MINISTRY OF
SOCIAL AFFAIRS AND HEALTH
National Advisory Board on Health Care Ethics

30.1.2001

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Ref. Your letter of 22.10.2000

Subject **ACT ON INFERTILITY TREATMENT**

With reference to your letter dated December 18, 2000, the National Advisory Board on Health Care Ethics (ETENE) has continued to discuss the matter related to the planned act on infertility treatment. On the basis of the questions discussed and positions taken at the meetings on October 30, 2000, December 12, 2000 and January 23, 2001, ETENE has prepared the enclosed memorandum on the matter. In it, ETENE has consciously sought to emphasize all the various aspects of ethically problematic issues and is of the opinion that decisions on who can be treated, and on what grounds, are the responsibility of political decision-makers.

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Chairman	Director General
ETENE	ETENE

ENCS Memorandum on Act on Infertility Treatment

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OPINION

22.1.2002

Ritva Halila

ACT ON INFERTILITY TREATMENT

An act on infertility treatment has been under preparation in Finland since the early 1980s. Most recently, the Ministry of Justice and the Ministry of Social Affairs and Health prepared a proposal for Government bills on the use of gametes and embryos for the treatment of infertility, and on revision of the Paternity Act. Despite the lengthy preparations and the extensive round of comment gathering, the unanimity needed to place a Government bill before Parliament was not reached and the proposal came back for further preparation in the autumn of 1998.

The National Advisory Board on Health Care Ethics (ETENE) discussed the various types of infertility treatment and the need for an act in the spring of 1999, and issued a statement explaining the necessity for the act and hoping that the Board would be asked for an opinion at the preparatory stage of the bill.

Representatives of the Ministry of Justice and of the Ministry of Social Affairs and Health met in 2000 and assessed the situation concerning the regulation of infertility treatment, concluding that the treatment of infertility should be regulated by law. The problems connected with the bill were listed and ETENE was asked to state its position on the matter before the draft for the new bill was finalized.

ETENE discussed the matter on the basis of a letter subsequently sent to it and the 1998 draft law. At its meeting on October 30, 2000, the Board stated that it was difficult to take a stand on the matter without a clear Government bill. Since this is a very important issue and because ETENE's stand on these key issues has been specifically requested, it was decided that the matter would be discussed in more detail at the Board meetings on December 12, 2000 and January 23, 2001.

ETENE was specifically requested to state its opinion on the following issues:

- the right of a child born from a donated gamete to know the donor's identity
- a heterosexual relationship and unintentional childlessness as the precondition for fertility treatment
- use of a surrogate mother

On the basis of the discussions at the meetings, ETENE emphasizes the following points:

The relationship between legislation and ethics:

Today, especially when drafting laws whose scope is felt to be very personal and private, there is a need to reflect carefully on the relationship between the legislation and the ethical ideals and various moral codes of conduct current in society. Increasingly often, religious and ideological considerations lead to rather strong moral stands being taken on issues, while the legislation takes a relatively neutral approach

and as such does not follow the ethical ideals of what are sometimes large population groups. In these cases, the legislation seeks to ensure the safety and equality of citizens (e.g. in the Abortion Act). In these matters the law diverges from many people's moral ideals. It does not necessarily recommend what it otherwise allows under the principle of equality, for example.

On the other hand, it is important to consider whether we should use the legislation to support a way of life which may be relatively common, but is perhaps not desirable or at least not uncontroversial. This applies, for example, to cases in which a child is born with intentionally just one parent as a result of treatment. In their everyday private lives people can make many kinds of choice as regards reproduction, for example, but the law and the public care system based on the law aim to support social security, consistency and the position of the weakest party. In this case, the position of the child is the key. Other aspects that should be taken into account relate to justness and equality and how human procreation, starting families, parenthood and the growth of the child, in all their forms, take place in natural circumstances.

The child's right to know the donor's identity:

The 1998 proposal for a Government bill incorporates a widely supported compromise reached earlier on the right of a child born of gamete donation to know the identity of the donor. The child's right to know his or her biological origin is a broadly accepted principle. Fears have been expressed in Finland, as elsewhere, that donor numbers may fall drastically if the identity of the donor is revealed to the child. In the light of international examples, the donor's attitude to revelation of his or her identity seems to vary, partly according to gender. According to international reports on the subject, most ovum donors, for example, accept that their personal data will be revealed to the child born of the gamete donation.

According to the 1998 proposal, the infertility treatment act would give the child the chance to find out his or her genetic origin but not require the parents to divulge the fact that the child was born as a result of fertility treatment. From the point of view of the child's rights this is not without its complications. Excluding a child from a 'public secret' may even be very damaging to his or her development. On the other hand, it may also be traumatic for a grown child to meet a person who is his or her biological parent but does not necessarily wish to meet the result of a donation made long before.

There have been some cases in Finland, as elsewhere, where the woman being treated for infertility knew the identity of the ovum donor because this person was her sister or some other member of her immediate family. The sole premise of the 1998 draft bill on which the ETENE discussion was based was, however, that the gamete donor is unknown. There is generally a strong emotional need to have children, and equally, the feelings connected with childlessness and infertility treatment run deep. For some people it might be easier to make the very intimate decision to have a child this way if the donor is someone they know. In preparation of the future infertility act more attention should be paid to the special situations arising from the use of ovum donations. Perhaps special provisions could be made to cover certain exceptional circumstances in which a donation of ova from a known donor could be considered.

Although the stipulations of the 1998 bill on disclosing the identity of the donor to the child are typically a compromise, they allow for a rather wide range of options covering a number of situations as regards this important issue.

Demand for a heterosexual relationship:

Although many international declarations state that children have a right to both a father and a mother, the number of single-parent families has been increasing rapidly over the past few decades, and there has been significant social and cultural change in this respect. The treatment of childlessness in a heterosexual relationship is considered to be a way of 'assisting nature' by using special technology and donated gametes. In the case of same-sex couples, the help of a third party is necessary. In this respect, the child to be born will always be the 'biological child' of only one of the partners. Under the present legislation, too, the child can in law be the child of only one of the partners. There is no evidence to show that the development of a child living in a stable lesbian or homosexual family where the parents are adults is more threatened or involves more conflict than that of a child whose parents live in a heterosexual relationship. ETENE did, however, express its concern that children growing up in same-sex families might face a higher risk of being bullied, for example, due to the higher social pressures they encounter.

A topic currently under discussion in Finland is the possibility of registering same-sex partnerships. The line currently drawn is that homosexual couples cannot adopt each other's children. If registration becomes official, however, it would provide a stronger foundation for a child to be born into households based on this type of partnership. Nonetheless, allowing infertility treatment without the possibility of adoption would be illogical in view of other legislation.

Infertility treatment for single women on medical grounds:

The 1998 bill is based on the principle that a single woman can be treated for infertility if the cause is medical. One reason why the bill has been strongly criticized is that in about one third of all cases the cause of childlessness can never be established. It would certainly be both absurd and unethical if people engaged in temporary relationships without protection against infections or pregnancy in order to ensure the prescribed indication. On the other hand, is not the infertility treatment of single women more a question of using reproductive technology than of actual treatment, at least in some cases? The question of who should be responsible for the costs of treatment in these cases is also ethically important.

Many international declarations and ethical arguments quite rightly point to what is best for the child. In the development of children, it is important that they have a safe relationship with their parents and other people close to them. The principle underlying the treatment of infertility is the parents' and adults' wish and need to parent a child, rather than the child's need to have a parent. On the other hand, it could be argued that this is also true more generally of 'having children'. In extreme cases, what might become blurred is whose interests are primarily aimed at, the child's who will be born or the parents'. Can we safeguard the child's intrinsic value and significance as a person so that his or her role is not primarily to satisfy the expectations of the parent/parents, i.e. to provide a 'cure' for an illness known as 'childlessness'? Both

couples and single parents have demonstrated such unrealistic expectations. With the higher success rate of infertility treatment today, social pressures are also growing, as having a child is sometimes seen as a measure of one's humanity. ETENE has expressed its concern that in some cases childlessness seems almost to have become a reason for social discrimination.

Use of a surrogate mother:

Some parties in Finland have suggested that the use of surrogates should be accepted for certain carefully specified medical conditions. Such cases have also occurred in practice here without causing any major problems.

In surrogacy, fertilized gametes in the form of an embryo/embryos are placed in the uterus of another woman, where pregnancy continues until the birth. Under Finnish legislation, and that of many other countries, the person who gives birth to the child is the mother. If some other arrangement has been agreed on, such agreement is legally invalid. Transfer of parenthood requires an adoption process.

In many places, including the Nordic countries, use of a surrogate is totally prohibited. In addition, Israel, for example, has prohibited use of a close relative as a surrogate mother. Commercial surrogacy has emerged as an option in Israel and some other countries, a situation we hope to avoid in Finland. The other Nordic countries prohibit surrogacy on the basis that it may create more problems than it will solve. About a dozen children have been born in Finland through surrogacy.

Surrogacy involves some major problems: if it is allowed, who will grant permission and on what grounds? If the parents and the surrogate mother make an agreement about adoption, what happens if either of the parties wishes to cancel the agreement, for example, because the child is not what they expected, or if the woman who gives birth to the child wishes to keep it? Would the agreement be valid if the child was abnormal in some way or if something happened to the foetus or the woman bearing it? As stated above, such an agreement is not legally valid under the present legislation.

Who is responsible for the risks to the surrogate mother or who would be responsible for the costs or the consequences? If the surrogate mother is a close relative, this would cause different problems. Would it be psychologically more difficult than can be considered reasonable for the woman to refuse surrogacy if her sister, daughter or some other close relative asked for it? Pregnancy always includes a certain risk and a financial sacrifice. Who pays and what, and what constitutes reasonable compensation for lost working and other time, and the health risks involved?

In countries where surrogacy is permitted, these types of problem have occurred. There has been no sign of such problems in Finland in the few cases that are recorded here. Many very deep emotions surround pregnancy, childbirth and childlessness and if these all culminate they may be extremely difficult to solve – particularly in situations where the parties involved are a woman or a couple who have long been hoping for a child, on the one hand, and a person who has given birth to the child and her possible companion, on the other. In such situations the potential problems may be very acute and disastrous. On the other hand, it is reasonable to ask whether these threats are enough to justify a ban on surrogacy in the case of those able to weigh up the risks, threats and emotional factors, who wish to acquire a biological child of

their own with the help of another, equally aware person. Threat scenarios may distort assessment of a person's ability to consider the facts and various aspects of the issue.

The essential question in surrogacy is whether the legislation ensures the legal rights of the child and those taking part in the treatment and sufficiently restricts the range of cases. For example, the aim of the legislation on adoption has been to safeguard the child's best interests, and to a large extent it has succeeded. In an adoption process, the future parents are required to take part in a number of evaluation processes to guarantee that the child will be raised in a sufficiently safe environment. The need to use surrogate mothers will probably never be very great but some believe that, instead of an absolute prohibition, other options could be considered – particularly as Finland has experience of surrogacy. In its discussions ETENE came to the conclusion that, at least at present, the legal rights of the child to be born, the surrogate mother and the child's parents cannot be sufficiently well safeguarded. For this reason the Board does not support the use of surrogate mothers under the law, although it also considered and justified arguments in favour of this.

Other problems related to infertility treatment:

Paternity questions:

The Finnish Paternity Act does not know or recognize a child born as a result of infertility treatment if the child's parents were not married when the child was born. From the point of view of the legal safety of such children, it is important for that the Paternity Act to be updated to correspond to the real situation and children's true interests.

The age of the woman undergoing infertility treatment:

Infertility treatment is available relatively freely in Finland today provided that the couples or the women have sufficient economic recourses to pay for it. Women at a rather advanced age have also been treated, at times with disastrous consequences. Although medical science is making advances, pregnancy is always a risk for the woman. As the mother's age rises, the probability of various complications also increases. For example, the risk of pregnancy-induced hypertension or gestational diabetes increases. These again increase the morbidity and mortality rate of both the mother and the foetus. The risk of premature birth also grows. Moreover, the success rate of infertility treatment falls sharply after the woman reaches the age of thirty, which is why the public health care system restricts their access to in vitro fertilization. For example, the age limit for women accepted for the IVF queue at Helsinki University Central Hospital is 38. The Finnish Population and Family Welfare Federation age limit for infertility treatment through ovum donation is 42 years, due to the long queues. There are no confirmed cases of in vitro fertilizations in Finland in which post-menopause women have used donated ova. The menopause, when a woman's own ovaries stop functioning, is generally a natural – although loosely definable - upper limit for infertility treatment. The age of menopause varies, so a woman's biological ability to produce ova is individual.

Approval of an upper age limit has been justified on both medical and financial grounds. Justifying its view with the great variation in women's health and the age at

which they have the menopause, ETENE proposes that no exact upper age limit should be prescribed for women to be treated for infertility, and that the matter should be expressed more broadly in the law. In the best interests of the child, the Board also emphasizes the social dimension connected with the parent's age in which case the father's age would be of importance, as well as the mother's.

Posthumous use of gametes:

The principle underlying the 1998 bill is that the posthumous use of gametes for infertility treatment should be prohibited. This is based on international recommendations. A much debated point around the world today is whether frozen embryos can be used to treat infertility after the death of the gamete donor. If our legislation did not refer to the matter, disputes could also arise in Finland. It is probably natural to assume that death is everywhere the absolute limit for reproduction, since posthumous fertilization is not possible in natural conditions.

ETENE also emphasizes the rights of the child in the ethical debate on infertility treatment. The legislation must first and foremost ensure the best interests of the child to be born. Doubts concerning the paternity of the child born as a result of infertility treatment are therefore considered the biggest shortcoming in the current stage of the legislation. In the debate on infertility treatment, the perception of whose interests are pursued easily becomes blurred. Are the children products of the treatment process, and can one person be used to fulfil the individual needs and wishes of another? ETENE also raised the question of whether childlessness has become such an 'evil' that whatever can be done to acquire a child must be done. Can one reasonably assume that in very emotional situations people are able to give an informed consent based on freely available information?

Allowing infertility treatment to certain groups of people can be justified in many ways. Some believe that settling the question of infertility treatment for same-sex couples or single women is primarily a political stand on the kind of families society wants. We should also consider whether the decision to seek treatment for infertility is primarily the woman's choice in a situation where she has a biological need to parent a child, but no male partner. This is in fact what a woman is doing when she makes a decision to abort. If lesbian couples were allowed infertility treatment, some people believe that, on the equality principle, male couples should also have access to it. In these cases, however, the only way to have a common child is to use a surrogate mother, which would present another problem.

If the grounds for infertility treatment were that this is a couple's only way to have a biological child, same-sex couples could not be treated for infertility. If medical grounds are required, i.e. diagnosed infertility, single women would also be excluded from treatment. The child's rights and other such issues connected with surrogacy might prove difficult to solve. If no restrictions are laid down, the risk is that the child becomes a commodity and is valued primarily as such by the recipient.

On the basis of its discussions, ETENE emphasizes the following points:

1. ***Right to know the identity of the gamete donor***: ETENE believes that the child's right to know his or her origin is a very important principle. The compromise solution in the 1998 bill seems quite realistic: the child is entitled to a description of the gamete donor but not

his or her personal data, unless the donor wishes to give them. What remains to be solved is the question of how we can safeguard the child's right to know, if the provision of such information is fully dependent on the parents. ETENE also proposes that the legislation should in certain special cases allow for the discretionary possibility of using the gametes of a known donor to treat infertility.

2. ***Right of same-sex couples to infertility treatment***:
To prohibit same-sex couples from acquiring joint children would in a sense be a form of discrimination against sexual minorities. Allowing homosexual couples access to fertility treatment would, however, be inconsistent in a situation where same-sex couples have no right to adopt each other's children. The position of the child is the key question. When legislating on the matter, attention should be paid to issues of fairness and equality and of how people's procreation, establishment of families, consolidation of parenthood and growth of the child could take place in as a natural way as possible.

3. ***Medical indication as a precondition for treatment:***
Logically, one can agree with the 1998 bill requiring medical grounds for the treatment of infertility. In practice, however, this is a problem, since the reason for childlessness remains unclear in one third of all cases. If so wished, the treatment could be restricted to cases where it can be justifiably proved, or at least assumed, that the childlessness is not primarily caused by the conscious choices of those being treated, choices which they can still influence.

4. ***Use of a surrogate mother:***
Under the present legislation or under the draft bill, the rights of the child to be born, the surrogate mother or the woman or couple wishing to have a child cannot be considered by ETENE as being sufficiently safeguarded. For this reason, ETENE believes that the law should prohibit use of a surrogate mother, although in some individual cases there might be very valid medical grounds for it.

5. ***Other issues***:
In its opinion, ETENE emphasizes above all the rights of the child, and social parenthood in addition to biological parenthood. The Board proposes that the law should not prescribe a specific age limit for women treated for infertility, but that the matter should be expressed more broadly in the law. ETENE also emphasizes the social dimension of the parent's age in view of the child's best interests, in which case the father's age is significant as well as the mother's. Most of the present shortcomings connected with the treatment of infertility are connected with the inadequate legislation. It is important to move the bill forward and make it a subject of public debate. Ethical issues have strong links with the surrounding cultural and social environment. The concrete decisions to be made are social and political in nature and the responsibility of politicians. But is also important to promote large-scale public debate in order to air the various aspects of the matter and clarify the possible policy lines. If social development leads to a situation in which some of the facts find greater public acceptance in the future, the law can, of course, be amended accordingly.

National Advisory Board on Health Care Ethics (ETENE)

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