


The medical habitus and intersex Experiences of parents

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The medical habitus and intersex

Experiences of parents

- Why parents?
- My theoretical lens
- Medicine and Intersex
- The German discourse
- Experiences of parents
- Conclusion

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The concept of Bourdieu's Habitus

- structure that forms “the schemes of perception, thought and action” (Bourdieu 1990, p. 54) of an individual or a group
- „(...) the individual habitus in so far as it expresses or reflects the class (or group), could be regarded as a subjective but non-individual system of internalized structures, common schemes of perception, conception and action, which are the precondition of all objectification and apperception.”
(Bourdieu 1990, p. 60)

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Freidson´s Construction of Illness

“Diagnosis and treatment are not biological acts common to mice, monkeys, and men, but social acts peculiar to men.

Illness as such may be biological disease, but the idea of illness is not, and neither is the way human beings respond to it. Thus, biological deviance or disease is defined socially and is surrounded by social acts that condition it.” (Freidson 1970, p. 209)

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“In Western culture, Intersex refers to the physical constitution of people whose sexually attributed characteristics such as chromosomes, gonads, hormones or the genitals cannot be clearly classified in the binary system of men and women from birth.”
(Krämer/Sabisch 2017 (translation by A.K.))

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Experiences of parents

- Since 1993/1996: Critiques of Intersex activist groups
- 2005: Chicago Consensus Conference
- 2008: Shadow report → CEDAW
- 2010: CEDAW decision
- 2012: Opinion paper German Ethics Council
- 2013: Sex entry must be left blank in civil register
- 2014: Inter-ministerial Work Group Inter- and Transsexuality
- 2014: Vanja's lawsuit begins
- 2017: Federal Constitutional Court rules in favor of Vanja



Photo credit: Ulrike Klöppel

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"In view of the biological dimensions and the lived experiences of people with differences of sex development, providing adequate psychological and medical support/ treatment requires a revision of the traditional normative view of man and woman. The awareness of the inadequacy of the 'either/or' of two separated sex/genders enables the specialist, together with the person concerned and their relatives, to rediscover and redefine the field of the lived gender, whether as a whole or in specific behaviors."

(Krege et al. 2016, p. 4 (translated by A.K.))

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1. Dissatisfaction with the hospital as a social place
 - Had to change the hospital several times
 - High organisational effort
 - Emotional stress

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2. Dissatisfaction with the clinical discussion
 - Shock due to lack of previous knowledge
 - Physicians focus on medical aspects
 - Parents needed emotional support

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Mother D: „ Blind vagina. Enlargement. Vaginoplasty, ahm, Iron-’tampon’ for dilatation, and I don't know what else. Our child was one year old, I had other worries: may she dress in pink? may she play with dolls? must she play with cars? Where does the journey go for us? So the existential, man or woman was gone. I didn't know it could be otherwise.“ (translated by A.K.)

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Mother E: „Yes for us it was of course a huge shock, also because of this speechlessness of the doctors and this, yes ‘You have got a diseased child’. So for us it was at first a big effort to adopt a different attitude.“

(translated by A.K.)

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Mother C: ‘So I confronted him and asked him why on earth he did that, why on earth he put the gonads in the abdomen and his answer was that he had understood that she should grow up as a girl (2) I said so far so good, but where is the problem? The problem is that at some point you might see them when they lie in the groin” (translated by A.K.)

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- ### 3. Dissatisfaction with the medical treatment
- Social instead of medical reasons for surgery
 - Crossing legal borders

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Mother D: „The doctor came back the night before we were discharged. The other one. We wouldn't do our daughter any favour. So, um, he would really urge us out of his experience not to make it public. So we left with this the-world-has-collapsed feeling and we couldn't tell anyone. We also couldn't talk to each other about it at first because I knew that the whole topic was terrible for my husband, and then when the genetic lab said that I am a carrier of the genetic disposition, a feeling of guilt burned inside me. This feeling: On top of this, this is my fault”

(translated by A.K.)

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Thank you for your attention!

