Intersex: Medical Measures on the Test Bed[1]

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SUMMARY

Intersex persons are regarded by medical practitioners as a disruption of the sex order because they have genitals that do not conform to the norm. The awareness for the impact of 'gender' also and in particular in the field of medicine does not seem to be very pronounced among its professionals, with the result that this term is largely absent in medical literature. However, in order to emphasize the impact and interrelatedness of both terms 'sex' and 'gender' they frequently appear together in the following text.[2] In the past, but also in the present, intersex persons were regarded as being in need of treatment and as a consequence were subjected to primarily genital assignment surgery in order to achieve a simulated superficial norming of their sex. In doing so, the norms of the German term 'Geschlecht',[3] also present in medicine, as well as the mechanisms of their implementation are ignored because the surgeons referred to here are only concerned with the body. What is crucial here is that these intersex persons are infants and children who owing to their age could not and cannot give their consent. However, surgery involves a high risk and damage to health. This contribution focuses on the special situation of girls with 46,XX-DSD, because it has shown that for a not unsubstantial 'quantity' surgical interventions in childhood can have the result that the sex/gender identity perceived by that person at a later age as belonging to her or him can no longer be taken into account.

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[1] Original version in German.

[2] This does not apply to German, since the term 'Geschlecht' comprises both aspects.

[3] The German term 'Geschlecht' includes besides the physical component ('sex') also the psychological ('sex/gender identity') and social ('gender') components.

INTRODUCTION

Since the Chicago Consensus Conference (Hughes 2006) and in the medical guidelines[4] intersex persons are catalogued under 'Disorder of Sex Development' (DSD) (see Woweries[5]) thereby according a key position to medicine. This goes hand in hand with the assumption that the heterosexual binary sex-related constitutiveness remains the basic point of reference, that sex as well as gender is assigned for life and that in intersex people the physical basis for either of these two sexes has yet to be established (Götze 2011). What this perspective ignores completely is that intersex, viewed from a totally different angle, could be regarded as an individual feature to be appreciated and not as a problem that calls for medical treatment (Voß 2012). This kind of sociocultural perspective is what the Swiss ethics commission (2012) attempts to take into account when it uses phrasings such as 'sex/gender variants' or 'differences of sex development'[6] in order to avoid a pathological connotation. It is with this in mind that it refers to "infants and children who are in principle healthy" but who "with reference to the child's welfare [...] have been subjected until very recently to sex/gender assignment surgery."[7] This medical view of sex disregards the psychological and social perspective.

What is being done?

The aim of all medical and surgical measures is to align the external genitalia that do not conform to the norm either with the male or the female genitalia. As a rule, multiple reassignment operations are performed on the genitalia to achieve a spurious superficial norming of the sex. These operations are irreversible. In general the following operations are performed:

1. In numerous intersex persons with a female phenotype, who however have a male 46,XY set of chromosomes, the testes are removed. This is in effect a castration which in Germany is punishable as grievous bodily harm.[8] This

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[4] | Deutsche Gesellschaft für Kinderheilkunde und Jugendmedizin (DGKJ) (2010): Leitlinien: Störungen der Geschlechtsentwicklung (Guidelines: Disorders of sexual development). In: AWMF-Leitlinien-Register Nr. 027/022. URL: http://www.awmf.org/leitlinien/detail/ll/027-022.html [01.08.2013]. Deutsche Gesellschaft für Kinderheilkunde und Jugendmedizin (DGKJ) (2010): Leitlinien: Adrenogenitales Syndrom (Guidelines: adrenogenital syndrome). In: AWMF-Leitlinien-Register Nr. 027/047.
URL: http://www.awmf.org/leitlinien/detail/ll/027-047.html [01.08.2013].

[5] | See Jörg Woweries' contribution in this publication: 'Who is sick? Who gets to decide?'

[6] | Statement of the Swiss National Ethics Commission for Human Medicine (2012): Zum Umgang mit Varianten der Geschlechtsentwicklung. Ethische Fragen zur 'Intersexualität'. (On dealing with variants of sex development. Ethical issues in 'intersexuality') p. 7.
URL: http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=de [01.08.2013].

[7] | Ibid., p. 5.

[8] | For children § 1631c BGB: "The parents cannot consent to a sterilization of the child. Neither can the child consent to a sterilization."

is however circumvented with the assertion that this is a surgical intervention for the welfare of the child by pointing to a debatable later possibility of a malignant deformation. Even though in rare cases there is the risk, much later in life, of a degeneration to cancer[9,10,11] regular preventive medical checkups can keep this risk to an acceptable minimum. However, the testes are almost always removed without any recognizable calculation of a possible risk of degeneration, because they do not match the external image of the female genitals that the surgery attempts to achieve.

2. Shortening of an elongated clitoris (clitorectomy, clitoral reduction).
3. Broadening and elongating a vagina regarded as rudimentary, resulting in a so-called neo-vagina.
4. Surgical modifications of internal genitalia.
5. A further complex of intersex phenomena, hypospadia[12], is not considered in this article for reasons of space.
6. Unilateral dystopic testes are not part of this system of genital surgery discussed here since they do not regard intersex people.[13]

Who is sick? Who is made sick?

A vital hormone substitution for loss of salt is necessary in a special form of intersex, the adrenogenital syndrome (AGS).[14] Medical, i.e. vital surgical interventions are only indicated in cases when the flow of urine is prevented. In these cases the parents have to give their child's consent by proxy as its life is at stake. All other forms of surgery are cosmetic or esthetic operations since they lack the medical indication in the sense of preventing a life-threatening condition. It is all merely about the external appearance.

Concerning the damage and risk of genital surgery one can safely say that it involves high rates of damage and an on the whole elevated risk. The risk of damaging sensitive nerves is clearly elevated and, as with all surgery, unavoid-

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[9] | "Data on the risk of malignant deformations are lacking completely here. The literature references on a definitive risk of a development of gonadal tumors are insufficient. In cases of gonadal dysgenesis and female assignment an early gonadectomy is therefore recommended (approx. at the age of 1 year or together with other surgery)". AWMF guideline register No. 027/022, p. 5.

[10] | For the complete androgen insensitivity syncrom (CAIS) the risk of a malignant tumor is 0,8%, for ovotesticular DSD it is 2,6% and for the partial AIS it is around 15%. In cases of gonodal dysgeny the risk can be over 30%. (Pleskacova, J. et al. 2010). The lifelong risk of breast cancer is around 12,2% (according to US National Cancer Institute) No doctor would dream of removing the breast in all girls because of this risk.

[11] | According to the relevant literature the risk of the development of a gonadal blastoma for XY women with dysgenetic gonads is above approx. 30%. Cools, Martine et al.: Germ Cell Tumors in the Intersex Gonads. In: Endocrin Rev 27, 5, pp. 468-484. Pleskacova, J. et al. (2010), p. 7.

[12] | In hypospadia the urinary tract does not end in the tip of the penis, but on the underside of the penis, on the scrotum or in the area of the perineum.

[13] | Rudimentary, functionless testes that do not lie in the scrotum without any indication of an intersex development.

[14] | AWMF guideline register No. 027/047.

able in practice (Bosinski 2005; Diamond/Sigmundson 1997; Meyer-Bahlburg 2008). "Even today patients with DSD incur the risk of being traumatized by medical and psychological treatment" (Birnbaum et al. 2013). And Kessler asks: "Why does the solution for ambiguous genitals always have to be the surgeon's scalpel?" Kessler (1998: 105). Statements on post-operative results have only been presented in the last years. With the conspiracy of silence that was part of the doctors' system of treatment the endocrinologists and surgeons obstructed themselves by dispensing with a retrospective review of their interventions (see Woweries[15]). A first convincing evaluation after more than 40 years of surgical practice concerned statements of intersex people in a retrospective non-representative study.[16] Surgery was performed almost exclusively on persons who were unable to give their consent.[17] Of the children of the age of 7 and 12 years 86% and 87% had surgery,[18] in today's adults the percentage was as high as 93,6% to 100% in three of four diagnostic groups. This leaves out of consideration that many had multiple surgery (Götz 2011; Kleinemeier/Jürgensen 2008). In many cases further operations had to be performed in later years, in puberty and after.[19] In the network study[20] 25% of the participants operated on complained about complications: most frequently about fistula formation in 40,5% of the cases, about constriction of the efferent urinary tract in 27%, about inflammation of the urinary tract in 32% and about problems with urinating in 21,4%.

In a catamnestic study 78 intersex adults have experienced their medical treatment as negative (Brinckmann/Schweizer/Richter-Appelt 2007; Schweizer 2012). 62% displayed clinically relevant psychological suffering and 47% contemplated suicide. These reactions are frequently a result of the numerous operations, together with being exhibited by doctors in the framework of medical student and specialist training and the appurtenant experience of feeling helpless and exposed. Kessler writes that "excess genital examination is a form of abuse" (Kessler 1998: 59). If recognition is a part of human social participation, then the "negative experiences with the tabooization of the issue" (German ethics commission 2012) and the mere statistical infrequency in public perception are sufficient for generating stigmatization. For this reason, intersex people often hide their otherness (Zehnder/Streuli 2012). 13,5% report about past self-muti-

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[15] | See Jörg Woweries' contribution in this publication: 'Who is sick? Who gets to decide?'

[16] | Kleinemeier, E., Jürgensen, M. (2008): Netzwerk Intersexualität: Erste Ergebnisse der Klinischen Evaluationsstudie im Netzwerk Störungen der Geschlechtsentwicklung/Intersexualität in Deutschland, Österreich und Schweiz. Januar 2005 bis Dezember 2007. URL: http://www.netzwerk-dsd.uk-sh.de/fileadmin/documents/netzwerk/evalstudie/Bericht_Klinische_Evaluationsstudie.pdf [03.09.2013].

[17] | Ibid. p. 16.

[18] | Ibid. p. 16.

[19] | Ibid. p. 16.

[20] | Ibid. p. 17.

lations – also for the reasons explained above. The parent-child relationship too is subjected to severe stress (Richter-Appelt/Schimmelmann/Tiefensee 2004). In addition, the network Intersexualität reports about psychological strain in 45% of adult intersex persons (Kleinemeier/Jürgensen 2008). The findings of a meta study indicate that the goal of a normal psychosocial development was not reached.[21]

A retrospective, non-representative recall study of 57 persons with the male XY set of chromosomes, but an at first sight female phenotype (complete or partial androgen insensitivity syndrome – CAIS or PAIS) (Köhler et al. 2012) established the following: the participants had had surgery in childhood so that their genitals would better match the female sex assigned by the attending doctor.[22] The recall study indicated that 47,1% of the participants experienced discomfort in the function of the vagina, i.e. the vagina was too small for tampons, 47,4% suffered considerable loss of clitoris sensitivity. 56,3% to 70% complained about continuous pains while having sexual intercourse, depending on the subgroup (CAIS or PAIS). In the light of these very frequent damages the authors could not but recommend that this kind of surgery should not be performed in childhood. They demand the consent of the adult patients themselves, not their parents. The German Ethics Council also recommends that the decision should on principle be made exclusively by those affected capable of giving consent (German Ethics Council 2012: 174).

Additional discussions about girls with 46,XX-DSD and andreno-genital syndrome (AGS)

The German Ethics Council refers to the surgery on the genitals of girls with 46,XX-DSD and AGS syndrome as sex disambiguation surgery (2012: 108). One should however attempt to understand which reasons might have led the German Ethics Council to differentiate between sex assignment and sex disambiguation surgery. From the literature published in the statement of the Ethics Council we can deduce the following: after a survey by the network Intersexualität and the Hamburg study by Richter-Appelt it was possible to establish that a large number of women with AGS are also later satisfied with surgery they had undergone in childhood. Many do not see themselves as intersex people. These persons live as adults in a female role. This fact has to be acknowledged. For this reason the German society for child endocrinology and diabetology (Deutsche

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[21] | Refers to 21 international studies from the years 1974-2007. Schönbucher et al.: Sexuelle Lebensqualität von Personen mit Intersexualität und 46,XY-Kariotyp, ZfS 2008, pp. 26 ff.

[22] | According to the consensus statements DSD persons with 46,XY CAIS and most people with PAIS were assigned as women. Hughes, I. A. et al. (2006): Consensus statement on management of intersex disorders. In: Arch Dis Child 91, p. 556.

Gesellschaft für Kinderendokrinologie und Diabetologie) recommends surgery in cases of AGS also in early childhood (Birnbaum et al. 2013: 161, 150). It is however surprising if in this situation the council concludes that this surgical procedure should include all children with AGS (surgery is recommended at the age from two to twelve months).[23] This ignores those intersex people who later, as adolescents or adults, do not wish to live in the female role. These voices thus remain unconsidered. A large proportion however lives either in a male role or does not feel it belongs to either sex. The German Ethics Council (2012: 86) states that 31% of the participants with AGS plead for leaving sex/gender reassignment open. Bora (2012: 28), expert of the German Ethics Council, stated that this was the case with 35-40% of persons with AGS. According to Nieder and Richter-Appelt "we know from research that the majority of persons with AGS, despite 46,XX karyotype, live in the male role."[24] The guidelines mentioned in the beginning report 17% (of these 5% of 46,XX women and up to 12% of 46,XX men with classical 21 hydroxylase deficiency) who complain about problems with the assigned gender role.[25] Of the women adult today 10% attained an unusually high score on the transgender scale, further 3% are very unsure concerning their sex/gender affiliation (Kleinemeier/Jürgensen 2008). These studies show methodological differences in evaluation, depending on whether the so-called AGS girls were asked whether they would prefer to be a girl or rather a boy or whether they are confused about their own gender identity. The data come from diverse sources and are thus inconsistent, but they concern a larger quantity for whom such operations constitute sex/gender assignment surgery. These people know only the experienced or imposed sharp dichotomous separation of the sexes and they mostly find themselves in a situation after genital surgery. Such surgical measures greatly impede a later transition to the other sex (Meyer-Bahlburg 2008). This prevents to an unknown extent a voluntary affiliation in another direction. It is conceivable that other, female-assigned people could profess to want to live in the male or in another gender role. This aspect contradicts the statement of the German Ethics Council that the surgery performed on children with 46,XX DSD and AGS only constitutes sex disambiguation surgery. Here,

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[23] "[...] it is undeniable that in prenatally virilized girls a corrective, feminizing operation of the external genitalia has to be peformed" [JW]. Riepe, F. G., Sippel, W. (2008): Das Adrenogenitale Syndrom. In: Kinder- und Jugendarzt 39, p. 112.

[24] Nieder, T. O., Richter-Appelt, H. (2009): Neurobiologische Korrelate bei Geschlechtsidentitätsstörungen. In: Psychiatrie im Dialog 10: 60.They also quote: Richter-Appelt, H., Discher, C., Gedrose, B. (2005): Gender identity and recalled gender related childhood play-behaviour in adult individuals with different forms of inter-sexuality. In: Anthropologischer Anzeiger 63, pp. 241-256; Jorge, J. C. et al. (2008): Male gender identity in an XX individual with congenital adrenal hyperplasia. In: The journal of sexual medicine, 5, pp. 122-131; Meyer-Bahlburg, H. F. L. et al. (2006): Gender development in women with congenital adrenal hyperplasia as a function of disorder severity. In: Archives of sexual behavior 35, pp. 667-684.

[25] AWMF guideline register no. 027/047.

the social aspect of 'gender' was not taken into account in the council's discussion of the issue.

The term 'sex/gender identity' also includes, besides the physical features, always also one's own determination of one's sex and gender, which comprises the self-perception as man or woman or something else, for instance whether one assigns oneself to one of the two sexes, to none of them or both of them. Depending on which subgroup of intersex people has been interviewed,15-30% or more have experienced a high degree of insecurity as to which sex/gender category they should assign themselves to (Schweizer/Richter-Appelt 2012: 187 f., 207 f., 225 f., 433 f.). A majority (58%) of intersex people and 31% of the AGS persons advocate leaving the educational gender open; this decision should be considered in a flexible way and not force children into a particular gender behaviour (German Ethics Council 2012: 86 f.). Even though the gender role can often be surmised already in early childhood, it is only later, around the time of puberty, that children's awareness and own views are better taken notice of (Diamond 2008).

There are indications from medicine and neuropsychology that in so-called AGS girls the own further orientation is determined already before birth by testosterone and testosterone-similar substances such as androgen. In the course of their development they see themselves later in a female,[26] a male role or one deviating from these.[27,28] "However, there appears to be no correlation between the severity of the genital phenotype and the existence of problems."[29] Diamond and Richter-Appelt (2008) comment on this: "The most important sex organ is between the ears."

The following can be considered an undeniable fact:

- Sex/gender identity cannot be recognized at birth, neither do the sex chromosomes (XX or XY chromosomes) determine sex/gender identity.
- There is no stringent causality between genital appearance and sex/gender identity.
- Sex/gender identity cannot be determined by any medical or psychological measure. This can only be done by the individuals themselves.

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[26] | Girls with 46,XX DSD are sometimes referred to as tomboys. This is however as a rule not regarded as an intersex variant.

[27] | Among others Berenbaum, S. A., Hines, M. (2003): Effects on gender identity of prenatal androgens and genital appearence: evidence from girls with congential adrenal hyperplasia. In: J Clin Endocin Metab 88, 3, pp. 1102-1106.

[28] | Holterhus, P. M. (2012): Prägung des menschlichen Genoms durch Androgene. Molekulares Gedächtnis der Androgenwirkung. In: Intersexualität kontrovers. Schweizer/Richter-Appelt (Eds.). Psychosozial.

[29] | AWMF guideline register No. 027/022.

- The awareness of one's own gender comes about in a developmental process that goes on for years and can continue beyond the time of puberty.
- Whether someone regards themselves as a man, a woman or something else cannot be assigned or established by any surgery.
- "An assimilation of intersexuals into one of the two sexes doesn't work", emphasizes Reiter (2000).

These aspects should be considered when judging surgery on infants, children and adolescents. Deciding to which sex one belongs is something only the person concerned can do, so sex disambiguation surgery on children is also inadmissible under whatever circumstances. Already some time ago Diamond and Sigmundson (1997) demanded that surgery that is not vital should be deferred until the persons themselves request it. As a consequence of much criticism an ethics group in Germany (Wiesemann/Arbeitsgruppe Ethik im Netzwerk Intersexualität 2008) has demanded that measures that are practiced without satisfying evidence, that are irreversible and performed without necessary medical indication should be postponed until the persons themselves wish to take the decision and are old enough to be allowed to do so. For the German Ethics Council (2012: 112) too it is a primary goal "that the self-determination of the child should not be limited unacceptably by unnecessary surgery." "We also know from the relevant literature that a higher than average percentage of people with various forms of disorder of sex development decide in the course of puberty or in adulthood to change the social gender assigned to them." (Jürgensen/Hiort/Thyen 2008). The German Ethics Council interviewed girls and women with the adrenogenital syndrome: around 50% of the questions were answered by the parents. This raises the question how often the parents' doubts concerning the surgery they approved of in the past have influenced the answers to justify their own decision, to apologize or to live with the decision they took at the time. One should here also note the parent's pressure for medical action (Kleinemeier/Jürgensen 2008: 17) and the research conducted by Dayner (2004). The latter showed that for 95% of the parents the genital appearance, i.e. the external image, is more important than erotic responsiveness. Then female students in the second part of the survey were asked to imagine having been born with a 1 cm long clitoris and thus, due to the supposedly excessive size, not conforming to conventional notions. An overwhelming majority of 93% of the students responded that they would not have wanted their parents to consent to surgery in order to change the genital appearance if this would have meant the loss of sexual responsiveness or of the ability to experience an orgasm. More than 50% of the students would not have wanted surgery, even if the outer appearance would have been perceived as unattractive or unpleasant. These students would rather have preferred other kinds of surgery, for instance to reduce the size of noses, ears or breasts instead of surgically shortening a supposedly too long clitoris.

Lembke's arguments in her note to the German Ethics Council (2011) also belong to this discussion: the imposition of notions about the 'right' genitalia, unambiguous sex, and the acceptable size of a clitoris or the 'right' sexuality violates fundamental human rights and has furthermore serious negative effects on the desired sex/gender equality by reproducing female stereotypes. This is exactly what the UN women's right convention wants to see stopped. Kessler (1998: 56 f., 107 f.) criticizes that a vaginoplasty is constructed in a girl for one reason only, namely to enable sexual intercourse with a man. The idea that all women desire heterosexual intercourse perpetualizes the notion of women as passive receptacles of male desire.

In 1961, a highly renowned pediatrician, Prof. Jürgen Bierich (1961: 387), wrote a contribution in a standard text book on intersex that was used well into the 1970s. While the reduction of a too large clitoris has remained a topic to this day, at the time he even demanded the extirpation i.e. the complete carving out of the clitoris, because the enlarged clitoris would be in the man's way during intercourse. For this reason Bierich recommended this operation on children under 4 years of age. The incredible brutality connected with such a procedure can compare with the genital mutilation still practiced on girls in parts of Africa, the female genital mutilations (FMG). These have been denounced since 1995 by the United Nations as a human rights violation. In 2013 the German Bundestag debated over a criminal code amendment act on the punishability of the mutilation of female genitalia.[30] With his call for genital mutilation Bierich had his co-perpetrators and predecessors. Medical journals can tell us that in the mid-19th century in Germany and other countries in Europe clitorectomy was performed hundreds of times for various reasons, e.g. to combat mental disorder and epilepsy, masturbation and lust in women.[31] As late as in 1938 the Zentralblatt der Gynäkologie (central journal of gynecology) described clitorectomy for treatment of masturbation.[32] It is very irritating that echoes of the past still linger on today, albeit in a subconscious or suppressed way. In some medical centres in Europe the complete removal of the clitoris (clitorectomy) is still the method of choice for an enlarged clitoris (Riepe et al. 2002).

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30 | Rechtsausschuss (judicial committee), 24 April 2013, StrÄndG. URL: http://www.bundestag.de/bundestag/ausschuesse17/a06/anhoerungen/archiv/46____Str__ndG/index.html [03.08.2013].

In several consensus statements and reviews one can read the following statements[33] about children with 46,XX and AGS:[34] the consensus statements of 2002 and 2006 (Clayton et al. 2002 and Hughes et al. 2006) suggest that 46,XX DSD children with a significant virilization should be presented as adolescents at the earliest. Surgery, such as vaginoplasty, should be deferred until adolescence or adulthood, since there are no controlled clinical tests on the effect of early surgery (under 12 months) compared to later surgery (in adults or older adolescents). Let me add here some additional study findings: after clitoral surgery 78% showed a high rate of non-responsiveness and a loss of ability to orgasm compared with 20% of non-operated women in a comparison study.[35] After vaginoplasty the appearance may be satisfying, but the vagina is too narrow for sexual intercourse, which occurs in more than 80% of the respondents (Creighton 2004). If a cosmetic surgery is desired one has to take the possibility into account that the artificially created opening will grow together again with the consequence that a vaginal dilation has to be performed. A number of articles warn against follow-up surgery on children and treatment by bougie, i.e. keeping the orifice open via mechanical instruments in many examinations over many months. These measures can lead to very severe and long-term psychological traumatization.[36,37,38] "Inserting a bougie in a girl's vagina amounts to rape", says Kraus-Kinsky (2012: 162). Kessler rates these numerously repeated procedures as sexual abuse. "All research on this subject reports throughout [...] reduced sexual responsiveness in AGS patients, which appears to correlate with the degree of [...] the corrective genital surgery" (Wünsch/Wessel 2008: 41). "Vaginoplasty is actually only necessary for penetration and can therefore be postponed until adolescence" (Bosinski 2005: 40). For these reasons Krege (2011), as a surgeon, prefers to perform surgery in a later period in life, because she can then discuss it with the girls themselves. One should therefore wait until the adolescents or the

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31 | Hulverscheidt, M. (2011): Weibliche Genitalverstümmelung. Mabuse-Verlag.

32 | Ibid. p. 19, quote Zentralbl Gynäkol 11, pp. 584-585.

33 | Clayton et al. (2002); Creighton (2004); Creighton/Minto (2001); Creighton/Minto/Steele (2001); Crouch et al. (2008); Hughes et al. (2006); Lee et al. (2006); Pagon et al. (2010); Speiser et al. (2010); Stein et al. in collaboration with the Canadian Pediatric Endocrine Group (2005).

34 | Kessler reports in detail on the older literature 1998, pp. 52-76.

35 |Mouriquand, P., surgeon, (text from the ARTE film of 04.10.2010 (in translation)) "It would be window dressing to assure the parents that a clitoral reduction would have no effect on responsiveness. No one can do that."

36 | Hoepffner, W. nach Finke/Höhne (2008) (ed.): Intersexualität bei Kindern. p. 133; Riepe F. G., Sippel, W. (2008) In: Kinder- und Jugendarzt 2, 39, p. 112; Bosinski, H. A. G. (2006): Sexualmedizinische Aspekte bei Intersex-Syndromen. In: Urologe 45, pp. 981-991.

37 | AWMF guideline register No. 027/022.

38 | Wünsch, L., Wessel L. (2008): Chirurgische Strategien bei Störungen der Geschlechtsentwicklung. In: Monatsschrift Kinderheilkunde 156, pp. 234-240.

adults themselves express the wish to undergo surgery. Anyone who advocates clitoral reduction lets himself be guided by randomly established cultural norms. Preservation of responsiveness after clitoral reduction cannot be guaranteed. Therefore clitoral reduction in childhood is not acceptable, it can only be desired by persons capable of consent – as a cosmetic operation – if they desire it at all. "Unfortunately there are only very few good long-term postoperative studies in this area, and the existing study findings refer to operative methods that have long since fallen out of use, since they are no longer regarded as acceptable today" (Grüters 2008: 34). Therefore, genital operations are basically all one-off experiments, because impaired sensitivity or too narrow vaginoplasty can be detected by the person concerned only after many years, in adolescence or adulthood.

Proposals to policy makers

Human rights organizations, self-help groups of intersex people and others demand an immediate halt to all cosmetic surgery on genitals in infants or other children under the age of consent. This also has to apply to people with the adrenogenital syndrome (AGS). Any surgical procedures that risk a permanent impairment of fertility or sexual responsiveness have to be terminated immediately.[39] These constitute serious violations of children's rights. This also reflects the view of the German federal government.[40]

The reports to the human rights commission of the United Nations have led politicians in the German Bundestag to question the views and practices of many medical practitioners and clinicians.[41]

Have the medical practitioners changed their stance following the accusations of the UN human rights commission and the German parliament? Up to now there have been no joint critical statements on the existing practices and the guidelines continue to remain in effect.

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39 | Deutscher Bundestag Drucksache 17/ 13253, 24. 04. 2013: The SPD calls on the German Bundestag/ government to "assure that sex assignment and assimilation surgery on juvenile intersex persons before their age of consent are banned. At the same time it has to be guaranteed that a unique by-proxy consent of the parents to irreversible sex assignment surgery of their under-age child is not permitted – except in life-threatening emergencies or when there is a medical indication." In addition also further motions by other parties: Deutscher Bundestag Drucksache 17/12859, 20.03.2013; Deutscher Bundestag Drucksache 17/12851, 20.3.2013.

40 | Deutscher Bundestag Drucksache 17/11855, 12.12.2012, p. 5.

41 | Deutscher Bundestag Drucksache 17/14014, 14.06.2013: Beschlussempfehlung und Bericht. (Decision recommendation and report). URL: http://dip21.bundestag.de/dip21/btd/17/140/1714014.pdf [02.12.2013].

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