Reproductive Medicine and Genetic Engineering
Women Between Self-Determination and Societal Standardisation

Proceedings of the Conference held in Berlin from 15 to 17 November 2001
About this publication
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Foreword

Svea Luise Herrmann | Margaretha Kurmann

It is, by nature, difficult to elaborate conference proceedings in a way that emphasises the possibility of using them as a basis for discussion. For reasons of readability, we have dispensed with literal and extensive protocols and instead recorded the course and results of the respective discussions. However, the debate is by no means conclusive, meaning that these proceedings are intended to encourage further discussion. We hope that they are used in the continued analysis of these issues by a variety of women’s programmes and groups, and thus keep the initiative of the conference alive.

The conference is the result of a discussion process involving the participation of many women from the Women’s Forum for Reproductive Medicine, who are not mentioned here by name. In view of the variety of topics presented here, the conference was thus only made possible by the unwavering commitment of ReproKult and the pooling of diverse competencies and experiences of individual women and those networked in its member groups.

We would like to thank the Federal Centre for Health Education (BZgA – Bundeszentrale für gesundheitliche Aufklärung) for supporting the conference, the Berlin Network of Women With Disabilities (Netzwerk behinderter Frauen Berlin e.V.) for providing sign-language interpreters, and the Self-Determination Interest Group (Interessengemeinschaft Selbstbestimmt Leben e.V.) for providing the audio system.

Svea Luise Herrmann, Margaretha Kurmann
June 2002

This publication documents the conference on “Reproductive Medicine and Genetic Engineering – Women Between Self-Determination and Societal Standardisation”, held in Berlin in November 2001 by ReproKult – Women’s Forum for Reproductive Medicine, in cooperation with the Prenatal Diagnosis/Reproductive Medicine Office.

The objective of the conference was to initiate a discussion on aspects of women’s policy that receive virtually no consideration in the current public debate surrounding “biopolicy”, and to simultaneously develop political strategies for coping with the associated technologies. The background, implications and consequences of reproductive medicine and genetic engineering were explored and critically examined from the standpoint of women in the fields of politics, media, science and practice. The papers, forums and panel discussions led to the identification of a broad range of aspects relevant to women. The conference clearly showed that viewing these issues from the perspective of women’s policy makes a key contribution to the critical examination of genetic and reproductive technologies.
ReproKult calls for participation in this discussion. It encourages public debate and specifically introduces the standpoint of women and social policy. ReproKult has drawn up position statements on the following core issues:

- A human being is a human being –
  The view of man in prenatal diagnosis and reproductive medicine
- Prenatal diagnosis in everyday pregnancy care
- Preimplantation genetic diagnosis (PGD)
- Harvesting and marketing eggs
- Research on embryos and embryonic stem cells

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ReproKult members are: Arbeitskreis Frauengesundheit in Medizin, Psychotherapie und Gesellschaft (AKF); Arbeitsstelle Pränataldiagnostik/Reproduktionsmedizin beim Bundesverband für Körper- und Mehrfachbehinderte e.V.; Beratungsstelle für natürliche Geburt und Elternein (Munich); Berliner Hebammenverband; Bund Deutscher Hebammen; Bund freiberuflicher Hebammen Deutschlands e.V.; Dachverband der Frauen gesundheitszentren; Familienplanungszentrum Hamburg; Feministisches Frauen Gesundheitszentrum Berlin; Genetisches Netzwerk e.V.; Netzwerk gegen Selektion durch Pränataldiagnostik; Weibernetz e.V. – Bundesnetzwerk von FrauenLesben mit Beeinträchtigungen; and a number of individuals: Dr. Giselind Berg (Berlin); PD Dr. Kathrin Braun (Hanover); Dr. Sigrid Graumann (Berlin); Ulrike Hauffe (State Commissioner for Women, Bremen); Svea Luise Herrmann (Hanover); Dr. Elke H. Mildenberger (Münster); Gabriele Pichlhofer (Berlin); Ulrike Riedel (Berlin); Dr. Eva Schindele (Bremen); Dr. Ingrid Schneider (Hamburg); Karin Schüler (AWO Bundesverband Bonn); Sybille Siebert (Berlin); Prof. Dr. Anne Waldschmidt (Cologne); Annette Will (Amsterdam); Dr. Ute Winkler (Berlin).
Reproductive Medicine and Genetic Engineering – Women Between Self-Determination and Societal Standardisation

ReproKult – Women’s Forum for Reproductive Medicine

Reproductive medicine and genetic engineering currently top the political agenda: in future, preimplantation genetic diagnosis promises perfect children, and research on embryonic stem cells new possibilities for treating disease. Women are affected in a very unique way by this development. On the one hand, conception, pregnancy and childbirth come under the pressure of becoming flawless production processes. Women’s bodies become objects of research interest. Women supply eggs and embryos – the raw materials of biomedicine. On the other hand, the prospect emerges of freeing women from the biological and social constraints imposed on them by their role in reproduction. These effects on women – from an individual and social point of view – are hardly addressed at all in the intense “biopolitical” debate currently going on. The conference on “Reproductive Medicine and Genetic Engineering – Women Between Self-Determination and Societal Standardisation” is an initiative for introducing a dimension specific to women and women’s policy in the professional discussion and in biopolitics.

Prenatal diagnosis (PND) has today become a standard part of pregnancy care in gynaecological practice. Gynaecology has also responded to the need of women for support during pregnancy by searching for abnormalities. Methods such as blood tests, ultrasound diagnosis and amniocentesis are increasingly becoming standard tests, which usually do not lead to the treatment of disorders when the results are positive, but rather offer the sole option of terminating a pregnancy that was wanted up to that point.

Preimplantation genetic diagnosis (PGD) is a method that makes it possible to scan embryos produced by in-vitro fertilisation (IVF) for “genetic abnormalities” prior to transfer into the uterus. After PGD, only the embryos that do not display the targeted trait are implanted in the uterus. PGD is highly disputed in both ethical and legal terms in Germany and currently prohibited by the Embryo Protection Act. It is primarily to be offered to couples at high risk of having a child with severe hereditary diseases. However, international practice and experience with prenatal diagnosis (PND) has shown that the method also allows expanded application beyond “high-risk couples”. For example, there are hopes that it will improve the success rate of in-vitro fertilisation.

As is currently the case with PND, proponents of PGD are demanding its introduction in the name of all women and their right to self-determination. So why should anyone be against it?

Since the 1980s, the women’s movement has critically confronted the subject of genetic and reproductive technologies, and women have always spoken out against the instrumentalisation of women’s needs for research purposes and promoted the analysis and evaluation of these methods within their social context. It may be true that PGD increases a woman’s freedom of choice
in a few cases, but – like PND already – it establishes social pressure to use these methods and thus forces women to face new critical decisions.

Self-determination and external control: preimplantation diagnostics, like prenatal diagnosis before it, is being touted as an enhancement of women’s self-determination. However, closer examination shows that this term – which has its feministic roots in the demand for basic human rights for women and the rejection of external control – acquires another meaning in connection with the practices of reproductive medicine: self-determination becomes the pursuit of individual interests, where an increase in medical control over pregnancy goes hand in hand with making women objects of research. Reproduction no longer appears to be feasible without outside “help”, and external control becomes an integral part of how pregnancy is handled. The social pressure on women is growing to have “healthy children” with the help of technology.

The Embryo Protection Act (EPA) forbids any use of embryos that is not geared to promoting a pregnancy. But the removal of these legal barriers is being discussed today in increasingly direct terms. Preimplantation genetic diagnosis, egg cell donation, embryo research and embryonic stem cell research are portrayed as promising technologies and practices. In addition to the broadly discussed ethical and legal questions, embryonic research has serious implications for women in particular, but also for men. Reproductive body substances (eggs, sperm) become resources for research and the biomedical market; embryos become research material, “spare-parts stores” or economically exploitable and patentable goods. This type of use – outside the realm of reproduction – degrades the status of women and men to that of raw material suppliers.

In contrast to sperm donation, harvesting eggs, and thus the currently forbidden act of egg cell donation, are associated with a high health risk for the donor. The hormone treatment given to stimulate maturation of the egg cells can cause cyst growth and the formation of hormone-dependent carcinomas. What is known as “hyperstimulation syndrome” can even have life-threatening effects in severe cases. The harvesting of egg cells for third parties, meaning not for personal IVF treatment, and the commercialisation of this practice can hardly be contained at this point: in the USA, egg cells are sold via agencies at prices ranging from USD 6,000 to 100,000; there are advertisements in Great Britain that ask for egg cells in exchange for free IVF treatment. The term “donation” not only clouds these economic interests, but also falsely implies that “donation” is voluntary: the inherent pressure to “donate” for economic reasons is covered up. The altruism demanded of women, which is evidenced by the term “donation”, is linked to the classical view of women: women are expected to supply parts of their bodies without compensation, while agencies and reproduction clinics turn a profit.

It is extremely problematic to take advantage of the physical services of third parties in order to fulfil a personal wish or promote research interests, particularly when the services are associated with high medical risks. Moreover, crossing biological boundaries breaks a sociocultural taboo by establishing social and familial relationships that never have existed before and by dissolving deeply rooted ideas of personal heritage.

In a social situation in which the common image of the disabled has always been associated with “suffering” and “tragedy”, but also “pity” and “sacrifice”, selective prenatal and preimplantation diagnostic practices – PND and PGD – take on another component
with grave implications: abortion and the selection of embryos based on "abnormal" test results contribute to disabilities increasingly being viewed as "avoidable suffering" or an "unreasonable burden". PND and PGD directly or indirectly promise healthy children. Illness and disability become a question of a woman's "culpability" should she not make use of the possibilities offered, or even consciously decide in favour of a child with a disability. This is underlined by the rhetorical separation of a disability from the person with the disability: ultimately, however, it is not the disabilities, but the people with disabilities, who are avoided. Health and normalcy are increasingly portrayed as personally creatable conditions. This view completely loses sight of the responsibility of society for the well-being of all its members.

The social and political consequences of these technologies were discussed from the female standpoint at the conference on "Reproductive Medicine and Genetic Engineering – Women Between Self-Determination and Societal Standardisation". Over 200 women and several men from a wide variety of backgrounds – politics, media, science and practice – spent three days talking in depth about the various aspects of genetic engineering and reproductive medicine that are relevant to social and women's policy, with the aim of developing strategies for drawing attention to the concerns of women and women's policy in the public debate, and for integrating women in decision-making processes.

ReproKult
Women's Forum for Reproductive Medicine
June 2002
Because only this comprehensive view does service to women, and the new technologies must also be evaluated against this backdrop.

No matter how much they want a child, many couples just cannot get pregnant.

There is a correlation between societal lifestyle processes and medical possibilities.
Taking an informed, independent decision is therefore very difficult for the majority of women. That is why I am pleased this conference is taking place and that we can offer a platform for women's concerns through our funding.

Reproductive medicine are especially priceless. The need to have control grows and the pressure on the quality of the result increases. The increasingly specialised methods of prenatal diagnosis are one answer. These priceless pregnancies “must” lead to the birth of the “healthiest” possible child. Responsibility for the pregnancy is thus increasingly transferred to the medical field. Made to feel uncertain and under immense pressure of success and responsibility, women consent to the procedures and relinquish responsibility for their own well-being and that of their unborn child. For its part, the medical field rates these pregnancies as high-risk pregnancies right from the start, thus making a woman feel even more uncertain about her condition. Women find it difficult to break out of this cycle. They often have to legitimise their rejection of this form of risk management.

– I would now like to talk about an area that is of particular concern to us at the Federal Centre of Health Education and one of our original tasks: providing general and patient information on these issues. As we determined by developing and evaluating media on the subject of reproductive medicine and prenatal diagnosis, the majority of women are not informed enough to understand what the medical field has to offer. There is often an enormous gap between the lay knowledge of women, their emotional perceptions and the expert knowledge of medical professionals. Women are confronted with medical knowledge that initially sheds doubt on their hopeful situation. They must take decisions in an extremely short space of time, including those concerning the life or death of their unborn child in the worst-case scenario. This is hardly possible for many women and forces a heavy burden upon them. There is still a lack of adequate information and counselling in this area that specifically address the psychosocial situation of women. We know that the organisations funding pregnancy counselling centres have already taken action and developed counselling services that unfortunately are still too unknown. As the first points of contact for pregnant women, gynaecologists in private practice must be recruited to advertise these offers. In other words, we still have some convincing to do in this quarter.

On the whole, it would seem that medical solutions are increasingly being offered for what are actually social and societal problems. Consequently, I would like to see these conditions analysed and identified with the aim of relieving and strengthening the position of women. I would like to thank the ReproKult Women’s Forum and the Prenatal Diagnosis/Reproductive Medicine Office, which is part of the German Association for the Physically and Multiply Disabled (Bundesverband für Körper- und Mehrfachbehinderte e.V.) for their great commitment in preparing and conducting this conference. I would also like to thank the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, which also provided funding in our budget for this conference. I hope the conference is successful; that it contributes to integrating the perspective of women more strongly into the public discussion and gives women a voice in future decisions concerning genetic engineering and reproductive medicine.
It is my job to give you some background information on this conference. What brought us together and what are our objectives? But before I begin, I would first like to briefly outline the development of the discussion on genetic and reproductive technologies in the German women’s movement and describe several of the core issues it took up. This will establish its relevance for the present debate, but also illustrate how different the emphasis is today.

For some time now, there has been an intense social debate on biomedical issues such as preimplantation genetic diagnosis, prenatal diagnosis and embryonic stem cells. However, the discussion is largely being conducted without giving consideration to women, despite the fact that they play a key role in it. On the one hand, the technical methods are primarily directed at them and, on the other, the prospects offered by stem cell research for curing disease, for example, can only be realised when women provide the egg cells.

The question of whether possibilities like these new reproductive methods enhance or restrict the freedom of women to make decisions concerning reproduction has been a central issue of the feminist debate from the very beginning. The answers have been highly contradictory. In contrast to the American feminist Shulamith Firestone, who demanded artificial reproductive techniques to free women from the burden of biological motherhood, the debate surrounding genetic and reproductive technologies in Germany went in a different direction. Of greater interest here was the question of whether women had to confront the possibility of being dispossessed of their role in reproduction in future by the methods of artificial insemination.

The new reproductive techniques also include methods that promote the birth of a child, as well as those that prevent it. With regard to a woman’s decision-making freedom, the example of the pill illustrates that the gain in autonomy made possible by a conscious decision for or against a pregnancy—the possibility of controlling Nature, as it were—simultaneously resulted in a kind of dual social dependence for women. In other words, modern methods, such as the pill, the IUD or the three-month depot injection, depend on prescriptions and routine examinations by doctors. As a result, doctors became experts on contraception, abortion and conception, and thus the managers of female fertility to a certain extent. In a broader sense, the use of these contraceptives also enabled greater social control of women, because—as Silvia Kontos said—they “add a degree of rationalism and plannability to reproduction decisions, which definitively removes them from the traditional realm of natural processes and makes them not only more individual, but also accessible to overall social planning”.

With regard to the social significance of the new
With regard to the social significance of the new reproductive techniques, it is also evident that they can expand the decision-making freedom of some women, but that the degree of external control over reproduction processes increases for others. For example, Barbara Katz Rothman calls on us to examine not only the individual woman and her freedom of choice, but to concentrate on the system that structures the choices of all women by rewarding some decisions and penalising others.

The concept of self-determination has gone through a remarkable development in connection with the new reproduction methods. It used to be a central argument in the conflict over Art. 218 of the German Penal Code; in other words, in the conflict over the social indication, which was reflected in the slogan, “My stomach belongs to me”, as a kind of symbol for the independent decision of women concerning their own reproduction. This claim met with great social resistance from both the churches and the professional medical associations.

To my mind, the establishment of ReproKult is an expression of a revived need to discuss the enormous dynamism of the new reproduction techniques.

“Self-determination” has since become a central paradigm in medical ethics. The field of reproductive medicine is currently calling for the introduction of new methods, such as preimplantation diagnosis and egg cell donation, and justifying its demand by claiming it does not want to withhold these opportunities for autonomous decision-making from female patients.

While the women’s movement used to be characterised – not exclusively, but certainly very strongly – by a critical attitude, the picture has now become more differentiated between scepticism and acceptance. The formerly common rejection of classical female roles has given way to the idea of no longer viewing education, career and children as mutually exclusive alternatives. However, this view must be relativised somewhat when we consider that one-third of highly qualified women are still childless.

To my mind, the establishment of ReproKult is an expression of a revived need – particularly in view of the pending political decisions concerning an act on reproductive medicine – to discuss the enormous dynamism of the new reproduction techniques in their increasingly close relationship to genetic methods in the medical field. This should result in the development of a women’s policy position for use in the public debate. For some women, this means tackling the subject for the first time, while others can exploit their experience with the discussion in the Eighties.

A lively public debate took place back then concerning the introduction of IVF, etc. Unlike today, the discussion was conducted on all levels of society: in political parties, associations, churches, organisations, on the parliamentary level (Study Commission on the “Opportunities and Risks of Genetic Engineering”) and in commissions (“Benda Commission”), which pursued laws that eventually led
to the Embryo Protection Act passed in 1990. An international, interdisciplinary women’s network played a central role in politicising this issue and in mobilising women: FINRRA\textsuperscript{GE}GE – Feminist International Network of Resistance to Reproductive and Genetic Engineering. Women from this network also played a major part in the second conference on genetic and reproductive technologies, which was held in Frankfurt in 1988.\textsuperscript{6} The following positions were discussed – quite controversially.

– An international connection between the new reproductive techniques and genetic engineering. The field of reproductive medicine had fiercely denied this for many years;

– The role of reproductive technologies in relation to women in industrial and developing countries as an expression of a dual perspective. While methods that promote the birth of children were being offered to white women, the situation in the “Third World” was just the opposite, including even the compulsory prevention of the birth of children;

– The self-determination of women. The task is to clarify the meaning of the term itself, and to agree on what it implies for dealing with reproductive medicine and prenatal diagnosis;

– The consequences for women of applying the technology. The focus was on the processes of subdividing and commercialising the female body and non-human Nature, as well as the role that the natural sciences play in this process.

After some ten years, which passed relatively quietly after the Embryo Protection Act went into effect, an initiative of the Gen-Ethics Network (Gen-ethisches Netzwerk) to get involved in another women’s policy debate met with widespread approval. The advancing technology of reproduction, and the influence of reproductive medicine on social attitudes towards reproduction, occasioned a conference that was held in Berlin in spring 1999 – in cooperation with the Feminist Women’s Health Centre in Berlin (Feministisches Frauengesundheitszentrum Berlin) – to address the subject of reproductive medicine and its social implications.\textsuperscript{7} There proved to be great interest in confronting the issue of prenatal diagnosis. Its development into a routine examination in pregnancy care and its inherently eugenic tendencies has been the subject of critical discussion for some time and has already led to interdisciplinary coalitions, such as the “Network Against Selection Via Prenatal Diagnosis” (Netzwerk gegen Selektion durch Pränataldiagnostik). The connection between reproductive medicine and genetic engineering – as was always maintained by critics – became obvious as soon as preimplantation diagnosis was introduced in Great Britain and the USA. The demand to establish this method in Germany as well, although it contradicts the Embryo Protection Act, had already given clear indication that the pressure to adapt laws to the new scientific and technical developments would increase. In view of the dynamism in this field – keywords being stem cell and embryonic research, therapeutic and reproductive cloning – it soon became clear that it was necessary to formulate a female position on these issues. This interest went beyond the conference and, following additional meetings in January 2000, led to the establishment of ReproKult.

In order to publicise this position, we elaborated a paper of principles that was presented at the “Reproductive Medicine in Germany” symposium and other events, and dealt with the following issues:

– Prenatal diagnosis,

– Preimplantation genetic diagnosis,

– Embryonic and stem cell research,

– Egg cell donation and

– The view of man in the new reproduction methods.
Corea predicted the industrialisation of the reproduction process, this leading to the expansion of reproductive services (sex determination, surrogate motherhood, etc.) and to increasing quality control of the developing “product”.

If we examine the period between the Frankfurt conference and the “Optimisation of Reproduction?” conference, which took place about ten years later, we can clearly see that the issues of 1988 have not become any less explosive. Although a discussion of women’s policy is hardly evident, a sustained level has been reached in the meantime. The issues were established in practice, be it in the framework of educational work, scientific debate and independent counselling programmes, or through the networking of women’s projects.

The increasing spread of the methods of reproductive medicine must also be seen as an expression of the normalisation process, where ethical limits are continuously being pushed outwards due to the continuous announcement of new treatments and the subsequent familiarisation phase.

The new methods of reproductive medicine introduced in the early Nineties, such as ICSI (Intracytoplasmic Sperm Injection) and preimplantation genetic diagnosis, considerably expanded the range of offers. ICSI offered a treatment option for male fertility disorders that were not treatable up to then and triggered an enormous wave of demand. This modification of in-vitro fertilisation, in which women still bear the burdens and risks of treatment, was occasion enough to be addressed from the female standpoint. A similar situation exists in regard to preimplantation genetic diagnosis. Attempts to introduce it here – as a kind of preliminary prenatal diagnosis – were accompanied by lively public debate. It is important to note that in connection with this confrontation, the public has once again become more aware of the problem of prenatal diagnosis.

In its day, the feminist debate in the Federal Republic of Germany was greatly influenced by the research of Gena Corea, who published the development status of the technologies, but also the goals (at least) of American researchers. What Corea predicted, and what was viewed as being purely speculative, has now become common practice or is soon to be implemented. This is illustrated by the examples of surrogate motherhood, artificial uterus, the use of foetal tissue for producing egg cells and cloning (concepts back then focused on embryo splitting). Examining the current publications of American or Japanese researchers, we can see that they hope their experiments on the “artificial uterus” will make pregnancies outside the female body possible in just a few years time.

Corea formulated a radical position in the Eighties, predicting the industrialisation of the reproduction process by the new reproductive methods, this leading to the expansion of reproductive services (sex determination, surrogate motherhood, etc.) and to increasing quality control of the developing “product”.9
However we view this assessment today – against the backdrop of the rapid change in the methods offered in the field, the hopes that they elicit and the future options promised for women – it is necessary to discuss a few basic principles once again. This applies in particular to the relationship between autonomy and self-determination. To prevent misunderstandings, it must be emphasised that the rights of women (and men) to free choice are not to be questioned in any way. However, we must include in our view the social context in which the decisions are to be made. Moreover, we would like to make an attempt with you to identify what is of interest to women in the various, sometimes complex, topical areas, also taking into account the ethical and social implications of technical developments. All these aspects should be integrated in the formulation of a women’s statement of position, which has received too little consideration in the political debate on biomedicine to date.

Footnotes


8 The egg cells are removed by puncture following hormonal stimulation of the woman. For fertilisation, a sperm is drawn up into a microsyringe and injected into the egg cell(s).

Female autonomy is a key term in the women’s movement. After all, its essential meaning was, or is, to free ourselves from external control and adhere to our own standards. In no area has the fight for the right to self-determination been fought so hard and so continuously as in reference to the question of reproductive rights. The conflict over Art. 218 has practically become a symbol of the fight for self-determination.

However, the term “self-determination” became increasingly unclear as reproductive technologies developed, because these technologies are increasingly taking control of women’s bodies and their psyche in a new way. Today, the issue is no longer just a question of decision-making options, but of the degree to which the motives behind the decisions are influenced and women put under pressure to decide. On the other hand, this development has also expanded the decision-making freedom of women, because women can now decide not only whether they want to carry a child to term, but also the traits of the child. Consequently, women can be viewed as being powerless at the mercy of the social power of medical science and politics, or “powerful” because they determine whether or not life is to exist – and increasingly not just whether life is created, but also the characteristics of this life.

In other words, the situation women face is very contradictory, because the more women can make their own decisions about their bodies, the more others can do the same. However, decision-making freedom is only enhanced for some women, namely only for those who have access to these technologies and have the resources to afford them. Consequently, this development also leads to further differentiation between women, because some can exploit these technologies as they see fit, while others are increasingly victimised by them.

It would be too easy to translate the ambivalence of the situation solely into a difference between women, because even if women can make use of these technologies, the situation continues to be contradictory for them. These contradictions are expressed in contrasting images, meaning the image of women as victims of medical monopolisation strategies against which they are powerless, or as spare-parts stores for biomedicine, and the image of women with power, who pursue their personal preferences in accordance with their individual ideas, if not to say their personal utilitarian considerations – without reference to the developing life. These polarised images of the powerful and powerless woman thus become trick mirrors distorting the view of this highly complex situation.
The power and powerlessness of women

The polarisation between the omnipotence and impotence of mothers is rooted in the complexity of the power relationships. This is most clearly illustrated by a comparison between the power of relationship and that of resources: on the one hand, the power of mothers results from their existential importance for a growing child. A mother’s support is vital for a child and thus becomes a symbol of power in the relationship, meaning the power that stems from the dependence of all people on support, affection and recognition. This power is experienced most extremely by infants and toddlers, who could not survive without a mother’s care. A child has the experience of being at the mercy of the mother, for good or ill. With regard to the male self-image in particular, this relationship is a continuous offence to a man’s personal narcissism and a threat to his own pursuit of autonomy. The memory of this early symbiosis, and also the yearning for it, are repeatedly reactivated in later relationships, this constantly provoking a defensive reaction. At least from a psychoanalytical standpoint, this is one of the main reasons why the fear and threat fantasies some people have against their mothers, and thus also against women in general, persist so stubbornly and why the areas in which women primarily work, such as education and care, are still associated with women and simultaneously looked down on in society.¹

Thus, women can certainly be powerful in one way, even if they are not in others. This image contrasts with that of women who are powerless and at the mercy of patriarchal structures. The powerlessness of women is primarily illustrated by their limited access to social resources. Women still have much less access to social resources, such as money, social status, political power and prestige. However, because power is not determined by these resources alone, particularly when it comes to interpersonal relationships, but rather also by emotional resources, such as love, support, attention, knowledge and communication skills, women do not always have less power. They only have less power when it is measured solely against “typical” male power, meaning resource power. This likewise applies to the ability to bear children, which is rated very differently in different societies, but still often perceived as power, even if it is ultimately a disadvantage to women in society.

Thus, women can certainly be powerful in one way, even if they are not in others.

The starting conditions of the sexes differ not only because women generally have less power than men, but also because they tend to possess different types of power.

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Women benefit from maintaining the current arrangement between the sexes, because it also gives them advantages, and they also associate it with their personal interests.

In view of the coexistence of different power levels, Hilary Lips speaks of a complex system of power and illustrates it with the relationship between parents and children: parents appear to have all the power. But does this mean that children have no power at all? For example, a child can refuse to meet the demands of the parents, thereby putting them under pressure. This is only possible because the parents have a relationship to the child, i.e. the child is important to them and they are interested in its well-being. Now, the child can disappoint their expectations and resist their demands. It can even betray them so that they no longer fulfil specific norms. Under certain circumstances, the parents must also expect to be sanctioned if their child misbehaves all too much. Ultimately, this means that the parents’ expectations give power to a child that initially appears powerless. Of course, this power is relative and goes only as far as the demands of the parents, i.e. they link their own well-being to the thriving of their child. As soon as the child is irrelevant to them, it would also lose most of its power over them.

The fact that power and powerlessness coexist also applies to the relationship between the sexes. In other words, women benefit from maintaining the current arrangement between the sexes, because it also gives them advantages in many ways, and they also associate it with their personal interests. In her analysis of the patriarchal society, Gerda Lerner therefore speaks of the subordination and not the repression of women, because they also approve of this society at least in part. In the German-speaking region, it is Margit Brückner who primarily analysed the interests of women in "patriarchal" relationships by showing, for example, how the delegation of power, strength and aggression to men permits women to pursue their ideal of selflessness and their fantasies of maternal omnipo-

tence. Simone de Beauvoir presented a similar argument in the past, saying that, for women, the dynamism of the relationship between the sexes is based on their need to escape responsibility and be relieved from choosing their own way in life. If we question the inherent opposition of male and female interests, the patriarchal society must be viewed as a product of the relationships between the sexes, which both sexes continuously reproduce, even if their respective starting conditions are very different. Consequently, in reference to reproductive technologies, the question arises not only as to the degree to which women are dominated by male-oriented science, but also what interests they themselves attach to it and the degree to which they tend to delegate responsibility for their decisions to others.

The more women attain truly powerful positions in society, the more the concept is lost of a specifically female component, of an alternative to the existing order that is represented by women. The image fades of the female being exclusively different.
For a feminist repression model, the explanation lies in the increasing adaptation of women to the patriarchal system, which is no longer openly repressive, but rather affects the ideas of women in a subtly invasive manner. In view of this superior power of the system, all women can do if they want to keep a critical distance is to retreat again and do without power. In this case, however, women continue playing the traditional female role in their relinquishment of power in the various niches of society. This presents us with a “tortoise-and-hare” dilemma: wherever the tortoise goes, the hare is always there first. Women are trapped in their roles, or they are controlled by all-powerful patriarchal structures, regardless of whether they try to enter into, or keep out of them.

Between self-determination and external control

Self-determination was never independent of external control, because whenever “self” makes decisions, others are affected by them. In this context, autonomy is a relationship concept. In the political sphere in the tradition of civil revolutions and emancipation movements, autonomy has always looked upwards, against whatever form of dominance has been successfully subdued. At the same time, autonomy also has an eye on what this means for others, and on the fact that personal emancipation often results in the repression of others. For example, Maria Mies impressively describes how self-determination and external control are inextricably tied together, that the rise of men is based on the fall of women and the progress of Europe on the regression of the colonies. However, even if self-determination is a win-lose situation, in which only one side can win while the other loses, we still must be aware that the male, domestic autonomy concept presumes the enslavement of others, particularly women, but also workers and colonised peoples, while at the same time denying this dependence. Autonomy can only be realised in a relationship network in which every decision represents a form of behaviour towards numerous other groups.

For example, the decision of a pregnant woman to carry a potentially disabled child to term or not has consequences not only for herself, but also for the child and the extended social environment, particularly in that this decision also expresses a certain normative orientation, which says something about the value and significance of the disabled in our society.
A decision-making situation of this kind is undoubtedly full of conflict for women, because they know that a disabled child can often mean numerous restrictions for themselves, because society usually places all responsibility on the mothers. Therefore, women fear that they must change their life plans and that they themselves will be indirectly affected by the stigmatisation of the disabled in our society. But a decision of this kind also means that they must abandon any narcissistic desires of seeing themselves reflected in their own child.

Reproductive technology is misleading, because it fosters the illusion that narcissistic eugenics is possible, namely instilling the ideal self in another, being able to create a person entirely after your own image. The more we succumb to our own narcissism, the greater the disappointment will be, because even with all the creative power available, the other person will always appear to us to be different, regardless of how much we try to manipulate him/her to fit our own desires. In the case of such disappointment, there is a risk of turning away from the outside world and retreating into an inner world of fantasy objects. But the relationship to the other is increasingly neglected and thus also the recognition of self through the other.

If a pregnant woman decides against a potentially disabled child, she confronts not only herself and her ideas of her future life, she is also reproducing social norms that say that the life of a disabled person is less valuable. She thus supports prevailing values of beauty, health and functionality, and she supports the opinion that there is a simple solution to complex problems. Moreover, she relieves herself and others form the demand to actively support a society in which a disability is no longer stigmatised as a for of suffering, an undesirable condition or something “inferior”, and in which the disabled have the same or comparable rights as the non-disabled. The goal of such a society would be to equally accept and respect a wide variety of experiences with life and coping strategies or, as Therėsia Degener writes: “to recognise disability as a neutral condition which – like gender – is not inherently associated from the outset with either suffering or happiness.”

In other words, a decision of this kind is not easy to take. There simply is no right or wrong answer. If a person wants to make a responsible decision, all sides must be evaluated and their aspects considered. And that can very well mean something different for different women. According to Laurie Shrage, such a decision must therefore be based on “pluralistic ethics” that take into account the fact that there is no right answer for everyone and for all time, rather that there can only be a right or wrong way depending on the context.
But however the decision is taken, there is no going beyond social norms. If we ourselves were in the fortunate or unfortunate position of being able to choose, for example, from which sperm donor we would like to have a child, whether he would be white or black, tall or short, intelligent or less so, athletic or not, etc., we would quickly become trapped in a maze of norms and possibly long for a situation where choices are unavailable, i.e. a condition of moral innocence.

The objective cannot be to deny that we are embedded in social norms and our own participation in their perpetuation. Rather, the only objective can be to accept this reality in its complexity and then head into confrontation. In a decision, this means including the various interests and views of as many participants as possible and taking a decision, which can be justified vis-à-vis the direct and indirect participants, the motives of which are comprehensible and which is of a moral quality that can be constructive for our own self-respect, but also for the other participants.

There can be no either-or and no unequivocal solution for reaching a right decision. It can only emerge by taking the broadest possible view of reality and confronting all potential points of view that are relevant to the decision. Contrary to what Habermas said in his acceptance speech for the Peace Prize of the German Book Trade in October 2001, parents cannot be accused of wanting to manipulate a child, because you could then counter with the accusation that not enough was done for the well-being of the future child, i.e. that no one intervened. The question of whether one is permitted to “meddle with God’s work”, or whether one should humbly accept one’s fate cannot be asked in this situation and is also unrealistic. We intervene constantly; we design and shape our environment, Nature and the conditions for future generations. Naturally, technical interventions are serious. It is possible, however, that only then do we become aware of the laws according to which we arrange situations. For example, choosing a partner is basically a form of “selection”, such as when women and men with great regularity choose partners who come from the same social sphere and have the same colour skin. It also a matter of course that the man must be taller and older than the woman. In all of these cases, love magically appears to help assert the laws of social selection.

Genetic interventions have an entirely different dimension than everyday behaviour. But decisions in this area are determined by normative attitudes, which function according to the laws of “normalism”.

“Normalism”10 – or the dominance of normalcy and the power of norms – marginalises all those who do not meet its criteria. Women are victims of this power, but they also perpetuate it. Consequently, self-determination can never be viewed as an emancipating ideal in a social/political vacuum, rather at most as a step towards this ideal, where the repressive sides of our own emancipation are acknowledged and continuously questioned or subjected to critical examination.

But however the decision is taken, there is no going beyond social norms.
The fact of discrimination against women does not guarantee per se a critical view of prevailing norms. For example, a study by Dietke Sanders (1999) on the attitudes of feminist women towards disabled women and men and hiring practices in women’s projects, showed that there are no differences compared to the rest of the population.\footnote{1} Personal experience with discrimination does not necessarily sensitise people to other forms of discrimination, but rather likewise leads to justification of a person’s own dominance. Discrimination towards others often has a self-determining function, because people who are the victims of discrimination themselves believe that they do not discriminate against others, or that they can afford to do so as a form of compensation.

Autonomy is and was a key term in the women’s emancipation movement. It promised freedom from external control and repression. However, autonomy is always a relationship concept, because self-determination is always realised within a relationship network. The feminists continuously demanded this dimension in their criticism of the male concept of autonomy, which was believed to be separate from others. This illustrates the ambivalence of the term autonomy, which resists external control, but also always has consequences for others. In turn, these consequences can be repressive. Consequently, autonomy is not only a relationship concept, but also always a distinction concept when it refers to the assertion of self against others.

Female autonomy is not emancipating per se. It too is integrated in a personal and social relationship network that makes every female decision contradictory. It too is integrated in a personal and social relationship network, in the interest and power relationships that also make every female decision contradictory. Just as women are integrated in power relationships and thus also associate them with personal interests, they are also integrated in normalcy and normal-
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Innovation beyond reasonable limits: Ethical and social guidelines for research in reproductive medicine and genetics

Regine Kollek

In modern societies, an increasing number of spheres of life are being penetrated by science. Knowledge has become a productive force of the first order, and science is the social institution in which knowledge is generated most effectively. With the establishment of modern reproductive medical research, the sphere of human reproduction has now also become affected. Today, not only the act of procreation, but also the early phase of human development have become accessible to the disenchanting scientific view and are becoming an increasingly active field of science and medicine.

Having your own, healthy children – that is the great promise that has propelled the success of reproductive medicine over the last two decades. Although this promise is only fulfilled for a fraction of the couples that seek infertility treatment, it has lost hardly any of its seductive power. In this presentation, I would like to illustrate how the developments in reproductive medicine are based on a one-sided view of progress. This view hinges not only on carelessly overstepping the boundaries within which human reproduction has evolved, but also and above all on the systematic suppression and externalisation of the physical, psychological and emotional consequences of overstepping these boundaries.

1. Reproductive medicine:
The control and standardisation of reproduction

Artificial insemination outside the female body has been practised since the end of the Seventies. In-vitro fertilisation (IVF) was initially postulated as a treatment for types of infertility that clearly resulted from identifiable, organic disorders, such as obstructed fallopian tubes. As was to be expected, the range of indications expanded relatively quickly and soon included not only various forms of male infertility, but also idiopathic indications, in which no organic causes of infertility can be identified.

In-vitro fertilisation: Efficiency problems

In order for embryos to be created in a test tube, a woman must first undergo hormonal stimulation of egg cell maturation and egg follicle puncture. The latter procedure was carried out in 45,487 cases in 2000 (1999: 44,086 cases). The chance of becoming pregnant by artificial insemination was approximately 26% per transfer in Germany in the year 2000. However, this was only true when fresh
embryos were transferred that had not been frozen in liquid nitrogen as fertilised eggs. In this case, the probability of a pregnancy is significantly lower. Either way, the chance of birth still amounts to slightly above 13% per embryo transfer. As a result, every woman who wants to have a child with the help of this procedure must undergo hormonal stimulation of the ovaries several times.

...The low efficiency rate of the method is a persistent problem. It is the reason why three, or in some countries even more embryos are usually transferred to increase the chance of achieving a pregnancy. The result of this practice is a drastically elevated rate of multiple births. In Germany in 1999, this figure was 32.4% for twins and 6.9% for triplets. It dropped in 2000 to around 22% for twins and 2.4% for triplets. In “normal” reproduction without hormones, this figure is only about 1.2% for twins. Multiple pregnancies are associated with considerably higher risks for the pregnancy and the physical development of the children, thus leading to a greater incidence of premature births, C-sections and low birth weight.

...A new strategy was examined in the mid-Nineties to improve pregnancy rates and simultaneously reduce the multiple birth rate. Embryos were transferred to the woman’s body not on the second day after artificial insemination as usual, but on the fifth day thereafter, meaning in the blastocyst stage. It became apparent that the transfer of blastocysts led to pregnancy rates of 50 or even 60% in individual cases. However, it was also observed that numerous embryos did not survive the long period of in-vitro cultivation. Consequently, the method is hardly acceptable for women who only have a few egg cells or embryos to offer due to their age or other circumstances. On the other hand, they are the ones most in need of an improved success rate. Moreover, it becomes apparent at second glance that the high efficiency rate obtained under study conditions frequently cannot be achieved in practice, and that it is not always associated with an actual benefit for the women treated. Only recently was it shown that, after applying the method in the first cycle, the pregnancy rate drops dramatically in the second and subsequent cycles. In other words, the cumulative pregnancy rate of two or three cycles is not necessarily higher than for one standard IVF procedure.\footnote{Papers}{2}

...While the low efficiency rate in the initial phases of development was attributed to the “artificiality” of the IVF method and its underdeveloped status, the explanation for it changed no later than after the introduction of PGD, which made it possible to analyse embryos on the genetic and chromosomal level. Now, it was the deteriorating quality of the egg cells and embryos as a woman ages that was identified as the cause of the inefficiency of the procedure and no longer the “unnaturalness” of IVF. Despite its low efficiency rate, IVF has become a standard treatment for people who remain childless against their will. Nevertheless, their problems are still not taken into consideration to an adequate extent. This includes ovarian hyperstimulation syndrome following hormone treatment, which is painful and can even be life-threatening in individual cases. Despite some efforts to resolve the problem, up to 4% of all women treated contract a severe form of this syndrome. It has occasionally even been referred to as an epidemic caused by doctors in healthy patients.\footnote{Papers}{3} According to the German IVF register, 0.7% of patients were affected by it in Germany in 2000.
ICSI: New risks

IVF proved to be primarily successful in the treatment of female fertility disorders. Intracytoplasmic Sperm Injection (ICSI) was introduced in the early Nineties for the treatment of male fertility disorders. ICSI is a method for the artificial insemination of egg cells. In contrast to “standard” IVF, in which the egg cell and sperm are merely brought into close contact in a test tube and the gametes (egg and sperm cell) fuse on their own, ICSI involves the injection of a single, previously selected sperm cell into an egg cell using a fine injection needle. The first pregnancy achieved with oocytes fertilised by means of ICSI was publicised in 1992.

In order to use this method, healthy and fertile women must usually undergo stressful hormone treatment to make their egg cells available in vitro. But the distribution of burdens is one-sided and this circumstance has been clouded over by the fact that IVF has advanced to the status of a “treatment for couples” since ICSI was introduced.

In ICSI, immature or immotile sperm cells that are not capable of penetrating the egg cell on their own can also be used for fertilisation. Consequently, ICSI greatly expands the range of application of IVF to include the group of couples affected by a male fertility disorder, which had previously been considered difficult or impossible to treat. A substantial proportion (up to 25%) of these male fertility disorders are attributed to genetic causes. For example, the spermatic cords do not develop in some heterozygous carriers of the cystic fibrosis gene: the affected men are sterile. They generate sperm, or initial forms thereof, which is prevented from reaching the ejaculate by the underdeveloped spermatic cords. Other men display chromosome

Among the children born after IVF in Sweden between 1982 and 1995, those with a birth weight under 2,500 g were 15 times more frequent, and those with a weight under 1,500 g 12 times more frequent than single babies born by natural reproduction. The risk of death during or shortly after birth was three times higher for IVF twins and the risk of spina bifida and anencephaly 13 times higher. The risk of cerebral palsy, which can be associated with vision problems, hearing disorders and other neurological symptoms, is six times higher in children with a birth weight between 1,500 g and 2,500 g, and 20 times higher in children under 1,500 g.

These elevated risks from IVF affect society (the healthcare system), the family (the stress of multiple births, disabled children or early childhood death), women (medical risks) and, last but not least, the children conceived in this manner. The risks still have not been studied adequately or publicised to a sufficient extent. This is an untenable situation in view of the resources invested in researching more and more of the technical details. These risks result from overstepping bounds in two respects characteristic of human reproduction: it takes place inside the female body and is usually monoovular, i.e. only one mature egg cell is normally fertilised. Twins and higher-order multiple births are the absolute exception. If the fertilised egg cells do not develop after natural fertilisation, no damage results, because the process can be repeated without any major technical or financial effort. The removal of fertilisation to the laboratory and the efficiency requirements imposed on such a stressful and costly treatment make it necessary to transfer several embryos − this logic is difficult to break through in the system of medically assisted reproduction.

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anomalies. Genetic factors of this kind that are responsible for infertility can be transferred to subsequent generations by ICSI\(^7\). For this reason, couples with an indication for ICSI are urgently advised to get a genetic consultation or test in order to estimate the potential genetic risk for their children.

In addition, chromosome anomalies have also been discovered after ICSI that were not passed on by the fathers (or mothers) and may indicate that the method itself causes damage. Only few studies exist to date in which the process of microinjecting sperm cells into egg cells and its potential consequences are investigated in greater detail. These studies show that damage to the cellular spindle, which is responsible for the correct distribution of chromosomes during cell division, cannot be ruled out during sperm injection. Moreover, there are indications that the process of “decondensation” of the chromosomes packed densely in the head of the sperm cell does not occur normally during sperm injection.\(^8\) This may be one reason why an increased percentage in the number of sex chromosome anomalies is found in association with ICSI.

Biologically, ICSI is an entirely new concept in reproduction. Sperm cells of various maturity levels and quality are used to create human embryos although they would not be capable of fertilising an egg cell in the natural way. Therefore, ICSI not only overcomes all biological barriers that are set up in the female reproduction tract to block defective sperm cells, but also circumvents the necessity for normal sperm development, morphology, concentration and function. The chromosome anomalies discovered are serious indicators that overcoming natural fertilisation barriers can have long-term consequences for the health of the children conceived by this method. Figures on the frequency of birth defects are still contradictory, despite the relatively large-scale studies now available. They fluctuate between an increase of 1.3 times the birth defect rate and a 50% increase.\(^9\)

ICSI was introduced without previously conducting animal experiments, which would have made it possible to at least find indications of potential risks. After the first children were born without any visible damage, a large-scale experiment was initiated in subsequent years that has since led to the birth of tens of thousands of children by this method. Overstepping scientific – or rather technical – bounds, meaning the “rape of the egg cell” with a microinjector at the beginning of this procedure, may be considered a heroic deed by some. But we will not know what stands at the end of this procedure for several decades, when the children conceived by ICSI become adults. The long-term consequences for the health, fertility and psychological development of the children still cannot be adequately assessed.

Preimplantation genetic diagnosis: Selection in a test tube

The idea that the children of medically assisted reproduction would not display any detectable flaws was already prevalent in the early stages of IVF introduction and it was also the basis of the agreement that Lesley Brown, mother of Louise Brown, had to sign as a prerequisite for her treatment with the experimental IVF method. If the foetus did not turn out to be normal, she agreed to have an abortion.\(^10\) This vision of an “immaculate” conception was and is an integral part of these technologies.
ICSI clouds the issue because it involves the transfer of paternal chromosome anomalies and is possibly associated with an elevated risk of chromosomal defects. Therefore, a demand was made at an early stage that embryos created with the help of ICSI be examined by means of preimplantation genetic diagnosis (PGD). PGD was introduced at virtually the same time as ICSI, although it took much longer for it to become established. PID is the genetic analysis of in-vitro embryos prior to transfer into the female body. For this purpose, two cells are usually taken from several 8 to 10-cell embryos and then genetically analysed. The embryos showing normal results are used or frozen for future transfers. Those showing abnormalities are discarded.

Although this method is primarily recommended for couples with severe hereditary diseases, the range of indications has increased rapidly since its establishment. In addition to classical monogenic hereditary diseases, the services of reproduction geneticists now include predispositions for diseases occurring late in life, treatable metabolic disorders such as PKU, or the screening of embryos following multiply unsuccessful IVF in order to identify embryos with chromosome anomalies. In addition, several cases have already become known in which embryos were selected specifically for their suitability as tissue donors (cord blood) for a sick sibling, or for gender.

Thus, PGD makes it possible for the first time to select from several embryos to establish a pregnancy. As a result, yet another boundary provided naturally in the reproductive system of the monoovular species Man has been overstepped. Due to the elevated risk of chromosomal defects, ICSI is also being discussed as an indication for PGD. Klaus Diedrich and his colleagues at Lübeck University Hospital are of the opinion that this may be the case. However, they are sceptical about the routine screening of embryos following ICSI because of the associated ethical (but certainly also economic) consequences. Instead, they recommend a “genetic ultrasound” at the end of the first trimester to detect any morphological signs of possible genetic defects at an early stage. This argument can hardly be referred to as anything other than cynical in view of the fact that PGD is supposed to be used to prevent abortions.

On the other hand, this example illustrates more clearly than is usually possible the paradox of a development in medical technology that is based on overstepping these bounds: the errors and consequences of a procedure are to be mitigated or avoided by introducing a new method, whose long-term medical consequences are likewise hardly known and whose social consequences could be dramatic with regard to our perception of reproduction.

Most couples at risk of passing on a hereditary disease or a disposition to a disease to their children do not have a fertility problem. In this case, the women alone must undergo IVF and bear the associated burdens for the purpose of PGD. This exploitation of the female body as a guarantee for the health of the offspring is usually not addressed in the

Therefore, a demand was made at an early stage that embryos created with the help of ICSI be examined by means of preimplantation genetic diagnosis (PGD).
The figures show that PGD prevents neither prenatal diagnosis nor abortions and miscarriages. Moreover, the success rates of this procedure are low and the risks considerable. This is illustrated by the figures in a report published by the European Society for Human Reproduction and Embryology (ESHRE) in December 2000, which summarises the statistics of preimplantation genetic diagnoses conducted over the last seven years in sixteen European centres. Of the 565 couples treated due to a risk of monogenic hereditary disease, the rate of pregnancies that went beyond the 12th week was 16.5% per cycle with egg cell removal.

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probably not meet the demands of science, because they frequently have chromosomal and structural abnormalities. Consequently, scientists will insist on good quality embryos for (sophisticated) research purposes. However, it is these very embryos that infertile couples urgently need for themselves.

A central dilemma becomes evident. Doctors in the field of reproductive medicine who are also interested in embryo research are confronted with a conflict of interests. On the one hand, they are expected – and want – to help female patients. On the other hand, they also want to tap into a source of high-quality research embryos. Their interest in embryonic research affects the practice of reproductive medicine and thus also the women treated.

In stem cell research and the development of embryonic cell cultures, embryos are instrumentalised and commercialised, and destroyed for the benefit of third parties.

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**Embryonic stem cells: Embryos as a resource**

PGD is just a context for reproductive medicine, in which “surplus” embryos are produced. Even IVF makes embryos available for research in a convenient way, at least in instances where there is no legal restriction on the number of embryos produced.

Information on this issue is provided by data from the Human Fertilisation and Embryology Authority (HFEA) – an agency in England that regulates, monitors and documents the use of new reproduction technologies. The data show that, in 2002, the rate of treatment cycles with the transfer of two embryos was significantly higher in centres active in embryo research than in centres that do not conduct any embryo research. In contrast, the birth rate following IVF was lower in academic centres (21.5%) than in commercial centres (26.5%). However, the rate of cycles in which cryoconserved embryos were transferred was the same for both types of centre. In the centres in which more transfers with two embryos are conducted, it only follows that they also freeze more embryos. But this fact is not reflected in the rate of treatment cycles with cryoconserved embryos. This figure is approximately the same for both types of centre.16

So what happened to the frozen embryos? Does the use of embryos in research explain this phenomenon? Centres that offer only IVF and do not conduct embryo research freeze embryos suitable for development and future transfers; embryos that appear to be irregular are discarded. These embryos would

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The health-related consequences and moral costs of this strategy are externalised and distributed over the gender hierarchy. Women and children are the losers in this development in several ways: they bear the primary burden of the health risks, as a group, they have only marginal input in the political regulation of this development, and they are subjected to a process of standardisation they can hardly escape. Therefore, the increasing technicalisation of reproduction is associated not only with an increase in decision-making freedom, but also with an increase in expectations and indirect constraints.

2. Contexts of biomedical research: Science and economy

How can these developments in reproductive medicine be integrated in the broader context of scientific and social development, and what conclusions can we draw? It is obvious that embryo and stem cell research results in new goals and conflicts of interest in reproductive medicine. It is not just about help for specific couples in search of advice, but about gaining knowledge and developing new therapeutic options for future patients, meaning uninvolved third parties. The human embryo becomes a territory to be conquered, which research still has to free from the “taboo zone of irrationalism”. According to Hubert Markl, the last president of the Max Planck Society, science must continuously overstep bounds and break taboos in order to make progress. He said that that is how it has always been and progress is not possible any other way. The heroes of such an emphatic perception of science are historical figures – such as Edward Jenner, the British discoverer of vaccination for smallpox – who overcame not only social prejudice, but also sometimes ethical maxims in order to obtain new knowledge.
The introduction of new and untested methods is also promoted in that working at the forefront of scientific and medical progress and developing new methods benefits social status and results in economic profit (keyword: patents).

However, the consequences of a treatment are decisively influenced by the procedures, methods and techniques used. If the goal is to relieve a specific ailment, such as childlessness, we can either use IVF, psychotherapy or adoption. Each choice will have consequences for the participating individuals or society that are more or less severe. However, various alternatives and their consequences are not examined with the same intensity as the application of cell-biological or genetic concepts in reproduction.

We all know that this image no longer applies as much today and perhaps never did. It corresponds neither to the practices of modern research nor to current concepts of scientific development and knowledge cultivation. Scientific practice today is characterised not only by extreme specialisation and division of labour, but also by diverse external influences. In other words, it in no way follows a single, internal logic. Rather, the life sciences are happy to offer their services in order to justify their activity by motives that originate outside the field of science. Patents are just one of the keywords to be mentioned here. When science offers its services for economic interests and also accepts a reward for doing so, it risks losing its independence and autonomy. The integration of research in the exploitation of economic interests, which politics consistently promotes, has repercussions for the scientific system and scientific development – also in the field of reproductive medicine – which are certainly not sufficiently understood as of yet and much too underrepresented in the public awareness.

Moreover, reproductive medicine and the associated research is a professional sphere dominated by men. This shapes the field and the way in which infertility problems are handled. As Swedish andrologist Ulrik Kvist remarks, it was not the serious results concerning the safety of ICSI that led to the premature introduction of the method, but rather “male competitive behaviour” and the “competition for patients”. Both of these aspects also play a key role in the experimental testing of other methods in reproductive medicine. Not to disregard the stimulating effect of competition in general, but when it does not allow time or mental capacity to address the scientific foundations and medical consequences of such a method, it can be dangerous – at least for the children born after its application.
It is evident that technological progress and the education of the public about its prerequisites and consequences in no way form a unit. The old paradigm, according to which scientific progress is equated with social progress, could come to mean the exact opposite in connection with research that knows no bounds, as we are experiencing right now in the field of biomedical and reproductive medical research. I think we have long since reached the point in our scientific development where there is no longer any unity of social education and scientific/technical development. Rather, as social scientist Jörg Becker recently put it in an open letter to the German Research Association (DFG), “there has been technology without education for a long time now, and we even need education against technology.”

What we need is not so much innovation through science – we still need some time to cope with the innovations of recent years anyway – but the innovation of science.

3. Innovation: What do we want to know?

Starting points are provided by more recent scientific concepts, according to which science is no longer viewed as a process that illuminates an objective reality independently of the observer. Rather, the scientific systemisation and definition of the observed leads first to the attainment of a certain understanding of the observed phenomena and objects. Inseparable in this context are experimental techniques, scientific concepts and social discussions, in which the validity of respective interpretations is examined and strengthened. The perceptions of an illness or a suitable treatment method that are considered valid in this process are just as dependent on the material circumstances of the study object as they are on the social structure of the respective scientific field, or the respective methods and techniques used to describe and change it.

In other words, the nature of knowledge production influences the nature of the knowledge. Consequently, the question of who is involved in producing knowledge is very important. It influences which issues are considered relevant and which answers/methods adequate. It affects the definition of the subject of knowledge production, its experience horizon and relevance criteria. At present, many experiences obtained from the production of relevant knowledge are excluded, including those of women who have been successfully or unsuccessfully subjected to reproductive medicine, but also those for whom the method failed or left behind physical and psychological scars.

The expected consequences could be one of the criteria that would enable us to examine the range of options permanently produced by experimental science and filter out those whose consequences we can
justify. Science, which obtains its knowledge from experimental laboratory systems, is blind to consequences. The future users are the ones who can best assess the consequences from their various points of view. Therefore, the perspective of both the developer and the user is important. In other words, assessing and rating the consequences involves not only interdisciplinary academic exchange, but rather also the various points of view that stem from the different circumstances existing in practice.

This may mean no longer using or developing certain technologies because their consequences are foreseeable and not tolerable. I believe this is the case in the development of embryonic stem cells. However, setting limits in this way simultaneously frees up capacity to research alternatives. I am certain that abandoning research on embryonic stem cells will not lead to scientific stagnation, but will positively promote research on alternatives, meaning adult stem cells.

The criteria of sustainability, as were developed for handling natural resources, must also be applied in medicine. They are already used in some areas of traditional medical ethics, the first and foremost principle of which is “primum nil nocere”, or “do no harm”! The concept of resource conservation can be taken even further in today’s reproductive medicine. Just as it is sensible to conserve natural resources, it may also be sensible to avoid consuming our moral resources without necessity, as they are part of the cultural heritage of our society. Voluntarily abandoning research on human embryos would be true progress and emancipation from the apparent internal logic of research, which is itself under suspicion of becoming an ideology today. Society and, above all, science still must face this challenge of voluntary abandonment.

**Footnotes**

1. See the German IVF registers for 1999 and 2000 for these and the following figures.
7. In the Belgian population of 1,082 children conceived by ICSI, 10 hereditary and 18 newly developed chromosome abnormalities were found, which corresponds to a rate of 0.9% hereditary and 1.7% new chromosome anomalies. Cf. Bonduelle, M., Joris, H., Hofmans, K., Liebaers, I., Van Steirteghem, A., 1998, Mental development of 201 ICSI children at 2 years of age, The Lancet, 351/9, 115. Cf. also Page, D.C., Silber, S., Brown, L.G., 1999, Men with infertility caused by AZFc deletion can produce sons by intracytoplasmic sperm injection, but are likely to transmit the deletion and infertility, Human Reproduction, 14(7): 1722-1726.
9. While the German study from Lübeck found a 1.3-fold increase in the rate of birth defects after application of ICSI, an Australian study found that the risk of birth defects after ICSI doubled as compared to children conceived naturally. Hansen, M., Kurinczuk, J.J., Bower, C., Webb, S., 2002, The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilization, The New England Journal of Medicine 346 (10): 725-730.


18 Frankfurter Allgemeine Zeitung, 1.11.2001.
Open discussion with women politicians

Aspects of reproductive medicine and genetic engineering as they relate to women’s policy

Summarised by Eva Schindele

What aspects of genetic and reproductive technologies are relevant to women’s policy and what role do they play in the public debate? How are women’s issues addressed in the respective debates conducted within the parliamentary parties? How can the standpoint of women’s policy be strengthened in the public debate? In order to discuss these questions, ReproKult initiated an open discussion between women politicians and conference participants. We invited members from all the political parties in the German Bundestag. They spoke with some 200 women, many of whom deal in their daily work with the impact medicine is already having on women today. The ninety-minute discussion is documented here in condensed form.

The following were forced to cancel at short notice due to internal party voting concerning the dispatch of German troops to Afghanistan: Helga Kühn-Mengel MdB, SPD (member of the Law and Ethics of Modern Medicine study commission; representative for the disabled in the SPD parliamentary party) and Andrea Fischer MdB, Alliance 90/Greens (head of her party’s Genetic Engineering Committee)

The following participated in the panel discussion:
Prof. Dr. Maria Böhmer MdB, CDU Christian Democratic Union (Deputy Party Chairwoman)
Dr. Irmgard Schwaetzer MdB, FDP Free Democratic Party (Sociopolitical Party Spokeswoman)
Petra Bläss MdB, PDS Party of Democratic Socialism (Vice President of the German Bundestag)
Ulrike Hauffe, ReproKult – Frauen Forum Fortpflanzungsmedizin (Bremen State Commissioner for Women)
Moderator: Evamaria Miner.
Moderator: Ms. Schwaetzer, your party considers the Embryo Protection Act to be too restrictive. You see great opportunities in embryonic stem cell research and therefore want to allow research on embryos up to the 14th day after fertilisation. In other words, you believe the embryo is not worthy of protection?

Irmgard Schwaetzer: Allow me to make a preliminary remark. I feel that the role of women comes up much too short in the discussion surrounding modern biotechnologies. Therefore, I expressly welcome the initiative of ReproKult. The FDP wants to allow embryonic stem cell research to a very clearly defined extent, in order to at least open up the chance of curing diseases that are incurable today. And I deliberately use the word chance! We do not know the degree to which this will be possible. But this research must be approved to a limited degree just to give people hope. And where do the embryonic stem cells come from anyway, when there are not supposed to be any surplus embryos in Germany according to the Embryo Protection Act? But you all know they exist! They exist because couples change their minds after fertilisation of the egg cell and decide not have the embryo implanted. That means that, if research on embryos is permitted, fertilised egg cells need not be produced separately, as existing surplus embryos can be used. Because only a few stem cells are needed for research, the demand is thus met. The FDP would never agree to allowing fertilised egg cells to be produced for research purposes only.

Moderator: The FDP also supports preimplantation genetic diagnosis, which has also been banned in Germany up to now by the Embryo Protection Act.

Irmgard Schwaetzer: In our opinion, preimplantation genetic diagnosis should be permitted, but only within very strict limits. Specifically, only for couples with genetic difficulties or for those whose desire to have children cannot be fulfilled naturally due to repeated miscarriages. Incidentally, I do not see any contradiction here in reference to a woman’s self-determination. However, I do believe that a woman’s right to self-determination is weakened in another area of medicine, namely prenatal diagnosis. This issue is not discussed publicly at all. Prenatal diagnosis has increased dramatically in recent years in a way we never would have believed. It has increased so much because it is not legally regulated. Various interests collide when it comes to prenatal diagnosis: gynaecologists do not want to be legally accountable to a woman they treated if she should give birth to a disabled child. On the other hand, a pregnant woman does not want to omit any tests that could possibly promote her wish to have a healthy child. In a hearing on prenatal diagnosis in the Bundestag Committee for Family Affairs, Senior Citizens, Women and Youth, all the experts confirmed that prenatal diagnosis has dramatically changed the perception of pregnancy: a time of hope has become a time of uncertainty. I think that’s a problem and I am therefore of the opinion that prenatal diagnosis must at least be given a legal framework in the form of a Pregnancy Care Act. Only in this way can this unfavourable development be curbed.
Moderator: Ms. Bläss, the PDS also wants to amend the Embryo Protection Act, but to increase the level of protection. You largely agree with Alliance 90/Greens in this context. Your party says that the inviolability of the body must take precedence over research and science. You want to apply this inviolability even to the fertilised egg cell. This hinders scientists, who say they want to use embryonic stem cells to manufacture, produce and research medicines, tissue and treatments for incurable diseases. After all, being healthy is a legitimate concern people have.

Petra Bläss: Those are a lot of questions on a complex subject that is a challenge to every woman and man in politics, regardless of party affiliation. These questions are not easy to answer by means of pro and con arguments. I myself was politically socialised during the fight against Article 218 and consider myself to be a layman on the subject of biomedicine, who is in search of a dialogue. Although the questions posed back then were already highly complex, the question of the freedom, restriction and responsibility of science in reference to modern biotechnologies is of an entirely new dimension. The PDS wants to defend the existing Embryo Protection Act. We are very sceptical of preimplantation genetic diagnosis and the sceptical voices are also in the majority when it comes to embryonic stem cell research. However, we cannot make progress by merely maintaining a defensive position. We are searching for alternatives. It has become clear in discussions with scientists that the opportunities for using adult stem cells for therapy need to be investigated more thoroughly.

Petra Bläss: There are three subjects that are mentioned repeatedly in today’s conference discussions: suitability, necessity and commensurateness. In my opinion, preimplantation genetic diagnosis and embryonic stem cell technology must be assessed according to these criteria in order to then set or remove political barriers depending on the result. Allow me to say something about a woman’s self-determination in this regard. One prerequisite for self-determination is to be informed. We recently held a hearing on prenatal diagnosis and preimplantation genetic diagnosis in the Committee for Family Affairs, Senior Citizens, Women and Youth. All women from the field of practice demanded that we politicians significantly improve the range of counselling offers. For example, they demanded that general pregnancy care and special counselling programmes for prenatal diagnostics not be handled by the same source. I see a need for political action here. I take the desire of affected couples to have a healthy child very seriously. Nonetheless, I also want to add the criteria of necessity and commensurateness to the decision-making process. I also take the warnings coming particularly from the disabled persons movement very seriously; as we all know, they have been involved in the subject for many years now. The question of eugenic selection was also part of the debate on Article 218 and the embryopathic indication. I fear that the approval of preimplantation genetic diagnosis will further intensify this trend.
It is not just about the status of the embryo, the individual woman or the parents. These decisions affect our lives, our image of Mankind and the future development of our society.

**Moderator:** What does politics have to decide, and what is it capable of deciding? Or do facts emerge beforehand to which politics can only react? Ms. Böhmer, you have spoken out against importing embryonic stem cells. Not everyone in your party thinks the way you do. For example, former Federal Minister of Health Horst Seehofer can very well imagine the use of surplus embryos for research, and the former pastor Peter Hintze does not want to protect embryos until the fourteenth day. Does a uniform foundation of values exist any more in your party, and how do the new biotechnologies mix with the conservative Christian view of women and family?

**Maria Böhmer:** I am not stepping on anyone’s toes when I say that everyone is very lost in thought about this point. And I also claim the right to reflect on it. Research in the field of biotechnology and genetic engineering is in great flux and we are confronted with new research results almost every day. I believe that, as a Christian Democratic Union, meaning the CDU (Christian Democratic Union) and CSU (Christian Social Union) alike, we are in a special situation, because the “C” in our party name naturally also means that we have particular obligations. But that does not make it easier to reach a decision! We struggle for answers that have a broad impact. It is not just about the status of the embryo, the individual woman or the parents. These decisions affect our lives, our image of Mankind and the future development of our society. I believe I am not going too far when I say that they even affect the development of Mankind.

**Moderator:** Don’t women also have a different view of these new technologies?

**Maria Böhmer:** I am very happy that we women are getting more involved in this discussion. No subject in the field of biotechnology and genetic engineering affects women as much as the questions relating to reproductive medicine, keywords being preimplantation genetic diagnosis and stem cell research. After all, we cannot talk about embryonic stem cells or embryos today and ignore where they come from; or, to put it as clearly as possible, we women are the raw material suppliers in both instances. How does this fact affect a woman’s right to self-determination? We have to view embryonic stem cell research and preimplantation genetic diagnosis separately in this context. The most obvious aspect of preimplantation diagnosis is the image of opening up a floodgate. The rapid spread of prenatal diagnosis in just a few years shows where things could head if preimplantation genetic diagnosis is approved in Germany. Prenatal diagnosis has gone from being a method applied in exceptional cases to a screening procedure. Pregnant women are reporting having difficulty refusing prenatal diagnosis. Women end up in a situation where their right to self-determination is questioned. Outside Germany, especially in the USA, preimplantation genetic diagnosis is already being used to increase the success rate of IVF. Due to these experiences, I do indeed have considerable doubts as to whether limits can be set by law or in some other mechanism. People in the field continuously mention figures like “80 to 100 couples” they want to
help have a healthy child by means of pre-implantation genetic diagnosis. There is a tendency to use small numbers to make the decision seem, shall we say, more attractive. But how are we to decide which disabilities are serious for the parents and which are not? Take the breast cancer gene for example, which can now be identified before birth or in the embryo in a petri dish. British and now also German doctors report that parents are asking for the breast cancer gene test for their future child. We do not need to explain what this means. No one knows whether the disease will occur or when. We end up making a decision in favour of life or death, also as a form of selection.

**Moderator:** Proponents argue that these prenatal tests strengthen a woman’s right to self-determination.

**Maria Böhmer:** I really doubt that. I fear that these procedures put women under increasing pressure to have only healthy children any more. Unfortunately, we have also had to learn this lesson the hard way in connection with prenatal diagnosis. In my opinion, this situation no longer has anything to do with self-determination. On the contrary: it reduces the number of options for self-determination. Therefore, we must conduct this discussion very offensively. The practice of prenatal diagnosis, including late-term abortions, must be subjected to critical examination. The Union has formulated a proposal with the aim of improving counselling prior to prenatal diagnosis. A woman should not only receive medical counselling prior to prenatal diagnosis, but should also be informed about what she is getting into once she agrees to such a procedure. In addition to this issue, there is also the problem of medical liability. We have to evaluate what a development like this means for our decision-making freedom. This also applies to importing human embryonic stem cells. And I ask the same question here: what does it mean for women when it one day becomes possible to cultivate replacement tissue from embryonic stem cells? Sick people have great hope that it will become a reality, even though scientists today say that it will still take another ten or twenty years. It cannot be accomplished with what we know today without using therapeutic cloning to prevent rejection reactions. In other words, science needs egg cells, and not ten or twenty, but rather thousands, if this method is to transition into the application phase. Where are these egg cells supposed to come from? Under constitutional law, this issue deals with more than just the question of human dignity and the beginning of protectable human life. There is also a rule of constitutional law which says that legislators must always consider the impact of a law on the value system represented by our constitution.

**Moderator:** Ms. Hauffe, do you think the interests of women are in conflict here? Some feel put under pressure to donate egg cells, while others want to finance their university studies via egg cell donation – at least that is how it is today already in the USA. Doesn’t that make a discussion among feminists very difficult?

**Ulrike Hauffe:** The debate that feminists have been conducting for some time now addresses the question of how we define self-determination in the age of biotechnology. The old feminist understanding of self-determination was
always rooted in the rejection of the power that men or the state wanted to have over women. Self-determination in this context is a political term. The term self-determination as it is frequently used by women today, and also functionalised by the field of medicine, has the character of a vending machine. In other words: “Come to me all who are heavily laden and burdened, and I will refresh you with my vending machine!” Whether or not this “refreshment” – as an offer of help – is associated with ethical problems is irrelevant. A gynaecologist today sees it as her job to support a woman throughout her entire life. But to do, she has to gain our partnership. The term self-determination is a good argument for making us believe that we can shape our lives more effectively with her medical help. It starts with the pill and continues with reproductive medicine and hormones during menopause. Medicine appears to “allow” women to adapt to a social reality that is based on the standard male biography. But women do not have the same opportunity as men to simultaneously have a career and children under a government that does so little for childcare. As a result, women are increasingly postponing having children to a later date, only to discover that they can no longer get pregnant without the help of reproductive medicine. So, the gynaecology “vending machine” is a good way to cover up a scandal in the social system. Medicine becomes the servant of this desolate initial situation; it becomes the repairman of social issues. Preimplantation genetic diagnosis must be discussed against this backdrop, as must the high acceptance of prenatal diagnosis among women.

**Moderator:** You mean that the field of gynaecology shapes the lives of women more than women want to admit?

**Ulrike Hauffe:** The groundwork for modern biotechnologies was laid when our society decided that the field of gynaecology is responsible for monitoring a healthy female condition, namely pregnancy. Incidentally, this is primarily the case in Germany, and not in the Netherlands or Sweden, for example, where midwives play a more central role in the support of pregnant women. In other words, an institution that actually exists for the purpose of healing is supposed to accompany a woman through a healthy condition. This fact is linked to a message: something that has to be healed, must first be defined as ill. The relationship between a doctor and a woman, who is automatically referred to as the “patient”, is characterised by inequality in scientific knowledge, but also in the definition of the relationship. “You, woman, are in a risky condition!” All of this is illustrated by the German “pregnancy card”, which became established very rapidly. In the space of twenty-five years, it went from being a flimsy piece of paper to an entire brochure, and not one that informs, but one that stokes a woman’s fears. We have nearly eighty percent risk pregnancies in Germany today because of the fifty-eight checkmarks listed in the pregnancy card as potential risks.

 reassurance
tive to the desire to control everything. After all, we have developed a sophisticated image of women: we are good-looking, in a career, the best mothers, politically active, sexually attractive, etc. But we can only afford to be all these things if we control our condition, or let it be controlled by the field of medicine. We have to have “healthy” children that can adapt to everyday life. Is that self-determination? And does this type of pregnancy care strengthen the competence of women? No – but this kind of medicine has got women to the point where they themselves are demanding biotechnologies. In order to reinforce the personal competence of women, structures must be changed – above all the guidelines for maternity. They must focus on the support of pregnant women, not on turning them into medical patients.

**Moderator:** I would now like to invite the audience to get involved in the discussion...

**Conference participant:** Just another remark about research. I am a molecular biologist and I dare to predict that if scientists are permitted to use stem cells and egg cells, they will not rest until they know everything a stem cell knows and until they can technologically control everything a stem cell can do. The question is how to create a vital infant from a stem cell. Once the stem cell has 20, 30 or 50 years of science under its belt, individual women with their egg cells and uteri will no longer be needed at all. And for me, this leads to the question of whether this dimension is recognised at all in politics? How is it considered and what social consequences do you foresee by freeing women from the biological reproduction of mankind?

**Conference participant:** I am a midwife and would like to say something about maternity guidelines and prenatal diagnosis. The maternity guidelines developed by the Federal Committee of Doctors and Statutory Health Insurance Funds oblige gynaecologists to conduct ultrasound examinations, for example, which are most certainly used to identify defects. Only in that way can they bill pregnancy care at all. Women are not obliged to accept all the medical service offered, but most women don’t know that – or are afraid to say no. Usually, they are also not given the corresponding information.
Anyone who opts for PGD must also endure the stress of IVF. In doing so, they also put themselves into the hands of the doctors who later analyse the embryos in the petri dish and decide which one should be implanted and which should not. Consequently have the unborn child prenatally diagnosed, despite the previous preimplantation genetic diagnosis. I must say it is unfortunate that the procedure still leads to an abortion in numerous cases, meaning that preimplantation genetic diagnosis does not prevent abortions. I believe the question is: how can we help and support women who are expecting a disabled child?

Conference participant: I am a lawyer and I want to agree with Ms. Böhmer’s statement that what is going on cannot be stopped. The debate we had about abortion makes it clear that it is impossible. Actually, the embryopathic indication has been done away with and the medical indication is only permitted when the mother’s life is endangered. However, this situation is now being twisted around to mean that the psychological stress caused by continuing a pregnancy that produces a disabled child is life-threatening. This example shows how people can get around these restrictions. All you have to do is reinterpret them. I dare to maintain that even if PGD is approved for very limited cases, people will still find ways to modify the interpretation and expand the limits.

Irmgard Schwaetzer: It seems to me that these discussions always target preimplantation genetic diagnosis and fail to establish the link to prenatal diagnosis. The FDP party is preparing a Pregnancy Care Act in which criteria for the application of prenatal diagnosis are to be defined. Prenatal diagnosis is not to be conducted by the attending gynaecologist, but rather only in special centres. Currently, the application of prenatal diagnosis is only decided between the doctor and the pregnant woman. There are no legal regulations. That’s why it has got so out of control. In contrast, there are to be precise legal regulations for PGD, and it will therefore remain limited. Incidentally, the elimination of the disabled has been going on for a long time using prenatal diagnosis, and it makes me so furious that a child diagnosed as disabled can still be aborted in the 20th week. But female critics of preimplantation diagnosis do not want to admit that PGD could spare women the very harrowing experience of a late-term abortion.

Maria Böhmer: Anyone who opts for PGD – and they are usually women who could have children the natural way – must also endure the stress of IVF. In doing so, they also put themselves into the hands of the doctors who later analyse the embryos in the petri dish and decide which one should be implanted and which should not. That is not self-determination. Moreover, women are still advised to sub-
**Moderator:** For the final round, I would like to direct a question at our panel guests: What can politics regulate? What must politics regulate? What influences it? And what have you learned from this discussion?

**Maria Böhmer:** I got into politics because I said to myself that I want to get involved in the issues. The only thing I can say to all of you out there is: do the same! After all, when I am in a debate in Parliament, I need not only the view of researchers, but also the voice of women who are often too quiet to be heard in Parliament... About the legal regulations: I believe we need international agreements to regulate human stem cell research. We will no longer be able to regulate this issue just nationally. In addition, the counselling programmes for prenatal diagnosis need to be regulated. Effective counselling must not dominate women, but rather help them assess medical information, which is often determined by liability concerns, in order to then arrive at an independent decision.

**Irmgard Schwaetzer:** I think it’s good this discussion led to a kind of consensus about the fact that pregnancy care needs new regulations and that the use of prenatal diagnosis must be subjected to legal limits. Furthermore, I believe that our Embryo Protection Act is a good one and should remain untouched. We want to regulate stem cell research in a separate act.

**Petra Bläss:** A woman’s right to self-determination must not be instrumentalised and abused. The term is currently being exploited by all sides involved. Therefore, let us speak of personal competence, as Ms. Hauffe suggested. The participation of women on all decision-making levels is also important. It is scandalous that women are still underrepresented in the entire debate surrounding reproductive medicine.

**Ulrike Hauffe:** The subject of counselling has come up several times in this discussion. I would like to warn everyone against letting it become the starting point for a solution. In the public debate, counselling often only serves to legitimise the various methods. No one considers whether the counselling is independent of the suppliers of prenatal diagnosis, for example, and how professional it is in terms of strengthening the competence of women. I would like to see the debate on this issue be brought more into the general public. The municipalities also play a big part in this context. We women have a tendency to be well-informed about the issues, but we have to establish more suitable structures for conveying our good messages to the public and ultimately getting the parliamentary majority on our side.
Where in this continuum of body-related technologies do women themselves draw the line as regards what appears important, sensible or justifiable to them, and where this is not (or no longer) the case? What degree of “planning” and quantitative or qualitative “feasibility” of children or “power of disposition” over life do they accept and what will they not (or no longer) accept? What do they (still) regard as self-determination and what do they not (or no longer)? What is the role of medicine, such as prenatal diagnosis? From the subjective point of view, is its utilisation “self-determination”, a “selection consensus”, or an attempt, based on false premises, to cope with the difficulties and anxieties involved in a life with children?

Starting point

Self-determination can only be discussed in the social context. This context encompasses the history of reproductive technologies that made the foundations of human life available to common-sense planning. This history ranges from old forms of obstetrics and medical techniques for abortion, condoms and the pill, all the way to artificial insemination and preimplantation genetic diagnosis. Today, it would seem to have reached a point where the freedom gained by utilising these inventions is turning into new constraints, just like the “dialectics of enlightenment” describe the turning of civilisation into barbarism. Where in this continuum of body-related technologies do women themselves draw the line as regards what appears important, sensible or justifiable to them, and where this is not (or no longer) the case? What degree of “planning” and quantitative or qualitative “feasibility” of children or “power of disposition” over life do they accept and what will they not (or no longer) accept? What do they (still) regard as self-determination and what do they not (or no longer)? What is the role of medicine, such as prenatal diagnosis? From the subjective point of view, is its utilisation “self-determination”, a “selection consensus”, or an attempt, based on false premises, to cope with the difficulties and anxieties involved in a life with children?
The plannability myth – Female self-determination through medicalisation

It is only possible to propose alternatives when provided with the answers to these questions, and a knowledge of what a certain type of behaviour (in this case, the advocacy and utilisation of prenatal diagnosis) is “good for” from a subjective point of view, meaning why it has subjectively become “necessary” and why it is believed to offer greater self-determination. Based on a special analysis of the “frauen leben” study (commissioned by the BZgA, 1997-2000), I would like to present the subjective notions that women in Germany associate with “plannability” and “self-determination”. The questions analysed for this purpose were those on attitudes towards avoiding pregnancy, the plannability of children in general, plannability in terms of gender and in relation to the exclusion of a potential disability.

Subjective attitudes of women towards plannability and self-determination

The general attitude towards plannability and self-determination takes two different directions, depending on whether the (accepted) avoidance of pregnancy or the (more controversial) planning of a child is involved. Women look for criteria to justify where to draw the line. It was generally agreed that women should be allowed to plan insofar as they may not be forced to continue an unwanted pregnancy – this is the absolute minimum degree of planning, and self-determination is firmly demanded in this context. Planning of the gender of the child, and also the exclusion of unwanted characteristics – the women came up with examples such as the colour of the hair or eyes, personality traits – was unanimously rejected, and there was also no talk of self-determination in this context. In this way, women make a major distinction between the termination of an unwanted pregnancy and the wanting and making of a specific child.

Generally speaking, “rough” planning was accepted for planning when a child was to arrive, whereas “100% timing” (such as specifying the birth month) was not. Planning in the sense of establishing favourable conditions for children to grow up in was accepted, the actual time of the pregnancy then being left to chance. One criterion that was repeatedly mentioned was: Can the woman manage to give the child what it needs? Can planning – whatever concrete form it may take – help her manage it?

Attitudes towards planning in general are full of tension: women feel pressured to plan in order to safeguard their own biography, but they also define limits. There are numerous, partly contradictory positions between the self-determination demanded on all sides and the feasibility rejected on all sides. On the one hand, there was strong pressure and a need to plan, the reasons being the responsibility for the (optimum) shaping of the conditions in which children are to grow up, the high demands imposed on the mother, the unreliability of partners and the welfare of the family. The more unfavourable the external social situation for mothers, and the more a child was perceived as being a risk, the more emphasis women placed on the need to safeguard themselves by planning.
On the other hand, there were also limits to planning. Some were of a technical nature ("Even contraception can fail") or of a biographical kind ("How are you supposed to plan if there’s no such thing as the right time in life to have a child?"). The third line drawn was based on the argument: “If children are a natural thing and can arrive at any time, and if you have faith that you’ll manage to cope somehow, there’s no need to plan”. The fourth limit was of an ethical nature: the act of planning automatically assumes that the planned event will actually occur. If it doesn’t, the reaction is disappointment and frustration – events that occur unplanned or differently than planned are rejected. In other words, children who don’t arrive at the planned time, who don’t have the desired gender, etc. are rejected. However, putting the existence and appearance of the child at our disposal, and denying the relationship in the event of deviation from what was wanted, violates the ethics of the “non-disposability of human life” (Habermas).

In terms of attitudes towards plannability and feasibility, there are differences between Eastern and Western Germany and differences between women with different levels of education. Women in Leipzig were more pragmatic regarding the use of technologies for planning their lives. As confirmed by other studies, they also avail themselves of “paternalistic” medical care without seeing it as external control. However, they also appeared to be more willing to accept a disabled child if it was simply “too late”. Women with less schooling, especially those from the Freiburg-Land rural district, most clearly accepted children with disabilities and most unequivocally rejected the use of medical feasibility technologies in this context. Women from Freiburg who had spent more time in education likewise rejected prenatal diagnosis, but mainly considered life with a disabled child from the point of view of themselves being totally overtaxed.

Women expect medicine to contribute to their self-determination in that it “can tell” them to what extent a child will be disabled, thereby helping them find an answer to an agonising question they cannot decide for themselves. In this context, many women are only inadequately informed about the capabilities and limits of modern medicine. The most urgent questions regarding planning and self-determination related to the decision for or against terminating a pregnancy following prenatal diagnosis. Almost all women felt helpless and overtaxed and wanted very personal, case-by-case decisions. Medical methods (especially imaging methods that “look inside” the body) were seen as having the ability to “determine” the existence of damage and “tell” the woman not only whether, but also to what extent the child was damaged or whether it was “perfectly healthy”, and thus whether there was "any point" in continuing the pregnancy to full term. The prognostically clear-cut verdict expected of medicine as regards the later health of the child became the decisive criterion that would relieve the women from the agony of having to decide for or against an abortion: the pregnancy would be terminated if medicine said things would be very bad. The “knowledge to be able to make a decision” was rated as being neutral and good.
Although the level of information of the respondents and their expectations regarding the availability and effectiveness of diagnostic options differed, it can generally be noted that there was a lack of differentiation between check-up examinations, early detection and specific diagnosis, as well as between statements regarding the state of health and dispositions. Some women also understood “disability” to mean disabilities that cannot be diagnosed at all.

Focusing on the end-point of the diagnostic process (decision for or against an abortion) excludes the possibilities for making decisions in advance and during the diagnostic procedure. Only a few women addressed the act of self-determination, meaning the conscious decision for knowledge or no knowledge, and only little attention was paid to new constraints arising from knowledge.

The social and autobiographical fears of not being able to cope with life with a child are magnified enormously when projected to the idea of living with a disabled child. Medicine is expected to alleviate these fears. In the context of prenatal diagnosis, women spoke of great pressure to achieve security through planning, on the one hand, but also of the limits to plannability, on the other. The pressure was, however, predominant, its main cause being the fact that disability is portrayed in drastic terms and life with a disabled child is regarded as being a catastrophe for all concerned. All women’s fears about a life with children were projected in accentuated form onto living with a disabled child: children need time and attention – disabled children need every minute, time and attention for their entire lives and leave no opportunity for the mother to live her own life. It is difficult to reconcile children and gainful employment – a disabled child forces a woman to give up her occupation. Children can be a burden on the partner and the family – if a child is disabled, the father flees and the family falls apart, etc. The fear of the “incredibly great” demands and, above all, of isolation become enormous. The pressure on women to plan should not be confused with a “selection consensus”. It is much more a question of whether the woman – and she alone is the one who always remains responsible when everyone else and society leave her holding the baby – can manage to give the child what it needs. In not one single interview (!) were options such as family support, external assistance or outside accommodation rated positively: boarding schools or homes were unanimously and strictly rejected as offloading the child.

However, limits to plannability were also mentioned: there was always “a degree of uncertainty”, and diagnosis was no guarantee of health. There were good reasons for rejecting knowledge and dispensing with diagnosis. Disabilities also had positive aspects. People should accept their fate or their job in life and not want a perfect child.
To sum up: in the continuum of reproductive technologies from contraception to preimplantation genetic diagnosis, the majority of women drew the line in that they spoke differently about the pressure of continuing an unwanted pregnancy than about the planning and “designing” of a child. On the one hand, they were under pressure to plan. On the other hand, they saw plannability as being a myth. The pressure increased when it came to the question of a potentially disabled child.

Medical diagnosis appears in two ways: as a lifeline in societally produced distress and as a help for self-determination. First, it gives certainty as to whether there is any reason for the social and autobiographical fears of being unable to cope with life with a child, which are projected onto the question of disability. And, in case of doubt, it relieves the agonising burden of reaching a decision, in that it shows how bad the future would be for all concerned. Only: medicine is not really capable of either one or the other. The belief that it can provide this certainty is based on a combination of incorrect information and the desire to alleviate unbearable fears.

The women spoke little of the social consequences of prenatal diagnosis and external control by doctors or the pharmaceutical industry. This is too abstract for one thing, and, for another, whenever a woman takes up an offer of medicalisation, she says, “I want it that way”, “Medicine can do that,” and “Knowledge is a good thing”. Taking this seriously, new approaches could include, for example, the demystification of medicine, a division into medical and social fears and the alleviation of social fears by means of social measures, as well as a separation of the discussions regarding the prevention of pregnancy and the planning of a child.

It is unclear whether the women interviewed would behave differently than they said if they were to find themselves in the situation of being pregnant (late in life). Nonetheless, there should be more discussions with women who are not pregnant, and attention should focus more on questions of shaping a life with children in general and not only on prenatal diagnosis. Only then can the context be established and a different answer be given to fears. This is because prenatal diagnosis mainly lives on the promise of the control and feasibility of health as a way of alleviating social fears and the agony of making a decision. It thrives on the fateful cycle wherein medicine fuels social fears, only to proffer itself as the answer to these fears and an aid to self-determination.

Footnotes

1 This special analysis is published by the BZgA. It is currently available for downloading from the Internet under “Studien” at www.bzga.de.

2 Conducted by the Sozialwissenschaftliches Frauenforschungsinstitut, Freiburg (C. Helfferich, M. Engelhardt, A. Heneka), the Nordig-Institut für Gesundheitsforschung, Hamburg (W. Karmaus, H. Klindworth, M. Küppers) and the Forschungsstelle Partner- und Sozialforschung, Leipzig (K. Starke, K. Weller). Design: (1) Questionnaire survey of 1,468 women in three regions (Hamburg, Freiburg, Leipzig) from a regional population sample of 20 to 44 year-old women; (2) Qualitative, biographical survey of a sub-sample of 101 women from Leipzig and Freiburg, contrasting sample composition. The results are available from the BZgA.
Another message of the pill – Self-determination through the medicalisation of our bodies?

Eva Schindele | Silke Koppermann

Self-determination was one of the central concepts of the new women’s movement that emerged in Western Germany in connection with the right to abortion without punishment. “My stomach belongs to me” was one of the demands in those days, making a plea against motherhood and for women to have to right to dispose freely of their own bodies. The pill, which was known as the “wanted-child pill” in East Germany and the “anti-baby pill” in West Germany, has become a symbol for self-determination and life planning.

Self-determination thus focused mainly on the female body and its reproductive capacities from the outset. Self-determination was the conceptual opposite to Sigmund Freud’s “biology as the female destiny”. As such, it tended to suppress the social and political context of female designs for life, but this collective demand had to be enforced against a patriarchally structured, repressive state and certainly had an emancipatory character as a result. The concept of self-determination has undergone a change in meaning since that time. Today, it means women managing their own lives individually. Does this concept perhaps even result in the issue being depoliticised? We would like to pursue this thesis, taking the pill as our example.

“The pill” shaped women’s self-image

The pill came out on the market in 1960, since which time women’s designs for life have become more varied (at least in the industrial nations). Life planning and self-determination are often used synonymously, with liberation from the traditional female role being regarded as an achievement of hormonal contraception. Even before the introduction of the pill, there were ways and means of preventing conception, such as the condom, although they had to be used by men and referred directly to the sex act. On the other hand, the pill gave women more power. Family planning now lay in their hands! For women, the connection between sex and reproduction now only existed in abstract form in the swallowing of a pill, no longer playing a role in sexual practice. Women learned to take precautions, swallowing the pill even if no sex partner was in sight. But there are two sides to the pill. Only gradually is the message behind the message becoming clear. Hormonal contraception paved the way for modern reproductive technologies and the medicalisation of women.

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food supplement. The pill is a chemically manufactured preparation that intervenes in the physiology of a healthy woman and manipulates her: it prevents ovulation by making the body believe that it is constantly pregnant. As a long-term treatment, it makes medical monitoring necessary and socially acceptable, since it promises women independence and self-determination in return.

Nowadays, women also apply this model to other spheres of life. “Acclimatisation to the pill was a symbolic pioneering feat,” writes historian Barbara Duden. The pill initiated the medicalisation of women.

**Healthy patient and hormonal styling**

The pill turned contraception into a medical problem and healthy women into patients. The consequence: a boom in gynaecology (the number of gynaecologists has tripled since 1968) and a flourishing pharmaceutical industry.

Today, gynaecology and the pharmaceutical industry promise “hormonal styling” and base their advertising on the image of the modern, emancipated woman who wants to be liberated from the “burdens of biology” with their help. This relates to contraception as well as to the trend towards preferably putting a complete stop to menstruation, which some women may find “bothersome”, and to the managing of phases of upheaval in a woman’s life, such as puberty, pregnancy and menopause.

This is an offer that works: women today “believe” that they need gynaecology to be able to take their lives into their own hands. So, it is not surprising that gynaecology becomes a dominant factor, especially in those phases of life where women see their autonomy as being threatened by physical processes (such as in pregnancy, which is such a process controlled by “Nature” and puts self-determination in its place). In this way, medicine succeeded in redefining both pregnancy and giving birth as risky conditions requiring constant monitoring by a gynaecologist. These days, many pregnant women live from one check-up appointment to the next. They mistrust their body signs and prefer to rely on the measurements their gynaecologist makes. This weakens self-competence, is distressing and creates anxiety. Consequently, a strange transformation takes place in the doctor’s consulting room: the woman’s competence is restricted (also by the woman herself), while that of medicine points the way. This often spoils the joy of pregnancy. Roughly 70% of women are classified as at-risk pregnancies today. Women overestimate the “risk” of having a disabled child and, at the same time, feel (socially) obliged to give birth to a healthy child – also on the condition that they abort a disabled child even at a late stage (meaning between the 20th and 22nd weeks) with the help of artificially induced delivery.

**Reproductive medicine as a social strategy**

The pill was celebrated as a way of separating sex and reproduction. Its message was that women could plan their children the way that fit best into their lives. This view ignores the fact that the pill may be capable of preventing children, but it cannot create them on demand. Reproductive medicine has also had little effect in changing this fact. Despite the enormous medical effort and the strain, especially on the woman, the success rates tend to be fairly modest: according to a study by the Federal Ministry of Research, an average of only 30% of women take a child home and 10 to 15% per treatment cycle. In other words, IVF treatment fails to result in a child in two-thirds of all couples.
Reproductive medicine also flies the flag of autonomous life planning and self-determination. Although laboratory insemination is usually paid for by the health service, since it “cures” women suffering from the “disease” of infertility, this conceals the fact that reproductive medicine has in the meantime become a social technology that seemingly enables women to plan the arrival of their child better and more in keeping with social conditions.

“Modern” women are expected to plan their lives on the basis of the standard male biography (and they also expect it of themselves). Accordingly, many women are postponing having children until later and later. They ignore the fact that the biological clock is ticking away and hope to be able to trick their “biology” by technical means, if needs be. As a result, there is often a space of just a few months between intentional and unintentional childlessness. Many women who were accustomed to practising contraception by planning are then confronted with the realisation that children cannot be planned promptly. But who advises them to be patient? Reproductive medicine then very quickly offers assistance, helping unintentionally childless women to obtain their alleged “right to a child of their own”. This is self-determination in the year 2001 – it denies that these interventions of reproductive medicine quite simply undermine female integrity and self-determination. Also, women allow themselves to be pumped full of hormones and let themselves be turned into cogs in the industrial insemination machine. They are willing to accept the goals of reproductive medicine, which (often) “subordinate the well-being of the treated women to other interests”.

In the opinion of Bremen’s Commissioner for Women’s Affairs and psychologist Ulrike Hauffe, women’s bodies are being used to repair a societal supply scandal that is given a medical label and costs the social insurance system billions. There are certainly various factors leading to intentional or unintentional childlessness. Nevertheless, reference data from other European countries suggest that there is a link between the reconcilability of career and family and the willingness to have children. Would it not be better to create a more child-friendly climate from the outset, enabling a woman even to have a child in her younger years? Finally, social policy still ignores young women’s concerns to justify their actions if, despite wanting a child, they fail to exhaust all the technical possibilities. Since the advent of the ICSI method, where a single sperm cell, even an immature one, suffices to fertilise an egg cell, male infertility has, de facto, become a thing of the past. By undergoing IVF-ICSI treatment, a fertile woman compensates for the deficit in her partner. This again leads to new expectations vis-à-vis women.

“Modern” women are expected to plan their lives on the basis of the standard male biography (and they also expect it of themselves). Medicine fools women socialised in the era of the “pill” into believing that they can plan their children to fit into their lives. This also includes the promise given by prenatal diagnosis or preimplantation genetic diagnosis (which is currently still banned) to guarantee healthy children. What woman would not be grateful for so much practical help with her life? Reproductive medicine is booming. In 1999, some 37,000 women in Germany were undergoing reproductive medical treatment. This figure almost tops the world rankings. At the same time, Germany has the world’s lowest birth rate, and hardly any other country in the world has such a dense network as Germany when it comes to diagnostic checkups during pregnancy.

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The pill has rung in a new era, a central element of which is the optimisation of humankind. The message: natural processes mean alienation. The technically manufactured, the cultured product is the more correct, more respected one today. As a result, women today often no longer want to be bothered with their given physical circumstances. Their bodies remain external, foreign and uncomfortable to them, possibly even being seen as obstacles. Manipulating their own female biology promises a better start in the battle with men for social acceptance and influence. Giving birth is notoriously painful and agonising, and the number of caesarean sections on demand is rising all the time. Giving birth used to be a metaphor for a fresh start. Will the future metaphor perhaps be a caesarean section on demand and the perfectly designed child?

There can be no doubt that the pill enabled many women to shape their lives more independently. However, it also accustomed us to the fact that the human female can be manipulated. While the pharmaceutical industry feared overstepping its bounds 40 years ago, all respect for "being the way you are" has since disappeared. From today's point of view, it is evident that the pill started a revolution by changing the biology of women on a large scale through hormonal styling. As a result, gynaecology has gained access not only to women's bodies, but also to their egg cells and embryos. In this way, the pill also prepared the ideological ground on which wild fantasies of breeding and optimisation are growing rampant and waiting to be realised. Women are the keys who fit this lock. That
puts women in a position of power. Power also means accepting responsibility. Women must face up to this fact. They bear central responsibility in this context. In other words, when they demand self-determination, they must also bear in mind the collective consequences of individual action and be aware of their responsibility.

Footnotes


Results

The topic of our forum was the connection between life planning and self-determination.

Cornelia Helfferich presented results from her empirical study, in which she investigated the attitude of women to the plannability of having children and the quality of their offspring.

Silke Koppermann and Eva Schindele illustrated how the concept of self-determination has become individualised and is tied to medical and drug-based instrumentalisation of the female body. This is a trend that was initiated by the pill 40 years ago.

The participants in the forum had a lively discussion on the results of the study by Prof. Cornelia Helfferich and the subject matter of the papers by Dr. Eva Schindele and Silke Koppermann. The discussion revolved around the following points:

- Differences in the attitudes of women in Eastern and Western Germany,
- Women’s fears regarding children, partnership and employment,
- Social conditions for raising, supporting and providing for children.

The participants contributed the following estimations:

The attitude towards children is different in Eastern and Western Germany. Western Germany is felt to be hostile to children. Children are not supposed to cost anything, not cause any trouble and not restrict the parents’ flexibility.

Not only society places high demands on child-raising and the multiple roles of women. Women also place high demands on themselves, thereby increasing the pressure – for instance, the pressure of wanting to do everything right as a mother, looking after the children themselves, assisting the children in such a way that they “turn out right”, having an active circle of friends, being an understanding partner, a good housewife, etc.

As Ms. Helfferich found in her study, all women experience fears about having children, quite independently of the question of whether a child will be, or could become, disabled. The fears relate to the impact of children on a partnership, social and working life, the economic survival of the family, the anticipation of being overtaxed and bearing sole responsibility. Children are clearly perceived as a risk for a partnership, a career and the social environment. Women are generally very much afraid of not being able to cope with everything and being totally overwhelmed. A potential disability of the future child is impermissibly made the focus of this anxiety in gynaecological practice and genetic counselling.

At the present point in history, there are great social uncertainties relating to gainful employment, the safeguarding of the family’s financial livelihood, and the stability of partnerships, and they have an enormous influence on the “children question”. The pressure to become more flexible demands that we keep all our options in life open for as long as possible. However, the decision in favour of a child makes other options impossible.
Women are unable to live out many options, such as raising children as single parents and studying/working, earning money and caring for sick children/relatives, etc. Even if individual women do defy the most adverse circumstances and fulfil several roles at once, this in no way means that all women can really live out the various options in life. Self-determination is meaningless in this context, since women often do not have every option at their disposal in reality.

The forum arrived at the following conclusions:

– Women’s anxieties must be regarded as normal and may not be exploited. Instead of offering techniques, the anxieties accompanying pregnancy as regards living with a child should be addressed as a normal part of family planning counselling or when talking to a doctor.

– Women must be enabled to find a place for themselves with their designs for life in self-determined fashion within a continuum, and no structural pressures should arise to take an “either-or” decision (“either a healthy child or no child at all”, “either a career or children”, etc.).

– Conditions in society must be structurally changed in order to alleviate women’s fears regarding having and raising children. This requires partner-independent security for pregnant women, for example, as well as free, dependable support in child care. All the options existing in the field of interaction between career, child, partnership and caring must be liveable in reality.

– The concept of self-determination, which is currently interpreted almost exclusively in an individualistic manner, must be (re-)politicised and redefined. One participant suggested that the World Health Organization’s concept of the “further advancement and development of human potential” be taken into consideration. Unfortunately, there was not enough time to go into greater depth on this point.
Forum 2
Safeguarding autonomy – Preventing suffering?
Arguments for offering and utilising prenatal diagnosis and preimplantation genetic diagnosis

Pia Goldmann | Margaretha Kurmann | Brigitte Faber | Martina Puschke | Anne Waldschmidt

Between acquiescence and indignation –
The current debate on prenatal diagnosis and PGD

Pia Goldmann | Margaretha Kurmann

Prenatal diagnosis (PND) is today a standard part of gynaecological pregnancy care. Currently, there are also demands for the approval of PGD, which is irreconcilable with various provisions of Germany’s Embryo Protection Act. The debate on PGD often ignores the IVF procedure it requires and everything it entails for the woman involved, as well as the extremely low success rates of these methods. This also applies to the physical, emotional and social risks and side-effects of prenatal diagnosis for women, such as miscarriages; the automatic quality and self-fuelled dynamics of the techniques; dependence on experts; waiting times; unclear findings; fixation on risks and plannability; the suppression of personal experience and physical perception; and the increase in social pressure on women to do everything they can to make sure they give birth to a “healthy” child. In the debate on PGD, there is talk of approval in strictly defined, “severe cases”. But how is the “severity” of an illness or disability to be determined? Who is willing and able to define when the life of the children – or that of the parents – would entail “unreasonable” suffering? And does this assessment by third parties justify selection? Experience with the spread of prenatal diagnosis and experience with PGD outside Germany indicate a door-opening function for research on and with embryos.

“I don’t want to be accused later on of not having done everything I could.”

“I can’t imagine living with a disabled child.”
There are extremely divergent opinions on this difficult subject. Women’s realities vary greatly, and this is also expressed in the different ways they approach the topic of selective diagnosis.

**Equation: Disability = Suffering**

The concepts of disability, suffering and illness are often used without differentiation and synonymously. Deviations from the norm in physical or mental performance, and dependence on help and support, are generally defined as being “full of suffering” by outsiders. The social dimension of “disability”, of beingimpeded by social barriers, is ignored.

**Equation: Self-determination = Independence**

The techniques of PND and PGD are promoted as “increasing women’s self-determination”. They promise that a woman can and should plan not only when she wants to have children, but also what kind of child she thinks she can cope with. For their part, women see the techniques as a way of liberating themselves from their “nature” as their “destiny” and also of taking reproduction into their own self-determined hands. The concept of “female self-determination” has positive associations for most women as a kind of battle-cry and a concept for defending themselves against suppression and external control. However, as used today in the context of genetic engineering and reproductive medicine, self-determination refers to the picture of the independent individual – independent of physicality, restrictions or needs. Although it is difficult to view the concept of “self-determination”, as important as it is for women, from such an angle, it simultaneously encompasses the equation of disability with suffering and dependence, and the impulse to avoid this, which is the opposite of self-determination. Beyond that, in the context of PND and PGD, self-determination also means individual responsibility for having to reach a decision (for socially acceptable solutions?) on the basis of probabilities.

**Avoidance of suffering and self-determination as acceptance-building rhetoric?**

Medical and genetic researchers claim that all research is geared to “the avoidance of suffering” – the techniques are neutral in themselves; what counts is the way they are used. This makes it harder to criticise the research in any way, since it is generally agreed that suffering must be combated. It appears “unseemly” to ask what new “suffering” is created by the development of new knowledge and methods in the first place: suffering caused by techniques that interfere with the integrity of the body, by newly created pressure to make decisions, or by changing society’s acceptance of people with disabilities, to name but a few examples. Reflection on this subject usually turns out in favour of the use of the medical techniques, while the social aspects fall by the wayside. The reference to women’s greater self-determination also often functions as a given truth, as it were. The demand for these techniques would appear to speak for itself. However, we have observed in recent years, especially in the field of PND, that techniques also create realities, that new offers of examinations generate new demand, and that this then gives rise to new pressures. Hardly any mention is made of the enormous economic interests behind this research.

“No matter how you look at it, women always end up bearing the responsibility.”

“It’s a good job that medicine has so many possibilities today.”

Medical and genetic researchers claim that all research is geared to “the avoidance of suffering” – the techniques are neutral in themselves; what counts is the way they are used.
The advocates argue with the practical realities. Controlled via the supply, this generates demand. The result is an effectively functioning cycle.

**Between acquiescence and indignation**

The debate concerning the approval of PGD has made prenatal diagnosis a topic of conversation again. On the one hand, it disrupts the acquiescence to selective everyday practice that has developed; on the other hand, however, we are experiencing that “selection” is becoming a subject open to discussion. We can see how things that are not yet possible are always made the subject of scandal – such as cloning – in order to be able to do things that are within the realms of technical feasibility. One shift in the borderline justifies the next. The advocates argue with the practical realities. Controlled via the supply, this generates demand. The result is an effectively functioning cycle.

**Offloading responsibility**

Following the initial introduction of all prenatal tests with surprisingly little hesitation (although no one could accept responsibility for the consequences), the problems have now become apparent. However, this has not led to the manner of their use being questioned, a review of the acceptability of the risks and side-effects, the admission of mistakes and the corresponding curbing of prenatal diagnosis, but now to favouring “compulsory counselling”. Counselling becomes the perfect way of resolving the contradictions of selective diagnosis. The call for “compulsory counselling” as a corrective measure of social ethics – the individual, the pregnant woman, and her partner are supposed to (and must) make the decision – such as is also currently being debated mainly by users, is part of the strategy of offloading responsibility for the consequences and implications of the techniques onto the affected woman and her partner. In the dispute over PGD, too, approval is demanded with reference to counselling as a regulative measure.

**Footnotes**

1. **Prenatal diagnosis (PND)** involves examinations and tests relating to the development of an unborn child in the course of pregnancy. They include ultrasound examinations, amniocentesis and risk specification by way of blood tests on the woman. In the event of unusual findings, there are generally no possibilities for treatment or cure. The only alternative is termination of the pregnancy.

2. **Preimplantation genetic diagnosis (PGD)** involves genetic diagnosis in the context of IVF (in-vitro fertilisation). One or two cells are taken from an embryo produced in the laboratory. These cells are examined genetically and, depending on the results, the embryo is either destroyed, put into storage or implanted in the woman. The aim of PGD is to give a heterosexual couple a genetically independent child that does not display a specific deviation from the norm. The production of excess embryos, to be either destroyed or used, is a necessary element of this technique. In practice, PGD has almost always been followed by invasive PND (amniocentesis) to confirm the findings.
Agony or autonomy –
The promises of reproductive medicine

Anne Waldschmidt

Preliminary remark

Alleviating suffering and safeguarding autonomy – these are the common promises of reproductive medicine that are generally accepted by the public without reserve. The promise of preventing, or at least alleviating, individual suffering has a highly suggestive power of legitimisation, as does the prospect of a self-determined life. Safeguarding autonomy and alleviating suffering both have a “subscription”1 to acceptance, as it were. Measures that aim to reduce suffering, or are at least reasonably convincing in declaring this to be their objective, can be almost certain of winning through. After all, who wants to face accusations of being responsible for the suffering of others? The same applies to offers of intervention that claim to increase the self-determination of the individual. Who wants to be rebuked for being in favour of restricting individual autonomy or even for having compulsory measures in mind? Against suffering, for autonomy – that is the acceptance and legitimisation formula of reproductive medicine.

Agony and autonomy –
Strategic concepts

I will now attempt to subject the concepts of “suffering” and “autonomy” to theoretical consideration. These two words are generally used in such a self-evident way in public discussions and private disputes, as though social consensus already existed about what they mean. On closer inspection, however, it becomes apparent that their content is seldom precisely formulated, nor are they operationalised. Exactly what kind of suffering is meant? What kind of autonomy is to be realised? There are extremely different meanings in the air when recourse is taken to either of the two words. Unequivocal conceptualisations are not even to be found in feminist discussions. Although the concept of self-determination plays a central role in feminism, in particular, there is no one concept of autonomy that a woman could refer to when it comes to elaborating women’s policy positions.2

Similarly, little thought has so far been given in feminist contexts to the concept of suffering. It is true that the women’s movement is based on the original thesis that women are victims, and thus sufferers, in history and society: they suffer repression and deprivation of rights; they suffer from a lack of education, denied rights and sexualised violence. They suffer from the anxiety that comes with pregnancy and from the double burden of child-raising and employment. Suffering is a word that came up, at least implicitly, in the feminist victim-accomplice debate of the early 1980s. Nonetheless, the women’s movement has not considered this concept to be worthy of any special theoretical reflection up to now.
I would maintain that reproductive medicine propagates only certain interpretations of autonomy and suffering, and also offers only limited strategies for coping with suffering.

The concept of suffering has had an amazing career: from being a household word, it has become a central term of great strategic relevance in the debate on genetic engineering. Experts and politicians alike refer to the objective of alleviating suffering when techniques like preimplantation genetic diagnosis are to be approved and grants awarded for human genome research. The same argument is used when patients take sides with the proponents and moral philosophers justify their advocacy of genetic engineering interventions in humans. If the discursive event of “suffering” is now taken as an occasion to take a closer look at the term, it soon becomes clear that it is not open to systematic attempts to formulate a definition. It would appear to be an empty phrase into which everyone can put everything in life that is not to their taste. There is an infinite variety of negatively rated experiences and emotions that can be labelled as suffering. As with illness, suffering is used for a negative pole, a condition that should be avoided wherever possible. But what is the positive pole, the opposite of suffering? Interestingly enough, there is no unequivocal answer to this question.

Incidentally, the concept of self-determination is similarly fuzzy. Autonomy can mean many things: being liberated at last from external pressures, or having as many choices as possible. Autonomy can also encompass the search for authenticity, or for a meaningful life. Everybody seems to associate different things with the word “autonomy”. Consequently, the concept of self-determination is in no way used consistently, often even serving to justify opposite practices and demands at one and the same time. And just like the concept of suffering, autonomy has now also acquired a strategic function in current discourses and practices. One indication of this is, for example, the non-directive concept of human genetic counselling, which is intended not to offer advice, but only assistance in reaching a self-responsible (sic!) decision.

Agony or autonomy – in the current debate on reproduction technology, this would seem to be the only choice. Reproductive medicine promises the individual client more self-determination and less suffering. Contrary to that, I would maintain that reproductive medicine propagates only certain interpretations of autonomy and suffering, and also offers only limited strategies for coping with suffering. I would now like to outline existing constructs of autonomy and suffering and illustrate their value for the debate on reproduction technology. It should become clear in this context that the acceptance with which reproductive medicine meets among women also originates from the fact that it links up to conceptions that are likewise supported by the women’s movement. At the same time, however, the alleviation of suffering and the safeguarding of autonomy, as promoted by reproduction technology, entail changes in content that, to my mind, cannot be in the best interests of women.

Self-control as a construct

The first identifiable conception of autonomy can be referred to as “self-control”. Historically associated with the humanist pathos of enlightenment and the name Immanuel Kant, it has probably made the biggest mark on our understanding of self-determination to the present day. Although, in the early days of bourgeois society, women, in particular – along with other groups, such as “savages” and disabled people – were regarded as subjects incapable of reason and thus of self-determination, the women’s movement has allowed itself to be
Self-determination in the form of self-control demands that people – men and women alike – rule themselves on the basis of reasonable standards.

The subjects of self-control are given the task of freeing themselves from the world of senses and passions, from their desires and longings, their pain and suffering. They are supposed to repress and negate the physical and, optimally, conquer or overcome it with the help of reason. Basically, the self-controlled subject may not suffer. The feeling of powerlessness and the threatening loss of control that are necessarily associated with every experience of suffering must be counteracted by self-discipline, for instance, by attempting to get life “under control” again as quickly as possible following a divorce, or by precisely adhering to the doctor’s instructions in case of illness and making an effort to become healthy and able to work again as soon as possible.

So far, so good. However, this form of autonomy is based on a notion of subjects where the individual is primarily perceived as being sovereign. According to one of the premises of this conception of self-determination, individuals striving for self-control should not let themselves be guided by instincts, desires and interests, but solely by reason. They should make their own laws and apply them to themselves – in such a way that the laws can simultaneously become general rules and regulations in accordance with Kant’s categorical imperative. In short, self-determination in the form of self-control demands that people – men and women alike – rule themselves on the basis of reasonable standards.

The great emphasis on human reason leads to the devaluation of the body in this conception. The subjects of self-control are given the task of freeing themselves from the world of senses and passions, from their desires and longings, their pain and suffering. They are supposed to repress and negate the physical and, optimally, conquer or overcome it with the help of reason. Basically, the self-controlled subject may not suffer. The feeling of powerlessness and the threatening loss of control that are necessarily associated with every experience of suffering must be counteracted by self-discipline, for instance, by attempting to get life “under control” again as quickly as possible following a divorce, or by precisely adhering to the doctor’s instructions in case of illness and making an effort to become healthy and able to work again as soon as possible.

We are certainly all quite familiar with this conception of self-determination and the associated manner of dealing with suffering. We constantly practise self-control on ourselves. It also comes to bear when a decision is taken to terminate an unplanned pregnancy, or when a 35 year-old woman has amniocentesis carried out because she wants to be “on the safe side”, even though she has the feeling that everything is really all right. Nonetheless, autonomy cannot be equated with self-control alone. There is more to it than that. It was mainly women who pointed this out at an early stage, and it was the new women’s movement that popularised another construct of self-determination that focuses on the self as the subject.
Those involved with “subject self” ask about their history and their essence; they strive to develop their personalities.

Self-control and “subject self” – in my view, these are the two conceptions of autonomy that have so far played the most important role in feminist contexts. While other designs for autonomy have been developed in the course of the centuries, they have, as far as I can see, hardly ever been made the subject of the feminist discourse to date. While a third construct – “self-styling” – still remains more in the background, a fourth way of interpreting self-determination has come more and more to the fore in the social sphere in recent years. It, more than all the others, appears to be the one that comes to bear in the practice of reproductive medicine.

“Subject self” as a construct

In the feminist self-development groups that existed in the 1960s and 1970s, individual autonomy was not taken to mean self-control, but the search for one’s own identity. This conception of autonomy, which I refer to as “subject self”9 and which has since become a leading idea in psychotherapy and teaching, is based not on a political approach, but on a (deep) hermeneutic one. It sees not reason, but the “self” as the nucleus of a human being. Here, self-determination becomes self-interpretation, a “will to know”10 about one’s self. The subjects ask about their history and their essence; they strive to develop their personalities. At the same time, the reflexive self-reference is supposed to permit a qualitatively better life. The blockade of an individual’s constructive capacities is to be broken through and the individual put in a position to handle life in a positive, authentic manner.

“Subject self” also puts a new emphasis on the relationship between reason and the body. While “the head” used to rule, “the gut” can now regain ground. In a person’s search for identity, the bodily dimension is actively incorporated as a medium in its own right, in line with the motto, “Follow the wisdom of your body – it knows the answer”. One’s own body becomes the prerequisite for true self-knowledge. The bodily dimension is credited with honesty, a genuine manner of expression that signals needs and anxieties directly and suddenly, far better than the mind. In line with this reference to the body, individual suffering is also not interpreted as a loss of control, but as a meaningful moment and an expression of a dialectic of life, in which there must be suffering in order to be able to perceive happiness, and in which experiencing suffering contributes to personal growth. Consequently, in the framework of this conception of suffering, unintentional childlessness or the birth of a disabled child is not regarded as an externally applied constraint, but as a biographical challenge that needs to be coped with constructively.

Self-control and “subject self” – in my view, these are the two conceptions of autonomy that have so far played the most important role in feminist contexts. While other designs for autonomy have been developed in the course of the centuries, they have, as far as I can see, hardly ever been made the subject of the feminist discourse to date. While a third construct – “self-styling”11 – still remains more in the background, a fourth way of interpreting self-determination has come more and more to the fore in the social sphere in recent years. It, more than all the others, appears to be the one that comes to bear in the practice of reproductive medicine.

Self-instrumentalisation as a construct

This conception of autonomy can be referred to as “self-instrumentalisation”.12 Incidentally, it is closely related to self-control. It, too, is a product of modern times. The two share the historical legacy of liberalism and enlightenment and they are connected by essential aspects, such as the central position of the concept of reason, the promise of personal sovereignty and the idea of an active subject. Self-instrumentalisation does, however, involve new, decisive changes that make it seem justifiable to see it as being a special facet. This form of self-determination is less political and more technically oriented. It means an instrumental, objectifying relationship to one’s self.
Self-instrumentalisation, which seems to be the dominant concept at present, brings economics to the fore. It is now less a question of power or identity, but more of rational management and thrifty use of resources, property and profit, expediency and utility. “Determination” no longer means just controlling or knowing one’s self, but using one’s self – in a dual sense of the word. The “self” is no longer a sovereign or a personality, but individual property that can be used for various purposes. Self-instrumentalisation calls upon the subject to develop entrepreneurial skills, to pursue personal interests effectively and efficiently and to realise personal happiness in life.

The goal of maximising happiness, which is inherent in self-instrumentalisation, also has an impact on the relationship between reason and the body. Under the influence of utilitarianism, this relationship is shaped into an end-and-means relationship. The body is turned into an instrument for the purposes defined by the mind. It is perceived as being a resource that can be exploited, but also needs to be controlled. Accordingly, the body is subjected to the strategies of rational effectuation. It is mainly intended to function, serve happiness in life and achieve prestige-promoting effects. Its own life, on the other hand, is of no interest to instrumental reason, which also regards suffering as an avoidable disturbance, a defect in the human machine that needs to be remedied as soon as possible. Moreover, seen from this angle, suffering also constitutes a cost factor that can have a negative impact on the personal life-time balance sheet.

In keeping with these premises, self-instrumentalisation as a conception of autonomy has great affinity with all those practices that relate to the utilisation and effectuation of vitality, the optimisation of health, vigour and constitution. In self-instrumentalisation, the human being becomes material for itself and others. This is particularly obvious in the context of surrogate motherhood, egg cell donation and destructive embryo research. However, prenatal diagnosis also reduces human life to a cost-benefit analysis, in that it forces people to weigh a disabled child’s right to live against the potential burden on the mother-to-be. Utilitarian aspects mainly come to bear in preimplantation genetic diagnosis, because its aim is to create a healthy, normal product – a baby that can be expected to cope with its success and happiness-oriented environment in later life.

Concluding remark

An individual pregnant woman who is currently under pressure to decide for or against amniocentesis would certainly be overtaxed by having to critically examine offers of autonomy options and coping strategies. Couples hoping that preimplantation genetic diagnosis will result in the birth of a non-disabled child are probably also too preoccupied with their own hopes and fears to objectively consider the theoretical implications of reproductive medicine. The feminist discourse, however, can be expected to face up to this challenge. If the women’s movement wants to stay
If the women’s movement wants to stay alive as a social movement and keep up its resistance at the same time, it must, in view of the challenge of reproductive technology, revive and intensify the old debate on the concept of self-determination. The conceptions of autonomy and the associated concepts of suffering applied to date must be examined self-critically and new ones most probably developed. It would, for example, be interesting to examine the utility of the ways of self-styling constructed by Michel Foucault\(^{13}\) based on his examination of philosophical notions of the ancient Greeks and Romans. Would it make sense, or under what general conditions would it be possible, to interpret self-determination as a caring relationship to one’s own body and to view one’s own life as a creative project in which experiences of suffering have a productive nature? In the search for alternatives, however, the critical question must, in my opinion, repeatedly be raised as to whether and to what extent patriarchal, hegemonial and economistic subject concepts and action patterns are perhaps reproduced in the feminist discourse without women being aware of it. If the practice of reproductive medicine were to lead to a comprehensive debate on the feminist concepts of self-determination and suffering, it would at least have had a positive effect at this level.

**Footnotes**

Self-determination or self-optimisation?

Brigitte Faber | Martina Puschke

Instrumentalisation of disabled people

In connection with the possibilities of prenatal diagnosis and preimplantation genetic diagnosis, people with an illness or disability are divided into two target groups:

1. The group that has to be helped. This primarily means couples with a hereditary disease or disability, who want nothing more than a healthy child who is genetically theirs, and unintentionally childless couples wanting to use IVF in order to have a child who is genetically theirs and whose constitution is to be “checked” while still in the test tube. The call for the approval of embryo research generally puts the spotlight on people with an illness or disability. Embryonic stem cells are the stuff dreams are made of. In the future, research in and the use of these cells is supposed to enable a fundamental cure of almost all diseases and disabilities.

2. The group “to be avoided”. This includes all people with disabilities that are rated as unacceptable for themselves or their parents, and possibly also for society. It is stressed in this context that it is not the person, but the disability that is unacceptable and is to be eradicated. What is concealed in this case is that disabilities do not occur independently of living or future human beings.

In all these cases, a disability, or living with a disability, serves as a deterrent and as an argument in favour of the creation of “health” by means of medical technology – at (almost) any cost. And the supposed advantages of embryo research and stem cell utilisation, particularly for disabled or chronically ill people as well, are increasingly being brought into the debate on the introduction of PGD, which openly serves artificial selection to avoid future, disabled life.

Personal blame for disability and social consequences

Despite the small percentage of genetically induced disabilities (0.2% of all disabilities), the promises made by modern reproductive medicine create the impression that life with a disability can be ruled out in the future. This notion not only changes an individual’s, and also society’s, attitude towards people with disabilities (“that kind of thing” can be prevented today...), it also makes the old subject of personal blame socially acceptable again. The utilisation of prenatal diagnosis – followed by abortion or rejection if the future child were to have a “severe” disability – is equated with responsible action. Women who act “irresponsibly” are subsequently not only to blame for their own situation, they also bear the blame vis-à-vis the child, on whom they impose this life, and vis-à-vis society, on which they impose this child. Examples from jurisprudence, and the growing number of attempts by health insurers to no longer pay disability-related costs in neonates, confirm this trend towards considering a dis-
ability as being a plight for which the individual is responsible and excluding disabled people from the support of the community.

Double standards

At the same time and especially in recent years, there has been increasing campaigning for greater acceptance of people with disabilities in society. Mention should be made in this context of the change of name of the Aktion Sorgenkind charity to Aktion Mensch, thus shifting the emphasis from disabled children to disabled people in general, and the new or improved national legislation in Germany. This leads to a paradoxical situation where the proclaimed acceptance of people with disabilities in society is growing, while personal acceptance is declining.

Women’s right to self-determination versus the right to life of disabled persons?

While the arguments for legalising PGD initially revolved around the general value of the life of a number of disabled people and the costs arising in connection with disability, the debate has since been expanded to include arguments relating to women’s right to self-determination. By setting up the equation “Disability = Suffering = Unacceptable = The opposite of self-determination”, the focus of a conflict that affects society as a whole is shifted to the groups of “women” and “the disabled”. In this context, the interests of the women’s movement contradict those of the disabled people’s movement – or so it would seem, at least. In connection with PGD and PND, self-determination is defined as women’s freedom to decide whether or not to have a disabled or chronically sick child. When disabled people demand self-determination, they mean their right to life and equal rights and opportunities in our society. In addition, the fact is ignored that it is not a question of the “right to self-determination” of all women. Women who want to take the self-determined decision to have a child with a disability must expect to encounter ever-increasing negative consequences. Even today, some women with a disability cannot even determine their own daily routine or their personal hygiene, they do not have a free choice of doctor as a result of structural or other barriers, and motherhood is considered to be beyond them, or it is prevented by way of sterilisation, to name but a few examples. The way society deals with this demand is completely disregarded in the debate on the various aspects of self-determination. Women, and also disabled people, are naturally granted self-determination, provided they adapt to the conditions prevailing in society. However, no provision is made for society also having to change in order to make self-determination possible.
Results

Forum 2 discussed the field of tension between female self-determination and the promise given by PND and PGD to eliminate suffering. It became clear that, in the framework of the current biopolitical debate, reduced conceptions of autonomy and suffering are propagated, which are based on bourgeois-rationalistic subject notions, utilitarian considerations and the debasement of the human body.

Experience with PND shows that it is essentially women’s circumstances in life that determine the individual decisions reached. Instead of having a real choice of options at their disposal, women today see themselves facing a situation where it is “only natural” to be supposed to utilise the services of reproductive medicine. In reality, against the backdrop of insufficient offers of support from society for mothers and their (disabled) children, women’s actions remain limited to individualistic “damage prevention”. The decision taken by an individual woman, who displays a high degree of external control, is primarily declared to be self-determined for reasons of legitimisation. In the final analysis, this restriction of female self-determination to an individualistic choice of offers of reproductive medicine can be interpreted as a strategy for instrumentalising the demands for autonomy in women’s policy for different interests. Also criticised in the discussion was current medical and societal practice, which is geared solely to the supposed avoidance of suffering, which really only means avoiding suffering people. Equating disability with suffering was rejected in this context. The impairment of health may entail suffering in individual cases, but this is not necessarily so and not the case for every individual. Referring to the problem area of “suffering”, which is also largely taboo in the feminist debate, it was demanded in the discussion that the dominant strategy of avoiding suffering be replaced by offers for coping with it. This is necessary not only in the framework of medicine, but also at the level of society as a whole. A social culture of support and welfare was demanded. Moreover, it was pointed out that a conception of self-determination that is intended as a relative and relational concept presupposes a variety of options for life that are equally legitimate, freedom from external and internal constraints, the absence of discrimination and isolation, as well as the dependability of personal relationships. In the long term, social structures must be changed in such a way that they make self-determined lifestyles possible in the first place. What we need is a “relationship society”, in which autonomy can be lived out in the context of relationships. Women should utilise their relationship power to realise this “relationship society”.

Self-determination
and suffering – strategic concepts

Coping with suffering
instead of avoiding it

Self-determination –
a concept of relationships
The use of the term “therapeutic” in this context is, however, misleading. So far, it is solely a question of cloning for research purposes. No human being has yet been treated, let alone cured.

Egg cell donation has so far been banned in Germany under the Embryo Protection Act. For this reason, “motherhood after menopause”, such as caused a great sensation in Italy and the USA and even helped women give birth at the age of 63, is impossible in Germany. However, reproductive medicine has for some time been calling for the approval of egg cell donation, making reference to “female self-determination”. But the real reason is mainly the new developments in stem cell research, specifically the technique of “therapeutic cloning”, which would lead to a great demand for egg cells.

“Therapeutic” cloning

“Therapeutic” cloning means that the cloning technique first practised successfully in “Dolly” the sheep is to be combined with embryonic stem cell research. In this context, the nucleus of any body cell from an adult is inserted into an enucleated egg cell. After four to six days of development in a test tube, the idea is then to extract embryonic stem cells from the totipotent embryo cloned in this way. These stem cells are then to be differentiated into one specific cell type and transplanted, in order to create an “individual” stock of spare cells.

The use of the term “therapeutic” in this context is, however, misleading. So far, it is solely a question of cloning for research purposes. No human being has yet been treated, let alone cured. “Therapeutic” cloning was legalised in Great Britain in early 2001.

Egg cell donation – Legal situation in Germany

The ban on egg cell donation in Germany results from Art. 1 of the Embryo Protection Act, according to which “Anyone will be liable to up to three years’ imprisonment or a fine who 1. transfers a foreign, unfertilised egg cell to a woman, 2. undertakes to fertilise an egg cell artificially for any purpose other than inducing pregnancy in the woman from whom the egg cell originates. Consequently,
the professional gynaecological societies and the centres for reproductive medicine advocates egg cell donation. This paper notes that the “instrumentalisation and commercialisation of the female body as a biological resource” should be ruled out. It does not, however, say how this should be done. A need is acknowledged for “intensive discussions as to which women (volunteers, IVF patients undergoing therapy) would be willing or able to donate egg cells, and whether this donation should be purely altruistic or remunerated (e.g. in the sense of a basic reimbursement for lost working time, travel expenses, etc.)” (Point 6).

Egg cell donation should “only be permitted on condition of an intensive counselling and examination procedure”. The same document also states that “options relating to therapeutic cloning for embryonic stem cell research/therapy should be kept open” (Point 15).

Footnotes

1 The Embryo Protection Act states that: “For the purposes of this Act, an embryo is defined as a fertilised, viable, human egg cell from the moment of karyogamy onwards, as well as every totipotent cell taken from an embryo that, given the other necessary prerequisites, is capable of dividing and developing into an individual”.


whether egg cell donation for cloning for research purposes is forbidden has since become the subject of legal controversy. In this case, there is no intention to transfer the egg cell to another woman, nor is the transfer of a cell nucleus to an egg cell “fertilisation” in the classical sense of the word. There is also argument on the question of whether a clone embryo is to be viewed as an embryo as defined by the Embryo Protection Act.1 Up to now, only few politicians (mainly from the liberal FDP party) and scientists (e.g. genetic researcher Detlev Ganten from Berlin) have advocated legalising “therapeutic” cloning.

Calls for the legalisation of egg cell donation in Germany

Nucleus transfer would create an embryo specifically and solely for the purpose of being used. It remains debatable whether this is ethically justifiable. “Therapeutic” cloning is dependent on women providing egg cells for karyogamy with body cell nuclei. Based on animal experiments, Alan Colman from PPL Therapeutics and Alexander Kind – one of the scientific “fathers” of Dolly, the cloned sheep – calculated that the production of every cloned stem cell line for treating a single patient would require at least 280 egg cells.2 Other researchers likewise assume that dozens, or even hundreds, of egg cells would be needed for each patient. The question is: How is this industrial-scale demand for female egg cells supposed to be covered?

The suspicion arises that the legalisation of egg cell donation is currently being propagated against this backdrop. For example, a joint position paper3 drawn up by

Researchers assume that dozens, or hundreds, of egg cells would be needed for each patient. The question is: How is this industrial-scale demand for female egg cells supposed to be covered?
Medical and financial aspects

Claudia Schumann

Physical strain on the woman

The collection of egg cells is an invasive procedure that puts a strain on health and entails risks. A prerequisite for egg cell donation is hormonal stimulation. For this purpose, the woman’s menstrual cycle is first deactivated (“down-regulation”) and the maturation of the egg cells then accelerated beyond the natural measure. This requires frequent injections, daily at times. Repeated blood sampling, gynaecological and ultrasound examinations are necessary to monitor success. When sufficient egg follicles ready for ovulation are detected in the ovaries, the egg cells are collected by means of ultrasonically monitored puncturing of the vagina (known as “egg harvesting”). The removal of the egg cells entails the risk of injury, bleeding and inflammation.

The side effects of this stimulation include physical symptoms, such as tension in the breasts, nausea or a bloated abdomen with a feeling of heaviness. Hyperstimulation syndrome of varying intensity develops in between one and four percent of the women treated: the egg follicles develop into large cysts that massively enlarge the ovary; water may be retained in the abdominal region and chest, causing pain and shortage of breath, accompanied by dangerous thickening of the blood and circulatory disorders. Treatment in an intensive-care unit may be necessary and there have been reports of deaths.

It is not yet clear whether there is a threat of long-term side effects in addition to the acute dangers. More and longer follow-up observations are necessary to establish whether stimulation really does increase the risk of ovarian cancer, as claimed in a number of studies. On the other hand, however, since long-term inhibition of the ovaries (by taking contraceptive pills) is known to reduce the risk of ovarian cancer, there is some reason for assuming that stimulation, at least if repeated and strong, could increase the risk of cancer.

When can a woman “need” egg cells?

Indications for egg cell donation for reproductive purposes include the following:

- Premature menopause with cessation of the function of the ovaries (cause unclear, probably of genetic origin);
- X-chromosome-related hereditary disease that is not to be passed on;
- Following chemotherapy involving destruction of the ovaries, or surgical removal of the ovaries (e.g. endometriosis);
- In IVF, if the woman’s own egg cells no longer exist or are no longer readily fertilisable due to her age.

Since the dawn of the IVF era, egg cells have been in great demand as a resource for research. Stem cell research and “therapeutic” cloning would result in a massive increase in the demand for egg cells.

Financial burden on the health system

Reproductive medicine is expensive: because of the high laboratory and drug costs, one stimulation cycle costs roughly 4,000 to 5,000 euros. Every woman is entitled to a maximum of four stimulation attempts at the expense of the health insurance fund – not
including treatments that are discontinued prematurely (e.g. due to insufficient reaction or over-reaction of the ovaries).

This means that the roughly 9,000 IVF children per year (1999 figure) “consume” 10% of the gynaecology budget – i.e. the total amount of money available for outpatient gynaecological treatment – which is then no longer available for other types of gynaecological treatment, such as psycho-oncological care following cancer. The figures will continue to shift in favour of reproductive medicine, since ICSI has recently been added to the list of benefits paid by the health insurance funds. The number of treatments is expected to double as a result.²

Who profits?

In the USA, egg cell donors are recruited in advertisements and on the Internet, with between 1,500 and 5,000 dollars being offered per stimulation cycle as “reimbursement” for the woman.

It is hard to calculate what the medical industry currently earns. However, a major portion of the costs is attributable to drugs, laboratory services and equipment (ultrasound devices, aspiration sets, etc.). Exact figures were not to be found on this subject – nor on how much research funding goes into this sector compared to other research fields in the health sector. The legalisation of egg cell donation would be lucrative for the pharmaceutical industry (hormone preparations, technical equipment), the attending doctors (new clientele) and researchers (research funds, reputation). While the autonomy and well-being of the woman is always emphasised officially, economic interests, the interests of scientific policy and struggles for funds can be suspected to be active behind the scenes.

Footnotes


² However, critical argumentation based primarily on the costs can also be dangerous. For instance, experts in reproductive medicine are demanding that PGD be legalised to ensure that only “good”, quality-tested egg cells are transferred. They argue that this could increase the baby take-home rate from approximately 15% at present to 50%, thereby reducing the number of treatments and effectively cutting the costs.
Ethical and sociopolitical aspects

Ingrid Schneider

Egg cell removal –
Breaking with the medical mandate to heal

In contrast to the situation where IVF is used as treatment in women who wish to have children, the risks of the medical intervention in the case of egg cell donation cannot be weighed up against any therapeutic benefit for the woman herself. The procedure exclusively serves a potential benefit for third parties, namely other women/couples, researchers and potential future patient groups. The intrapersonal risk-benefit assessment is transformed into an interpersonal assessment between donor and recipient. However, being an intervention for the benefit of third parties, it breaks, in terms of medical ethics, with the precept of medical actions not causing harm. Consequently, from the point of view of professional ethics, it is irreconcilable with the medical mandate to heal. In our opinion, this intervention would legally be interpreted as inflicting bodily injury, even if the woman in question had given her consent.

Where are the egg cells for stem cell research and cloning to come from?

The question remains open as to how egg cell “donors” are to be recruited. The professional literature mainly assumes “voluntary donation following informed consent”. In our opinion, it is not sufficient to reduce the question of the permissibility of egg cell donation to whether the women are fully informed about the research objective and the risks arising for themselves, and whether they voluntarily gave their consent to removal. The solution based on individual informed consent would have to be preceded by a debate as to whether the research objectives and the means used for the purpose are ethically justified. Generally speaking, society must establish the framework conditions for deciding whether egg cell donation is acceptable at all.

There are three conceivable ways of obtaining egg cells. First, from IVF treatment; second, from commercialised donation and, third, from donation within the family.

The practice of IVF would be lastingly changed if egg cell donations were to be “diverted” from the treatment of unintentionally childless couples – thereby possibly even reckoning with “surplus” production from the outset. This would give rise to a conflict of interests with the use of the egg cells for fulfilling the wish of couples to have a child.

Egg cells for money

An example of the progress already made in the commercialisation of egg cell procurement can be seen in the USA. The egg donors are usually women between the ages of 20 and 30, who use the income to finance part of their studies or the cost of living. Do these women actually realise that, after making several donations, they are running the risk of having scarred ovaries, possibly being infertile if they later want to have children of their own and then being dependent on the services of an egg cell donor? It has not yet been determined whether a donating woman exposes herself to an elevated risk of cancer in the long term. There are few studies on this subject, although it is a question that urgently needs to be answered.
In the USA, the question is hardly ever raised as to whether people should “give” egg cells (or sperm) in return for money at all. Donated egg cells have also already been used there for stem cell research. In Europe, there has so far been a widespread consensus that stem cell lines should only be produced from “surplus” egg cells that were produced for the purpose of inducing pregnancy, but were not used for this purpose due to the woman becoming ill or the couple being divorced, for example.

In a research project at the Jones Institute in Virginia, embryonic stem cell lines were prepared from embryos produced specifically for this purpose, for which the egg cell “donors” received payment of roughly 2,000 dollars. Following hormone treatment, 162 mature egg cells were obtained from 12 women and fertilised with the sperm of two sperm donors. Three stem cell lines were developed from the 40 successfully produced embryos. Some of the egg cell donors were women who were not included in the regular egg cell donation programme because of an “undesirable family history”, probably meaning a ‘hereditary affliction’. The other women had been accepted as “suitable”, but were not chosen by a corresponding “receiving couple”. This almost sounds as though these women were “second-class” egg cell donors.

The medical article points out that, for later transplantation therapies, both the egg cell donors and the sperm donors would have to undergo “extensive clinical tests” in order to prevent the transmission of known illnesses. In addition, the attention of the donors would have to be drawn to the fact that the medical staff “could have personal interests that are not connected with the health of the patient and could result in a scientific or economic benefit” (p. 136). This refers to any patent rights to stem cell lines produced in this way, which not only yield royalties, but can as well be sold to pharmaceutical companies for hard cash.

A second project in the USA falls back on previously purchased egg cells. Advanced Cell Technology of Worcester, Massachusetts, has conducted research projects on producing cloned embryos with egg cells from women in order to obtain stem cell lines from them.

The money paid for egg cell removal can restrict the voluntary nature of donation. Economically underprivileged women could feel forced to sell their egg cells, although it is never referred to as the “sale” of egg cells, the money instead being declared as “reimbursement” for the “service”.

Egg cell donation “out of female altruism”

The third way of obtaining egg cells would be “altruistic donation” within the family. This model has already been tried and tested in the “live donation” of organs (kidney, part of the liver), where the majority of the “donors” are women. It seems fatal in this context that the classical expectations of the role of women – the provision of unpaid care services for children, the aged and the sick – are not only perpetuated, but also radically expanded to include the unreasonable physical sacrifice of germ cells. Young women within a family network could come under substantial social pressure to donate egg cells for sick relatives. The voluntary nature of egg cell donation must be doubted when emotional dependences exist. However, sympathy and solidarity with the sick should not entail any obligation on the body. Rather, the state would have to protect people from new situations of social obligation of this kind.
Social obligations of women

The legalisation of cloning for research purposes would mean that women would have to become contract egg cell producers. Thus, clone research involves an imminent, but unspoken tendency towards a social obligation of the female body. There are signs on the horizon of a new contract between the sexes and the generations, where young, fertile women are expected to provide the material resources for the treatment of the old and sick. Speaking normatively, it could, in contrast, be postulated that women’s egg cells should not be available for third parties and for purposes other than reproduction, meaning that they may be neither sold nor donated for free. So far, egg cells have been integrated in the context of female physicality, in connections between sexuality and reproduction. The decision to also enable egg cell “donations” for research purposes beyond the reproductive sector oversteps existing cultural and psychosocial borders. After all, egg cells – and also sperm – have so far been linked to sexual intimacy and potentially to generative processes, meaning offspring and subsequent generations. It is questionable whether it would be desirable to break with this cultural and social tradition.

Footnotes


Assessment

To open the discussion, we first watched the film “Egg cell exchange” produced by BBC TV. It observes Californian agencies dealing in egg cells for reproductive purposes. There are statements by egg cell donors and recipients, and a meeting with a child produced in this way was filmed. The attractive egg cell donors emphasise what a good thing it is and convey the impression of it being a natural thing to do. The brokers (exclusively women in the film) hold talks with clients. The website and the catalogue of donors (including photos of their pets) are shown, as are recruitment interviews. Also demonstrated are the painful hormone injections and the removal of egg cells with ultrasonic monitoring.

The film has no off commentary whatsoever. Although the egg cell donors were enthusiastic about their “job” and in no way matched the stereotype of the “poor, exploited woman”, we were still overcome by a very uncomfortable feeling. We tried to identify more exactly what we felt was not quite right and what our criticisms of egg cell donation were.
Although the donors stress that it is a question of “love” and of “making” a baby, there is usually no personal relationship between the donor and the social parents – anonymity prevails. Anonymity prevails.

The broker agencies:

Their business is the placement of egg cell donors. To this end, they compile catalogues of the women “on offer”, including photos and personal details, which are in some cases accessible on the Internet. In the discussion, this gave rise to spontaneous comparisons with marriage agencies or prostitution (pimps). In this new service sector, however, there is no talk of money – at least according to the film – although this is probably the reason for the “donation”. The commercial nature is concealed by a mask of kitsch and sentimentality: the egg cell donors are referred to as “angels”, who earn their “ticket to heaven” in this way; a scene is presented that is reminiscent of Christmas. However, the creation of happiness seems to be superficial; the women gave the impression of being “contented hens”. Although the donors stress that it is a question of “love” and of “making” a baby, there is usually no personal relationship between the donor and the social parents – anonymity prevails. At the same time, the chances of placement and, to some extent, probably also the prices are regulated by the market mechanisms of supply and demand. What stuck in our minds were the words of a “broker”, who used to work as an estate agent and said the process was a similar kind of “matching” of the two parties involved. The egg cells – and the child potentially resulting from them – serve as a placeable commodity.

The egg cell sellers:

It was noticeable that the donors were heroised. The women stylised themselves as being the ones who bravely bear any pains without complaint because it is a question of “higher purposes”: making it possible to have a child. Some of them gave the impression of being naïve, and the suspicion of “caretaker syndrome” was also expressed. Some of the participants in the forum rated the sale of egg cells “out of (human) kindness” as “abuse of the needs of women”. The relationship between the egg cell donors was striking: on the one hand, it was characterised by solidarity, by being “in the know” following the initiation – the first hormone treatment and puncture – which was described as being very painful and an emotional roller-coaster ride. At the same time, there was obviously competition between the women. They boasted about the number of egg cells collected during a single puncture. The question of how often a woman had already donated and whether this had resulted in a child also appeared to play a role in the social hierarchy of the donors. We were also interested by the picture the women presented of their own bodies: they were proud to use their ovaries as production equipment. To us, this female fertility in abundance appeared to correlate with a male model, namely the fantasy of a man’s own semen being “spread all over the world” (“femalism”, “women showing-off their potency”). However, sperm and egg cell donation were presented differently: while the relationship to sperm emphasised potency, but was considered as being “as cold as possible”, egg cell donation was associated with suffering, but also with “warmth” and care for others, which can well correspond with being tough on one’s self (daily hormone injections).
The man plays only a minor role. He is assigned the job of sperm supplier in a small room with porn magazines.

The doctors:

The matter-of-fact, functional attitude towards a woman donating egg cells is intermingled with sexism, such as in the remark before egg cell aspiration: “Do you want to be a good hen, then?” The fact that the woman herself has no indication for the intervention is not a topic at all. Benefit-oriented, numerical ethics prevail.

However, the informed consent falls down towards the end of the film, when the couple is in the situation of having to decide “on the spur of the moment” how many of the embryos produced are to be transferred and what is to be done with the “surplus” ones. There is the fear of a multiple birth, but also the fear of the unreasonable demand to accept “selective reduction” – intrauterine foeticide. No detailed information on the subject is provided, nor are a time and place arranged for a discussion, where the doctor faces the process of reaching an understanding on the matter.

Women’s autonomy?

There was a controversial discussion about whether there can be a “right” to self-instrumentalisation and self-injury. Advocates of the ban on egg cell donation often have to put up with being accused of paternalism or “maternalism”. However, it is in no way patronising if the political aim is to prevent the emergence of social conditions in which new expectations are imposed on women to make themselves available as egg cell producers. It makes sense to establish social boundaries, also in relation to individual

The egg cell donors to their bodies is characterised by fragmentation and appeared mainly to refer in a performance-based and functional manner to the objective of producing as many healthy, fertilisable egg cells as possible. Any suggestion of sexuality and motherhood was avoided. Consequently, upholding female altruism follows the traditional image of women, while the otherwise customary ties between female fertility and motherhood are severed. The potential damage that egg cell donation can cause was repressed, as were the social complications that a donation of this kind can entail, either in reality or in the ways of coping psychologically with egg cell donation.

The egg cell buyers:

There is a three-cornered relationship between the egg cell donor (genetic mother) and the mother who bears and raises the child (the physical and social mother). The meeting of the two women and the child is marked by subtle, subliminal tensions. This is a highly emotional situation characterised by enormous gratitude, but also by competition and a sense of having deficits compared to the other woman (not having any egg cells, not being a mother). Beyond all assurances regarding the far greater importance of social parenthood (as opposed to genetic parenthood), fears become noticeable and are vaguely expressed: the latent fear that the egg cell donor could turn up and claim to be the “real mother”. Under extreme circumstances, this could end up in a “Caucasian Chalk Circle”.

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needs, such as the entitlement to fulfil the wish to have a child in cases of organic impossibility. The question must be raised as to the price others in society have to pay for fulfilling the wishes and interests of individuals. The problem is that reproduction is becoming a market activity.

As it stands, we cannot support the conventional division in the ethical assessment, according to which the donation of egg cells is to be advocated, while the sale of the egg cells is rejected as commercialisation. Similarly, the “altruistic donation” of egg cells, even if it is an “act of friendship” for someone who is personally close to the donor, will never be free of social pressure and can entail social complications. In contrast, the anonymous donation of egg cells would have to be questioned as regards its motives – the potential damage that can be caused by egg cell removal would be against it. The sale of egg cells turns the donation of egg cells into a contractual relationship with the purchaser. Given that all concerned (agencies, doctors) are remunerated for their services in the process of egg cell donation, it would be hypocritical to exclude the egg cell producer as the donor of a body part. However, one problem is that economic constraints could take effect when deciding on the sale of egg cells. The conception of the body as property must also be rejected.¹

**Arguments against egg cell donation:**

- Potential damage to health, immediately after the intervention or in the long term, both in the women and in the resultant children
- Potential psychological problems arising from divided motherhood, both for the women and for the children (harder to find their identity)
- Danger of women in economic distress being exploited
- Contradictory to the medical mandate to heal and to traditional medical ethics
- The manic rush to immediately do whatever is feasible
- Dangers arising from a marketable technique becoming independent
- Due to the fact that a child can develop from it, embryonic material is of special personal, social and symbolic significance and should thus not be treated like a sellable commodity
- The legalisation of egg cell donation would mean a certain kind of availability in the image of women, in the construct of womanhood, for all women. It presupposes an instrumental attitude towards one’s own body and that of others. Ultimately, it means the purchasability of egg cells for the woman herself and for others. Could this have a “domino effect” on the purchasability of the person or the purchasability of reproductive relationships?
- If egg cell donation is legalised, women could find themselves in the position of having to justify their actions, and implicit social responsibility for donating egg cells could arise. However, the legitimacy of claims on the bodies of the others must be questioned.

**Other points raised included the following:**

- The imbalance in the financing of high-tech medicine and other fields, such as psychosocial care, physiotherapy
- A different kind of research promotion policy is necessary
- Alternatives, especially adult stem cell research, should be demanded instead of embryonic stem cell research and “therapeutic” cloning, not as a “complement” to them

**Footnote**

The dynamics of reproductive medicine

Giselind Berg

The entire field of reproductive medicine has proven to be enormously dynamic since the birth of the first child conceived by in-vitro fertilisation (IVF) in 1978. While the original indication was the bridging of disturbed tube passage – due to a woman’s tubes being obstructed or absent, for example – modifications and new potential applications were soon developed.¹ The fertilised egg cell was transferred to the tube or uterus of the woman at various stages of development, for instance as an embryo or also as a pronucleus, meaning before fusion of the nuclei of the egg cell and sperm cell. These modifications were given corresponding names, such as Pronuclear Stage Transfer (PROST) or Tubal Embryo Transfer (TET). More commonly used was a method in which the eggs and the sperm were taken up in a cannula and injected into the tubes, where fertilisation was to take place more or less “as usual”. This procedure of Gamete Intrafallopian Transfer (GIFT) was mainly used in cases of male fertility problems, or if no medical cause of sterility could be found (idiopathic sterility).

Expansion of the indications

These various attempts to develop forms of treatment for male infertility have lost their importance since Intracytoplasmic Sperm Injection (ICSI) was introduced roughly ten years ago and established itself as the most successful, albeit most invasive, form.² In this case, a single sperm is injected into the egg cell in an IVF procedure. Even if sperm are completely absent in the ejaculate, it is today possible to extract sperm from the testes or the epididymides and use them for fertilisation by ICSI.
Rationalisation of the process

To increase the efficacy of the method, changes have been made in every stage of the IVF process – stimulation, aspiration of the egg cells, fertilisation and embryo transfer. This particularly applies to stimulation, and also to the removal of the egg cells, which is no longer performed by laparoscopy, but through the vaginal wall (transvaginally) with ultrasound monitoring. This avoids the risk of using an anaesthetic.

Above all, however, the laboratory conditions have changed. For instance, new methods of cultivation have been developed, or of deep-freezing embryos or pronuclei. Various procedures have been tested with the aim of increasing pregnancy rates, including what is known as “assisted hatching”, which involves mechanical opening of the oolemma, using a laser for example, in order to facilitate hatching of the embryo and embedding in the uterus, or blastocyst transfer, which is not yet permitted in Germany. In this case, the embryos are no longer cultivated for the previously customary three days, but up to the fifth day (blastocyst stage), in order to then transfer only the most viable ones. The chances of becoming pregnant, especially for older women, are to be increased by experiments aimed at improving the “quality” of the egg cells. One example is the currently controversial method of cytoplasm transfer, where the “aged” ooplasm, which is considered to be one cause of chromosomal aberrations and is held responsible for abortions and miscarriages, is replaced by the cell fluid of a younger donor.
Nowadays, not only male and female gametes are used for artificial fertilisation, but also precursors of sperm, so-called spermatids, for example. The use of sperm from moribund men has also been reported. Both methods have led to the birth of children.

To counter the shortage of egg cells, use has already been made of underdeveloped egg cells, meaning egg cells not having an oolemma.

For some time now, consideration has been given to freezing gonadal tissue from cancer patients soon to undergo chemotherapy, in order to preserve their chance of having children of their own. The cryoconservation of ovarian tissue would be one such possibility. In the meantime, however, the use of foetal ovarian tissue with subsequent in-vitro maturation of immature egg follicles has also gained importance in the context of assisted reproduction. There are hopes that it will reduce the risks of hormonal stimulation in the long term, while at the same time offering the opportunity to obtain more egg cells. Thought is also already being given to ovarian donations.

There are now reports on various attempts at producing human egg cells with the help of cloning techniques, for instance by using immature cells into which the nucleus of a body cell was injected. If further tests are successful, this is supposed to be a way of helping women who are incapable of producing their own egg cells.

IVF was initially envisaged for women with tubal problems. In Germany, it was generally to be used in women under the age of 40. Here, too, the age of the treated women has gradually risen. Moreover, as revealed by the widespread use of ICSI, a substantial percentage of the treatments is now carried out on the basis of male-induced fertility disorders, although the stress and the health-related risks still have to be borne by the woman.

If we take a look at international developments, examples of women having children beyond the age of 50 or 60 – with the help of IVF and egg cell donation – show that the age limit has virtually been abolished. The idea that the methods of reproductive medicine should be used to help childless (married) couples have a child has – as indicated by the practice of egg cell and embryo donation or surrogate motherhood with all its facets – long since been overtaken by reality.

The use of methods of assisted reproduction has changed the conception of parenthood and family relationships. Things that were certain in the past, such as the succession of generations, are open to disposition. Only a few years ago, great public attention was attracted by cases in which a woman bore her daughter’s child, or a young woman a child for her mother, meaning her (genetic) brother. Another spectacular facet of new family constellations was contributed at the end of 2000 by the 62 year-old French woman.
who bore her brother’s child following egg cell donation. In addition to this son, for a large sum of money, the brother and sister, the new parents, also ordered another child from the American surrogate mother, who also acted as egg cell donor.

For all these children, there is no longer a straightforward answer to the question “Where do I come from?”, which is considered to be of great importance for the development of their personality.

On the whole, it can be seen that the boundaries have shifted continuously in the context of reproductive medicine. While IVF was initially considered to be the last resort, and its use only considered to be indicated when every other possibility had been exhausted, it is obvious that the indications are now being expanded substantially.

The boundary as to what is still considered permissible has likewise been constantly pushed back. Today, it lies at cloning humans, but certainly not without controversy. Interventions in the human germline, cloning or the production of mixtures of humans and animals (chimeras) were absolutely taboo subjects not long ago, but they have today entered the realms of possibility. Or they are in the process of being realised, if we look at the creation of chimeras in China for the production of stem cells, or read the announcements made by various protagonists that they intend to clone humans in the near future. However, what has not changed over all the years is the justification, namely that it is (almost) exclusively a question of fulfilling the wish of childless couples and giving them the opportunity to have a child of their own.

Footnotes
9 Gosden, Roger, Tan, Sean Lin, Oktay, Kutluk, 2000. Oocytes for late starters and posterity: are we on to something good or bad? Fertility and Sterility, Vol. 74, No. 5, p. 1057.
Results

In view of the dynamic development of reproductive medicine in the past few years, the Forum had set itself the goal of taking up the discussion in relation to further developments in this field, such as preimplantation genetic diagnosis (PGD).

Working against this backdrop, the questions not least to be examined were how these prospects are judged and what consequences can be seen to result from the technical innovations, both for women and for society as a whole.

As expected, the discussion was strongly influenced by the two papers, which touched on different approaches, especially at the action level. For example, the suggestion was made to not participate in the discourse about reproduction technologies at all, because picking up the discussion on its possibilities and potential consequences would mean helping to establish reproductive medicine. It was said to be important instead to always draw attention to the unity of foetus and woman and the physical integrity of pregnant women, as well as emphasising that pregnancy is an occurrence having the nature of a process. In contrast, there was the view that the offers of reproductive medicine are already in widespread use and have gained an influence over society’s ideas about pregnancy and birth.

The debate mainly revolves around embryos, their dignity, ethics in general, and also Germany as the location. A need was seen to formulate the women’s viewpoint and bring it up in different political contexts in the future.

Today, and not least intensified by portrayals in the media, an idea has gained acceptance in the public eye that circumstances previously ascribed to fate are now accessible to individual influence by using medical techniques. One example of this is unintentional childlessness, which can be remedied by the capabilities of artificial fertilisation. In this context, not only are the causes of childlessness disregarded; the fact is also ignored that most couples still complete the time-consuming, physically and emotionally stressful treatment without having a child. The situation is similar as regards the birth of a disabled

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child. The fact that prenatal examination methods are available during pregnancy, such as amniocentesis and chorionic villus biopsy, has created the impression that disability is avoidable. Both the concrete conditions for use of these methods and the frequently stressful decision-making conflicts that the women face are disregarded, as are the concrete capabilities of prenatal diagnosis. Since, for instance, only a small percentage of disabilities are genetically induced, it is a mistake to assume that the birth of a disabled child could be ruled out in this way. Illness or other fateful circumstances cannot so far be avoided by technical means. Consequently, it was emphasised as an important element of the discourse that there is a need to give the role of fate an appropriate position in human life again, almost as a kind of counterpart to the pressure to act imposed by society.

2. In view of developments in reproductive medicine and biomedical research, as well as the far-reaching promises of healing given by doctors and researchers — in connection with stem cell research, for instance — existing and new techniques can be expected to encounter growing social acceptance. Research and the further development of practical reproductive medicine are being advanced, making reference to the suffering resulting from unintentional childlessness. Against this backdrop, the Embryo Protection Act is perceived as being an obstacle, and there are demands for amendment or for new regulations in the form of a Reproductive Medicine Act with a view to expanding the range of offers, such as PGD and egg cell donation.

These efforts disregard the social impact of new methods in reproductive medicine, and especially that on women. The development of prenatal diagnosis in Germany can be taken as a basis for estimating the potential consequences of introducing new selective techniques, such as PGD. Bearing in mind the enormous extent to which prenatal diagnosis has been used since its introduction, different factors emerge.

It is quite common for women to find themselves in an ambivalent situation. Making use of prenatal diagnosis promises them a certain degree of decision-making latitude. Not least in view of the allocation of roles in the family that still prevails today, where women mainly bear the responsibility for the children, they may well feel overtaxed by having to look after a disabled child, given that they receive no support from society. On the other hand, the expansion of the offer’s availability is accompanied by the expectation of its being used, this in turn often being perceived by women as social pressure to utilise these techniques. The growing belief in the capabilities of medicine, and also the institutionally encouraged hopes, foster notions that, by putting in enough effort, childlessness can be overcome and also a healthy child “made”.

This tendency is supported by the system of antenatal care, which has nurtured the idea that technical means are capable of controlling the individual bodily process, and thus has encouraged selection by way of prenatal diagnosis. Establishing pregnancy is virtually inseparable from a visit to a doctor; the regular ultrasound examinations easily become a habit, as long as nothing

Consequently, it was emphasised as an important element that there is a need to give the role of fate an appropriate position again, almost as a kind of counterpart to the pressure to act imposed by society.
Similarly, the social consequences also need to be taken into account. For example, in reference to the possible legalisation of PGD, it is important, in view of the hopes described, to also clearly point out the social pressures it may entail for women. Consideration must also be given to the costs of the treatment, which have been largely ignored to date. The introduction of new techniques would involve an increase in the already disproportionately high percentage of the gynaecology budget of the statutory health insurance system that is accounted for by reproductive medicine.

The following political demands resulted from the discussion:

- Preservation of the Embryo Protection Act
- Research into the causes of unintentional childlessness
- Public, broadly-based discourse on normality and disability
- Transformation of the social context to make life with a disability easier for parents and children
- Change in antenatal care, e.g. through greater involvement of midwives, and in the pregnancy guidelines, which often lead to a spiral of increasingly invasive diagnostic methods
- Rejection or expansion of discussions that consider the embryo in isolation from the woman and pregnancy as a process-like occurrence
- No research funding for germline therapy or cloning

Family planning is indispensable today if women want to realise their designs for life, such as having a career and children. This often involves contraceptives, on the one hand, and, on the other hand, the attempt to find out whether “everything’s OK” in the event of pregnancy. Since even a healthy child poses a risk of poverty today, the birth of a disabled child often additionally entails social isolation of the women/parents.

3. With regard to the action level, it was noted in the context of dealing with future developments in the field of reproductive medicine that, since utilisation of these possibilities is seen as a matter of course, it must be assumed that it will only be possible to exert an influence on this in the case of new offers if a new direction is taken at an early stage. This is another reason for participating in the debate as soon as possible.

In this field, too, experience shows that the utilisation of technical methods is tending to become normal. To be able to assess biomedical developments, it was also considered indispensable to disclose the various interests involved, since scientific and economic ambitions, for example, are hardly mentioned at all.
Incorporating the viewpoint of women in politics and research, achieving goals in women’s policy and strengthening lobbying work are necessary prerequisites for increasing the representation of women and for making the specific conditions of their lives a basis for political decisions.

In order to participate actively in the political sphere, it is necessary to learn how legislative and executive structures, and their advisory and operational bodies, are organised and how they interact.

The type of organisation naturally depends on the political decision-making level to be influenced: the municipal, state or federal level, or possibly the level of the European Union as well. A municipal structure functioning on the basis of a bottom-up process (e.g. municipal women’s health work) can prove to be exemplary and develop considerable influence. European developments and decisions involve a top-down process in that directives are adopted for the Member States of the Union, which must then be implemented, e.g. in Germany.
Top-down strategies

In the gender issue, the concept of “gender mainstreaming”, which is prescribed by the European Union and ratified by the German Federal Government in the Amsterdam Treaty, proves to be helpful for the work of all organisations. It is an instrument of planning and control for the gender equality of political decisions and administrative activity.

Gender mainstreaming is an administrative (re)organisation principle that affects all levels and all spheres of institutions/organisations. Just as an administrative body considers costs and cost/benefit ratios in all its projects and programmes, it will also examine how a programme impacts both men and women for the purpose of gender mainstreaming. Does the programme comply with the precept of equal opportunity, or are control measures necessary to satisfy equally the interests of men and women, boys and girls?

The underlying idea is that the more closely (political) decisions are geared to the actual living situation and quality standards of the target group, the greater the effect. Thus, gender mainstreaming is also a necessary element of effective quality management. The gender mainstreaming approach will be implemented in all institutions in the near future, from the Federal Government, unions and universities, all the way to local clubs and societies.

Numerous different strategies are required in order to influence the self-government structures of the statutory health insurance system and the medical community. The social insurance assembly elections (every six years) offer fund members the opportunity to be voted onto the administrative committees of the statutory health insurance funds. These committees are largely made up of men. The average age is very high. The last social insurance assembly elections showed that individual statutory health insurance funds are very interested in having younger committees and greater female participation. However, the road to an elected office unavoidably passes through the groups it represents (e.g. unions), which must first be contacted.

Of great significance is the Federal Doctors/Health Insurance Funds Committee, which decides, for example, which services are to be covered by the funds. The Federal Ministry of Health (BMG) fulfils the supervisory function for this committee.

A difficult, but necessary undertaking is to increase and exert influence on research (Federal Ministry of Education and Research – BMBF, German Research Association – DFG, etc.). A key demand – one which is ultimately also made by the Conference of the Ministers of Women’s Affairs (GFMK) and the Conference of the Ministers of Health (GMK) – is that health-policy decisions and research project funding be examined to ensure gender equality and greater representation of women’s issues.

Claudia Bormann’s paper gives an example of how decision-making processes and mechanisms function in establishing priorities for funding.
Experience gathered in practice is to be incorporated in advising decision-makers, in order to elaborate programmes for improving the living and healthcare conditions of women.

**Bottom-up strategies**

There are innumerable issues and concepts in women’s health work which have been developed on the municipal level and for which model solutions have been found. Despite the clearly growing professionalism in the women’s health “scene”, the results of its work still do not have any major structural impact. This is neither helpful, nor resource-oriented, meaning that it would make sense to consider structures for transferring project work.

The Bremer Forum Frauengesundheit (Bremen Women’s Health Forum) is an example of an organisational model for influencing women’s health policy on the municipal level: the Forum Frauengesundheit is a women’s alliance and a lobby for women’s interests. It is a body of experts that discusses interdisciplinary aspects of women’s health, and develops and publicises women-oriented alternatives in the form of action and decision-making guidelines – for both healthcare practice and advising politicians. The interdisciplinary backgrounds of the participants, who act as official representatives of their departments/institutions/offices, etc., have proven to add a new dimension to the discussion of complex problems.

The Forum is a plenum for interdisciplinary discussions on women’s health issues with representatives of women’s projects, counselling centres, educational institutions, professional associations (e.g. nurses, midwives), hospitals, businesses, chambers, health insurance funds and government agencies (health, youth and social affairs) – all from the fields of health, education and science. Women experts – with a mandate – participate in the Forum as professionals from their respective fields, but also as people who are personally affected by the issues, as patients, as a “target group”.

The Forum Frauengesundheit addresses issues from the female point of view which have so far received little attention in health policy discussions, but are of fundamental significance for women’s healthcare.

Discussion results are passed on to the media in the form of written statements, presented to a larger audience at public events or sent to political decision-makers as petitions in cooperation with municipal or state political organisations.

The German Cities Assembly (Deutscher Städtetag) recommended in 1998 that the municipalities organised under its roof establish structures for exerting this form of influence in municipal women’s health policy.

Discussion groups on the subject of women’s health are not a new invention. Nevertheless, the Assembly’s committees on women’s affairs and equal opportunities, and on health, recommended that the Forum Frauengesundheit become a model for other municipalities. The innovative aspect is the intention to establish on the municipal level regular expert forums on specific topics that bring healthcare practitioners together with players from the (decision-making) sphere of politics and administration.

Through this kind of networking, experience gathered in healthcare practice is to be incorporated in advising decision-makers on municipal policy, in order to elaborate programmes for improving the living and healthcare conditions of women.
Knowledge of government agency tasks and structures is naturally required in order to convey ideas relating to women's health policy in politics and administration. Knowing who should be presented with what, where and when, because they have the competence to make proposals and decisions, is the key to strategic action. When concentrating contacts on the government (responsible for the political direction) and its administration (the professional background, usually with many years of experience), the fact is frequently overlooked that parliament is the constituent body. In addition to personal contact with members of parliament (for the respective constituencies), who need “guidelines” from grass-roots professionals, the parliamentary committees are also important forums for concrete debates on the respective policies. Healthcare Committee hearings, for example, are a good stage for presenting opinions on women's health policy. Having contact with individual members of parliament is the prerequisite for being invited to hearings as a private expert advisor or association expert advisor. Depending on its size, every parliamentary party has the opportunity to invite a certain number of expert advisors to the hearings in order to fill the time allotted to the party. Today, it has become established practice to invite self-help groups, women’s health associations and consumer protection associations. Hearings are usually public and are always a good opportunity to network.

It frequently makes sense to exploit the competence of government agencies working in specific areas. The Federal Centre for Health Education (BZgA) is a good example for illustrating fields of responsibility and competence, defining the opportunities and limits for influencing institutional work.
The role of parliament, government and government agencies

__The Federal Centre for Health Education (BZgA) is a government agency under the control of the Federal Ministry of Health (BMG). Following the adoption of the Pregnant Women’s and Family Assistance Act, its task since 1992 has also been to develop and publicise concepts and programmes on sex education, contraception and family planning. This task is under the professional supervision of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ). This task is based in the Equal Opportunities Department of the BMFSFJ. The responsibilities of the BZgA primarily include the development of mass media publications, such as brochures, films and advertisements, where these educational materials must be distributed to the general public free of charge. Furthermore, it promotes innovative concepts in the practical field by means of pilot projects and supports multipliers by offering continuing education projects and working materials. The BZgA promotes the professional exchange of information through conferences and congresses. Social science studies and accompanying scientific research serve to ensure the quality of these programmes on behalf of the BZgA. The BZgA has at its disposal a total budget of some EUR 5 million a year to fulfil this task.

Networks and close contacts –
Two important, but different strategies

__Establishing successful structures for exerting influence also means exploiting existing alliances. In the case of women’s health, these are, for example:

– The Women’s Health Association in Medicine, Psychotherapy and Society (AKF – Arbeitskreis Frauengesundheit in Medizin, Psychotherapie und Gesellschaft e.V.) and the National Coordinating Office for Women’s Health (BKF – Bundeskoordinierungsstelle Frauengesundheit)

– The National Women’s Health Network (Nationaler Netzwerk Frauengesundheit)

– The Federation of Women’s Health Centres (Dachverband der Frauengesundheitszentren)

– The Women Doctors Association (Ärztinnenbund), etc.

__On the next level up, lobby groups that play a key role in women’s policy can also be of interest, e.g.

– The German Women’s Council, and

– Party organisations for women’s policy.

__Successful strategies for implementing women’s policy interests must include the following steps:

– Influencing public opinion-forming by disseminating information acquired in women’s health work

– Identifying and utilising political structures and responsibilities on the municipal, state and federal levels

– Establishing connections, networks and close contacts with other women, and formulating goals for these groups

– Informing contact persons in politics and administration

– Making targeted use of women scientists

– Demanding participation in decision-making processes: e.g. the quota-based make-up of committees
Decision-making processes and mechanisms involved in establishing key funding areas and the implementation of research projects within the framework of the health research financed by the Federal Ministry of Education and Research – What is the benefit for women’s research?

Cornelia Bormann

The Federal Ministry of Education and Research (BMBF) has an annual budget of almost DM 16 billion, which is approximately 3.3% of the federal budget. Roughly DM 650 million of this is available each year for the health research financed by the BMBF. On top of that comes funding for human genome research, which came from the sale of UMTS licences and totals some DM 350 million for three years. In turn, the DM 650 million are divided into about DM 430 million for institutional funding, e.g. the Radiation and Environmental Research Association (GSF), the German Cancer Research Centre (DKFZ), the Max Dellbrück Centre (MDC) and other non-university research establishments under the supervision of the BMBF. An annual amount of some DM 220 million is available to the BMBF for project funding. The following statements refer to this segment.

The Federal Government issues a new health research programme about every five years (corresponding to medium-term financial planning). The current programme, entitled “Health Research: Research for Mankind”1 was adopted by the Federal Cabinet in November 2000 and encompasses the period from 2001 to 2004. It includes the following objectives:

- Study of the causes and developmental processes of diseases, with the aim of devising more effective methods of prevention and therapy. This primarily involves the funding of research on severe diseases characterised by high incidence, early death, chronic progression or sustained suffering.
- Research on the healthcare system. The focus in this area is on research for the improvement of healthcare activities, specifically the optimisation of the workflow and organisation of patient care. In particular, action concepts are to be identified to improve the care of the elderly and chronically ill.
- Health research and innovation in the economy and science. The new health research programme is intended to achieve greater interaction between science and the economy. Results of health research are to be transferred more rapidly to the pharmaceutical and medical technology industries in order to transform enormous innovative opportunities into products and methods more quickly.
- Strengthening of the research landscape by means of structural innovations. The new programme puts particular emphasis on structural improvements in the research landscape. Existing deficits in German health research are to be overcome in this way. This applies mostly to the implementation of clinical studies, meaning treatment optimisation studies and comparative studies on treatment.2
Taking gender-specific aspects into account in health research is an essential basis for a coordinated overall strategy (gender mainstreaming) in health policy.

The programme also mentions that there is a backlog in women's health research: “Women and gender-specific risks, protection factors and stress constellations must be identified as a prerequisite for developing more effective measures in prevention, treatment and rehabilitation, which are intended to strengthen objective and subjective resources for good health. In this context, the view of these aspects must be geared to the lives of women and/or men, giving consideration to the different issues such a view is associated with. Taking gender-specific aspects into account in health research is an essential basis for a coordinated overall strategy (gender mainstreaming) in health policy, which can trigger a broad discussion of better – gender-specific – care models. The results should lead to the more effective and targeted use of preventive and treatment services.”

Apart from these statements at the beginning of the programme in the description of the current situation, the subject of women's health does not appear anywhere later on in the concrete discussion of the need for action and the implementation of the programme, meaning that we must question the importance attached to this issue.

Before this new programme could be defined, it was necessary to set priorities in relation to the individual fields of action in order to concentrate funding on programmes of top priority in health and research policy, and to achieve a high degree of efficiency in implementing political objectives. The following assessment criteria were applied for this purpose:

- Social need: number of affected persons, mortality and morbidity, suffering and personal burden
- Blatant deficits in care
- Economic significance
- Significance for the healthcare system: effects on the efficiency and effectiveness of the healthcare system
- Scientific and technical innovative force
- Potential to strengthen leading-edge research
- Economic exploitation potential, particularly for securing and creating jobs
- Ethical and legal requirements and consequences

The subject of women is again missing.

In order to implement the health research programme, the BMBF established an advisory system encompassing the following bodies, which share responsibilities on the various levels of the programme:

<table>
<thead>
<tr>
<th>Programme</th>
<th>Health Research Council</th>
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<tr>
<td>Specific programme areas</td>
<td>Science Committee, Medical Technology Committee</td>
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<tr>
<td>Key funding areas</td>
<td>Expert groups</td>
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 Participation of women in political decision-making processes

The Health Research Council was established in 1990. It is essentially made up of representatives of the major research and funding organisations in Germany and abroad. It advises the BMBF on interdisciplinary issues of health research and on the development of the health research programme. The purpose of the council is to promote cooperation between the Federal Government and the states, between the representatives of the research and funding organisations involved in health research, and between the representatives of the research fields and organisations in the healthcare sector. The sessions of the Health Research Council, which are held once a year, are also coordinated with those of the Expert Council for Concerted Action in Healthcare (SVR – Sachverständigenrat für die Konzertierten Aktionen im Gesundheitswesen), which functions under the Federal Ministry of Health (BMG). This coordination is to be intensified within the framework of the current programme.\(^5\)

Two of the seventeen members are women: one represents the German Science Foundation (Stifterverband für die Deutsche Wissenschaft), and the other is a professor in a medical/natural science discipline.

The Health Research Council is supported by the Science Committee and the Medical Technology Committee.

The Medical Technology Committee advises the BMBF on project and institutional funding in the field of medical technology. It formulates recommendations on the programme and key area levels and votes on the nature of the medical technology action plan – an interdisciplinary funding strategy combining all the programmes and activities of the BMBF relating to medical technology.\(^6\)

The Science Committee is involved in the details of the BMBF’s funding programmes in the field of biomedicine and healthcare, and supports their development. In coordination with the Heath Research Council, it assesses new topic proposals and funding concepts, evaluates current funding programmes, and formulates recommendations for the future content and structure of the research landscape, taking institutional funding into account.\(^7\)

The Science Committee has fourteen regular members, three of whom are women. All but two of the members come from natural science disciplines in the field of basic medical research. The two other members represent social medicine and biometry/methodology. The make-up of the Science Committee leads to the assumption that it is very difficult to gain acceptance not only of concepts for establishing women’s health, but also of key funding areas that have a broader reference to the population and do not concentrate on purely medical aspects, but rather are based on a bio-psychosocial approach. Because the Science Committee only meets about twice a year, implementing new key funding areas is time-consuming, particularly if a concept for a new key funding area needs to be discussed several times.

Once a concept for a new key funding area has been adopted by the Science Committee, the project management organisation prepares a call for proposals, which is usually submitted to the Science Committee prior to publication. For the last two to three years, calls for proposals have been required to draw attention to compliance with gender-specific aspects.

Two of the seventeen members of the Health Research Council are women: one represents the German Science Foundation, and the other is a professor in a medical/natural science discipline.

The make-up of the Science Committee leads to the assumption that it is very difficult to gain acceptance of concepts for establishing women’s health.
that only one or a maximum of two women are to be found in each expert group. The low participation of women in the expert assessments is due in part to the fact that the percentage of women professors in universities continues to be below 10%, even though various programmes have been launched in the recent past to change this situation. In other words, there simply are not many women who can be recruited as expert assessors, so that they can act as advocates of women's interests. On the other hand, it is my experience that women professors do not exploit their work as expert assessors so much as a position of power, as men do, or use it to establish a network of close contacts. After an expert assessment has been made, the next institution to influence the shape of a research project is the project management organisation. The BMBF gives the project management organisation responsibility for planning, coordinating and implementing the health research programme. These responsibilities specifically involve:

1. Implementing funding programmes while complying with the specific provisions of administrative law
   – Advising applicants
   – Preparing funding decisions with the help of expert groups
   – Technical and administrative project support
   – Evaluating success, including an exploitation study
2. Financial management
3. Public relations work: participation in disseminating research results
4. Supporting the bodies responsible for the programme (Health Research Council, Science Committee, etc.)
5. Supporting the updating of the programme, as well as the planning and evaluation of key funding areas
6. Participating in international partnerships
7. Providing information and advice to German applicants for the EU’s “Quality of Life and the Management of Living Resources” programme

Although the project management organisation does not have any real authority to make decisions, it can indirectly have a considerable influence on the shape of a research project, because it usually determines whether the requirements of the expert assessment have been fulfilled, the amount and distribution of the funds applied for, and the suitability of the interim and final reports, and because it formulates requirements that must be fulfilled during the term of the project. Moreover, the project management organisation writes the draft concepts for new key funding areas, which are then debated by the Science Committee.

If we want to draw conclusions from this information for the more extensive inclusion of women-specific aspects in health research, I believe we must take various approaches. It can generally be said that the principle of gender mainstreaming has so far only been introduced in the decision-making structures of research promotion up to a point. Only a few women are in the bodies described – the Health Research Council, the Science Committee and the expert assessor groups. It is important to significantly increase the percentage of women in these bodies. Only in this way can women’s issues be discussed on a regular basis. However, this presupposes that the number of women professors and women in management positions will be increased. We undoubtedly need a lot of stamina to reach this goal. Fortunately, the initiatives launched by the Federal Government and the pending generational transition in the professoriate are pointing in the right direction.

We must also question whether it is appropriate to establish just one governing body, which is highly focused on basic medical research, for the entire field of health research, meaning that the psychosocial aspects of medicine, for example, have only a slight chance of receiving funding. I believe the need for change in this area is very urgent.

Another means for integrating women’s issues more effectively in research promotion is the establishment of an instrument that sensitises decision-makers to gender aspects and helps them formulate decisions. This would make it possible to introduce the integration of women’s concerns as an assessment criterion in the evaluation of project proposals. A criteria catalogue of this kind would have to be based on:
- The issues involved in the project,
- Precise definition of the target group,
- Adequate consideration of the needs of the target group,
- The gender-adequacy of the approach,
- Consideration of the gender-specific framework conditions, and
- The development of gender-sensitive criteria for evaluating the effectiveness of a project.

The gender-sensitive planning of research projects, but also of key funding areas, does not mean that all projects must explicitly be dedicated to the gender issue. Rather, thought must be given to whether gender plays a role and, if so, what consequences it has.

The criteria catalogue must be available to the applicants prior to submitting project proposals, but also to the expert assessors during the assessment process. It must be made clear that fulfilling these criteria is a crucial factor when deciding whether or not to grant funding for a project.
A criteria catalogue of this kind would be important for project funding by the Federal Government, the German Research Association (DFG), foundations and other research promotion organisations. However, it would also be logical to consider gender aspects in the appropriation of state funding to universities. Up to now, funding appropriation in most states depends on the science-impact factors earned through publications. High impact factors are awarded for publications in natural science journals in the framework of basic research. In contrast, the results of women’s health projects and psychosocial research are usually published in health and social science journals that have a low science-impact factor. Consequently, women researchers in the field of women’s health are also disadvantaged in the distribution of state funds. In order to prevent this, gender aspects should also be taken into consideration for state support.

A survey of funded projects must be made in order to make past Federal Government funding more transparent. Such a study should clearly indicate the objective and the women-specific results of the project, as well as the amount of approved funding. We would then have evidence illustrating the gender bias in research promotion. If a survey of this kind is repeated on a regular basis, it also becomes a means for examining the implementation of the gender mainstreaming principle in research promotion, and could thus serve the purpose of quality assurance.

All these points can only be pushed through if sufficient political pressure is generated, as was the case, for example, in the USA with the establishment of the Women’s Health Initiative.
The term “counselling” is playing an increasingly important role in the social debate surrounding genetic and reproductive technologies. There are three primary fields of practice in which the call for counselling is particularly loud: prenatal diagnosis, postnatal genetic testing and, increasingly, preimplantation genetic diagnosis, which is banned in Germany. There is widespread demand for prenatal diagnosis to be automatically linked to mandatory counselling, in the belief that it will have a limiting effect. Another common idea is that predictive genetic tests on already-born persons should also be linked to obligatory counselling in the hope of preventing the uncontrolled spread of testing. Finally, it is also suggested that preimplantation genetic diagnosis (banned in Germany), meaning selection in a test tube, should be regulated based on the model of Art. 218 of the German Penal Code. In other words, PGD should be marked as socially and ethically problematic, but still permitted. This contradiction is to be remedied by imposing an obligation to obtain prior counselling. In all these instances, counselling is supposed to assume the function of controlling the ethical and/or social problems and risks associated with these practices. Consequently, counselling is intended to function as an instrument of social control. There is a need to discuss whether counselling can really achieve this effect, or whether it is inherently incapable of doing so.
In the case of genetic and prenatal tests, it is not so much the methods themselves that are considered problematic and therefore require patient information. Much more problematic are the results, namely, the knowledge these test methods provide. They are problematic in two respects: it can be assumed that the results represent a risk for the tested person, because knowledge of a future disease or the disability of a future child is an extreme burden, especially if there is no possibility for treatment. Furthermore, direct relatives, such as children, siblings and parents, can also be threatened, because, at the very least, the test also reveals probabilities concerning their genetic make-up.

However, there is a second dimension in which the testing itself can be considered so problematic that a link to counselling is viewed as a necessity, and that is the social dimension. This is particularly the case in the PND debate, although proponents of this view are also voicing their opinion in the debate on approving preimplantation genetic diagnosis. Many criticise the fact that prenatal diagnosis has become a routine pregnancy examination, because the healthcare system thus signalises that preventing the birth of people with disabilities is a socially acceptable practice and, at the same time, a commendable goal of medical treatment. It is feared that the social isolation of people with disabilities will be further intensified as a result. Therefore, this knowledge can entail a risk of socially problematic consequences.

In order to clearly portray the problem, we must once again examine what “counselling” really is in this context. What do the practices that are to require counselling have in common? PND, PGD and predictive genetic testing are all not classical diagnoses, but tests. The term test goes further than the term diagnosis. In everyday usage, diagnosis refers to the determination of a pathological condition or change, e.g. a disease or injury. In contrast, tests are used not only to identify existing disorders, but also to determine a disposition to future diseases (predictive testing) or the presence of a disability not necessarily associated with disease, such as missing arms or legs. The demand for counselling can partly be explained by this difference between diagnosis and testing. A diagnosis is generally assumed to be necessary for taking preventive and therapeutic measures. The patient can and should expect to be informed by the doctor about the necessity of the diagnosis (e.g. an X-ray), as well as about any risks and side effects.

However, counselling usually has a more extensive and different meaning compared to this kind of information (notwithstanding that there is room for improvement in the information normally provided to patients). In conventional medicine, it is basically assumed that carrying out a diagnosis is a medical necessity. At most, the only problem is the associated risks and side effects. By informing the patient, this problem can be put into perspective relative to the medical benefits. However, things are different in the new fields of testing: the tests usually do not offer an option for treatment or prevention, often only providing information on the probability of a future disease. In the case of genetic and prenatal tests, it is not so much the methods themselves that are considered problematic and therefore require patient information.
Counselling is viewed as an instrument for restricting a practice considered to be problematic. This function fundamentally distinguishes counselling from patient information.

The demand for more and better counselling on genetic and reproductive technologies is based on certain assumptions, namely that a) a specific practice is problematic, b) the excessive spread of this practice can be prevented by linking it to counselling, and c) the decision to implement this practice should continue to be a personal one, i.e. no restrictions should be imposed by state or social institutions. By this definition, counselling is to fulfil the function of socially controlling a personalised practice. Whether this is always a desirable idea must be discussed. In my opinion, the following questions must be posed in the given order:

- a) In which cases and for what reasons can and may a practice that is considered to be so problematic be left to the decision of the individual?
- b) Is counselling a sufficient instrument of social control, or should other control instruments be utilised, at least in some instances?

To be able to answer the first question, it would be expedient to differentiate between tests that are ethically and legally justifiable, and those that are not. I believe this can best be determined by asking whether the purpose of performing the tests is basically legitimate. The possible purposes of genetic and prenatal tests are:

1. Cure, alleviation, delay or prevention of a disease
2. Determination of drug intolerances (pharmacogenetics)
3. Establishment of a basis for deciding whether a person wants biological children
4. Establishment of a basis for deciding whether to terminate a pregnancy (PND)
5. Establishment of a basis for deciding to implant an embryo produced in vitro into the uterus (PGD)
6. Research for third-party interests, a) either with voluntary and informed consent b) or on persons unable to give their consent
7. Acquisition of data on the frequency and distribution of specific genetic factors in the population as a basis for policy and planning.

Although the legality of these purposes cannot be discussed in depth here, it can nonetheless be said that it makes no sense to leave a practice to the decision of an individual, if this practice is generally held to be illegal. If I am of the opinion that PGD or third-party research on persons unable to give their consent contradicts fundamental constitutional principles, I cannot leave the decision concerning their application to individuals. In this case, I would have to exclude counselling as an instrument of control and select another instrument, namely statutory prohibition. Only if the purpose is basically legitimate can counselling be used as an instrument, because counselling, by nature, is always based on the ultimate discretion of the individual.
When specific practices are viewed by society as dangerous or socially undesirable, it is illusory and contradictory to push responsibility for these practices onto the individual alone – even if counselling is involved. This demand can also be interpreted as meaning that counselling is not primarily intended or designed to help those involved, but rather to be functionalised to serve the interests of the medical system.

**Counselling: Function and functionalisation**

Ursula Hommerich

“No decision without qualified counselling” is the title of a working paper of the “Reproductive Medicine and Embryo Protection” working group of the Academy of Medical Ethics. Is this demand in the interest of women, or is it the result of a practice of reproductive medicine that is no longer questioned, i.e. another means of legitimising this practice? This demand can also be interpreted as meaning that counselling is not primarily intended or designed to help those involved, but rather to be functionalised to serve the interests of the medical system.

In order to resolve the question of the necessity, purpose and female orientation of counselling work, here are a few brief preliminary considerations regarding the premises of the counselling concept described above:

1. Pregnancy is viewed as a medical risk, where the “risk factor foetus” is the focus of medical interest: the “treatment goal” is a healthy child that conforms to standards.

2. The effects of PND on the pregnant woman, the foetus, the relationship to the unborn child and the experience of pregnancy are not of interest.

3. This view functionalises the female body and the foetus, resulting in a performance and quality-oriented image of humankind; the health and normality of the foetus become a required performance of women. Reproductive medicine pushes the responsibility for the illness or health of a child onto their shoulders.

State support of socio-political alternatives (e.g. living with a disease or disability),

State support of medical alternatives (e.g. research on treatment options instead of test methods).

Particularly when specific practices are viewed by society as dangerous or socially undesirable, it is illusory and contradictory to push responsibility for these practices onto the individual alone – even if counselling is involved.
The expectant mother finds herself in a borderline ethical situation, in which she is expected to make “impossible decisions”, i.e. to say “yes” or “no” to a wanted child, even though, or precisely because, the child is the way it is.

For many women who become pregnant and enter into an unfamiliar, i.e. exciting and unsettling, phase of life, prenatal diagnosis represents an opportunity to allay their vague anxieties and insecurities about the health of their child. Promises of greater certainty through the use of various methods of prenatal diagnosis appeal to this state of mind. A commonly used phraseology, for example, is that the pregnant woman can gain assurance that “the unborn child is ok”. Personal fears, the pressure of social expectations (partner, attending doctor), and the threat of ostracism for refusing to take these tests, put considerable, albeit subtle pressure on pregnant women, which many cannot escape and do not wish to. These tests are legitimised by claiming to calm and reassure pregnant women.

But what happens in the event of an abnormal result, e.g. from an ultrasound examination? The anxiety triggered by such a result usually leads to further invasive diagnostics and causes women to experience growing unease, or often even panic.

The greatest problem when using PND is that most diagnosed abnormalities and diseases are still not treatable during pregnancy, meaning that an abnormal result forces the expectant mother into a decisional conflict of either carrying a possibly disabled or sick child to full term, or having an abortion. Frequently, the mother is not even aware that, for example in the Triple Test, the result is not even a diagnosis, but rather a probability with only about 60% accuracy.

For these reasons, the period between the decision to undergo PND and receipt of the test results is a time of extreme anxiety and tension for most pregnant women. Considering that this period can range from one week for chorionic villus biopsy to six or seven weeks for amniocentesis, it must be assumed that the burden is enormous and has a variety of effects on the relationship to the unborn child. It has not yet been proven that the foetus is not also negatively affected by this stress (the latest research results on ultrasound suggest this to be the case).

Many women keep their pregnancy secret until the test results come in, remain inwardly detached, do not dare to rejoice and describe this “tentative pregnancy” as by far the most stressful part of pregnancy. This stress may be a cause of the increasing number of nervous, cranky babies, etc. For all these reasons, undergoing PND requires that it be preceded by an informed, self-determined decision, i.e. information, education and counselling of the women.
Objective and function of the various forms of counselling

Information

Information is intended to provide women with factual knowledge about prenatal examinations and tests, including information on the risks and side effects of these methods, about the meaning of the findings, the reliability of the results, the treatment options during pregnancy and, not least, information on alternative preventive methods and support options. The extent and depth of the information should be geared to the needs of the pregnant woman, enabling her to weigh the various options and thus make a well-founded decision to accept or reject PND. In my opinion, the demand to provide information geared to the needs of the women excludes an approach based on the principle of mandatory counselling. Because PGD is permitted in neighbouring countries, the need for information also applies to women who are thinking of taking such a step.

Education

Education goes a step further by showing women/couples the relationship between diagnosis and treatment options for the foetus, by pointing out effects on the course of pregnancy (tentative pregnancy) and late-term abortion as a possible consequence.

Counselling

Unlike human genetic counselling, which targets the condition of the foetus, psychosocial counselling is entirely focused on the woman in need of advice. Counselling is intended to be an explanatory and decision-making aid for PND, helping a woman digest the test results and get through subsequent decisional conflicts. It is tailored to the expectations and personal questions of the client. The outcome is open, meaning that the counselling result depends on the insight gained from jointly evaluating the woman’s specific situation in life, her personal conflict situation, her plans for the future and her values with regard to the pending decision. The counsellor – who is aware of her own values, but keeps them in the background – is entirely focused on her client’s personal frame of reference, helping structurally but without actively offering advice. The objective is to help the client weigh the various options, as well as the emotional significance of their respective effects. In the process, the counsellor takes the woman’s biographical and psychodynamic context into account. The personal notions of the woman or couple regarding their future plans in life, i.e. their idea of a “good” life, are just as important as the woman’s relationship to the unborn child, the pregnancy and her related anxieties and desires.

Not least, the significance of a woman’s social context, her partnership, the attitudes and expectations of her partner, as well as the social pressure exerted on her by family and doctors, and the expectations of society, which are often unconsciously involved in the decision-making process, must be illuminated. Women frequently experience a conflict...
between their own wishes and needs, and those of their partner or environment. The compulsion to have a healthy child on the one hand, and the concern about the unborn child on the other, often constitute a double-bind situation for clients, in which every choice is the wrong one, no matter which option they choose: either they decide in favour of PND and accept the health risks for the foetus and a tentative pregnancy, or they decide against PND and then possibly bear the “blame” for the illness or disability of the child. For most, making a decision does not put an end to the stressful experience of doubt. However, a well-considered, conscious decision makes it easier to identify coping strategies and sources of assistance that help a woman deal with the decision taken.

Because women-oriented counselling focuses on the resources and strengths of women in a special way, it poses the following questions: what helps them cope with the psychological, ethical and social consequences of their personal decision? How will a client deal with a miscarriage caused by PND, for example, or with raising a handicapped child? Jointly identifying existing, personal, inner resources plays a key role in this context: it must be determined how a client resolved difficult decisional conflicts in the past, and what inner sources of strength she has, such as personal values and skills. The better the selected alternative corresponds to a woman’s own wishes, ideals, moral beliefs and emotional limits, the better she will be able to cope with the future. Information on outside resources is another key topic in counselling. This includes information on alternative pregnancy care, counselling programmes run by self-help groups for the diseases or disabilities in question, as well as institutions for the disabled that can offer the expectant mother support. Clients often know very little about the manifestations and consequences of a specific disease or disability their child has, or where to get help. Probably the most difficult thing for everyone involved, meaning both the affected women and the participating professionals, is the preparation for, and implementation of, a late-term abortion.

All these counselling efforts serve to prevent and resolve emotional, ethical/moral and social conflicts that can be triggered by PND. Because most women who get counselling are under immense psychological pressure and running out of time – making lengthy counselling impossible – priority is given to identifying and focusing on the central conflict and the psychological background, combined with the person’s current situation in life, which is relevant for the pending decision. For her part, a counsellor is required to have outstanding competence, meaning sound knowledge of psychological and social relationships, so that she can promote optimum conflict resolution based on women’s proven coping strategies, resistance and defences.

Equally important are experience and knowledge regarding the rules and methods of communication, and particularly crisis intervention. The latter is frequently necessary due to the existential nature of the decisional conflict, which affects central spheres of life. One of the most important prerequisites in this process is a relationship of mutual respect that supports the woman’s self-determination.
Mandatory counselling collides with the counselling principle of patient-orientation, which takes the information requirements, capacity and needs of expectant mothers as a guideline for the professional approach taken.

Although various participants are emphasising the need for information and counselling, we are still far from making concrete plans for practical implementation, which requires corresponding institutions with skills in the medical, psychosocial and ethical fields.

Mandatory counselling – yes or no?

Information and counselling on PND are undoubtedly a priority task for doctors and midwives, and the mandatory consent of pregnant women to targeted and non-targeted PND an important guideline for medical practice. However, I believe that mandatory counselling collides with the counselling principle of patient-orientation, which takes the information requirements, capacity and needs of expectant mothers as a guideline for the professional approach taken.

In any case, however, forms of counselling must be devised that are independent of the people who perform PND, in order to counteract the risk of functionalising counselling to serve their interests. Consequently, independent counselling institutions are required, which are not integrated in the medical system – such as Pro Familia, the Network Against Selection by Prenatal Diagnosis (Netzwerk gegen Selektion durch Pränatalagnostik) and the like – and which supplement and counterbalance the information provided in doctor’s offices.

Demands on participating professional groups

As already presented in 1994 in a study for the German Bundestag, a survey of professionals showed that expectant mothers receive poor information and education in common PND practice, which is due in part to the inadequate knowledge of gynaecologists concerning the various methods, the relevance of PGD results, etc. Since then, further studies of the information and advice provided to patients by their attending doctors conducted for an EMNID survey have shown that information and education – not to mention counselling – in outpatient medical care is in a very poor state. However, the study further shows that corresponding training programmes for doctors substantially improve the counselling dialogue and advising skills, and result in more effectively reassured and informed patients.

The only possible conclusion for the field of PND is that gynaecologists and human geneticists need appropriate preparation and training to develop counselling skills, as the medical profession itself already calls for. The same applies to midwives. It is questionable whether counselling and information services of this kind can be ensured in real outpatient medical care without being appropriately remunerated. The health insurance funds need to take action on this issue.

While professional competence is ensured in the field of psychosocial counselling, such as that offered by Germany’s Pro Familia organisation, it is uncertain whether the current organisational structure can meet the demand for counselling, especially since there is talk of requiring proof of counselling prior to PGD if it is legalised, and of offering general family planning counselling in view of the new reproductive technologies.
Psychosocial counselling takes place on the personal and emotional level. The scientific and social debate surrounding prenatal diagnosis forms the background. However, the debate cannot take place in this setting, or be “shifted” to it, as this would mean the functionalisation of counselling. In order to exclude the possibility of functionalisation, the institutional and socio-political framework in which PND is anchored (e.g. medicine and research) is called upon to commit to this goal. The Forum compiled the following ideas and demands for this purpose:

**Results**

Counselling cannot solve the problems resulting from the planning and performance of prenatal diagnosis. Nevertheless, it can have a key function in this context.

However, a distinction must be made between information, education and counselling. This Forum supports the method of psychosocial counselling. This type of counselling can help women recognise the significance of using technologies during pregnancy and to reconcile it with the plans they have in life and the phases of life they are in. The objective is to enable women to make a decision that is good for them.

If mandatory counselling is not established, then we urgently need to intensify the public debate on PND issues, as the Federal Centre for Health Education, for example, is capable of doing with the support of the media. Only with widespread knowledge of the possibilities, limits and risks of PND can attitudes ultimately be changed and a problem-conscious basis for making decisions established on the social and personal level. To this end, however, guidelines for pregnancy care must developed and supported by all professional groups involved. For example, midwives must be included as alternative-care providers. The extent to which, and the conditions under which, selective methods are incorporated in the maternity guidelines should be decided jointly by all professional groups involved. A diverse, independent programme of information and counselling, which meets the various needs of women, is required to fulfil these counselling tasks. In addition to the counselling providers already active in the field, these tasks could also be handled by family education centres and similar adult education institutions. The crucial issue, however, continues to be the creation of public awareness in preparation for making a personal decision.

**Footnotes**

Therefore, independent counselling structures must be recognised and funded as a corrective measure.

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- Pregnancy care and the search for abnormalities are to be clearly separated from one another as services offered to pregnant women
- The groups responsible for offering these services must have different staff and premises (gynaecology and special centres)
- The associated billing practices and the agreements between health insurance funds and doctors must also be differentiated
- Collaboration between participating professional groups (midwives, gynaecologists and counsellors) is to be institutionalised
- The spheres of responsibility of midwives and gynaecologists should complement one another
- A woman’s right to know or not know must be universally accepted
- The interests of health insurance funds in selective PND must be clearly presented
- The practical implementation of Art. 2 of the Pregnancy Conflict Act (SchKG – Right to counselling) must be ensured, particularly the expansion of education work
- Doctors should voluntarily commit themselves to point out the right to counselling
- Book IX of the German Social Security Code (SGB IX – Equality for people with disabilities) must be implemented without delay
- Children with disabilities are to be admitted to the long-term care insurance scheme

**Counselling**
- plays a key role in personal decision-making,
- but is not a solution to social problems.

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Forum 6 addressed the fact that independent counselling geared to the needs of women – regulated as a right to counselling in Art. 2 of the Pregnancy Conflict Act (SchKG) – plays a crucial role in effective personal decision-making processes. At the same time, however, a trend is evident towards counselling being politically functionalised to legitimise questionable developments in medicine and politics. In this context, counselling is reduced to the function of cushioning negative social effects and garnering acceptance for the use of medical technologies during pregnancy. Therefore, independent counselling structures must be recognised and funded as a corrective measure. The primary guideline for counselling is every woman’s right to know or not know.
In the current discussion of embryonic stem cell research and preimplantation genetic diagnosis, one angle of argumentation enjoys particular popularity: the application of a double moral standard is evidenced by the fact that abortion – particularly abortion for social reasons – is tolerated by society, while the life of embryos produced in a laboratory is strictly protected. It is maintained that Art. 218 of the German Penal Code and the Embryo Protection Act lead to ethical and legal inconsistencies because in-vitro embryos enjoy greater protection than much more developed foetuses during pregnancy. In reference to this situation, there is often a call for both fields of conflict to be treated equally, which would necessarily mean abandonment of the current embryo protection concept and thus legalisation of preimplantation genetic diagnosis and embryonic stem cell research. This argument often implicitly or explicitly supports a gradualistic view of human dignity, according to which a foetus is allowed “more” human dignity than an early-stage embryo, and an infant “more” than a foetus. According to people like Reinhard Merkel, those who do not share this view fall into the “abortion trap”. On the other hand, they say that those who uphold this view can claim to support the interests of female self-determination, as formulated by the women’s movement in reference to sexuality and family planning, for two reasons. First, in-vitro embryo selection and research cannot be rejected without rejecting free choice concerning the continuation or termination of a pregnancy – Elke Mildenberger takes a critical look at this argument in her paper. Second, it would serve the interests of women to abandon embryo protection, because IVF, preimplantation genetic diagnosis and prenatal diagnosis promote self-determination for women. This aspect is explored in the following paper by Sigrid Graumann.

Against this backdrop, most feminists steadfastly refused to discuss whether unborn life was worthy of protection. Together with the refusal to assume social responsibility for children, it was viewed as a means for denying women a self-determined and equal role in society. Thus, the feminist concept of self-determination in reference to sexuality and reproduction was primarily a defence against the external control of women in partnership, marriage, family, society and politics. The concept made no claim to a right to have your own, healthy child. Furthermore, this definition of female self-determination targeted not only a woman’s personal choice concerning the continuation or termination of a pregnancy, but also the social constraints preventing women from independently deciding whether, when and how many children they wanted to have.

“Neither abortion, nor giving birth to a child is in itself an act of self-determination. Rather, self-determination refers to being able to make the decision to terminate or continue an (unwanted) pregnancy without external influence.”

In any case, this means that, from the feminist standpoint, the abortion issue cannot be reduced to the “protection-worthiness” of unborn life, but rather must be discussed in a social context.
This raises the unpleasant question of whether it is justifiable to critically examine the interests of these women from the feminist standpoint.

– It can hardly be denied that the “old position” just described portrays the affected women as victims of external control in an almost paternalistic manner. However, at least some women take advantage of these medical services in a self-determined and proactive manner, thus raising the unpleasant question of whether it is justifiable to critically examine the interests of these women from the feminist standpoint.

– It has also been criticised that the “old position” is associated with a kind of feminist mother ideology, which places female power solely in natural motherhood and is thus at risk of rehabilitating a conservative view of women—a maternal image the women’s movement still vehemently fought against in the conflict over Art. 218. Making natural motherhood the norm for a fulfilling life also diminishes other lifestyles pursued by women. Moreover, feminist theorists justifiably criticised the establishment of femininity and motherhood as norms, saying that this was essentialist. They countered by demanding equal recognition of different lifestyles as a new norm of the women’s movement.

Genetic and reproductive methods were the focus of feminist criticism in the Eighties. The dominant position in the women’s movement was the uncompromising rejection of prenatal diagnosis and in-vitro fertilisation. The attempt to transform fertility, pregnancy and birth into medical and technical issues was viewed as a new strategy for disempowering women. Portraying childlessness as a disease created an image of women that reinforced motherhood as the only fulfilling path in life and a societal norm. Doctors and researchers faced the accusation that their real motive was to gain control over human life and to degrade women to the status of a “foetal environment”. Genetic and reproductive methods were further viewed as part of a eugenic and racist population policy that aimed to control the quality of children in the north and the quantity of children in the south.

Inner-feminist criticism

“Key technologies”, such as prenatal diagnosis and in-vitro fertilisation, which were attacked by the women’s movement back then, are now widely established in society and used by many women. Thus, the flat rejection of these methods is apparently a thing of the past. This does not mean, however, that there is no longer any substance to the feminist criticism.

These circumstances, as well as the critical discussion of recent years within the feminist movement, are reason enough for all of us to elaborate a more differentiated position on the issues:
Women are not only victims, but also self-determining players on the market of medical possibilities and, as such, also bear responsibility.

**Conclusion**

In view of the plurality of feminist positions on socio-political controversies, in view of the variety of theoretical feminist approaches and in view of the functionalisation of female self-determination to legitimise research interests, we need a criterion for determining exactly what characterises a feminist position. Recourse to the interests of women cannot suffice, because no uniform female interests exist and probably never did. Moreover, the individual interests of women have inevitably always been criticised by the women’s movement, at least if they were interpreted as acquiescence to personal repression. Feminist positions can only be characterised as such by referring – also critically – to the women’s movement as an emancipation project.

The women’s movement as an emancipation project pursues the socio-political goal of establishing equality for all women, regardless of property, sexual orientation, skin colour, cultural origin, age, health or individual abilities. This goal makes it necessary to develop argumentation strategies that counteract direct and indirect discrimination against women. Direct discrimination means unjustified unequal treatment or ostracism (also against women by other women). Indirect discrimination refers to social values and norms that express contempt for women or other social groups.

For PND and PGD, this means, for example, that the views of women with disabilities and women with disabled children must also be incorporated.

Feminist positions can only be characterised as such by referring – also critically – to the women’s movement as an emancipation project.
Female self-determination should be supported in the debate as a term defined in a specific context.

This means that the pursuit of individual women’s interests should be criticised if the rights of other women are violated (such as egg cell “donation” and surrogate motherhood), or if they promote social developments that lead to direct or indirect discrimination against other people (such as prenatal diagnosis and preimplantation genetic diagnosis).

However, it would be unfair to make individual women responsible for the establishment of new methods if they possibly used them under direct or indirect psychological or social pressure. The responsibility for offering methods, such as in-vitro fertilisation, prenatal diagnosis and preimplantation genetic diagnosis, lies primarily in the hands of political and professional policy. Attempts to make individual women responsible for erroneous socio-political developments, as is currently being done, must be rejected.

Female self-determination should be supported in the debate as a term defined in a specific context. Social changes that enable a self-determined life for all women, with or without disabilities, must be demanded in the name of female self-determination. Against this backdrop, we must criticise medical practice that promises to fulfil the desire to have your own, healthy child by technical means, and that legitimises itself through the fear of having a disabled child or remaining involuntarily childless. By making perfect motherhood the norm, such a practice upholds the tradition of a misogynist mother ideology. This cannot be reconciled with the feminist view of female self-determination. The same applies both to naïve optimism regarding technical progress and to blind rejection of it. Feminist argumentation strategies should go beyond this kind of polarisation and aim to be socially critical instead.

The supposed freedom of choice on the market of biomedical services does not have much in common with this view of female self-determination.

Footnotes


5 Duden, Barbara, 1991, Der Frauenleib als öffentlicher Ort, Hamburg

6 Cf., for example, Fox-Keller, Evelyn, 1986, Liebe, Macht und Erkenntnis, Vienna, and Corea, Gena, 1988, Muttermaschine, Frankfurt


8 Cf. Mies, Maria, 1992, Wider die Instrumentalisierung des Lebens, Pfaffenweiler
Why unwanted pregnancies, embryo selection and embryo research must generally be treated differently

Elke H. Mildenberger

The main point of conflict in the debate surrounding reproductive medicine is the question of the “protection-worthiness” of artificially produced embryos. A specific argument is popularly used to support the demand for less strict protection of embryos “in a petri dish”: it is a contradiction that Germany’s current Embryo Protection Act (ESchG) gives the in-vitro embryo absolute protection from the earliest possible moment, while growing life in the uterus receives only relative protection under Art. 218 ff. of the German Penal Code. This argument calls for critical examination.

Relativised protection of the embryo in Art. 218 ff. of the German Penal Code

According to Art. 218 I 2 of the German Penal Code, the protection afforded by penal law begins not at the time of fertilisation, but rather about fourteen days later with the conclusion of implantation of the fertilised egg in the uterus. Art. 218 a I provides that an abortion is not an offence if the pregnant woman requests one within the first twelve weeks of pregnancy, having first gone for counselling. In the event of a “social medical indication” (Art. 218 a II), abortion is even possible shortly before birth, e.g. if the unborn child is expected to be disabled. Therefore, growing life in the uterus is given graduated protection under Art. 218 ff., while the in-vitro embryo is given absolute protection from the point of karyogamy onwards under the Embryo Protection Act. Would it not be an obvious step, in view of the therapeutic promises of (bio)medicine and science, to demand that the in-vitro embryo also be put under graduated protection?
Norbert Hoerster formulated an example in this connection: Case 1 – A woman kills an embryo, which was produced for the purpose of satisfying lust, at the age of two weeks by preventing implantation by mechanical or chemical means. According to current abortion law, she is permitted to do so without a doctor and without counselling. This is true. Case 2 – A scientist allows an embryo, which he produced artificially for the purpose of treating severe diseases, to die at the same age after concluding his experiments. According to the Embryo Protection Act, he would be jailed for up to three years or have to pay a fine. This is also true. Hoerster’s conclusion: “Certainly, one must never have read a philosophy book to see that a blatant contradiction exists between these two laws, both of which supposedly serve ‘to protect unborn life’.”

Quite apart from the fact that it is not medically possible to treat diseases with artificially produced embryos, this concluding statement reveals a fundamental lack of understanding of the difference between the two situations. Hoerster is not the only one who speaks of the supposed contradiction between the restrictive provisions of the Embryo Protection Act and the provisions on abortion in the German Penal Code. This is a primary line of argument used by the proponents of liberalisation in the field of reproductive medicine: they claim that those who speak out against embryo research cannot simultaneously support abortion.

It is a fundamental error in the debate to derive arguments for the release of embryos for research purposes, or for the ethically and legally highly controversial method of preimplantation genetic diagnosis, from the provisions on abortion contained in Art. 218 ff. German Penal Code. The demand to treat unwanted pregnancies, embryo selection and embryo research differently is not contradictory, at the very least because two entirely different areas of regulation are affected. Different circumstances must be handled differently in legal terms. This results from the general principle of equality in Art. 3 I of Germany’s Basic Law, but can also be derived from the principle of due course of law. Ethically, there is a crucial difference whether the embryo is inside or outside a woman’s body. The situation of an embryo in the context of a pregnancy and that of an artificially produced embryo are not comparable.

A pregnancy is not always wanted. It is mainly the unwanted pregnancy that leads to a pregnancy conflict and thus to the question of how to settle it. If we want to avoid forcing women to give birth, the conflict can only be resolved by either helping the woman develop an accepting relationship to the foetus, or giving her the right to abort. Forcing a woman to give birth would violate the dignity of women, their basic right to self-determination and their basic right to physical
integrity. Moreover, a “special” relationship exists between a pregnant woman and the embryo, in that the unborn life exists only in and through the mother. It is this real, physical connection that makes differentiating regulations imperative. Graumann justifiably characterises pregnancy as “a unique form of an existential, physical care relationship”. The unborn child is protected by this relationship to the mother, at least if she is willing to develop a physical and emotional relationship to the embryo. However, this can only occur on a voluntary basis. The abortion laws attempt to cater to the real, personal conflict situation a woman faces in an unwanted pregnancy.

The situation of the embryo is entirely different in the case of artificial insemination. There is no comparable conflict situation here, because an embryo in a test tube “exists” outside the womb. Artificial reproduction is deliberate and intended. Only couples who want children undergo the IVF procedure, which is very stressful for the woman. In this instance, the embryo does not exist only in and through the woman, but rather on its own to a certain extent. At this point, it has no physical or real connection to the mother. The mother, who does not yet carry the embryo in her body, does not provide any additional protection. Consequently, a pregnancy-specific conflict cannot manifest itself in this case. The decision to discard an embryo is not comparable to the pregnancy-specific coping process a woman experiences.

On the legal level, this different context means that an embryo produced outside the body must be given greater protection than an in-vivo embryo. Protection of the in-vitro embryo could only be analogous to the abortion laws if the circumstances of a pregnancy, which justify impunity, were to exist in the case of embryo research or PGD, but this is not the case. Therefore, it is only logical that the Embryo Protection Act protects an artificially inseminated egg cell directly from the time of karyogamy, while Art. 218 ff. gives priority to the interests of the woman in an unwanted pregnancy in a specific conflict situation.

Under constitutional law, the entitlement of an embryo in a petri dish to greater protection can be explained as follows: Germany’s Basic Law obliges the state to protect human life, including unborn life. The German Federal Constitutional Court reaffirmed this in its decision on the revision of the abortion laws, pointing out that the duty to protect is rooted in the principle of human dignity. The decision states that even unborn human life is entitled to human dignity. The extent of the duty to protect unborn life must be defined in relation to the significance and vulnerability of the object of legal protection on the one hand, and of conflicting objects of legal protection on the other. The court says that the entitlement of an unborn child to protection vis-à-vis its mother can basically only be fulfilled if the law-makers impose on her a legal obligation to bear the child. Even a mother’s basic rights could not claim general priority over the right to life of the embryo. However, the court at least also admits that, in reality, it can only be left to the woman herself to decide whether or not she can accept the obligations associated with motherhood. The court confirms that, at least in the early phase of a pregnancy, effective protection of unborn
In contrast to the basic right of human dignity, the right to life provided by Art. 2 II Basic Law can, within limits, be weighed against other constitutionally guaranteed rights. However, we must differentiate with regard to the protection of unborn life: it involves protection against intervention by third parties (medical profession/research) on the one hand, and the termination of an unwanted pregnancy on the other. The fact that the embryo cannot claim its right to life independently of the mother means that a woman’s basic rights take priority over the embryo’s right to life. The situation is different when the objective is to protect an embryo existing outside the womb from third parties. Because no one other than the mother has a special relationship to the embryo, the embryo’s basic right to life becomes a right to defence against third-party intervention. Unlike in a pregnancy, different, isolated individuals with basic rights are involved in this situation. Even if the right to life arising from Art. 2 II 1 Basic Law is not protected absolutely, the fact must not be ignored that this basic right must be interpreted in the context of human dignity. Consequently, the ban on functionalisation imposed by Art. 1 Basic Law has an impact on the interpretation of Art. 2 II. Therefore, the embryo’s right to life must take priority over third-party interests that restrict this right, if these interests serve the purposes of third parties, e.g. the research interests of others, or also the reproduction interests of parents. The right to life is given the highest priority when it comes to the possibility of weighing it up against other basic rights.\(^4\)
In-vivo and in-vitro embryos must be given equal protection against efforts to allow selection.

A contradiction exists between the restrictive treatment of PGD in the Embryo Protection Act and the broadly defined social medical indication in Art. 218 a II German Penal Code, insofar as the latter enables de facto selective abortion of a foetus. However, this imbalance in the legal evaluation of the medically feasible cannot be remedied by lowering the legal barriers protecting artificially created life. In-vivo and in-vitro embryos must be given equal protection against efforts to allow selection.

Selective abortion of disabled foetuses

These considerations, however, do not take into account the fact that Art. 218 a II German Penal Code permits the abortion of an abnormal foetus. The argument stating that the abortion of disabled children is possible, and that PGD must therefore also be permitted for the sake of consistency, requires differentiated examination. With regard to the social medical indication, it can be said that, according to the formulation of the law, an expected disability in a child does not justify an abortion per se. Rather, an abortion is justified only if it averts “a risk to the life of the pregnant woman, or a risk of severe impairment of her physical or psychological health”. In contrast, in PGD following IVF, only the disability is decisive, because such a risk cannot manifest itself at all in this case. This statement is based on the premise that the decision to terminate a pregnancy is more difficult to make than the decision to dispose of a “mass of defective cells”. Thus, there is no contradiction so far – if we take the actual concept of the law as a guide. However, this does not apply to the common practice of affirming a social medical indication solely on the basis of the abnormality of the child, at least not when a pregnant woman only considers the expected disability of the foetus in her decision to have an abortion. My intention here is not to point out that a woman’s personal decision not to give birth to a disabled child is in itself discriminatory. The question is whether and to what degree this decision is influenced by social reality and the social pressure not to (or no longer to) bring children with disabilities into this world.

Footnotes

1 See Frankfurter Allgemeine Zeitung, 24.02.2001, p. 46
3 German Federal Constitutional Court Decisions (BVerfGE) 88, 203 ff.
4 See German Federal Constitutional Court Decisions (BVerfGE) 39, p. 42
5 Details in Graumann’s conference paper
Results

- Getting involved in the “prevailing debate”
- Overcoming individualised interpretation by addressing social/cultural changes

The discussion in this Forum began with the “contradiction” currently dominating the public debate on PGD and embryonic stem cell research. It is maintained in this debate that an ethical and legal contradiction exists in that abortion is extensively tolerated, while embryos produced in vitro are strictly protected. Feminists are targeted in the discussion by the claim that it is inconsistent to reject PND, PGD and embryo research, while holding fast to the right of women to self-determination in deciding to continue or terminate an unwanted pregnancy.

There was general agreement in the discussion that it is necessary to get involved in the “prevailing” legal debate in order to effectively repudiate this supposed contradiction. From a feminist/legal standpoint, the unique relationship between a pregnant woman and her unborn child plays a key role, which is unjustifiably negated by many lawyers, politicians and ethicists. Only an unwanted pregnancy affects inalienable women’s rights, which is why the foetus can only be protected with, and not against, the woman in this case. If the embryo is formed in vitro, this does not affect the rights of any other person. Therefore, the protection of life provided under constitutional law must be given priority. Doubts about whether we should even get involved in the debate on the protection of life from a feminist viewpoint were countered by the suggestion that we must pursue this legal argumentation strategy, because the legal regulations effectively start here and nowhere else.

At the same time, however, concentration on the “protection of life” in the public debate should be rejected and the social consequences of IVF, PND, PGD and embryonic stem cell research shifted into the focus of the discussion. To this end, a context-based definition of “female self-determination” must be elaborated, which imposes responsibility on women as self-determined individuals, but simultaneously takes into account the social constraints under which women make decisions. In this context, recourse can be made to the self-reflection process of the women’s movement in the feminist theory of recent years. As a consequence of the feminist “differentiation debate”, the self-determination concept must take all women into account, thus also women with disabilities and women with disabled children. We must be careful to keep mother ideologies at a critical distance in developing our argumentation strategies and thus avoid the accusation of essentialism (rejection of how doctors and researchers overrate the desire to have children, but also avoidance of overrating the “naturalness” of reproduction). Furthermore, we must make sure we do not get taken in by a general and unexamined anti-technology attitude, which was criticised as being a barrier to the participation of women in society. These traps can be effectively avoided, because the feminist criticism of IVF, PND, PGD and embryonic stem cell research can be soundly justified by the negative consequences for the individual women involved and for the standing of women (with and without disabilities) in society.
Kabarett auseinsmachzehn
was nützt der bauch, wenn nichts mehr drin steckt

Kabarettistisch verarbeitet in Wort, Ton und Spiel von Anita Walter | Gaby Pochert | Ulrich Schlumberger

Du musst verstehn! Aus Eins mach Zehn
Und Zwei lass gehen, und Drei mach gleich,
So bist du reich. Verlier die Vier!
Aus Fünf und Sechs – so sagt die Hex’ –
und Neun ist Eins, und Zehn ist keins.
Das ist das Hexeneinmaleins!

Tauschmarkt für Neuwertiges, Getragenes und Unerträgliches

Frech-fröhliche und nachdenkliche (Un-) Gereimtheiten,
den menschlichen Wert und Unwert betreffend

Manche tanzen manchmal wohl ein Tänzchen,
immer um den heißen Brei herum.
Mit etwas Glück und Salz und mit Pfeffer,
erzielt man manchmal völlig ungeahnte Treffer
und hat das Neue nur einen winzigen Zacken mehr,
wir müssen´s haben, bitte sehr, man ist ja wer!
Wer könne denn wirklich wissen,
was später aus einem anfangs ganz reizenden Kinde wird.
Der Doktor sagt, das wird schon werd’n,
die meisten leb’n net lang und sterb’n!
Das Leben kommt auf alle Fälle aus einer Zelle,
und manchmal endet´s auch bei einer solchen!

Kontakt: Gaby Pochert, Bergstr. 135, 53129 Bonn
The purpose of this panel discussion was to develop strategies for adding a dimension to the current debate that would be specific to women and women’s policy, and to get women more involved in decision-making processes. The results of the discussion forums of the previous day formed the basis for debating intervention options and strategies for women’s policy work in the fields of genetic engineering and reproductive medicine. While a consensus had already been reached on the first day that the entire debate surrounding genetic and reproductive methods and research must be presented to the broad general public, the end of the conference focused on questions of practical implementation: how can feminist views gain greater attention, or be more broadly acknowledged in the current conflict over preimplantation genetic diagnosis (PGD), embryonic stem cell research and “therapeutic” cloning? What political latitude is available for achieving this goal? What kinds of activities are suitable for this purpose and how can they be initiated/implemented?

Self-determination –
A concept in search of a “true” definition

In the discussion with the panelists, “self-determination” was introduced once again as a fundamental concept that is an “old battle-cry” in women’s policy and thus needs to be redefined and differentiated.
The term “self-determination” has many facets and levels, such as:
- Rejection of restrictions and thus rejection of attempts to usurp decision-making autonomy.
- The right of other women to self-determination must not be restricted.
- The term must incorporate the relationship level, as well as the social, socio-economic and political prerequisites and basic conditions that allow, restrict or even suppress the choices available to women, and it must not be limited to the bodies or personal situations of individual women or groups of women. On the contrary, this standpoint would pave the way for abuse by others, who would instrumentalise the term for their own purposes in the name of women.
- Self-determination implies participation and decision-making, i.e. women must be involved in making decisions that affect them.
- Self-determination must apply to all women: other standards are applied to women with disabilities in reference to pregnancy, the desire to have children or not, and a self-determined lifestyle.

Deciding between risks

By restricting the self-determination concept to individual women and their choices and decision-making options, responsibility for the social development of genetic engineering and reproductive medicine is shifted onto individual women. However, the real responsibility lies particularly in the hands of the medical profession and politics, which try to give women the message that the decision for or against PND or PGD is a purely personal one and independent of social factors.

Genetic policy is everybody’s business?!

In order to impress on the public the political and social implications of bio- and genetic policies, it must first be emphasised that they involve not only “women’s policy”, but also welfare policy, economic policy, research policy and social policy. Ultimately, they constitute a future policy that affects everyone – men and women alike. The rapid progress in the various practices of reproductive medicine and genetic engineering follows the capitalist principle of exploitability in some respects, where a person becomes a “product” and the goal is “healthy performers” who enable optimum exploitation. Consequently, the feminist analysis of reproductive technologies must include a critical view of capitalism, society and power. It is not just about an individual dimension, as scientists in reproductive medicine often suggest, but also about money and power.

Interventions and strategies

The discussion covered various strategies, intervention options and ideas for future political work with regard to their different effects and the different levels on which they will take place. However, they must always be viewed or applied in connection with the respective political situation. Moreover, the potential of active participants must be matched to the actions planned, and judged and utilised realistically.

Self-determination implies participation and decision-making, i.e. women must be involved in making decisions that affect them.

Self-determination must apply to all women.

The feminist analysis of reproductive technologies must include a critical view of capitalism, society and power.
The following strategies and interventions were formulated:

- **Strengthen networks**
  Societies, associations, initiative groups, etc. that deal with bio- and genetic policy issues must become more networked than in the past in order to identify common goals and address them jointly. The objective is to be perceived as a movement.

- **Engage in an active policy of alliances**
  Because the subject of genetic engineering and reproductive medicine encompasses numerous different aspects, allies must be found in a variety of areas/groups, e.g. women’s associations, the disabled persons movement, the health movement, the churches and other socio-political associations. These groups must be actively contacted with the aim of involving them in the political work. It must be made clear that the subject affects us all, even if a direct link is not apparent at first glance.

- **Increasingly include the European level in future plans**
  When we think of “future genetic policy”, we mean more than just national considerations. More and more decisions are being made on the European level. Consequently, it would be desirable to establish a network of allies and groups critical of genetic engineering and reproductive medicine in Europe. We must seek contact and exchange with networks active on the European level. In addition, the international effects of national programmes must be considered and explored.

- **Point out connections**
  Many people are unaware of the implications of genetic engineering and reproductive medicine. This makes it all the more important to point out the extent to which people are affected by applied and future technologies, and particularly the effects on women (their bodies) and the female biography. Not only direct changes/consequences must be illuminated, but also their impact on other, seemingly unrelated spheres, such as labour and social policy, medical care and social security.

- **Tackle false conceptions**
  Opinions on, and conceptions of, genetic policy and biopolicy are not only very divided, but also frequently false or at least misleading, even though they are propagated as being correct. Therefore, it is crucial to tackle prejudices, false and incomplete information. The instrumentalisation of people with disabilities, who are portrayed as “the beneficiaries of these new developments”, completely overlooks, for example, the social consequences of the new technologies, especially for people with disabilities: groups for the disabled have repeatedly pointed out that the goal of PGD and PND is not to prevent disease and disability, but to prevent the birth of people with disabilities, and that these technologies challenge the right to life of people with disabilities.

- **Distribute information for specific target groups**
  The flood of information on issues of bio- and genetic policy has increased immensely in recent months and easily overwhelms even the interested layman. Therefore, it would be desirable if the wealth of information could be summarised and distributed to specific target groups, particularly multipliers and decision-makers. Modern information technologies are well-suited to this purpose. However, this also requires financial support.

- **Establish and utilise parliamentary contacts**
  Key decisions are made in the German Bundestag. Therefore, women politicians on the municipal, state and federal level must be specifically addressed and informed. There must be a close exchange between the parliamentary and extraparliamentary levels, also for the purpose of mutual support. Women in other groups that deal with genetic engineering and reproductive medicine must also be involved.
This also requires learning more about parliamentary structures, voting practices and requirements, as well as possible ways to contact members of parliament and thus influence political decisions.

--- Plan targeted campaigns

Various campaigns must be carried out repeatedly in order to raise awareness of genetic and biopolicy issues among the general public and at the political level. The campaigns can involve the specific dissemination of relevant information, lobbying work with female politicians, an exchange between women both inside and outside political decision-making structures, the establishment of networks between women, and an exchange of information between the various sectors. Public campaigns should be examined beforehand with regard to their effect: it is important to consider whether the respective campaigns really make sense or could possibly awaken “sleeping dogs”, i.e. result in trouble rather than success. Example: a targeted signature-collecting campaign, or a single letter to a woman politician, could be more likely to elicit her support than an extensive e-mail campaign, which stuffs an electronic mailbox just like a mass-mailing or can even cripple a communication system.

--- Outlook

In the discussion of strategies for work in genetic and biopolicy, it became clear that a broader network is required in order to be effective in the long term. ReproKult made an important step in this direction by organising the *Women Between Self-Determination and Societal Standardisation* conference. ReproKult was initially established as an alliance dealing with actual issues and a discussion platform for women experts in the field. The conference turned this focus outwards by including in the discussion other political networks and alliances of women and critics of genetic engineering and reproductive medicine. The conference established new connections. Now, collaboration with other organisations for women and people with disabilities must be expanded.

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Genetic and biopolicy issues must be discussed broadly and the various facets and consequences for women illustrated. Corresponding structures and networks are required for this purpose, and for the ability to influence political decisions (see also opening discussion). The conference made its contribution in this respect, opening up opportunities for increased networking, and especially for motivating women in societies, associations and initiative groups (also outside the field) to actively voice their critical opinions in future discussions and decision-making situations. Existing and newly established contacts and connections must be intensified in the future to enable improved networking and cooperation, and to successfully implement joint activities and campaigns.

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There must be a close exchange between the parliamentary and extra-parliamentary levels, also for the purpose of mutual support.
Speakers

__Dr. Giselind Berg__
Sociologist, Institute of Ecology at Berlin Technical University. Concentration: Migration and health, women’s health research, reproductive health, public health/health sciences, genetic and reproductive technologies.

__Dr. Cornelia Bormann__
Sociologist, scientific assistant until 2001 on the North-Rhine Westphalian State Legislature’s study commission on “The future of woman-oriented healthcare in North-Rhine Westphalia”. Concentration: Prevention/health promotion, healthcare research, public health, rehabilitation research, medical ethics.

__PD Dr. Kathrin Braun__
Political scientist, Institute of Political Science at Hanover University. Concentration: Biomedical policy, political philosophy, particularly legal philosophy and democratic theory, feminist political theory. Advising member of the Law and Ethics of Modern Medicine study commission of the German Bundestag.

__Marion Brüssel__

__Prof. Dr. Barbara Duden__
Historian, teaches social science at the Institute of Sociology at Hanover University. Concentration: History of the body, the senses and the somatic self-reference.

__Brigitte Faber__

__Monika Fränznick__

__Pia Goldmann__
Gynaecologist, many years of experience with the critical confrontation of women’s health issues, member of the Network Against Selection By Prenatal Diagnosis, AKF e.V., and other affiliations.

__Dr. Sigrid Graumann__
Biologist and philosopher. Scientific assistant at the Institute of Humankind, Ethics and Science (IMEW) in Berlin. Research concentration on the ethics of modern biomedicine and reproductive medicine. Advising member of the Law and Ethics of Modern Medicine study commission of the German Bundestag.

__Silke Koppermann__
Gynaecologist, in the Hamburg Family Planning Centre since 1997, medical counselling on partnership, sexuality, fertility, contraception, conception, abortion and prenatal diagnosis. Member of the Women’s Health Working Group (AKF e.V.), Network Against Selection By Prenatal Diagnosis, German Association for Psychosomatic Gynaecology and Obstetrics.

__Prof. Dr. Cornelia Helfferich__
Professor of sociology at the Protestant Technical College (EFH) – College of Social Work, Deaconry and Religious Education, Freiburg. Director of the Social Science Women’s Research Institute at the Research Contact Office of the EFH (SoFFIK.).

__Svea Luise Herrmann__
MA, political scientist. Concentration: Biopolitics, biomedical policy; currently completing doctoral work at Hanover University.

__Ulla Hommerich__
Graduate psychologist, psychological psychotherapist, supervisor primarily for women’s projects. Continuing education provider for women in the psychosocial field. Lecturer at the German Institute for Psychotraumatology. EMDR therapist and supervisor at the EMDRIA Institute of Germany, Bergisch Gladbach.

__Prof. Dr. rer. nat. Regine Kollek__
Professor of risk assessment for modern biotechnology in medicine at Hamburg University. Deputy Chairwoman of the National Ethics Council. Research concentration: Risk assessment (RA) for biotechnology in medicine. RA studies in genetic diagnosis, neurobiology, reproductive medicine, and cell and tissue replacement methods. Medical ethics.

__Ulrike Hauffe__
Graduate psychologist, Bremen State Commissioner for Women. Chairwoman of the Women and Equality Committee of the German Cities Assembly. Vice President of the German Association for Psychosomatic Gynaecology and Obstetrics.
Margaretha Kurmann
Graduate theologian, work in the field of continuing education, women’s issues and health, including counselling on prenatal diagnosis, work for the Prenatal Diagnosis/Reproductive Medicine Office of the German Association for the Physically and Multiply Disabled, founding member of the Network Against Selection By Prenatal Diagnosis.

Dr. iur. Elke H. Mildenberger
Scientific assistant at the Institute of Criminal Science at Münster University, member of the Criminal Law Commission of the German Women Lawyers Federation. Research concentration: Criminal proceedings law – witness protection; criminal law: sex crimes law (and its reform); bioethics: research on humans, reproductive medicine, Embryo Protection Act.

Gaby Pochert
Actress, musician, studied violin and piano at Stuttgart Academy of Music and acting at the College of the Arts in Berlin. Fifteen years as a film and stage actress with appearances in Munich, Ulm, Mannheim, Freiburg, Berlin, Bonn and other locations.

Rita Polm

Martina Puschke
Graduate educator, Chairwoman and founding member of Weibernetz e.V. – National Network of WomenLesbians and Girls with Disabilities. Active in the women’s movement and the self-determination movement of disabled people.

Concentration: Genetic and reproductive medicine from the standpoint of disabled women, self-determination of women and the disabled, political lobbying.

Prof. Dr. Birgit Rommelspacher
Rector of the Alice Salomon College of Social Welfare in Berlin, instructor at Berlin Technical University. Research and work concentration: Gender research, racism and anti-Semitism. Numerous publications, e.g. on women and anti-Semitism, foreignness and power, multicultural society.

Ulrich Schlumberger
Accordion, studied at the Music Colleges in Trossingen and Essen. Winner of various national and international competitions, holder of a scholarship from the Art Foundation of Baden-Württemberg. Diverse work as a concert accordionist, with various tango troupes and as a freelance theatre musician.

Dr. Eva Schindele

Dr. rer. pol. Anne Waldschmidt
Social scientist, professor in the Nursing Management Department of Nuremberg Protestant Technical College. Research concentration: Sociological aspects of human genetics and prenatal diagnosis, self-determination and bioethics, disability and normality. Founding member of the Network Against Selection By Prenatal Diagnosis.

Anita Walter
Actress, musician, studied flute at Franz Liszt College in Weimar and acting at the College of Film in Potsdam-Babelsberg. Twenty-five years of acting experience in Germany and Switzerland, appearances in Darmstadt, Bonn, Cologne, Bern, Basel, Bremen and other locations. Solo cabaret programmes for more than ten years.

Annette Will
Graduate biologist, reproductive rights activist. Active in national and international political contexts. Concentration: Women’s health, reproductive rights, population and contraceptives policy, genetic and reproductive technologies, pharmaceutical industry, drug research.

Dr. med. Claudia Schumann
Gynaecologist/psychotherapist, office for psychosomatic gynaecology in Northeim, Chairwoman of the Women’s Health in Medicine, Psychotherapy and Society Working Group (AKF e.V.).

Brigitte Sorg
Graduate social educator, employee of the Feminist Women’s Health Centre in Berlin. Concentration: Reproductive medicine, contraception, hysterectomy, abortion, women’s health policy. Member of ReproKult, the Network Against Selection By Prenatal Diagnosis, and other affiliations.

Dr. rer. pol. Anne Waldschmidt
Social scientist, professor in the Nursing Management Department of Nuremberg Protestant Technical College. Research concentration: Sociological aspects of human genetics and prenatal diagnosis, self-determination and bioethics, disability and normality. Founding member of the Network Against Selection By Prenatal Diagnosis.

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__BioSkop mit Newsletter Behindertenpolitik, ed.: BioSkop Forum zur Beobachtung der Biowissenschaften und ihrer Technologien e.V.Bochumer Landstr. 144a, D-45276 Essen
Tel.: +49-(0)201-53 66 706, Fax: 53 66 705
E-mail: erika.feyerabend@t-online.de
BioSkop publishes information sheets on current issues at irregular intervals.

__Materials published by the Federal Centre for Health Education (BZgA), available from:
Bundeszentrale für gesundheitliche Aufklärung
Ostmerheimer Strasse 220, D-51109 Köln
Fax: +49-(0)221-8992-300;
E-mail: order@bzga.de

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Feministisches Frauen Gesundheits Zentrum e.V. (FFGZ), Berlin
Bamberger Strasse 51, D-10777 Berlin.
Tel.: +49-(0)30-21 39 597,
Fax: +49-(0)30-21 41 927
E-mail: ffgzberlin@snafu.de

__Dr. med. Mabuse, Zeitschrift im Gesundheitswesen
Mabuse Verlag GmbH
Kasseler Str. 1a, D-60486 Frankfurt am Main
E-mail: info@mabuse-verlag.de
http://www.mabuse-verlag.de

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__Gen-ethischer Informationsdienst (GID), Information & Kritik zu Gen- und Fortpflanzungstechnologien, ed.: Gen-ethisches Netzwerk e.V.
Brunnenstrasse 4, D-10119 Berlin
Tel.: +49-(0)30-68 57 073,
Fax: +49-(0)30-68 41 183
E-mail: gen@gen-ethisches-netzwerk.de
http://www.gen-ethisches-netzwerk.de
The Gen-ethisches Netzwerk publishes materials on genetic engineering and reproductive medicine.

__Koryphäe, medium for feminist natural sciences and technology
Cloppenburger Str. 35, D-26135 Oldenburg

__Ohrenkuss ... da rein, da raus, a magazine by people with Down's Syndrome.
In der Maar 10, D-53175 Bonn
Tel.: +49-(0)228-38 62 354,
Fax: +49-(0)228-54 97 16
http://www.ohrenkuss.de
E-mail: redaktion@ohrenkuss.de

__Circular published by the Netzwerk gegen Selektion durch Pränataldiagnostik. Published biannually, available from the Bundesverband für Körper- und Mehrfachbehinderte e.V.
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Ed.: Behindertenbeauftragter des Landes Niedersachsen, Postfach 141, D-30001 Hannover.
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Concept and editing: Angelica Ensel, Silke Mittelstädt. Published with the Bund Deutscher Hebammen e.V. Available from: Bundesverband für Körper- und Mehrfachbehinderte e.V.

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__Was ist Bioethik? Brochure by initiative groups against the planned Bioethics Convention.
Contact address: Tübinger Initiative,
Erlenweg 40, D-72076 Tübingen
Tel.: +49-(0)7071-60 01 11,
Fax: +49-(0)7071-93 04 79

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Document 14/9020, 14.05.2002

__Weise Wege – Alternative Gedanken und Informationen zur Gesundheit von Frauen.
Planungsgruppe Klinik für Ganzheitliche Frauenheilkunde e.V., c/o Beratungsstelle für Natürliche Geburt und Eltern-Sein e.V., Häberlstr. 17, D-80337 München.
Positions for discussion

Human is human

The image of humankind in prenatal diagnosis and reproductive medicine

The common image of the disabled has always been associated with “suffering, a hard fate, tragedy, burden, punishment and trial”. Even well-intended comments made in dealing with disability, such as “compassion, sacrifice, care, good deed” or “despite being disabled”, contain this negative basic view. This assessment of life with a disability can also be found in the wording of laws and in research. In the case of an abortion performed on the basis of an abnormal prenatal diagnosis result, a disability is considered to be an “unreasonable burden”; in preimplantation genetic diagnosis (PGD) and in connection with the new genetic technologies, it is viewed as “suffering”, and in this area increasingly also as “avoidable suffering”.

A picture of incapability, unhappiness and stress is drawn in every instance – for the person with the disability as well as for others. The new technologies claim to want, and in this area increasingly also as “avoidable suffering”.

The cost factor

The question of cost often comes up in connection with prenatal diagnosis and the new medical technologies: people with disabilities simply cost a lot (too much?). More and more people are asking just how much the community based on solidarity can bear. Statements such as “we can’t afford that any more” are being heard more and more frequently. A person’s worth is increasingly judged by economic aspects alone, with reference to the general good.

Statistics

Only about 5% of severe disabilities (defined as being over 50% disabled) are congenital. Of these, roughly 0.5% can currently be detected by means of prenatal diagnosis. The promise of “preventing suffering and costs” seems absurd in view of these figures. It poses the question of whether the “nightmare of disability” and the promise of being able to dispel it are not being used to gain social acceptance for technologies whose interests are rooted to a significant extent on the scientific and economic level.

The question of “guilt”

According to the promises of prenatal diagnosis and genetic engineering, a healthy child becomes a manufacturable commodity. Quality control “guarantees” the quality of the “product child”. Disease and disability are no longer viewed as things that concern us all, that can affect us all and are part of life, but rather as things for which the individual is personally responsible. Disability thus becomes a question of personal guilt. The guilt of a mother if she does not take advantage of the possibilities offered, or even consciously decides in favour of a disabled child. The guilt of doctors if they do not “discover” a disability and do not recommend or urge abortion emphatically enough. Recent court decisions illustrate this development. For example, children with dis-
abilities have repeatedly been declared a “loss” and doctors sentenced to compensate for the loss by way of maintenance payments. Consistent with this trend are also the efforts of insurance companies, e.g. in the USA and France, which no longer want to cover costs related to a disability for newborns with a congenital disability.

**Separating “disability” from “people with a disability”**

In order to avoid suspicions of a new form of eugenics, disability itself is separated from people with a disability. Naturally, people with a disability are not devalued. They have an unrestricted right to life. Only the fact of disability is supposedly to be prevented. However, this separation is a theoretical construct, because the fact of disability always involves people who have a disability. The separation into “disability” and “people with a disability” legitimises the applied methods and clearly of the accusation of being eugenic practices. However, the consequences of these practices affect not only disability itself, but also people with a disability.

**Promises of a cure**

The promise of healthy children and the headlines about genetically manufactured medications or future “spare parts” for previously untreatable diseases and disabilities elicit (frequently unfulfillable) hopes in the affected people and thus promote acceptance of the new technologies, even among disabled people. At the same time, however, the overall social pressure to get and be healthy is increasing. The “magic world” of medicine and technology makes it seem as if virtually nothing is untreatable any more.

And for diseases that are still not treatable despite all past efforts, the scientific community implies that all it needs is suitable research material, which includes not only “surplus” embryos, but also people unable to take a personal stand on this kind of research. It is argued that people unable to give their consent would surely make themselves available for research purposes if they could express themselves, in order to make their personal contribution to “conquering disease and suffering”.

Even in the case of existing diseases and disabilities, the affected persons are thus increasingly being made responsible for their condition. Either they have not exploited every option or, as a group, have not made their contribution to the well-being of others and the solidarity community by acting as research objects.

**Equal rights and autonomy**

While the avoidance and destruction of “disabled life” has occasionally been on the agenda of past governments in history, every person today is supposedly free to decide for or against a disabled child. However, in a solidarity community that is increasingly only willing to support those in need of little or no support in the health sector, it is questionable to what extent we can still speak of freedom, or of equal rights and the acceptance of people with disabilities.

The same also applies to the autonomy of women. Even today, women are still primarily responsible for the care and raising of children, regardless of whether the women work or not. They receive little social support in this task. Consequently, “healthy children” are portrayed as a modern woman’s guarantee of the opportunity for self-realisation. In combination with the increasing assignment of guilt if a disability should occur, the supposed possibility of having healthy children quickly becomes a compulsion to do so.
Conclusion

Regardless of the numerous possible causes of disability and disease (accidents, stress at work, environmental pollution, “wear and tear”, poor social conditions), health and normalcy are increasingly portrayed as personally creatable conditions, for which each person is to be made responsible. Health becomes a personal performance criterion and a characteristic of “socially responsible” behaviour. The responsibility of society (e.g. including that of the economy and industry) for the well-being of all people increasingly slips into the background. And while everyone is called upon to do everything they can for the well-being of society, society itself is denying people more and more support should they no longer be capable of performing. This process affects all people. However, the rising pressure to be healthy, beautiful, capable and eternally young is easier to market by means of the “nightmare of disability” and the promise to dispel it by technical means. But despite these promises, disease and disability will always be part of human life.

Accordingly, we support the following principles:
– Every person is valuable just the way he or she is, regardless of his or her respective physical, mental or psychological make-up.
– Every woman and every man has the right to “imperfection”, because there is no guarantee for a life without physical, emotional or mental restrictions.
– Every person has the right to live. No one has the right to define whether or not someone else’s life is worth living.
– No one has the right to make others available for scientific experiments.
– No one has the right to use women in the fulfilment of his or her own interests.
– The birth of a disabled child is not a question of personal guilt. Guilt may not be assigned based on the possibility of avoiding a prenatal disability.

Positions on prenatal diagnosis

Prenatal diagnosis in routine pregnancy care

Prenatal diagnosis is a standard part of pregnancy care in gynaecological practice today. The field of gynaecology has responded to the needs of women and their partners for support in the pregnancy process with a concept that focuses on examinations and tests of the unborn child and any possible deviations from the norm the child displays. These measures – at least during pregnancy – target impairments, disabilities or diseases that are usually not treatable, and their results often suggest that termination of a previously wanted pregnancy is the only available alternative.

Selective methods of this kind are used every day as a matter of course in routine pregnancy care. For every woman, they include blood tests and ultrasounds, which look for indications of a possible disability/impairment, as well as invasive methods such as amniocentesis, which is usually offered to women over 35. Above all, the ultrasound examination is becoming increasingly important: the nuchal translucency test, the goal of which is to specify the risk of Down’s Syndrome, for example, is becoming established as a new screening procedure in early pregnancy. As part of social norms, these examinations and tests measure the unborn child against supposed standards, evaluate and isolate, and turn the underlying mentality into a normative standard.
This leads to fears that our image of humankind is becoming less and less diverse: only achievers without impairments appear to be acceptable. We share our concern about the selective intentions and consequences of prenatal diagnosis with many social groups and institutions.

Prenatal diagnosis has a number of “risks and side effects” relating to women's health, how pregnancy is treated, and how disease and disability are viewed. They are neglected or trivialised in a discussion that is largely conducted away from the public eye. Despite the debate among experts who criticise these circumstances, the use of prenatal diagnosis has spread and is becoming increasingly common. In the intensifying conflict over this issue, the reality of social and women's policy is being ignored, as are the negative, stressful experiences of women. Ironically, the spread of these technologies is justified by precisely the desperate situations individual women find themselves in.

The contradictions and decisional conflicts associated with prenatal diagnosis must be borne by women and the people accompanying them (partners and professionals in the social/medical system), while those who promote these technologies enjoy the economic benefits and can pursue their research and career interests.

**Positions**

Society is responsible for limiting what is feasible. The methods, possibilities and nature of selective diagnosis must be justified on the supply side in reference to their social and ethical significance. This requires us to pause and reflect. Above and beyond the criticism of the selective aspects of prenatal diagnosis, the Women's Forum places emphasis on their consequences for women, regardless of the fact that many women want to, and can, make use of these technologies for themselves.

Women are called upon to make their own decision to use or reject these technologies. They can only do so on the basis of social expectations and realities. Everyday use of the methods has created new responsibilities. It has contributed to burdening primarily women alone with the responsibility for children, for doing everything they can to give birth to – “healthy” – children.

For women, pregnancy is a phase of life that is significant not only physically, but also emotionally and with regard to social interaction. However, prenatal tests on an expected child presuppose a primarily medical relationship to pregnant women and they influence the image and understanding of pregnancy in their own way. They can make women dependent on experts, their explanations and interpretations. If they agree to undergo prenatal diagnosis, women are forced to rely on “experts” in making decisions, despite the fact that these experts do not actually assume responsibility for the results in the event of a conflict (e.g. if a woman has a miscarriage as a result of amniocentesis or is confronted with an abnormal result). In everyday prenatal diagnosis, we cannot identify any framework conditions that enable, promote, support and expand the opportunities of women for self-determination. Routine pregnancy care, as defined in the maternity guidelines, does not even require informed consent for an ultrasound.

These technologies are developed and advanced on women's bodies and souls. For many women, prenatal diagnosis is associated with traumatic experiences: decisional conflicts, insecurities, anxieties, degradation, miscarriages, difficult abortions and missed opportunities for shaping their own lives. These experiences are given little consideration, while suffering that is presumed to be “avoidable” serves to legitimise selective prenatal diagnosis.

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Self-determination and external control

Prenatal diagnosis is said to promote the self-determination of women. But closer examination reveals that the term is interpreted in a new way in this context. The fight for self-determination is rooted in the demand for basic human rights, for women too. It is defined by the rejection of external control and claims to power. In connection with prenatal diagnosis, however, we are seeing an impermissible interpretation of the term: self-determination becomes the pursuit of personal interests. The spread of medical control over pregnancy and birth – and thus over women – is associated with a pathological view of women. Women become deficient beings who need medical help to bear truly good children. Consequently, external control is an integral part of this manner of dealing with pregnancy. On the other hand, the female uterus has become “public property”, and the foetus a separate subject, whose status must also be defended against women and thus restricts women’s self-determination. The double standard applied becomes apparent in the discussion of Art. 218 German Penal Code.

Demands

– Accompanying and supportive pregnancy care must focus on the pregnant woman and her needs, not on the foetus with its “qualities”, and it must be geared to health. The development of alternative models for women-oriented support of the pregnancy process by midwives must be promoted.

– Selective diagnosis methods must be eliminated from the maternity guidelines and thus from pregnancy care in gynaecological practice. Preventing the birth of a child with a disability/impairment/disease must not be part of the treatment agreement between a pregnant woman and her gynaecologist.

– Women must have the opportunity to refuse selective diagnosis and take advantage of an alternative form of pregnancy care.

– Commissions that elaborate guidelines for pregnancy care must be put together in such a way that socially relevant groups – above all, midwives as additional care providers – are included and pregnancy thus receives recognition as a sociopolitically relevant process.

– Counselling must be provided before and after prenatal diagnosis by someone other than those who administer the tests.

– People who apply these methods must be obliged to provide information on psychosocial counselling programmes and other support options for women and their partners.

– Politics must initiate a change of course in research policy, define new focal areas and distribute resources differently. The solidarity community must ensure that women (families) with a child requiring special support, time and attention get the help they need to provide this care. This also applies to adults who need support that goes beyond the common structures. Social and health policy are called upon in this context.

We would like to call on women to get involved in the debate on prenatal diagnosis and to critically review their understanding of pregnancy, risk, responsibility and the limits of personal interests.
Preimplantation genetic diagnosis (PGD) is a new technology in reproductive medicine, which makes it possible to examine embryos in an early phase of development in the laboratory. For this purpose, one or two cells are separated from the embryo as part of in-vitro fertilisation and tested for genetic abnormalities. Subsequently, only embryos that do not display the targeted trait are implanted in the uterus. PGD is an ethically and legally disputed method – at least in Germany.

Fields of application

PGD is primarily recommended today for couples at high risk for having a child with a severe hereditary disease due to a chromosomal disorder or an abnormality in a single gene. Proponents of this method argue that it is less stressful because women can be spared from having an abortion after prenatal diagnosis.

Problems with PGD

In Germany, where PGD is prohibited by the Embryo Protection Act, the German Medical Association recommends this method for couples at high genetic risk. However, as international practice has already shown, the method also permits expansion of the user group beyond “high-risk couples”. For example, by selecting the best embryos, scientists hope to increase the success rates of in-vitro fertilisation (IVF) for “older” women. Furthermore, as a result of PGD, a child’s sex and, in future, even its genetic susceptibility to diseases of civilisation, such as cancer and cardiovascular disease, could also become criteria for a selection process.

... in-vitro fertilisation

PGD can only be performed in connection with test-tube fertilisation. IVF is associated with considerable disadvantages for women. The success rates of IVF are still extremely low: a (worldwide) average of less than 20% of treatments end in the birth of a child. The psychological burden on women is compounded by physical risks from the invasive procedure of removing egg cells, including the risk of hyperstimulation syndrome – which is caused by the hormonal stimulation of egg cell maturation and can be life-threatening in severe cases – and the as yet unexplained delayed effects of hormone treatment. If a pregnancy is achieved, there is considerable risk of miscarriage (approx. 25%) and multiple pregnancy (approx. 27%), because several embryos (a maximum of three in Germany) are usually implanted in the uterus. This can result in an increase in complications for the pregnant woman, such as high blood pressure or haemorrhaging. With a multiple pregnancy, the probability increases of the children being born prematurely, having an excessively low birth weight, and requiring a caesarean section. The families also face special challenges after the birth of twins, triplets or quadruplets, which relate to the extreme demands on the parents in caring for the children and to the development of the children.

... the diagnosis itself

“Single-cell genetic diagnosis”, which is performed in PGD, is relatively unreliable. Faulty diagnoses have already been documented. Therefore, amniocentesis is also recommended to confirm the diagnosis. This means that PGD cannot exclude an abortion in every case. It is still unclear whether the diagnosis damages the embryo – if it survives the procedure at all – or the future child.
... the social consequences

In addition to the above-mentioned risks for the women, and possibly the children, the use of PGD creates ethical and social problems with previously unknown implications.

PGD makes it possible for the first time to distinguish between several embryos and select the most “suitable” one(s). Unlike prenatal diagnosis, where a negative selection can be made, PGD opens up an entirely new opportunity, namely the positive selection of embryos.

In a kind of quality test, a decision can be made concerning which embryos are “worthy” of preservation and which are not. Moreover, if we consider the internalisation of social norms and their implementation in the framework of personal decisions, it becomes pointedly clear that the application of preimplantation genetic diagnosis makes it possible to take eugenic measures of a previously unknown nature based on personal justification.

Therefore, it is to be feared that the establishment of PGD will foster the rejection of the disabled in society and intensify discrimination against them. Not least, the persistent crisis in the social security system negatively affects the lives of the chronically ill and people with impairments. Against this social backdrop, the availability of prenatal diagnosis consequently exerts a subtle, in part internalised, pressure to avoid the birth of a disabled child with the help of high-tech medicine. This problem would be aggravated by PGD.

... from the feminist standpoint

Proponents of PGD demand its introduction in the name of all women. So why are we, as a group of women, resisting the introduction of PGD? In the women’s movement, reproductive medicine and human genetics have been viewed very critically since the 1980s. Women have always fought against the instrumentalisation of women’s needs for the interests of research. The desire to have children has always been viewed in its overall social context and critically analysed. Although PGD would increase the alternatives available to women in reference to reproduction decisions in some cases, it would also establish social pressure to use the technology, which would force women to face new decisional conflicts. Restricting the argument to the level of personal needs conceals the social consequences of this technology.

... future research developments

The field of biomedical research is highly interested in PGD. Among other things, it establishes the prerequisites for intervention in the germline.

Demand

PGD entails risks for the women involved and for the future child, as well as highly problematic social consequences. From the feminist standpoint, the price paid for fulfilling the desire of a woman or couple to have a child through PGD is too high. Therefore, we call for a definitive legal ban on PGD.
Positions on embryo and embryonic stem cell research

The Embryo Protection Act forbids destructive embryo research and any use of embryos that is not geared to achieving a pregnancy. German law has so far not permitted embryos to be used simply as material for research. However, positions in favour of relaxing or circumventing these legal barriers are being discussed more and more openly.

The strict bans on human cloning and germline manipulation are also being treated increasingly lightly. Proponents refer to “economic factors” or “competitiveness” (that Germany supposedly lags behind the international standard in research and industry), or they speak of supposed “fairness arguments” (Germany uses methods that were developed in other countries only on the basis of embryo research). They claim to pursue “high-ranking research goals” that sound like promises: more knowledge of embryo development, better medications and treatment prospects for numerous diseases, such as cancer and Parkinson’s.

Occasions and methods for which relaxation of the ban on embryo research is being discussed are:

- Preimplantation genetic diagnosis (PGD)
- Human cloning (“reproductive” cloning)
- Embryonic stem cell research (and “therapeutic” cloning)
- Germline “therapy”

Our viewpoint

We doubt that the primary goal of biomedical research on embryos is to ensure the well-being of patients, simply amass knowledge and have the prospect of curative treatment. Economic interests, gaining status in the scientific community, career ambitions, as well as patent and commercial exploitation must also be disclosed as motives.

The frequently invoked “freedom of research”, and the individual interests of science mentioned earlier, must not become the primary, and certainly not the sole, yardstick for policy, particularly in areas where basic rights – especially of women – are affected.

For the first time, in-vitro fertilisation (IVF) has enabled embryos to exist outside the body, which are no longer protected by a physical relationship to a woman in pregnancy. Consequently, it is only this technology that makes embryos generally available for manipulation and selection. The embryo research projects made possible as a result indicate two future prospects. First, genetic control and the vision of technically designing children; pregnancy increasingly becomes a production process for making a genetically tested child. Second, the technically manufactured embryo becomes a simple substance that can be consumed for research projects. The embryo thus becomes a raw material for further production steps. Both of these prospects radically alter the view of the female body. Women themselves gradually become invisible, while the female body is increasingly at the disposal of others. New technologies and offers repeatedly make the female body a site for fulfilling individual interests – in genetic planning of future generations, as well as in the procurement of material for new markets that are made attractive by promises of treatment. Moreover, every technological innovation requires destructive embryo research on a massive scale.

Consequently, PGD involves the filtering of embryos that display specific “genetic defects”. PGD promotes positive eugenics (see our position paper on PGD).
Cloning involves a “copy” of a living or dead person, or the replication of an embryo (“splitting”). Cloning turns human reproduction into asexual replication. The goal of embryonic stem cell research is to create potential replacement cells, tissues or even organs. Embryonic stem cell research sacrifices embryos and female egg cells to exploitation, in favour of making unfulfilled, and possibly also unfulfillable, promises of treatment.

Germline manipulation already attempts to “correct” genetic abnormalities in an embryo or even to “enhance” its genetic make-up. Germline manipulation is a non-controllable, but irreversible intervention. The genetic constitution of a future person and his or her subsequent generations is manipulated. Every attempt to “enhance” humans must be rejected as human breeding.

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Embryo research instrumentalises women and men. Their reproductive body substances (egg cells, sperm, embryos) are used as a means to an end in research and in new biomedical markets, or are even to be produced specifically for the purpose of exploitation. The decisive point is that it is not just a question of the intention of enabling a medically/technically controllable pregnancy or making it standard, but also of the availability of embryos as research material, as future “spare parts”, or as economically exploitable and patentable goods.

Exploitation outside the sphere of reproduction would implicitly degrade women and men to the status of raw material suppliers for research. The physical integrity of women, in particular, would be violated by the invasive procedures required to obtain egg cells, and women would be demoted to the status of contract suppliers of egg cells or “surplus” IVF embryos (i.e. intentional overproduction). This is unethical and socially unacceptable.

Moreover, any embryo research that attempts to turn its “results” or “products” into a human being must be rated as an intolerable experiment on the women who carry the genetically altered embryos, and on the children “made” in this way.

The protection of human dignity must not be sacrificed to promises of treatment. Reproductive substances should not be available to third parties and must not be exploited for commercial and industrial purposes.

We support the upholding of the ban on destructive embryo research, any and all variations of cloning and germline “therapy” in the Embryo Protection Act. Embryonic stem cell research, in which foetal cells and tissue from abortions are used, must also not be legalised.
The use of third-party egg cells is prohibited in Germany by the Embryo Protection Act. The procedure is not regulated, but still implemented in most European (and non-European) countries. Germany is also debating whether egg cell donation should be permitted for use as a procedure in the framework of in-vitro fertilisation (IVF). The use of third-party egg cells makes it possible to expand the indications for IVF. “Fertilisation tourism” to other European countries is already evident. German IVF centres arrange egg cell donations in cooperation with foreign centres.

Risks for donors

In contrast to sperm donation, which has been documented since the last century, the use of third-party egg cells for artificial insemination is a relatively new procedure. The birth of a child conceived by means of egg cell donation was reported for the first time in 1984.

Unlike sperm donation, which harbours no risks whatsoever for the donor, harvesting egg cells is a complex and very invasive procedure. The donor’s body is induced through medication to produce several mature egg cells. The egg cells are then removed through the vagina, usually with the guidance of ultrasound. In some cases, aspirating the egg cells can lead to vaginal haemorrhaging and infections. In addition, there is the general risk associated with anaesthesia.

The hormones administered for stimulation are suspected of causing hormone-related carcinomas, such as ovarian cancer. One “concomitant symptom” of hormone therapy is hyperstimulation syndrome. It can cause accumulation of fluid in the abdomen or the formation of cysts on the ovaries. In its most severe form, hyperstimulation syndrome has life-threatening effects. It is a phenomenon which, at this frequency of incidence, was triggered by doctors in the first place. The negative effect on a woman’s health is even confirmed by some doctors of reproductive medicine, when they suggest that only women undergoing IVF treatment should be considered as egg-cell donors, because it would not be justifiable to expose healthy women to this risk for the benefit of third parties.

Commercialisation

The commercialisation of egg cells can hardly be contained at this point, thanks to the use of modern media, such as the Internet. In the USA, agencies are selling egg cells for a price of roughly USD 6,000. Up to USD 100,000 are now being offered in advertisements for an egg cell donation. Egg cells are also being sold in European countries. It is a basic ethical principle that body substances, regardless of whether they stem from regenerative or reproductive organs, should not be bought and sold. For this reason, the term “reimburse-

Egg cells for research

Egg cells are highly sought after as raw material, not only for reproductive medicine, but also for research. They are the basis of “therapeutic” cloning (stem cell research) and “reproductive” cloning, germline research and the study of embryo development (see also our positions on embryo research). Due to the scarcity of available egg cells, other options for obtaining egg cells are
now being explored: the maturation of foetal egg cells (from gametes or ovarian tissue), the removal of ovarian tissue during operations or post mortem, and the in-vitro maturation of egg cells.

**Positions**

- The use of third-party egg cells propagates the idea that claims can be made on someone else’s body parts to treat health problems. This could intensify the ethically based pressure on women, in particular, to fulfil the desires of others. We consider it to be extremely problematic to take advantage of the physical services of third parties in order to fulfil a personal wish. The donor exposes herself to a high medical risk for this purpose. In our opinion, egg cell donation is a medically and ethically illegitimate intervention that serves the interests of third parties.

- Using third-party egg cells establishes biological and social relationships that have never existed before, dissolves deeply rooted ideas of personal heritage and can thus lead to identity conflicts. Crossing biological borderlines breaks a sociocultural taboo.

- Due to the scarcity of available egg cells for research, the possibility cannot be ruled out that women will be forced by financial incentives to provide “surplus” egg cells for research purposes, within the framework of IVF treatment, for example. We believe that egg cell donation expands IVF in a way that intervenes deeply in sociocultural values and locks women into the role of reproductive suppliers. Egg cells are produced inside a woman’s body. Making them available means another step towards control of the female body and instrumentalises women and their reproductive capacity.

**Demands**

- We demand that the ban on the use of third-party egg cells for IVF be upheld. Egg cell donation cannot responsibly be permitted in view of the physiological, psychological and social effects on women and their health. Egg cell donation for research purposes must also be prohibited. Making egg cells available is a prerequisite for research on embryos and for germline manipulation.

- We furthermore demand a ban on the marketing of egg cells. Although the use of third-party egg cells is prohibited, the trading of them is not.

- Egg cell donation should not be viewed in isolation. Rather, the underlying practices of IVF should be critically examined and the medical risks and ethical/sociocultural implications scientifically analysed and publicly debated.

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