



**Parallel Report  
To the 5<sup>th</sup> National Report of the Federal Republic of Germany  
On the United Nations Covenant on Social, Economical, and  
Cultural Human Rights (CESCR)**



**Compiled by:**

**Intersexuelle Menschen e.V. / XY-Frauen  
Association of Intersexual People / XY-Women**

Lucie G.Veith  
Neu Wulmstorf  
[lucie@intersexuelle-menschen.net](mailto:lucie@intersexuelle-menschen.net)

Cl. J. Kreuzer  
Trier  
[wedernoch@aol.com](mailto:wedernoch@aol.com)

Sarah Luzia Hassel-Reusing  
Volker Reusing  
Wuppertal  
[chatling@gmx.de](mailto:chatling@gmx.de)

**Impressum:**

Lucie G.Veith  
Neu Wulmstorf  
[lucie@intersexuelle-menschen.net](mailto:lucie@intersexuelle-menschen.net)

**Editor:**

Intersexuelle Menschen e.V.  
Lucie G.Veith  
Neu Wulmstorf  
[lucie@intersexuelle-menschen.net](mailto:lucie@intersexuelle-menschen.net)

**Authors:**

Lucie G. Veith  
Sarah Luzia Hassel-Reusing  
Claudia J. Kreuzer  
Volker Reusing

**Contact:**

Lucie Veith  
Postweg 11  
21629 Neu Wulmstorf  
[lucie@intersexuelle-menschen.net](mailto:lucie@intersexuelle-menschen.net)

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## Contents

<b>Foreword / Executive Summary</b> .....	6
<b>Questions to the German Government</b> .....	8
<b>1. Preamble and Part II of the CDESCR (Articles 2-5)</b> .....	9
1.1. Application of the CDESCR in Germany .....	9
1.2. Definition – What is Intersexuality? .....	11
1.3. No official Contacting of the Intersexed People by the Federal Government yet, positive Developments in several provinces, with regard to the , and by the Ethics Council .....	12
<b>2. Right to Participation in the Achievements of Scientific Progress (Art. 15 Par. 1 lit. b + Par. 2 CDESCR)</b> .....	15
2.1. The Gender Theories by Prof. Dr. John Money violate Human Rights.....	15
2.2. Outdated Specialist Literature.....	18
2.3. Lack of Participation in the Achievements of scientific Progress because of Off-Label Use of Medicaments.....	19
<b>3. Right to Health (Art. 12 CDESCR)</b> .....	19
3.1. Medical Experiments on Human Beings, Violated of the Informed Consent .....	19
3.2. Gonadectomy (Castration) .....	22
3.3. Genital Amputation .....	23
3.4. Irreversible Genital Surgery on Minors and Adults .....	24
3.5. Medical Treatment according to the civil status instead of according to Health Requirements .....	24
3.6. Hormone Substitute Therapy and Off-Label-Use of Medicaments .....	25
3.6.1. Consequences of adequate Hormone Substitution Therapy .....	26
3.6.2. Consequences of paradox Hormone Therapies (paradox HT) .....	26
3.6.2.1. Physical und Psychosomac Consequences of paradox HAT .....	26
3.6.2.2. Psychological Consequences of paradox HAT .....	28
3.6.3. Off-Label-Use .....	29
3.7. Documentation of Treatment .....	30
3.8. Effective Legal Protection .....	30
3.9. Consequences of Treatment in Scope of Medical Definition .....	31

<b>4. Social Security and Right to National Insurance (Art. 9 CDESCR)</b> .....	<b>31</b>
4.1. Health Insurances .....	32
4.2. Disability .....	33
<b>5. Protection of the Family (Art. 10 CDESCR)</b> .....	<b>35</b>
5.1. Violation of the special Protection of the Family by Letting happen Violations of the Human Rights of the Child .....	35
5.2. Violation of the special Protection of the Family by Disruption of the Parent-Child-Relation .....	35
5.3. Insufficient Social Security .....	36
<b>6. Special Mechanisms</b> .....	<b>37</b>
6.1. A Possibility of Reconciliation: Truth Commission to Raise Awareness on the Violation of Human Rights of Intersexed People .....	37
<b>7. Claims and Recommendations</b> .....	<b>38</b>
7.1. The Claims of the Persons Concerned .....	38
7.2. Necessary Aid Programs for Persons Concerned .....	38
<b>**Addendum – Case Studies – Links</b> .....	<b>39</b>
1. Case Study Christina T. ....	39
2. Case Study Frances .....	39
3. Links .....	39

-Milton Diamond, Hazel Glenn Beh

## Foreword – Executive Summary

This parallel report to the national report of the Federal Republic of Germany, on the basis of the beliefs and experiences of the authors, this shadow report is devoted to revealing the denied human rights of intersexed people according to the UN covenant on social, economical, and cultural human rights (CESCR).

Within intersexual people both, female and male physical characteristics can be found. But next to the variety of their sex chromosomes and/or genitalia, in the majority of cases, no further pathological criteria exist. Despite, in Germany as well as in numerous other countries, intersexed persons are target of irreversible medication and surgery from early childhood on. As a consequence, these medical interferences result in life-long obligatory medical treatment.

In the majority of cases, intersexed children are medically treated in order to visually and mentally adjust them to what is perceived as being “female” in the respective cultural contexts. This is done although a medical indication as well as a quality control (art. 12 general comment no. 14 on the CESCR) is completely absent.

There are also cases however in which medical scientists try to adjust intersexual persons to a male gender - including the wrongful extraction of completely intact female genitals and sexual organs, with brutal consequences concerning the possibility of motherhood, self perception and body image, as well as sexual self determination.

These persons are forced into a gender whereby they lose their natural, individual development potential. The necessity of medical interferences is justified through social aspects, for instance, the concern that the intersexual child without clearly defined sexual characteristics could become a victim of sexual discrimination.

Official estimates classify approximately 80,000 - 120,000 people who live in Germany today, with a medical classification of being “intersexed” (“DSD”, Disorder of Sexual Development).

The aim of this shadow report is to clarify the physical, psychological and social situation of intersexual people in Germany, with the goal of a full-fledged realization and implementation of the economical, social, and cultural human rights, among them especially of the human right to health (art. 12 CESCR) of all intersexed persons. Germany has to fulfill its obligation to protect for the economical, social, and cultural human rights, it must not ignore any longer the violation of the rights of the social pacts against intersexed people.

Connected with this shadow report is the hope, that the CESCR committee will work towards the application respectively accomplishment at Germany of the human rights of intersexed people arising from the CESCR.

The intersexed people provide their own shadow report because of the very specific forms of violence and discriminations they are exposed to.

Intersexuality touches on a multitude of universal human and women’s rights. This shadow report concentrates on depicting human rights violations on the basis of lacking implementation of articles 2 - 5 (underlying principles of the CESCR: equality, non-discrimination, and state obligations), article 9 (social security), article 10 (family), article 12 (health), and article 15 (participation in the achievements of scientific progress).

All human rights are universal, interdependent and interrelated. Following Article 28 of the Universal Declaration of Human Rights (UDHR), “*every human being is entitled to a social and international order in which the rights and freedoms can be fully realized*”. CESCR stresses in its preamble, that „in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family, is the foundation to freedom, justice, and peace in the world.“ This is appreciated by the intersexed people with great respect.

Given the sense of universal and interdependent human rights, the concerns of intersexual people will need to be communicated to other UN treaty bodies (particularly to the Human Rights Committee, the Committee on Civil and Political Rights (ICCPR), the Committee on the Elimination of the Discrimination of Women (CEDAW), the Children's Rights Committee, and the Committee against Torture, as well as to the Special Rapporteurs for the protection against torture and violence against women and children.

## Questions to the German Government

1. What will the Federal Government undertake to ensure, that the dignity, the right to a life free of discrimination, and the health (Artikel 1 UDHR, art. 2 CESC, art. 12 CESC) are made feasible also for intersexed people?
2. Which steps will the Federal Government take to ensure, that also people classified as intersexed can fully enjoy the rights of the CESC?
3. When will the Federal Government start a dialogue with the affected people, with the NGO?
4. Why has the Federal Government not taken any steps yet to ensure, that medical treatment standards are introduced for people classified as intersexed, which suffice the requirement of the ratified UN treaties?
5. What will the Federal Government do to ensure, that, from now on, no irreversible medical interventions on intersexed people take place without the free informed consent of the intersexed people themselves?
6. By means of which measures does the Federal Government make sure, that people classified as intersexed can participate in the achievement of scientific progress?
7. Why does the Federal Government tolerate the traditional cosmetic interventions on the genitalia of people/children classified as intersexed, and why does it regard them as higher than the right to the best possible health?
8. When will the medical professional associations be demanded by the Federal Government to introduce non-discriminating treatment standards with active participation of the people affected?
9. How does the Federal Government want to protect the human right to health of people classified as intersexed with regard to enforced sexually norming treatments within the scope of the two gender system?
10. Which legal initiatives will the Federal Government gesetzlich realize in order to guarantee the social inclusion of people classified as intersexed?
11. When does the Federal Government propose to include the term „sexual variants“ into its laws and regulations?
12. Will the German Government during the next four years promote or support a truth commission which contributes to the public awareness and which regulates the compensation (according to Canadian model) of intersexual people injured by medical treatment or non-treatment?



# **Parallel Report to the 5<sup>th</sup> State Report of the Federal Republic of Germany on the International Covenant of the United Nations on Economical, Social, and Cultural Human Rights (CESCR)**

## **1. Preamble and Part II of the CESCR (Articles 2 - 5)**

The International Covenant on Economical, Social, and Cultural Human Rights affirms in its preamble, that „ *in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family, is the foundation to freedom, justice, and peace in the world* “. In the articles 2 – 5, the principles of equality, non-discrimination and state obligations are prescribed, which are fundamental for the CESCR.

The present alternative report by the Association of Intersexual People (Intersexuelle Menschen e.V.) and its affiliated support group “XY-Women” refers particularly on the principle of equality and on the prohibition of discrimination because of gender. Already art. 55 UN Charter prohibits the gender discrimination with regard to the human rights of the UN. Since the CESCR, by its art. 2 par. 2, obliges the ratification states to guarantee, that no discriminations, particularly with regard to gender or other status, occur, and since particularly the human right to health is protected comprehensively for Germany solely by art. 12 CESCR, the CESCR is one of the most crucial legal foundations for the protection of the intersexed minority. In this regard, the prohibited ground of discrimination are, with regard to intersexed people, because intersexuality is a physical phenomenon, are particularly the features sex and, as far as gender identity and the health status are concerned, the feature other status; art. 32 of the general comment no. 20 on the prohibition of discrimination of the CESCR names the gender identity as a prohibited ground of discrimination of intersexed people with regard to harassment at school and at the working place. Art. 33 prohibits the discrimination on ground of an actual or supposed health status. This parallel report concentrates particularly on the human rights to health (art. 12), social security (art. 9), protection of the family (art. 10), and participation in the achievements of scientific progress and its applications (art. 15).

It has been developed in the knowledge of the obligation of the treaty states, to reach full implementation step by step by all suitable means, particularly by legislative measures (art. 2 par. 1 CESCR), and bearing in mind, that limitations of these human rights are only allowed as far as they are determined by (public) law and only as far, as it is necessary for the common benefit in a democratical society (art. 4 CESCR). As a result, all limitations of economical, social, and cultural human rights, which are based on lower-ranking foundations than public laws, particularly on private law like, e. g., medical standards or just customs within medical professions, are prohibited. In addition to that, all limitations, which exceed the extent necessary for the common benefit in a democratical society, are prohibited. The parallel rapporteurs are convinced, that the lack of compliance especially with the responsibilities to protect, which arise from the CESCR, bitterly damages the awareness of the public for human rights and the (material) rule of the law, thus it bitterly damages also the common benefit in a democratical society according to art. 4 CESCR.

### **1.1. Application of the CESCR in Germany**

This parallel report contributes to application of the universal human rights of the United Nations as directly applicable and binding rights in Germany in the every day work of the

judiciary and of politics, as the concluding observations of the CEDAW committee of the 10.02.2009 with regard to Germany have already demanded for CEDAW (art. of the concluding observations). The very same is valid for human rights treaties of the UN, which are ratified by Germany, because all universal human rights are indivisible, i. e. equally ranking and equally binding with each other (preamble of the UDHR, art. 5 Declaration of Vienna of the UN General Assembly of the 12.07.1993 (file number A/CONF. 157/23), art. 6 Abs. 2 of resolution 41/128 of the UN General Assembly on the right to development, preamble of resolution 48/141 of the UN General Assembly on the creation of the office of the High Commissioner on human rights).

Art. 28 of the Universal Declaration of Human Rights (UDHR) prescribes, that every human being is entitled to a social and international order, in which the human rights of the UN can be fully realized. According to art. 1 no. 3 UN Charter, the universal human rights belong to the goals, whose realization the United Nations have been founded for. The UN Charter is, according to its art. 103, the highest ranking international treaty. The firm establishment of the universal human rights in the goals of the UN Charter shows, that they belong, as well as the UN Charter, to the „ius cogens“, which is the highest category of international law (art. 30 and 53 Vienna Treaty Law Convention). The belonging of the universal human rights to the „ius cogens“ has also been affirmed by the EU Court of First Instance (no. 279 – 282 of the judgement on file number T-306/01).

According to art. 25 of the German Basic Law, the general rules of international law (and so also the universal human rights of the United Nations as a part of the „ius cogens“) stand, at Germany, above the simple laws and directly create rights and obligations for the inhabitants of Germany, thus they are directly applicable law, to be applied particularly by the judiciary, but also by the legislative and by the executive.

The friendliness of the Basic Law for the international law shows itself even clearer. According to art. 1 par. 2 Basic Law, whose wording is inspired by the preamble of the Universal Declaration of Human Rights, the German people confesses itself, because of the inviolable human dignity, to inalienable human rights as the foundation of any human community, of peace, and of justice in the world. The result of the inalienability of the human rights “in the world” ist, that the human rights, which are flowing from an international, particularly from the universal, legal source, cannot be ignored, as well as the human rights of the German Basic Law. The whole art. 1 Basic Law (including its par. 2, which protects the inalienability of the human rights and the material rule of the law) belongs to the parts of the Basic Law, which are protected by the eternity guarantee (art. 79 par. 3 Basic Law) against any restricting change. This eternity guarantee, in turn, has, according to no. 218 of the Lisbon judgement of the German Constitutional Court of the 30.06.2009, a universal foundation since the existence of the United Nations. That is why the German Constitutional Court has decided in guiding principle 3 of the Lisbon judgement, that with regard to the implementation of the EU law at Germany, there has to be left enough space for the implementation of the economical, social, and cultural human rights.

The direct application of the CESCR for Germany is of crucial importance also for the intersexed minority, particularly, because a human right to health, which expressively protects the highest attainable degree of physical and mental health for every human being, exists for Germany only by art. 12 CESCR.

## 1.2 Definition – What is Intersexuality?

Nature produces – next to men and women - also persons who do not fit into the binary, culturally grown system of being male or female. Intersexed people are persons, whose essential sexual characteristics, i. e., the chromosomes (and the genes on them), the gonads (testicles, ovaries and mixed gonads), and the genital (size, function, and course of the urethra) do not all point to the same sex as man or woman. The official estimates classify approximately 80,000 - 120,000 people in Germany living with the classification of being “intersexual” (“DSD”, Disorder of Sexual Development).

The concept of intersexuality depicts persons who have sex chromosomes, genitalia and/or gonads which deviate from the culturally motivated norms of sexual constructions. Following birth, some 95% of this group of persons have already had or will undergo genital surgery and various medical interventions to change their fundamental and individual sexual characteristics. These interventions are oriented by the medical feasibilities with the aim to arbitrarily (for ignoring binding human rights and even without any valid medical standard) produce “sexual clarity” – albeit their personal rights, their physically and biologically determined construction and, under the absence of evident scientific proof. The intersexual people regard this interference, without their acceptance and without a comprehensive reconnaissance taking place, as a forbidden interference against their autonomy and as an undignified act of violence.

forbidden interference against their autonomy and as an undignified act of violence. The irreversible and extensive psychosomatic and psychological damages as well as the preservation of the secondary sex characteristics through medical treatment during the total lifespan, result in an extensive oppression of the persons concerned. In particular, a hormone therapy in opposition to the biological chromosomal sex leads to a reduction of the physical and psychological capacity and, in the long term, to significant side-effects to one's health.

Intersexual people, concerning their biographies, may be classified into two groups. There are on the one hand, those born before 1945 who were essentially victims of the “racial cleansing” of National Socialism. Those who survived this time were hidden by their families. The normality of hermaphroditism had been made a life-sustaining taboo. The second group are the ones that were born after 1946, particularly those, today the majority, who were born after 1950. This report concentrates on the group that was born after 1946, although there are also some intersexual people from the time before 1945 who have survived and are still living today.

Gender announcements in Germany are carried out by state regulation based on regulations that date back to 1937. This regulation, despite the National Socialist background, has always had a continued existence. It has evolved for intersexual people often to grave consequences. Since 2009, the law regarding the civil status has been improved inasmuch, as it is now possible to leave the gender registration at birth open for an indefinite time. But if you leave the gender open, you only get a registration document. In Germany, you still get an official birth certificate only, if the registration of the gender as male or female has been made up. You can exercise many rights in Germany only, if you present a birth certificate. You need it for the first application for an identity card. You need an identity card for travelling into the foreign countries or for starting a banking account. Those intersexed people, who, because of their gender identity, do not want to be committed to a registration as male or female, do either not get a birth certificate, or their get their gender announcement as male or female still enforced at their registration prescribed by an official assessment according to the evaluation by the medical officer – a discrimination according to art. 10 lit. b of the general comment no.

20 to the CESCR. The discrimination by the law on the civil status has not been removed, just the urgency after the birth has been alleviated. For the discriminations on the basis of an incorrect gender registration or of the withholding of a birth certificate, please refer to the chapters of this parallel report on the human rights to health (art. 12 CESCR), on social security (art. 9 CESCR), and on the protection of the family (art. 10 CESCR).

These people - totally normal yet endowed with varying individual sex characteristics, are classified as intersexual people, and their bodily variation considered under the DSD syndromes.

It is pivotal to note that intersexed people without surgery and/or medical treatment do, except for a few exceptions [e. g. with regard to the possible salt-losing with CAH<sup>1</sup>], not have to fear any grave or even life-threatening physical diseases during the further course of their life because of their specific sex characteristics at birth.

The parallel rapporteurs, as well as the majority of intersexed people, hold, in contrast to the medical mainstream, the view, which is justified by nature, that they have their own sexual development, their own individual sex at birth, and, just like all other human beings, a right to the preservation of their sex at birth and to the preservation of their gender identity. The bodily varieties of intersexed persons must not be the cause for leaving their innated sex to whatever interpretation and to whatever medical intervention by other people, especially be physicians. People not classified as intersexed are allowed to develop very diversely with regard to all aspects of their gender, without having to fear any medical interventions for this. Only if a human being comes, during the course of his/her individual physical and psychological sex / gender development, freely and without any medical interventions, to the conviction, that his/her bodily variant does not fit with his/her gender identity, or that he/she feels it as harmful, only then the variant can have a pathological implication in need of treatment. The utilization of the medical support, however, can only be in the self-determined discretion of this person himself/herself, after complete information on the health related consequences<sup>2</sup> of medical interventions.

### **1.3 No official Contacting of the Intersexed People by the Federal Government yet, positive Developments in several provinces, with regard to the AGG, and by the Ethics Council**

In the past, two parliamentary requests were submitted to the German Government with the aim of achieving an official statement about the situation of intersexed people in Germany. The answers of the German Government to these requests are documented in the government printed papers 14/5425 and 16/4322. The answers of the German Government are particularly criticized by the authors in that these originate exclusively on the basis of information of certain medical circles / scientists who have been treating affected persons and, who have an interest in sustaining their previous clinical practice. Intersexed people and their organizations were not heard for this. Also, the available information from independent psychological studies<sup>3</sup> on the situations of intersexed people with disastrous findings have not been

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<sup>1</sup> There are a few exceptions e.g. CAH = Congenital Adrenal Hyperplasia, the clinical pattern is a result of overproduction of the androgen steroid through the adrenal cortex, with or without adrenogenital salt-depletion syndrome. This leads to effects of virilization for persons with XX- chromosomal pattern

<sup>2</sup> „Informed Consent“

<sup>3</sup> It is meant here the example of the research group under the leadership of Prof. Dr. Hertha Richter-Appelt, from the Center for Psycho-social Medicine, Institute for Sexology, University Clinic of Hamburg (as well as the Hamburger Study of Evaluation).

included.

Also, several of the studies conducted on intersexual people, and their metabolic situation, as being treated with paradoxical hormones substitute therapies, in the course of countersexual compulsive allocation, were not taken into consideration.<sup>4</sup> So, on a regular basis, intersexed girls and adolescent women are castrated even before the completion of their bodily development. Then following, they are exclusively treated with non-age-based contraceptives<sup>5</sup> or post- or menopausal<sup>6</sup> or even paradox hormone therapy.

The fatal consequences for the concerned children, girls and women are noticeable even without specialist knowledge and were neither elicited nor found mention in the report of the German Government.

The responsible ministries have not yet taken up the demand of the NGO Intersexuelle Menschen e. V. (association of intersexed people) for a dialogue with the German government; this demand has been explicitly supported by art. 61 and 62 of the Concluding Observations of the CEDAW Committee from the 10.02.2009 (file number CEDAW/C/DEU/CO/6) regarding Germany.

Art. 3 par. 3 of the German Basic Law prohibits discrimination on grounds of sex. In 2009, there has been a legislative initiative of the provinces Hamburg, Bremen, and Berlin, to complement art. 3 par. 3 Basic Law with the prohibition of discrimination on grounds of sexual identity. The term „sexual identity“ refers to sexual preference and to gender identity as well. Unfortunately, this initiative has not found a majority within the Bundesrat (upper house of the German Parliament).

According to page 59 of the 5<sup>th</sup> national report of Germany on the CESCR, the Federal Government concentrates, since the health reform of the year 2000, inter alia, on the strengthening of the promotion of good health, on support groups, and on the extension of patient rights and of the protection of patients. The NGO Intersexuelle Menschen e. V. appreciates these steps and expects, in this regard, particularly the complete implementation of the informed consent (art. 8 of general comment no. 14 on the human right to health) and the complete payment by the health insurances of all necessary medical treatments, particularly of the treatments of the health damages resulting from the hitherto treatment without any medical standard, in particular the payment of a hormone substitute therapy fitting to the biological chromosomal sex.

At the 12.02.2010, a legislative initiative (file number 867/09) of the provinces Baden-Württemberg and Hessen has been filed for a new §226a Strafgesetzbuch (StGB, Penalty Code), which contains for the mutilation of the female genital by circumcision or other means prison sentences, which are longer than those for simple physical injury (§223 StGB) and for dangerous physical injury (§224 StGB).

According to the explanation of the legislative initiative, the new §226a StGB will particularly also protect against the partly or complete removal of the clitoris. The explanation

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<sup>4</sup> “Consequences of low level sex hormone substitution in young intersex females”, Clüsserath et.al. 2001; “Consequences of sex hormone substitution, out of metabolism regulation,” Clüsserath et.al. 2004; “Intersexuality Disrupted Between Science and Reality” University of Lüneburg, DGSS u. DGSS- Institute, Clüsserath et.al. 2004; “Effects of Testosterone Treatment in a Female Assigned Subject with Swyer-Syndrome after 30 Years - A Self Report” University - Clinic Lübeck Kreuzer/ Kreuzer et.al 2006.

<sup>5</sup> Lowest doses of synthetical hormones for contraception

<sup>6</sup> Low doses of hormones for the treatment of signs of old age of older women

refers mainly to the protection against genital mutilation on religious pretext, aber does not regard its scope as limited on this area, and does explicitly also refer to cosmetical surgery. According to the explanation of the legislative initiative and to §228 StGB, already today, a consent into cosmetical surgery at the clitoris can only be valid insomuch, as they are not connected with a loss of the sensitivity. The circumcision of not more than the male foreskin is explicitly not within the scope of §226a StGB. At the 12.02.2010, the initiative has been concluded by the plenum of the Bundesrat and then been sent to the Federal Government for the opportunity of a statement, and has, after that, been sent to the Bundestag (lower house of the German Parliament). Since the 24.03.2010, the legislative initiative (file number 17/1217) is before the Bundestag, which however still has not yet discussed or decided on it.

The parallel rapporteurs appreciate the initiative for the new §226a StGB as an important step to a stronger deterrence and criminal prosecution against the mutilation of female genitalia. The clarification in the explanation with regard to §228 StGB can become a crucial support for intersexed people, whose genital has been amputated or lost its sensivity because of the method of the surgery, so that the infringements of the law against them will be punished. A clarification, however, that the new prescription also protects genitalia, whose characteristics (size, course of the urethra, erectile tissue) do not completely allow a clear classification as a penis oder as a clitoris, is missing. As a result, there is a lack of legal clearness, if the new prescription of the penalty code will protect all intersexed people, whose genital has been altered without their own consent.

At the 23.06.2010, the German Ethikrat (ethics council) has held an official hearing within the „Forum Bioethik“ on intersexuality, which two of the parallel rapporteurs have participated in on behalf of the NGO Intersexuelle Menschen e. V. (association of intersexual people). The German Ethikrat is a counselling body of the state for ethical issues of life sciences, which acts on its own initiative and on demand by the Bundestag (lower house of the German Parliament) or by the Federal Government. The hearing by the German Ethikrat, however, is not comparable with an official contacting the responsible German ministries towards the associations of the intersexed people.

The German Ethikrat has held the hearing at the 23.06.2010 with the following questions:

- How are correcting and reassigning interventions during child's age, resulting in life-long effects on the affected people, to be assessed with regard to the right to physical and psychological integrity and self-determination?
- What is there to be said against a variety of bodies, gender identities and role behaviours?
- Which responsibility does the society have in the contact with people, who are different? Is political action needed?
- Which experiences and which needs do affected people have, and which conclusions can be derived from that?

The „Allgemeine Gleichbehandlungsgesetz“ (law on equal treatment, AGG) of the 18.08.2006 prohibits the discrimination on grounds of ethnic origin, sex, religion or philosophy of life, handicap, old age, or sexual identity. The prohibitions of discrimination on grounds of sex and of sexual identity (§1 AGG) protect also intersexed people, which is affirmed by the official explanations of the public anti-discrimination office. Also the discrimination with regard to social security and to health services is prohibited (§2 Nr. 5 AGG). The area of application of this law contains the professional area (§6 AGG), insurances under private law, and contracts under private law in the mass business (§19 Abs. 1 AGG). According to the official explanations of the public anti-discrimination office, the scope of §19 Abs. 1 AGG contains not only to all insurances under private law, but also the public social insurance. The violations of art. 9 CESC, which are explained in section 4 of this parallel report, because of

the discrimination of intersexed people by insurance companies are, at the same time, also violations of the AGG, so that the AGG can become an important instrument to end the discrimination of human beings classified as intersexed with regard to health insurances.

The worst human rights violations against intersexed people, however, happen by the way medical professionals treat them, which is without the area of application of the AGG.

## **2. Right to Participation in the Achievements of Scientific Progress (Art. 15 Abs. 1 lit. b + Abs. 2 Sozialpakt)**

The medical and psychological treatment of intersexed people orientates itself to the gender theories of Prof. Dr. John Money (USA) from the 1950ies and to their modifications<sup>7</sup>. This theory says: If you, by medical means, create a genitoplastic on children, as early in their life as possible, which corresponds to the destined sex, and if you use the personality changing effect of sex hormones, that then the reeducation into the favoured, heteronomous gender socialization will be successful.

### **2.1 The Gender Theories by Prof. Dr. John Money violate Human Rights**

The theories of Prof. Dr. John Money and their modifications, even though already for a long time proven wrong in a horrible way by the David Reimer case<sup>8</sup>, are, still today, official content of medical professional and educational literature. And so the resulting teaching content for education of doctors still clearly holds on to positions which lead to offences against human rights, followed by other infringements against the law. We, the authors of this report, regard these publications of Prof. Dr. John Money and variations of them as incitement and instructions to the infringement of the law.

In the late 1950ies, the experimental surgical sex reassignment of intersexed infants, based on the „time window“ theory, began. This „time window“ theory has been developed by the psychiatrist Prof. Dr. John Money of the Baltimore university, and it says, that gender identity was indefinite until a certain age, which was somewhere between 6 months and 2 years after birth, and that the gender identity, for this reason, could be reeducated, if just the bodily appearance was unequivocally surgically reassigned to the female or to the male sex within this time window.

In the beginning of the 1970ies, the sex reassignment has been declared a medical standard in the then German Democratic Republic and in the Federal Republic of Germany, even though no scientific proofs at all have been brought, just because of the fame of the case of one single Canadian boy, David Reimer (under the pseudonym “John/Joan“ case). This boy had been born unequivocally male and has lost his penis because of an accident during his infancy. On the advice of Prof. Dr. John Money, he has not got a reconstructive phalloplasty, but he has been surgically reassigned to a girl, including the removal of his healthy testicles, and has been reared accordingly. On the basis of positive short-time results of this single case, the seeming-to-be standard for the surgical sex reassignment for intersexed infants and for infant boys, who have lost their penis by an accident, has emerged.

Since only one case – and not a sufficient number of provenly successful long-term experiments - has been the basis of the pushing through of Prof. Dr. Money's concept, it has

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<sup>7</sup> The more modern variations refer to the improvement of the applied medical means

<sup>8</sup> e.g. [http://de.wikipedia.org/wiki/David\\_Reimer](http://de.wikipedia.org/wiki/David_Reimer)

never exceeded the experimental status. It has created, for more than 30 years, an illusion of a standard, even though it has been, without any interruption, a human experiment.

Even this one case has turned out as a failure. In 1994, the sexologist Prof. Dr. Milton Diamond (University of Hawaii) detected, that the boy, who had been, without his own consent, sexually reassigned, has been living in the male role again since 1980, and that he has, on his own urging, been reassigned back to the male sex, as far as it has still been possible. In 1997, the truth about his case has been introduced to the world public. In the year 2002, the normally raised twin brother and then in 2004, David Reimer, who had once become famous under the pseudonym "John/Joan case", have committed suicide (on the case of David Reimer please also see the text of Prof. Dr. Milton Diamond, which has been attached to the parallel report of the NGO Intersexuelle Menschen e. V. to the 6<sup>th</sup> national report of Germany on CEDAW).

Prof. Dr. John Money has, in his „time window“ theory, misunderstood the gender identity (the gender one feels belonging to) with the gender role behaviour. The role behaviour, i. e., if someone behaves as it is typical for a boy or for a girl, can be educated, but not the gender identity.

According to the mass experiment by Prof. Dr. John Money, which has legally never become a standard, the creation of a sexually unequivocal appearance has to be finished within the „time window“. Many medical texts regard the process of the decisionmaking of the parents respectively their consent to the sexually reassigning surgery on their infants as a medical emergency. Prof. Dr. Money was afraid, that the parents could be traumatized, if they saw their child with an intersexed genital, and that they then would not accept their child. Under this concept by Prof. Dr. John Money, which has never become a standard, the parents often are incomplete or even false information on the exact biological constitution of their child, on the exact way of the medical treatment, and on its experimental character. Therefore, it has been recommended to tell parents, that their child had been born sexually incomplete, and that the medical professions could complete the child. This only seeming-to-be doctrine, persists stubbornly till today, even though there have very well been also other professional opinions. Prof. Dr. Overzier, e. g., has, already in 1957 and 1961, held the opinion, that the removal of the gonads in a case of AIS is unnecessary and even damaging to health.

The research network Intersexuality DSD at Lübeck today stands up against the false impression of a medical emergency and for a better informing of the parents, and so significantly distinguishes itself against Prof. Dr. Money. A confession, however, to the right of the intersexed people themselves, however, is still missing. And the recommendations of the research network are not yet reality at all hospitals.

The guidelines of the German society for pediatrics and youth medicine of the year 2007 also recognize, that intersexuality isn't a medical emergency. They explicitly regard the parents as entitled to the decision on the treatment.

The international DSD guidelines, which have been published at the 16.08.2006, say, that enough time should be left for the making of the decision of the parents in those cases, in which intersexuality is no emergency.

So in Germany, the physicians have already significantly distanced themselves from the improper interpretation of the medical emergency, which had been from Prof. Dr. Money. But the parents still are not unequivocally informed, that no medical standard exists. Also the German physicians still want to load the decision on irreversible sex altering interventions at



their intersexed infants onto the parents. That, however, is no informed consent, because an informed consent can only be made by the intersexed person himself / herself, because having an ambiguous sex is no medical emergency. So the DSD guidelines violate art. 8 of general comment no. 14 to the CESCR and, as a result, violate the human right to health (art. 12 CESCR).

Also the DSD guidelines are no medical standard, because they, as well as the concept of Prof. Dr. Money, are not based on a sufficient number of successful long-term experiments. They are still dealing with human experiments (art. 8 general comment no., art. 12 CESCR, art. 7 s. 2 ICCPR). The DSD guidelines refer, in addition to that, to already disproven studies. In the „Consensus Group“, which has worked out the DSD guidelines, the associations of the intersexed people have been significantly underrepresented in comparison with the representatives from the medical professions. Even if the relation of their numbers had been democratically balanced, the DSD guidelines could nevertheless be no standard because of the lack of a sufficient number of successful long-term experiments. Missing scientific knowledge cannot be replaced even by democratical votings.

The legal rank of the DSD guidelines as well as that of the concept by Prof. Dr. Money's is not more than that of customs, rather that of practices, because they are no valid medical standards. So they stand below the simple public law and below any international law (art. 27 Vienna Treaty Law Convention), even more under the human rights of the United Nations, which belong to the „ius cogens“ (art. 28 UDHR). So all treatment concepts have to remain unapplied insofar, as they are incompatible with the universal human rights.

The parallel rapporteurs criticize the violations of the Federal Republic of Germany against the law to participation in the achievements of scientific progress (art. 15 Abs. 1 lit. b CESCR) also insofar, as the active distribution of the newest knowledge of the research on the failure of Prof. Dr. Money's „time window“ theory is concerned. The parallel rapporteurs hold the legal point of view, that Federal Government has an obligation to active protection and support (art. 15 Abs. 2 CESCR) with regard to the measures necessary for the distribution of the actual scientific knowledge, in particular, if, like in this case, the affected professional organizations themselves do not do this sufficiently, and if this inaction results in the persistence of the violation of many other human rights.

The scientific knowledge of Prof. Dr. Milton Diamond und Ph. D. Hazel Glenn Beh (see attachment of the parallel report of the NGO Intersexuelle Menschen e. V. to the 6<sup>th</sup> national report of Germany on CEDAW), that there is no treatment standard for the the sex reassignment of intersexed people at all, because a treatment can legally only become a treatment standard, if a sufficient number of successful long-term experiments can be proven in favour of it, and that such proofs do not exist for Prof. Dr. Money's theory, has not led to respective consequences for the medical practice of the treatment yet. Particularly, because, in most cases, the parents have neither been told, that the medical sex reassignment is an experiment, neither how the human rights situation with regard to the protection of their child looks like (violating art. 44 of the general comment no. 14 to the right to health).

The participation in achievements of the progress of scientific knowledge is being denied by the medical professions to a sexually identifiable minority, with grave consequences especially to the human dignity (art. 1 UDHR), to the prohibition of unconsented human experiments (art. 7 s. 2 ICCPR), and to the human right to health (art. 12 CESCR). This is, at the same time, a clear violation against the obligations of the state to protect and to fulfill according to art. 2 par. 2 CESCR, according to which any discrimination based on sex or on birth is prohibited with regard to all rights of the CESCR.

The informed consent is explained more detailedly in the section on the human right to health of this parallel report.

## 2.2 Outdated specialist literature

The lacking incorporation of the actual state of scientific knowledge on the prenatal sexual development of human beings still leaves space for discrimination based on sex, particularly for the incorrect information, that people born intersexed were incomplete, and that the medical profession only would complete them. In medical text books as well as in other educational materials, a false representation that up until the seventh week of pregnancy every child was phenotypically female.

In actuality, all embryos until the seventh week have both internal gender organs of either sexes in their early stages (i. a. Wolffsche Gänge and Müllersche Gänge and an early stage of gonads, which are not yet differentiated into testicles or ovaries). Also the external gender organs require up until birth a high complex differentiation towards male or female. However, up to the seventh week of pregnancy all people are intersexed, phenotypically and with regard to the still undifferentiated early stages of the inner sexual organs. Only after the twelfth week of pregnancy, will one develop into a bracket of male or female, whereas intersexed individuals remained in an undifferentiated status, more or less . The information about the attributes and condition of people up until the seventh week is of substantial interest to the stop of all discriminations based on sex / gender, not only those directed against intersexed people.

In parts of the medical specialist and educational literature, it is assumed that intersexual persons have a tendency to be asocial, psychically unstable and often mentally retarded. The intersexed parallel rapporteurs regard these generalized statements as not compatible with their dignity as human beings (Article 1, UDHR), and they regard the competent ministry in the responsibility according to art.15 par. 1 lit. b + par. 2 CESCR, to put through a deletion of these scientifically untenable generalized statements.

At page 88 of the 5<sup>th</sup> national report on the CESCR, the Federal Government refers to a comprehensive assortment of brochures and educational material of the federal office for health education (Bundeszentrale für gesundheitliche Aufklärung (BzgA)), which addresses itself especially to children and to the youth. The parallel rapporteurs regard it as an appropriate way to guarantee the human right to participation in the achievements of scientific progress, if the Federal Government developed, in cooperation with the NGOs of the intersexed minority, health educational material on intersexuality, which corresponded with the actual state of knowledge particularly with regard to medical ethics, with regard to the human rights situation, and with regard to the prenatal development of human beings, and which would be distributed to the public via the BzgA.

With regard to the professional education and training of physicians, the Federal Government is, according to the legal point of view of the parallel rapporteurs, obliged to work towards the comprehensive education of the physicians to enable them, that they, on their part, make sure that the parents of intersexed children are informed comprehensively, from different perspectives, and including colleagues from other medical disciplines and counsellors of support groups, and this comprehensive education also has to contain the education on the human right to health (art. 12 CESCR, Art. 12 CEDAW, Art. 24 CRC; art 44 general comment no. 14 on the CESCR). This way, the intersexed people are enabled to give an informed consent in compliance with art. 8 of the general comment no. 14 on the human right to health.

### **2.3 Lack of Participation in the Achievements of scientific Progress because of Off-Label Use of Medicaments**

Since there are, world-wide, no official authorizations of medicaments for the paradox (contra-chromosomal) hormone therapy (HT) of intersexed people, these medicaments are prescribed off-label for intersexed people. Many people, in addition to that, do not even know, that they have been born intersexed, and that they are treated off-label. This results in the situation, that the producers of the medicaments nearly do not get any answer at all regarding, in how far their pharmaceuticals are needed and well tolerated by intersexed people. So the intersexed people remain excluded from the further development of hormone medicaments.

This can even lead to the result, that better tolerated medicines are replaced by those with more side-effects, because research does only consider the tolerance of the medicament for the majority of men and women.

A whole section of the population is excluded from the participation in the achievements of scientific progress (art. 15 par. 1 lit. b CESCR). For the implementation of this human right, the state is obliged to necessary measures for the preservice, the development, and the distribution of science (art. 15 par. 2 CESCR). Making feasible a functioning communication between the intersexed people and the producers of the medicine, belongs to the obligation to distribute scientific knowledge; for this purpose, it is necessary to inform all intersexed people about their sexual condition they have had at birth. For smaller sections of intersexed people, the research for whose medicaments does not promise any profits, the state is obliged to do the research by itself or to support charitable research.

## **3. Right to Health (art. 12 CESCR)**

The human right to health guarantees, according to art. 12 par. 1 CESCR, “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. The same applies, according to art. 12 CEDAW, explicitly also for women and, according to art. 24 par. 1 of the Children's Rights Convention (CRC) also for children. Intersexed people must not be discriminated regarding these rights. (art. 2 par. 2 CESCR). Health relates to the individual, physical and psychological well-being of people. It's not about obtaining complacency within a social order, which can only be achieved through medical treatment with unknown lifelong consequences for bodily integrity. The State is furthermore obliged to take all necessary actions for the wholesome development of children (Article 12 (2) (CESCR)). This includes the protection from dangerous, illegal and unsecured medical treatment.

### **3.1 Medical Experiments on Human Beings, Violated of the Informed Consent**

According to art. 8 of the general comment no. 14, the human right to health includes the freedom to self-determination on one's own health and on one's own body, including the sexual and reproductive freedom, the right to be free from interventions, and the right not to be maltreated, and not to be made subject to unconsented medical treatment or to unconsented medical experiments. In art. 8 of general comment no. 14, the indivisibility of the human rights for the protection against unconsented medical experiments, which are prohibited by art. 7 s. 2 ICCPR as well as by art. 12 CESCR, becomes particularly obvious. Art. 8 proves, in addition to that, that the full implementation of the patient's right to informed consent is indispensable and inalienable for the realization of the human right to health. The right to informed consent itself is not a human right on its own, but it has emerged from a medical

tradition, but it is an integral part of the human right to health (art. 12 CESCR) and, as far as human experiments are concerned, of art. 7 s. 2 ICCPR.

The parallel rapporteurs hold the legal point of view, that, as explained above, the sexual freedom and the right to be free of medical interventions and of medical experiments belong to the right to health (art. 12 CESCR), and that from the human right to health, in connection with the human right to the protection of the identity (art. 8 CRC) follows, that no one is entitled to irreversibly intervene into the sexual condition a child is born with, without the consent of the child himself / herself.

The patient's right to informed consent prescribes, that the patient hims / herself has to be comprehensively informed about his/her health situation, and that the patient hims / herself decides regarding the treatment, which does also include the possibility to reject a treatment. For this, the doctor in attendance does not only have to explain his favourite method of treatment, but also known treatment alternatives. An informed consent does only exist, if the information and the consent have taken place correctly. The correct compliance with the patient's right to informed consent is a matter of course in most medical disciplines. There are only two exemptions of the informed consent: the emergency and the therapeutical privilege. For the content of the patient right to informed consent, the parallel rapporteurs refer to the already mentioned text of Prof. Dr. Milton Diamond and Ph. D. Hazel Glenn Beh.

Because of the lack of a sufficient number of long-term experiments, Prof. Dr. John Money's treatment model has never become a standard, it has never exceeded the experimental state, what has resulted into the situation, that still today there is no treatment standard, even though many physicians today do not refer to Prof. Dr. Money any more. The parallel rapporteurs refer to section 2.1 of this parallel report.

The overwhelming majority of the intersexed people at Germany has, because of incomplete or false information, not given any legally valid consent to the human experiments, which have been conducted on them. According to the legal point of view of the parallel rapporteurs, the omission or even false education regarding the experimental character and the medical risks of particularly the surgical and contra-chromosomal hormonal interventions have led to the result, that they have received no legally valid consent. In addition to that, for decades, medicaments have been prescribed off-label for intersexed people. On the contrary, they are even given the impression, that their kind of treatment was according to a medically solid standard.

An emergency is defined as a situation, in which the loss of the life or the loss or the failure of an organ is threatenig, so that decisions on the treatment have to be made fast. Even in emergencies, other persons than the affected persons themselves are only then entitled to decide, if the affected persons are not able to speak, e. g., because they of not yet learned to speak, or they are in a coma. Then, at first the persons having custody, and else the next relatives, have to be asked. Only if, in an emergency, no one can be asked in time, then the doctor in attendance can decide in so far, as it is necessary for the preservation of life or of the ability of an organ of the patient.

In real medical emergencies, the parents can give a valid informed consent to the treatment of their intersexed infants. But this applies only to a few situations, e. g., in the case of a lack of the hormone aldosteron, which can lead to a life-threatenig salt depletion syndrome, and which occurs with an increased frequency at people with CAH. Here, the parents can, as a matter of course, consent to the hormon substitute treatment necessary for the prevention of the salt depletion syndrome.

Regarding the violation of the informed consent concerning surgery at the genital or concerning the removal of gonads, it is referred to the next sections.

The therapeutical privilege refers to situations like an emergency, i. e., danger to life or threatening failure of an organ, but concerning persons who are basically able to consent. It applies, if the orderly information of the patient would, with a high degree of probability, cause grave psychosomataical effects, and would so cause a significant worsening of the health. Concerning patients with a high risk of a cardiac attack, or concerning patients, whom other life-threatening psychosomataical reactions are known of, the obligation to the full information can be reduced, but there must not be any application of the therapeutical privilege outside medical emergency situations.

The patient right to informed consent is connected with the human right to health also insofar, as art. 8 of general comment no. 14 prescribes, that the health system must guarantee, on an equal basis, the realization of a highest attainable degree of health, and as, according to art. 11 ( of general comment no. 14 ), orderly education has to be conducted also regarding sexual health, including reproductive health.

Most cases of the patient right to informed consent and, as a result, also of the human right to health, in Germany, remain till today, disregarding the responsibility to protect the human rights, without any legal consequences, even though medical treatment experiments without the valid informed consent of the test person himself / herself are prohibited according to art. 7 s. 2 ICCPR and according to art. 12 CESCR in connection with art. 8 general comment no.14. Intersexed people must not be discriminated concerning the practice of the human right to health (art. 2 par. 2 CESCR). This applies in particular to genital mutilation, to genital amputation, to genitoplasty, to the removal of gonads in the scope of an ablative hormone therapy<sup>9</sup>, and to the „Bougierung“ (widening of the vagina).

According to art. 2 par. 1 CESCR, there is no obligation to realize all rights of the CESCR immediately. As art. 31 of general comment no. 14 on health explains, their implementation has, however, to be done as fast as possible. And, according to art. 30, their implementation has to start immediately, at his to be done right from the beginning without any discrimination, also without any discrimination on grounds of sex / gender (art. 2 par. 2 CESCR).

The „immediate“ - moment according to art. 30 general comment no.14 is, regarding the state responsibility to protect the right to informed consent, which is indispensable for the realization of the right to health, according to the legal point of view of the parallel rapporteurs, has been no later than, when in the middle of the 1990ies more and more meanwhile adult intersexed people have complained about the violation of the informed consent, and when finally the failure of the „John/Joan“ case has been made known to the public. At latest then, the state was obliged to take the initiative to reevaluate the present way of treatment.

The longer one is waiting concerning the putting through of the informed consent, the graver becomes the violation of the state responsibility to protect the human right to health (art. 49 general comment no. 14).

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<sup>9</sup> The castration in its narrower scientific meaning already is a hormone therapy, for the removal of the hormo-nally active germ tissue and of its effects on the psychosexuality and on the development of the bodily features is an ob- jective of it. It is used, besides against intersexed women, particularly against sexual offenders.

According to art. 35 of general comment no. 14, the state responsibility to protect the human right to health does explicitly also include:

- laws and measures for an equal access to health care and to health services Gesetze und Maßnahmen für gleichberechtigten Zugang zu Gesundheitsfürsorge und Gesundheitsdiensten (was nicht gegeben ist, wenn bestimmten Patientengruppen das Recht auf Informierte Einwilligung verweigert wird)
- state control over medical facilities (also for putting through human rights in force)
- prevention of damaging traditional practices like genital mutilations (Not validly consented genital surgery is comparable with genital mutilations, particularly, if it effects the loss of the sensitivity or even of the genital.)
- state responsibility to protect groups in need of protection, like women, children, youth, and elderly people, against violence on grounds of sex / gender (Not validly consented surgery at the genital or at the gonads of intersexed infants are violence on grounds of on sex.)
- protection against third persons impairing the access to health information and health services

Art. 51 of general comment no. 14 explicitly names as examples of the violation of the responsibility to protect the human right to health:

- omission of the state, to take all necessary measures, to protect, within its sovereign territory, against any violations of the human right to health by third persons
- omission to regulate third persons in a way, that would prevent violations of human rights by third persons
- omission to protect consumers and workers from health damaging practices, i. a., of pharma producers
- omission to stand up against continuing health damaging traditional medical practices (The experimental sexual reassignment is such a medical practice damaging to health, even less than a custom, as it would the case, if it was a medical standard.)

The violations of the human right to health against intersexed people are, at the same time, violations of the prohibition of discrimination on grounds of an actual or supposed health status (art. 2 par. 2 CESCR, art. 33 general comment no. 20 on the prohibition of discrimination concerning the CESCR).

### **3.2 Gonadectomy (Castration)**

The removal of the gonads (testicles, ovaries, or mixed gonads) of intersexed people, particularly in cases of AIS, mixed gonads, or true hermaphroditism, are still recommended and enforced practices. Though the non-existence of a medical indication, healthy gonads are still removed instead of regular medical checkups, because of fears, that there might be an increased risk of cancer. For this, only the consent of the parents, not of the intersexed children themselves, is requested. A legally valid consent of the parents, however, is only possible in these cases, if really already a tumor has developed, because only then an emergency exists. Only the healing of really existing life-threatening diseases can justify the removal of an ill organ.

The mere danger of a getting a cancer disease, however, is no emergency, so that for the very most gonadectomies at the cost of intersexed infants, no legally valid consent of the parents exists, resulting in a violation of the human right to health (art. 8, 11, 24, and 44 general comment no.14).

At latest the study of Prof. Loin Jenga, according to which the risk of cancer concerning

several sections of intersexed people is very low, would have had to lead to a stop of all removals of intersexed gonads, at which no tumor exists.

These measures are proposed by the doctors in attendance to the parents, a consent of the affected children is not requested. They do not wait for their natural development. The majority of the intersexed people and of their parents has been informed falsely or even not at all concerning the effects of the castration and of the scientifically unsecured hormone substitute therapies. Many affected people experience the castration and the paradox hormone therapy connected with it as an intervention into the most elementary human and personality rights.

The unexplained castration of minors and of adults, as it is still practised against intersexed people in the Federal Republic of Germany, in addition to that, violates, according to the legal point of view of the parallel rapporteurs, the human dignity (art. 1 UDHR). There is, except for torture, nearly no graver bodily intervention against the human dignity imaginable than a medically unnecessary castration.

It is, at the same time, a grave violation of the human right to health (art. 12 CESCER), which includes, according to art. 8 general comment no. 14, in particular, also the right to a self-determined sexuality, to the self-determination regarding one's own body including the sexuality and the preservation of the reproductive capacity, and the right to a healthy development of the child (art. 12 par. 2 lit. A CESCER).

In addition to that, it is a particularly serious violation of art. 2 par. 2 CESCER in view of the serious discriminations on grounds of sex / gender concerning the human right to health, because regarding other groups of patients, especially concerning persons with an increased risk of cancer, not the removal of the organ, but the recommendation to earlier medical checkups is usual. No one would seriously raise the idea to preventively amputate parts of the lung of a smoker. The offences are still not pursued in the Federal Republic of Germany. The protection by the state is withheld from the intersexed people.

The violations of the human right to health regarding the castrations at the infant's age concern in particular:

- the consent of the parents without any medical emergency, resulting in a violation of the informed consent (art. 8 general comment no. 14)
- the acceptance of ways of medical treatments, which prevent instead of guarantee the highest degree attainable for the respective human being of physical and psychological health (art. 8, 37, and 48 general comment no. 14)
- the lack of education on sexual and reproductive health (art. 11 general comment no. 14)
- acceptance of unacceptable medical treatments (art. 12 general comment no. 14)
- disregard of the preeminence of the well-being of the child concerning all measures for the realization of the health of children and young people (art. 24 general comment no. 14)

### **3.3 Genital Amputation**

An enlarged clitoris means neither danger to life nor the danger of the failure of an organ, and so it does also not mean a medical emergency. So parents cannot validly consent to the genital surgery on their intersexed infants. If such a consent takes place nevertheless, it is a violation against art. 12 CESCER in connection with art. 8 of the general comment no. 14 to the CESCER.

The medical services claim to have the ability to shorten the clitoris, without loss of sensitivity or destroying the libido. Up till circa 1986 however, a clitoris classified as being too big was generally amputated. A practice that resembles female circumcision (art. 21, 22, 35, 36, 37, and 51 general comment no. 14). This life-destroying procedure is still taking place on children with ambiguous genitals, even though their development is not yet completed, and no one can say with certainty whether this decision is even close to being correct.

In addition, although the loss of male glans (head of penis), even in parts, will be assessed as a higher degree of disability than the loss of the sensation of a clitoris.

This violates, according to the legal point of view of the parallel rapporteurs, especially the human dignity (art. 1 UDHR), the human right to health (art. 12 CESCR), and the prohibition of discrimination on grounds of sex / gender and of birth (art. 2 par. 2 CESCR) concerning the human rights of the CESCR.

The violations of the human right to health regarding the genital surgery at the infant's age concern in particular:

- the consent of the parents without any medical emergency, resulting in a violation of the informed consent (art. 8 general comment no. 14)
- the acceptance of ways of medical treatments, which prevent instead of guarantee the highest degree attainable for the respective human being of physical and psychological health (art. 8, 37, and 48 general comment no. 14)
- the lack of education on sexual and reproductive health (art. 11 general comment no. 14)
- acceptance of unacceptable medical treatments (art. 12 general comment no. 14)
- disregard of the preeminence of the well-being of the child concerning all measures for the realization of the health of children and young people (art. 24 general comment no. 14)

### **3.4 Irreversible Genital Surgery Interventions with both Minors and Adults**

- Castration without secured indication.
- Castration without consent.
- Castration under default of an inappropriate indication.
- Castration of minors
- Clitoral/Penis amputation as well as clitoris and penial plastic implants without consent.
- Arrangement of neovaginae and neopenis for babies, children and adults without approval.
- Forced enlargement / widening of the artificially invested organs.
- Absence of a medical association which holds a quality education for these interventions.
- Absence of quality control of these interventions.
- Absence of definition of quality characteristics.

### **3.5 Medical Treatment according to the civil status instead of according to Health Requirements**

The discrimination of intersexed people starts already with the health insurance card, which allows only an entry as male or female, and which follows the entry of the civil status in the birth certificate. The payment for medical checkups as well as the reference values for investigations of the blood, in turn, orientates itself according to the gender entry on the health insurance card. This results in the denial of necessary investigations and their payment,



at the cost of people with an incorrect gender registration, and it leads to wrong diagnoses.

They try to adapt also the secondary sex characteristics to the sex / gender, which has been surgically reassigned and announced in the birth certificate, in order to promote the identification of the affected people with the sex they have been reassigned to, which includes a life-long, often contra-chromosomal, hormone medication. Even though the „time window“ theory of Prof. Dr. John Money about the alleged reeducationability of the gender identity has, already for long time, been disproven, and even though today many physicians do not refer any more to Prof. Dr. Money respectively even distance themselves from him, and even though interventions into the identity of the child are prohibited (art. 8 CRC), are worst health damages still caused against intersexed people, are healthy people still forced into a life-long dependence on hormones – a drastical violation of art. 12 par. 1 + par. 2 lit. a CESC.R.

Insofar as physicians prescribe hormone medicaments, they do this exclusively according to the registered civil status – without any regard to the question, whether or not the hormones are adequate to the chromosomal sex. Even if the medicaments fit to the registered gender, the prescribe the hormon medicine off-label, without consideration of the fact, that their patients are bodily intersexed persons, for whom the medicaments are not officially registered. If, on the other hand, an affected person demands for a hormone substitution therapy, which does not fit with the registered gender, the physicians refuse to prescribe them, even if it is a chromosomally adequate hormone therapy, and then claim, that it is an off-label use <sup>10</sup> Even in cases of obvious intolerabilities of a paradox hormone therapy, which the affected people are suffering from, the prescription of sexually adequate hormone treatments is refused. Also health insurances and their medical services refuse to bear these costs <sup>11</sup> The enforced sexual reassignment and the preservation of this reassignment dominate over every life interests of the affected people, thus violating the human right to health (art. 12 CESC.R) and the human dignity (art. 1 UDHR).

The violation of the human right to health is most obvious regarding art. 8 general comment no. 14 on the CESC.R. The right to health is broken concerning the right to self-determination on one's own body, to the right to be free from interventions and maltreatments, and to the right to be free from not orderly consented medical treatments and human experiments. And, in addition to that, a physically adequate hormone substitution therapy, which could allieviate the damages, is refused, if it is not compatible with the enforced gender registration.

### **3.6 Hormone Substitute Therapy and Off-Label-Use of Medicaments**

According to the medical thesis, the medical intervention into the sex via sex hormone medicaments shall take place life-long corresponding to the prescribed gender. If, following the decision of the doctor, the reassignment shall be done corresponding to the biological chromosomal sex, then the hormonal and other medical treatments orientate themselves to the existing physical predispositions. They are made sexually adequate <sup>12</sup> If, following the decision of the doctor, the reassingment shall be done opposite to the innated sex, then the hormonal interventions, as well as the, for this reason, decreed ablative castrations, are directed against the existing predispositions and the potentials for the sexual development of the intersexed people. Thus, they are executed sexually paradoxically<sup>13</sup>.

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<sup>10</sup> attachement doctor and hormones

<sup>11</sup> attachement IKra and UH letter health insurance medical service (MdK)

<sup>12</sup> medical: sexually adequate = corresponding to the genetical sex (genotype)

<sup>13</sup> medical: sexually paradox= opposed to the genetical sex (genotype)

### **3.6.1 Consequences of adequate hormone substitution therapy (HET)**

Regarding adequate hormone substitution therapies in consistence with the biological chromosomal sex, only relatively few damages to one's health of intersexed people have been reported to the parallel rapporteurs.

Concerning castrated minors with genotypically female sex chromosomes 47, XX, however, the medical supply is not secured, because they regularly only get hormone substitution therapy with the amount for the menopause, i. e., with the amount for older people, or they get, even more insufficient, only contraceptives as a hormone substitution therapy.

The only oestrogen therapies do, particularly concerning gonadectomied persons, not take into account, that female human beings produce, besides the so-called female sex hormones (oestrogen, gestagen) (Östrogenen, Gestagene) also a lower amount of male sex hormones (testosterone) benötigen. This leads to early atypical health disorders like osteoporosis, to disorders of the immune system, and, also atypical for younger people, to significant reductions of the physical, psychological, and social capability, and to painful physical dysregulations. Regularly, the recommended duration<sup>14</sup> of application of the medicaments, has to be, by far, exceeded particularly regarding castrated younger people. This leads, consequently, to a significant increase of the risk of life-threatening and unforeseeable diseases<sup>15</sup>.

### **3.6.2 Consequences of paradox hormone therapy (paradox HT)**

Concerning paradox hormone therapies, which are conducted opposed to the biological chromosomal sex, many health disorders are known to the parallel rapporteurs. The people affected by contra-chromosomal enforced sex reassignment do, after the preparing ablative castrations, not have the physical basis for the development of the secondary sex characteristics of the prescribed sex. For this reason, doctors life-long prescribe to the affected people medicaments with hormonal effects, designated for the other sex. Many recorded pieces of information on the paradox HT and on its very different effects are available to the parallel rapporteurs. The paradoxen HT have physical and psychological effects, resulting in also health, social, and legal effects. The analysis by the parallel rapporteurs of a large number of treatment documentations of intersexed people, who have been treated with paradox HT, has found out, that, to a significant extent, pending on the used active substances, on the dose, and on the duration of application, significant health disorders and alters of all tissues an organs manifest themselves.

A large part of the effects of the medicaments obviously seems to be completely unknown to the medical professions. In view of the large number of findings regarding the effects, the parallel rapporteurs can only present the gravest effects.

#### **3.6.2.1 Physical and psychosomataical consequences of the paradox HT:**

The paradox HT alter, like the surgical changes on the genital, in an unnatural way, the outer physical sex characteristics. Their effect is also in opposition to the own sex predispositions and sex-specific developmental potentials, which have remained after the castration<sup>16</sup>. The long-term effects of the paradox HT including the alteration of metabolic functions,

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<sup>14</sup> Up to 8 years of application in total, depending on the medicament and the active substance

<sup>15</sup> attachment: „Marie” study

<sup>16</sup> Frances Dr. Drohm

interactions, and alterations of organs, still have, too a large extent, not been explored yet as well as the interactions with other medicaments. In the least case, only the effect of other medicine is reduced. Since the beginning of the paradox HT on intersexed people in the 1950ies, no evidence-based studies have been carried out on the tolerability and on the intended success of the treatment. The physical characteristics, particularly the secondary sex characteristics, which have been created by the paradox HT, only look similar to those of the other sex and do not correspond to their natural model concerning their development, structure, and function. They show, often diagnostically secured, disorders regarding the differentiation and have an infantile status of development<sup>17</sup>. Especially the paradox HT hold, because of their dysgenesis caused by medicaments, a risk of cancer, which is difficult to estimate, for the genetically determined foundations of the functioning of the bodies of the intersexed people are contradicting with the side effects of the medicaments.

Besides, a significant risk of cancer and of functional disorders exists regarding all genotypically determined organs and their functions because of effects of the medicaments, which are chromosomally opposed to them. The prescription exceeding the recommended duration<sup>18</sup> increases the risk of cancer in particular<sup>19</sup>. These risks hit especially younger, minor, human beings, for whom the medicine is prescribed by the doctors, for a duration, which exceeds the recommended duration by far<sup>20</sup>.

According to the knowledge of the parallel rapporteurs, the dysregulations of the metabolism, resulting from the alteration of the functioning of organs and tissue caused by the effects of paradox HT, are a significant physical cause of psychosomata disorders. Among them, are disorders of the supply of glucose and oxygene to brain tissue and to the nerve tissue, which does not take place corresponding to the innated sex, and their psychological effects like, i. a., nervous diseases, lack of drive, and physical caused depression, which is often misdiagnosed as a psychologically caused depression. A further significant physical cause of psychological disorders happens with paradox HT because of the dysregulation of other organs and tissues, e. g., of those, which are involved in the stress management. Also alterations of the hypophysis and of its regulative functions<sup>21</sup> are involved in this. Regarding castrated genetically male intersexed people, who get paradox HT, you can see anemias, diabetical diseases and disorders of the functions of the kidney and of the adrenal body (e.g. Addison syndrome) as well as the psychological disorders associated with these physical ones. Also the suppression of the natural psychological development by a contra-chromosomal hormone treatment belongs to the psychosomata area, because the psychological disorders resulting from it, often vanish with the change to an adequate HET.

Because of the castration and of the paradox HT, the necessary age-adequate regulating hormonal impulses, an the psychological developments and potentials of activity fail to materialize, so that under paradox HT, there regularly isn't any libido in existence any more. This causes pain in two ways – on the one hand because of the absence of one's own lust, on the other hand, because the expectations of a possible partner cannot be fulfilled (compare art. 8 general comment no. 14).

Altogether, from the view of the parallel rapporteurs, it has to be stated, here, that many of the affected people have got heterogenous psychological disorders because of the paradox HT. The parallel rapporteurs are also informed, that, for several affected persons, it has been

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<sup>17</sup> attachment FK infantile breast tissue

<sup>18</sup> ca. 8 years total application depending on the medicament and on the active substance

<sup>19</sup> MARIE study

<sup>20</sup> Cases are known of by far more than 40 years of paradox HT

<sup>21</sup> hypophysis - gonad - axis

proven socialmedically, that they have got gravest psychological impairments resulting from paradox HT. These have led, in single cases, into the complete, in many cases into the partial, inability to work.

The parallel rapporteurs know from the patient files of affected persons, that the psychosomatical disorders have proven as resistant to psychotherapy during the administering of paradox HT, but after the change to a chromosomally adequate HET, the psychological troubles often have been significantly alleviated or have even disappeared completely.

### **3.6.2.2 Psychological consequences of the paradox HT**

According to the knowledge of the parallel rapporteurs, psychological disorders of intersexed persons, whose sex has not been made subject to a medical therapy, are rare. They also only rarely enlist support groups.

Psychological pressures on intersexed people treated with paradox HT have been observed especially regarding the following facts:

- The artificially altered sexual characteristics cannot fulfill the expectations of the society.
- The concealing to the affected persons and often also to the later doctors in attendance of the knowledge concerning the implemented sexually reassigning interventions, leads to significant psychological burdens and undermines the possibility to develop one's own life strategies for their situation.
- Many intersexed persons considerably suffer from the sex characteristics of the other sex, which have grown under the paradox HT, because neither a surgical nor a hormonal treatment can change the innated gender identity. This pain can only be prevented by respecting and protecting the sexual condition at birth, and by doing sexually reassigning interventions only after an informed consent of the intersexed person himself/herself.
- False pieces of information by the physicians concerning erectile capacity, menstruation, and fertility cause psychological suffering, because the incorrectly informed intersexed persons do not understand, why the physical abilities do not function at them, in contrast to the statement of the doctor. To the deceptions at the cost of intersexed people, belong the prescription of contraceptives to castrated people and the untrue claim, that the German laws prohibited the reproduction by means of artificial insemination<sup>22</sup>. Altogether, the people having been treated this way, regularly are not able to fulfill the reproductive pressure of their social sphere, and they even make a fool of themselves at visits to public authorities relating to this. As a result, one can notice a strong, psychologically burdening, feeling of inferiority with many affected people. They regularly suffer badly from the fact, that they cannot keep up with their contemporaries and try to nevertheless fulfill the expectations of the other by means of play-acting. This causes, permanent, often life-long, pressure not to be allowed to reveal the truth, which cannot be maintained psychologically in the long term. This results in anxiety neuroses.

The paradox HT does not comply in any regard with the experimental medical objective to impose on human beings a different sexual constitution than the one they have been born with, and to impose on them a different gender identity, in order to make the sex and gender of people unequivocal. On the contrary, it causes worst physical and psychosomatical damages (including the psychological effects of alterations, and the psychological effects of the hormone medicaments, which are often felt as brain-washing); the psychosomatical damages are often misunderstood with the psychological ones. Most of the real

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<sup>22</sup> FK artificial insemination

psychological damages develop because of the irreparable destruction of the sex they have been born with, without any respect to their gender identity, because of the destruction of their fertility and of their libido, and because of the withholding to them of the information about the sexual condition at birth and about the interventions having been done on them.

### 3.6.3 Off-Label-Use

The paradox HT have never been systematically scientifically explored und reviewed. There are no controlled clinical studies regarding this at all. So most of the health damages under paradox HT, which the parallel rapporteurs know about, relate to the experience of their own work within the NGO and the support group. According to secured knowledge of the parallel rapporteurs, the medicaments used for the paradox HT of intersexed people, do, at least concerning Germany, not have any official authorization for this use<sup>23</sup>. But also world-wide, the parallel rapporteurs do not know any such authorization. So, according to the legal point of view of the parallel rapporteurs, the prescription of a paradox HT is an off-Label use of medicaments.

The off-label use results in the failure of the state control mechanisms concerning quality, tolerance, effects, and risks of the chromosomally paradox use of these medicaments on the affected people. Laws are circumvented, like the German law governing the manufacture and prescription of drugs („Arzneimittelgesetz (AMG)), which has the objective to protect the population against damages to health, by means of rules concerning the authorization of, the trade with, and the prescription of medicine. The applications of paradox HT on the affected people are completely beyond any state control, so that the state is unable to fulfill its responsibilities to protect (art. 12, 35, and 51 general comment no. 14). According to art. 35 general comment no. 14 on the right to health, the state has to, within the scope of its responsibility to protect, keep the control over the medicaments being made use of. If, as it happens concerning intersexed people, large amounts of medicaments are used off-label, the state is obliged to broaden their authorization corresponding to the needs of the realization of the right to health of the intersexed minority, and to, at the same time, warn, that the exact dosage and the side-effects are not sufficiently explored yet.

The off-label use undermines the enforcement of compensation for health damages related to medicaments. Affected people in Germany would, e. g., have, according to §15 Produkthaftungsgesetz (ProdHaftG, law on the liability for products) in connection with §84 AMG (risk liability) no title to compensation for the violation of their body and of their health by the medicaments, because the prescription of these medicaments for them has not been conducted within the authorization, but off-label.

In addition to that, the health damages resulting from the off-label use have not been registered in official and openly accessible databases, so that health damages caused by off-label uses of medicaments do not find any entry into the patient information and into the professional information. The affected people are still exposed to avoidable health risks.

In fact, due to the off label used, the patient information enclosed to the medicaments do not contain any information on the chromosomally paradox use<sup>24</sup> But also the relevant reference books<sup>25</sup> have no pieces of information or knowledge at all on this. In addition to that, one has to bear in mind, that most often, the affected people themselves do not have any information

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<sup>23</sup> e.g. letter of the BFarm

<sup>24</sup> patient information leaflets e.g.

<sup>25</sup> red list

concerning their sexually reassigning treatment and concerning their biological foundations. As a result, the doctors responsible for the prescriptions and the pharmacists distributing the medicaments are unable to forward the prescribed consumer information to the intersexed persons, who are treated with this medicine.

### **3.7 Documentation of Treatment**

- Misinformation and/or false information of persons affected and/or their relatives.
- Deliberate “false clarifications” about diagnostic information.
- Insufficient diagnostic action, by omitting necessary diagnosis procedures.
- Keeping patient's documents, with the intention to let them remain unclear about their true existence.
- Denial of patient documents and files to prevent them from taking juridical steps.
- Neither briefly nor long-term quality control of treatments, nor recordings in a central register, for example, as it is the case with cancer.

The state is obliged within its responsibility to protect the human right to health (art. 12 CESCR), to ensure, that third people do not hinder the access of the patients to health related information (art. 35 general comment no.14). The parallel rapporteurs are convinced that, as far as the withholding of patient files would thwart the tracking of violations of the prohibition of discrimination according to art. 2 par. 2 CESCR, and would so also thwart the filing of means of legal redress and the reception of compensation, the burdening of the physicians with a reversal of the burden of proof, as explained in art. 40 of the general comment no. 20 on the prohibition of discrimination regarding the CESCR, is necessary.

### **3.8 Effective Legal Protection**

The belonging of the human rights of the CESCR to the „ius cogens“ and the inalienability of the universal human rights („in the world“) for Germany according to art. 1 par. 2 of the German Basic Law have already been explained in section 1.2 of this parallel report. In addition to that, already art. 8 UDHR prescribes a guarantee of legal protection at the national level concerning the human rights of the national constitutions and concerning the human rights on a basis of simple national law. The latter refers to the human rights from international origins, which have been given validity on the national level by simple national laws consenting to them. Art. 19 par. 4 of the German Basic Law prescribes a guarantee to legal protection at the German courts concerning all rights of the persons living in Germany. Among these rights are all human rights treaties of the United Nations, which Germany has joined. Exemptions (of this right to legal protection at the German courts) are only possible insofar, as there are international courts for the treatment of violations of international human rights treaties. Such courts are the European Court of Justice for the human rights of the European Union and the European Court of Human Rights for the human rights of the Council of Europe. These international courts, however, have no responsibility for the universal human rights of the UN, because, according to art. 4 UN Charter, only states can be members of the UN. Since the UN does not have any court responsible for the jurisdiction on individual cases regarding the universal human rights, only the responsibility of the national courts remains for the fulfillment of the guarantees of art. 8 UDHR and of art. 19 par. 4 Basic Law to legal protection concerning the protection of the universal human rights. This is the more important, because international law, which belongs to the „ius cogens“ according to art. 25 Basic Law, is, as it has been shown in section 1.2 of this parallel report, for Germany directly applicable law.

Despite the obvious direct applicability of the universal human rights at Germany, they are still not taken into account yet by many German courts. Also for this reason, Germany is still far away from the complete implementation of the human rights of the CESCR for intersexed people. But also concerning the legislation and concerning measures of the executive, particularly the social human rights of the UN often remain uncondidered.

### **3.9 Consequences of Treatment in Scope of Medical Definition**

- Life-long dependence of intersexed persons on hormone substitution therapies and other medical treatments determined by the legal civil status registration at birth
- In case of the incorrect gender allocation of intersexed individuals medical redefinition of the affected persons now as transsexuals
- Treatment “of intersexual people” according to the treatment of transsexual people.
- Application to the administration of justice being based on the bill for transsexuals (TSG – Transsexuellen Gesetz: Transsexual Bill) concerning rights of intersexuals for i.e. individuals pensions, social security and insurance, etc.
- Refusal of medical communities, to undertake the necessary studies on the effectiveness and the metabolic consequences of paradox hormone substitution therapies and other complementary therapies
- The refusal of physicians, who are treating adults, to actively participate in the renewal of the methods of treatment and the disinterest in studies directed at a pediatric purpose. For example, this is clearly documented through the project “Clinical Evaluation Study: Medical and surgical results of treatment, psychosexual development and health-related issues affecting the quality of life of patients with problems in their sex/gender development” (conducted by Prof. Dr. med. U. Thyen (Lübeck)).

The aforementioned inappropriate behaviours with regard to medical interventions concerning intersexuality are provable and have also been proven publicly by jurisdiction<sup>26</sup>. The German Government has been informed provenly informed by affected people and knows about these problems.

## **4. Social Security and the Right to Social Insurance (art. 9 CESCR)**

The human right to social security including social insurance (art. 9 CESCR) is of crucial importance for the guaranteeing of the human dignity (art. 1 UDHR) in all situations, in which human beings are not able to completely realize their rights according to the CESCR by themselves (art. 1 general comment no. 19 on the human right to social security).

The protection regarding pension, impairment, and costs of diseases are among these rights (art. 2 general comment no. 9). The state has a broad scope how to shape the social security; a sufficient social security for affordable contributions as a result, however, is a binding state obligation (art. 4).

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<sup>26</sup> Michel Reiter 722UR III302/00 v. 2001; 1 BVR 390/03 v.29.10.2003, Verfahren C.J. Clüsserath; 2 BVR 1833/95, a Transsexual with intersexual background.

## 4.1 Health Insurances

The human right to social security can, as well as the human right to health, also be fulfilled regarding the security concerning the costs of illnesses, within the scope of the private health insurance. The state, however, is obliged to put through, that the contributions are affordable (art. 9+13 general comment no. 9, art. 4+5+36 general comment no.14).

For parents of intersexed children, however, it often is impossible or only possible at exorbitantly high contributions, to have their newborn intersexed or gonadectomized child insured within a usual private insurance, even though the Federal Government increasingly demands for private insurances. This hits particularly hard those parents, who are completely privately medically insured themselves, because they cannot insure their children within the public health insurance.

Concerning all insurance treaties, which presuppose a certain gender and corresponding biological realities and sex-related health conditions, as life, health, accident, professional, and care insurances etc., the insurance contributions are calculated depending on the registered gender. Besides this, paradox HT are assessed as increasing the risk.

This leads, according to the knowledge of the parallel rapporteurs based on concrete cases, to the result, that particularly intersexed people treated with paradox HT are from the start, excluded from certain insurances or disadvantaged regarding them, or that due insurance benefits are denied to them. Particularly regarding the exclusion of intersexed people from insurances and regarding the denial of the payment of medically needed benefits, the German state does not sufficiently comply with its responsibility to protect the right to social security (art. 11, 46, and 59 general comment no. 19).

The social security concerning the costs of diseases (art. 2 general comment no.19) is also violated by the denial of chromosomally biologically, regarding the dosage, and regarding the age, adequate hormone substitution therapy by public and private health insurances as well. One reason of this is the concealment for decades of the existence of the intersexed minority, what has resulted in the fact, that the appropriate dosage for intersexed people has not been considered for the authorization of the hormone medicaments. For this reason, doctors often only give private prescriptions even to members of the public health insurance, because of fears of liability risks. Private prescriptions have to be paid by the patients themselves. Here, legislative measures for the protection of the access to social security are necessary (art. 45 and 66 general comment no.19).

Intersexed people with the androgen insensitivity syndrome (AIS), who, in most cases, have been deprived of their healthy testicles without any medical necessity, need substitution with testosterone, which is not paid by most health insurances, because the medicament does not have a corresponding authorization. AIS means, that the chromosomes (XY) and the gonads (testicles) are male, but that the body, because of a, in most cases complete, insensitivity for the male sex hormone testosterone, develops completely or in most characteristics female. Most people with AIS have a female phenotype and are registered as female, which is an additional hurdle for the prescription of testosterone. For the compliance with the human right of intersexed people with AIS to social security, the state has to ensure by means of legislative measures (art. 45 general comment no.19), that the needed testosterone medicaments are paid by the health insurances, and that they are authorized as soon as possible for intersexed people with the remark, that the dosage needed for intersexed people has not been sufficiently explored yet.



A further reason for the exclusion and the denial of benefits concerning hormone medicaments by the health insurances results from the actual jurisdiction on the off-label use. According to the jurisdiction of one of the senates of the Bundessozialgerichts (highest social court of Germany), the payment by a health insurance for the use of an unauthorized medicament is excluded already for the reason, that the use of the medicament takes places on the basis of punishable behaviour, and an obligation of a health insurance to pay cannot arise from a prohibited action (Bundessozialgericht 19.03.2002, BSGE 89, 184 ff).

The state responsibility to guarantee concerning the right to security regarding the greater risks of the costs of diseases by means of an affordable health insurance (art. 36 general comment no.14, art. 2+13 general comment no. 19), which is contained in the human rights to health (art. 12 CESCR) and to social security (art. 9 CESCR), is violated regarding the intersexed minority, and this takes place in many cases particularly concerning the costs of a life-long hormone substitution therapy.

## 4.2 Disability

Intersexuality as such, as well as having been born with a body, that can be interpreted as unequivocally female or male, is not a disability. The way of the medical treatment, however, has made many intersexed people disabled. A castration leads to a considerable physical and, in most cases, also psychological impairment; often hormone deficiency symptoms or side-effects of contra-chromosomal hormone therapies are added to it. A gonadectomy as well as a genital operation in infancy, and also the withholding of information regarding the surgical interventions performed, can have a traumatizing effect and so lead to bad psychological impairments.

All these physical and often also psychological disabilities (on the definition of disabilities for the purpose of the CESCR see art. 3 of general comment no.5 to the CESCR), which have been imposed from outside, often include a significant limitation to the capacity to earn one's livelihood by oneself, thus also significantly impairing the enjoyment of the human right to work (art. 6 par. 1 CESCR).

Intersexed people often receive no or only insufficient compensations of disadvantages according to the law of disabled persons. This in particular, because the principles of the „Versorgungs-Medizin-Verordnung“ (regulation for the assessment of the degree of a disability) regard the impairments of castrated women as less than the impairments of an equally affected man. In addition to that, the knowledge of the socialmedical specialists and experts of the authorities responsible for stating the degree of disability, regarding intersexuality often is insufficient, which results in considerable discriminations. Intersexed people, who are treated with a genotypically adequate hormone substitution therapy, are, according to the experiences and the knowledge of the parallel rapporteurs, also discriminated to a considerable extent on grounds of sex / gender on of their disability. The principles of the Versorgungs-Medizin-Verordnung (VersMedV) and the older Anhaltspunkte (AHP) both differentiate on the basis of the biological constitution. This applies also to sex specific organs and tissues.

In the administrative procedures of intersexed people regarding the disability, basically all health disorders and disabilities concerning the sexual constitution, which are caused by paradox HT, are ignored by the socialmedical experts of the responsible public authorities. Instead, the disabilities are often named with discriminating and ashaming terms. They are discriminating also because of the fact, that the announced degree of the disability is always

below those of the genders (man and woman) mentioned in the VersMedV.

A person with male chromosomes, testicles and a penis, which had been underdeveloped solely concerning its size, e.g., has been castrated and been surgically reassigned towards a female appearance and has then for 32 years been treated with paradox HT. Finally, a degree of the disability of 20 ° has been announced with the discriminating description „man with complete exterior female genital“.

A man, who is not intersexed, and who suffers from the loss of his penis, in contrast to that, is entitled to a degree of disability of 50°<sup>27</sup>.

The aforementioned example is based on the case of the parallel rapporteur Frances Kreuzer<sup>28</sup>. He has put to the disposal of the CDESCR committee all socialmedical statements of his long-standing disability procedure (from 2007 to provisionally 2010), in order to explain, how far the disadvantages and discriminations of intersexed people, based on sex / gender and on disability, go in the social law.

The parallel rapporteurs have, based on their knowledge from the procedures regarding the degree of disability, which they know, come to the conclusion, that the behaviour particularly of the socialmedical experts, is incompatible with the social law and its objectives concerning disability, prevention, and rehabilitation. Since such a behaviour is nearly identical at all provinces (art. 73 general comment no. 19) and by nearly all responsible socialmedical experts, the parallel rapporteurs regard this illegal behaviour as structural violence of the state against intersexed people within the scope of the social law and of the law on disabled persons, and as a violation of the human right to social security (art. 9 CDESCR, art. 4, 29, 40, 59, and 78 general comment no.19).

The NGO Intersexuelle Menschen e.V. has already supported numerous intersexed people concerning the application to the announcement of a disability, concerning the enforcement of disability pension and of compensation according to the Opferentschädigungsgesetzes (OEG, law on the compensation of victims), if necessary, including taking the cases to the social courts.

According to art. 20 and footnote 17 general comment no. 19, the human right to social security of the CDESCR, this includes for disabled persons the formal announcement of a disability as well as benefits for the compensation of disability related losses of income. This refers, according to the legal point of view of the parallel rapporteurs, also to disability pensions. The Federal Republic of Germany should, corresponding to art. 30 general comment no. 19, concentrate more attention to the disabilities of intersexed people caused by false medical treatments, in order to reach an acceleration of the processings.

According to art. 2 par. 2 CDESCR, intersexed people, also concerning the human right to social security, must not in any way be exposed to any discrimination on grounds of sex or other reasons. This applies in particular regarding the equal treatment concerning the degree of disability, concerning the naming of the disability, and concerning the duration of the proceedings. According to art. 31 general comment no.19 on the right to social security, the state is obliged to support such sections of the population, who have, as experience shows, more difficulty in enforcing their rights to social security than the average of the population, in enforcing their rights. According to art. 31 general comment no. 19, disabled persons explicitly belong to these sections of the population.

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<sup>27</sup> VersMedV part B section 13

<sup>28</sup> attachment Frances Kreuzer socialmedical statements

The most important thing, however, is, that Germany has to comply with its responsibility to protect the informed consent, which belongs, according to art. 8 of protocol no. 14, to the human right to health, also for intersexed people, to make sure, that intersexed people are not any more made disabled by the medical system!

## **5. Protection of the Family (art. 10 CDESCR)**

Art. 10 Nr. 1 S. 1 CDESCR prescribes, that the family „is the natural and fundamental group unit of society“, which „widest possible protection and assistance should be accorded“ to, „particularly for its establishment and while it is responsible for the care and education of dependent children.”

### **5.1 Violation of the special Protection of the Family by Letting happen Violations of the Human Rights of the Child**

The parallel rapporteurs hold the legal point of view, that the state protection of children against grave human rights violations is included in the obligation to the special protection of the family.

The parallel rapporteurs are convinced, that this includes particularly the protection of the identity of the child (art. 8 CRC), which in turn especially includes the gender identity of a child. Even the temporary uncertainty of doctors, parents, and other people regarding the sexual ambiguity of their child has to be accepted, in order to ensure the protection of the gender identity of the child, also against the medical professions, because the best interest of the child has to be given priority concerning all medical measures (art. 24 general comment no. 14).

The enjoyment, without any discrimination (art. 2 par. 2 CDESCR), of the human right to health (art. 12 CDESCR) has to be completely realized also for intersexed children. The state has to ensure this also within the scope of its responsibility to the special protection of the family (art. 10 CDESCR). As far as postponable medical decisions are concerned, like, e. g., the surgical-medicamental sexual reassignment, the right of the intersexed child to the free and informed consent has to be protected also against the parents, and the parents have to be protected against giving, just because of a lack of knowledge, a consent to such treatments, which would violate human rights. The use of castration, genitoplastics, and medical alteration of the natural developmental potentials of the body during and after the phase of the physical development of intersexed individuals are effective means of discrimination grounded on sex with life-long effects to the affected people. The so-called „Bougieren“<sup>29</sup> is felt by the affected people as a sexual abuse and leads, in view of years of postoperative states of pain, regularly to gravest traumatizations.

### **5.2 Violation of the special Protection of the Family by Disruption of the Parent-Child-Relation**

Within the scope of Prof. Dr. Money's way of treatment, the parents have been told by the medical practitioners to educate their sexually reassigned child restrictively within the scope of the aimed gender. In addition, parents are requested to life-long withhold from the the child

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<sup>29</sup> The forced widening of an artificially created vagina with sticks, with growing diameter, for the purpose of preparing an orifice of the body for the penetration by the penis of a man at the adult age.

all information about the medical interventions and about his / her true sexual condition. The medical explanation for this action lie in the sexual-social security which the child is supposed to develop in his / her reassigned gender.

This medical indoctrination of the parents concerning the sexual condition of their child makes them excessively observe the sexual development of their child. The restrictive education concerning the gender permanently destroys the primal sense of trust between the mother and the child respectively between the parents and the child. The natural and normal protective instincts of a mother for her child are replaced by a mechanism aiming to protect the child from its individual own sexual development. The natural protective instincts of the mother, whose objectives are the normal life, the survival, and the viability of the child, are polarized and suppressed by the doctor's will to the imposed sexual reassignment. The substantial reason is, that the own individual development of the child is presented to the parents as an enormous threat. This is documented by the knowledge gained by the work of the support group xy-women and their advisory services as well as by psychological studies, which very often deal with the distanced relation between intersexed persons and their parents.

The new international DSD guidelines recommend a considerably better informing of the parents of intersexed children, without making unmistakably clear, that there is no medical standard. They, however, still want the parents to decide on irreversible sexually reassigning interventions on their intersexed infants, which is incompatible with the informed consent and, as a result, with the human right to health (art. 8 general comment no. 14, art. 12 CESCR). The parents are still made violate the human right to health.

Concerning one important point, the DSD guidelines are even an aggravation to the parents. The economical liability risk of the physicians threatens to be passed to them, who are now better, but concerning the human rights still completely insufficiently, informed.

The state is, within its obligation to the special protection of the family (art. 10 CESCR) obliged, particularly by legislative means, to protect the relation between parents and child. For this aim, the complete informed consent of the intersexed children and also the education of the whole society about this minority are necessary, so that parents can to the same extent lovingly accept their extraordinary child without excessive fears of discriminations, as they can accept their child born with unequivocal sexual condition.

### **5.3 Insufficient Social Security**

Article 10 CESCR prescribes the special protection and assistance for all members of the family. The social security of the partner is feasible in Germany in particular by means of the marriage for heterosexual couples and by means of the registered same-sex partnership<sup>30</sup> for homosexual couples. According to art. 2 par. 2 CESCR, also intersexed people must not be discriminated in this regard. In Germany, the registered same-sex partnership is disadvantaged in comparison with the marriage particularly concerning the income tax and concerning the adoption of children, resulting in a denial of the more comprehensive protection of the marriage to many intersexed people, who have been sexually reassigned to the false gender. Intersexed individuals, who make use of their meanwhile legally existing law to leave open their gender registration, do not get a birth certificate. Without a birth certificate, they can neither enter into marriage nor into registered same-sex partnership, so

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<sup>30</sup> The registered same-sex partnership means the law on the „Verpartnerlichung homosexueller Lebensgemeinschaften“. The registered same-sex partnership is legally not treated as equal to the marriage.

that particularly the social protection regarding pension and regarding heritaged is denied to them. These disadvantages on grounds of gender (art. 2 par. 2 CDESCR) concerning the social protection of the family have to be removed by legislative measures.

The healing of these human rights violations cannot consist in the transsexualization<sup>31</sup> of intersexed persons. The application of the law on transsexual people (Transsexuellengesetz, TSG) on intersexed people forbids itself by the different medical-scientific etiology and genesis.

## **6. Special Mechanisms**

### **6.1 A Possibility of Reconciliation: Truth Commission to Raise Awareness on the Violation of Human Rights of Intersexed People**

By the concealment of intersexuality during the Nazi Regime, then later following by Prof. Dr. John Money's "standard", and more recently by the trial to classify these people incorrectly as men or women with DSD, have led to the disappearance of a whole section of the population from the perception and from the memory of the majority population as well as from the members of this minority themselves . For the protection of intersexual people, it is the utmost priority that these violations become apparent by the general public. The knowledge of human rights violations on intersexed people and their suffering must be included into general education in order to prevent these violations from ever happening again. Therefore, determined action is needed. The authors of this report find the instrument of a Truth Committee as especially appropriate. According to the model of the Canadian Truth Committee for the processing of the injuries to human rights in the Indigenous re-education residential schools, a state financed driven committee of historians should be set up in close cooperation with intersexual people. A compensation for pain and suffering should be financed via tax means and contributions of the doctor's unions - including the possibility of the fund to claim to get the money back from the actual offenders. Taking the South African Truth Commission as a model, in those cases where German penal laws have been violated, it must be clear that mitigation of punishment may be guaranteed, but not entire exemption from punishment. The precondition for mitigation of punishment is the entire disclosure of all patient's records towards the respective patients and the publication of all relevant facts towards the state driven committee of historians, as well as the support of restoration of the patients health.

Countless physicians have been accomplices, whether in good hopes or in fear, by looking away and by remaining silent. Hence, mitigation of punishment seems to be acceptable if in turn public reconciliation is achieved. The claim of compensation is already being openly discussed at different levels.

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<sup>31</sup> Transsexualization means the incorrect classification of intersexed people as transsexuals. This, however, is false: Transsexual people make a free and self-determined decision on the adaption of their sexual phenotype to their gender identity, whereas a sex is forcibly imposed on intersexed people.

## **7. Claims and Recommendations**

### **7.1 The Claims of the Persons Concerned**

1. Omit irreversible surgical and medication interventions, so as long as there are no life-threatening indications.
2. Cosmetic interventions only by explicit consent of the person concerned and to be documented under precise written clarification.
3. The treating doctors must voluntarily hand over an entire copy of the individual's medical file to the persons concerned.
4. The treating doctors have, in particular when organ removal is concerned, to clarify all present and future risks of the intervention to the patient.
5. In particular, the obligation is to be imposed on doctors to explain the drug therapies resulting from the intervention, concerning their effectiveness and their risks towards the patients, in writing.
6. Specific vocational training of professionals on intersexuality in all medical disciplines.
7. Establishment of consultation teams for parents of intersexed children, consisting of doctors, psychologists and affected persons.
8. Establishment across the country of counselling and advice centers led by intersexed people.
9. Financial and structural support for intersexual self-help groups.
10. Inclusion of the term "intersexuality" into law.

### **7.2 Necessary Aid Programs for Persons Concerned**

1. Establishment of an aid and compensation fund for affected persons (according to the model of the compensation of the victims of Canadian "residential schools")
2. Because intersexed persons are detained from professional advancement through traumatization and hormone treatment, they need a financial support to increase their pension contribution to the average level.
3. Specialized pension regulations for intersexual people and special regulation for victims of sex reassignment surgeries.
4. Establishment of a rehabilitation plan and a medical center for the restoration of physical health (as much as restoration is still possible)
5. Exemption from surcharges and any additional payments in health insurances.
6. Access to a medical supply without any discrimination, and which corresponds to the individual needs of the sexual condition.
7. Establishment of an index to verify the degree of disability through treatment, non-

treatment or wrong treatment of the persons concerned.

8. Special educational and vocational training measures for the purpose of mitigating the discriminations concerning the participation in life, having been suffered as a result of the forcibly imposed measures on grounds of sex.
9. Establishment of an office engaged by a person classified as intersexed, at the public anti-discrimination office.

### **Addendum – Case Studies - Links**

The case study Frances K. and the actualized case study Christina T. will be sent before the main session of the CESCR committee.

#### **Links:**

parallel report of the NGO Intersexuelle Menschen e. V. to the 6<sup>th</sup> national report of the Federal Republic of Germany on CEDAW:

[www2.ohchr.org/english/bodies/cedaw/docs/ngos/AIP\\_Germany43\\_en.pdf](http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/AIP_Germany43_en.pdf)

[http://intersex.shadowreport.org/public/Association\\_of\\_Intersexed\\_People-Shadow\\_Report\\_CEDAW\\_2008.pdf](http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CEDAW_2008.pdf)

An Emerging Ethical and Medical Dilemma: Should Physicians perform Sex Assignment on Infants with Ambiguous Genitalia? (Hazel Glenn Beh and Milton Diamond Ph. D.)

[www.hawaii.edu/PCSS/biblio/articles/2000to2004/2000-emerging-ethical-dilemma.html](http://www.hawaii.edu/PCSS/biblio/articles/2000to2004/2000-emerging-ethical-dilemma.html)