Who has a Disorder? Who gets to Decide?[1]

Jörg Woweries

Summary

This paper discusses the definitional power of medicine in the assignment of intersex persons, followed by a brief historical overview of the importance of notions of social norms particularly with reference to dichotomically organized normative concepts of body and mind. The right of self-determination and other human rights occupy a special place in the discussion about ascriptions of disorders, since it is precisely those incapable of giving their informed consent that are particularly affected by the application of medical measures. The critical discussion of certain hitherto standard medical practices not only sheds light on the implications for the individuals concerned and their personal environment, but also for medical practice. Looking ahead, the author also discusses the significance of legal solutions for individual and social practices.

Introduction

Whoever turns to a doctor or a psychiatrist has to reckon with the likelihood that the mentioned issues are classified under the rubric of disease. The ICD 10 (International Classification of Diseases, 10th Version) constitutes the guideline for the work of these professional communities.[2] This is moreover used as the currently valid basis of the billing system doctors and psychotherapists use with health insurance organizations. Terms such as 'intersexuality', 'hermaphrodite' or 'intersex-related constitutiveness' do not figure in the systematic overview of the ICD 10. Specific diseases are named and assigned figures of the ICD 10, e.g. E25 adrenogenital disorder, E29 testicular dysfunction, E34.5 androgen insensitivity syndrome, Q56.0 hermaphroditism and others.

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1 | Original version in German.

2 | URL: http://www.who.int/classifications/icd/icdonlineversions/en/ [20.06.2013].

The nomenclature of the Chicago "Consensus Conference" (Hughes 2006) substituted traditional terms such as 'hermaphrodite', 'hermaphroditism', 'intersex-related constitutiveness' or 'intersex' with Disorders of Sex Development (DSD)[3] translated in the German medical guidelines[4] with Störung der Geschlechtsentwicklung. According to this medical classification we have a case of DSD in "congenital conditions in which development of chromosomal, gonadal and anatomic sex is atypical".[5] This also applies to people to whom neither an unambiguously male nor an unambiguously female genital can be assigned. The term 'disorder' was fiercely attacked, intersex persons were dismayed at being ascribed to disorder and disease. Self-help groups,[6] but also the network Intersexualität, based at the University of Lübeck, now uses the phrasing of 'peculiarities of sex development' (Besonderheiten der Geschlechtsentwicklung).[7] The self-help groups want to tone down the pathological implication of disorder in American usage. The proposal made by representatives of the intersex community to speak of Variations in Sex Development was turned down in Chicago (Thomas 2006). The Swiss Ethics Commission however supports this demand and speaks of Varianten der Geschlechtsentwicklung, translated as differences of sex development.[8] Disorders of Sex Development are considered in the systematic view of ICD 10 exclusively under physical aspects. In such cases, current procedures in medicine and sexual psychology presume a norm. What is happening here is thus a norming of biological diversity, referring to the dichotomous or binary notion of sex and gender?

As a next step in medical procedure, a deviation from the norm is regarded as a disease, illness or disorder. Everything that questions this normative order is portrayed as abnormal, unnatural or pathological. If we reject these concepts of medicine we can arrive at a different point of view.

Are variants of sex development really deviations from a norm? What is the norm here? Or is it about biological diversity? Milton Diamond speaks of biolog-

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3 | URL: http://pediatrics.aappublications.org/content/118/2/e488.extract# [12.11.2014].

4 | Deutsche Gesellschaft für Kinderheilkunde und Jugendmedizin (DGKJ) (2010): Leitlinien: "Störungen der Geschlechtsentwicklung". In: AWMF online – Leitlinien-Register Nr. 027/022. URL: http://www.awmf.org/leitlinien/detail/ll/027-022.html [01.08.2013].

5 | URL: http://pediatrics.aappublications.org/content/118/2/e488.extract# [12.11.2014].
URL: http://www.uksh.de/kinderhormonzentrum-luebeck/Forschung/Netzwerk+DSD.html [01.08.2013].

6 | "Intersexualität, was ist das? Der Begriff bezeichnet biologische Besonderheiten bei der Geschlechtsdifferenzierung." URL: http://www.intersexuelle-menschen.net/intersexualitaet/ [01.08.2013].

7 | Intersexuelle Menschen e.V.: the network 'DSD/Intersexualität' deals with congenital particularities of sex development, or in the 'official' terminology Disorders of Sex Development (DSD).
URL: http://www.uksh.de/kinderhormonzentrum-luebeck/Forschung/Netzwerk+DSD.html [01.08.2013].

8 | Swiss National Advisory Commission on Biomedical Ethics (Schweizer Nationale Ethikkommission im Bereich Humanmedizin) (2012): Zum Umgang mit Varianten der Geschlechtsentwicklung. Ethische Fragen zur "Intersexualität". English version: On the management of differences of sex development. Ethical issues relating to "intersexuality".

ical variants.[9] Mind games about the so-called third sex are of little help (Blackless 2000; Fausto-Sterling 1993). Because of the great diversity of phenotypes there is no unambiguous third sex. Biological sex is very complex and cannot always be clearly demarcated (Voß 2010). What is more important for intersex persons themselves, however, are the legal and cultural aspects, which can contribute crucially to their becoming visible and accepted? Drawing on Gronenberg (2012), it would be more appropriate to speak of persons 'in-between-sexes and genders' than of 'intersex'. This term has the advantage that it 'constitutes a clear rejection of questions of sexuality' (such as hetero-, homo- or bisexuality) and can avoid 'confusing intersexuality with bisexuality'. Due to the historical and socio-cultural contingencies and the different biological theories the terms are based on, the term 'inter'[10] seems to make a lot of sense.

In their internet forums many intersex people demand that in the registry of births and in personal files there should be no registered sex whatsoever. They say they find it degrading if – possibly inexperienced – delivery nurses or doctors determine the sex at birth based on the outer appearance as either exclusively male or female. This is why some intersex persons, when they reflect their situation as adolescents or adults, see themselves as, for instance, male and female, as both one and the other or as neither nor. But only very few are prepared to publicly admit to this status.

Intersex is however often confused with transsexualism,[11] mostly out of ignorance. The term 'transsexualism' is listed in the ICD 10 under gender identity disorders. This classification too remains linked to the system of illnesses.[12] In Germany for instance, changes of first name and gender are regulated in the Transsexuellengesetz (TSG) (Transsexual Act).[13] In 2006 the psychologist Ahler

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9 | In the original: 'biological varieties', Diamond, M., Sigmundson, H. K. (2009): Management of Intersexuality: Guidelines. In: Arch Ped Adol Med.
URL: http://www.hawaii.edu/PCSS/biblio/articles/2010to2014/2010-intersexuality.html [08.12.2011].

10 | See contribution by Jörg Woweries in this publication: Intersex – Medical Measures on the Test Bed.

11 | On the definitions: besides transsexualism there are also other terms in use with very different backgrounds and meanings that frequently defy fixation such as: trans identity, transgender, transsexuality, cross-dresser, drag king, drag queen. Here too the term 'Trans' seems appropriate.
URL: http://en.wikipedia.org/wiki/Transsexualism [01.08.2013].

12 | In the medical classifications transsexualism is listed as follows: in the ICD 10, F64. For adolescents in the period of puberty also F66. In SOC-VI of the Harry Benjamin International Gender Dysphoria Association (Standards of Care for Gender Identity Disorders. Sixth Version, 2001). In DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 1994, fourth edition). DSM-V is due to be issued in 2013. Trans person organizations may possibly manage to have Gender Identity Disorders completely deleted from DSM and ICD. This term had been introduced in the version DSM-IV, substituting the term 'transsexualism'. The guidelines of the German Society for Child and Adolescent Psychiatry and Psychotherapy (published by the Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften/AWMF) agree with the statements of the ICD 10. As yet there are no German guidelines for adults. In the DSM-V, which has meanwhile come into effect, the term 'gender identity disorder' (in German 'Geschlechtsidentitätsstörung') has been replaced by the term 'gender dysphoria' (in German 'Geschlechtsdysphorie'). It denotes that there is no psychological disorder, but instead a significant psychological strain that justifies the application of medical measures.
URL: http://www.dsm5.org/documents/gender%20dysphoria%20fact%20sheet.pdf [10.07.2015].

gave a talk about transsexualism and transvestism.[14] He frequently mentioned dichotomy, a concept that can also be found in the text books. In psychoanalytical understanding the dichotomy of male and female has hitherto been taken for granted (Quindeau 2012). One can however observe that dichotomy is a guarded border. There a people who want to reach the other side of the border, men or women, each in the respective other direction.

The only thing they can show in the way of a border document is their own conviction that they want it this way: "I want to cross!" Ahlers identified gender by the normal physique, i.e. by whether one can detect a penis or a vagina, ovaries or testicles. Medical practice classifies persons attempting to cross this border as pathological and as having gender dysphoria,[15, 16] because of the disorder of their gender identity,[17] and refers them to psychiatric treatment. However, neither psychology nor psychiatry nor anyone else in medicine is capable of reading the border pass of these people, i.e. their own will, meaning there is in effect not one single psychological or medical means of diagnostics. As a result, border fortifications are erected: long-term monitoring by psychological evaluators, numerous bureaucratic obstacles before being able to choose another first name, compulsory surgery and resulting infertility.[18]

But the German federal constitutional court took a different view and gradually eased the opening of the border.[19] "Pedagogical measures for re-education are nonsense" says the psychologist and psychotherapist Udo Rauchfleisch (2012), who believes it is important to dissociate ourselves from the concept of the pathological. There are therefore people who want to cross, want to cross completely. Others only want to do so temporarily. One thing has become clear here: there is life on the border. There are not many, but there are people on the border. It is not a no-man's land.

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13 | Gesetz über die Änderung der Vornamen und die Feststellung der Geschlechtszugehörigkeit in besonderen Fällen (Transsexuellengesetz – TSG). (Law on changing the first name and gender status in exceptional cases) Federal law, 10.9.1980. The TSG does not concern intersex people.

14 | On 12.09.2006 Ahlers presented the official stance of the Charité Berlin, Institut für Sexualwissenschaft und Sexualmedizin (Institute of Sexology and Sexual Medicine) in the Fachbereich für gleichgeschlechtliche Lebensweisen (unit for same-sex lifestyles, currently LGBTI Unit) of the Senate of Berlin.

15 | Schweizer and Richter-Appelt also use this term for intersex people. Schweizer, K. Identitätsbildung und Varianten der Geschlechtsidentität, p. 459-484. Richter-Appelt. Psychologische und psychotherapeutische Interventionen: p. 357-361. Both in: Schweizer/Richter-Appelt (Eds.) (2012): Intersexualität kontrovers. Gießen: Psychosozial.

16 | In her research on many intersex persons Richter-Appelt (2012b) also detects a great deal of vagueness in gender identity.

17 | ICD 10: F64.

18 | Law on changing the first name and gender status in exceptional cases (Transsexuellengesetz, TSG, §8).

19 | BVerfG: 2 BvR 1833/95 of 15.08.1996 (Addressing transsexual persons after a name change). 1 BvL 3/03 of 06.12.2005 (naming rights and sexual self-determination). – 1 BvL 1/04 and 12/04 of 18.7.2006 (TSG and foreign transsexuals). – 1 BvL 10/05 of 27.5.2008 (transsexuals may remain married after gender reassignment). – 1 BvR 3295/07 of 11.01.2011 (civil partnership, without surgery changing visible sex/gender-related features).

So where are the intersex people? The author's experiences

For almost three decades I worked at a large hospital in Berlin and was mainly occupied with the care for newborns. In the course of this work I encountered, in my initial examinations, newborns whose genitals did not correspond to the medical norm. When I began to enquire about what had become of these people I received no information. Only later did I realize that this is precisely part and parcel of the medical system. These people – we have now accustomed ourselves to referring to them as intersex people – had a genital which was treated as atypical, as a flaw, as a defect. Medicine and surgery in particular offered to make external adjustments to this so-called flaw by making it look like a genital determined as normal.[20,21] Due to a lack of craftsmanship – "it is easier to make a hole than to build a pole" (Diamond 2008) – in almost 80-90% of the cases superficially female-looking genitals were created. The parents were discouraged from discussing this with anybody, telling anyone about it, not the relatives, not even their own child, let alone the neighbors. The medical practioners involved had caught themselves in a trap of their own making: With their conspiracy of silence, endocrinologists and surgeons have turned their backs on science. Because an indispensable attribute of science is transparency and critical evaluation of one's own results. For this reason there is to this very day a lack of controlled evidence-based findings,[22] i.e. proven findings (Clayton et al. 2002; Creighton/Minto 2001; Creighton 2004; Crouch et al. 2008; Hughes et al. 2006; Lee et al. 2006; Pagon 2010; Speiser et al. 2010; Stein et al. 2005). This is also a violation of the World Medical Association's Declaration of Helsinki. It demands that even the best current interventions be evaluated continually through evidence.[23] Some text books of psychiatry and somatic medicine only know the principle of right or left for the division of men and women. One frequently comes across the word dichotomous. That is Greek and means: separate, cut apart. Then there is nothing in between. Others speak of binary, that means yes or no, in the sense

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20 | Deutsche Gesellschaft für Kinderheilkunde und Jugendmedizin (DGKJ) (2010): Leitlinien: "Störungen der Geschlechtsentwicklung". In: AWMF online – Leitlinien-Register Nr. 027/022.
URL: http://www.awmf.org/leitlinien/detail/ll/027-022.html [01.08.2013].

21 | Dr. Dagmar l'Allemand, for instance, writes in the Swiss journal "Beobachter" 20, 2012, p. 25, about genital surgery on a girl: "Why shouldn't one determine the sex right away instead of letting this child grow up with ambiguousness? Why shouldn't one make sure right away that everyone – also the parents – are not reminded every day that it has a defect?"

22 | Evidence-based medicine (EbM) operates with various levels of evidence: "Level 1: Evidence from systematic review of numerous randomized clinical trials. Level 2: Evidence from at least one randomized controlled trial Level 3: Evidence from at least one well-designed cohort or case control study, i.e. a controlled trial which is not randomized Level 4a: Evidence from clinical reports. Level 4b: Opinions of respected authorities, based on clinical experience, descriptive studies or reports of expert committees ". Text based on Wikipedia, URL: http://en.wikipedia.org/wiki/Evidence-based_medicine#Assessing_the_quality_of_evidence [01.08.2013].

23 | (WMA), Version 2008: A7, B 18. URL: http://www.wma.net/en/30publications/10policies/b3/17c.pdf [01.08.2013].

of modern scientific language: only occurring in two conditions, from the Latin binarius, twofold. There, too, there is nothing in between.

That is exactly what has happened to intersex people: dichotomy – they have been cut apart. These surgical interventions are performed as early as possible in infancy so that the children do not remember them (Eckhold 2008). In the forums of the individuals concerned one can read that they see themselves more as monsters, as freaks.[24] The word 'flaw' is used in a diplomatic obfuscation. Initially this was linked to intersex children because their genital did not correspond to the so-called normal appearance. Later they saw themselves as victims of a genital mutilation. Today they write about their feelings, anger and hate, even decades after surgery. Many suffer from serious psychological trauma. Schweizer and Richter-Appelt (2009) speak of a high degree of psychological strain and demand that the psychological needs of those who have undergone surgery be acknowledged. Intersex in particular graphically underscores the implications, one would like to call it insanity, of this construction – the construction of yes or no. One the one hand, there is the definition that there can be nothing between yes and no. On the other, people who find their own sex/gender identity, contested by no one, in the middle are denied their desired registration in the birth register as hermaphrodite. They are assigned arbitrarily and on compulsion to one side as male or, because of the simpler surgical technique, usually as female.[25] This can lead to the gender being entered contrafactually, i.e. incorrectly in the birth register. In so-called Western societies there is a strong pressure to decide for either male or for female. Presumably the great majority of people have no doubt about their own sex/gender. The parents of an intersex child can choose a sex/gender of rearing for their child, so either male or female. They can also paint the nursery pink or blue. But after that they should patiently wait and see how their child later decides for itself. But none of this can be seen as proof that the dichotomous or binary model also has a scientific/rational base.

This dichotomous, binary conceptual model of the yes or no can be explained with a glance into the history of science and is described in the socio-cultural science in different and partly contradictory ways.[26,27] I would like to offer a different perspective. If we look in other places of biological and medical literature we find descriptions of the human being that fit another, non-binary sex/gender model: there are indications that the personality of a human being

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24 | Very frequent statements by persons on whom this kind of surgery had been performed. URL: http://zwitterforum.ath.cx/index.php [02.10.2011].

25 | Netzwerk Intersexualität: Erste Ergebnisse der Klinischen Evaluationsstudie im Netzwerk Störung der Geschlechtsentwicklung/Intersexualität. 2008 (First findings of the clinical evaluation study in the network gender identity disorder/intersex): "until about 15-20 years ago there were a lot more children with ambiguous sexual organs who were raised as girls without any further diagnostics", p. 13.
URL: http://www.netzwerk-dsd.uk-sh.de [03.05.2011].

consists of many internal features that range on a spectrum between the two polar ideals of male and female. For Beier (2012) the behaviour of gender roles is of a statistical-descriptive nature and only becomes evident in the comparison of gender groups (Beier 2012: 747). At no point is it claimed that a feature, e.g. mathematical talent, only occurs in one single (male) gender and not also in the other (female) gender. Medical text books describe that typical male and female hormones should occur in both sexes (Fine 2010; Hines 2004; Lautenbacher et al. 2007; Pfaff 2011; Pinker 2008). All human beings combine features and behaviours which are, according to some views, assigned to either male or female on the grounds of evolution and biology, or, according to other opinions, are only read into them through cultural influences. One should be skeptical towards both of these interpretations and await further scientific results. They maintain that so-called women have a disposition for female and so-called men for male attributes, advancing proven gender-typical differences as evidence.[28,29] Through education, in particular gender roles, this development can be varied in the sense of nature versus nurture (Fausto-Sterling 2012). But we are dealing with individuals, so that role clichés, i.e. dichotomous thinking, do not do justice to the individual complexity and interindividual diversity. If we were to draw distribution curves for men and women of readings of, for instance, testosterone or estrogen, as well as of empathy, language ability, spatial awareness and many other characteristics, we would get curves that display a significant degree of overlap.

One can also phrase it differently: the sex/gender identity of every human being is constituted of a series of characteristics that are governed by the principle of much or little. For instance a great variation in physical form and size, as seems characteristic of men and women and that includes pronounced overlapping, is accepted by our culture. This is why some authors point to developmental biology and realize that believing in an absolute dimorphism is erroneous. The neuroscientist Cordelia Fine (2012) observes the numerous characteristics that are assigned in different ways more or less to men and women. She considers the views of other authors as prejudices and gender fairy tales, in which the

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26 | Honegger, C. (1991): Die Ordnung der Geschlechter. Frankfurt a.M.: Campus. Laqueur, T. (1992): Auf den Leib geschrieben. Die Inszenierung der Geschlechter von der Antike bis Freud. Frankfurt a.M.: Campus. Maihofer, A. (1995): Geschlecht als Existenzweise. Frankfurt a.M.: Ulrike Helmer.

27 | "Feminist theory generally makes a distinction between […] sex and gender […]." […] "The separation between biological and social gender insists that there is no causal relationship between the two." Maihofer, A. (1995): Geschlecht als Existenzweise. Frankfurt a.M.: Ulrike Helmer, p. 19.

28 | Spatial awareness. Aggressiveness in men. Men and women score differently in group coordination tests. Women score better than men in verbalization tests. Differences are also noted in sexual orientation. Fegert, J. M. et al. (2012): Psychiatrie und Psychotherapie des Kindes- und Jugendalters. Berlin/Heidelberg: Springer, p.747.

29 | Lautenbacher, S. et al. (2007): Gehirn und Geschlecht. Neurowissenschaft des kleinen Unterschieds zwischen Mann und Frau. Berlin/Heidelberg: Springer, p. 65.

differences between men and women are portrayed with much imagination. Many differences that used to be considered as unalterable have meanwhile disappeared. Ultimately she can detect no biologically founded difference in the behaviour of the two sexes/genders.

I would like to choose the polar model to describe the man-woman dualism. This model describes a continuum with two ends, is derived from the Greek polos and signifies an axis. This refers to the continuum between the two poles. There is therefore always something in between.[30] In this model, like the Earth with its two poles, all individuals will find themselves somewhere: every human being, not only intersex people, is somewhere on a continuum, on a broadly distributed spectrum between the poles.

Knowing this is important for dealing with each other: knowing about the variability of gender. I here also think of the term inclusion.[31] This term shows us that difference is completely normal. Intersex people are not the only human beings who show that difference is completely normal. Milton Diamond (2008a) speaks of biological variants. Susan Pinker (2008) applies this positive view also to the relationship of so-called normal men and women and observes it is after all an advantage if there are not only extremes. A broad diversity in social behaviour and in the biological constitution in men and women should be regarded with optimism. This is an enrichment of the diversity of human life. Why the dualism male/female in evolution has won over in the observations of the present will continue to remain a subject of debate.[32] I see an explanation in the principle of much or little. I do not here wish to elaborate on the socio-cultural literature on sex/gender identity and sex/gender roles. It is quite different to the medical-psychiatric system of definition. I would only like to mention Judith Butler (1995, 2003, 2009) here. With her critique of the traditional dichotomous, binary point of view she identifies problems at the gender border and the ensuing gender trouble. Defectors and border inhabitants, this is what we know from real life, also need border guards, barriers etc. Without a border, without binary/dichotomous divisions this would lead to mixings, to ambiguities and indeterminacies as well as uncontrollable relationships in a society that wants to defend gender dimorphism. Diamond (2008b) phrases this idea in the following way: "Biology loves variation, but society hates it". One always needs to ask: how do individuals find their way in the contradiction between their own choice and the social constraints of a frequently intolerant environment? In this sense there is a psychological and biological diversity of intersex people and there are different

30 | In contrast to my own view, socio-cultural literature very frequently uses the terms dichotomous, binary, polar and bipolar as synonyms.

forms of expression of representations of gender that elude a strict rigid control and, because of the violation of their human and children's rights by third parties, that should be subject of an anti-discrimination office that denounces phobias and intolerance.

Practical implications of this kind of medical approach

The medical approach adopted over the years has led to two effects that significantly influence practice and are palpable in everyday life. The conspiracy of silence surrounding intersex people that has been an intrinsic part of the treatment system of doctors, has served to conceal information about this phenomenon from the public, resulting in large knowledge gaps in public perception. But the doctors themselves are often left clueless about the subsequent fate of these people.

Numerous consensus statements and reviews clearly registered a very significant lack of follow-up examinations (Clayton et al. 2002; Creighton/Minto 2001; Creighton 2004; Crouch et al. 2008; Hughes et al. 2006; Lee et al. 2006; Pagon 2010; Speiser et al. 2010; Stein et al. 2005). There is a lack of proven, i.e. evidence-based[33] controlled studies that are based on a high level of evidence. All there is at the moment are opinions of expert committees which corresponds to the lowest level of evidence, since these constitute subjective case-related assessments. Moreover there are for instance no data that compare the sexual-psychological health of girls and women that were subjected to early surgery (in the first year of life) and of those who had undergone later surgery (as adolescents or adults) (Speiser et al. 2010).

Hardly anyone of us knows intersex people in our everyday lives, as they usually conceal themselves to evade the kind of pathological evaluation as commonly applied by medicine. Zehnder and Streuli (2012) use the term 'stigma' and argue that intersex people endeavour to conform to normality and conceal their otherness. All figures are however just rough estimates. The only attempt at a very comprehensive count from 2000 to 2002 by the ESPED[34] was not successful, with only 21% responses from the many relevant clinics in Germany (Thyen et al. 2006). One estimate (Hughes et al 2006) based on an older calculation by a self-help group (ISNA)[35] states roughly 1 in 4500 births (Kleinemeier/Jürgensen 2008).

With approx. 680 000 births for 2008 one thus arrives at a total of around 340 intersex persons. This is a lot of people, possibly we can even assume one

31 | Journal: Frühe Kindheit, Kindheit, 2, 2010: Inclusion of children with and without a handicap.

32 | EMBL (2010): The Difference between the Sexes: From Biology to Behavior. Conference in Heidelberg. URL: http://www.embl.de/training/events/2010/SNS10-01 [02.08.2012]. EMBL (2012): Biodiversity in the Balance: Causes and Consequences. Conference in Heidelberg. URL: http://www.embl.de/training/events/2010/SNS10-01 [02.08.2013].

33 | Evidence-based medicine (EBM): see footnote 22.

intersex person in every 1000 births, depending on which variants were not recorded. Voß (2010) describes a great number of genetically-related changes in the hormonal or anatomical blue print. Here another border appears, i.e. the principal question: which variant to take on board and which to ignore? If one includes hypospadias[36] then there are significantly more: again, roughly estimated, this affects one boy per couple of hundred births.[37]

Another source calculates after a detailed review of the pertinent literature in 2% of births a deviation from the ideal-typical male or female sex-related features and arrives at probably one or two cases with genital surgery, including hypospadias, in 1000 births per year (Blackless et al. 2000). One should note here that in approximately half of all intersex newborns the genital does not appear unusual, so the diagnosis of intersex is not yet obvious (Thyen et al. 2006), but only years later, for instance during or after puberty. In half of the intersex people with 46,XY-DSD the biological and patho-physiological cause remains unclear (Hughes et al. 2006).

Are there possible solutions?

Until recently a number of demands put to legislative politicians included the deletion of a sex/gender entry in the civil register at any age, or at least the deletion of a sex/gender entry in the births register for all persons under 18 years of age (or until marriage) (Woweries 2011a). It is important to add that not only 'sex' plays a crucial role in society, but 'gender' too. Since 2009 it is possible to dispense with the entry of sex/gender in the birth certificate, but not in the register.[38,39] Only later, i.e. in adulthood, is the introduction of a further description besides 'female' and 'male' advocated, for instance 'other', as the German Ethics Council has proposed (but not: no sex/gender, for every intersex person has a sex/gender: their own), always without any compulsion and without legal proceedings. Sex/gender assignments or attributions by medical evaluators should in any event be forbidden by law. Only the persons concerned should be allowed to comment on this.

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34 | Survey unit for rare pediatric disorders in Germany (Erhebungseinheit für seltene pädiatrische Erkrankungen in Deutschland).

35 | Calculation of specific variants see: Intersex Society of North America. URL: http://www.isna.org/faq/frequency [01.08.2013].

36 | Hypospadias is a condition where the opening of the urethra is on the underside of the penis, on the scrotum or in the area of the perineum.

37 | For instance in 1:125 to 1:300 of male live births. URL: http://www.hypospadie.com/index.html?menu=2 [01.08.2013] or 1 to 8 in 1.000 births. URL: http://www.urologielehrbuch.de/hypospadie.html [01.08.2013]. The Hypospadie Zentrum Wien (Vienna Hypospadias Centre) gives 0,3 to 3,8 per 1.000 births, URL: http://www.hypospadie.info/3.html [01.08.2013], with significant regional differences owing to the effects of dioxins and furans, PCP, organochloride pesticides and insecticides, phytoestrogens and other substances.

In the past only very few intersex people have publicly admitted to leading a life between the two dominant sexes/genders. They came out in the open in order to draw attention to the situation of intersex people.

Parents are very confused, often even under a heavy psychological strain, if they are told that their child's sex cannot be determined unequivocally (Richter-Appelt/Schimmelmann/Tiefensee 2004). They are easily urged by doctors advocating an intervention or persuaded by others to choose surgery for their child. As a rule, this is performed when the infant is between two and twelve months old. A newborn child should however not be classified, provoked by the presence of medicine, under categories such as normal or not normal, or happy or unhappy (Woweries 2011b).

Diamond was one of the first to point to a different approach, namely dispensing with medical measures in intersex children (Diamond/Sigmundson 2009 [1997]).

On 31.01.2013 the Bundestag amended §22(3) of the Civil Status Act (PStG).[40] From now on children with ambiguous genitals need not be registered either as female or male, but are recorded in the birth register as children "without sex entry" (ohne Eintrag), besides boys and girls. This is a totally new situation. One the one hand, it should be appreciated that the existence of intersex people is also legally recognized. On the other hand, parents of a newborn intersexual child can be expected to possibly resist such a registration.[41] This new provision of §22 (3) PStG should above all not lead to the wish for cosmetic surgery (Woweries 2011a). It is however conceivable that in practice a doctor could, for a child "that can be assigned neither to the female nor the male sex", nevertheless have it registered under one or the other, either female or male. Here, the doctor either erroneously does not follow the procedure proscribed by the law or else – anticipating the presumed development – he advises the parents after the child's birth to have it registered either as a girl or a boy, thus in effect ignoring, deliberately or unwittingly, the legal provision for children with ambiguous genitals. The legislator has failed to take a changing development of sex/gender into account. What has remained unresolved and undiscussed is the question how to proceed if the parents come to realize in the course of the child's devel-

38 | § 59 birth certificate: "(1) The birth certificate will include 1. the child's first name and name at birth, the child's gender, [...]. (2) If so requested, information according to section 1 No. 2, 4 and 5 is not included". However, a certified copy of the birth register has to be presented when marrying, enrolling at school and for numerous social welfare benefits applications.

39 | Since the term 'gender' is actually wrong it should say 'registered civil status'.

40 | §22 (3) PStG: "If the child can be assigned neither to the female nor the male sex, then the civil status case must be entered into the birth register without this information."

41 | German ethics council, Intersex, statement: (personal translation) "Experts report from professional experience that a significant number of parents cannot accept their children if their gender remains undetermined.", p. 88.

opment and education before, during or after puberty that they, or their child, regard a different sex/gender than the one previously assigned as the more adequate one. What can these people, as adolescents or adults, apply for themselves at their own initiative and under what medical and administrative conditions? Such – multiple – changes must not and cannot be declared every time as a "rectification by" reviewing doctors. It is only a person's own free choice for their gender that should be considered in social life and legislation. Comprehensive information of all those concerned is necessary to ensure that intersex people are not discriminated in the family, in the neighbourhood, in the kindergarten or at school, which would ultimately lead to psychological stress. The network Intersexualität has already identified many cases in the past where it was possible to avoid discrimination. Moreover, the majority of parents with an intersex child who discussed it with friends or neighbours did not experience any stress. Only 6% of the intersex people reported as adults today negative reactions when mentioning their own situation.[42] On the other hand, ¾ of all adolescents do not want their parents to discuss their situation with others.[43] The majority of parents of intersex children will presumably choose to raise their child in one of the two traditional gender roles as a boy or a girl. Richter-Appelt's recommendation is important here that the parents speak candidly and lovingly with their children: about day-to-day life and about the sex/gender identity the child will later choose for itself – this is very important for the developing gender identity (Richter-Appelt 2012b).

It would be desirable and should be demanded that § 22 (3) PStG permits a choice via implementation regulations laid down in new paragraphs of the PStG. There should not be a permanent entry already after birth, for this new provision induces an outing (compulsory outing) in day-to-day life that is not the child's choice.

Here it should be ensured that only the persons concerned can decide on the identity of their gender. A low-threshold transition has to be possible too, because with some intersex children it is only during or after puberty that a different situation emerges. With around half of all intersex newborns (Thyen et al. 2006) an intersex variation can only be detected at the time of puberty or after.

It remains important that health-related self-help groups and independent psychological counseling become an integral part and are financed. The ethical guidelines and principles contain a number of recommendations (Wiesemann

42 | Kleinemeier, E., Jürgensen, M. (2008): Erste Ergebnisse der klinischen Evaluationsstudie im Netzwerk Störungen der Geschlechtsentwicklungen. p. 34. URL: http://www.netzwerk-dsd.uk-sh.de. [03.05.2011].
43 | Ibid, p. 35.

2008), including: "Categorizing gender exclusively on the basis of biological and morphological facts fails to do justice to the individuality and subjectivity of the individual as well as the contingency of gender identity on social and psychological factors."

All human beings have a body of their own.
All human beings have a gender identity of their own.
All human beings should be able to decide for themselves!

Imposed, dichotomous concepts, norms for body and mind
curtail human rights.

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