Intersex and Human Rights[1]

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Summary

According to a statement by Luxembourg's political parties of September 2012 there are no intersex people in Luxembourg. This is a surprising assessment since there are intersex people all over the world. One reason for this invisibility of intersex people is that also in the 21st century society is still marked by sex and gender binary and heterosexuality. Anyone who cannot or will not fit into to these paradigms is regarded as abnormal and has to be aligned. Children are still operated on to align them with one of the two standard sexes and respective genders, some of them are even aborted before birth. But there are also countries that do not have this tradition of mutilation, such as Nepal or some Indian Federal States. In recent times an increasing number of countries have included further gender categories in official documents. In addition, more and more international declarations and recommendations are issued that take an unequivocal stance against sex/gender assignment surgery and other medical interventions on people below the age of consent.[2]

Introduction

Participating in a round-table discussion with Luxembourg's political parties on the issue of intersex at the conference "Gender Normativity and its Effects on Childhood and Adolescence" I was extremely surprised to hear that there are supposedly no intersex people living in Luxembourg. This is hard to believe considering that in France according to medical practitioners 8000 intersex chil-

1 | Original in French.

2 | These other medical interventions mainly consist in hormonotherapy, non-health related nude examinations, as well as photography taking, as well as gender role prescription.

dren are born every year[3] and in the Western countries intersex is more common than previously thought, with every 2000th birth and a proportion of 1,728% of the population on entering puberty (Fausto-Sterling 2000: 53). This raises the question how in a small, wealthy and very modern country such as Luxembourg something can be named that does not exist (Guillot 2008) and above all, why it doesn't exist? The reasons advanced by the participants of the round-table discussion were that Luxembourg has only since very recently a cancer registry, but as yet no comparable data bank of other disorders – and thus also not of intersex – that the sex/gender assignment operations, which I would like to describe as mutilations, are outsourced to neighbouring countries and that intersex people are not mentioned in Luxembourg's legislation. But I believe the essential causes for this absence lie somewhere else and a corresponding survey among practitioners potentially attending intersex people (gynecologists, endocrinologists, urologists etc.) could contribute to identifying them. One should also bear in mind that the sex and gender binary and heterosexuality shape our Western societies for whom a sex(/gender)-atypical person seems to be something inconceivable. The coitus is per force heterosexual, whether penetrating or penetrated. A man has to urinate standing up, everything is measured by the presence or non-presence of the penis and the rest is regarded as an undesirable fragment to be eradicated. In addition, the consistent invisibilization of these non-conformable people is the result of a biopolitics (Foucault) and was systematized by the psychologist Money in the middle of the 20th century in the form of the Hopkins protocol. Children that cannot be assigned to one of the standard sexes (male/female) are assigned a sex directly after birth in an emergency operation – usually the female one – thereby deleting every trace of their singularity. Parents and relatives are expected to continuously stabilize discursively the sex selected by the doctors, regarded as the true sex, and to deny the children concerned their original otherness. This leads to the intersex paradigm: "We are not allowed to say that which we have not been told that we are." (Guillot 2008). In my view, these traditional medical interventions amount to genital mutilations and physical torture. At best they damage sexual responsiveness, at worst and very often they lead to serious problems such as incontinence, fistula formation or chronic pain which in turn frequently require numerous surgical corrections. Furthermore, these children are as a rule castrated and artificially turned into life-long hormone patients, and this only because they violate sex and gender norms. But the interventions also constitute psychological torture because the institu-

3 | Interview by René Frydman with the pediatric surgeon professor Claire Fékété on 22 January 2013 on France Culture. URL: http://www.franceculture.fr/player/reecouter?play=4566631 [02.09.2013].

tionalized silence creates shame and ignorance about one's own body, which all through one's youth flare up anew with every encounter with the doctors, since the repeated treatments are never openly justified – because they cannot be justified medically. This psychological torture can be reactivated for an entire life with every contact with the medical world, since the person's inter sex/gender-related constitutiveness is systematically negated or silenced when they ask for explanations from the doctors. These interventions are regarded by biopolitics as medical and (psycho)social emergency measures whose aim it is not to relieve the affected persons themselves, but the supposed psychological suffering of a third party, the parents (American Academy of Pediatrics 2000; Fausto-Sterling 2000; Gueniche et al. 2008; Lee et al. 2006; Meyer-Bahlburg 2008).

In other words, intersex is one of the rare cases in modern medicine where the one group of people (the children) are physically mutilated to relieve the other (the parents) psychologically (Aaronson 2004; Holmes 2008, 2011; Karkazis 2008). This does not pay off, neither for the children, who do not feel comfortable in their body and will be sick for the rest of their lives, although they enjoyed the best of health before, nor for the parents, whose initial anxiety about the birth of a child with atypical sex characteristics makes way to a continuing pain which places a burden on the entire family for generations with its mixture of taboo, secrets and doubts about the choice of the right or wrong sex. There is nothing to justify these mutilations, because even if the external sexual organs of intersex persons are not conventional, they are nevertheless healthy and functional in the sense of sexual responsiveness. Adult intersex persons describe their mutilation experiences as very stressful and traumatizing. (Guillot 2008; Karkazis 2008; Kessler 1998; Picquart 2009). Since some time some doctors recommend an in-utero sex normalization by giving dexamethasone to pregnant women whose fetuses are potential carriers of the adrenogenital syndrome (AGS). This practice is at the centre of current bioethical debates and exemplifies the desire of biopolitics to not only delete sexually non-conventional bodies, but also homosexuality and transidentity (Dreger/Feder/Tamar-Mattis 2012). If in the various prenatal tests the suspicion of intersex emerges, then abortion is widely recommended or even imposed in the West.

Criticism of these mutilation practices common in the Western world is not new: the first intersex persons who denounced this voiced their concerns with the establishment of the American Intersex Society of North America, ISNA. In the following years further associations would be set up, the most significant of which is the Organisation Intersex International, OII established in 2002 (Bastien Charlebois/Guillot 2013). Meanwhile, biopolitics insisted on its scholarly

position and in the light of growing criticism did no more that revise the periphery of its discourse, while systematically delegitimizing that of the persons concerned (Bastien Charlebois).

Changes in sight?

Nevertheless, successful law suits and the work of human rights organizations have created more visibility for intersex people. In dialogue with certain doctors it was furthermore possible to end hormonal-surgical mutilation of intersex children in some places and help them to achieve self-determination, as for instance in the Swiss canton Waadt. Thanks to this ground work by associations of intersex people across the world – also partly in cooperation with organizations of lesbians, gays, bisexuals and trans persons (LGBT) – it was possible to spark off a debate on the issue of intersex which also the legislators of various countries have directed their attention to. Some countries have chosen the inclusion of a further gender category in official documents, which however does not necessarily need to be understood as a third gender. Some made this choice because they have no mutilation tradition, such as Nepal, Pakistan and some Indian federal states. Here the traditional recognition of the existence of persons beyond the gender norm was merely inserted into existing laws. Other countries, by contrast, could only be persuaded under pressure of so-called sexual minorities and the movement of intersex people to take this step, such as New Zealand and Australia. The practice of genital mutilation was initially not denounced here. The first country to put the termination of hormonal-surgical mutilations into law is Malta,[4] this last April 2015. In Switzerland it is only the termination of hormonal-surgical mutilation that is discussed,[5] the introduction of a third gender category is however rejected at this point in time.[6] We therefore experience both in the poor countries and the so-called rich countries different new conceptualizations of sex and gender and observe at the same time a paralyzing inactivity in modern democracies such as the Grand Duchy of Luxembourg. And this considering that the enormous challenge is not so much the existence of intersex bodies but rather the biopolitical co-option of the way society deals with the issue that has been going on for a good 60 years. Most of the intersex bodies do not deviate externally from social gender norms, and where this is the case it is as a rule only visible

4 | German ethics council (ed.) (2012): Intersexualität. Stellungnahme. URL: http://www.ethikrat.org/dateien/pdf/stellungnahme-intersexualitaet.pdf [25.07.2013].

5 | Nationale Ethikkommission im Bereich Humanmedizin, NEK-CNE (ed.) (2012): On the management of differences of sex development. Ethical issues regarding "intersexuality". Opinion no. 20/2012, p.19. Bern.

6 | Nationale Ethikkommission im Bereich Humanmedizin, NEK-CNE (ed.) (2012): Medienmitteilung. "Intersexualität": Das Wohl des Kindes steht an oberster Stelle.

in private. The numerous testimonies by non-mutilated intersex people that we have knowledge of indicate that they can handle their situation perfectly well, appreciate their special body and identity and also receive sympathy and live a fulfilled private and professional life. Indeed, also in the so-called West there are people that have escaped medical mutilation practice, and in countries without traditional mutilation practice adult intersex people also attest to this fact. The medical professionals however ignore this category of persons in their studies, since they are not aware of them.

In general, these people see themselves as one of the currently socially admitted sexes. A part of them are either women or men, only a minority demands an alternative identity. As grown-ups some of these people want to align their bodies to their gender identity via hormonal-surgical measures and have in the course of this procedure to shoulder the burden of a psychiatrization via an official transsexualism diagnosis, which is the precondition for access to corresponding treatments and a change of the sex in the civil register. Considering the number of intersex persons that there are everyone of us will know someone from this group of people without necessarily being aware of their being intersex. To give another example: Purely in statistical terms there is at least one intersex person sitting in a tram during peak times!

While Luxembourg legislation completely ignores the existence of intersex persons, other countries or supranational bodies include these in their legislation or recommendations. Without referring once more to the countries that traditionally recognize people with bodies beyond the sex and gender norm we will in the following turn to the progress that has been made so far.

International Declarations and Recommendations

The Yogyakarta Principles for the implementation of international human rights with regard to sexual orientation and gender identity[7] define gender identity. This text thereby constitutes a landmark for the legal protection of gender identity. Even if intersex persons are not explicitly mentioned as such, its chapter 18 is directed at them:

> "Take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that, in all actions concerning children, the best interests of the child shall be a primary consideration".

7 | The Yogyakarta Principles (2008): Yogyakarta Principles. The application of international human rights law in relation to sexual orientation and gender identity. URL: http://www.yogyakartaprinciples.org/principles_en.pdf [04.07.2015].

In the declaration of Montreal[8] of 2006 the issue of inter sex/gender-related constitutiveness is explicitly addressed for the first time. It states that "intersexual individuals experience a particular form of violence, in the form of genital mutilation resulting from unnecessary post-birth surgery, designed to make them conform to a rigid binary model of physical sex characteristics" and demands "that genital surgery on intersexual persons be prohibited, unless they are old enough to understand it and consent to it." In the declaration of Stockholm of 2012[9] the Second International Intersex Forum made the following demands:

1. To put an end to mutilating and normalizing practices such as genital surgeries, psychological and other medical treatments, including infanticide and selective abortion (on the grounds of intersex).
2. To ensure that the personal, free, prior, and fully informed consent of the intersex individual is a compulsory requirement in all medical practices and protocols.
3. Creating and facilitating supportive, safe and celebratory environments for intersex people, their families and surroundings.
4. In view of ensuring the bodily integrity and health of the intersex child, psycho-social support and non-pathologizing peer support be provided to parents and/or care providers and the child's immediate family instead of surgical or other medical treatment unless such interventions are life-saving.
5. The provision of all human rights and citizenship rights to intersex people.
6. The provision of access to one's own medical records and any documentation, and the affirmation of the intersex person's right to truth.
7. The acknowledgement and redress of the suffering and injustice caused in the past.

The Forum urges the United Nations to take on board intersex rights in its human rights work. Other regional and national human rights institutions are called on to address the human rights of intersex people in their work and in turn call on their respective governments/institutions to confirm them.

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8 | Lesbian & Gay Liberation Front e.V. (2004): International Conference on LGBT Human Rights in the framework of the 1st World Outgames from 25.07.- 05.08.2004 in Montreal. URL: http://www.declarationofmontreal.org/DeclarationofMontreal.pdf [25.07.2013].

9 | http://www.ilga-europe.org/home/news/for_media/media_releases/intersex_forum_2012_media_release [25.07.2013].

Human rights organizations and LGBTI specific organizations are expected to give visibility and inclusion to intersex people and their human rights concerns. OII Francophonie, the francophone section of the International Organization of Intersex People, has supported this declaration but points out that hormone substitution therapies aiming at normalizing modifications of the body should be classified in the category of the questionable further medical treatments.[10] Furthermore, the increasing rate of abortion of fetuses with intersex diagnosis is regarded with great concern, since here eugenic social effects are feared. Further demands are that the persons concerned are made familiar with the arguments of groups critical of pathologization and can contact them and also have at all times total access to their medical file, i.e. concerning the practices they are subjected to, as well as the medical evaluations about their body qualified as 'ambiguous'.

The special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment of the UN human rights commission, Juan E. Méndez, refers in his report of February 2013[11] for the first time to physical modifications that are performed without the consent of the persons concerned and qualifies these as torture. In 2012 the Swiss ethics commission (NEK-CNE) in the field of human medicine has positioned itself against genital mutilation and recommends, as a principle for dealing whose sex development vary from the norm, not to initiate sex determining treatments that have irreversible effects and can be postponed. the child or person person should decide for her/himself. A psychosocial indication alone is in the view of the NEK-CNE not sufficient to justify such a procedure.[12] In the Australian federal state of Victoria in February 2013 an advisory group of medical experts and representatives of intersex people advocated the use of the term 'intersex'. But it must be emphasized that not all people with an intersex condition/constitution identify themselves as intersex, only because some of them do, and that not everyone regards his/her condition as intersex or even as a condition.[13] As a result of the Consensus Statement on Management of Intersex Disorders (Lee et al. 2006) the international medical community has shifted its nomenclature from her-

10 | OII Francophonie (2013): Second forum intersexe international de l'ILGA 2012. Communiqué de presse. URL: http://oiifrancophonie.org/156/second-forum-intersexe-international-de-lilga-2012/ [25.07.2013].

11 | Méndez, J. (2013): Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. United Nations. General Assembly (ed.). URL: http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf [25.07.2013].

12 | Nationale Ethikkommission im Bereich Humanmedizin (NEK)(2013): 'Intersexualität': Das Wohl des Kindes steht an oberster Stelle. Medienmitteilung. URL: http://www.bag.admin.ch/nek-cne/04230/index.html?lang=de [25.07.2013].

13 | State of Victoria, Department of Health (ed.) (2013): Decision-making principles for the care of infants, children and adolescents with intersex conditions. URL: www.aph.gov.au/DocumentStore.ashx?id=d071fbda-68aa. [25.07.2013].

maphrodite and intersex to the newly coined term 'Disorders of Sex Development'. However, intersex activist groups, supporters and academics have voiced critiques of this change. Intersex should no longer be referred to as a disorder or condition/constitution, since it is rather a genetic, chromosomal or hormonally-related human variation. In the light of this terminological disagreement the term 'intersex condition' is being used more frequently.

Conclusion

Since intersex people have started speaking up in the 1990s they were able to acquire a certain visibility thanks to the dissemination of gender theories and their integration in feminist movements as well as LGB and finally LGBT movements. Some of them have organized themselves in patient association, others in various protest movements, in their majority within organizations that advocate the rights of sexual minorities or feminist goals. Initially, their discourse was systematically delegitimized under the guise of lacking objectivity by biopolitics, which in turn positioned itself as the only objective authority. They were also accused of reporting only personal (and thus insignificant) experiences which were merely expression of a mental disorder from which they suffered as opposed to a supposedly silent majority happy with its fate, which until now no scientific study has been able to map.

Considering the juridification of the intersex issues of inter-sex/gender-related constitutiveness as well as the testimonies, situated experiences[14] and scientific publications from the perspective of intersex people, the boundaries have shifted from a demand often mistakenly interpreted as communitarian, to a veritable human rights concern, which, against the background of hormonal-surgical mutilation, joins the fight against torture and ritual clitoridectomy. The only difference between a ritual clitoridectomy and a hormonal-surgical sex assignment – be this a non-consensual medical mutilation or another physical modification of intersex bodies – lies in the motives for the deed. In the first case the reasons are of a supposedly animist and medieval nature, and in the second scientific. But in both cases there is torture, mutilation and traditional, cultural practices in the name of a third party (god or society). What is surprising is the fact that ritual clitoridectomy are regarded in the West, where these practices are marginal features of immigrant ethnic groups, as mutilation and torture that can be brought before the French jury court (see

14 | Internet Encyclopedia of Philosophy (IEP): Feminist Standpoint Theory. URL: http://www.iep.utm.edu/fem-stan/ [08.09.2015].

§ 222-9 and 222-10 of the French penal code), but that the legislators do not seem to recognize mutilation and torture in the systematic mutilation of intersex children. The exotic object is punished, the medical fact is untouchable: this is undeniably ethnocentrism, the racist, sexist and homophobe result of a biopolitics which due to the potential loss of its dominance in the field of knowledge production, of power, as well as material gain is not able to question itself. In that it is helped by a civil society which mainly remains passive as it is kept ignorant about medicine's current practices. The cause of this ignorance is the silence about torture and genital mutilation institutionalized by biopolitics, while intersex issues are hardly taken notice of due to the permanent reproduction of heteronormativity in Western societies.

In this sense the issue of intersex is not a communitarian concern, but a tool for the emancipation of the masses. The increased visibility of intersex people, of both their corporality as well as the varied identities they can be associated with is one of the crucial basic conditions for the emancipation of all those who are not male/man/heterosexual. Inter-sex/gender-related constitutiveness does not mean the end for men, women or heterosexuality, but rather offers the foundation of a new awareness of sex and gender. In other words societal alternatives to heteronormativity offer all people a foundation of awareness of their own sex/gender affinities and thus new possibilities of acceptance of their bodies, their sex, and their sexualities. It is therefore a matter of being able to make the statement, for instance, "I am female/a woman/heterosexual" (which is rarely made since it is supposedly self-evident) in full awareness and not as a pure routine. Not one single element in the debate about intersex denies the existence of male-heterosexual men or other categories permitted by society. There merely exists something else, something equally normal, and in this area of possibilities all humans can evolve.

Intersex should also be put urgently and immediately on the political agenda of countries such as the Grand Duchy of Luxembourg. Here the debate must not limit itself to the purely legal level, but has to reach into all sectors of society and primarily into the education system, by including intersex in the corresponding curricula of schools and medical training in collaboration with the persons concerned and from an affirmative perspective.

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