar.

In the Hamburg Intersex Study, general life satisfaction is assessed by the criteria of health, work and occupation, financial situation, leisure and friends, acquaintances and relations. The responses are compared with a reference group of the same sex without DSD by means of standardized questionnaires. A significant result is that the general life satisfaction of DSD individuals living in a feminine gender role differs hardly at all from the reference sample. The highest satisfaction levels among people affected by DSD are recorded for girls and women with CAH (46,XX). On the other hand, DSD individuals living in a masculine gender role have lower life satisfaction levels than the reference sample in all subgroups.[91]

However, the Hamburg Intersex Study also records psychological problems, described under headings such as depressive symptoms, anxiety and distrust. On this point, 61% of respondents (42 out of 69) are found to exhibit clinically relevant levels of pathology, individuals with disturbances of androgen biosynthesis having the highest values (6 out of 7), followed by late-onset CAH (3 out of 4), PAIS (8 out of 12), CAIS (8 out of 13) and CAH with salt wastage (6 out of 10). Only the subgroup of CAH individuals without salt wastage had a lower level of psychopathology.[92]

In the Network Study, which uses a comparable approach, the adult DSD individuals living in a feminine gender role have, in terms of quality of life, higher values than the reference sample for physical health but lower values for mental

91 See Richter-Appelt et al. 2008, 74.
92 See Richter-Appelt et al. 2008, 27.

health. Adult individuals with DSD living with a male identity do not differ from the reference sample in terms of their general satisfaction with life. Psychological problems are reported in 45% of participants, no differences being observed between those with male and female identities. If the respondents are again broken down by CAH and other forms of DSD, CAH individuals do not exhibit above-average psychological impairment, whereas other DSD individuals living in a feminine role show a high level of psychological difficulties.[93]

The specific evaluations of the data for children and adolescents participating in the Network Study also confirm that these individuals' general quality of life differs hardly at all from that of the reference sample. However, parents of children with DSD in all age and diagnostic groups often take a less favourable view of their children's psychological well-being than the children themselves. On the other hand, respondents in the 8–12 age group more frequently consider their physical well-being and family life to be impaired. This view is expressed particularly often by girls with CAH in this age group and boys with reduced androgen activity. In the case of the girls, the study authors attribute this to the fact that they are permanently reliant on therapy with cortisone or aldosterone and have to pay attention to their body's signals, possibly resulting in conflict within the family. The negative values in boys are attributed to the consequences of sometimes repeated surgery and its complications.[94]

In the German Ethics Council's survey, respondents are asked to provide a subjective assessment of their quality of life, scored in accordance with a multi-level scale. People with CAH consistently take a positive view of their quality of life in all the fields considered (between 86% and 99%). A different picture emerges from the group of other DSD individuals, whose subjective quality of life is rated positively in an average

93 See Kleinemeier/Jürgensen 2008, 22 ff.
94 See Kleinemeier/Jürgensen 2008, 21.

of 55% to 65% of cases. The aspects of mental health and sexuality are less favourable, only 40% rating their situation as positive. In terms of the assessment of physical health, a slight age effect is evident in the responses of people with other DSD diagnoses: in this group, the majority (69%) of respondents under the age of 37 rate their physical health as good or very good, while the majority of over-37s (61%) consider their physical condition to be at most average, poor or very poor.

In a number of posts by affected people in the online discourse, negative assessments of subjective quality of life predominate, mostly attributed to the psychological and physical consequences of medical interventions. Affected individuals report psychological problems such as depression and trauma, with consequent difficulties in embarking on social relationships. Some posts also betray despair at the contributor's individual situation and the position of intersex people in society.

For the assessment of overall quality of life, particular importance attaches to the sexual element and hence to issues of partnership, the subjective experience of sexuality, bodily experience and sexual identity.[95] On this aspect, the results of the studies reveal a different trend from those relating to quality of life in general.

Some 61% of respondents in the Hamburg Intersex Study give conspicuously negative responses concerning the criteria of attractiveness/self-confidence, uncertainty/negative feelings and sensitivity/accentuation of the body. There are no significant differences between the various diagnostic groups of DSD in this connection. Overall, about 40% of the affected respondents in the Hamburg Intersex Study feel that their physical attractiveness and the self-confidence based on it are impaired, while 30% feel uncertain about their bodies.[96]

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95 Sexual identity is defined here as a person's inner sense of belonging to a given sex, which may be female, male or indeed other. Gender role, on the other hand, relates to a person's role as outwardly exhibited and the expected behaviour associated with it. See also Section 3.

96 See Richter-Appelt et al. 2008, 28.

Again according to the Hamburg Intersex Study, female participants with CAH had their first sexual experiences later, and had less sexual experience, than women of the same age without DSD and are more likely to be living alone. Although they claim to be content with their sex life in general, they are often dissatisfied with their appearance or the functioning of their genitals, especially if these have undergone surgery. No differences emerged in terms of sexual orientation and particular sexual problems.[97]

People with other forms of DSD, on the other hand, are more likely to be dissatisfied with their sex life than the reference sample. Again, those concerned are significantly more likely than the reference sample to be living alone,[98] significantly more likely to experience uncertainty in social and sexual situations, and more likely to have same-sex or both female and male partners. In particular, however, individuals in this group – partly because they have undergone genital surgery such as clitoridectomy, vaginoplasty or urethral correction – are significantly more likely than the reference sample to experience sexual problems such as fear of sexual contact, problems of sexual arousal, difficulty in initiating sexual contacts, fear of injury during sexual intercourse, dyspareunia and vaginismus.[99]

The Hamburg Intersex Study finds that 47% of DSD individuals with the 46,XY karyotype who have undergone genital surgery (clitoridectomy, vaginoplasty or urethral correction) are significantly more likely to experience fear of sexual contact and fear of injury during sexual intercourse than those who have not had functional plastic surgery. This trend is not evident in CAH individuals (46,XX) who have undergone the

97 See Richter-Appelt et al. 2008, 34 f.
98 In the German Ethics Council's survey, about a third of the respondents stated that they were living with a partner; on this point, there were no significant differences between the various forms of DSD.
99 See Richter-Appelt et al. 2008, 33.

same kinds of operations but with the aim of making them unambiguously female.[100]

Evaluation of the data from the Network Study on adolescents between the ages of 13 and 16 shows that particular problems in the fields of sexuality and partnership are generally of early onset. For instance, by the age of puberty girls with DSD already exhibit less sexual activity and have fewer male and female friends than their coevals without DSD; the authors of the Network Study attribute this finding to shame and fear of having to disclose their DSD status. There are no reports of such difficulties in boys with DSD. However, adolescents – both girls and boys – who need sex hormone therapy in puberty present these difficulties to an even greater extent.[101]

Regarding their original gender role designation at birth, 70% of respondents in the Hamburg Intersex Study claim to be satisfied. At the same time, however, nearly half (48%) of the respondents show a conspicuously high level of uncertainty about their sexual identity. More than a quarter (28%) of the entire group subsequently exhibit pronounced elements of transgender identity. Another significant finding concerns the low values on a scale of identification with the feminine role: 35% of individuals living in a feminine role have conspicuously low femininity ratings and 19% even have high masculinity ratings.[102]

A similar result emerges from the Network Study. Female sexual identity is stated to be less pronounced among DSD individuals with a feminine role than in women belonging to the reference group. Individuals with DSD living in a masculine role were not found to differ from men in the reference group in terms of their sexual identity.[103]

In the German Ethics Council's survey, approximately a third of respondents stated that they were living with a

100 See Richter-Appelt et al. 2008, 34.
101 See Kleinemeier et al. 2010, 968 f.
102 See Schweizer et al. 2012, [8].
103 See Kleinemeier/Jürgensen 2008, 29.

partner; there were no significant differences between the various forms of DSD on this point.

Asked how they would like their sexual identity to be specified, 50% of respondents in the German Ethics Council's survey answer "female" and 10% "male". Another 10% reply "intersex", while 6% do not wish to specify their sexual identity. Very small numbers of individuals describe themselves as androgynes, hermaphrodites, human beings, "transidents" etc. A breakdown of these responses into the categories of CAH individuals and other individuals affected by DSD shows that 86% of the former place themselves within the currently applicable binary system (*female/male*), whereas the same is true of only 28% of those with other forms of DSD.

6.4 Correlation between medical treatment and life satisfaction

It is argued in the public debate on intersexuality as well as in the literature that the life satisfaction of affected people is often low in consequence of medical treatments. In this context, it is important to establish whether this alleged correlation is reflected in the studies and whether the impairment of quality of life and life satisfaction is due to the problems of coming to terms, both psychologically and physically, with medical interventions.

In the studies considered here, this correlation is addressed in two groups of questions, concerning firstly satisfaction with the treatment itself and secondly subjective appraisal of how far the respondents' current level of life satisfaction correlates with the medical interventions. From this perspective, some of the experts consulted by the German Ethics Council point out that there may be a variety of reasons for satisfaction or dissatisfaction on the part of those concerned. These include the treatment measures themselves, the circumstances of the treatment and consequent medical complications, as well as

the degree of satisfaction with the individuals' own body, social integration, the individuals' reaction as experienced or remembered, how their parents treated them as "different children" and their subsequent working life.

In the Hamburg Intersex Study, 43% of respondents report that they are satisfied with the results of surgery, 11% are partly satisfied and partly dissatisfied, while 46% are dissatisfied. The highest levels of dissatisfaction are expressed by people with complete androgen insensitivity who have undergone surgery.[104] The majority of adult participants in the Network Study claim to be dissatisfied with their treatment.[105] On a scale of satisfaction with scores of up to 32, in which a score of under 24 is rated as "low satisfaction with treatment", the average result is 23. However, the scores vary widely according to the specific diagnosis. For instance, individuals with CAH score up to 26.4, while those with CAIS living in a feminine role average 18.7. While the number of operations has no effect on satisfaction, satisfaction is greater in those who received psychological treatment or counselling. Affected individuals without psychological treatment or counselling have an average satisfaction score of 22.3, compared with 25.4 for those who have received psychological treatment or counselling. It is also reported that dissatisfaction with medical treatment is strongly correlated with the difficulty experienced, either in the past or currently, in obtaining competent specialist help.[106]

The Network Study includes a specific evaluation of non-CAH adult participants concerning satisfaction with treatment in general, genitoplasty and sexuality and the correlation between these parameters. 37.5% of respondents claim to be dissatisfied with their treatment in general. People with PAIS

104 See Schweizer et al. 2012, [7].

105 Regarding treatment satisfaction on the part of the children and adolescents participating in the Network Study, only the parents were asked about their satisfaction with diagnosis and information management, coordination, the general clinical and treatment context and the doctors' conduct.

106 See Kleinemeier/Jürgensen 2008, 18 f.

living in a feminine role express particular dissatisfaction with the outcome of surgery (47.4%) and the capacity for sexual arousal (47.4%). People with CAIS have even higher dissatisfaction scores (63%).[107]

In the German Ethics Council's survey, between 30% and 45% of respondents consider surgery to be correlated with their psychological and physical health on the one hand and their gender role and sexual satisfaction on the other. Among this group, no clear picture emerges on the life satisfaction of intersexual DSD individuals in terms of gender role (approximately one third each responding "high", "medium" or "low"), whereas the response of those with CAH is predominantly (90%) "high". On mental health, the distinction between the CAH group and the group of people with other forms of DSD is even clearer in the group that considers a correlation with surgery to exist: 63% of intersexed DSD individuals rate their satisfaction as "low" and 23% as "high", while the responses in the CAH group are 86% "high" and 7% "low". Some 40% of respondents correlate their general life satisfaction with their surgery: 50% of intersexed DSD individuals rate their satisfaction as "low" and only 20% as "high", while 92% of the CAH group answer "high". Unlike the aspects mentioned above, the fields of work, financial situation and social contacts are felt to be only relatively weakly correlated with surgery (range 16% to 28%). The differences between the various forms of DSD are not significant in this respect.

In 62% of cases, participants attribute effects on physical health to hormonal medication. Of these participants, 34% of intersexed individuals rate their life satisfaction as "high" and 52% as "low", 75% of CAH individuals as "high" and 12% as "low". An appreciable number of respondents also correlate their general quality of life (44%), gender role (33%) and mental health (37%) with their hormonal treatment. Here again,

107 See Köhler et al. 2011.

the life satisfaction of people with CAH is in general higher than that of those with other forms of DSD. Overall, only about one in five individuals correlate their hormonal medication with sexual satisfaction and social contacts, although the distribution of the degree of satisfaction between the groups is again unequal.

As might be expected, the effects of psychiatric or psychotherapeutic treatment on satisfaction are substantially connected with the field of mental health (49%), as well as, to some extent, with those of the financial situation and social contacts. CAH individuals consider the consequences of psychiatric and psychotherapeutic treatment to be less important than people with other forms of DSD. However, the difference is not statistically significant.

Some of the respondents with experience of surgical, hormonal or psychiatric/psychotherapeutic treatment deny that it has had any effect at all on their life satisfaction: 25% of respondents consider such treatments to be unrelated to their mental health, 29% to their sexual satisfaction, 31% to their general quality of life, 40% to the aspect of work, 48% to their financial situation and 43% to social contacts.

In the view of the majority of the social-science experts consulted by the German Ethics Council, the issue of satisfaction with treatment calls urgently for further research. This should cover at least the following aspects: the behaviour of the attending medical personnel towards those concerned; satisfaction with the decisions on specific measures; satisfaction with the nature and extent of information provided; and satisfaction with the treatment outcome. The experts also consider it urgently necessary to obtain information from people affected by DSD who have not undergone medical treatment. Research is likewise held to be necessary on information provision and management, in particular in terms of patients' individual experience, as well as in the fields of parental experience and support. Comparative studies are needed on both medical and societal approaches with those of other countries.

An urgent need for research is also considered to exist on psychosocial issues associated with DSD: for example, the psychosocial development of children and adolescents with DSD, broken down by diagnostic groups; resource-oriented approaches to psychotherapeutic treatment (depth psychology and psychoanalysis); longitudinal studies of child development; studies of parent–child relationships (attachment representation); evaluation of psychological/psychotherapeutic care at medical facilities (reference hospitals and centres) with the aim of optimizing psychological/psychotherapeutic treatment provision and minimizing additional pressures (in relation to treatment and/or its context); and the establishment of DSD-specific tests to identify potential stressors on parents and children, as well as developmental factors.

6.5 Discrimination

An important part in assessment of the quality of life of people with DSD is played by their experience of discrimination, disadvantaging and violence. On this point, significant differences emerge in the German Ethics Council's survey between CAH individuals and people with other forms of DSD. Whereas respondents with CAH are most likely not to report such experiences, a completely different picture is revealed in the group of other individuals with DSD. The following experiences of disadvantaging are mentioned (in descending order of frequency): instances of discrimination and exclusion; negative experiences of a taboo on the issue; problems with binary sex classification; physical violence; lack of information and confusion with transsexualism; incorrect medical treatment; and mockery and insult. The small number of respondents in this group who do not report negative experiences are predominantly (8 out of 9) aged under 37.

A number of posts and comments in the online discourse also relate to this point. Participants complain that intersexed

people do not benefit from the protection of minorities in society and feel deprived of protection and dignity.[108]

Appreciable differences between the CAH group and the other individuals with DSD are also observed in the responses on the question of positive experiences in relation to the individuals' intersexuality. Whereas most of those with CAH do not feel that this question is relevant to them because they do not see themselves as intersex and therefore leave the question unanswered, 65% of those with other forms of DSD report positive experiences. Some 10% feel that the possibility of being "both" and of engaging in a special internal dialogue with themselves or enjoying certain special rights is a positive experience.

6.6 Hurdles in daily life

Here again, an appreciable difference is observed between CAH individuals and those with other forms of DSD. A significant majority of the former group state in the German Ethics Council's survey that they do not have problems in their daily lives. Those with other forms of DSD mention a number of hurdles attributable to their ambiguous sexual status. These include the need to conceal their intersexuality; having to decide on a daily basis between the sexes (e.g. when using public toilets); inflexible answer options in questionnaires; and designation for the purposes of sport.

In the online discourse, some affected people point out how far the reality of a individual's life is dictated by the sex-related definition of a human being: the situation of existing between

108 For example, Lucie Veith, Federal Chair of the Association of Intersex People, stated in the online discourse: "I experience my membership of the caste of intersex people in our system of two sexes as a state of deprivation of rights, protection and dignity [...] because the existing protective mechanisms, whether those of society or the state or those of parents, ethics, morals, religion or philosophy have not worked."

the sexes is not easy to imagine or to live with. Affected people note in this connection that the right not to be discriminated against does not in practice exist for people with DSD. Statutory provisions that include only the categories of male and female are also seen as discriminating against intersex people.

On the question of individual societal integration, 87% of the CAH individuals in the German Ethics Council's survey state that they are well or very well integrated, whereas this is true of only 46% of those with other forms of DSD. While only 3% of those with CAH feel poorly integrated, this is the case with 36% of people with other forms of DSD. Overall, the respondents rate the general integration of people with DSD as substantially poorer. Only 13% of the respondents feel that intersex people are in general well or very well integrated, while 42% consider them to be poorly or very poorly integrated. There are no significant differences in this respect between CAH individuals and those with other forms of DSD.

With regard to health insurance, approximately one fifth of respondents report problems. The difficulties as a rule concern the approval of and payment for therapies relating to the specific diagnosis, but problems of communication with the health insurance funds and high premiums demanded by private health insurers and complementary insurance providers are also mentioned. Some participants report particular difficulties with sex-specific classification. On the one hand, it is disagreeable to be addressed by a individual-specific *Frau* or *Herr* at the doctor's surgery when one's appearance is ambiguous or apparently inconsistent with the form of address, while on the other drug dosage is determined by one's sex as recorded in the civil register. This may lead to an overdose or insufficient dose of potentially harmful or vitally necessary medicines.

The sphere of contact with other affected people is also important for an understanding of the world in which people with DSD live. Whereas the majority of those with CAH (four fifths of respondents) have little or no contact with their peers,

four fifths of people with other forms of DSD have occasional or even frequent contacts with other DSD individuals, for example via social media or public or social commitment.

With regard to social discrimination and hurdles in daily life, the experts consulted by the German Ethics Council to point out that the public perception of intersexuality was for a long time characterized by denial and silence. It is only in the last few years that increasing public perception of an interest in the subject has been observed. Both the results of the three studies and the impressions gained from the experts' professional contacts with individuals with DSD suggest overall that the participation of these people in society is restricted.

Here again, the experts' views on CAH are the exception, indicating a generally high level of integration and life satisfaction on the part of the affected individuals.

The experts all agree that, besides the predominance of the medical discourse, societal treatment of intersexuality is characterized principally by a failure to address the subject, whether in the context of daily life and language or indeed on the institutional and legal level. In the experts' view, those affected consequently often have the impression of existing outside the normal categories of life, while on the other hand feeling under pressure to conform to norms with which they are unable to comply.

6.7 Attitudes and assessments

A particularly important question in the debate about DSD is whether and, if so, in what cases early medical interventions should be restricted or prohibited. Respondents to the German Ethics Council's survey were presented with different statements on this point, on each of which they were able to comment.

Whereas 85% of all those with CAH agree with the statement that failure to designate a child as belonging to a specific

sex at an early age is psychologically harmful, thus justifying parental consent to such measures, this is true of only 6% of individuals with other forms of DSD.

Only 11% of CAH individuals agree with the statement that except in cases of medical emergency genital surgery should not be conducted before those concerned are old enough to decide for themselves, whereas the equivalent figure for people with other forms of DSD is 97%.

In the online discourse, on the other hand, only demands for the prohibition in childhood of surgery not essential for survival are expressed. In addition, implementation of the right of self-determination for children with DSD is called for. Many cannot understand why this demand was not acceded to long ago. In the German Ethics Council's public hearing, however, mothers of affected children opposed a ban. On behalf of *AGS-Eltern- und Patienteninitiative* (an association of CAH parents and patients), the mother of two girls with CAH argued in favour of early surgery for girls with CAH. The mother of a child diagnosed with another form of DSD said that, in spite of all misgivings, it should still be up to the parents and the child to decide.[109] As to whether an ambiguous-sex child should be brought up in accordance with a specific gender or whether this should be left open, a majority of those approached in the German Ethics Council's online survey (58%) favoured the latter course. A breakdown by CAH individuals and individuals with other forms of DSD shows that only 31% of the former group favour leaving the situation open, as against 92% of the latter.

On this point, the experts consulted by the German Ethics Council on the one hand mention the difficulty of rearing a child without a specific sex designation.[110] In their view, many

109 The hearing can be accessed online at http://www.ethikrat.org/veranstaltungen/anhoerungen/intersexualitaet [2012-02-07].

110 The German Ethics Council is in possession of two reports by parents on this situation. One of the cases concerns the parents, resident in the Netherlands, of a child now aged 6 with mixed gonadal dysgenesis (46,XY)

parents feel unable to cope with this situation. Nor can it be assumed that all affected individuals wish, or are able, to live openly as intersex. This decision should be left to them. For this reason, these children's upbringing should be flexible and they should not be forced to conform to a fixed gender role. Sex designation should be reversible and modifiable, as the development of individual sexual identity with DSD is as a rule unpredictable.

The experts confirm that early sex assignment and surgery under the conditions experienced by people of ambiguous sex who are now adults have often had traumatic effects and resulted in psychological and even physical harm. For this reason, some experts call for the suspension of current surgical practice, the development of a new action algorithm with an explicit ethical dimension and the prohibition of castration before those concerned can decide for themselves.

On the other hand, it is also pointed out that trauma results not only from (surgical) sex assignment but also from the management of the phenomenon within the family and society. For this reason, a distinction should be drawn between medical sex assignment and the way the phenomenon is dealt

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who decided against surgery and are leaving the child's upbringing open until the child can make the decision. The situation is stated to be not "either/or" but "both/and". On the question of psychosocial difficulties, these parents report that in their experience the attitude of neighbours, other parents and teachers has been extremely helpful and understanding. They see their task as parents not as "protecting [their child] from potential hostility of any kind, but instead as letting the child grow up to be as strong and self-confident as possible so as to defy hostility." The other case relates to parents of an XY girl (a true hermaphrodite), now 11 years old, who underwent surgery for ovotesticular gonadal dysgenesis at the age of 18 months, to which the parents now believe they were wrong to consent. The parents report that their experience of bringing up the child without a fixed sex designation is overwhelmingly positive. They say: "Having reached the age of 11, our daughter is now certain that she is a girl, has a diverse, loose circle of friends (both boys and girls), is still more interested in technology than in fashion, and knows what she wants and in particular what she does not want. She sees her situation, her diagnosis and her medically anomalous appearance as something given, as a part of herself (but by no means the most important part) which she can live with perfectly well in spite of all dire predictions. Up to now she has refused genital correction as something that makes little sense."

with (gender assignment). With regard to the latter, there is still a dearth of validly based studies indicating what might be helpful for children and families. Owing to the focus on medical issues in DSD, the problems of managing the condition (in the family, at school, in society, etc.) are not addressed.

Some of the experts consulted report that in their professional experience quite a few parents are unable to accept their children if their sex remains undecided, and therefore consider the choice of a gender to be absolutely justified. According to these experts, the emotional acceptance of a child is so important that the parents should be supported and assisted in their choice of gender. The same applies in their view if parents want this choice to be underpinned by physical measures. However, stereotyped responses must be avoided. The priority must always be the eventual decision of the child on the basis of powerful experiences of attachment, facilitated by psychological counselling of the parents after birth or diagnosis. On the one hand, in one expert's opinion, the definitive attribution of a sex to a child whose sex development prognosis is unclear should be left open; on the other, the child should be consistently brought up and treated in a particular gender role provided that the child does not resist the choice of gender.

Experts complain that none of the positions in the debate is actually supported by empirical evidence because, firstly, too few cases that have not undergone surgical sex assignment are known and, secondly, the cases of DSD which have undergone surgery have not been systematically followed up.

In the case of CAH individuals, it is suggested that parents be required to seek the advice of doctors, therapists and support groups prior to any genital surgery.

A similarly varied picture emerges on the law of civil status and registration of sex: whereas the majority of the individuals with CAH who responded to the German Ethics Council's online survey do not call for a change in the law of civil status, those with other forms of DSD frequently voice this demand.

With regard to the question whether the current binary sex system should be retained for statutory purposes, the result is as follows. Only 43% of all respondents argue in favour, whereas 22% advocate the addition of a third category and 35% would prefer a different solution (for instance, no designation at all or more than three categories). A breakdown of this result by diagnostic groups shows that 70% of CAH individuals favour retention of binary sex categorization, whereas this is true of only 5% of those with other forms of DSD.

On possible legal alternatives, people with CAH tend to favour a modification, such as the addition of further sex categories or provision for leaving sex registration open during childhood, whereas those with other forms of DSD incline more to the abolition of sex registration, accepting the introduction of additional categories as a substitute only.

In the online discourse too, a variety of positions on sex registration are voiced. Nor do participants agree on the form of any change in the law of civil status; however, none of these positions can be associated with any particular DSD group. Three different groupings can be discerned: one calls for registration of civil status to be left open either permanently or for a specific period, or for provisional registration of sex to be allowed; a second advocates registration of a third sex; while another regards the question as irrelevant and attaches more importance to a change in surgical practice for affected children.

Affected individuals justify their criticism of compulsory early registration as either female or male on the grounds that doctors may use it as the basis of their advice on precocious surgery.

On the question of whether registration of a third sex should be allowed, some argue that this would be equivalent to a new form of discrimination and therefore inappropriate, while others take the view that it would signify recognition of intersex people, so that provision should be made for this possibility.

The experts consulted by the German Ethics Council are also divided on this issue. Some fear that a third sex could further boost discrimination, and instead advocate complete abolition of sex registration. They argue that its value is minimal and increasingly questionable. Others consider that a third category, *unspecified*, should be introduced. Anyone could opt for this category on the basis of self-definition. Another possibility might be the introduction of a "hermaphrodite" category, which could be amended to *female* or *male* up to the age of sexual majority or, as the case may be, retained. According to this view, an additional sex category should be introduced only subject to the proviso that no new obligation or form of disadvantage should arise, but that intersex individuals should be free to choose registration as female or male. Some experts consider it essential to involve intersex individuals in the discussion of a possible third category for the purposes of daily life. In addition, a number of specific proposals were made – for example, not requiring an individual's sex to be stated in their passport; the use of three categories in statistical surveys as elsewhere; or abolishing the requirement to notify a child's sex within a week of birth. Another recommendation is to set an age limit for gender majority, along the lines of the provisions governing religious majority, so that a child could choose a gender (or no gender) from, say, age 12 even against the parents' will.

With regard to the question of damages and compensation, the German Ethics Council's online survey of affected people shows that many do not regard this as a practical option, because those affected do not feel strong enough to engage in judicial proceedings and the risk of retraumatization is considerable.[111]

111 On this point, Lucie Veith, Federal Chair of the Association of Intersex People, comments as follows in the online discourse: "Based on my experience in the field, I can tell you that after 20 years most people have no prospect of obtaining any record that is (a) complete and (b) adequately documented. Histological results cannot be located, have been lost in a fire

As an alternative to legal action for the infliction of bodily harm, many affected individuals suggest the establishment of a state assistance fund for people with DSD who suffer physical and mental harm after medical treatment.

A few of the experts consulted have also discussed the possibility of an assistance fund.

6.8 Demands for improvement of the position of people with DSD

With regard to suggestions for improvement of the societal situation, no significant differences are observed between the various DSD diagnostic groups on a number of aspects.

Some 36% of the affected individuals responding to the German Ethics Council's survey express the wish for better public information, removal of taboos, and the creation of public awareness and visibility for DSD. 10% of respondents favour the provision of information in schools and universities, while 12% call for more information, specifically for medical practitioners and psychologists. 86% of respondents agree that non-clinical contact and advice centres for information and networking of people affected with DSD should be publicly funded and expanded.

The same trend emerges from the statements in the online discourse. Participants regret that society takes too little account of intersex people, with the consequence of incomprehension, discrimination and exclusion. The comments of affected individuals often reflect the fact that they do not see themselves as a part of society and feel excluded by it. The

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or flood, or else, as in my case, there are two different and diametrically opposed histological results on the testes – both issued on the same day by the same laboratory." Furthermore: "With regard to these historical cases, some of whom have been damaged many times over, you cannot send these people on another journey through hell by expecting them to engage in legal proceedings that may take years."

demand for recognition is therefore of vital importance to many affected individuals and is repeatedly stressed in a variety of forms. The demand is for information and publicity, commencing at an early age in schools. Many affected individuals want to be able to proclaim their sexual identity openly and without discrimination.

Special financial and structural aid for support groups is called for, enabling them to form a network of assistance covering the entire Federal Republic, as well as the establishment of advisory centres staffed by people with DSD to offer assistance on a peer-to-peer basis.

Not only affected individuals but also family members and academics recommend the setting up of interdisciplinary centres of competence in which a wide range of professions would collaborate and provide abundant counselling, while leaving sufficient time for the relevant decisions to be made.[112]

Some doctors too advocate allowing parents more time to obtain information about potential measures and to discuss the situation with their child before any action is taken. Many of those commenting, again including medical practitioners who carry out the relevant treatment, sum up their demands by calling for a change in the medical mindset on DSD and for directives to be issued to guide practitioners on their approach to affected people. This would also involve, for example, taking more account of individuals' feelings about their sex, in turn requiring much more time to be devoted to diagnosis and counselling.

The purely biological approach to sex should be abandoned. A particular recommendation is for more account to be taken of the right of self-determination of children with DSD.

112 Here is a pertinent comment by an individual with DSD in the online discourse: "If it were compulsory for children born intersexed in Germany to be referred to centres of competence staffed by a team of (specialized) paediatric endrocrinologists, urologists and psychologists, that would for a start put an end to the 'uncontrolled proliferation' of doctors performing instant operations."

Here too, the demand is expressed for better, holistic information on medical interventions, their lifelong consequences, and documentation of this information. Another suggestion is that alternatives to medical interventions be included in advisory and information-related consultations. In particular, parents should be allowed more time to decide after receiving medical information.

The majority of the experts consulted by the German Ethics Council likewise favour the establishment of non-clinical contact and counselling centres and public funding for public education and information. The experts disagree on whether the state should fund a network of facilities for people with DSD covering the entire Federal Republic. Some stress the need to offer affected children an independent "advocate" or guardian *ad litem* to protect their interests. Other demands are for the updating of medical textbooks, training of medical students in the conduct of psychological consultations, the incorporation of issues of DSD and intersexuality in the training curricula of psychotherapists and medical specialists, and the registration of psychotherapists with the relevant additional qualification by the associations of statutory health insurance fund doctors.

6.9 Conclusion

The survey results portrayed in the above sections present a variegated picture of the situation and quality of life of people with DSD. Depending on their individual forms of sex development and the vicissitudes of their life with DSD, the experience of those affected shows considerable diversity. CAH individuals in particular differ from those with other forms of DSD such as androgen hypofunction or anomalies of gonadal development.

The overall conclusion must be that, except for CAH individuals, the life situation of people with DSD is still, notwithstanding possible early signs of improvement, largely

characterized by suffering, a lack of respect on the part of the medical profession, insensitivity in the social environment, administrative and bureaucratic obstacles and widespread societal ignorance of the reality of their lives. People with CAH as a rule consider their social situation to be less problematic.

The results of all these studies indicate that the requirements of informed consent to surgery, at least at an early age, have often not been met. This is particularly true from the perspective of today's criteria. From the point of view of those affected, the need for comprehensive information, counselling and involvement in decision-making is in many cases not adequately satisfied even today. Since surgical treatment of DSD is often carried out in childhood, the additional problem arises of the appropriate degree of involvement of minors in the decision and the permissibility of substitutive consent by a parent or other person with the right to care for the child. The studies show that people with DSD, except for CAH individuals, feel left alone with their problems in this regard, whether owing to an unsatisfactory legal situation or to practitioners' insensitivity towards them.

Similarly, many people with DSD consider that they are given inadequate, if any, information about their medication (as a rule, hormone therapy). CAH individuals who received drug treatment usually accept it because they felt it to be essential to their survival.

Differences between CAH individuals and persons with other forms of DSD are also observed in relation to experiences of discrimination, disadvantaging or violence. The latter group frequently report instances of discrimination and exclusion, as well as negative experiences due to the taboo on the subject of intersexuality. People with DSD also experience problems with the binary sex system, physical violence, ignorance and confusion with transsexualism, incorrect medical treatment and occupational disadvantages.

The wishes and demands expressed in the studies cover a very wide range. One of the most frequent is for public

education and information and the removal of the taboo on intersexuality, especially at schools and universities for medical practitioners and psychologists. Publicly funded non-clinical contact and counselling centres for the provision of information to and the networking of intersex people are likewise advocated.

Some DSD individuals advocate a ban on surgery during childhood except in cases of medical emergency. A small group of respondents reject surgery for DSD in any circumstances.

In view of the difficulties experienced by many people with DSD in their daily lives because the law of civil status is based on the binary sex system, the blanket demand expressed in all studies is for a review of the legal situation. However, respondents disagree on provision for registration in a third sex, non-registration of a sex in the future, or whether individuals should be free to register in the sex of their choice.

Finally, some affected people demand financial support in compensation for or recognition of their past suffering.

Most of the study participants call for wide-ranging social education and information and removal of the taboo on the subject of intersexuality, as well as for CAH individuals to be distinguished from people with other forms of DSD; apart from these demands, the detailed results of the studies can be summarized as focusing on the following three groups of issues, all of which are the subject of vigorous debate:

- the treatment situation, including the demand for a blanket ban on surgery, and the legitimacy of substitutive consent to surgery in minors by those with the right to care for them;
- the law of civil status, including the possible registration of a third sex or the abolition or deferral of sex registration;
- demands for financial support in compensation for or recognition of past suffering.

7 ETHICAL ASPECTS OF THE SOCIETAL AND MEDICAL APPROACH TO INTERSEXUALITY

7.1 Considerations of social philosophy and social ethics

7.1.1 New responsibilities in the relations between man and nature

The phenomenon of intersexuality raises a number of fundamental ethical issues. The Greek word *ethos* had a number of very different meanings, denoting both provenance (animal housing, pasture or a dwelling, or custom) and the behaviour, particularity and competence of a human being. Natural factors, as observed in the environment or manifested in the population or the individual, came to be associated with the desired, required and preferred forms of conduct of both groups and individuals, intersecting in ways that were hard to unravel in any particular case.

The ethics that arose in Greece in the fifth century B.C. always included an awareness of this connection between nature as given and the requirements of society. Virtue demanded conformity with the norms corresponding to the customs, status and pretensions of the individual; at the same time, however, the natural conditions of an action situation had to be satisfied and account had to be taken of the available means, particularities of geography and the season, one's age and also, of course, an individual's sex – one's own as well as that of others.

In modern ethics, it occasionally seems as if nature no longer has any part to play. It is in particular the methodological demands imposed by the critique of the "naturalistic fallacy" that give rise to the impression that nature no longer exists except as an object under the tutelage of the laws of reason, and that it must always submit to the demands of morality, the

categorical imperative, self-respect, the desire to avoid suffering, or respect for other people.

This impression is, however, deceptive. Regardless of the premises applied, modern ethics too must take account of the external and internal conditions of an action situation – even where it sets store by the avoidance of fallacies. These conditions always also include the determinants, deemed (either for the time being or permanently) to be invariable, of a process which one is attempting to influence in accordance with one's own conceptions. Even when action must be taken under pressure of time, nature is involved. Natural factors are present as soon as birth or death, or the avoidance of a disease or a psychological emergency situation, are at issue. These factors call for a reaction commensurate with the situation. Moreover, from this point of view alone, it is impossible to disregard either the relationship between cause and effect or the demands of a particular situation. The techniques deployed ultimately also include a factor of nature – and not only when they have irreversible consequences.

These constraints of nature, both external and internal, must be borne in mind if the impression arises, given the greater freedom to manipulate an individual's naturally occurring sex permitted principally by medicine, that mankind had succeeded in releasing itself from its connection with nature. It is indeed the case that, as in all facets of our cultural development, we have gained a considerable measure of freedom of action, but this demands the exercise of more caution and consideration in our societal acts and presents us with the need for a dense network of ethical and legal norms. The freedom won entails additional social responsibility. This interconnection is revealed with exemplary clarity in DSD, so that all affected people, as well as those wishing to contribute to solving the relevant problems, must be conscious of it.

7.1.2 New responsibilities for sex

The problems of sex have since time immemorial made us aware of both the conditions and the limits of the constraints of nature on ethics. The manifestations of sexual ambiguity have always attracted particular attention in this connection. For instance, hermaphroditism was a much discussed phenomenon in antiquity, and Plato's *Symposium* contemplates the possibility that there might originally have been three sexes. So a plurality of sexes is anything but a new idea. Philosophy, pedagogy and medicine can point to a prolonged tradition of reflection on the treatment of ambiguous sexual status.

However, a new situation has manifestly arisen by virtue of the development of medicine, and in particular the possibility of surgical correction of individual organic particularities. Now that unambiguous surgical alignment with a given sex is feasible, and that is sometimes also possible to make alternative choices or to leave the relevant decision completely open, consequential problems with further ethical implications have arisen. These concern not only the fact of choosing a sex and the scope of the available options, but also the question of who is to take the decisions, the share of responsibility for these decisions to be assumed by doctors, parents and affected individuals, the possible (or necessary) societal model for such decisions and, lastly, the question of whether and for how long final decisions on the choice of sex can be left open.

This complex of issues gives rise to new responsibilities on the part not only of those affected but also of the attending physicians and the parents and advisers involved. These call for close scrutiny and thoroughgoing reflection, and their importance cannot be overestimated. It would therefore be appropriate to demand that it be possible for every decision taken in this field to be based on consideration from a number of different perspectives and the greatest possible degree of advice, the fundamental principle being that responsibility for deciding on an individual's sex must be taken by that

individual. If nature has not produced a body whose sex is unambiguous, the decision on that sex must be made only by the individual concerned. Here too, the guiding ethical principle must be *self-determination*.

The plasticity of human nature, its societal malleability and the individual's cultural aspiration to self-realization do not constitute ethical grounds for refusing an individual with DSD the freedom to choose the sex, the person feels to belong to. In the case of DSD, there is no fundamental ethical objection to exemption from the constraints of the binary sex system. Any person of ambiguous sex who wishes to be neither female nor male must be free to choose a sex that does not conform to either of these designations. Such persons must then live with their congenital intersexuality and are entitled to expect not to be required to conform to the usual classification. Here again, the principle applies that ethics cannot readily forbid what nature spontaneously dictates – provided that this corresponds to the explicit wishes of the individual and is not detrimental to that individual's health.

Other considerations would apply to the fulfilment of wishes for extreme deviations from the natural norm. Not everything that is technically feasible can be regarded as salutary for the individual. In addition, account must be taken of the societal compatibility of corrective interventions; this is surely also in the interests of the individual who desires the extreme deviation concerned. Of course, everyone involved has an ethical obligation to draw individuals' attention to the possible harmful consequences of their decision.

7.1.3 Substitutive decision-making

According to the principle of self-determination concerning a person's sex where this is ambiguous at birth, the wishes of the affected individual must take priority at all stages of diagnosis and therapy. This must also be allowed for during the subject's

development to sexual maturity and majority. Understandable as parental fears and expectations may be, while the decision on the individual's sex is still open, it may be taken by others only on the grounds of justified concern for the health of the affected individual. For this purpose, those involved must have access to independent medical and psychological counselling.

No individual of ambiguous sex must be compelled by societal circumstances or current law to make a decision on this issue against that individual's wishes. Furthermore, society has a duty to ensure that such a person is not disadvantaged, contrary to the principle of equality, on account either of the decision taken for or against a given sex or of the wish to leave the decision open. For this reason, ambiguous sex must not be regarded as a deficiency to be eliminated if at all possible, independently of the welfare and wishes of those concerned. Instead, where substitutive decision-making and action by others – in particular, parents – are necessary, the welfare and wishes of the affected individual are the only criterion applicable to this decision and action. Even then, these people will often not be spared difficult situations before and after necessary decisions. With the best will in the world, parents and medical practitioners may make substitutive decisions that prove to be wrong and do not always prevent suffering. It is nevertheless inappropriate rule out such decisions completely or to prohibit them in all cases; they must instead always be taken where necessary for unequivocal medical reasons.

It would be a misunderstanding to expect ethics to provide value judgements or standards in anticipation of medical developments. Living nature is the epitome of dynamic development; and within it, human nature has proved to be particularly flexible and productive. Culture, which is after all an aspect of our humanity, is incessantly bringing forth new forms of human behaviour. These can be restricted only if they violate fundamental principles of mankind's conception of itself and are likely to interfere with human dignity. This is the case neither with the naturally occurring forms of DSD

nor with the possible corrective medical treatments as such. For this reason, such treatments cannot be subject to blanket ethical rejection; however, some of the forms of application of these treatments are certainly incompatible with human dignity and must therefore be deemed unethical.

The wish of a person of ambiguous sex to be released from the binary system of *female* and *male* and to attempt to live a life with a different form of sex or gender cannot be opposed by invoking nature. Provided that the individual's wishes have been clearly expressed, that information conforming to the latest state of our knowledge has been offered and that the rights of others are not infringed, there are no general ethical reasons for opposing such an aspiration.

7.2 Recognition of suffering due to medical action

Human societies as a rule have a clear idea of what characterizes a man or a woman. Although societal images of sex and gender bear the stamp of historical, social and cultural factors that have not always resulted in a rigid binary system of categorization, an ambiguous sexual identity can nevertheless give rise to confusion, since it does not fit in with the biological and social two-sex model. The notions of sex predominant in a given society have repercussions in all fields of human action, and also influence the treatment of people of ambiguous sex. The consequence may be stigmatization and discrimination. In this context, in medicine as elsewhere, for a long time the idea prevailed that the aim of the treatment of intersexed people and those with particularities of the sex organs due to hormonal factors should be their "normalization" – that is, alignment with one of the two sexes. The predominant attitude was one of "benevolent paternalism".[113] It was argued

113 See Wiesemann 2010.

that the development of a clear gender in an affected child was best served by not enlightening him/her as to the nature of the variations present and the extent of the corrections deemed necessary. For a long time, practice was thus characterized by incomplete provision of information and by early sex ambiguity correction or sex assignment surgery: those affected or, if not yet competent to understand or decide for themselves, their parents were in some cases given either inadequate or no information at all, were not correctly asked for their consent, or were even categorically advised to undergo or permit such surgery.[114]

This led in many cases to substantial physical and psychological problems in those treated, and often to great suffering. Many affected individuals who underwent "normalizing" surgery in their childhood later experienced it as a mutilation and would never have consented to it as adults. There is now a much greater understanding of the problems that may accrue from a diagnosis of DSD and its treatment. Many doctors and parents are now aware that surgery of the sex organs can be traumatic.

For this reason, an initial step in improving the situation of those affected is to recognize and name the problems caused by the past medical and social treatment of DSD: the bodily and mental integrity of many affected people was severely damaged and lifelong physical and psychological suffering was inflicted on them. The resulting harm is in many cases irreversible. It is difficult to react appropriately if only because, as a rule, the decision-makers and medical practitioners were not in breach of the statutory provisions or professional standards applicable at the time of the intervention. Instead, the sex assignment or ambiguity correction operations were predominantly carried out with the approval of the parents and in the conviction that they were in the best interests of the affected child or indeed of the family. In a

114 See Daaboul/Frader 2001.

society for which unequivocal sex designation is constitutive and which has little tolerance of ambiguous gender roles, it is an obvious course to take advantage of the medical possibilities of facilitating the social integration of those concerned by providing them with a sexual identity presumed to be unambiguous. This was the background to what are now seen as often unnecessary, mutilating operations that gave rise to suffering, carried out on the authority of parents and doctors as sanctioned by law at the time. These operations were performed under the impression that a child's sex and gender could be moulded without inflicting harm.[115] This view has now proved to be wrong. However, although the physicians who carried out such operations in the past did not break the law, this does not mean that the suffering inflicted should not on that account be recognized.[116]

It has gradually come to be accepted that such interventions frequently did not have the desired consequences and often resulted in psychosocial and health-related tragedies, but this realization has also in some cases been deliberately ignored. It became clear only in the course of time that they were in fact not infrequently inconsistent with the welfare of the children concerned. A decisive contribution to the growing understanding of these problems was made by the affected individuals and their support groups themselves. At first, a number of committed patients drew public attention to the problems of the medical treatment of DSD, thus condemning the secrecy surrounding these issues, and thereafter the calls for complete information to be given on the symptoms and for sex-organ surgery without a medical indication to be deferred at least until adolescence became ever more vociferous. These calls were crucial in paving the way for the growing awareness that traditional practice no longer coincided with

115 See Money/Hampson/Hampson 1955.

116 Possible practical embodiments of such recognition are discussed in Section 8.3.8.1.

modern psychosocial conceptions and ethico-legal standards and that the aims and criteria of the medical approach to DSD had to change. In consequence, doctors nowadays no longer consider the priority to be alignment with a given sex – that is, "normalization" at any price. This notion is instead being replaced by an interdisciplinary approach to treatment that takes account not only of present-day psychosocial and medical conceptions, but also, and in particular, of the subjective experience of those affected, with particular emphasis on the principles of self-determination, care, and the avoidance of suffering and harm.

These changes are not taking place in isolation, but must be seen in the context of macrosocial trends. In the last few decades, not only have the images of masculinity and femininity changed dramatically; gender roles, which previously tended to be static, have also become more flexible. Besides heterosexual marriage, which was for a long time seen as the norm that permitted of no exceptions, same-sex couple relationships have achieved legal recognition with the acceptance of homosexuality. Last but not least, the paternalistic medical conception that was fixated on anatomical normalization and assumed that patients were ignorant of medical issues and therefore in need of guidance has gradually given way to a psychosocially informed approach focusing on the notion of informed and self-determining subjects with the right to be involved in medical decisions and to make interventions concerning their own bodies conditional on their consent.

7.3 Diagnosis and treatment of DSD: ethical guidelines and principles

As a reaction to the critique of the medical approach to DSD, in the first decade of the twenty-first century a number of international professional societies have drawn up and issued

new guidelines on the treatment of children with DSD.[117] In these guidelines, intersexuality is as a rule seen as a subcategory of DSD. The Chicago Consensus Statement[118] can be regarded as a milestone in this connection. It abandons the old paradigm of "optimum sex designation", and surgical sex ambiguity correction and sex assignment are recommended only after exact diagnosis and subject to certain restrictions. For example, clitoridectomy is advocated only with effect from a given size deviation, vaginal dilatation not before puberty, and plastic surgery such as vaginoplasty and penoplasty only in adulthood. Prepubertal gonadectomies are recommended in cases of gonadal dysgenesis, as well as in the various forms of androgen insensitivity.

Criticism of the Chicago Consensus Statement has led to further changes in the medical treatment of DSD and intersexuality. It is emphasized that measures not based on satisfactory scientific evidence and those with possible irreversible consequences for sexual identity or adverse effects on sexuality and fertility require "a compelling medical indication".[119] This demonstrates an increasing reluctance to undertake surgery on the sex organs, even though the concept of a compelling medical indication still leaves considerable scope for flexible interpretation. Some authors therefore go a step further. For instance, some paediatricians,[120] in the context of a "full consent policy",[121] were already calling some years ago for a moratorium on all medical interventions that were not vital to life until those concerned were competent to decide for themselves

117 See, for example, the Consensus Statement for the Management of Intersex Disorders compiled jointly by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology (see Lee et al. 2006; Hughes et al. 2006). The Consensus Statement now seems to have gained international acceptance as a clinical guideline and to be implemented in practice (see Pasterski/Prentice/Hughes 2010).

118 See Hughes et al. 2006.

119 *Arbeitsgruppe Ethik im Netzwerk Intersexualität* 2008, 245.

120 See Kipnis/Diamond 1998.

121 In this case, this means the deferral of surgery pending competence to consent.

or pending the accrual of valid evidence on the success of these measures.[122]

Yet until 2009 there were no published ethical guidelines or principles constituting a comprehensive foundation for, and ethical guide to, the relevant treatment decisions.[123] The principal challenge in the formulation of ethical principles in this field is that certain decisions on treatment must be taken when the individuals concerned are very young children and are not yet capable of deciding for themselves, so that the parents are necessarily responsible for their welfare and also wish to take responsibility for it.[124]

The initial basis for the formulation of sound, practical ethical principles must be as accurate as possible a knowledge of the context of the problem and of the relevant action. This must include distinguishing between forms of DSD in which unambiguous sex designation is possible and other forms. A distinction must accordingly be drawn between interventions for the purpose of sex ambiguity correction and those for sex assignment, because the conditions for and consequences of such interventions are fundamentally different. Whereas ambiguity correction interventions, for example, correct a biochemical/hormonal dysfunction that is potentially harmful to health and bring the individual's biochemical and anatomical sex into line with that individual's genetic sex, in the case of sex assignment treatments parents and doctors are interfering much more profoundly with the child's personality, because they are deciding, in the case of uncertainty, to which sex the child is to belong. However, this distinction does not necessarily legitimize any form of intervention without detailed consideration of the individual case concerned.

A further need is for an evidence-based, systematic procedure for establishing such principles and criteria and for the

122 See Kipnis/Diamond.
123 See Wiesemann et al. 2010.
124 Decisions on treatment include decisions not only for but also against one or more surgical and/or hormonal interventions.

identification of realistic treatment objectives. Certain ethical principles are nowadays deemed fundamental to the entire field of medicine. Chief among these are the principles of self-determination, care, and the avoidance of suffering and harm, all of which are in the service of the supreme medical objective of promoting the patient's welfare. It will then often be possible only to minimize suffering, but not to eliminate it completely. In addition, rules should be developed for specific fields of action in response to the particular requirements and problem situations applying in those cases. With regard to the approach to DSD and the relevant decisions, it is therefore necessary to ascertain the applicable particularities and the guidelines that must be formulated in order to address them. From today's perspective, it is essential for the affected individuals themselves or, as the case may be, those representing their interests to be involved in this process.

First of all, however, the question arises as to the practical significance of the principles of care and of the avoidance or minimization of suffering and harm in the context of DSD. As a first approximation, these principles underlie the requirement to abstain from unnecessary interventions, or at least those which are not required at a particular time, where these interventions are potentially harmful to bodily and psychological integrity. Equally, however, they require the timely conduct of necessary interventions whereby an unequivocal risk to the child's health can be avoided. From the medical point of view, therefore, it is essential to determine first of all whether an intervention is intended merely to correct the appearance of the genitalia or whether it is medically necessary. The latter may be the case, for example, with gonads lacking the capacity for maturation or rudimentary gonads with a high probability of malignant degeneration.

The principle of care may in certain circumstances take precedence over that of physical integrity. To ensure healthy development of bodily functions and the avoidance of irreversible malformations or dysfunctions, hyperfunctions or

deficiencies in the steroid hormone balance of children with DSD must also be treated or compensated for. Another aspect of care is the requirement to preserve potential fertility and sexual sensation. From the perspective of the avoidance of harm, this means that erotogenic organs must not be removed, except in an emergency and subject to an unequivocal medical indication. It will admittedly not always be easy to decide, now or in the future, what should be done in order to avoid not only physical but also psychological damage to children. At any rate, the principle of care, considered together with that of the avoidance of suffering and harm, affords an important guide to the handling of DSD.

A second important principle is self-determination and the consequent requirement of informed consent to any physical intervention. In the case of people competent to decide, it is beyond question that they can always decide for themselves unless their decision-making capacity is restricted by other circumstances. In many cases, however, decisions on treatment must be taken shortly after birth or in infancy. Newborns or very young children, being unable to understand the nature and implications of a possible intervention, can also not give valid consent. For this reason, some critics demand complete abstention from surgery in childhood except in the case of a vital (i.e. life-threatening) medical indication.

An associated problem, however, is that certain treatments must be carried out very early on or even immediately after birth, since that is when the optimum surgical result can be achieved. This is the case, for example, with operations intended to facilitate correct functioning of the urogenital system. Reductions of an excessively large clitoris, too, are generally viewed favourably by girls with CAH who have had this treatment if it was carried out early on. Yet even if children or adolescents are already capable of understanding and their consent has been duly obtained, it is by no means certain that problems will not arise. The interests of the perhaps still small child or of the adolescent may perfectly well differ from those

of the adult-to-be. Future adults who rejected surgery in early adolescence might well subsequently wish that they had consented to the operation at that time. It is only as an adult that an affected individual will be truly in a position to decide what would have been in the interests of the child that the person once was. But this cannot be the sole reason to abstain from such interventions.

Where children have not yet reached the age of majority or lack decision-making capacity, parents in such a situation will normally have an interest in deciding on their behalf, and will also possess the emotionally, socially and historically justified right to do so. Yet the arbitrary exercise of this right, or its exercise based only on the parents' own interests, is not acceptable. For example, it is inappropriate for parents who wanted to have, say, a boy to take this wish as the sole basis for decision if the child's sex is unclear and for them to disregard the medical situation, the possibility of waiting until the individual child can decide, or the emerging preferences of the child or adolescent. It is admittedly not always a simple matter for parents to rear a child of unclear sex, since societal notions of *male* and *female* and of what is considered normal or necessary for these sexes and their upbringing constitute important parental guides to the raising of children. Although an approach based on gender stereotypes is less evident today, children and adolescents being allowed more freedom to develop their own personality and sexual identity, a child of ambiguous sex nevertheless represents an appreciable challenge to many parents and families in a society in which the binary sex system is still axiomatic. It is therefore correct for parental circumstances and possibilities to be taken appropriately into account in arriving at a decision. The meaning of the word "appropriately" in this context can be determined only by careful interdisciplinary analysis of each individual case.

The priority in the decision must always be the welfare of the affected child. This means that the conditions for healthy physical and mental development must be satisfied.

In addition, it is essential to ensure that the child's self-determination is not impermissibly constrained by early, possibly irreversible interventions that may not be medically essential. For this reason, possible future options for action should as far as possible be kept open so that the eventual decision can be taken by the individual concerned. This should be seen in the context of the child's right to an open future without unnecessary deprivation or restriction of the possibility of subsequent decisions and life options. Hence any planned intervention affecting a child's bodily integrity must therefore be preceded by critical consideration of whether the intervention is really in the service of the child's welfare. Of course, although the child's welfare in the current situation can in most cases be determined relatively reliably, this is not the case with the adult-to-be's eventual wishes and preferences. As a rule, of all those involved, it is most likely to be the parents who can appreciate what is beneficial to the child's welfare and what constitutes a good decision in the child's situation. Nevertheless, the concentration on the child's welfare, while setting limits to compliance with parental interests and wishes especially in relation to irreversible surgical interventions, does not mean *a priori* that they cannot be taken into account. Their consideration follows from the particular closeness of parents to their children and their responsibility for them, as well as from the associated right of care, which may in certain cases call for the striking of a difficult balance with the child's right to an open future.

The above considerations on the principal ethical principles involved in the treatment of DSD offer only a limited picture of the complex ethical debate in which various groups both in Germany and abroad have been vigorously engaged for some years. One of the first bodies systematically to address the drafting of ethical criteria for decision-making in this field was the Göttingen research group "Bioethik und Intersexualität" (Bioethics and Intersexuality) of the German research network "DSD/Intersexualität" (DSD/intersexuality), which is

assisted by the Federal Ministry of Education and Research.[125] The guiding principle in the composition of this working group, and hence an aspect of an approach based on ethical motivations and criteria, was that not only clinicians from a variety of disciplines, ethicists, psychologists and sociologists, but in particular also representatives of support groups should take part in the drafting and formulation of principles on a basis of equality. The working group identified three fundamental ethical principles to guide decision-making and action in this field:

1. The welfare of the child and adult-to-be must be facilitated.
2. Children and adolescents have the right to participate in decisions that affect them now or will affect them in the future.
3. The family and the parent–child relationship must be respected.

The group also drew up nine recommendations for addressing intersexuality and other forms of DSD, to facilitate the procedural embodiment and implementation of the above ethical principles in clinical practice. The overall objective of the principles is to modify the paradigm of "optimal gender policy"[126], which was formulated in the 1960s with the emphasis on the appearance and functionality of the genitals. The aim is to arrive at a form of practice directed towards *optimizing the child's emotional and social development*, while at the same time seeking to reinforce the participation of the child and adult-to-be in the decision process and to promote the parent–child relationship.[127]

Somewhat more differentiated criteria were proposed, also in 2010, by a working group at the Royal Children's Hospital

125 See Wiesemann et al. 2010.
126 A therapy programme for intersexuality devised in the 1960s with the focus on the appearance of the genitals and their reproductive capacity.
127 See Wiesemann et al. 2010, 675.

in Melbourne, Australia.[128] According to the authors, they initially apply only to infants and young children who cannot yet understand their situation and are not yet competent to decide.[129] These criteria too were established by a systematic process, based on an analysis of individual clinical cases and their consideration in terms of morality theory. The following six criteria were formulated on this basis:

1. Minimizing physical risk to the child
2. Minimizing psychosocial risk to the child
3. Preserving potential for fertility
4. Preserving or promoting capacity to have satisfying sexual relations
5. Leaving options open for the future
6. Respecting the parents' wishes and beliefs

The authors state that these principles permit systematic access to responsible decision-making in the often complex medical field of intersexuality/DSD. On the one hand, they embrace accepted standards of practice as drawn up, for example, jointly by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology as long ago as in 2006.[130] On the other hand, they are general enough to be applied to each individual case; they are neither specific to any particular disorder or symptoms nor tied to the state of the art and techniques in medicine or other disciplines concerned (psychology, sociology, etc.). They facilitate the identification of realistic treatment goals precisely for the cases in which, in particular, suffering can and should be reduced but physical and psychological restrictions cannot be avoided.

128 The corresponding principles had already been accepted in 2009 by the 5th World Congress on Family Law and Children's Rights (Halifax, Nova Scotia, Canada) as a part of the Halifax Resolution; they can be accessed online at http://www.lawrights.asn.au/previous-congress/5th-world-congress/76.html [2012-02-07].

129 See Gillam/Hewitt/Warne 2010.

130 See Lee et al. 2006; Hughes et al. 2006; Pasterski/Prentice/Hughes 2010.

Furthermore, they constitute flexible guides to action rather than fixed rules, but are sufficiently specific to allow the setting of priorities in the decision-making process.[131]

To sum up, the ethical principles discussed above provide a framework for the comprehensive consideration of factors relevant to decision-making in these cases, regardless of whether the decision is taken in a clinical setting or with the involvement of ethics committees. Although originating in different contexts and using different methods, they do not contradict each other, but are productively complementary.

These principles must also be taken into account in the formulation of legally binding guidelines and laws.

131 See Gillam/Hewitt/Warne 2010, 417.

8 INTERSEXED PEOPLE AND THE LAW

8.1 Historical outline

8.1.1 Sex and the law

Attitudes to intersexuality have been ambivalent since antiquity. On the one hand, hermaphrodites were seen in Greek mythology as possessing divine features, because they embodied characteristics of the gods Hermes and Aphrodite in a single figure. On the other hand, they were often regarded as unnatural manifestations[132] and killed[133]. An attitude of this kind was opposed by Greek philosophers who took the view that hermaphrodites were not "freaks", but merely not classifiable unequivocally as men or women.[134]

It was not until the end of the eighteenth century that the *Preussisches Allgemeines Landrecht* (PrALR – Prussian General Land Law) implicitly stipulated that human beings with a human "form and configuration" were entitled to family and citizens' rights (Section 17 I 1 PrALR).[135] No such provision was contained in the *Bürgerliches Gesetzbuch* (BGB – Civil Code), which entered into force on 1 January 1900.

However, the incorporation of intersexed people into the binary sex structure accepted by society always presented problems. In the Digests of 533, Ulpian considered that hermaphrodites should be equated with their preponderant sex.[136] In canon law (parts of which remained in force until 1918), hermaphrodites could choose their sex on reaching marriageable

132 See Wacke 1989, 877 f. with further references.
133 See Kolbe 2010, 74; Wacke 1989, 877 ff.; Groneberg 2008, 109 with further references.
134 See Wacke 1989, 879; Kolbe 2010, 74 f.
135 Section 17, First Part, Title 1, General Law Code for the Prussian States of 5 February 1794: "Births without human form and configuration have no entitlement to family and citizens' rights."
136 See Kolbe 2010, 75; see also Wacke 1989, 879.

or oath-taking age; until then the father provisionally enjoyed a substitutive right of decision.[137] However, this applied only to hermaphrodites whose sex was ambiguous, but not if a preponderant sex was identifiable. This was justified on the grounds that others could also not choose their sex.[138]

Various legal codes in the German-speaking lands also contained explicit provisions concerning individuals born with ambiguous sexual characteristics. Under the Bavarian Codex of 1756, they were designated as belonging to the sex that predominated "according to the counsel and opinion of persons of wisdom" (that is, of physicians), or were required to choose their sex themselves (if the physicians were unable to decide); they could not change their minds later.[139] According to the Prussian General Land Law of 1794, the parents initially had the right to choose (Section 19 I 1). However, having reached the age of 18, those concerned could change their sex (Section 20 I 1); this was considered necessary because the parents might be mistaken owing to the ambiguity. The age of 18 was presumably chosen on the basis of the age at which men could marry, as the maturational process of puberty was then at an end.[140] If third-party rights depended on the sex of a presumed hermaphrodite, however, the decision was made by an expert,[141] even if it was contrary to the choice made by the hermaphrodite or the hermaphrodite's parents (Sections 22 and 23 I 1).[142] Lastly, according to the Saxon Civil Code of 1865, hermaphrodites were "counted as belonging" to the preponderant sex (Section 46 sentence 2).[143]

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137 See Bräcklein 2008, 298; see also Wacke 1989, 888.
138 See Kolbe 2010, 77.
139 First Part, 3rd chapter, Section 2, sentence 3, half-sentence 1 of the *Codex Maximilianeus Bavarius Civilis* of 1756. For more details, see Lang 2006, 134; Kolbe 2010, 79; Wacke 1989, 883.
140 See Wacke 1989, 888.
141 The expert was involved only if the determination was required by the third party. For more details see Kolbe 2010, 80; see also Wacke 1989, 888.
142 If a predominant sex could not be identified, the choice made by the hermaphrodite or the hermaphrodite's parents remained valid. See Kolbe 2010, 80.
143 For more details, see Wacke 1989, 883; Kolbe 2010, 81.

Over the course of time, differing levels of significance were thus attached to the self-determination of the affected individual. However, individuals eventually had to be assigned to one of the two sexes.[144] A "hermaphroditic" sex in addition to *male* and *female* was not recognized.[145] Where physicians were entrusted with the assignment, they always did so on the basis of the child's external appearance – that is, in accordance with the preponderant external sexual characteristics, even though this was extremely problematic in the case of hermaphrodites.[146] Hence, on the one hand, physicians around 1800 tended to categorize hermaphrodites as female on the grounds that the male features were spurious, while, on the other, according to jurists of the *usus modernus*, the child ought to be baptized with a male forename on the principle of *in dubio pro masculo*, in order to preserve male feudal rights and rights of inheritance.[147]

For fear of undiscovered homosexuality, only a once-for-all choice was permitted and was intended to be binding on an intersexed individual.[148] For instance, any departure from one's designated sex[149] was treated in Bavaria along similar lines to forgery and accordingly punished severely.[150] In the draft of a *Corpus Juris Fridericiani* of 1749/1751, which was never completed but took effect in certain parts of Prussia, hermaphrodites and/or people of ambiguous sex likewise had a right to choose. However, as in the Bavarian Codex, departure from the original choice was punishable.[151] Although the Prussian General Land Law also indirectly prohibited departure from the

144 See Lang 2006, 134; Kolbe 2010, 87.
145 See Wacke 1989, 872; Kolbe 2010, 80, 87.
146 See Wacke 1989, 879, 902; Kolbe 2010, 86 f.; see also Groneberg 2008, 109.
147 See Wacke 1989, 887; see also Kolbe 2010, 77 with further references.
148 See Lang 2006, 134; see also Kolbe 2010, 79; Wacke 1989, 883, 886.
149 If, for instance, the male sex had originally been chosen but the person later lived as a woman in order, for example, to marry a man.
150 First Part, 3rd chapter Section 2 sentence 3 half-sentence 2 of the Bavarian Codex. See Wacke 1989, 885; Kolbe 2010, 79.
151 I 1.4 Section 3 of the *Corpus Juris Fridericianum* draft; for more details, see Kolbe 2010, 78 with further references.

chosen sex (pursuant to Section 21 I 1[152]), violations no longer gave rise to prosecution, or were at least no longer punished.[153]

With the introduction by the state of civil status and civil registers at the end of the nineteenth century, designation as belonging to a given sex became even more important. The right to choose that had previously existed in some jurisdictions was now transformed into a right of assignment by others.[154] The *Gesetz über die Beurkundung des Personenstandes und die Eheschlie?ung* (Act on the Documentation of Civil Status and Marriage) of 6 February 1875 already provided that a child's sex had to be recorded in the register of births.[155] If the sex could not be determined directly owing to anomalies, physicians were required to establish the child's "true sex".[156] However, the true sex could not always be identified immediately and unequivocally owing to deficient medical knowledge and possibilities. The Act itself did not include any instructions on how sex was to be established.[157] Nor was sex defined by the *Personenstandsgesetz* (PStG – Act on Civil Status). However, provision was made only for registration as male or female in accordance with the binary system[158] – the concept of a hermaphrodite was and is foreign to the law of civil status.[159]

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152 "[The person's] rights shall be appraised in future in accordance with this choice": this was construed as meaning that only a once-for-all choice was possible and that the person's rights would thereafter be based on it.

153 See Wacke 1989, 888.

154 See Kolbe 2010, 47.

155 See RGBl. 1875, No. 4, 23 ff.

156 See Wacke 1989, 866; Koch 1986, 172 f.

157 It was not until the application of the *Dienstanweisung für die Standesbeamten und ihre Aufsichtsbehörden* (Service Instructions for Registrars and their Supervisory Authorities) as amended in 1971, which remained in force until 2010 and was then superseded by the *Allgemeine Verwaltungsvorschrift zum Personenstandsgesetz* (PStG-VwV – General Administrative Instructions Applicable to the Act on Civil Status) that registrars were required to ask for the production, if possible, of a certificate by the doctor or midwife present at the birth (Section 259(1)). The registrar was at any rate required to obtain such a certificate in the event of doubt as to the child's sex; the entry was then based on it (Section 266(5)). Under these provisions, sex continued to be determined in accordance with the rule of preponderance.

158 See Hepting/Gaaz 2000, Section 62 PStG para. 18a, Section 21 PStG para. 71; Wacke 1989, 870 citing *Motive* BGB (Civil Code explanatory notes) I 26.

159 See Kolbe 2010, 81.

According to the relevant case law and the literature too, registration as a hermaphrodite was and is not possible, as this concept is unknown in German law.[160]

In other countries, on the other hand, a number of cultures permit designation in an additional sex category to *male* and *female* – for instance, the *hijras* in India, the *travestis* in Brazil, the *tobelija* in Kosovo, the *berdache* in north America and the *banci* (or *waria*) in Indonesia.[161] However, many of those concerned are men wishing to live as women or vice versa. This is not the case with the *guevedoces* ("penis at age 12") in the Dominican Republic and the *kwolu-aatmwol* in New Guinea. These are terms used to denote the sex of intersex people – namely, girls who experience virilization at puberty (*guevedoche*) and boys with a hermaphroditic sexual identity (*kwolu-aatmwol*).[162]

Until the twenty-first century, the predominant sex was also important for the choice of a child's forename, which was required to indicate a child's sex. This requirement was derived from the moral law and its implied limits.[163] By virtue of its function of permitting identification of the individual, the forename had to allow unequivocal recognition of the child's sex.[164] For this reason, sex-neutral names could not be registered by themselves.[165] This requirement was abolished by the *Bundesverfassungsgericht* (BVerfG – Federal Constitutional Court in 2008 because it lacked a statutory foundation and considerations of child welfare did not necessitate a restriction of this kind on the parental right of determination.[166]

160 See *Deutscher Bundestag* 2001a, 14; KG Berlin, JW 1931, 1495; Hepting/Gaaz 2000, Section 21 PStG para. 71; Kolbe 2010, 91; Lang 2006, 132 f.
161 See Kolbe 2010, 49 ff.
162 See Kolbe 2010, 58.
163 See BGH, NJW 1979, 2469; LG Braunschweig, NJWE-FER 2001, 72; Wendt 2010.
164 See Wendt 2010, 13; LG Berlin, StAZ 1999, 373.
165 See LG Berlin, StAZ 1998, 208; OLG Frankfurt on the Main, FamRZ 1999, 46 L.
166 See BVerfG, NJW 2009, 663 (664).

8.1.2 Rights of intersexed people

Under Roman law, intersexed people could not enter into any commitments, as they were not regarded as entire men. For this reason, they could not act as witnesses to transactions or wills.[167] Inheritance was also called into question.[168] A hermaphrodite could act as a witness to a transaction or the making of a will only if the male sex predominated, this being determined partly on the basis of the hermaphrodite's gender role as declared and presented.[169]

German legal history reveals a similar situation to that prevailing in the Roman Empire. However, hardly any legal records exist prior to the Middle Ages. Thereafter, sex-related provisions existed concerning, in particular, the law of inheritance, family law, marriageability and the right to marry. For instance, under the *Reichsnotariatsordnung* (Reich Notarial Code) of 1512, which invoked the Digests, hermaphrodites could not witness a will because, like women, they were unable to inherit and to bequeath.[170]

Furthermore, under canon law, which, as is still the case today, allowed marriage only between partners of different sexes, a woman could enter into a union only with a predominantly male hermaphrodite and vice versa.[171] Marriage was allowed on the basis of an oath by the hermaphrodite as to which sex the hermaphrodite was more drawn to. However, to obviate deception of the prospective spouse, an *inspectio corporis* (medical examination) was usually required.[172] Authorities disagreed on whether a hermaphrodite who had married and for this purpose chosen a specific sex could subsequently depart from

167 See Wacke 1989, 883; the same applied to the Talmud and the Tosefta – see Kolbe 2010, 73.
168 See Kolbe 2010, 75, who points out that these restrictions manifestly no longer applied in the late classical period.
169 See Wacke 1989, 880 f.
170 See Kolbe 2010, 76 f.; see also Wacke 1989, 883.
171 See Kolbe 2010, 77.
172 See Wacke 1989, 884 f. with further references; Kolbe 2010, 79.

it if the hermaphrodite's spouse had died.[173] Although a change of sex was considered disgraceful, a marriage in the new sex was nevertheless deemed valid.[174] Apart from possible "annoyances in the Republic", eighteenth-century jurists considered impediments to be now virtually non-existent.[175]

In other cultures, on the other hand, rights are sometimes determined on the basis of the choice of sex, so that an *Igbo* girl in Nigeria living in the role of a boy can also inherit and possess land. Similar provisions exist in Kosovo, where women assume the masculine role in the home and sometimes take on a male sexual identity.[176] The *kwolu-aatmwol* in New Guinea, too, often choose a masculine role in order to enjoy the privileges of the male sex.[177]

With the entry into force of the Civil Code, all provisions on intersexed people disappeared from the German legal system. The existence of hermaphrodites was denied in the explanatory notes to the Civil Code; instead, they were described as sexually malformed women and men.[178] Nor was a definition of sex included in statute law, since it was taken for granted that there were only men and women.[179] Where the determination of sex was impossible in a particular case because the characteristics of one sex did not predominate, the draft Civil Code provided that provisions based on sex were not applicable.[180] The final version of the statute did not in fact include any provisions on intersexuality.

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173 See Kolbe 2010, 77.
174 See Wacke 1989, 886.
175 See Wacke 1989, 886 citing *Zedlers Lexikon* (Vol. 12, 1735, col. 1725).
176 See Kolbe 2010, 53 f.
177 See Kolbe 2010, 58.
178 The relevant passage reads: "According to the current state of medical knowledge, it may be assumed that neither sexless persons nor persons who unite both sexes in themselves exist, and that every 'hermaphrodite' is either a sexually malformed man or a sexually malformed woman" (*Motive* BGB I 26).
179 See Kolbe 2010, 83; Lang 2006, 133; Wacke 1989, 870; see also Spickhoff 2011, Section 1 TSG para. 2.
180 *Motive* BGB I 26. However, the legal consequences arising, according to the circumstances, out of the state of uncertainty or impossibility of proof were nevertheless supposed to ensue (see Wacke 1989, 870).

8.2 Relevant issues in the law of civil status

8.2.1 Fundamental considerations

Intersexed people do not feature in German statute law. For practical legal purposes, every individual is categorized as belonging to either the *female* or the *male* sex. This also applies if unambiguous designation as *female* or *male* is not possible owing to the bodily constitution of the affected individual and that individual's parents are also unable to effect a designation. Sex has been registered by the state since the introduction of the civil register in 1876. Under Sections 18 ff. PStG, the parents (taking priority over other persons who were present at the birth) or, in the case of births at a clinic, the institution responsible for the clinic, are/is required to notify the birth of a child to the registry office within one week. In the absence of notification, the registry office may impose a recurrent penalty (Section 69(1) PStG).

In addition to the names of the child and parents and the date and time of birth, "the sex" of the child must also be notified (Section 21(1) No. 3 PStG). Sex is thus an attribute that belongs to a person's civil status and serves to identify him/her.[181] Although the wording of the Act on Civil Status does not explicitly define sex as *female* or *male*, normal practice, directives as to implementation[182] and current legal doctrine[183] require a child's sex to be registered as either *male* or *female*, since "sex" is deemed to include only the categories of "woman" and "man". A small number of authorities consider that the Act on Civil Status can be interpreted as permitting the

181 See Kolbe 2010, 89; Plett 2003, 26.

182 See PStG-VwV of 29 March 2010, which took effect on 1 August 2010: "The child's sex shall be entered as 'female' or 'male'" (No. 21.4.3).

183 See Pfeiffer/Strickert 1961, Section 21 PStG para. 18; Hepting/Gaaz 2000, Section 21 PStG para. 71; Gaaz/Bornhofen 2010, Section 21 PStG para. 28; see also *Deutscher Bundestag* 2001a, 14; *Deutscher Bundestag* 2007b, 2; *Deutscher Bundestag* 2009, 4.

recording of a third sex or of the child's sex as "hermaphrodite" or "intersex".[184] This possibility does not exist for practical legal purposes.

There is no provision for non-registration of a child's sex or for leaving it permanently open, unlike the situation in, for example, Belgium, where the sex can be registered as indeterminate.[185] However, if the institution responsible for the clinic reports that a child's sex cannot be determined for the time being because it is deemed ambiguous, registry offices have discretion, according to the view of some authorities, to disregard the period laid down in Section 18 PStG and temporarily to leave the child's sex open pending clarification, subject to a declaration to that effect by the parents.[186] Since the amendment of the Act on Civil Status in 2009, Section 59(2) PStG provides that the sex need not be recorded in the birth certificate issued to the affected individual or the individual's parents in the event of a request to that effect.

Since the relevant legal provisions do not define the terms *female* and *male*, these must be determined on a medical/scientific basis.[187] In the event of doubt upon the birth of a child, a certificate must be obtained from the doctor or midwife,[188] and will then determine the registered sex.[189] Legal designation as belonging to a given sex is always based, according to legal doctrine, on the external bodily situation,[190] although a person's sex involves not only the external appearance but also other both biological and psychosocial aspects.[191] In cases of doubt, designation should be based on the predominant bodily

184 See Spranger 2011; Plett 2011.
185 See Kolbe 2010, 92; see also Basedow/Scherpe 2004, 20 f.
186 See Rothärmel 2006, 284.
187 See *Deutscher Bundestag* 1996, 3.
188 See Section 266(5) of the Service Instructions for Registry Offices; although these were superseded in 2010 by the PStG-VwV, according to Gaaz/Bornhofen 2010, Section 21 PStG para. 28, the midwife must still, in cases of doubt, decide which sex is ultimately to apply.
189 See Hepting/Gaaz 2000, Section 21 PStG para. 71.
190 See Kolbe 2010, 89 ff. with further references; Koch 1986, 173.
191 See also Section 3.1.

characteristics.[192] If no sex is predominant, then according to legal doctrine, and indeed also to the original explanatory notes to the Civil Code, the provisions which presuppose a given sex cannot be applied.[193] However, since the law of civil status requires designation, it is unclear what is supposed to be registered in these cases. Although the *Landgericht* (LG – Regional Court) of Munich, in a decision involving an application for entry as a hermaphrodite in the register of births, left open the question whether registration as a hermaphrodite was necessarily impermissible, it rejected this possibility in the specific case if only because the applicant was not a true hermaphrodite with both male and female gonads.[194] The Court likewise rejected the alternative application for entry as "intersex" or "intrasexual" on the grounds that these terms did not denote a given sex but were generic terms for various disorders of sex differentiation. Registration as a hermaphrodite is rejected in the legal literature because it is not a concept recognized in law.[195]

Under Section 4(1) No. 6 of the *Passgesetz* (PassG – Passport Act), the holder's sex must be stated in a passport. This Act too does not include any further details of the entries that may be recorded. In pursuance of Section 4(1) sentence 3 PassG, the entry is determined by the population register, while, according to sentence 4 and Section 4.1.6 of the Administrative Instructions, "a passport shall on request be issued stating the sex other than that registered at birth" where the person's forename has been changed in accordance with Section 1 of the *Transsexuellengesetz* (TSG – Transsexuals Act). Unlike the situation in Australia and India,[196] this suggests that there are only two possibilities – namely *male* and *female*. Furthermore, according to Section 6(2a) sentence 2 PassG, the entry of a name differing from the sex registered at birth has no legal

192 See Spickhoff, in: Spickhoff 2011, Section 1 TSG para. 2.
193 See Kolbe 2010, 91.
194 See LG Munich, FamRZ 2004, 269.
195 See Hepting/Gaaz 2000, Section 21 PStG para. 71; Kolbe 2010, 9.
196 See Kolbe 2010, 110.

effect. The holder's sex is not specified in the domestic identity card. Most authorities consider that this is because Germany requires the use of sex-specific forenames,[197] or did so require until the decision of the Federal Constitutional Court of 2008 (see Section 8.1.1 above).

The legal sex entered in the register of births can be changed only in pursuance of Section 47(2) PStG and under the Transsexuals Act. Section 47(2) PStG provides that an entry of birth must be corrected if a child's sex proves to have been wrongly determined.[198] If the designated sex of an intersexed individual changes or if the individual's intersex status emerges only at a later date, a correction can be applied for, but only within the binary categories of *female/male*. For this purpose, evidence must be produced that the entry was incorrect from the beginning.[199] The entry is assumed to be incorrect only if a preponderance of sexual characteristics of the other sex – i.e. the non-designated or non-registered sex – can be established.[200] If the preponderance of the sex other than that registered emerges only at a later date, the entry is deemed to have become incorrect and may then, by application of the legal principle underlying Section 47 PStG, be corrected.[201] Applications for amendment of the registered sex must be capable of being supported on the basis of bodily characteristics. Contrary to the situation of a sex change under the Transsexuals Act, psychological processes are not deemed sufficient.[202] Once corrected, the entry can no longer be amended. The Act assumes that the mistake has been corrected by the once-for-all amendment.[203]

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197 See Kolbe 2010, 93 with further references.
198 On the following, see Kolbe 2010, 94 ff.
199 Since 1 January 2009 (Section 47 of the amended version), the correction can also be made by the registrar after the views of those concerned have been heard.
200 See Kolbe 2010, 95 with further references; Augstein 1982, 241.
201 See LG Hamburg, StAZ 1958,128; Kolbe 2010, 95 f.
202 According to BVerfG, NJW 2011, 909, the Transsexuals Act is unconstitutional in so far as sex assignment surgery is made a precondition for amendment of a person's registered sex and in so far as the possibility of contracting a marriage or civil partnership depends on the registered sex.
203 See Kolbe 2010, 96 with further references.

Under the *Gesetz über die Änderung von Familiennamen und Vornamen* (NamÄndG – Act on Changes of Surnames and First Names), a forename can be changed, according to Section 3(1) – which in pursuance of Section 11 applies *mutatis mutandis* to forenames – only for important reasons, which, however, should include wrongly determined sex. According to No. 28 of the *Allgemeine Verwaltungsvorschrift zum Gesetz über die Änderung von Familiennamen und Vornamen* (NamÄndVwV – General Administrative Instructions Applicable to the Act on Changes of Surnames and First Names), which, in pursuance of No. 62, applies mutatis mutandis to forenames, an important reason is deemed to exist if an interest of the applicant that merits protection predominates. In the view of the *Oberlandesgericht* (OLG – Higher Regional Court) of Cologne, the giving of a name to a child, which is in itself constitutive, is legally void where a child was erroneously given a forename incompatible with that child's sex, and also does not become legally effective by virtue of the entry in the register of births.[204] The forename can at any rate be changed by order of the court in pursuance of Section 48 PStG.[205]

The fundamental amendment of the Act on Civil Status in 2009 took no account of the interests of intersexed people. It merely permitted a birth certificate to be issued without the person's sex being registered.

In the law of marriage, family law and the *Lebenspartnerschaftsgesetz* (LPartG – Civil Partnership Act), too, issues of status and legal consequences are determined by the categories of *female/male*. According to settled case law and legal doctrine, marriage can be entered into only by persons of different sexes (within the binary categories of *female/male*), although this is not evident from the wording of Article 6 of the *Grundgesetz* (GG – Basic Law). The Basic Law is considered to regard marriage as a particular form of human cohabitation which

204 See OLG Cologne, NJW 1961, 1023.
205 See BayObLG, FamRZ 1995, 685.

"presupposes the union of a man and a woman in a life partnership entered into on a long-term basis".[206] A registered civil partnership, on the other hand, is open only to persons of the same sex. However, same-sex marriages and opposite-sex civil partnerships can even now come into being retrospectively, because the Federal Constitutional Court has declared the provision of the Transsexuals Act which requires divorce as a condition for a change in the legal sex of a married person to be unconstitutional.[207] The same must then apply to people living in a registered civil partnership.

8.2.2 Appraisal of the current legal situation in terms of constitutional law

8.2.2.1 Interference with the general right of personality

The general right of personality pursuant to Article 2(1) in conjunction with Article 1(1) GG guarantees protection of the intimate personal sphere of life and the preservation of its fundamental conditions, which cannot be conclusively embraced by the traditional guarantees of freedom. This relates to modes of behaviour that exhibit a particular connection with human dignity as protected in Article 1(1) GG and therefore call for stronger protection than all other modes of behaviour as protected by Article 2(1).[208] According to the Federal Constitutional Court, the general right of personality assures every individual of an autonomous area for the conduct of that individual's private life for the development and preservation of that individual's individuality.[209] It is the right of all individuals to live their lives on a self-determined basis and by their own lights, and to act and be treated in accordance with the identity

206 See BVerfGE 105, 313 (345); also in NJW 2002, 2543 (2547 f.).
207 See BVerfGE 121, 175.
208 See Dreier 2004, Art. 2 GG para. 50 with further references; Kolbe 2010, 99.
209 See BVerfGE 79, 256 (268); Jarass, in: Jarass/Pieroth 2011, Art. 2 I GG para. 41; Kolbe 2010, 99.

that best corresponds to their subjective feeling. This includes self-determination in relation to the attributes that particularly concern a person's psychological, cultural and social identity, and hence also a person's sexual orientation and identity as a man or woman.[210] The general right of personality includes the right to live a life in conformity with one's own sexual identity as subjectively experienced.[211]

Sexual identity is expressed legally in the sex recorded in the register of births. From this perspective, the provisions of the law of civil status fall within the field of protection of the general right of personality. This was already the view taken by the Federal Constitutional Court in its first decision on transsexuals, which paved the way for the Transsexuals Act. The general right of personality requires that people's civil status be aligned with the sex to which they belong in accordance with their psychological and physical constitution.[212] In its latest decision on the Transsexuals Act, the Federal Constitutional Court ruled that the general right of personality included the right to align a person's civil status with that person's subjective sexual identity. It accordingly declared the statutory provision in the Transsexuals Act which requires, as one of the conditions for a change of sex for the purposes of the law of civil status, persons to have undergone surgery to modify their external sexual characteristics to be incompatible with the right to sexual self-determination under Article 2(1) in conjunction with Article 1(1) GG and with the right to physical integrity under Article 2(2) sentence 1 GG, and therefore repealed this provision as unconstitutional.[213]

The above provisions of the Basic Law also protect intersexed people who cannot designate themselves as either female or male owing to their subjective sexual or gender identity. The enforced designation as female or male and the corresponding

210 See BVerfGE 115, 1 (14 ff.); 116, 243 (262 f.); Kolbe 2010, 99.
211 See Kolbe 2010, 98 f. for a more detailed account.
212 See BVerfGE 49, 286 (298).
213 See BVerfG, NJW 2011, 909.

entry in the civil register thus constitutes an interference with the general right of personality, because it is not possible for intersexed individuals who cannot align themselves with the binary system to be legally classified in accordance with their physical and psychological constitution.[214] The interference is substantial. The problems ensuing from the interference with the fundamental right are experienced not only once or temporarily, but permanently, with repercussions on the entire life of the person concerned, influencing and impeding the conduct of the person's life in many respects, such as, for example, the choice of forename, rearing, clothing, marriage and partnership. Such an interference is permissible only where necessary for the protection of a common good which is of at least equal value to the substantial interference with the right of personality of the intersexed individual and which justifies its restriction. The purposes adduced for possible justification of the registration of only two sexes and the current provisions and practice of the law of civil status are as follows: more accurate identifiability of the person; statistical surveys for state planning; compliance with international standards;[215] recognizability of citizens' rights and obligations such as compulsory military service; identification of sex for entry into a marriage or civil partnership; security and/or regulatory interests;[216] and equality of opportunity in sport.

On the other hand, it is pointed out that the purposes of compulsory registration of sex as *male* or *female* in the civil register (more accurate identifiability, recognizability of rights and obligations, or statistics) can also be achieved in other ways.[217] Equality of opportunity in sport too can be ensured by mechanisms other than a provision of the law of civil status.

214 See Kolbe 2010, 101.

215 However, some other states have different standards and provide in their passport legislation for additional designations – e.g. Australia (*male, female, X*) and India (*male, female, others*); see Kolbe 2010, 110.

216 See Rothärmel 2006, 274 f.; Kolbe 2010, 107; Dethloff 2011.

217 See Kolbe 2010, 109, 111 ff., 116; Adamietz 2011; Plett 2011; Dethloff 2011.

Given the problem of whether societal interests that merit protection are sufficiently important to justify the substantial interference with the general right of personality experienced by intersexed people as a result of the current compulsory binary designation system in the law of civil status, it is appropriate to seek further possibilities of registration in addition to *male* and *female* or indeed alternatives to any registration at all.

8.2.2.2 Interference with rights of equality, Article 3(3) GG

The non-recognition of a specific sex category for intersexed people is also regarded in legal doctrine as discrimination on the grounds of sex as addressed by Article 3(3) GG.[218] Particular arguments in favour of this view are the openness of the definition of sex and dynamic, as opposed to static, interpretation of the constitution.[219] Some, however, also call for the inclusion of the attribute of sexual identity in Article 3(3) GG.[220] Intersexed people who cannot designate themselves as belonging to either the female or the male sex are at any rate disadvantaged, as compared with men and women, in so far as there is no provision for them to register in accordance with their sex.[221] If it is deemed impermissible to include intersexed people too in the term "sex" in Article 3(3) GG,[222] the unequal treatment of intersexed people at any rate constitutes an infringement of the general principle of equality pursuant to Article 3(1) because in this case something unequal (persons who do not experience themselves as *female* or *male*) is treated as equal (as *male* and *female*). It cannot be concluded from the formulation of Article 3(2) sentence 1 ("Men and women shall have equal rights") and from the precept that the state shall promote

218 See Jarass, in: Jarass/Pieroth 2011, Art. 3 III GG para. 122; Adamietz 2011; Kolbe 2010, 121 f.; Kolbe 2011; Plett 2011; see also Vöneky/Wilms 2011.
219 See Spranger 2011.
220 See Lembke 2011.
221 See Adamietz 2011; Kolbe 2010, 134; Kolbe 2011; Dethloff 2011; Plett 2011.
222 This appears to be the prevailing opinion; see Kolbe 2010, 120 with further references.

equality (Article 3(2) sentence 2) that for the purposes of constitutional law only these two sexes may exist.

8.2.3 The General Equal Treatment Act

Section 1 of the *Allgemeines Gleichbehandlungsgesetz* (AGG – General Equal Treatment Act) lays down the objective of preventing or eliminating disadvantages on the grounds of race or ethnic origin, sex, religion or philosophy of life, a disability, age or sexual identity.

The aim of the General Equal Treatment Act is protection from discrimination in the world of work and certain other civil-law fields. The prohibitions on discrimination are particular manifestations of the precept of equality that follows from Article 3 GG.

No one disputes that the General Equal Treatment Act is also applicable to intersexed people and that its formulation can embrace both a third sex and sexlessness;[223] the only question is which attribute in the Act protects intersexed people. Possible attributes are sex and sexual identity. Contrary to the prevailing view on Article 3(3) sentence 1 GG, most authorities now consider that intersexed people are protected by the attribute of sex.[224] Contrary to the assumption in the explanatory memorandum to the General Equal Treatment Act,[225] intersexed people, according to this view, are not covered by the attribute of sexual identity.[226] This is because the attribute of sexual identity, also contained as such in the

223 See Vöneky/Wilms 2011; Lembke 2011; Kolbe 2011; Plett 2011; Spranger 2011.
224 See Thüsing, in: Säcker/Rixecker 2012, Section 1 AGG para. 58; Schlachter, in: Müller-Glöge/Preis/Schmidt 2012, Section 1 AGG para. 6; Kolbe 2010, 121 f. with further references; Tolmein 2011; Plett 2011; Remus 2011.
225 See *Deutscher Bundestag* 2006, 31; with regard to the reform of the Works Constitution Act (BetrVG), see *Deutscher Bundestag* 2001b, 45; see also Thüsing, in: Säcker/Rixecker 2012, Section 1 AGG para. 89; Kolbe 2011; Plett 2011; Remus 2011.
226 A different view is taken by Bauer/Göpfert/Krieger 2008, Section 1 AGG para. 49.

Betriebsverfassungsgesetz (BetrVG – Works Constitution Act) (Section 75), derives from European Directive 2000/78/EC, which is intended to subsume only sexual orientation therein. Here, sexual orientation merely denotes preference in the choice of a sexual partner in terms of "heterosexual, homosexual and bisexual".[227] The explanatory memorandum also conflicts with recent decisions on transsexuals by the European Court of Justice (ECJ) to the effect that the disadvantaging of transsexuals constitutes disadvantaging on the grounds of sex.[228] This means that gender identity must be distinguished from sexual identity (or orientation). Gender identity denotes the sense of being male, female or hermaphroditic.[229] For this reason, intersexed people are protected from discrimination by the attribute of sex.

The protection from discrimination afforded by the General Equal Treatment Act relates primarily to the occupational field (Section 6 AGG), social and health protection (Section 2(1) No. 5 AGG), private-sector contracts of insurance and civil-law obligational relationships in mass retail financial services (Section 19(1) AGG).[230] Family law, on the other hand, is not covered by the Act. Since social insurance is also involved and intersexed people frequently have problems with health insurance, the General Equal Treatment Act may possibly be infringed in this respect too.[231]

Protection from discrimination in relation to health services concerns not only the public healthcare institutions but also all private healthcare institutions. All contracts for medical

227 See Thüsing, in: Säcker/Rixecker 2012, Section 1 AGG para. 89; for a more detailed consideration, see Krüger 2006, 260 f.; Richardi, in: Richardi 2010, Section 75 BetrVG para. 31.

228 See Thüsing, in: Säcker/Rixecker 2012, Section 1 AGG para. 89 citing ECR 1996, I-2143 – *P v S and Cornwall County Council*; for a different view in US law, see *Holloway v Arthur Anderson & Co.*, 566 F. 2d 659 (9th Cir. 1977); the House of Lords agrees with the ECJ: *A. v Chief Constable of West Yorkshire* [2004] UKHL 21.

229 See Thüsing, in: Säcker/Rixecker 2012, Section 1 AGG para. 89.

230 Hence a critical view is taken by Tolmein 2011; Lembke 2011; Remus 2011; Spranger 2011.

231 See *Intersexuelle Menschen* 2011, 15, 48.

attention and treatment are therefore covered by the prohibition on disadvantaging.[232] The treatments concerned need not necessarily be "essential to survival" in the sense of basic medical care; instead, they also include physiotherapy or psychotherapy, convalescence at health resorts, acupuncture, "beauty operations", etc.[233] Hence intersexed people must be treated in accordance with the same rules and to the same extent as any other patient.

However, the protection from discrimination can take effect only if the potential discriminating party – e.g. an employer – is aware of the other, or changed, sexual identity. The discriminating party thus enjoys a "right to be mistaken". In certain circumstances, the discriminating party cannot then be blamed for, say, not providing a changing room conforming to the sexual identity of the person concerned.[234]

8.2.4 Consideration in terms of international law

In terms of international law, German law is influenced in particular by the European Convention on Human Rights (ECHR); an extensive body of case law shows that the Convention constitutes directly applicable law.[235] Other instruments of particular importance are the Charter of Fundamental Rights of the European Union and the UN Convention on the Rights of the Child. In addition, the International Covenant on Civil and Political Rights (ICCPR) is relevant.

8.2.4.1 European Convention on Human Rights

According to the case law of the European Court of Human Rights (ECtHR), in protecting private life Article 8(1) ECHR,

232 See *Deutscher Bundestag* 2006, 32; Schlachter, in: Müller-Glöge/Preis/Schmidt 2012, Section 2 AGG para. 13; Bauer/Göpfert/Krieger 2008, Section 2 AGG para. 37.
233 See Thüsing, in: Säcker/Rixecker 2012, Section 2 AGG para. 31.
234 See Bauer/Göpfert/Krieger 2008, Section 1 AGG para. 51.
235 See Vöneky/Wilms 2011.

like Article 7 of the Charter of Fundamental Rights, also protects the right to identity and development of the person.[236] This includes all individuals' identification with their own sex. Every individual is assured of the right to be treated in accordance with that individual's subjective sexual identity.[237] Some consider that, for the purposes of the freedom of sex/gender, it is necessary for abstention from designation as belonging to one of the two sexes to be possible and for a sexual identity once chosen not to be unmodifiable because it is usually determined other than by the person concerned.[238] Since the choice of sexual identity belongs to the inner area of private life and hence embraces behaviour within the intimate sphere, it is held in the literature that a positive obligation to recognize the third sex exists notwithstanding the flexibility accorded to contracting states.[239]

In addition, the state has a positive obligation to protect physical integrity. The duty of protection may be infringed if a person's health is harmed in a public or private clinic and the state has not done everything necessary for the protection of patients. It must enact the required legal provisions and ensure that compliance with them is monitored. It must furthermore be possible to hold those responsible for errors in treatment to account in both the civil and criminal law.[240]

Article 12 ECHR guarantees men and women the right to enter into a marriage. Notwithstanding the neutral formulation, states are not obliged by Article 12 ECHR to make marriage possible for same-sex couples.[241] Again, the European Convention on Human Rights here allows only for the two conventional sexes and therefore does not guarantee intersexed people access to the married status.

236 See Meyer-Ladewig 2011, Art. 8 ECHR para. 7.
237 See Meyer-Ladewig 2011, Art. 8 ECHR para. 7; see also ECtHR, NJW 2004, 2505 (2506); Vöneky/Wilms 2011.
238 See Büchler/Cottier 2005, 125 f.
239 See Vöneky/Wilms 2011; see also Remus 2011.
240 See Meyer-Ladewig 2011, Art. 8 ECHR para. 13.
241 See Meyer-Ladewig 2011, Art. 12 ECHR para. 3.

Article 14 ECHR provides as follows: "The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status." The scope of the protection from discrimination provided for in Article 14 ECHR is not conclusively specified. The attribute of sex has the aim of securing equal rights for men and women.[242] A possible generic attribute is discrimination on the grounds of an "other status", which could also include sexual identity and sexual orientation. Hence Article 14 ECHR is more far-reaching than Article 3(3) GG, although the legal appreciation of both is nevertheless presumably comparable.[243]

8.2.4.2 Charter of Fundamental Rights of the European Union

Article 21 of the Charter of Fundamental Rights contains a ban on discrimination corresponding to Article 14 ECHR, so that the above remarks again apply.

8.2.4.3 UN Convention on the Rights of the Child

The UN Convention on the Rights of the Child does not include any explicit provisions on sex. However, together with identity Article 8 also protects a child's position as a legal personality with rights of status – in particular, the right to self-determination of sexual identity.[244] Article 3 places the focus of all measures affecting children on the "best interests of the child".[245] The obligation to register birth enshrined in Article 7 does not include any reference to sex. This point is therefore left to the States Parties.[246] Article 24(3) obliges States Parties to

242 See Meyer-Ladewig 2011, Art. 14 ECHR para. 16 f.
243 See Spranger 2011.
244 See Vöneky/Wilms 2011; Remus 2011.
245 See Lembke 2011.
246 See Vöneky/Wilms 2011; see also Spranger 2011.

take all effective and appropriate measures to abolish traditional practices prejudicial to the health of children. A few authors consider that these include the requirement to register a sex, as this may in certain circumstances be the occasion for sex-correcting surgery.[247] Like Article 14 ECHR, the prohibition of discrimination in Article 2 affords protection from discrimination on the grounds of a child's sex or other status. Article 12 ultimately provides a child with the opportunity to be heard in judicial or administrative proceedings and hence with as large as possible a degree of involvement in decision-making processes.[248] Some authorities consider that this requirement of protection of the personality is not satisfied if only the parents decide on sex assignment measures.[249]

8.2.4.4 International Covenant on Civil and Political Rights

Like the Basic Law, Article 17(1) of the International Covenant on Civil and Political Rights (ICCPR) provides for a right to free development of the personality. This also includes protection of private life and hence of individual identity. It is assumed in the literature that compulsory application of the binary sex structure conflicts with Article 17 ICCPR.[250] However, the Covenant too requires equality for men and women only (Article 3). Article 24(2) requires the registration of birth, but not that of a sex.

8.2.5 Possible conclusions

The legal experts consulted by the German Ethics Council on the legal issues raised by intersexuality unanimously state in their opinions that the compulsory categorization of intersexed people as belonging to either the *female* or *male* sex

247 For instance, Lembke 2011.
248 See Spranger 2011.
249 See Rothärmel/Wolfslast/Fegert 1999, 296.
250 See Vöneky/Wilms 2011.

constitutes a grave interference with those persons' right to self-determination and right of personality; however, with regard to the practical consequences, different solutions are proposed – namely, provision for non-registration of sex;[251] voluntary registration of sex;[252] provision for registration of a third sex or for freedom of choice of designation;[253] or leaving the registration of sex open or provisional registration of sex until the attainment of adulthood.[254] Representative organizations all call for the incorporation of the concept of intersexuality into law.[255]

8.2.5.1 The third sex

In the opinion of many experts, the right of self-determination inherent in the general right of personality and the prohibition of discrimination protect individual sexual identity, which is seen as the right to be treated in accordance with a person's subjective gender. The dichotomous classification as *male* and *female* is held to conflict with fundamental and human rights[256] and the non-recognition of a specific sex category for intersexed people is regarded as discrimination on the grounds of sex as addressed in Article 3(3) GG.[257] The rights of those affected can be adequately allowed for, and protection from discrimination rendered more effective, only by the recognition of a third sex.[258] This, it is felt, will very probably lead to greater societal acceptance, permit more comprehensive mechanisms of protection and result in those affected no

251 See Adamietz 2011; Kolbe 2010, 192 ff.; Remus 2011; Plett 2011; Vöneky/Wilms 2011; Lembke 2011.
252 A blank field allowing free choice of designation (see Tolmein 2011; Kolbe 2011).
253 See Dethloff 2011; Plett 2011; Spranger 2011; Tolmein 2011.
254 See Kolbe 2011; Rothärmel 2011. However, the last two of these variants do not solve the problem of impermissible interference with the right of personality if designation within one of the binary categories *female/male* is then compulsory upon the attainment of adulthood at the latest.
255 See *Intersexuelle Menschen* 2011, 39; *Intersexuelle Menschen* 2008, 19.
256 See Adamietz 2011; Dethloff 2011; Spranger 2011; Tolmein 2011.
257 See Jarass, in: Jarass/Pieroth 2011, Art. 3 III GG para. 122; Kolbe 2011.
258 See Spranger 2011.

longer being regarded as ill.[259] For treatment purposes, patients' sex as registered in their medical records is held to be of appreciable importance, so that appropriate treatment would be more likely if registration of a third sex were possible.[260]

The absence of a fixed definition of sex and the dynamic nature of interpretation of the constitution are already held to argue in favour of the recognition of a third sex under current law. The Act on Civil Status need not even be amended; an appropriately broad interpretation would suffice.[261] At least the law governing registration should allow for the fact that intersexuality is not an unknown phenomenon in German law.[262] In other fields – in particular, in family law – only drafting amendments would be necessary.[263]

Nor is it considered that international law argues against the recognition of a third sex – on the contrary, it is held to favour such recognition. For instance, the European Convention on Human Rights and the associated case law of the European Court of Human Rights, as well as the UN Convention on the Rights of the Child, can be interpreted in the sense of recognition rather than non-recognition of a specific individual sex.[264] Again, these instruments prohibit any discrimination on the grounds of sex but do not define the term "sex" in detail, so that a third sex is not precluded. The attribute of identity in Article 8 of the UN Convention on the Rights of the Child can also include the child's individual sexual identity;[265] in addition, the existence of a broadly construed gender-related freedom can be deduced from Article 8 ECHR, although its exact form would be a matter for the contracting states.[266]

259 See Kolbe 2011; Remus 2011.
260 See *Intersexuelle Menschen* 2011, 25.
261 However, PStG-VwV 21.4.3 presents a problem; see Lembke 2011.
262 See Spranger 2011; see also Krüger 2006.
263 See Remus 2011.
264 See Plett 2011.
265 See Spranger 2011.
266 See Vöneky/Wilms 2011.

Overall, many legal experts do not consider there to be any societal interests deserving of protection – including regulatory interests – that might justify the exclusive recognition of the categories of *male* and *female* as registrable sexes.[267] In ethico-legal terms, too, some authors consider there to be no reason not to recognize a third sex, as lifestyles are in any case changing.[268] A stable society and its legal order would not be confused by a third sex.[269]

Other authors, on the other hand, take the view that a third sex does not conform to the current status of the natural sciences and is also foreign to German law as currently in force.[270] In particular, marriage and civil partnership are held to be open to men and women only, so that persons of a third sex cannot enter into a comparable commitment.[271] Another consideration adduced is uncertainty as to the criteria on which designation in a third sex should depend; this uncertainty could entail a large number of difficulties of definition and demarcation and hence result in legal uncertainty.[272] A further issue is the correct description of those designated as belonging to a third sex, as well as the criteria for designation. It is considered essential for the description to be acceptable to as large as possible a number of affected individuals.[273] Owing to the multiplicity of forms assumed by intersexuality, a third sex can only be a catch-all category, a reservoir for people who do not conform to the binary sex norm. However, since some people feel neither male nor female and also do not consider themselves to be living in a third sex, the designation of a third sex cannot take account of the needs of all those concerned,

267 See Adamietz 2011; Remus 2011; Dethloff 2011; Lembke 2011; Kolbe 2010, 116.
268 See Lembke 2011.
269 See Rothärmel 2011.
270 See LG Munich, NJW-RR 2003, 1590 (1591); Spranger 2011.
271 See Dethloff 2011.
272 See LG Munich, NJW-RR 2003, 1590 (1591); Matt 2011; Remus 2011.
273 "Indeterminate" or "no information" (Dethloff 2011); "neither/nor" (Plett 2011); "both/and" or "hermaphrodite" (Rothärmel 2011); "intersex" (Spranger 2011; Matt 2011).

so that the problem would only be shifted elsewhere.[274] There would still be a categorization, and with it also the possibility of discrimination.[275] Again, new categories might contribute to the consolidation of old categories, so that the recognition of a third sex might lead not to acceptance by society but might even – and more probably – result in more extensive exclusion and stigmatization.[276] Some therefore consider the introduction of a third sex for this reason to be at most a transitional or stopgap solution,[277] while some indeed completely reject it.[278] A suggested compromise is provision for designation as belonging to both sexes or even to neither.[279]

According to an even more far-reaching view, everyone should be able to make an individual choice of what to register;[280] this would mean that registration of one's sexual identity ought not to be restricted to just two or three possibilities. Of course, it may then be objected that the registration of a freely chosen sex designation would be devoid of legal significance because no preconditions of any kind could be stipulated in law, so that no legally certain consequences could be associated with specific preconditions either.

8.2.5.2 Abolition of sex registration

Several experts consider it preferable to dispense completely with a legal obligation to register a sex.[281] It is pointed out in particular that registration of a given sex and the distinguishing of different sexes no longer play a particularly important part in German law, especially as military service has been suspended

274 See Vöneky/Wilms 2011; Remus 2011; Adamietz 2011.
275 See Kolbe 2011; Tolmein 2011; Matt 2011; Vöneky/Wilms 2011.
276 See Matt 2011; Remus 2011; Lembke 2011; information and education are at any rate necessary according to Dethloff 2011.
277 See Adamietz 2011; Kolbe 2011; see also Remus 2011.
278 See AG Munich, StAZ 2002, 44; LG Munich, FamRZ 2004, 269 ff.; Vöneky/Wilms 2011.
279 See Adamietz 2011.
280 See Tolmein 2011.
281 See Adamietz 2011; Remus 2011; Plett 2011.

and other determinants apply in competitive sport.[282] Identification of a person and protection from discrimination do not present problems even without the registration of sex.[283] Sex is still considered to be most significant in family law, in particular in terms of the law of filiation and of contracting a marriage or civil partnership. It is indeed the case that the law of filiation is based on the existence of a female and a male sex. The mother is the woman who gave birth to the child. The father can only be a man. On the basis of these considerations, it is proposed that the terms "mother" and "father" be replaced by "person". In addition, the concept of "parenthood" could be used on a general basis.[284] The law of filiation can in any case already make distinctions relevant to the birth and upbringing of a child on the basis of biological and social contributions.[285] Social parenthood too, would become more significant in law by virtue of the acceptance of responsibility.[286] From the perspective of preventing discrimination, non-designation as belonging to a sex or non-recording in a register are held to be likewise necessary. Other aspects of prohibitions of discrimination too are not based on the binary system or dependent on entry in a register – for instance, the ban on discrimination on the grounds of ethnic origin or religious persuasion.[287] Again, if registration of sex were not required, this could relieve the pressure on parents and medical practitioners in relation to early sex assignment surgery.[288] Nor is registration of sex necessary for appropriate medical treatment, as patients can be treated on the basis of their individual bodily constitution – for instance, the presence of specific organs and any associated pathological findings.[289]

282 See Lembke 2011; Krüger 2006, 262; Tolmein 2011.
283 See Kolbe 2011.
284 See Remus 2011; Dethloff 2011; Lembke 2011.
285 See Adamietz 2011.
286 See Lembke 2011.
287 See Adamietz 2011; Remus 2011.
288 See Lembke 2011.
289 See Adamietz 2011.

Others, however, question the idea of completely dispensing with the registration of a sex owing to the constitutional requirement of equality for men and women. After all, it is considered that the aspirations to equality demanded by Article 3(2) require the possibility of designation at least in the female sex.[290] The neutrality of the law associated with the abolition of categories might in certain circumstances no longer afford protection from discrimination.[291] According to this position, any kind of planning in all fields of services of public interest necessarily presupposes recording of the sex of newborn babies.[292] On the other hand, others specifically reject this consideration because the services of public interest hitherto based on the binary system can perfectly well be replaced by sex-neutral provision. A proposed compromise is therefore that of voluntary registration.[293] The change to voluntary registration would avoid the imposition of freedom-curtailing compulsion on intersexed people, while not depriving women of the option of designation as female with the associated legal privileges pursuant to Article 3(2) GG.[294] Instruments involving advantages for women (e.g. the *Bundesgleichstellungsgesetz* [Act Providing for Equality in the Federal Administration]) or providing for equality for the severely disabled would need to be amended by statute so that they also applied to intersexed people.

8.2.5.3 Deferral of registration of sex

With regard to minors, it is suggested that the registration of sex be left open at least until adulthood,[295] or that their sex be registered as indeterminate or registered provisionally, in which case the barriers to amendment must not be set too high.[296]

290 See Lembke 2011;Vöneky/Wilms 2011.
291 See Lembke 2011; Rothärmel 2011.
292 See Rothärmel 2011.
293 See Vöneky/Wilms 2011.
294 See Vöneky/Wilms 2011.
295 For example, *Intersexuelle Menschen* 2008, 19.
296 See Kolbe 2011; Adamietz 2011; Lembke 2011; Spranger 2011; Vöneky/Wilms 2011.

This is justified on the grounds that Article 2(1) in conjunction with Article 1(1) GG, in protecting the intimate personal sphere of life, also protects the intimate area of sex, which includes sexual self-determination and hence also the discovery and recognition of one's sexual identity.[297] Hence the conclusion that no individual must be forced into a role that does not conform to that individual's identity and self-experience.

8.3 Legal framework of medical interventions in minors with DSD

8.3.1 Introduction

Children whose sex is regarded as ambiguous by parents and doctors at birth or later are often subjected to medical sex ambiguity correction or more drastic sex assignment measures such as surgery and hormone treatments.[298] These have the aim of rendering a recognized sex less ambiguous or of achieving conformity with the choice of a sex. Owing to widespread criticism, particularly by intersexed people themselves, and to scientific and empirical research on acceptance and late sequelae, such interventions are currently the subject of changing attitudes in the field of medicine.

For a long time, jurisprudence virtually ignored the problems of sex assignment and sex ambiguity correction interventions. In the last few years, however, a considerable body of legal literature dealing comprehensively and in detail with these issues has arisen,[299] and the German *Bundestag* too has

297 See Spranger 2011; Kolbe 2011; Remus 2011; Plett 2011; Vöneky/Wilms 2011; Dethloff 2011; Steiner, in: Spickhoff 2011, Art. 2 GG para. 3.

298 See Section 3 for terminology.

299 See Kolbe 2010; Rothärmel 2006; Krüger 2006; Plett 2005; Plett 2007; forthcoming: Tönsmeyer: "Die Grenzen der elterlichen Sorge bei intersexuell geborenen Kindern de lege lata und de lege ferenda"; Remus: "Strafbarkeit von genitalverändernden Operationen an intersexuellen Minderjährigen".

already considered the fundamental legal issues involved in the medical and legal treatment of intersexed people.[300] To date, only a single case is known in which a German court was required to rule on the legality of a sex correction measure. However, compensation of 100 000 euro for pain and suffering was awarded in this case independently of the aim of the surgery, owing simply to the failure to furnish information on and obtain consent to the operation. The person concerned was already of age at the time of the operation, and instead of female sex organs thought to be atrophied, fully functional organs had been removed from her body and no information had been given to her.[301]

8.3.2 Medical interventions as bodily harm: the requirement of consent

Medical interventions are deemed to constitute the criminal offence or civil tort of bodily harm even if they are medically indicated – and hence therapeutic measures – unless the person concerned has validly consented to them. This follows from the affected individual's right of self-determination, the principal constitutional basis of which is the right to physical integrity (Article 2(2) sentence 1 GG) and the general right of personality (Article 2(1) in conjunction with Article 1(1) GG). Consent is not a legal transaction but a permission that justifies the intervention. As a rule, the treatment contract and consent are separate from each other.

The consent is valid only if the person giving it has decision-making capacity. The person with decision-making capacity must be capable of understanding the nature, significance and scope of the intervention or of the non-conduct of

300 See *Deutscher Bundestag* 2011; see also the 143rd Session of the German *Bundestag* of 24 November 2011.

301 See LG Cologne, ref. 25 O 179/07; OLG Cologne, ref. 5 U 51/08; Kolbe 2010, 149.

an intervention and of appreciating the consequences of the decision;[302] in particular, it must also be possible for the affected individual to apprehend and assess the urgency of the intervention. Competence for consent and hence for decision-making are generally considered to be conditional upon the capacity for judgement and insight.[303] Unlike the capacity to contract, there is no statutory basis for determining when minors, who are at issue here, attain this decision-making capacity. In legal doctrine, a fixed age limit[304] – usually 14 or 16 – is often taken as the rule for minors who have developed normally; below this limit, the presumption should as a rule be that the person lacks the capacity to give consent and hence to decide. Some advocate a reduction to the age corresponding to the capacity to institute proceedings for the assertion of fundamental rights.[305] Others take the completion of puberty as a guide to establishing capacity for consent and decision.[306] Still others base these conditions exclusively on the situation in a specific individual case.[307] It is unanimously agreed that the greater the dangers to life and limb of a minor and the more far-reaching the consequences of the intervention, the more stringent are the requirements in terms of self-determination of the decision and hence the less store should be set by the decision-making capacity of the minor concerned.[308] A minor's capacity for judgement calls for particularly critical examination especially where interventions carry the risk of permanent

302 See BGHZ 29, 33 (36); Dethloff 2011 with further references; Rothärmel 2006, 281; Wölk 2001, 81; Amelung 1995, 8.
303 See Dethloff 2011; Plett 2011.
304 See Lembke 2011; Tönsmeyer 2011; Spranger 2011; Rothärmel 2011; Rothärmel 2006, 281; Laufs, in: Laufs/Kern 2010, Section 62 para. 9; Deutsch/Spickhoff 2008, para. 256.
305 See Spranger 2011; ten years in the case of irreversible interventions according to Vöneky/Wilms 2011; the tenth/twelfth year, with possible consideration from school age on, according to Tolmein 2011; age 8 as in Colombia according to Matt 2011.
306 Permissibility of sex determination could coincide with completion of puberty according to Kolbe 2010, 194.
307 See Tönsmeyer 2011; Kolbe 2011; Plett 2011; Dethloff 2011.
308 Not before age 14 for interventions on the body according to Dethloff 2011.

loss of sexual sensation and loss of fertility. The aim here is the avoidance of over-hasty decisions in order to protect the child from unforeseeable risks.

The veto capacity of a minor who lacks decision-making competence must be distinguished from that competence. In the case of significant interventions, the *Bundesgerichtshof* (BGH – Federal Court of Justice) presumes that the child has a right of veto provided that deferral of the intervention is medically acceptable.[309] The child cannot be accorded a right of veto if failure to carry out the intervention carries the risk of serious harm to the child's health – some confine this risk of harm to *physical* health[310] – or the death of the child. If this is not the case, some experts consider that "account must be taken of" de facto rejection as an expression of the child's wishes, at least provided that the failure to carry out the treatment is unlikely to result in physical harm.[311] Others take the view that a right of veto is unnecessary, in particular because the parents can in any case give consent on behalf of their child and treatment without the agreement of those concerned would be unlawful.[312]

8.3.3 Substitutive consent by the statutory representative

Sex ambiguity correction and sex assignment interventions in minors who lack decision-making capacity require the consent

309 Judgement of the Federal Court of Justice of 10 October 2006, ref. VI ZR 74/05; see also Laufs, in: Laufs/Kern 2010, Section 62 para. 9.

310 According to Vöneky/Wilms 2011, the de facto agreement of the child who lacks competence for consent but has the capacity for insight (from about age 10) must have been obtained where there is a risk of psychological harm.

311 See Plett 2011; see also Amelung 1995, 15; Tolmein 2011. This is already the case from the age of 2½ according to Rothärmel 2011; provided that it is "not compellingly necessary" according to Vöneky/Wilms 2011; while less strict requirements as to the capacity for insight apply in the case of refusal according to Dethloff 2011.

312 See Remus 2011; Plett 2011; Tönsmeyer 2011; Adamietz 2011; as in the Colombian model the potential wishes of the adult-to-be should be the deciding factor according to Matt 2011.

of the parents who have the right to care for them. The parents' right of representation is constitutionally guaranteed. According to Article 6(2) sentence 1 GG, the care and upbringing of children is the natural right of parents and the primary duty incumbent on them. This right comprises care for the child's physical welfare and mental/intellectual development. In terms of non-constitutional statute law, the parental function of representation is based on Sections 1626, 1627 and 1629 BGB, according to which the parents have not only the right but also the duty to care for a child while a minor, as well as the right to represent the child.

However, the right is accorded to parents not for their own sake or as a right of self-determination, but has the character of a service. It is granted for protection of the child and corresponds to the parents' duty to base the care and upbringing of the child on the child's welfare. In this connection, the parents admittedly enjoy a degree of discretion. Yet the parents are not allowed to harm the child's welfare; indeed, in certain cases a strict prohibition of representation applies (e.g. Section 1631c BGB: prohibition of the sterilization of minors). Furthermore, Section 1626 II BGB provides that the parents must take account of the child's growing capacity and need for autonomous and responsible action and must consequently involve the child in important decisions. Some consider that this implies a duty on the part of the parents to give the minor full information.[313] One problem, however, is that Section 1626(2) sentence 2 BGB is specifically applicable only to the parent–child relationship, and hence not to the relationship with the doctor.[314] This provision does not therefore directly give rise to duties incumbent on the doctor.

Although parental care is normally exercised, for the purposes of child welfare, on the basis of parental responsibility

313 See Tolmein 2011; Laufs, in: Laufs/Kern 2010, Section 62 para. 10.
314 See Rothärmel/Wolfslast/Fegert 1999, 296.

and without state involvement,[315] Article 6(2) sentence 2 GG provides for possible state intervention if the limits of parental rights are exceeded and the welfare of the child is impaired. Intervention may also be possible on the basis of the state's duty to protect the child's fundamental rights where these are impermissibly impaired by parental measures. The state has a duty to protect children and minors who cannot yet defend themselves independently from interference with their rights by their parents and doctors. Fundamental rights are admittedly intended primarily to protect the individual from interference by the state; however, threats to fundamental rights may also be presented by third parties. According to the undisputed doctrine concerning the duty of protection developed on the basis of Article 2(2) sentence 1 GG,[316] the state authority therefore also has a duty actively to protect individuals' fundamental rights from interference by third parties; where required for effective protection of fundamental rights, this must be enshrined in statute law. Section 1666(1) BGB provides in very general terms that the Family Court may intervene if a child's mental or physical welfare is at risk. Such intervention is admittedly conditional on the Family Court's learning of an actual threat to the welfare of a specific child, for instance if the parental duty of care is not discharged; for this reason, the procedure is sometimes held to be inadequate.[317]

If minors themselves possess decision-making capacity, their right of self-determination conflicts with the parental right, particularly if their strictly personal objects of legal protection are at issue as in the present case. According to both

315 See *Deutscher Bundestag* 2007c, 6 f.; Section 1627 sentence 1 BGB reads: "The parents shall exercise parental care on their own responsibility and by mutual agreement in the interests of the child's welfare."

316 "The state's duty of protection [...] not only prohibits direct state interference with the developing life, but also requires the state to adopt a protective and facilitating posture towards that life – which means in particular that it must also protect it from unlawful interference by others [...]", BVerfG, NJW 1975, 573 (575).

317 See Kreuzer 2012; Krüger 2008, 59; consent should be subject to review in all cases according to Dethloff 2011.

legal doctrine and case law, a minor with decision-making capacity takes priority in any conflict of competence between the wishes of the parents and those of the person they represent.[318]

The principle that the child's welfare is paramount gives rise to a restriction of the medical measures to which parents may consent on behalf of their child. The decisive factor is the welfare of the child and adult-to-be and not that of the parents or society.[319] Owing to the exclusively serving character of the parental right of care, parents must also not exercise their right of care in order to fulfil personal conceptions and to "shape" the child's body by medical interventions – for example, they must not cause the child to undergo beauty operations.[320] An exception is occasionally made to this rule in the case of uncomplicated, relatively minor aesthetic interventions such as, for instance, the correction of protruding ears or the removal of birthmarks.[321] However, that said, the sole criterion should really be the welfare of the child, although it is perfectly permissible for the parents to have a degree of discretion. Having regard to the foregoing, some consider it sufficient for a risk of psychological problems to exist should malformations not be treated.[322]

As a rule, a measure for which a medical indication exists will be in the interests of the child's welfare. A medical indication exists at least if the aim is to eliminate or prevent functional disorders or significant health impairments. From this point of view, some experts hold that the condition must first be determined to constitute a disorder.[323] Although the pressure

318 See Schönke/Schröder 2006, preliminary note re Sections 32 ff. StGB para. 42.
319 See Matt 2011; see also Arana 2005, 18 (re No. 13); on the necessity of penetrability, see Dietze 2003, 18.
320 See Kolbe 2010, 164; Kolbe 2011; Werlen 2008; see also Lembke 2011; Matt 2011.
321 See Eser/Sternberg-Lieben, in: Schönke/Schröder 2006, Section 223 StGB para. 50b; Kolbe 2011.
322 See Eser/Sternberg-Lieben, in: Schönke/Schröder 2006, Section 223 StGB para. 50b.
323 See Kolbe 2010, 165 ff.; Kolbe 2011; Matt 2011.

of psychological suffering on the child may be deemed to constitute pathology, this cannot be taken for granted in the case of a very young child; the issue is often in fact parental suffering.[324] For example, a gonadectomy is held to be medically indicated in the case of atrophied gonads owing to the increased risk of malignant degeneration,[325] but because the risk cannot be unequivocally appraised, some experts consider such an intervention to be indicated only in the event of actual gonadal pathology.[326] Owing to the uncertainties, some call for a system that distinguishes between manifestations which require treatment and those which do not.[327]

Sex ambiguity correction surgery for alignment of external appearance (e.g. vaginoplasty or operations on the penis and clitoris), sex assignment surgery and hormone treatments are intended to match the body to a given sexual norm. The aim is the achievement of a stable sexual identity and better psychosexual and psychosocial development. The issues here are psychosocial, but in some cases they may concern only the child's social adaptation. A medical indication can at any rate not be assumed to exist where it is merely a matter of the child's social adaptation (unlike the case of an actual risk of psychopathology). Furthermore, recent research shows that such adaptation affords no guarantee of success in the achievement of a stable sexual identity and of undisturbed sexuality.[328] It is also questionable whether children really do suffer psychologically from teasing due to their unusual appearance and, if so, whether they suffer so badly that psychological harm results. These fears seem to be refuted by a small number of reports that portray children as substantially very open-minded.[329] It is

324 See Lembke 2011.
325 See *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010, 5.
326 See Tönsmeyer 2011.
327 See Spranger 2011.
328 See Kolbe 2010, 167; Brinkmann/Schweizer/Richter-Appelt 2007a, 141.
329 See Kolbe 2010, 168; also Dr. Bitta Julia Dombrowe's letter of 27 July 2011 to the German Ethics Council with an example from the Netherlands.

more likely that the parents' handling of their special child's particularity, the strengthening of the child's self-confidence and the nature of the child's upbringing will critically influence the child's psychological situation. There are admittedly no studies on this point. Instead, sex assignment surgery tends to be carried out prophylactically, because it is assumed that in our society a child can grow up happily only as a boy or a girl. Societal norms can of course change, and manifestly are changing in relation to the situation of intersexed people, as the encouraging reports by parents of intersexed children and by intersexed people themselves show[330] and as society's treatment of transsexuals proves. Sex assignment and sex ambiguity correction surgery and hormone treatments are drastic and involve a high degree of interference[331] with what is a very sensitive field for a human being. Gonadectomy results in the elimination of fertility and hormone production, unless the removed gonads were already non-functional in these respects.[332] Fertility is constitutionally protected as a fundamental right (Article 2(1) and (2) GG). Only the person concerned may decide on its termination. The law currently in force already provides that parents cannot consent to the sterilization[333] or castration[334] of their child (Section 1631c sentence 1 BGB). The prevailing view is that parents can validly give consent only in the case of a compelling medical indication not having the aim of eliminating fertility (e.g. if the gonads are

330 See the report by Julia Marie Kriegler at the German Ethics Council's hearing of 8 July 2011, accessible online at http://www.ethikrat.org/veranstaltungen/anhoerungen/intersexualitaet [2012-02-07].

331 On the degree of interference, see the detailed account in Kolbe 2010, 170 ff.

332 Hormone production and the risk of malignant degeneration must be verified on a case-by-case basis prior to an intervention.

333 Sterilization means elimination of the capacity to father or give birth to a child, normally by vasectomy or tubal ligation respectively – see Ulsenheimer, in: Laufs/Kern 2010, Section 126 para. 1; see also Meier, in: Jurgeleit 2010, Section 1905 BGB para. 1.

334 Contrary to its wording, castration may also be covered by Section 1631c BGB; see Kemper, in: Schulze et al. 2012, Section 1905 BGB para. 3; see also Spickhoff, in: Spickhoff 2011, Section 1905 BGB para. 3, 5; Heitmann, in: Kaiser/Schnitzler/Friederici 2010, Section 1905 BGB para. 4 f.; a different view is taken by Bienwald, in: Staudinger 2006, Section 1905 BGB para. 11 f.

actually cancerous),[335] in particular since it is virtually impossible to determine the necessity and the effects because development is not yet at an end.[336] Sexual sensation and the capacity for orgasm are likewise protected as fundamental rights. Genital surgery for alignment of external appearance with the parental and medical sex designation or with the sex determined chromosomally and gonadally often still leads to the loss of these capacities, notwithstanding recent advances in surgical techniques. Such operations in many cases do not have the aim of eliminating functional disturbances. Except in the case of cortisol replacement therapy in CAH, hormone treatments too are not intended to eliminate pathology, but result in far-reaching physical and psychological changes, such as beard growth, mood swings or modification of sexual identity. On the contrary, hormone replacement therapy in fact frequently results in pathology that did not previously exist – e.g. osteoporosis – since there are no suitable medicinal products for children, so that hormone preparations licensed only for adults are used and moreover have to be taken for a prolonged period.[337] In particular, it must also be borne in mind that some people would rather have diseased organs than none at all.[338]

Parental competence to decide on medical measures in a child pursuant to Article 6 may conflict with important rights of the child – in particular, the right to physical integrity (Article 2(2) sentence 1 GG) and the right to sexual self-determination and procreative freedom (Article 2(1) in conjunction with Article 1(1) GG). Consent to such interference with the core area of fundamental rights is in all cases strictly personal and cannot be given on a substitutive basis. Only the person concerned can truly assess the subjective significance of these

335 See Tönsmeyer 2011; Plett 2011; Rothärmel 2011; Dethloff 2011; Kolbe 2010, 165; *Intersexuelle Menschen* 2011, 23.
336 See *Deutscher Bundestag* 1989, 76; Tönsmeyer 2011; Dethloff 2011; see also Kern/Hiersche 1995, 467.
337 See Kolbe 2010, 159, 169, 172; see also *Intersexuelle Menschen* 2011, 28.
338 See BGHSt 11, 111 (113); Rothärmel 2006, 281.

rights and capacities. This means that the decision on a medical treatment, of whatever kind, must always be left to the child or adult-to-be.[339] For this reason, many experts completely reject treatment during childhood, invoking the child's right to an open future;[340] some call for a clarification or expansion of Section 1631c BGB or the incorporation of a new provision to that effect.[341]

Overall, then, strict requirements must be applied to parental competence for consent to irreversible sex assignment interventions. For this purpose, the problems existing without the intervention must be weighed against the eventual consequential problems caused by the intervention. Again, castration/sterilization and the loss of hormone production are acceptable only as a side-effect of an essential medical treatment; only in those circumstances can Section 1631c BGB be presumed not to have been infringed.[342] In the assessment of possible treatment measures for intersexuality, account must be taken of our relative ignorance of the facts and uncertainty as to the medical and psychological repercussions of early sex assignment measures and further intensive treatments. The consequences of uncertainty must not be borne by the child.

8.3.4 Violation of the parental duty of care in the event of rejection of a medically indicated treatment

On the other hand, by virtue of their child welfare obligations, parents are required to consent to medical interventions where these are necessary in the interests of the child. Refusal of a treatment that is unequivocally medically indicated and/or in

339 See Kolbe 2011.
340 See Remus 2011; Matt 2011; *Intersexuelle Menschen* 2008, 55; Holzleithner 2009, 42.
341 See Adamietz 2011; Tolmein 2011; Lembke 2011; Plett 2011; Tönsmeyer 2011.
342 See Tönsmeyer 2011; Rothärmel 2011; Vöneky/Wilms 2011.

the interests of the child's welfare constitutes failure to discharge the parental duty of care. The question of failure to discharge the parental duty of care in the event of refusal of consent to medical treatment of an individual with DSD arises principally for parents of 46,XX girls with CAH.[343] These people are unambiguously female in genetic, chromosomal and gonadal terms and, given medically appropriate treatment, as a rule fertile. Mistakes in sex determination at birth in the CAH syndrome are due to the virilization of the external sexual characteristics then observed. These are due to an enzyme deficiency and a consequent deficiency of the hormone cortisol, which in turn gives rise to overproduction of androgens during the prenatal phase of development and hence to virilization of the external genitalia. The standard medical treatment with cortisone, which is not a sex hormone, stabilizes the girl's female hormone balance, so that further developmental harm is prevented. In the absence of cortisone treatment, further disturbances of development occur, such as stunted growth and contrasexual manifestations at puberty. According to the available information on people with CAH who feel themselves to be intersexed or are living (or wish to live) in a masculine gender role, these individuals were not treated sufficiently early with cortisone in accordance with the accepted medical standard because the syndrome was not recognized or because treatment was refused by the parents, possibly on the grounds that they wanted a boy. There is no currently recorded case of a 46,XX girl with CAH who was cared for and appropriately treated with cortisone at an early stage but nevertheless wanted to switch to the masculine role. Rejection by the parents of cortisone treatment conducted in accordance with the state of the art for stabilization of the female hormone balance would be deemed an infringement of the requirements of child welfare and a failure to discharge the parental duty of care, as well as an interference with the procreative freedom and sexual identity of the CAH subject.

343 On the CAH syndrome, see Section 4.3 a.

Identification of a child's welfare and of possible failure to discharge the parental duty of care is less clear-cut with regard to substitutive consent to surgical alignment of the external sexual characteristics – e.g. clitoral reduction – on behalf of a girl who as yet lacks decision-making capacity. Surgery is at any rate medically indicated and in the interests of the child's welfare if the CAH-related virilization of the external sex organs is associated with malformations that may lead to pathology such as infection of the urinary tract or abdominal cavity, as is often the case with Prader V.[344] If early intervention can avoid iatrogenic traumatization and/or promises a more successful outcome, this argues in favour of such an operation even if there is no risk of impairment of physical health and hence of the child's welfare. If sexual sensation is likely to be lost, this instead suggests that it is preferable to wait until the child attains decision-making competence and can give informed consent. Whether refusal of or consent to an operation to match the external genitalia to the genetic/chromosomal/gonadal sex of a child who as yet lacks decision-making capacity is consistent with the child's welfare can therefore be decided only in the concrete situation of an individual child and that child's family, as well as on the basis of the child's psychosocial situation. In this case at any rate, the presence or absence of a medical indication cannot be deemed to coincide legally with facilitation or abuse respectively of the child's welfare.

46,XY boys/men affected with CAH[345] are not intersexed either anatomically or in terms of appearance. For this reason, the disorder is often recognized only if a salt wastage crisis occurs. The overproduction of androgens is addressed in this case too by the standard treatment with cortisone to avoid disturbances of development.

344 See Section 4.3 a.
345 See Section 4.3 b.

8.3.5 The requirement to furnish information

If patients themselves or those with the right to care for them are to be able to give their consent legally, the person giving consent must first be given the relevant information. If a person lacking decision-making capacity is represented by whoever has the right to care for him/her, the person who cannot yet decide must also receive information on the proposed treatment according to the nature and severity of the treatment and in accordance with the person's age and ability to understand.[346] This is an expression of the minor's right of self-determination and personality, for which substitution is not possible owing to its strictly personal nature.[347] Some recommend the involvement not only of independent doctors but also of intersexed people in furnishing the information.[348] In this way a subsequent shock could be avoided and the child accorded the right to an open future.[349]

The information concerned relates to the diagnosis, the course of the disorder, the proposed treatment, possible alternatives, the risks associated with the treatment and the uncertainty of its outcome.[350] The extent of the duty of information depends substantially on the severity and necessity of the intervention, on the extent to which the procedure conforms to the accepted medical standard and on how accurately the outcome can be predicted. The patient must be informed in so far as this is necessary, reasonable and desired by him/her.[351] Some call in addition for information to be given on the availability

346 See Rothärmel/Wolfslast/Fegert 1999, 297; Rothärmel 2006, 283; *Arbeitsgruppe Ethik im Netzwerk Intersexualität* 2008, 244 f.; Plett 2011; Kolbe 2011; Büchler 2011; Dethloff 2011.

347 See Rothärmel/Wolfslast/Fegert 1999, 296 with further references.

348 See Plett 2011; Vöneky/Wilms 2011.

349 See Matt 2011.

350 See Spranger 2011; Vöneky/Wilms 2011; Krüger 2008, 58; Rothärmel 2006, 279.

351 Therapeutic privilege plays a major part in this consideration; on this point, see Deutsch/Spickhoff 2008, para. 282; Laufs, in: Laufs/Kern 2010, Section 57 para. 3 ff., Section 60 para. 19 f.

of advisory services and the relevant cultural and societal background.[352]

The more severe, risky and controversial an intervention, the more comprehensive the information given must be. The obligation to provide full and candid information is significantly more stringent in the case of purely cosmetic surgery than with operations necessitated by pathology.[353]

In the event of doubt concerning the indication of a medical intervention, or if the diagnosis is unclear or a waiting posture is acceptable, the patient must be fully informed of the situation.[354]

Patients must also be informed if an intervention does not conform to the accepted medical standard or if such a standard does not yet exist.

8.3.6 The accepted medical standard

Both the information to be furnished and the appropriate treatment are critically determined by the medical standard accepted at the time of the intervention. This standard indicates which medical measure conforms to the latest medical and scientific state of the art, having regard to practical experience and professional acceptance.[355] In other words, the accepted medical standard corresponds to what is expected of an experienced, conscientious practitioner specializing in the relevant field. The standard is not static, because both science and practical experience may sometimes be in the throes of rapid change.[356] Here, customary practice is the determining

352 See Dethloff 2011; Werlen 2011; Kolbe 2011.
353 See Deutsch/Spickhoff 2008, para. 289 with further references; Dettmeyer 2006, 47.
354 See BGH, VersR 1992, 747; OLG Cologne, VersR 2000, 361; Deutsch/Spickhoff 2008, para. 269, 292, 298; Laufs, in: Laufs/Kern 2010, Section 64 para. 13.
355 See *Deutsche Gesellschaft für Medizinrecht* 2003; Hart 1998, 9 f.; Katzenmeier 2002, 279; Taupitz 2009, 64 f. with further references.
356 See Dressler 2000, 381; on the variability of the concept of the "status of medical science", see also Ulsenheimer 2004, 607.

factor, unless the relevant basis is the more advanced status of medical science – as attained, for instance, at research centres.[357] Nor can spearhead technologies using the most expensive hardware be demanded immediately and everywhere.[358] Even when a new method or new medical equipment has come into general use, a certain period of grace may be acceptable before it is applied.[359] For this reason, the deciding factor is whether it is still medically acceptable[360] to use an older procedure (e.g. one that carries more risk or has less good prospects of therapeutic success).[361]

If a doctor acted in accordance with the prevailing state of the art at the time of the intervention, he cannot be accused in later proceedings of having failed to take account of more recent advances.[362] However, he must not close his mind to new knowledge, but must undergo continuous professional development and be open to new methods of treatment. This is moreover provided for in the professional codes of the regional medical associations (for instance, Sections 4 and 5 of the Model Professional Code for Medical Practitioners Working in Germany, issued by the Federal Medical Association).

To determine the status of medical knowledge and for treatment quality assurance, the guidelines of the relevant specialist societies are important in medical practice.[363] The currently applicable guideline is that of the *Gesellschaft für Kinderheilkunde und Jugendmedizin* (German Society of Pediatrics and Adolescent Medicine) on disorders of sex development

357 See BGH, NJW 1984, 1810; Gehrlein 2006, para. B4, B11; Taupitz 2011, 358.
358 See BGH, NJW 1992, 754 (755); BGH, NJW 1988, 763 (764).
359 See BGH, NJW 1992, 754 (755); BGH, NJW 1989, 2321 (2322); BGH, NJW 1988, 763 (764); Frahm/Nixdorf/Walter 2009, para. 83; Gehrlein 2006, para. B10 f.
360 By taking "acceptable decisions" as the basis, one of the points made by the Federal Court of Justice is that, in the field of liability for errors in treatment, there is no scope for legal decisions in disputes between different schools of medical opinion (BGH, MedR 1987, 234 [235]). See Laufs/Kern, in: Laufs/Kern 2010, Section 97 para. 7.
361 See Taupitz 2011, 359.
362 See Deutsch/Spickhoff 2008, para. 213; Rothärmel 2011.
363 For a detailed account, see Taupitz 2011, 362 ff.; Rothärmel 2011.

(027/022 of 12 May 2011 [10/2010]).[364] The guidelines are supposed to express the accepted medical standard for a given situation.[365]However, they as a rule concentrate on "normal cases" or "typical cases". The applicable standard in each case is described for these only. Any departure from the normal or typical situation encountered in practice demands consideration of the appropriate response.[366] In other words, the doctor owes the patient not a stereotyped treatment, but diagnosis and therapy consistent with that patient's individual particularities, symptoms, disorder or disorders.[367]

8.3.7 Civil and criminal liability

There is no legal obligation for compensation in the case of sex assignment and sex ambiguity correction interventions provided that doctors have acted in accordance with the state of the medical art prevailing at the time of the intervention, unless the intervention was undertaken without the required informed consent of the person concerned, that person being competent to decide, or, in the event of incapacity to decide, without the informed consent of the parents who have the right of representation. Acts conforming to the accepted standard could be seen as unlawful notwithstanding exonerating national provisions or national practice only if these acts were conspicuously at variance with general notions of justice (as most recently assumed in the penal sanctions imposed on the marksmen who targeted escapees from the German Democratic Republic scaling the Berlin wall). This cannot be held to apply to the medical interventions at issue here if and as long

364 *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften* 2010; this guideline is graded as Development Level 1, which means that its force is not very great. For more details, see Deutsch/Spickhoff 2008, para. 217.
365 See Taupitz 2011, 362 ff.
366 See Taupitz 2011, 376.
367 See Taupitz 2011, 359 with further references.

as the practice, with parental consent, was deemed according to international standards to be the correct treatment in the interests of the child's welfare.[368]

The principle of *in dubio pro reo* applies in criminal proceedings. For this reason, a doctor will be potentially liable to criminal sanctions only if he can be proved to have made an error in treatment or to have failed to obtain the valid consent of the person concerned or of that person's statutory representative; and the consent may be invalid if not preceded by the furnishing of adequate information.

In civil proceedings (for damages and/or compensation for pain and suffering sustained by the patient), the patient must, in order to prevail, prove that the doctor has made an error in treatment; the onus is on the doctor to prove that sufficient information was given, followed by valid consent based on it.[369] In the absence of appropriate documentation, it may be difficult for the doctor to prove in another form that complete information was given and consent forthcoming.[370]

According to the relevant professional codes, treatment documentation must be preserved for only ten years. However, under Section 199(2) BGB, claims in respect of bodily injury may in certain circumstances lapse only after 30 years,[371] so that the documents ought to be preserved at least for this entire period.[372] Having regard to the far-reaching consequences of the treatments here at issue, and considering that these often emerge fully only after some decades, preservation for an even longer time is indicated in order to protect the rights of those affected to knowledge of the medical measures carried out.

Authorities disagree as to whether a doctor may be placed at a disadvantage in terms of the law of evidence if he has not

368 See Vöneky/Wilms 2011.
369 See Deutsch/Spickhoff 2008, para. 328.
370 There is also an obligation under Section 10 I MBO-Ä; on this point, see Schlund, in: Laufs/Kern 2010, Section 55 para. 9 with further references.
371 See Deutsch/Spickhoff 2008, para. 457, 461.
372 See Schlund, in: Laufs/Kern 2010, Section 55 para. 13.

preserved the documents beyond the ten-year period required by the professional code.

The periods before action becomes time-barred in the criminal law are extremely variable; however, a detailed discussion is beyond the scope of this consideration. For the potential criminal acts that might principally be relevant here, the periods concerned, according to Section 78 of the *Strafgesetzbuch* (StGB – Criminal Code), range between five and ten years, but may in certain circumstances be as long as 20 years. Since these operations are usually undertaken on infants, the periods have often expired once the person concerned learns what has happened to him/her. For this reason, the law provides that time-barring is suspended in the case of wrongful treatment of persons entrusted to someone's care (Section 225 StGB) – that is, if a minor or a defenceless individual is crudely mistreated or tormented by the person to whose charge or care that individual is entrusted or to whose household the individual belongs, and in the case of criminal acts against sexual self-determination, until the individual concerned reaches the age of 18, so that the time-barring period runs only from this point (Section 78b StGB) This provision should be extended to embrace all criminal acts whereby a child's (future) fertility and/or sexual sensation has been irreversibly damaged.

Under Section 208 BGB, time-barring of civil-law claims for violation of sexual self-determination is suspended until the obligee has reached the age of 21; from this perspective too, it would be appropriate to extend this provision to all claims in respect of acts whereby (future) fertility and/or sexual sensation have been irreversibly damaged.

8.3.8 Possible conclusions

8.3.8.1 Compensation fund

In the debate on these issues, affected people in particular,[373] as well as some experts,[374] suggest the provision of financial compensation for the consequences of irreversible medical sex assignment or sex ambiguity correction interventions where these no longer correspond to today's accepted medical standard and as a result of which those concerned are subject to constant suffering or whose quality of life is substantially impaired.[375] This would afford at least symbolic compensation especially to those who, on account of what would now be seen as incorrect medical treatment, are afflicted with physical or psychological suffering and often also incur expense that would not have arisen without this treatment. Some of those concerned have been so badly damaged by earlier medical interventions that they are not able to engage in normal gainful employment,[376] or are severely disabled on account of these interventions. It is proposed that the compensation be provided by a state-financed fund or a foundation. The medical profession and clinics cannot be required to finance such a fund, since it cannot as a rule be assumed that unlawful acts were committed in the past, so that the law applicable to the liability of individual physicians does not apply. State funding is regarded as appropriate because the medical measures now deemed to be wrong were tolerated, or not prevented, by the state, were usually carried out in clinics governed by public law and funded by the statutory health insurance funds, while the state did not provide for protective provisions or intervention. Individual claims for damages often also fail because

373 See *Intersexuelle Menschen* 2008, 19; *Intersexuelle Menschen* 2011, 39; *Intersexuelle Menschen*/Humboldt Law Clinic 2011, 30.
374 See Plett 2011; Tolmein 2011; Remus 2011; Lembke 2011; Adamietz 2011.
375 Compensation is also recommended by the UN Committee against Torture 2011.
376 See Remus 2011.

the medical records have been destroyed. It is held that the state is partly responsible for this too, because it failed to lay down appropriate rules for the treatment of medical records. Compensation arrangements are also considered to be necessary in so far as the claims concerned have lapsed and cannot be referred to the courts by those concerned, through no fault of their own, because the state failed to enact protective provisions in this respect too.[377]

Whether a fund of this kind should be established is a question of legal policy. On the one hand, it can be assumed that intersexed people who underwent sex assignment or sex ambiguity correction treatments suffer appreciably from the irreversible consequences and that compensation is appropriate in accordance with general considerations of justice.[378] In other words, they are in a particularly painful situation. On the other hand, the question arises as to why precisely they and not others treated in accordance with a past state of the art that later proved to be wrong should benefit from compensation. Again, how could the state possibly have understood the relevant medical situations better than the medical profession itself? Furthermore, a debate on a compensation fund that was not established owing to lack of financial resources could result in retraumatization. For this reason, some consider that financial compensation is less important than the creation of appropriate social conditions for those concerned and sensitive treatment of their families.[379]

8.3.8.2 Provisions on the limits of parental consent

In their opinions on the extent and limits of parental competence in decisions on medical interventions for the treatment of intersexuality, the legal experts consulted by the German Ethics Council predominantly state that under current

377 See Remus 2011; Adamietz 2011; Lembke 2011.
378 See Spranger 2011.
379 See Rothärmel 2011.

constitutional and family law, consent to medical interventions with effects on a child's sexual self-determination, sexual identity and procreative freedom is necessarily a strictly personal matter, so that substitutive parental consent on behalf of a child born intersexed is possible only if there is no doubt that the intervention is urgently or "vitally" medically indicated in the sense of preventing a risk to life or grave harm to health.[380] In view of the uncertainties in the practical field, a statutory system whereby the limits of parental consent are defined more clearly is seen by most experts as appropriate.[381] The representative organizations make the general demand that irreversible surgical and medicinal interventions should be undertaken only in the case of a threat to life.[382] Others, on the other hand, doubt that a statutory system can at the same time afford legal certainty and allow adequately for the individual particularities of those concerned – particularly because the syndromes of DSD and intersexuality, and hence also the medical measures adopted, are extremely heterogeneous.

8.3.8.3 Involvement of an independent institution

To lend more weight to the child's self-determination relative to parental wishes, the involvement of an independent institution in the decision-making process is contemplated. However, the need for the involvement of such an institution depends also on whether the parents' decision-making competence is limited by statute (e.g. by a prohibition of sex assignment measures before the person concerned attains decision-making capacity) or whether parents retain their relatively wide-ranging decision-making competence.

380 See Lembke 2011; Tönsmeyer 2011; Rothärmel 2011; Plett 2011; Kolbe 2011; Vöneky/Wilms 2011.
381 See Tönsmeyer 2011; Tolmein 2011; Plett 2011; Kolbe 2011.
382 See *Intersexuelle Menschen* 2008, 19; *Intersexuelle Menschen* 2011, 39.

Involvement of an ethics committee

Some advocate the involvement of an ethics committee, by analogy with the procedure applicable to live organ donation. In their view, protection by professional, interdisciplinary oversight is always appropriate where the welfare of the person concerned might be threatened by third-party interests and that person's autonomy is at issue.[383] Since the situation with intersexuality remains extremely unclear, especially with regard to indications, particular interdisciplinary competence is held to be called for precisely in this case, so that the committee should also include people with DSD.[384] Where parents contemplate treatment that may have substantial repercussions on their child's future, the child's wishes and interests should therefore be appropriately allowed for by means of independent consideration by an ethics committee.[385] In this process the interests of the minor concerned could also be protected by a guardian *ad litem*.[386]

However, most reject the involvement of an ethics committee. Its decision too would constitute determination by a third party, whereas the position of the minor alone should be decisive.[387] Again, in cases of doubt, the committee's decision would not be justiciable.[388] Furthermore, there is in any case felt to be an excessive proliferation of ethics committees.[389] Besides the decision-making competence of those concerned and those with the right to care for them, the ethics committee would represent an impermissible extension of decision-making powers to a third entity.[390] The comparison with organ donation is considered dubious, since live organ donation is in any case prohibited in minors and furthermore there is no risk

383 See Rothärmel 2011.
384 See Werlen 2011.
385 See Dethloff 2011.
386 See Büchler 2011.
387 See Adamietz 2011.
388 See Plett 2011.
389 See Spranger 2011.
390 See Vöneky/Wilms 2011.

of any kind of commercialization comparable with the trade in organs, the avoidance of which is the reason for the involvement of an ethics committee in the organ donation process.[391] Again, in the absence of decision-making capacity, patient consent calling for ethical review does not as a rule exist. If the patient were competent to decide, for that reason alone there would be no reason to have the patient's decision reviewed, unlike that of the parents.[392] Another problem is considered to be presented by the composition of the ethics committee, since medical practitioners, psychologists and lawyers were substantially responsible for creating the "intersex syndrome". Although affected individuals could be included on the committee, peer advice by other affected people would probably be more trustworthy and afford more expertise, so that the furnishing of complete information to the parents and the person concerned, followed by peer advice, would suffice, thus rendering the involvement of an ethics committee superfluous.[393]

Involvement of the Family Court

Since the Family Court already exists and is competent to decide on, for example, issues of the right to care for a child, some propose that decisions on medical interventions be reviewed by the Family Court. For this purpose, the Family Court could appoint expert assessors to examine the necessity of the treatment and the decision-making capacity of the person concerned. Some also hold that oversight by the Court is needed by analogy with the existing limitation of parental competence to represent a child pursuant to Sections 1629(2) sentence 1 and 1795 BGB and with Family Court oversight in the cases referred to in Sections 1643(1) and 1821 f. BGB; although only financial risks are concerned in those cases, oversight by the Family Court is regarded as all the more necessary in the case

391 For such an argument, see Plett 2011; Tolmein 2011.
392 See Tolmein 2011.
393 See Remus 2011.

of medical measures that have much more far-reaching repercussions on the conduct of the affected individual's life.[394]

However, some misgivings are also expressed with regard to the involvement of the Family Court. One objection is that the necessary expertise cannot be provided by the family courts themselves, so that the problem is merely shifted elsewhere.[395] Furthermore, the courts would probably find it difficult to make decisions outside the framework of existing societal norms, so that recognition of a departure from the norm would if anything be unlikely.[396] The court proceedings could further traumatize those concerned, in particular because of the need for expert assessment.[397] The current procedure for protecting child welfare as laid down in Section 1666 BGB is felt to be insufficiently effective, since the courts are too reluctant to assume that a child's welfare is at risk and the limits of such a risk to the child's welfare are not sufficiently clear-cut.[398] Lastly, the courts have so far been able to intervene as provided in Section 1666 BGB only when they have received the necessary information, but this is not as a rule the case.

However, failure to take full advantage of judicial competence to protect minors is not a valid argument against the existing statutory provisions and their extension, but at most against current practice. For this reason, one possibility would be compulsory involvement of the Family Court prior to sex assignment surgery in children at least in particularly problematic situations. Compulsory involvement of the Family Court before medical interventions is already provided for in Section 1904 BGB. Under Section 1904(1) BGB, where persons under custodianship are to undergo an examination of their state of health, a therapeutic treatment or a medical intervention, the consent of the custodian must be approved by the

394 For such an argument, see Dethloff 2011.
395 See Werlen 2011.
396 See Westenfelder 2011, 599.
397 See Coester-Waltjen 2010, 855.
398 See Rothärmel 2001, 201 f.

court of custodianship in the event of a justified risk that the persons under custodianship might die or suffer severe and prolonged harm to their health as a result of the measure. Without this approval, the measure may be carried out only if deferral would be dangerous. Section 1904(2) provides that, where persons under custodianship are to undergo an examination of their state of health, a therapeutic treatment or a medical intervention, the non-furnishing or revocation of consent by the custodian must be approved by the court of custodianship in the event of a justified risk that the persons under custodianship might die or suffer severe and prolonged harm to their health as a result of the non-adoption of the measure or of its interruption. Approval pursuant to Section 1904(1) and (2) is not required if the custodian and the attending physician agree that the granting, non-granting or revocation of consent conforms to the wishes of the person under custodianship (Section 1904(4) BGB).

Since the foregoing provisions are enshrined in law for certain medical measures in persons under custodianship (who are of age), it is an obvious course to introduce comparable provisions on parental consent to a sex assignment operation in a child that may have substantial repercussions on the future course of that child's life. This implies a requirement to obtain a ruling from the Family Court at least in situations of conflict between the wishes or declarations of the child and the wishes or declarations of those with the right to care for the child on medical measures that may irreversibly impair the child's (future) fertility and/or sexual sensation. These cases present a conflict of interests which argues in favour of the involvement of an independent institution.

9 RECOMMENDATIONS

This Opinion was drawn up in response to the Federal Government's instruction to the German Ethics Council to examine the situation of intersexed people and the associated challenges in a dialogue with affected individuals and their support groups while taking due account of the relevant therapeutic, ethical, sociological and legal perspectives.

The term "intersexuality" is used by the public not in a single, well-defined sense, but to embrace a large number of heterogeneous particularities of sex development. It sometimes also includes persons who do not regard themselves as intersexed and who indeed oppose the application of the term to themselves.

The present Opinion uses the term "intersexuality" to denote an intersexual variation in which a person's sex cannot be unambiguously determined, and discusses the ensuing ethical, social and legal problems. DSD,[399] on the other hand, is used as a generic medical term for all the particularities of sex development addressed in the Opinion. Each of the various forms of DSD is associated with particular problems and needs on the part of those affected, and must therefore be considered individually in terms of the ethical and legal issues involved.

With their particularity and as members of a society that espouses diversity, people with DSD deserve the respect and support of that society. As the autobiographical reports of those concerned graphically show, grave suffering was inflicted on many intersexed people in the past. Intersexed individuals must be protected from undesirable medical developments and discrimination in the community, while parents of children with DSD need expert support. Wide-ranging education and information are necessary to promote the respect and support of intersexed individuals in society. The life situation

399 See Section 1.

of those affected must be considered in its entirety, taking account of all dimensions of human life and quality of life. In this context, the German Ethics Council makes the following recommendations.

9.1 On medical treatment

1. Medical and psychological counselling for those affected with DSD and their parents, as well as the diagnosis and treatment of people with DSD, should be provided only at specialized interdisciplinary centres of competence and given by medical practitioners and experts in all the relevant fields.
2. Regular, ongoing medical care of people with DSD should be offered by independent specialized centres distributed conveniently throughout the country in such a way as to be accessible within a reasonable time.
3. Both the centres of competence and the independent specialized centres should guarantee the provision of counselling to affected individuals and their parents by other affected people and their parents and by support groups (peer advice).
4. The basic and continuing training of doctors, midwives, psychotherapists and other medical staff, coupled with the provision of comprehensive information to doctors in private practice and general hospitals, should ensure that people with DSD can be identified as early as possible and referred to a specialized interdisciplinary centre of competence for diagnosis and treatment.
5. The avoidance of any possible discrimination or insensitivity in the medical treatment of people with DSD should also be ensured by appropriate training and further training of medical practitioners.
6. Irreversible medical sex assignment measures in people with DSD whose sex is ambiguous constitute an

interference with the rights to physical integrity, to the preservation of sexual and gender identity, to an open future and often also to procreative freedom. Decisions on such measures are strictly personal and should therefore always be taken by the individual concerned when competent to decide. In the case of an affected individual who has not yet attained decision-making capacity, such measures should be adopted only after thorough consideration of all their advantages, disadvantages and long-term consequences and for irrefutable reasons of child welfare. Such a reason at any rate applies if the measure concerned serves to avert a grave concrete risk to the life or physical health of the affected individual.

7. In the case of a individual affected with DSD who is not yet competent to decide but whose sex is unambiguous, as with CAH, the decision on surgical alignment of the genitals with that sex should always be based on thorough consideration of the medical, psychological and psychosocial advantages and disadvantages of early intervention. The guiding principle here too should be the welfare of the child. In cases of doubt, such operations should not be carried out before the person concerned is competent to decide.
8. With regard to identification of what constitutes the child's welfare (Recommendations 6 and 7), the affected child, even if not yet fully competent to decide, should be informed as early as possible in accordance with the child's state of development and involved in all decisions on medical measures; the child's wishes should be taken into account as far as possible. A manifest attitude of refusal on the part of the affected child should also be taken into account.
9. Correspondingly strict requirements should apply to decisions to abstain from intervention.
10. Affected individuals and those with the right to care for them should be given complete information and advice on all treatment options, including no treatment. The information should include details of all expected consequences,

including the physiological and psychological side-effects and long-term repercussions; it should be furnished on an interdisciplinary basis at a centre of competence (see Recommendation 1). Affected individuals and parents should be allowed a sufficiently long period for reflection prior to a decision. A prompt decision is appropriate only in cases of medical emergency.

11. There should be a statutory requirement for a ruling to be obtained from the Family Court at least in situations where the wishes or declarations of the child concerning a decision on medical measures with potentially irreversible effects on the child's (future) fertility and/or sexual sensation conflict with those of the persons with the right to care for the child.
12. Comprehensive documentation of all treatment measures must be ensured; owing to the lifelong effects of measures in people affected with DSD and in order to preserve their right to knowledge of the measures carried out, documentation on treatments should be preserved for at least 40 years and access to it granted only to the persons concerned.
13. Appropriate measures should be adopted to ensure that bureaucratic obstacles do not make it difficult for affected people to be reimbursed with the cost of off-label drugs such as sex hormones prescribed by the attending physician.
14. The time-bar provisions applicable to criminal acts against a child whereby (future) fertility and/or sexual sensation has been irreversibly harmed should be suspended until the person concerned has reached the age of 18; Section 78b of the Criminal Code (StGB), which currently relates only to criminal acts against sexual self-determination and the abuse of persons in care should be extended accordingly. Time-barring of corresponding claims in civil law should be suspended until the claimant has reached the age of 21, for instance by an extension of Section 208 of the Civil Code (BGB), which at present covers only claims for violation of sexual self-determination.

15. Many affected individuals have been profoundly wounded in their personal identity by past treatments which cannot, or can no longer, be deemed from today's perspective to conform to the state of medical science and technology and were based on discriminatory societal conceptions of sexual normality. They have sustained pain, personal suffering, difficulties and permanent restrictions of their quality of life. A fund should therefore be established to facilitate the recognition and assistance of people with DSD.
16. An ombudsman should be appointed, to whom affected individuals can present their concerns and to act as an adviser to affected people and a mediator between affected individuals and decision-makers.
17. In addition, support groups and representative organizations of people with DSD should be assisted with public funds.
18. The medical care of people with DSD – in particular, the long-term effects of treatment with sex hormones, indications for surgery and the quality of care, including psychological and psychotherapeutic care – should be the subject of ongoing monitoring and research. For this purpose, the German Ethics Council recommends the establishment of a Europe-wide anonymized database for research purposes.

9.2 On the law of civil status

The German Ethics Council takes the view that personal rights and the right to equality of treatment are unjustifiably infringed if persons whose physical constitution is such that they cannot be categorized as belonging to either the *female* or the *male* sex are compelled by law to be designated in one of these categories in the civil register.

1. Provision should be made for persons whose sex cannot be unambiguously determined to register not only as "female" or "male" but also as "other".

Provision should also be made for individuals' sex not to be registered until they have decided for themselves. A maximum age for affected people to decide should be laid down in law.

2. In addition to the existing possibility of amendment of one's registered sex under Section 47(2) of the Act on Civil Status (PStG), provision should be made for affected individuals to request amendment of their registered sex should the original entry prove to be incorrect.
3. If provision exists for a person's sex to be entered as "other" in the civil register, such a person must also be allowed to enter into a responsible and reliable relationship recognized by the state and in law. Under current law, marriage can be contracted only between a woman and a man and a registered civil partnership only between same-sex partners designated as female or male. The German Ethics Council proposes by a substantial majority that persons whose sex is recorded as "other" should be able to enter into a registered civil partnership. Some Council members also take the view that they should in addition be permitted to marry.
4. As a basis for future decisions on legislation, the purposes of compulsory registration as provided by current law should be evaluated. A review should be undertaken to determine whether the recording of a person's sex in the civil register is in fact still necessary.

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ABBREVIATIONS

AG	Amtsgericht (Local Court)
AGG	Allgemeines Gleichbehandlungsgesetz (General Equal Treatment Act)
AIS	Androgen insensitivity
BAnz.	Bundesanzeiger (Federal Gazette)
BayObLG	Bayerisches Oberstes Landesgericht (Bavarian Higher Regional Court)
BetrVG	Betriebsverfassungsgesetz (Works Constitution Act)
BGB	Bürgerliches Gesetzbuch (Civil Code)
BGBl.	Bundesgesetzblatt (Federal Law Gazette)
BGG	Behindertengleichstellungsgesetz (Act on Equal Opportunities for Disabled Persons)
BGH	Bundesgerichtshof (Federal Court of Justice)
BGHSt	Entscheidungen des Bundesgerichtshofs in Strafsachen (Decisions of the Federal Court of Justice in Criminal Cases)
BGHZ	Entscheidungen des Bundesgerichtshofs in Zivilsachen (Decisions of the Federal Court of Justice in Civil Cases)
BVerfG	Bundesverfassungsgericht (Federal Constitutional Court)
BVerfGE	Entscheidungen des Bundesverfassungsgerichts (Decisions of the Federal Constitutional Court)
CAH	Congenital adrenal hyperplasia
CAIS	Complete androgen insensitivity syndrome
CEDAW	Committee on the Elimination of Discrimination against Women
CESCR	Committee on Economic, Social and Cultural Rights
DNA	Deoxyribonucleic acid
DSD	Disorders/differences of sex development
ECHR	European Convention on Human Rights
ECJ	European Court of Justice
ECR	European Court Reports
ECtHR	European Court of Human Rights
FamRZ	Zeitschrift für das gesamte Familienrecht
GdB	Grad der Behinderung (disability rating)
GG	Grundgesetz (Basic Law)
ICCPR	International Covenant on Civil and Political Rights
ICD	International Statistical Classification of Diseases and Related Health Problems
ISNA	Intersex Society of North America
JW	Juristische Wochenschrift
KG	Kammergericht (Berlin Higher Regional Court)
LG	Landgericht (Regional Court)

LPartG	Lebenspartnerschaftsgesetz (Civil Partnership Act)
MBO-Ä	(Muster-)Berufsordnung für die in Deutschland tätigen Ärztinnen und Ärzte ([Model] Professional Code for Medical Practitioners Working in Germany)
MedR	Medizinrecht
NamÄndG	Gesetz über die Änderung von Familiennamen und Vornamen (Act on Changes of Surnames and First Names)
NamÄndVwV	Allgemeine Verwaltungsvorschrift zum Gesetz über die Änderung von Familiennamen und Vornamen (General Administrative Instructions Applicable to the Act on Changes of Surnames and First Names)
NJW	Neue Juristische Wochenschrift
NJW-RR	NJW-Rechtsprechungs-Report Zivilrecht
NJWE-FER	NJW-Entscheidungsdienst Familien- und Erbrecht
OLG	Oberlandesgericht (Higher Regional Court)
PAIS	Partial androgen insensitivity syndrome
PassG	Passgesetz (Passport Act)
PrALR	Preußisches Allgemeines Landrecht (Prussian General Land Law)
PStG	Personenstandsgesetz (Act on Civil Status)
PStG-VwV	Allgemeine Verwaltungsvorschrift zum Personenstandsgesetz (General Administrative Instructions Applicable to the Act on Civil Status)
ref.	Reference
RGBl.	Reichsgesetzblatt (Reich Law Gazette)
SRY gene	Sex-determining region of the Y gene
StAZ	Das Standesamt
StGB	Strafgesetzbuch (Criminal Code)
TDF	Testis determining factor
TSG	Transsexuellengesetz (Transsexuals Act)
UKHL	United Kingdom House of Lords
UN	United Nations
VersR	Versicherungsrecht

GLOSSARY

3-beta-hydroxysteroid dehydrogenase	Enzyme of which a genetic deficiency may result in congenital adrenal hyperplasia
5-alpha-reductase	Enzyme of which a genetic deficiency may result in a disturbance of testosterone metabolism
11-beta-hydroxylase	Enzyme of which a genetic deficiency may result in congenital adrenal hyperplasia
17-alpha-hydroxylase	Enzyme of which a genetic deficiency may result in congenital adrenal hyperplasia
17-beta-hydroxysteroid dehydrogenase	Enzyme of which a genetic deficiency may result in DSD with androgen hypofunction
21-alpha-hydroxylase	Enzyme of which a genetic deficiency may result in congenital adrenal hyperplasia
21-beta-hydroxylase	Enzyme of which a genetic deficiency may result in congenital adrenal hyperplasia
Adolescence	Youth; age range between childhood and adulthood
Adrenal cortex	Hormone-producing part of the adrenal gland; secretes the hormones aldosterone, cortisol and androgens and is therefore also involved in regulation of the salt/water balance
Adrenal cortex hyperplasia	Enlargement of the adrenal glands resulting in increased hormone secretion
Aldosterone	Hormone that plays an important part in regulation of the salt and water balance
Allosomes (or sex chromosomes)	Sex-determining X and Y chromosomes
Androgen	Hormone that performs regulatory functions in the male organism in particular
Androgen insensitivity	Genetic defect in the androgen receptor gene resulting in androgen hypofunction
Aneuploidy	Numerical sex chromosome abnormality
Atresia	Absence or closure of a natural passage in a hollow organ (in this case, the vagina)
Autosomal recessive	Inheritance of autosomal genes; the relevant characteristic is then expressed only in the event of a mutation on both homologous autosomes
Autosomes	Chromosomes other than sex chromosomes – i.e. chromosomes 1 to 22; each cell possesses two copies of each autosomal chromosome
Binary	Having two values or parts
Biosynthesis, disturbance of	Disturbance of the formation of organic compounds in the body
Bladder exstrophy	Congenital division of the anterior wall of the bladder

Castration	Measure whereby functioning gonads are removed or rendered non-functional
Catalysis	Acceleration of a chemical reaction by means of a substance (enzyme) that reduces activation energy without itself thereby being consumed
Chromosomal mosaic	A person whose chromosome set is not identical in all cells and tissues
Chromosome anomaly	Structural or numerical alteration of the chromosome set
Chromosomes	Carriers of genetic information, consisting of DNA and associated proteins; genes are located on them; humans have 23 chromosome pairs
Clitoridectomy	Surgical removal of the clitoris
Cloacal exstrophy	Severe malformation of the urogenital and rectal tract, sometimes with exposed abdominal organs
Complete androgen insensitivity syndrome (CAIS)	Complete androgen resistance; owing to complete inhibition of androgen activity, a chromosomally male baby is born with female genitalia; the intersex status emerges at puberty
Congenital adrenal hyperplasia (CAH)	Congenital defect of the adrenal cortex resulting in cortisol deficiency
Control gene	When a control gene is activated, functionally interconnected gene networks are simultaneously activated by its protein product or by structural changes in the DNA
Cortisol	Hormone produced by the adrenal cortex
Cortisone	Hormone produced by the adrenal cortex
Cryptorchidism (or undescended testes)	Anomalous position of the testes in the abdominal cavity
Dichotomous	Divided into two parts
Differences of sex development (DSD)	Term preferred to disorders of sex development
Dihydrotestosterone	Hormone that performs regulatory functions in the male organism in particular
Dilatation	Widening of hollow organs
DNA	Deoxyribonucleic acid; a biomolecule that carries genetic information
Dyspareunia	Disorder of sexual function characterized by the absence of orgasm and by painful sexual intercourse
Embryo	Organism developing from a viable fertilized egg up to the conclusion of organ formation (ninth week of pregnancy)
Endocrine organs	Organs that secrete hormones and release them into the body; they include the pituitary, thyroid, endocrine pancreas, adrenal glands, ovaries and testes
Enzyme	Protein molecule with catalytic effects in the metabolism

Fetus	Human organism developing in a woman's body after the conclusion of organ formation
Fistula	Abnormal tubular passage between hollow organs or between a hollow organ and the body surface
Gamete (or germ cell)	Generic term for an egg or sperm cell
Gender	Interpretation of anatomical, genetic and hormonal sexual characteristics in terms of human relations
Gender role	Group of expectations operative in human relations associated with a person's anatomical and hormonal sexual characteristics
Gene	Smallest functional unit of the genome; DNA sequence containing genetic information, for example for a specific protein
Genitalia	See sex organs
Genitoplasty	Plastic surgery of the genital organs
Germ cell	See gamete
Glucocorticoids	Vital "stress hormones" with effects on carbohydrate metabolism
Gonadal dysgenesis	Atypical development or absence of gonads
Gonadectomy	Removal of the gonads
Gonads	Organs in which the gametes (egg/sperm cells) are formed; in the female sex these are the ovaries and in the male sex the testes
Hermaphroditism, true	Presence of gonads of both sexes in a single organism – i.e. of both ovarian and testicular tissue
Hormone	Metabolic messenger substance
Hydrocortisone	Synonym of cortisol
Hyperplasia	Enlargement of a tissue or organ due to increased cell division
Hypertrophy	Enlargement of a tissue or organ due to an increase in cell volume
Hypospadias	Atypical urethral meatus (opening) in the penis
Indication	Something indicating the necessity or advisability of medical treatment
Indication, emergency	Acute clinical picture calling for life-saving measures
Indication, vital medical	Life-threatening clinical picture calling for life-saving measures
Intersexuality	Condition due to bodily sex particularities whereby the subject cannot be designated as unambiguously male or female
Karyogram	Graphic representation of the complete set of chromosomes in a cell
Karyotype	Visualization of the number and appearance of chromosomes in a cell

Klinefelter syndrome	Abnormal number of sex chromosomes in men who have two X chromosomes in addition to the Y chromosome
Lactation	Secretion and yielding of maternal milk by the female mammary gland, usually after childbirth
Late-onset CAH	A form of CAH with relatively minor symptoms, with onset usually at puberty, without salt wastage
Leydig cell agenesis/ Leydig cell hypoplasia	Rare autosomal recessive genetic disorder, occurring in men only, in which the Leydig cells fail to develop owing to a mutation in the LH receptor; phenotype varies between female and male
Leydig cells	Testosterone-producing cells in the testicular connective tissue
Malignant	Cancerous
Mastectomy	Surgical removal of a breast
Micturition, difficulty of	Difficulty in emptying the bladder
Mineralocorticoids	Hormones that play a vital part in salt/water balance regulation
Mosaicism	Mutational event in the early phase of embryonic development, resulting in the presence of chromosomally or sex-chromosomally distinct cells in one and the same individual
Müllerian duct	Early embryonic, as yet sexually undifferentiated structure from which the Fallopian tubes, uterus and vagina subsequently develop in the female embryo; it regresses in the course of male sex development
Mutation	Spontaneous modification of a cell's genetic information
Neovagina	Surgically constructed artificial vagina
Oestradiol	Hormone that performs regulatory functions in the female organism in particular
Oestriol	Hormone that performs regulatory functions in the female organism in particular
Oestrogen	Hormone that performs regulatory functions in the female organism in particular
Off-label use of medicinal products	Use of medicinal products other than for the application approved by the licensing authority
Osteoporosis	Disorder of the skeletal system resulting in reduced bone density and consequent increased risk of fracture (reduced bone mineral density)
Ovotesticular DSD	A condition in which both testicular and ovarian tissue are found in the same organism
Partial androgen insensitivity syndrome (PAIS)	Partial androgen resistance; the inhibition of androgen activity is not complete but only partial, so that the body develops more in the male direction, resulting in a mixed male/female or predominantly male appearance
Pathological	In the nature of a disease or disorder

Peer advice	Advice given to affected persons and/or their parents by other affected persons and/or their parents and support groups
Persistent Müllerian duct syndrome	Non-regression of the Müllerian duct with simultaneous formation of male internal sex organs (not gonads), so that anatomical forms of both sexes exist alongside each other
Prader I to V	Scale classifying the size of an enlarged clitoris by the stages Prader I (slight enlargement) to Prader V (substantial hypertrophy, penis-like)
Prenatal	Before birth
Progesterone	Hormone that performs regulatory functions in the female organism in particular
Replacement therapy	Treatment of a disorder by the administration of substances that normally occur in the organism but are lacking
Salt wastage crisis	Loss of salts necessary to life due to aldosterone deficiency, with consequent life-threatening water loss; typically occurs in cases of undiagnosed CAH in the second or third week of life
Sex, biological	Bodily sex, including chromosomal, gonadal and hormonal sex
Sex, chromosomal	Sex as determined by the sex chromosomes
Sex, gonadal	Sex as expressed by the type of gonads
Sex, hormonal	Sex as expressed by hormone status
Sex ambiguity correction	Sex ambiguity correction is the term used in this Opinion to denote medical measures having the aim of adapting anatomical particularities of the external sex organs to the existing sex where the person's sex designation is otherwise unambiguous
Sex assignment	Sex assignment is the term used in this Opinion for medical measures (including surgery) directed towards eliminating the intermediate condition in cases of sex ambiguity and creating an unambiguous sex
Sex chromosomes	See allosomes
Sex organs (or genitalia)	Reproductive organs of the human body, both internal and external
Sex organs, external	In the female sex, these include the clitoris, mons veneris, labia and certain glands, and in the male sex the penis, scrotum and certain glands
Sex organs, internal	The sexual components not visible externally; in the female sex, they include paired ovaries, the Fallopian tubes, uterus and vagina, and in the male sex paired testes, the epididymis, vas deferens, prostate and certain other glands
Sexual characteristics	Characteristics that distinguish the male and female sexes, classified as either primary or secondary

Sexual characteristics, primary	Sexual characteristics directly serving the purpose of reproduction and already present at birth; in the female sex these include the ovaries, Fallopian tubes, uterus, vagina and vulva, and in the male sex the testes, epididymis, seminal ducts and penis
Sexual characteristics, secondary	Sexual characteristics that develop at puberty; in the female sex these include breasts, female type of hair growth and characteristic fat distribution, and in the male sex the beard, body hair and lower vocal pitch
Sexual identity	Generic term for a person's sexual self-categorization in relation to that person's body, hormonal make-up, feelings and biography (including rearing during childhood) and consequent emerging sexual identity; relates to a person's basic sense of belonging to a given sex
SRY gene	Gene located on the Y chromosome that codes for testis determining factor and is therefore needed in embryonic development for restructuring into male internal sex organs
Stenosis	Narrowing of hollow organs or vessels
Sterilization	Elimination of the capacity to father or give birth to a child, usually by vasectomy or tubal ligation
Steroid hormones	A group of hormones including cortisol and the sex hormones
Steroid-5-alpha-reductase deficiency	Genetic enzyme defect resulting in the persistence of genitalia of the female phenotype with concealed testes
Streak gonads	Non-functioning, degenerated ovaries which contain no gametes and produce no hormones
Swyer syndrome	Complete gonadal dysgenesis caused by a mutation of the SRY gene, resulting in a female phenotype despite the presence of a male chromosome set
Testicular biopsy	Removal of a tissue sample from the testes
Testis determining factor (TDF)	Protein coded for by the SRY gene of the Y chromosome, responsible for differentiation of the initially undifferentiated gonadal primordium into testes
Testosterone	A hormone that performs regulatory functions in the male organism in particular
Transgender identity	Identity of a person not wishing to be designated as either female or male
Transsexualism	Sexual identity differing from the subject's biological sex; transsexuals typically feel that their physical sex is the opposite of their gender
Turner syndrome	Chromosomal abnormality in which only one X chromosome is present in each cell (no second X chromosome in the female or no Y chromosome in the male)

Undescended testes	See cryptorchidism
Urogenital sinus	The originally combined embryonic vaginal/urethral primordium
Urogenital sinus, persistent	The urogenital sinus is persistent if the vagina and urethra do not undergo normal separation
Urogenital system	The urinary and sex organs considered as a whole
Vaginismus	Involuntary spasm of the vagina, usually of psychological origin; prevents introduction of the penis in sexual intercourse
Vaginoplasty	Surgery to construct a vaginal passage and internal vagina
Virilization	External masculinization of the body

APPENDIX

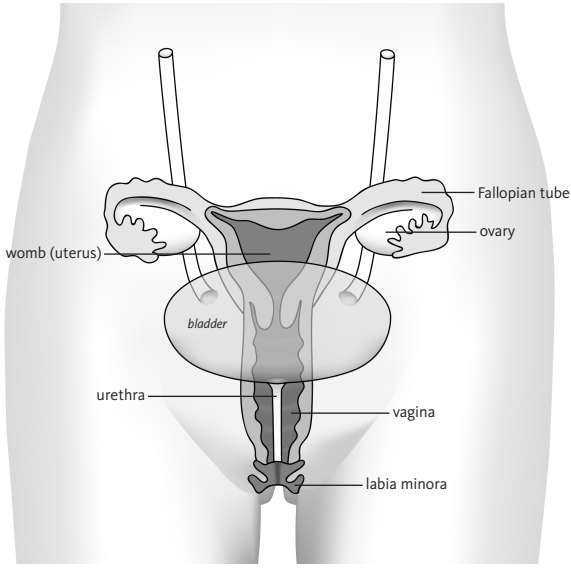

ILLUSTRATION: MANFRED BOGNER

Figure 1: Diagram of female sex organs (from front)

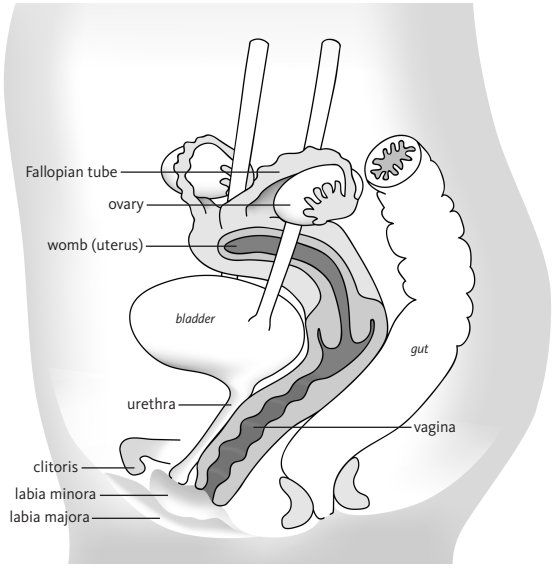

ILLUSTRATION: MANFRED BOGNER

Figure 2: Diagram of female sex organs (from side)

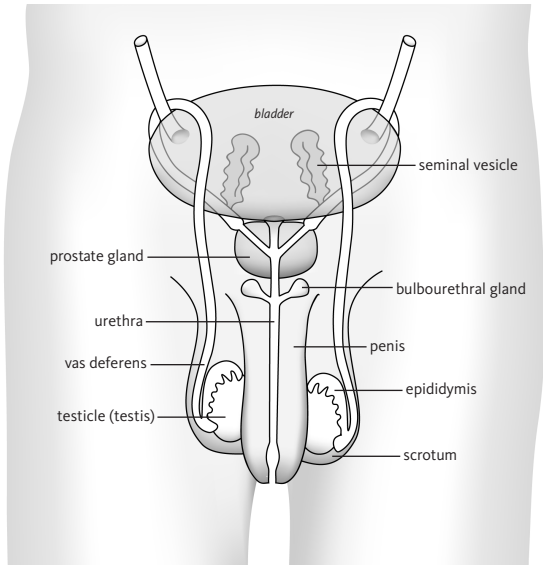

ILLUSTRATION: MANFRED BOGNER

Figure 3: Diagram of male sex organs (from front)

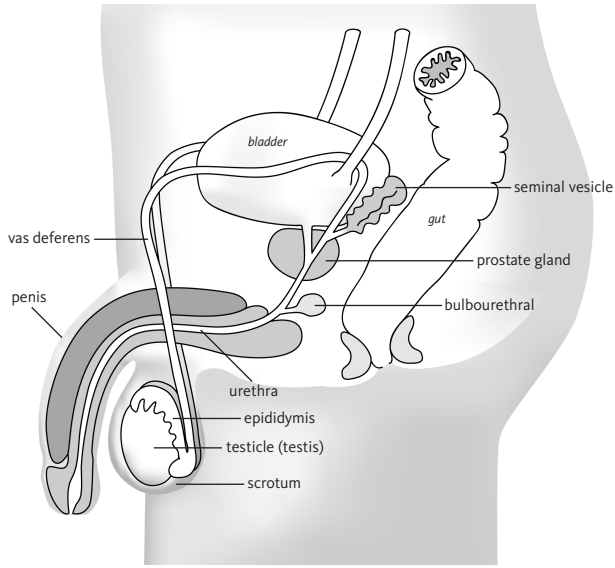

ILLUSTRATION: MANFRED BOGNER

Figure 4: Diagram of male sex organs (from side)

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Dr. h. c. Erwin Teufel, former Prime Minister of the State of Baden-Württemberg
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Kristiane Weber-Hassemer, former State Secretary in the State of Hesse
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