Shadow Report

Referring to the 6th State Report of the German Federal Government
on the Convention on the Elimination
of All Forms of Discrimination Against Women
(CEDAW)

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Questions to the Federal Government

Question 1: What are the plans of the Federal Government to enable involuntarily childless couples access to assisted reproductive treatments, regardless of their individual financial situation, the underlying disease(s) and their marital status? When will these plans coming into effect?

Question 2: When will the Federal Government replace or amend the German Embryo Protection Act of 1990 with an appropriate Embryo Protection Act or with a Reproductive Medicine Act which meets the recent scientific learnings and allows for innovative techniques like cultivation of more than three embryos and pre-implant genetic diagnostics in cases of severe hereditary diseases? When will the Federal Government allow innovative treatments like egg donation and embryo donation in Germany?

Question 3: What measures will the federal Government take to enable involuntarily childless couples to get access to optimal treatment conditions and to appropriate diagnostics and prevent them from unnecessary treatments?

Question 4: Which actions will the Federal Government undertake to prevent unmeant childlessness in future?

Question 5: How will the Federal Government support women in ensuring and optimising the compatibility of their professional life and the necessary assisted reproductive therapy?

Contents

III. Article 11 CEDAW

IV. Article 12 CEDAW

Introduction of the preparation of this report

We thank the German Institute for Human Rights for the invitation to take part in the preparation of the Shadow Report to CEDAW. We also thank the leading coordinator of the work group for Preparation of the Shadow Report, especially Ms Marion Böker, Ms Henny Engels, German Women's Council, Ms Katrin Adams, KOK, and Ms Renate Ramps, LSVD, who provided us with crucial and helpful information. This allowed us to complete the report according to relevant regulations within the given timeframe.

We thank all women from the "Kinderwunschforum" www.wunschkinder.net and www.klein-putz.de and the members of Wunschkind e.V. for their narratives of their individual experiences they gained during the long journey to their desired child. Communicating with concerned unwanted childless couples and also former unwanted childless couples had been an important need in order to draw a realistic picture of the situation of concerned couples and especially of those women in Germany.

Also many thanks go to Doctor Elmar Breitbach, a Reproductive Specialist and operator of the Internet Forum www.wunschkinder.net, for his corrections in the Sections 5.3. and 5.4. "Reproductive medical treatment-related Health Services".

This report is the result of numerous hours, weeks, months and years of research and countless dialogues and correspondence with childless couples who desire their own biologic children, who feel abandoned and left in the lurch from the German Federal Republic on the way to their desired pregnancy and child.

I. Annotation of the 6th Shadow Report of the German Federal Government

Part A of State Report; I. (Equality Policy)

Citation: “It is about equal chances of women and men with or without children, of every age and in every phase of life as well as in special life situations:”

This should also include the special situation of “involuntary childlessness”. Page 5 – 7 of the State Report broaches the subject of special life situations of women. The topic “involuntary childlessness” is missing.

The paragraph “Equality policy as success strategy” on page 7 talks about “support in typically female distress”. But there is no discussion at all about the typical female distress of involuntary childlessness. Even men suffer from it, but in the average population, women are those who suffer more. Besides the awareness of never having a child who will carry the own genes, women additionally suffer from the fact that they will never experience a pregnancy. Human reproduction is an elementary need. Lack of reproductive capacity and strong desire of getting a child has therefore to be defined as a distress.

The paragraph “National and international cooperation” is of special interest for the authors. Also unwanted childless women are part of the group of women who are especially discriminated. They wish for “equal opportunities” and belong to the “diversity of men and women”. But the policy of the Government obviously excludes those women from any equal opportunities. This fact should be documented in the State Report.

In the paragraph “Living conditions of women in the Federal Republic of Germany” some surveys and statistics regarding this topic are mentioned. At a closer look, none of them addresses the topic of involuntary childlessness.

Part A of State Report; II. (Provision of Convention and Execution)

Article 1: Term of “Discrimination”
The Government is referring to the Act of General Equal Treatment (AAG). Its aim is to eliminate disadvantages and discrimination due to ethnic origin, religion, individual conviction, handicap, age or sexual orientation.

Reproductive disability is a handicap. Therefore reproductively disabled people should have the right to avoid discrimination. At least, the disadvantage of involuntarily childless people should be defined as an immediate impairment. This would be similar to the way the Federal Government defines a pregnant woman or a mother as immediate impaired due to her pregnancy or her motherhood.

Partial discrimination of involuntarily childless people exists because certain couples have to bear 100 % of expenses due to assisted reproductive treatments, whereas other childless couples with a different diagnosis, but the same prospect of success and the same treatments, get a part of their expenses reimbursed by the health insurance.

1. Involuntarily childless couples who depend on donor sperm due to infertility of the man have to bear the full treatment related expenses. This is even more astonishing when compared with infertile woman due to tubal sterility and married to a fertile man, who become

pregnant after In Vitro Fertilisation (IVF) get reimbursed 50 % of their treatment related expenses. In the case that the same woman with tubal sterility is married to an infertile man and the couple is forced to get treated with donor sperm because there are no alternatives the couple has to bear the full expenses. The same applies to lesbian couples. Because of the legal situation in Germany, lesbian couples are not allowed to get treated with assisted reproductive procedures and, even if they are infertile, they do not get any reimbursements of their treatment related expenses at all.

2. Reimbursement is excluded if one of the partners is younger than 25 years or older than 40 years (woman) and 50 years (man), respectively. This is obvious discrimination due to age. It is indeed acceptable that the expenses of reproductive treatments of couples whose infertility is caused by advanced age can not be unlimited borne by the mutual solidarity, however there is no acceptable reason to refuse financial support to people between 18 and 25 years of age and women who are younger than 40 years suffering from tubal sterility who are in a relationship with a fertile man older than 50 years. The same applies to an infertile man who is younger than 50 years who is in a relationship with a healthy woman who is in her early 40ies. Reimbursement of treatment related expenses is not allowed despite their favourable prognosis of becoming pregnant[1], even though the cause of infertility is not due to the partner who has passed the age limit.

3. The same applies to the lack of reimbursement in the case of egg donation and embryo donation. If the man is fertile and the woman suffers from tubal sterility, the treatment related expenses are partially reimbursed, whereas if the man is fertile and the woman suffers from immature eggs there would be no reimbursement at all.

4. If a partner is HIV positive there is no access to any reimbursement of treatment related expenses. This is not only a discrimination due to the this additional disease but also risky, because those couples may try to become pregnant by means of regular unprotected sexual contact due to lack of financial support. Those couples hazard the consequences of the transmission of the virus.

Especially in the cases of egg donation, embryo donation and lesbian relationships the discrimination is not only due to the refusal of financial support, but also due to the legal prohibition of getting assisted reproductive treatments in Germany. Those people are forced to get treatments abroad.

Furthermore, abolition of disadvantages due to religion or personal conviction is necessary. An important reason for the lack of sufficient support of involuntarily childless couples is due to the German Act of Embryo Protection and the illegal interventions of Christian-religious tendencies in the German legislation. The legal definition of the time point when human life begins is concordant to the Christian definition. Both define that human life begins exactly in the instant when egg and sperm cell fuse[2]. Other religions and atheists define it otherwise[3].

[1] P. ex. The pregnancy rate is higher than 15 % in women over 40 years, if they have sufficient antral follicles, AMH within the normal range and Inhibin > 10, according to Prof. Brähler, chairman of the German IVF Register (D.I.R.)

[2] Kreß, Hartmut (2005): View of Protestantic ethic. From: Fuat S. Oduncu/ Katrin Platzer/ Wolfram Henn: The approach to the embryo. Ethical, legal and cultural-comparing aspects of assisted reproductive medicine, Vandenhoek Ruprecht, Göttingen, p. 77

But the German Act of Embryo Protection forces every single couple who wants to get treated with assisted reproductive therapy in Germany to follow a law that contradicts their own conviction or religion.

Article 2:
General Equality Policy Act (AGG); p. 9

The Federal Government says: “Expenses due to pregnancy and maternity should not lead to higher insurance rates (in private insurances)”.
The authors are of the opinion that this applies also to expenses due to reproductive treatments. In reality, someone who suffers from infertility would be forced to admit it to the private insurances; otherwise the reimbursement of treatment related expenses would be excluded. The private insurance company then has the right to claim higher rates or to decline the admission entirely. Similar problems occur to self-employed workers. Their Sickness Daily Allowance Insurance usually refuses to cover downtime due to assisted reproductive treatments.

According to the AGG, discrimination due to pregnancy and maternity is prohibited, whereas discrimination due to a planned or expected pregnancy is not considered. This leads to disadvantages of young women at work. If a woman in her fecund years gets into a relationship or marries, the employer expects her to interrupt her career during pregnancy and maternity leave. To avoid this, some employers try to find ways to dismiss women before pregnancy occurs. Further examples of discrimination at work among women getting reproductive treatments are mentioned below.

Article 5:
Parental Leave/Parents Money

A woman who became pregnant with the aid of reproductive treatments could be discriminated, if she has lost her employment due to the treatments preceding the pregnancy or if the treatments forced her to reduce working hours or to quit her job. Self-employed women who achieved fewer orders/contracts due to time-consuming assisted reproductive treatments receive less parent money, because this benefit is calculated on the basis of the income before the pregnancy.

Article 7:
7.4 European Action Program for Equality of Men and Women

The topic “unwanted reproductive disability” is missing.

[3] P.ex. Staszewski, Schimon (2005): medical ethic and Jewish law – introduction to methodology and positioning. From: Fuat S. Oduncu/ Katrin Platzer /Wolfram Henn: The approach to the embryo. Ethical, legal and cultural-comparing aspects of assisted reproductive medicine, Vandenhoek Ruprecht, Göttingen, p. 119 ff. or
Bilgin, Yasar (2005): becoming human being in Islam. From: Fuat S. Oduncu/ Katrin Platzer/ Wolfram Henn: The approach to the embryo. Ethical, legal and cultural-comparing aspects of assisted reproductive medicine, Vandenhoek Ruprecht, Göttingen, p. 77

Article 10:
10.2 Sexual Education, Family Counselling, Antenatal Counselling

We appreciate the numerous measures that targets to avoid pregnancy, but we miss advice regarding enabling pregnancy, although this should also be part of sexual education and family counselling. The authors recommend including the topic of involuntary childlessness into the education during the last school year to prevent infertility. Young people should be able to plan their life in a way that they can have a child before turning 30. They should be aware of how strongly involuntarily childless people suffer and how hard the way is to get a child through assisted reproductive therapy. They should learn about the manifold causes of involuntary childlessness that cannot be influenced by their own behaviour or way of living. This makes it easier to accept people who are unable to conceive in a natural way, as well as young people can get prepared and include it in their future plans if they themselves are concerned. Furthermore, young people should learn that there are a lot of different ways of being a family and that all ways should be respected by society.

None of the above mentioned (paragraph 10.2) current projects and surveys handle the topic of “involuntary childlessness”. It seems that this special problem does not exist!

Article 11:
11.1 Employment – Figures and Facts

The problem of involuntary childlessness is not mentioned at all. The female labour force participation rate has risen. But one have to consider that since the health care reform 2004 a lot of couples have to bear at least half of, but often the full treatment related expenses. This hinders a lot of couples in getting necessary assisted reproductive treatments. The birth rate is further decreasing and women without children have better opportunities to be employed.

11.4 Maternity Leave
The issue is the missing protection of potential mothers. This has been already discussed in detail in paragraph 2.1.

11.9 Compatibility of Family and Employment
The Federal Government has realised that compatibility of family and employment is a notable factor regarding realisation of starting a family. But we would like to point out that this is already an issue earlier during the family planning phase: those who are unable to conceive in a natural way often have difficulties to reconcile working life with assisted reproductive treatments.

Appointments in the clinic/practice often occur suddenly and unexpected. It is often difficult to bring them in line with the professional schedule while being forced to hide it from colleagues and the superior. Women who want to conceive are often disliked in the firm. As soon as the employer knows about it, the woman might expect dismissal or mobbing. If the woman is self-employed, the treatments constantly endanger her income because she is no longer able to execute the usual number of orders, the order volume decreases. The longer the distance between workplace and clinic/practice is, the more difficult it is for the woman to reconcile work and reproduction activity. Women who are shift working or who are bound to a certain work schedule and, at the same time, fear to lose their job when revealing their disease, do not have any possibility to keep all scheduled appointments for diagnostics or treatment. Therefore, a lot of women spend their whole holidays for assisted reproductive

treatments. The original purpose of holidays – recuperation – can not be met. If more than one treatment cycle is necessary, holidays are used up quickly; therefore absence from work can occur.

Article 12:
12.1 Female Specific Concerns in Health Policy

The Federal Government says: "Everybody gets necessary health service, regardless of sex, age and social position". To the authors, this has to be concretised. Who defines "necessary health service"? Necessary for what reason? To survive? To get cured? To avoid future diseases? To maintain a standard of living as high as possible?
It seems that the Federal Government doesn't deem health services that are related to reproduction as necessary health services. Otherwise, couples in a low social position would not be excluded from getting assisted reproductive treatments.

In the authors' experience, prevention of infertility is too low considered in the society. This is obvious, because the support by the Government regarding starting a family only refers to pregnancy and maternity leave. Children in kindergarten learn about contraception, but not about problems due to infertility and its prevention. The life story of involuntarily childless people often reveals that they had undergone medical malpractice or had been given poor medical advice before finally learning about their infertility. Men who have to undergo a treatment that can impair fertility (like chemotherapy) are not always advised to freeze sperm. If they do, the patient has to bear the full expenses due to cryopreservation. A lot of young women who had suffered from a silent Chlamydia infection are now infertile due to clotted tubes. The necessary screening-test that enables to detect Chlamydia infection in an early stage is not included in the standard medical check-up package. Women who want to undergo this screening-test have to bear the full expenses. This is the reason why a lot of young women do not make use of it and therefore many Chlamydia infections remain undetected.

General Practitioners and Specialists who could detect diseases that may lead to infertility at an early stage are often insufficiently trained. There are no guidelines regarding protection against infertility. If there were, patients could hold the physicians liable for medical malpractice if they do not follow those guidelines.

Couples undergoing assisted reproductive treatments sometimes get only incomplete diagnostics; this sometimes leads to unnecessary invasive treatments without any chances of success.

12.2 Health Care Reporting and Health Care Information

The report "involuntary childlessness", written by the Robert Koch Institute in 2004, specifies certain issues in the Shadow Report. Especially the problems of multiple pregnancy and assisted reproductive therapy tourism due to the rigorous German Act of Embryo Protection, the incompatibility of working life and assisted reproductive treatment and the severe psychological problems reproductive disabled people suffering from were mentioned. Some of the authors' suggestions of solutions are similar to those mentioned in the Report of the Robert Koch Institute, emphasising the need for early prevention of infertility and the need to train physicians regarding early detection and treatment of reproductive disability. But all health care reporting is useless if no implementation follows.

12.5 Pregnancy and Prenatal Diagnostics

The authors wish for similar counselling services regarding pre-implant genetic diagnostics as it is already common for pregnant women. According to the German Embryo Protection Act, pre-implant genetic diagnostics is not allowed in Germany. This is contradictory to the right of terminating a pregnancy due to a pre-implant genetic diagnostics result indicating a severe hereditary disease. The unicellular embryo is therefore better protected than the further developed embryo. A woman with a severe hereditary disease unable to conceive in a natural way may therefore face three consecutive invasive procedures: harvesting her eggs, amniocentesis, and, -in the case the embryo suffers from a severe hereditary disease-, abortion. Actually only one procedure would have been necessary: eggs harvest with subsequent fertilisation and pre-implant genetic diagnostics.

Couples wishing for pre-implant genetic diagnostics are forced to travel abroad. Spain, Belgium and the Czech Republic are popular countries that offer such a procedure. However, a lot of couples are poorly informed about the prognosis of pre-implant genetic diagnostics. Every couple that does not have the right to get enough information about that procedure because it is prohibited in Germany depends on information given by the foreign clinics. This information is often insufficient due to translational difficulties. This may be the reason why some older couples make use of pre-implant genetic diagnostics hoping for increasing the chance to conceive, even though studies have shown that the chance of success is decreased in older couples after pre-implant genetic diagnostics.

A European committee has detected lower or missing standards and quality guidelines in certain foreign fertility clinics. A Government that really cares for its citizens should offer necessary medical treatments and procedures of high quality and with the best possible information. German couples are forced to travel abroad instead[4].

The authors recommend providing concerned couples considering pre-implant genetic diagnostics with an adequate counselling service. Furthermore, they recommend permitting pre-implant genetic diagnostics if the man suffers from a severe hereditary disease. Hereditary diseases in women can usually be detected with polar-body diagnostics; this procedure is allowed in Germany.

12.8 HIV-infection and AIDS

The topic “involuntary childlessness” and HIV is missing. Nowadays people infected with HIV have access to treatments allowing them to conduct a life of a high quality of life. Unsurprisingly, they also have the desire to have their own children. A healthy woman who is married to an HIV-positive man faces the risk contracting HIV while having unprotected sexual intercourse, even if the risk is low due to the medicinal treatment of the man. If the woman wants to conceive, fertilisation without risk would be possible treating the sperm with a special procedure. After that treatment, insemination nearly carries no risk of viral transmission. This treatment unfortunately is not reimbursed by the health insurances. Couples with a small budget may try to conceive in a natural way, while the woman and the

[4] Anniek Corveleyn, Eleni Zika, Michael Morris, Elisabeth Dequeker, James Lawford Davies, Karen Sermon, Guillermo Antinolo, Andreas Schmutzler, Jiri Vanecek, Fransesc Palau, Dolores Ibarreta
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child jeopardising their health. This risk has to be abolished! Furthermore, the exclusion of reimbursement is an impermissible discrimination of HIV-positive disabled people[5].

Article 13:
13.1 Family Benefits

Citation: "Family policy sustainably targets to help realise life plans with children".

From the perspective of involuntarily childless couples this declaration seems to be pure derision! The Government has taken certain measures to facilitate life with children. However, it did not take any measure to help reproductively disabled couples realise their life plans with children. On the contrary, the Government has rather made it more difficult due to the Health Reformation in 2004. Before that Reformation, couples suffering from involuntary childlessness got reimbursed the full treatment related expenses of four in vitro fertilisation cycles; after that Reformation, only half of the expenses of only three cycles are covered by the health insurances. If one of the partners is younger than 25 years or older than 40 years (woman) and 50 years (man), respectively, any reimbursement is excluded. Unmarried couples, lesbian couples and couples that depend on sperm donation are excluded from any reimbursement as well.

Citation: "Currently there are 145 family related benefits in Germany of a total financial volume of 184 billion Euros."

The authors have asked the Federal Ministry of Family Affairs how many of those benefits are designed for helping becoming pregnant. The answer was that none of them have been designed for this objective. The Federal Ministry of Family Affairs dos not have any data available regarding the allocation of the budget to measures increasing the birth rate and assisted reproductive treatments.[6]

Summary:

In conclusion, the Federal Government of Germany does not take the issue of involuntary childlessness seriously. In the 6th State Report this topic has not even been mentioned. The responsible politicians can not claim that they had not been aware of that issue, because it has been addressed to numerous politicians in the past, especially to the Federal Ministry of Health and to the Federal Ministry of Family Affairs. In the authors' experience, the responsible people of the Ministries listen to the concerned people, but do not draw any practical conclusions. No improvements for people suffering from involuntary childlessness have been made so far[7]. The Federal Ministry of Family Affairs constantly ignores initiatives of groups that advocate improvements of reproductive disabled couples[8].

[5] Information concerning HIV and unwanted reproductive disability are available from Ulrike Sonnenberg-Schwan, who published the "German-Austrian Guidelines of diagnostics and treatment of HIV-positive couples wishing for children"; ulrike.sonnenberg-schwan@t-online.de

[6] Thomas Fischer, referent of department 201, "Principle Affairs, Family Benefits" of Federal Ministry of Family Affairs, Senior Citizens, Women and Youth; e-mail from 27th of May, 2008

[7] The authors talked to Helga Kühn-Mengel, substitute of Ulla Schmidt (Minister of Health) in September 2006. Ms. Kühn-Merkel did not make any promises regarding improvements, but wanted to gather further information and send them to the authors. This did not take place to date, despite three inquiries and a registered mail.

[8] The authors sought to make an appointment with Ursula von der Leyen (Minister of Family Affairs), but Ms. von der Leyen deemed it unnecessary. Inquiries regarding the situation of reproductive disabled people end up in the Department of Abortion (within the Ministry of Family Affairs) that only knows little about unwanted reproductive disability. A special department for this disease does not exist.

IV. Article 16 CEDAW

(1) The contractual states will take all measures to abolish the discrimination of women with regard to marriage or family issues and will guarantee the following rights on the basis of equality of men and women:

e) equal right for free and responsible decision on number and age difference of their children as well as access to any information, educational institutions and means necessary to execute these rights.

1. Introduction

1.1 Further acts which define the right of starting a family

Even the General Declaration of Human Rights constitutes in article 16(1): „Nubile men and women are entitled to marry and to start a family without any restriction regarding race, citizenship or religion. They have the same rights within the moment of marriage, during marriage and on dissolution of marriage."

Article 10 of the International Pact on economic, social and cultural rights (CESCR) says: „The contractual states acknowledge that family being the natural origin of society shall enjoy the biggest protection and support possible, especially when starting a family..."

Article 23 (1b) of the treaty on the rights for handicapped persons stipulates that „the right of handicapped persons on free and responsible decision about number and age difference of their children as well as age-adapted access to any information, education on reproduction and family planning will be acknowledged and that they will have any means necessary to exercise these rights. "

According to EU-Charte, articles 9 and 21, there is a basic right to start a family and the prohibition of discrimination:

Article 9: „The right to marry and the right to start a family will be safeguarded by single state law which will regulate the execution of these rights."

Article 21: „(1) Discrimination, especially because of sex, race, color of skin, ethnic or social background, genetic traits, language, religion or conviction, political or other opinion, adherence to a national minority, assets, birth, handicap, age or sexual orientation are forbidden."

According to the Common Right on Equal Treatment (AGG), §1, nobody shall be discriminated because of a handicap. According to §2(1), ciphers 5 and 6 of this law, this applies as well to health services and social benefits. Reproductive handicap being a handicap too, thus health services and social benefits have to be offered to any person suffering from this type of handicap.[9]

[9] Law against discrimination of the German Federal Republic of 2006

According to §10 SGB, anybody suffering from a corporal, mental or psychic handicap or anybody endangered to suffer from any of these handicaps, has the social right (regardless or the origin of his/her handicap) on help to secure his place within the community which comes up to his affections and abilities, especially when it comes to work life and to counteract discrimination because of his/her handicap. „Thus, rehabilitation is not meant to be healing or alleviation of disease, but the abolition, adjustment or diminution of any damage to avocation, family and society arising from this disease.“[10]

The unfulfilled desire to have children is a disease according to the definition by the WHO. There is an abnormal state of the body (mind or soul) asking for treatment. Even the Federal Court of Justice ascertained in an judgment of 17th December 1986 that infertility has to be regarded as a disease notwithstanding the respective causation.[11] It is undisputed that sterility is an acknowledged disease and that fertility impairment is a handicap/ corporal dysfunction according to medical experts.[12]

Fertility is the biological prerequisite for human life like nutrition, movement and communication. Impairment of those thus constitutes a considerable biological deficit.

In case of success, assisted fertilization can heal the disease of „Fertile impairment“ or abolish consequential damage. It is compulsory that the decision of a couple to undergo assisted reproduction to fulfill their need to reproduction when necessary can be taken regardless of personal financial means and independent from the type of family chosen.

The opinion of the German Court and the Churches cooperating closely with legislation (which in itself violates the ideological neutrality of the state) that support of special types of families (starting a family by egg donation, embryo donation or by a lesbian couple) cannot be ethically justified due to possible damage to the wellbeing of the resulting child, do lack any basis. Several studies showed that children of lesbian mothers can enjoy the same development as other children.[13]

There are studies on egg donation showing that these children grow up normally.[14] Legislation being really interested in the wellbeing of these children would be interested in

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[10] Gisela Fischer, „Falsches Signal“, Gesellschaftspolitische Kommentare Nr.8 – August 2003 – p. 16 ff., http://www.fertinet.de/news/temp/Fischer-gpk-08-03.pdf

[11] “Neue Juristische Wochenzeitschrift” 1987; 703 – 704;II2 b: Judgment of the Federal Court of Justice in Germany (BGH) 17th Dec 1986 – IV a ZR 78/85

[12] in D “AHP “ 2003 reasons for medical assessment accepted by the social court in Germany in social law of reimbursement. Also according to WHO definition “ICF“ International Classification of Functioning, Disability and Health, applicable classification of infertility (see http://www.dimdi.de/de/klassi/index.htm); ICD 10 : N97 + N46; ICF: b 660 + b 6600 ; AHP: 26.13 + 26.14

[13] „Dokumente lesbisch-schwuler Emanzipation“ Nr. 16, „Lesben und Schwule mit Kindern - Kinder homosexueller Eltern“, Lela Lähnemann, issued by the administration of the senate of school, youth, and sports, unit for homosexual living, 1996, Berlin-Kreuzberg

Brewaeys, Dufour und Kentenich (2005): „Sind Bedenken hinsichtlich der Kinderwunschbehandlung lesbischer und alleinstehender Frauen berechtigt?, Journal für Reproduktionsmedizin und Endokrinologie; 2(1), p.35-40

[14] Clare Murray , Fiona MacCallum , Susan Golombok: Egg donation parents and their children: follow-up at age 12 years.; Fertil Steril. 2006 Mar ;85 (3):610-8 16500327

In addition to this see further studies from Golombok

these studies or would even initiate own studies on this subject. Unfortunately, this is not the case.

A society being interested in the wellbeing of children should accept, strengthen and support evolving families. The biggest problem of children does not seem to be the type of family but still existing discrimination by society in the 21st century.

1.2 Acts of the German Federal Republic which are opposed to the right of starting a family

§1 of the Law for protection of Embryos (German Act on Embryo Protection – EschG), that was passed on 13.12.1990 by the German Bundestag, says:

(1) Punished with prison sentence up to three years or financial sentence gets, who

1. transfers a someone else's unfertilized egg cell to a woman
2. artificially fertilizes an egg cell to a use other than creating a pregnancy of the woman the egg cell came from
3. transfers more than three embryos at a time to a woman during one cycle
4. fertilizes more than three egg cells during one cycle by means of intratubar transfer of gametes
5. fertilizes more egg cells of a woman than supposed to be transferred within one cycle
6. takes out an embryo from a woman's uterus before the nesting has ended for the reason of transferring it to another woman or a use other than it's preservation, or
7. transfers a human embryo or carries out an artificial insemination to a woman who is willing to give her child to a third party permanently after birth (surrogate mother)

(2) Punished gets also, who

1. Artificially causes a human sperm cell to penetrate a human egg cell or
2. Artificially transfers a human sperm cell into a human egg cell without the will to create a pregnancy of the woman to whom the egg cell belongs.

(3) Not punished get

3. In the cases of paragraph 1, nr. 1, 2 and 6 the woman to whom the egg cell or embryo belong or the woman to whom the egg cell or the embryo shall get transferred as well as
4. In the case of paragraph 1 nr. 7 the surrogate mother and the person who want to overtake the child permanently after birth.
5. In the cases of paragraph 1 nr. 6 and paragraph 2, the attempt is punishable.

Excerpt from SGB V, § 27a, Artificial Insemination

(1) The performances of medical treatment also include medical measures to create a pregnancy, if

1. These measures are necessary according to medical diagnosis
2. There is sufficient prospect on creating a pregnancy by those measures according to medical diagnosis; sufficient prospect is no longer given, when the treatment has been applied three times without success.
3. The persons who want to in claim those measures are married to each other
4. Egg cells and sperm cells of the spouses are used exclusively
5. The spouses have had a medical consultation prior to the final medical treatment about the treatment according to their medical and psychosocial points of view by a doctor who is not involved in the treatment and if the doctor has referred the spouses to doctors or institutions who have been granted permission according to § 121a.

(2) Paragraph 1 is also valid for inseminations after measures of stimulation and which result a higher risk of pregnancies with three or more embryos. For other inseminations, paragraph 1 nr. 2 second half-sentence and nr. 5 are not applicable.

(3) Claims on material benefits according to paragraph 1 are only given for insured persons who have completed the 25th year; the claim is not given for insured females who have completed their 40th year and for insured males who have completed their 50th year. Before beginning with the treatment, the health insurance has to permit a treatment plan. The health insurance overtakes 50 of hundred of those measures that have been granted with the treatment plan and are carried out on the insured person.

(4) The common federal commission of medical scientists, clinics, and health insurances in Germany (Gemeinsamer Bundesausschuss) determines in the guideline according to § 92 the medical details for prerequisites, kinds and extents of the measures according to paragraph 1.

2. German Act of Embryo Protection

The policies of the German Act on Embryo Protection cause that

2.1 in Germany, no egg cell donation can be exercised
2.2 in Germany, no donation of embryos can be exercised
2.3 in Germany, no pre-implantation diagnostics (PID) can be accomplished
2.4 in Germany, no more than three embryos are allowed to develop

2.1 The issue of egg cell donation

Women, who do not have own egg cells or whose egg cells are genetically damaged and thus cannot become pregnant in conventional ways, but do heavily suffer from their childlessness, take a decision on accepting an egg cell donation.

There are many reasons for the absence of developable egg cells. It is possible, that a woman has lost her ovaries for the reason of illness and operation. Also, the ovaries can be damaged due to chemotherapy. A woman can possibly become untimely menopausal in her 30ies, so that the ovaries will not work anymore. Other women could not start to care for own children before their 40ies for reasons, such as the lack of a partner, an occupational situation that made having a family impossible or the lack of money for the necessary treatment in younger years, and now had to realize, that their egg cells do no longer have the attributes to guarantee sufficient prospects of success for reaching a pregnancy and birth. Other women try to get pregnant for years but are misadvised or sometimes even mistreated by their doctors, so that their egg cells got older during the process.

Many of these women do not want to give up their dream of having a child of their own with their chosen partner. Reproductive medicine has created the possibility of transferring donated egg cells, fertilized by their own men's semen, to these women and thus creating a pregnancy.

The opponents of egg cell donation in Germany claim different arguments for the interdiction. On the one hand, they consider the procedure to hurt the human rights of the donator. On the other hand, they affirm the procedure to cause a divided motherhood, going together with psychologically problematic development for the child. The authors want to examine these aspects more closely.

The interdiction of egg cell donation in Germany does not hinder many of the affected couples to use this method. This behaviour is related to the fact that procreation is an elementary force, which cannot be forbidden. Thus, the problem of a possible hurting of the donator's human rights is not abolished but displaced abroad. This indeed is to be considered problematic, because donators are often recruited in such countries, where people are forced to fight hard for their existence. During the last years, several cases became public, in which women agreed to donate their egg cells for the shortage of money. Clinics, such as in Rumania, do not enlighten these women capaciously about the medical risks and do not treat them up to the necessary medical standards. Clinics, which try to rip off the women, do not consider the health of the donators. This does not mean, that all clinics in the Europe are working this way; there are a lot of good clinics in Spain, the Czech Republic or Poland, that do apply medical standards equal to German clinics.

Nevertheless, this should not be a reason to overlook the hurting of the human rights of egg cell donators in poorer countries. Most Clinics abroad do not even keep the donators record and unable the children to ever find their genetic roots. As we know of now grown up people who have come out of a treatment with donated semen, this is a very important aspect for the children.

Furthermore, the opponents of egg cell donation argue that there would possibly be a "divided motherhood" for the child having both a genetic and a carrying and social mother. This is considered to cause psychological problems for the child. We want to counter on this, that the FRG should aim on reassessing these affirmations with scientific studies. This has not been done. We do not consider an interdiction due to simple assumptions justified.
Studies in other countries can be consulted.[15] Clare Murray, Fiona MacCallum and Susan Golombok for example have examined that children having come out of an egg cell donation do develop as good as other children do.

Proposal:

→ The authors propose to allow controlled egg cell donation in Germany. Women should not be recruited as egg cell donators under exploitation of major distresses. Instead, women who do want to help couples that are unable to procreate should be recruited as egg cell donators. Donators have to be extensively enlightened about the risks and be assured of the best possible medical treatment. Women who do not have own children should be excluded as donators. The donator's record should be kept lifelong, to enable the grown up child to get into contact.
The Federal Court of Justice declared in a sentence in 1989, that every child has a right to know about its ancestry.[16] The lacking storage of the donators record is considered to be a violation of a child's right. With not creating these possibilities in Germany, the FRG gives advantage to this violation abroad.

→ To ease the difference between supply and demand, the focus should be laid on the donation of embryos. This would be possible more easily without burdening the egg cell donators. As soon as a donated embryo is available more cost effective than a donated egg cell, couples will decide more often on the acceptance of a donated embryo. Another reason is, that today, because of the situation abroad, even couples with both partners having no developable gametes do accept egg cell donation.

→ Additionally, situations in which couples can only have children via egg cell or embryo donation should be prevented. The named reasons for which women sometimes decide to have children in their 40s give some hints on that. Education on decreasing fertility should start more early. Women should be enabled to have children more early despite having a job career. People in our country should be taught to be more capable of having a relationship to enable them to find their lifetime partner more early. This could possibly be influenced by a policy that gives more time for relationships to people. Finally, the amount of medical cases of false diagnosis, mistreatment or stringing around the patients should be reduced by a

[15] Clare Murray , Fiona MacCallum , Susan Golombok: Egg donation parents and their children: follow-up at age 12 years.; Fertil Steril. 2006 Mar ;85 (3):610-8 16500327

In addition to this see further studies from Susan Golombok

[16] BVerfG FamRZ 1989, 147; BVerfG FamRZ 1989, 255; BVerfG FamRZ 1994, 881; BVerfG FamRZ 1997, 869;

better education of medics. People who have a procreation disability and who lack the money for a reproductive treatment have to be given the possibilities to use such means in their younger years.

2.2. The issue of embryo donation

In case of IVF treatments, redundant embryos are often produced, because it cannot be predicted, how many egg cells are produced via hormonal stimulation of the woman. As chances of IVF are rather small when only one egg cell is transferred, women are supposed to take stimulating hormones to create a higher amount of egg cells that can be taken out. Statistically, not more than every 10th fertilized egg cell develops to a human. One reason for that is that many egg cells or sperms do not have the ability to develop that far. Concluding, all the egg cells taken from a woman are brought together with a sperm. In Germany, all fertilized egg cells that exceed the count of three have to be destroyed or cryo-conserved before the cell division and thus segmentation starts.. Such conserved embryos can be transferred to a woman in later cycles. In other countries, embryos that are not immediately transferred to the mother can also be frozen in a later state of the development. In any case, a stock of deep frozen embryos, which can develop to a human later on, is laid in.

These embryos are not always used by their genetic mothers later on. In most cases, that is because a pregnancy has already been achieved and a child has been born, but the parents do not want to have more children. Sometimes, the genetic mother cannot bear out another child because of health issues. As a rule, the frozen embryos are destroyed in such cases. But many couples would be willing to donate their frozen embryos to other infertile couples. This would be an ideal way of founding a family for those couples in which both partners are genetically unable to have children on their own. Also, couples in which the woman cannot produce developable egg cells and the man does not find it extraordinarily important to pass on his own genes would accept an embryo donation. Even some couples with a procreation disability, which rejects hormonal stimulation and taking out egg cells from a woman, would bear out an embryo, which would have been destroyed otherwise. Nevertheless, this is impossible and not practised in Germany because of the predominant interpretation of the German Act on Embryo Protection.

This rejection of embryo donation as well as the rejection of egg cell donation is founded with a “divided motherhood”. The authors have already elaborated on this question in 2.1.

Proposal:

→ *The authors propose to allow controlled embryo donation in Germany. The donator’s record should be kept lifelong, to enable the grown up child to get into contact.*

→ *The donation of embryos should, in contrast to a practice used in some clinics abroad, be arranged to enable the highest chances of success. This is the only way to avoid the need for the often more successful egg donation – possibly abroad – for couples, where the man is infertile. The highest chances of success for an embryo donation could be achieved, when more than 2 or 3 embryos per attempt are thawed and those embryos, that are morphologically the most promising, are transferred. Embryo donation could be offered with low costs, because the expensive hormonal stimulation, the selection and at least a part of the test-tube cultivation are no longer necessary. Many clinics abroad do still offer embryo donation for high amounts of money, as this is an effective business.*

2.3 The issue of pre-implantation genetic diagnosis (PID)

PID is useful in cases of couples where both partners do carry the layout for severe genetic diseases that, in combination, can cause seriously ill and sometimes not capable of living children. Also, PID can be useful in cases of male partners carrying a genetic defect that aggravate ore hinder the surviving of the child. Genetic disturbances that are transmitted by women only, can already be found via polar body diagnosis in Germany.

There are genetic diseases that cause the children to suffer from severe physical and / or mental disabilities. These diseases are often already known to the family and the parents-to-be do not want their child to suffer the same. Some genetic diseases cause the child to die shortly after birth or even before birth. Women, who have already experienced a trauma like that once or even more times, do not want to live trough that another time. Furthermore, there are genetic constellations that hinder a pregnancy, for example the so-called “balanced translocation” of the man.

Opponents of PID argue on the one hand, that after a PID of embryos, some embryos will be sorted out, and that these embryos are already humans with a right to live and human dignity. On the other hand, opponents of PID argue that the selection of genetically disabled embryos would hurt the dignity of already born humans with the same diseases. In the following, the authors are further elaborating on those two arguments.

From when on a human is considered to be a human being is more than anything a question of belief. Following today’s Christian definition, it is the moment of the completed karyogamy. Examining the reasons for why the Christian churches follow that definition, astonishing things come to light. The Christian churches consider that moment to be the time when god gives a human soul to the embryo. But this opinion has not been uttered before 1661, when Paul Zaccias, medic of pope Innozenz X. said, the rational soul would be given to the human being in the moment of conception, otherwise, the celebration of “Marias immaculate conception” conception would celebrate a non-rational material. This consideration of the holy virgin would be “inappropriate”. Officially, pope Pius IX. declared a general interdiction of abortions in 1869 and stated, that a child receives its soul in the moment of conception. [17]

The change in church-law was caused by the dogma of “Marias immaculate conception”, made dogma by Pius IX in 1854.[1]

German law considering the protection of the embryo is absolutely compliant to the actual view of the Christian churches. Obviously German politicians cooperate in the creation process of new laws quite closely with church representatives. We know from other religions that the very first step of live in a human organism can be defined in completely different ways.[18] The authoresses of this text conclude that therefore people with severe hereditary illnesses are forced not to have own children or go abroad for treatment, because otherwise

[17] Ranke-Heinemann, Uta: Eunuchen für das Himmelreich – Katholische Kirche und Sexualität, Heyne-Verlag, Munich 2004

Ranke-Heinemann, Uta: „Nein und Amen – Mein Abschied vom traditionellen Christentum“, Heyne Verlag, Munich 2004

[18] See for example: „Der Zugriff auf den Embryo. Ethische, rechtliche und kulturvergleichende Aspekte der Reproduktionsmedizin“, Vandenhoeck & Ruprecht, Göttingen

the “immaculate conception of Maria” could be insulted. This is, not only for non-christian believers an arrogation, which certainly reigns above the human right of freedom of religion.

The phrase „human right“ is in this case a problem, because „human right“ is not clearly defined anywhere. Even supporters of the church view use the phrase in their own special argumentation. The phrase “human right” [3] as such is also used to describe non-fundamental human rights[19] and is clearly used in an inflationary way .[20] That is why the authoresses suggest to use the phrase “human rights” more honest in the way of the real meaning which is described precisely.

Concluding the facts, the authoresses cannot see a real human being in a just impregnated female egg cell with all its dignified protection and its all-embracing human rights.
A less extensive way of protection should be considered only if parents or mother would specially ask for it. The egg-cell has no specified interest as such, the more so the parents do.
It is about their right of reproduction and to have no severely disabled child. No woman can be forced to give birth to a severely disabled child. The former president of the Max-Planck-institute, Hubert Markl, once said: “I am most horrified by the spirit of merciless moral and at the same time by the force of law to put the effected individual behind so-called interests of society. Regarding the woman and her reproductive ambitions, even the exploited disabled person, as a belonging of state, which donates or denies, following the voice of actual moral majority, her the very freedom and right to decide matters of her own reproduction, and in worst case enforces her to give birth to and raise up a severely disabled child, just to create an example for others.”[21]

At this point we come to the arguments of organized disabled persons groups (and others who exploit their argumentation to put through own religious and moral beliefs), the selection of embryos which genetically carry a certain illness would undermine the dignity of people which are already born with this illness. There is certainly a clash of interests. The interests of potential parents to have a child and preferably one without severely disabling illnesses should rule supreme over a group of uninvolved members of society, who have only the declared aim to give a cluster of a few cells personal rights and identity.

There might be odd individual disabled persons, who would want more people with the same disability or embryos with the genetic specifications causing this disability not being selected by PID, but the authoresses want to point out clearly, that the wish of these disabled persons cannot rule supreme over the right of potential parents of a disabled child. There is no human right that allows enforcement of disability upon other human beings.
The assumption, that a disabled person with a certain kind of disability is discriminated because embryos which underwent PID are selected due to these criteria, the cause of that disability, is a hypothesis without reason, but likely used as truth. It is nothing but a hollow

[19] For example in the catechism of the Catholic Church, which is amongst others identifying sex between unmarried couples as a strong violation of dignity of these persons : “Katechismus der Katholischen Kirche”, Munich 1993, Nr. 2353

[20] See amongst others: Birnbacher, Dieter: „Mehrdeutigkeiten im Begriff der Menschenwürde“, in: „Aufklärung und Kritik“, Gesellschaft für kritische Philosophie, Nuremberg and

Hoerster, Norbert: „Ethik des Embryonenschutzes“, Reclam, 2002, p. 23

[21] Markl, Hubert (2001): „Freiheit, Verantwortung, Menschenwürde: Warum Lebenswissenschaften mehr sind als Biologie“, in: „Die Zeit“

assumption. PID is used for several years, to select embryos which develop into a disabled person. This procedure has not caused any significant increase of discrimination.
The authoresses want to stress that it is for them a matter from their hearts, to abolish all kinds of discrimination, if it might be caused genetically, non-genetically or anyhow else.

Additional the authoresses want to point out, that there are certain genetic conditions, which often cause failure of impregnation or miscarriage. In these cases "selection" according to PID cannot be talked about, because these human beings would not have existed anyhow.
But even for these women, PID is omitted.

The prohibition of access of PID in Germany very often misleads from the obvious intention of state for genetically affected couples either not to have children or to have disabled children. The prohibition forces a lot of couples, which situation is socially stressful anyhow, to bear even more stress and burden to go abroad for treatment. That is nearly an unbearable task for some couples. Additional to that, medical advice abroad is often not sufficient or the barriers of the foreign language make it most difficult. Consequently, scientists who compared the situation in several European countries pointed out the facts of missing scientifically reliable standards for the procedure and demand more and better patient information." Problems with reliable medical information, difficulties with language or different medical system, can potentially expose patients to a dangerous situation."[22]

Proposal:

→ *The authoresses propose to allow pre-implantation genetic diagnosis (PID) in Germany according to certain directives.*

→ *PID should be allowed for individual cases, where the genetic situation in this couple is so distressing, that pregnancy is most unlikely or creates children with severe, life-threatening illness or disability. Operating experiences from abroad show couples without certain genetic conditions, like older women, do not benefit from the procedure and there is no increase of pregnancy-rates and therefore an admission of these cases would not be necessary.*

A way to realize this proposal into working order would be to create a catalogue of permissive criteria and for those cases, which are not in the catalogue, there should be the right of application for admission.

→ *Above this there should be an all embracing and medically qualified information for the couples about their specific hereditary disease. Statistics in gestational diagnostic show, that it is opted for abortion even in minor cases of expected disability. Parents are not always aware of the consequences how little impact the expected disability would have on future family-life.*

[22] Anniek Corveleyn, Eleni Zika, Michael Morris, Elisabeth Dequeker, James Lawford Davies, Karen Sermon, Guillermo Antiñolo, Andreas Schmutzler, Jiri Vanecek, Fransesc Palau, Dolores Ibarreta
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2.4 The issue of the prohibition of cultivation of more than 3 embryos

According to the Law on Protection of Embryos only 3 embryos shall be transferred to a woman during an in vitro fertilization process. The limitation to max. 3 embryos transferred makes sense as multiple pregnancies have to be expected, being a considerable health threat to the mother as well as to the children. Under the assumption that only 3 embryos may be cultivated, the permission to transfer only 3 embryos makes sense as well. Although this may result in a triplet pregnancy, the cultivation of only 2 embryos would even lower the anyhow low prospect for success of in vitro fertilization.[23] The hormonal stimulation of the woman necessary for in vitro fertilization as well as egg cell pick-up and the waiting period for the hopefully positive pregnancy test result is a considerable psychological and physical impairment which has to be minimized to the most extent.

Only about 60 % of all embryos have the potential to develop to a human being. Not until the 3rd day following conception it is possible to choose embryos with higher potential for success, due to purely morphological aspects. Those embryos show an even cleavage and little fragmentation. Interesting for persons emphasizing the „handicap potential" of reproductive techniques: there is no possibility to predict a potential handicap of the resulting child. Would it be possible to cultivate more than 3 embryos and to choose out of this amount the one with the best potential, higher pregnancy rates could be achieved. Even by choosing just one single embryo the existing pregnancy rates could be maintained. The risk of multiple pregnancies however would be considerably lower. The rate of multiple pregnancies in Germany is 25% today. In Sweden, where choice of single-embryo transfer based on morphological choice, only 5% of all births after IVF or ICSI are multiples.

Multiple pregnancies lead to a higher risk for mother and children. These children often are born premature. The higher the degree of multiple pregnancies, the more critical the pregnancies become. Thus, triplets are rarely carried to the end of normal pregnancy. Premature birth is related to damage to the newborn. Some of these children remain handicapped. It happens often that the pregnant mother has to lie down for months to prolong gestation time, and birth often has to be a cesarean. After birth, the young mother has to encounter burdens exceeding her capability.

The cause for the prohibition of further cultivation of more than 3 embryos is that our legislation (being inclined to church) is of the opinion that starting from nuclear fusion an embryo is a human being whose human dignity and protection of life should be enforced by any means. This problem was already discussed in chapter 2.3 Pre-implantation genetic diagnostics.

Proposal:

→ *The authors suggest permitting the cultivation of more than 3 embryos in Germany by compliance with guidelines.*

According to the proposal of German physicians up to 6 embryos could be cultivated further, depending on prospect for success in the individual case. This procedure takes into account our respect for the developing life. Especially when it comes to couples with little prospect for

[23] The birth-rate in Germany is about 18-19% per embryo-transfer in IVF/ICSI treatments

success, it can be expected that not more than 2 promising embryos would result anyhow. In case that more than 2 embryos are resulting, the remaining embryos could be cryo-conserved and transferred at a later date. This could happen under the assumption that really only two embryos being transferred at max.

2.5. Summary of the suggestions for improvement and solutions

→ The Wunschkind-Association suggests amending the Law for Protection of the Embryo so that all measures described can be common practice by safeguarding any regulations for protection, hereby taking into account the suggestions for solution described. Alternatively, the Law for Protection of the Embryo dating from 1990 could make way for a more comprehensive Reproductive Law based on the scientific findings during the 18 years passed in the field of reproductive medicine and in the field of studies on wellbeing of the child in alternate family types.

3. The code of social law (SGB)

The policies of the Social Code effect that it is only on condition of certain criteria being met that the solidarity group of insured people of the German statutory health insurance cover half of the cost of 3 treatment cycles in the field of reproductive medicine. The following are excluded from cost reimbursement

3.1. Couples who receive treatment with donor sperm due to the man's infertility.
3.2. Couples who try to achieve pregnancy with donor egg cells due to the woman not having any eggs that can be successfully fertilized.
3.3. Couples who try to achieve pregnancy with a donor embryo due to the woman not having any viable egg cells, possibly in combination with the man's infertility.
3.4. Couples who employ other methods to achieve pregnancy and which are illegal in Germany, e.g. PID or the cultivation of more than 3 embryos.
3.5. Lesbian couples
3.6. Unmarried couples
3.7. Couples who are not within the age limits required by law.
3.8. Couples where one of the partners is HIV positive.

3.1 Couples who receive treatment with donor sperm due to the man's infertility

Couples who receive treatment with donor semen due to the man's infertility are excluded from the partial reimbursement of cost by the statutory health insurers. This puts these couples into a worse position than those couples who receive reimbursement from the health insurers for a certain number of treatments, even though the type of treatment is the same.

It cannot be accepted that a woman is not entitled to compensation for her treatment only because she is married to a man who is infertile. It is not feasible that legislation is such that a woman has to choose her husband/partner on basis of his fertility. This would also constitute a discrimination of all infertile men.

If in addition to the man's infertility, the woman also has fertility problems, she is also unjustifiably barred from insurance compensation. For example, a woman with closed tubes and a fertile husband receives insurance compensation at least in part, whereas a woman with closed tubes and an infertile husband has to bear the cost completely.

Those German politicians whom the authors have so far approached concerning this unequal treatment have tried to legitimate this decision with the special protection of the institutions of marriage and family by the German constitution. However, the question as to why a marriage to an infertile man should not be recognised as a marriage to be equally well protected has so far remained unanswered.

Also the argument frequently brought forward that fertilisation with donor semen is not sufficiently regulated by law cannot be a reason for not granting reimbursement of cost, because the fact that there is no satisfactory legal solution has been known by politics at least since the mid-80ies. Rather, politics should aim to create a regulation which is in the child's interest as well as in the donor's, the parents' and the doctor's interest. It appears rather strange that the lawmakers discriminate against a minority group precisely because they have for years omitted to find a satisfactory legal provision.

3.2 Couples who try to conceive with donor egg cells due to the lack of developable eggs of the women

The circumstances of egg donation have been detailed in Item 2.1 above and it was shown why this procedure has to be made legally available in our own country. The authors are of the opinion that the statutory health insurance should also bear the cost of treatment with donated egg cells. The reasoning corresponds to the points made in item 4.1.

It is not feasible that legislation is such that a man has to choose his wife/partner on basis of her fertility. This would also constitute a discrimination of all infertile women. In consideration of the fact that female fertility usually terminates at a certain age and thus all women at that age are treated equally, the authors would suggest that the cost of egg donor treatments be covered until an age of 43 years.

3.3 Couples who try to conceive with donor embryos due to man's infertility lack of developable egg cells of the the woman or a combination of both

The circumstances of embryo donation have been detailed in Item 2.2 above and it was shown why this procedure has to be made legally available in our own country.
Also in the case of embryo donation, costs should be borne by the health insurers. Embryo donation is an appropriate method to enable infertile couples who are suffering badly as a result of their childlessness and who under the circumstances do not attach existential importance to being able to pass on their own genes to become parents after all, including the experience of pregnancy.

In consideration of the fact that female fertility usually terminates at a certain age and thus all women at that age are treated equally, the authors would suggest that the cost of treatments involving embryo donations be covered until an age of 43 years.

3.4 Couples who employ other methods to conceive and which are illegal in Germany, e.g. pre-implantation genetic diagnosis (PID) or the cultivation of more than 3 embryos)

The circumstances of pre-implantation genetic diagnosis (PGD) and the cultivation of more than 3 embryos have been detailed in Items 2.3 and 2.4 above and it was shown why this procedure has to be made legally available in our own country. Also in these cases, costs should be borne by the health insurers. Reasons why a couple is involuntarily childless are manifold. Therefore, there are manifold possibilities to help such a couple to overcome their childlessness. If society helps one couple with a certain diagnosis to a certain extent, but not another couple with a different diagnosis, this can only be understood as discrimination of the concrete reproductive impairment of the second couple.

3.5 Lesbian couples

Women living in a same sex relationship who want to become parents sometimes also have to rely on reproductive treatment in order to get pregnant. These treatments are also excluded by the statutory health insurers. And in addition, these women have only limited possibilities to get access to medical treatments in Germany. IVF treatment for lesbian women is not possible in Germany. With regards to insemination, lesbian couples have to perform these themselves, at most having been instructed by a doctor.

The authors are of the opinion that this situation also constitutes a form of discrimination. Lesbian women as well can have issues with their own fertility, regardless of the fact that they are not in a relationship with a man. As they are jobholders receiving a salary and thus are paying their premiums into the statutory health insurers just as any other jobholders, they should basically receive the same support that heterosexual women with the same type of impairment are entitled to.

Meanwhile there are several studies showing that children of homosexual couples grow up just as well-being as children with heterosexual parents.[24] To exclude them from insurance coverage/reimbursement of cost or even to prohibit treatment because of a possible risk for the child therefore has no basis whatsoever.

3.6 Unmarried couples

To grant benefits contingent on the status of legal marriage goes contrary to our modern society with a growing number of (permanent) domestic partnerships with children.

Unmarried couples who wish to receive reproductive treatment due to an impairment of their fertility and who do not have the monetary means to pay for the necessary treatment themselves are thus forced to marry. This, however, contradicts Article 16 (1b) CEDAW which has stipulated the right to „marriage only with free and full consent“.

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[24] z.B.: “Dokumente lesbisch-schwuler Emanzipation” Nr. 16, „Lesben und Schwule mit Kindern - Kinder homosexueller Eltern“, Lela Lähnemann, issued by the administration of the senate of school, youth, and sports, unit for homosexual living, 1996, Berlin-Kreuzberg

Brewaeys, Dufour and Kentenich (2005): „Sind Bedenken hinsichtlich der Kinderwunschbehandlung lesbischer und alleinstehender Frauen berechtigt?“, Journal für Reproduktionsmedizin und Endokrinologie; 2(1), p.35-40

3.7 Couples who do not meet the age criteria required by law

If one of the partners is under 25 or the woman is over 40 / the man over 50 years of age, this couple is excluded from cost reimbursement. This constitutes discrimination due to age. Whilst it can be appreciated that society cannot indefinitely bear the cost of reproductive medicine for couples who are infertile due to their age. However, this does not apply to people over 18 but under 25, and neither does or should this apply to a couple where e.g. the woman is under 40 and has closed tubes, but has to pay for her treatment herself due to her fertile husband being over 50. Another case would be a couple where the man is under 50 but has poor semen quality and the woman is over 40 but with relatively good prospects.[25] Also in this case, the insurer would not pay, even though the reason for the necessary reproductive treatment does not lie with the partner who is beyond the age limit.

The age limits stipulated by the German government are arbitrary and lead to an unfair disadvantage of certain couples who could with the assistance of reproductive medicine still produce their own child.

3.8 Couples where one or both of the partners is HIV positive

These days there are medical resources which enable an HIV positive person to lead a long life with an adequate life quality. Obviously, these people also often have a desire for their own children. A healthy woman married to a man who is HIV positive but is under medical treatment, still runs an albeit minor risk of catching the virus when they have unprotected intercourse. If this couple wants to have children, fertilization without running the aforementioned risk would be possible. For this purpose, the semen has to be treated in a certain way and can afterwards be used without any risk to inseminate the woman. This method however is excluded from coverage by the statutory health insurers if one of the partners is HIV positive. If the couple cannot pay this treatment themselves, they might feel forced to try natural impregnation, thus endangering both the woman and the child by exposing them to the virus. This danger has to be done away with! And last but not least because an exclusion from cost reimbursement due to a disability constitutes an unlawful discrimination.[26]

It must be respected that couples with disabilities also have a desire to have their own children. The missing assumption of cost by the insurers is especially problematic in connection with HIV positive people because a considerable proportion of these people are living in financially difficult situations and thus cannot afford to pay for the necessary treatments.

It is not only in order to avoid the transmission of the virus that couples with at least one partner being HIV positive might have to revert to reproductive medicine to fulfil their desire to have children. Studies show that these couples in many cases have reproductive problems as well. It is very important for HIV positive women that they achieve a singleton pregnancy. Therefore, only one embryo is transferred. As the German embryo protection Act

[25] Even for women over 40 pregnancy rates of more than 15% can be achieved in case of sufficient antral follicles, AMH within the normal range and Inhibin > 10, according to Prof. Brähler, chairman of the German IVF Register (D.I.R.)

[26] Information on the HIV topic in context with involuntary childlessness can be found at Ulrike Sonnenberg-Schwan, which also published the German-Austrian guidelines re diagnosis and treatment of involuntarily childless couples infected by HIV

stipulates that only as many embryos may be cultivated as will be transferred, only a single embryo can be cultivated, which reduces the chances for success for these women considerably.

3.9 The issue of reimbursement of medical treatment related expenses of only 50% of 3 treatments

Prior to the health care reform in 2004, those couples who were not excluded from statutory health insurance in the first place were granted full cost assumption for four attempts (IVF and ICSI). Since then, only 50% of the costs for those couples are taken up by the statutory insurers, and only for three attempts. Furthermore, age limits have been introduced. The German IVF register shows a dramatic reduction in the number of treatments since then. As a result of the new legislation, each year there are over 10.000 children less being born. The IVF register also shows that the number of treatments has declined especially in the poorer German states. The federal states of Bremen, Mecklenburg-Western Pommerania, Saxonly and Thuringia observe a decline in egg cell pick-up cycles in 2004 compared to 2002 by 44 – 51%, whilst this decline was only between 20% - 28% in Baden-Württemberg, Rhineland-Palatinate and Hesse.[27] The average age of women who received treatment went up by 1.5 years, as many couples first have to save up money. This means a waste of valuable time, as the success rate declines with age.

So we are now in a situation where the possibility of reproduction for reproductively impaired couples depends on their financial means. The amounts to be paid by the treated couples range from about 1.600 Euro for their own share for the first three IVF treatments to about 3,000 to 6,000 for fully self-paid treatments and are thus much too high for average wage earners. For a top-earning civil servant with 10,000 Euro salaries per month, it obviously does not present a problem to pay for such a treatment. A cashier or a hairdresser on the other hand will under the current legal situation have a much harder time to fulfil her desire for a child.

Those in favour of the current legal situation argue that reproduction is a private matter and thus not to be borne by society as a whole. They further stress that costs would be much too high and in view of insufficient funds it would simply not be feasible to finance such an "luxury". The authors would like to address these points, as the costs are not all that high if brought into the right context**.**

In 2000, prior to the health care reform, the total burden for the statutory health insurers was the equivalent of 142.4 million Euro for all assisted fertilization treatments. This equates to an annual premium for each insured person of 2.80 Euro. As a result of the health care reform in 2004, about 100 million Euro per year for assisted fertilization treatments are saved. Scaled down to the number of insured citizens with the statutory health insurers, this means less than 2 Euro for each insured person. This preliminary effect on savings, however, is rather short-sighted, because as a result of couples' not being able to afford fertility treatments, less children are born who would have paid their own insurance premiums later on and also contributed to our pensions. Economists at the Ifo Institute for Economic Research at the University of Munich have calculated that in the long run, children contribute more to society economically than they "cost". In their calculation, a child of currently five years of age will on average produce a balance of EUR 77,000 for society. Therefore, cutting the insurers' cost compensation for fertility treatment backfires in more than one respect.

[27] www.deutsches-ivf-register.de, annual report 2004, p. 10

And there is not just an economic answer to the question of why our society based on the principle of mutual solidarity should bear the cost. In principle, everyone can be affected by involuntary childlessness. And in most cases, these couples are not at fault. Some causes for fertility problems lie in the general situation and behaviour in our society. For example, a person working at a gas station is statistically especially in danger of infertility due to his working environment. If such a person has a poor spermogram, everyone driving a car or being driven is co-responsible. A further point is the social aspect. Fertility an thus the capability to get children is one of the basic aspects of human life, like being able to eat, to move and to communicate, and can therefore not be compared to luxury desires, e.g. for a fast car, your own house or aesthetic surgery. A couple must be able to answer the question of whether or not they will get children and become parents irrespective of their financial means.

3.10 Suggestion for improvement and solutions

→ The authors propose to put all couples with an unfulfilled desire to have children on a par with each other as regards the statutory health insurers' cost absorption, irrespective of their handicaps and of the reasons for their childlessness, and irrespective of the type of family they will form (in view of the types of families described above).

Where insufficient legal provisions heretofore hindered the insurers' cost assumption, these should be added to/changed as soon as possible. Regarding the cases of donations of sperm, eggs or embryos, the donators are to be exempted from any claims whatsoever. Furthermore, their personal data must be secured by law to ensure that the child may later successfully enquire about its parentage. There must be a legal solution which enables lesbian couples and couples who, due to their type of fertility problem are dependent on PGD, egg or embryo donation to receive treatment in Germany.

→ As regards age limits, we propose that the lower limit of "under 25" be deleted or replaced by a limit of "under 18". The upper limit should be fixed at 43 or alternatively be made contingent on the individual prospects of success. The upper age limit for men should also be made dependent on the individual chances of successful treatment.

→ As studies have shown that the statistical chances for a successful in vitro fertilisation only show a significant decrease after the fifth unsuccessful treatment cycle, the authors propose that up to 5 treatment cycles be paid for by the statutory health insurers.

Only when all persons concerned – including those groups of people who have so far been self-pay patients – receive compensation from the statutory health insurers for five treatment cycles, either in full or at least partial payments, will there be quality control by the insurers themselves as well. Treatment of self-pay patients is not subject to control by the insurers. However, all treatments of all patients with fertility problems should be subject to quality control!

→ In view of the fact that many couples cannot afford to have fertility treatment costing several thousands of Euros, a socially acceptable solution ought to be found. A deductible of EUR 100 per treatment seems feasible, or else a co-payment which may not exceed 2% of the net income.

III. Artikel 11 CEDAW

(1) Signatory states take all necessary measures to abolish all discrimination of women in their professional lives in order to grant them the same rights as men, based on the concept of equal opportunities for men and women, in particular:

b) The right of equal job opportunities including the same selection criteria regarding hiring

c) The right to job security

e) The right to … social security …

f) The right to health and safety at work, including the protection of fertility

(2) In order to prevent discrimination of women due to marriage or motherhood, and to grant women an effective right to work, the signatory states take adequate measures

a) To prohibit – on pain of penalties – dismissal due to pregnancy or maternity leave as well as discrimination on grounds of marital status at the time of dismissal.

d) To guarantee special protection of women during pregnancy in jobs which have proven to be harmful for pregnant women.

4. Discrimination of involuntarily childless couples at work being in medical reproductive treatment

4.1 Process related necessities

Reproductive medical treatment often involves many trips to doctors. During one treatment cycle, a woman averages about 4-5 ultrasound appointments and additional medical appointments to give blood or get injections.
Additionally, there is the insemination or – in the case of a planned In vitro fertilisation – the egg cell pick-up. This egg cell pick-up is usually done under a short anaesthesia which renders the woman unfit to work during that day. Two to five days after egg cell pick-up the embryo transfer takes place. These appointments are not easy to plan for, as they are largely dependent on the woman's cycle and the egg maturation. The ultrasound checks and blood tests serve to find the optimum time for the insemination or egg cell pick-up. If the time slot thus ascertained cannot be met, the entire treatment is endangered. In some cases, this results in over-stimulated ovaries which necessitates several days of hospitalisation.

Reproductive medical treatment is very rarely immediately successful. The baby-take-home rate of in vitro fertilisations is at about 18% per fresh embryo transfer. If one includes into the calculation all treatment cycles without a transfer and all cycles with cryo-preserved embryos, this results in a birth rate of a good 15% per cycle. This is about the same success rate as with insemination. This easily shows that a woman needs on average 6 – 7 treatment cycles to finally get pregnant and for the pregnancy to reach term. Expressed in terms of doctors appointments, this means somewhere between 50 – 140 appointments which are difficult to plan. As many women need even more than the average 6 – 7 attempts, the number of doctor's appointments can easily reach 200 and more.

The longer the distance of the work place to the fertility centre, the more difficult the situation gets for the woman. Especially women in rural areas often have to travel far. But also women, who need a special treatment which only certain clinics offer, often have to face a trip of 100km and more. Especially women who need a treatment, which is prohibited in Germany and thus have to travel abroad, are often faced with several hundred kilometres for each appointment.

These women's willingness to realise their wish to have children even in the face of the most adverse conditions alone shows the urgency of their human need. This means that women with an unfulfilled desire for a child will reduce their quality of life to the lowest possible level rather than abandon the chance of becoming a mother.

4.2 Impacts on working life

The above circumstances inevitably result into quite some difficulty for the women concerned to reconcile their reproductive medical treatment with their jobs. This is known to the federal government, as issue 20, page 18 of the health report of the federal government. About one third of the couples report job problems during their treatment, due to the secrecy involved with their fertility problems or due to frequent absences from work." Frequent and sudden doctor's appointments need to be brought in line with job-related appointments, and this often with the utmost discretion towards the employer. Women who want to get pregnant are not looked upon favourably in many companies. Once the employer has been informed, women run the risk of being sacked or mobbed. Being made redundant at the same time results into less income. However, someone who has to pay up to EUR 6,000 for one treatment cycle needs money urgently and thus cannot do without their jobs. For this reason, many women keep their treatment secret from their employers.

Freelancers are faced with the situation that they can undergo their treatment only under significant financial losses, as they will often not be able to accept jobs around the time of their treatment cycle. This is especially the case when their jobs involve a lot of travelling. Insurance payments for self-employed people do cover two weeks after a sick time, however, this does not apply to reproductive medical treatment, in which case the woman is left to cover the costs due to her inactive period (due to sick time) on her own.

As men are not as heavily involved in the treatment cycle (they are required only once to give their sperm), this situation constitutes a serious disadvantage for women. And this is irrespective of the cause of infertility lying with either the man or the woman. But the man also sometimes has difficulties – depending on his job – to realise this one unpredictable date within the treatment cycle, especially if the clinic is far away from his workplace. On the whole, couples who are reproductively challenged are at a disadvantage regarding their working situation compared with couples who do not have any problems with their reproduction.

In order to reduce their absenteeism, many women use their annual paid leave for their reproductive treatments. Most often, however, this does not suffice. As such a treatment is anything but a holiday, women – sometimes for many years – do not have any regeneration during vacation. Some women cannot even effectively use their annual leave for their treatments, because, for example, they have to announce their leave times by the end of the previous year, and it is not possible to predict the female cycle this much in advance

Some women have such great problems to reconcile their treatment with their job that they give up their jobs or else reduce working hours if this is at all financially possible. Other women who are still in their vocational training quit their training in order to work and thus earn the money necessary for their fertility treatment.

Women who have had a miscarriage or a tubal pregnancy[28] and where this fact is known to their employers, but also sometimes women who have recently married, run a risk of losing their jobs because this is viewed by the employer as something of a „last chance" to fire a potentially soon-to-be-pregnant woman.

4.3 Impacts in specific jobs

In some jobs there are tasks which have an adverse effect on pregnancies. As soon as a pregnancy is known, the employee concerned will be placed in maternity protection and must be given tasks which are not potentially dangerous for the pregnancy. As long as the pregnancy is not known, the woman does not come under maternity protection.

The first week of pregnancy counts from the first day of the cycle in which fertilization took place. At this point in time, the pregnancy is not known. However, the embryo can be severely harmed by the mother's job especially in the first few weeks of pregnancy. In some cases, this results in an abortion, in other cases it leads to a handicapped child. The situation that maternity protection does not become effective before the pregnancy is known is an adverse situation for women in these kind of jobs and ought to be changed. For women undergoing reproductive treatment, however, the situation is hardly bearable, as these women are especially aware at that early time that they may be pregnant. As they do not want to harm in any way their hard won child and are very afraid of an abortion, and as they must be especially worried that they may never be able to become a mother, as the success of this particular treatment cycle will determine whether they will have to pay another several thousands of Euros for yet another treatment and thus will have to continue to run the gauntlet at their workplace, these women are under an enormous pressure. Examples for these kinds of jobs are nurses and doctors working in intensive care, or x-ray technicians. Another example is police work where there is danger of becoming involved in violent situations or where one has to be outside even in extreme weather conditions.

Women shift workers are facing the difficulty of having to change shifts a lot as a result of not being able to plan the appointments in advance, and thus having to explain themselves at their jobs. Again, this applies to women in medical jobs, but also to sales personnel, nursery school teachers, police women and workers in production.

Many jobs have fixed hours, which definitely collide with doctor's appointments. The situation of teachers - being only one example of several job groups where this applies – who take off frequently for their reproductive treatment will result in an adverse situation for their students, as their lessons keep being cancelled.

Other jobs entail a fixed agenda, where the cancellation of only one date will have large-scale ramifications which will put the woman under additional pressure. This is the case, e.g. for judges who have to plan their hearings at least two months in advance, invite all parties

[28] Tubal pregnancies occur during assisted reproductive treatments in about 2% of the overall number of cases.

concerned, and then, shortly before their ICSI have to cancel and un-invite everyone. Also, women whose jobs entail a lot of travelling, or women who are doing further training courses, are faced with this problem.

Women working via an agency for temporary work (temp agency) and hoping to find a permanent job, have very bad prospects of being hired on a permanent basis if they frequently have to miss work due to their reproductive treatment. As companies working together with temp agencies often use this constellation over a period of several years, it is unfortunately not an option for these women to simply postpone their reproductive treatment.

4.4 Discrimination of women during pregnancy and during maternity leave

Irrespective of reproductive treatments the authors would like to point out that some women are at a disadvantage during their pregnancy and maternity time. For example, this applies to self-employed women who do not earn any money if they get ill and are unable to work because of their pregnancy and during their maternity time. This will also later on affect these women's "Elterngeld" (parents' money) which takes into account their lower income before the pregnancy.

4.5 Suggestion for improvement and solutions

→ The authors propose to extend the protection against dismissal for women who are in the process of starting a family to include the time of reproductive treatments to achieve pregnancy. Ideally, protection should start not later than from the beginning of the first reproductive treatment cycle. This special protection could end – in case the treatment remains unsuccessful – about one year after such a treatment.

→ The dismissal protection should also be extended to include women who have had an abortion, a tubal pregnancy or similar, as these instances suggest that the woman will try to achieve another pregnancy. It would also be welcome if such a dismissal protection could become effective after a wedding, again, for example, for a one year period.

→ Sanctions against mobbing at the workplace, especially by superiors, should be tightened, especially in the above-mentioned cases.

→ If an employee misses work frequently due to her reproductive medical treatment, and if she in fact gets pregnant and enters maternity leave, this always means additional costs for the employer. This can be a severe situation, especially for small businesses. It is therefore sometimes understandable if an employer tries to get rid of a female employee who is trying to get pregnant. In order to spread the burden more evenly and to protect the employer from losses caused by the pregnancy of a certain employee, the authors propose a fund, in which a certain amount for each employee (be they male or female) has to be paid, and from which these employers receive compensation for their losses which are caused by a female employee starting a family. This could, for example, be realised by higher employers' contribution to health insurances, which would keep additional administrative efforts at a minimum.

→ However, an employee should not be obliged to notify her employer of her reproductive medical treatment. This should be regulated in such a way that the woman is free to choose

whether she wants to inform her employer and thus place him into a position to benefit from the a.m. fund. Family-friendly employers who are trusted by their employees would be at an advantage in this situation.

→ As regards self-employed women, there should be an insurance which also covers a shortfall due to reproductive medical treatment, pregnancy and motherhood. Such insurance should be mandatory for all self-employed professionals. It should especially be ensured that men as well pay into this insurance. This could well be realised if each private health insurance included this component into its programme, and if a private health insurer would not be allowed to base their acceptance of new insured persons on the attribute of their fertility.

→ Females working in jobs which can be hazardous to a pregnancy should be entitled to notify their employers of their plans to start a family in order to be exempted from all potentially hazardous practices during the times in question. Female shift workers should be entitled to miss work at any time in connection with their reproductive medical treatment. If the employee is able to be open about her problem, this should also make it easier for the employer to develop contingency plans.

→ As shown above, the financing of reproductive medical treatment should be fashioned in a socially acceptable way. Thus, women would no longer be forced to quit job training for financial reasons. Companies working with temp agencies should be obligated to hire the temporary worker after half a year. This would mean a foreseeable period for a fertility-impaired woman after which she would again be in a position to enter fertility treatment.

III. Article 12 CEDAW

(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

(2) Notwithstanding the provisions of paragraph I of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

5. Criticism of health services which should preserve fertility and criticism of health services which offer reproductive treatments

5.1 Health services which should preserve fertility

When listening to the numerous stories of involuntarily childless couples, one is bound to ask if it had not been possible to avoid infertility in many cases. It is preferable to prevent infertility than to have to heal it later on. Therefore the authoresses attach great importance to prevent infertility in cases where this is possible.

Society doesn't care very much about the prevention of infertility. More or less all social services linked with family planning are restricted to pregnancy and maternity. In school, children are educated about contraception but never about fertility or how to prevent infertility. The stories about involuntarily childless couples also show, that sometimes they have been even been informed or treated wrongly by medical scientists. The story of an involuntarily childless lady doctor illustrates the problem plainly:

"The doctor prescribed my husband cyto-statical medications because of his kidney disease. Nobody would have informed us about the embry-otoxical effect of this medication, if we would not have asked about this explicitly. After we had informed ourselves about the potential side effect of future infertility (which nobody else had mentioned) we consulted an urologist for further advice. The urologist advised us, that because of the limited time until the beginning of the urgently needed therapy nothing could be done. My husband would only be able to freeze one or two sperm sample, which would be too little to be of any use (which was false).
The problem was that nobody advised us to freeze a sperm sample. Nobody can expect a patient in such a difficult situation to get all the needed information by himself. Nor can he be expected to be ready to pay for all the extra costs to preserve his fertility in such a situation. I do know some young cancer patients who just couldn't afford the sperm freezing and so weren't able to preserve their fertility for later on.
I maybe must add that I myself had not had a single lesson during my medical education which dealt with fertility or reproduction medicine. You can't really blame the colleagues that they know so little about fertility and reproduction. I also never noticed that any further (postgraduate) education dealing with fertility or reproduction is offered for other groups than gynecologists. The only thing you learn is which treatments to use in already pregnant woman, but you never learn that some therapies might hazard fertility. Medicine in Germany protects already created children. It helps to prevent or eliminate handicapped children – but it doesn't feel responsible to help to create children."

One of the preventable fertility problems of males are unrealized testicles which are not treated early enough. We will only know in about twenty years how thoroughly our children are screened for that. As there are many vaccination opponents in Germany, many boys are not vaccinated against mumps. The risk for an adult male who has not been vaccinated to lose his fertility if infected is quite high.

One example for fertility problems of females are damaged tube systems. The cause is often an infection with Chlamydia which has not been recognized or treated. Test for Chlamydia infections are not paid by the insurance system and therefore rarely offered. Endometriosis is often diagnosed to lately and even more often treated to lately or not treated at all. Ovary cysts are also often not treated.

The protection of the reproductive system and genitals in Germany remains an utopia. Intersexual persons still are in danger of having their internal or external genitals removed or medically damaged (AGS), without having been able to give their informed consent. Transsexual Persons have to give up their fertility in order to be able to live their felt sex.

5.2 Suggestions for improvement and solutions

→ The authoresses suggest that there should more education about preventable causes of infertility. Particularly young people should be informed. This could take place in connection with the sexual education in school. Pupils should be educated about the connection of fertility and age in order to enable them to decide about when to plan a family. They also should learn that some sexually transmitted diseases such as Chlamydia infection can hazard future fertility. They also should be educated about what impact infertility can have and how difficult it can be to achieve a pregnancy if the help of reproduction medicine is needed.

→ Family doctors and other doctors who could be able to detect preventable infertility causes should be specifically educated. Guidelines should be developed which shall be obligatory for all doctors. If those guidelines are not being followed and infertility results, persons who have been injured should be able to sue for malpractice. The costs of the resulting infertility treatments should then be paid by the doctor and not -as it is now practice – by the injured patient.

→ If there are treatments needed which possibly could affect fertility, young males should be offered and advised to freeze sperm samples. In a welfare state it should be possible to have the health system pay for the freezing. Especially young people often do not have the money to afford the freezing and the storing. One also cannot expect young males to overlook the later suffering caused by infertility especially if they are seriously ill at that point of life.

→ Parents who do not want their children being vaccinated against mumps should be informed that a mumps infection in an adult can lead to infertility.

→ The freezing of not fertilized egg cells as well as the extraction and cryo-conservation of ovarian tissue for later re-transplantation is still experimental. Still females having a therapy that might affect their fertility should be educated about these possibilities.

→ Screening for Chlamydia infection as well as other measurements to obtain fertility should be part of the general health system. Those screenings should be offered together with the normal routine checking offered for women.

→ There should be no longer any discrimination concerning intersexual genitals. There should be a general reform of the medical legislation concerning intersexuality. Transsexual people should have the right to preserve their fertility and still be able to live their felt sex – even if this is not identical with the sex proposed by their external genitals. The individuality of the human body, the sexual organs, fertility and hormonal balance are equal values which should be protected more strongly. This could be achieved if every sexual organ would legally be protected no matter if the persons concerned live a different sex.

5.3 Healthcare institutions in connection with fertility treatments

Reports of couples undergoing reproductive treatment due to infertility often show a lack of diagnostic procedures prior to the beginning of therapy. Well informed couples who have searched the internet on causes of unsuccessful reproductive treatments have a clearly higher chance of fulfilling their dream for a baby. But one cannot expect patients to study and analyse the possible causes for their problems by themselves and then to come to the right conclusions.

Now a couple of examples to show which diagnostic procedure are too rarely done. Possible causes for the failing of reproductive treatments are hypothyroidism and autoimmune diseases of the female thyroid gland. Women with thyroid dysfunction have a smaller chance of getting pregnant.[29] Still these tests are not a standard procedure before starting reproductive treatment. Without thorough testing these patients feel healthy because as far as they know their thyroid gland is well and therefore not a reason for their infertility. The authors have also .noticed that most specialists in reproductive medicine do not know enough about this organ. They often think that the thyroid cannot be a reason for infertility.

Genetic coagulation disorders such as the MTHFR-Polymorphism often impair fertility and are quite common in Europe. About 40% of the population are heterozygous and 11% homozygous for the altered gene. Combined with the accompanying folic acid deficiency it can adversely affect implantation of the embryo and even cause congenital malformations in the child. Other coagulation disorders such as Protein C- or Protein S-deficiency (Incidence: 2-3% of the population) often cause abortion or disturb implantation.
Undiagnosed women with one of these conditions undergoing IVF have a significantly higher risk for thrombosis. Stimulating these women with female hormones during the IVF-cycle without administering heparine as well as the later phases of pregnancy further increase the risk of thrombo-embolic events. Studies show a correlation between coagulation disorders and implantation. This correlation has been confirmed by affected couples and their experiences.

Still women in fertility centres are not regularly tested on coagulation disorders. In cases where coagulation disorders have been diagnosed prior to treatment appropriate medical

[29] Websites by Dr Leveke Brakebusch/ Prof. Heufelder with extensive and updated information on hypothyroidism: www.hashimotothyreoiditis.de and hyperthyroidism www.morbusbasedow.de. Literature on the thyroid gland and the desire for a child: “Die gesunde Schilddrüse”, published by Mosaik-Verlag, or Dr Redha Arem “The Thyroid Solution”, published by Ballantine Books New York)

therapy can be started. Reports of concerned patients show that such diagnoses are often not discovered until after several negative cycles of IVF or ICSI.

Studies show anatomic malformations of the uterus in 10-30% of women with infertility (depending on the study). According to the severity of the malformation it can affect implantation. Still a hysteroscopy is very rarely performed at the beginning of fertility treatment.

Not all of the urologists have enough experience in diagnosing infertility. Men are tested too late for sterility. Often it follows after several courses of unsuccessful therapy of the woman. The WHO criteria for sperm analysis regarding period of abstinence and transport of the specimen are not always applied. Some couples are asked to bring the sample to the laboratory from home merely in a cup without further protection. The wrong temperature can cause the semen to die before analysis. The validity of the sperm count is dependent on the investigator, delegating the task to inexperienced personnel can cause false results. Therapy options are not known to most urologists. Some urologists even prescribe testosterone although it is proven to have negative effects on fertility. Hormone dysfunctions in men can affect spermatogenesis and are often medically treatable thus allowing some couples to succeed without invasive therapies. Due to wrong diagnostic procedures and false treatments of the men the women have to endure unnecessary invasive fertility therapies.

The German IVF register (Das Deutsche IVF Register)[30] shows success rates (pregnancy rate per embryo transfer) in germane fertility clinics. One notices clearly differing success rates. The two centres with the highest pregnancy rate per embryo transfer achieve 41% whereas the worst centre only achieves 3%, followed by a couple of centres with 5% success rate and another one under 10%. The names of these centres are not published. Thus couples/ women undergoing therapy in these clinics do not know that their failure is almost predictable.

Not only incomplete diagnostic procedures cause unnecessary invasive treatments for the women. The German law for the safety of embryos (Embryonenschutzgesetz) is also often the reason why women have to undergo fertility treatments more frequently than it is necessary since the optimal procedure is not allowed (i.e. cultivating more than three embryos, see above). Unnecessary ovarian stimulations and egg retrievals are a form of bodily harm.

5.4 Suggestions for improvement/ solutions

→ The authors suggest establishing binding guidelines for physicians practicing fertility medicine regarding useful investigations prior to fertility treatments. Physicians should be liable for failing to do the necessary tests if it is revealed later on that there was a medical problem that could have been diagnosed before starting treatment. In such cases the physicians should pay for the unsuccessful courses themselves plus compensation for bodily harm for the patients.

→ The investigation of the thyroid gland should not just include TSH, but in the case of elevated TSH (greater than 2,0 or 2,5 mIU/L) also the levels of thyroid hormones and

[30] www.deutsches-ivf-register.de/ annual report 2006

antibodies in the blood (fT3, fT4, TPO-antibody titer). The costs of the analyses are quite low in comparison to an IVF cycle.

→ Also the search for coagulation disorders in the woman and one significant semen analysis of the man along with his blood levels of the hormones testosterone, LH, FSH, prolactin and TSH should be standard procedure before starting the first course of treatment (insemination, IVF/ICSI).

→ Additionally there should be a hysteroscopy scheduled after the first failed course of treatment under otherwise good conditions for detecting handicaps for implantation.

→ Necessary tests should always be made as early as possible and should not reduce the physician's budget. The health insurance companies should also be interested in reducing the number of failing IVF/ICSI cycles due to incomplete diagnostics since they partially pay for them. In cases where the couples have to pay for their courses of therapy without the help of health insurance quality supervision should be obligatory as well.

→ Couples depending on reproductive medicine should be entitled to specific and competent advice by their treating physician. This advises should be written down and follow a fixed pattern.

→ Couples having gone through failing courses of treatment possibly due to incomplete diagnostic procedures beforehand should be legally entitled to refunding of their expenses. At least these attempts should not be added on to the three supported cycles granted by health insurance.

→ Miscarriages should always be genetically analyzed to discover a possible risk for spontaneous abortions in the mother. Women with a higher risk should be properly advised about the chance of repeated miscarriages during future pregnancies and receive all the necessary support.

→ Fertility doctors should not treat only according to their own experience but use a specialized and flexible diagnostic pathway and consider the individual patient and her/his problems. They should be able to perceive connections beyond their own specialty. This requires a submission of the necessary knowledge to all physicians in reproductive medicine including regular updates.

→ Fertility centres with low success rates should be committed to external quality control (i.e. by the medical association (Landesärztekammer) or resident doctors' association (Kassenärztliche Vereinigung) and lose their licence to treat patients supported by health insurance. Success rates of fertility centres should be made transparent for the interested patients. A success related grouping of the centres by impartial advisory boards could be a suggestion. Seals of quality could be awarded by a product test institution such as "Stiftung Warentest" in Germany. Publishing extracts of the not anonymied success records regarding similar groups of patients could be possible as well. To achieve correct data a compulsory registration of couples on a special server at the beginning of therapy would have to be ensured

Concluding remarks

In the past our association repeatedly tried to attract the attention of the responsible political boards to the unbearable situation of infertile couples in Germany and to improve it. We are aware that other initiatives tried to alert the politicians for the same reasons. Moreover a lot of concerned people protested, sent mails and letters or even talked to their representative to explain their problems. But none of these activities has shown any greater success.

It is our hearts' wish that our government together with the federal ministries for family and health uses this letter to finally change the law according to our proposals and therefore stop the violation of human rights of infertile couples, especially the women.

Furthermore we want to remark that the problems discussed in chapters two and three concern violations of human rights in children as well. In cases of gamete donation made possible by touring countries allowing this procedure donor data is almost never saved. By provoking multiple pregnancies more children with impaired health are born. Prohibiting pre-implantation diagnosis (PID) could result in children born with and suffering from the same hereditary disabilities as their parents who would have decided for PID if it were allowed. In all the cases mentioned above and in cases where our caring society did not help the couples concerned on their way to parenthood - neither financially nor organizationally – the resulting children will grow up feeling tolerated but not accepted.