

## FEMALE SELF-DETERMINATION BETWEEN FEMINIST CLAIMS AND 'VOLUNTARY' EUGENICS, BETWEEN 'RIGHTS' AND ETHICS

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**Synopsis**—The new reproductive and gene technologies give us reason to reflect on the concepts of reproductive freedom or autonomy and feminist self-determination. These concepts have played a key role in women's fight for free abortion and birth control within the last two decades. We are faced with new choices and new decisions now that more and more women are making use of the techniques of prenatal diagnosis and selective abortion that have become available. Ostensibly, these technologies enable women to decide whether or not to have a disabled child. But the greater "choice" they apparently bring is deceptive. These technologies do *not* help women to decide whether or not to give birth to a disabled child. A woman might have an abortion because her doctor has diagnosed a chromosomal disorder which might cause the child to have Down's syndrome. Yet there are thousands of other disabilities which cannot be detected by prenatal diagnosis and even if a nondisabled child is born s/he may subsequently become disabled. So if these technologies offer no safeguards against disability, why do many women demand access to them? Some feminists argue that women should have a right to choose, that utilizing prenatal diagnosis is a part of women's reproductive autonomy and a component of their right to self-determination. The author argues that it is not. Prenatal diagnosis and genetic counselling are based on the ideology of eugenics according to which a disabled person is less valuable than an able-bodied person. Eugenics considers the disabled to be inferior because disability is viewed as a dilemma, as a barrier to happiness for the whole family. The eugenics movement has always relied on selective policies in its bid to reduce the number of disabled in the population by controlling or eliminating the carriers of disability. Genetic counselling and prenatal diagnosis have to be viewed within this context. Seen from this perspective, prenatal diagnosis is a eugenic method and using such methods encourages the spread of eugenic ideology. There may be many reasons why women today feel forced to undergo prenatal diagnosis: the pressure of family members, husbands, or doctors. But if we discuss feminist Utopia and the concept of reproductive autonomy and self-determination, then the question of prenatal diagnosis is a question of feminist ethics, a question of balance between the principles of individual freedom and equality.

**Synopsis**—Die neuen Gen-und Reproduktionstechnologien geben Anlaß, sich mit den Konzepten von Reproduktionsfreiheit und feministischer Selbstbestimmung auseinanderzusetzen. Während der letzten zwei Jahrzehnte waren diese Begriffe zentral im Kampf der Frauenbewegung um freie Abtreibung und Verhütung.

Durch die Einführung von Pränataldiagnostik mit der anschließenden "Option" der selektiven Abtreibung als reguläre Schwangerschaftsvorsorge, werden Frauen zunehmend vor neue Entscheidungen gestellt. Mit Hilfe dieser Technologien scheinen Frauen nun in die Lage versetzt, darüber zu entscheiden ob sie ein behindertes Kind haben werden oder nicht. Aber der Schein trügt: Diese Technologien helfen Frauen gerade *nicht*, eine derartige Entscheidung zu treffen. Zwar mag sich eine schwangere Frau für eine Abtreibung entscheiden, weil ihr Arzt eine Chromosomenstörung diagnostiziert hat, die möglicherweise zu der Geburt eines Kindes mit Down Syndrom geführt hätte. Aber es gibt Tausende von Behinderungsarten, die ihr Arzt nicht pränatal diagnostizieren kann. Und selbst wenn sie ein nichtbehindertes Kind gebiert, dann ist das noch keine Garantie dafür, daß ihr Kind auch nichtbehindert bleibt.

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Wenn also diese Technologien keinerlei Sicherheit gegen ein behindertes Kind bieten, warum fordern Frauen dennoch Zugang zur Pränataldiagnose? Einige Femistinnen argumentieren, daß Frauen ein diesbezügliches Wahlrecht haben sollten, daß die Inanspruchnahme von Pränataldiagnostik ein Teil ihrer Reproduktionsautonomie bzw. ihres weiblichen Selbstbestimmungsrechtes ist. Die Verfasserin dieses Artikels behauptet das Gegenteil.

Pränataldiagnostik und Humangenetische Beratung basieren auf einer eugenischen Ideologie, nach der eine behinderte Person weniger wert ist als eine nichtbehinderte Person. Nach der eugenischen Ideologie gelten behinderte Menschen als minderwertig, denn Behinderung bedeutet trostloses Leben, bedeutet Unglück für die ganze Familie. Eugenische Bewegungen waren und sind immer durch ihren Rückgriff auf selektive bevölkerungspolitische (Zwangs-)maßnahmen gekennzeichnet, denn eines ihrer Ziele ist die Reduzierung des behinderten Bevölkerungsanteils durch Kontrolle oder Elimination der Träger von Behinderungen. Vor diesem Kontext müssen die Diskussionen um Pränataldiagnostik und Humangenetische Beratung geführt werden.

Vor diesem Kontext erweist sich Pränataldiagnostik als eugenische Methode und der Einsatz dieser Methode dient der Verbreitung eugenischer Ideologie.

Es mag viele gute Gründe geben, warum Frauen heutzutage keinen anderen Ausweg als den der Pränataldiagnostik sehen: der Druck der Familie, des Ehemannes oder der ÄrztInnen. Viele gute Publikationen beschäftigen sich mit dieser neuen Frauenrealität. In der Diskussion um feministische Utopie und diesbezüglicher Konzepte von Reproduktionsautonomie und weiblicher Selbstbestimmung stellt sich die Frage nach Pränataldiagnostik allerdings als eine Frage der feministischen Ethik; als eine Frage nach dem Verhältnis von Freiheits- und Gleichheitsprinzipien im Rahmen dieser Ethik.

Many of the articles on human genetics and prenatal diagnosis published in the Federal Republic of Germany point to the continuity between National Socialist race hygiene and human genetics in the Federal Republic. In the late 1950s to early 1960s, scientists and doctors who were actively engaged in the compulsory sterilisation of hundreds of thousands of disabled people, and later responsible for their extermination in the euthanasia programmes under National Socialism, were appointed to establish human genetics institutes or offered chairs at the universities without ever having been called to account for their crimes.<sup>1</sup>

Spectacular break-ins to secure papers and files from human genetics counselling bureaus and the subsequent publication of excerpts from these documents have exposed the catastrophic methods employed in today's counselling centres.<sup>2</sup> It is clear that there has been no ideological break with the National Socialist doctrines of race hygiene.

A closer examination of less scandal-stirring work of the human genetics counselling centres also shows that the modern variant of eugenic population control employs far subtler methods to guide women's reproductive patterns in the desired direction. The ideology of *neo-eugenics* no longer employs the Nazi concepts of Volksgesundheit

(people's health) and Volksschädigung (damaging <the health of> the people). Neo-eugenic population-control policies no longer principally rely on compulsory state intervention but on *voluntary eugenics* from below. The focus is now on the sovereign self-responsible individual with her/his own economic and social interests. The neo-eugenicists limit their activities to the forefield of prenatal decision-making. They offer what appears to be neutral, objective information that is supposed to aid women in exercising their right to self-determination and facilitate decision-making; not, however, without having previously divided fetus and woman into two legal entities with conflicting interests.

This is because prenatal diagnosis also transforms pregnancy into more and more of a technological and medical problem. With its high-tech apparatus, the medical profession has assumed control over pregnancy. The fetus is regarded as a patient in its own right and thus becomes more and more of a person. This patient can be rendered visible by ultrasound and analysed section by section in the earliest weeks of pregnancy. Human geneticists have written whole books on suspicious fetal spasms and other behaviour patterns. The ability to identify fetal defects has risen rapidly with the aid of gene technology and other methods.

The height of medical practices of this kind that elevate the fetus to the status of a patient is the development of *fetal therapies*, that is, operations on the fetus while it is still in the womb. Elevating the fetus goes hand-in-hand with demoting the pregnant woman, who is thus relegated to the status of *fetal environment*. Pregnancy becomes a medical production process in which women, at the most, constitute the means of production, with production management having long since passed into the hands of gynaecologists and human geneticists.

Women only become subjects again if something goes wrong in the production process, that is, if the question of selective abortion arises. The decision is then declared her responsibility. The woman must then determine for herself whether or not to have a child that “the law cannot reasonably expect of her,” as it was formulated by the West German civil law supreme court in 1983.<sup>3</sup> However, the technological advances made by human gene technology and prenatal diagnosis, have not improved the situation of pregnant women with regard to feminist self-determination. Indeed, in more ways than one the situation has gone from bad to worse. Prenatal diagnosis now forces women to fulfill their eugenic duty. Women who bear children with Down’s syndrome can no longer acquit themselves by disclaiming previous knowledge of the fact. For many women this new responsibility to become conversant with the facts has made pregnancy become an anxiety-filled phase in their lives. And, finally, reducing pregnancy to a medical condition means that women are degraded to the status of a fetal environment.

#### **FEMINIST SELF-DETERMINATION RE-EXAMINED**

There’s nothing new about these insights—they have been discussed within the women’s liberation movement for some years now.<sup>4</sup> However, one of the things to have emerged from these discussions has been a critical re-examination of the feminist concept of self-determination. Much has been published on this subject and opinions vary. German sociologist Maria Mies, for instance, has radically advocated dropping a slogan that for many years was thought to express the very essence of feminist self-determination; “My belly belongs to me” was the battle-cry of the anti-§218

movement in the 1970s, calling for free abortion and condemning pro-natalist state intervention in women’s self-determination. Mies sees this slogan as expressing the philosophy of bourgeois property relations which postulates the primacy of the mind over the body. Mies replaces this slogan with another: “I *am* my body. I am a whole indivisible person. That also means,” Mies continues, “demanding no ‘rights’ from the state, no ‘right’ to abortion, no ‘right’ to sperm banks, etc. For all ‘rights’ are based on the bourgeois concept of property and can only be achieved if we treat ourselves, our children, as private property” (Mies, 1986, pp. 114, 118).

The most prominent opponent of this view is probably American lawyer Laurie B. Andrews, who demands that women’s right to self-determination should be protected by law precisely because, among other things, women could then rightfully consider themselves owners of their own bodies and themselves be able to profit financially by selling parts of their body and their bodily services (Andrews, 1986, p. 26). Andrews’ utopia of “reproductive freedom” is thus essentially geared towards achieving women’s equality with men within the capitalist relations of production. The American concept of reproductive autonomy was taken up by German sociologist Silvia Kontos. She opposes Maria Mies’ position by demanding reproductive autonomy for women. She prefers the concept of reproductive autonomy because it goes further than the concept of the right to self-determination, as it was defined in the 1970s, and clearly encompasses more than just the right to abortion or free contraception. Kontos writes:

It means autonomy within the entire reproductive process starting from the way we deal with our sexual feelings and needs, menstruation, contraception and abortion, the course we follow during pregnancy and birth right up to the various possibilities of organizing the care and education of babies and infants or the transition from adolescence to adulthood. In this sense, autonomy means fighting for the greatest possible liberty for women to make their own decisions and choose their own courses of action. (Kontos, 1986, pp. 137, 139)

While Kontos envisages the achievement of reproductive autonomy as something that includes the possibility of utilizing the new gene and reproductive technologies (including prenatal diagnosis)—as long as they are controlled by women—she also demands that a critical reassessment be made of the reproductive process and the responsibility confronting women in their choice between various reproductive alternatives (IVF abortion, use of prenatal diagnosis, assuming this responsibility is precisely what Mies rejects.

At the Second Federal Women's Congress Against Gene and Reproductive Technology, in Frankfurt, 1988, she defined her criticism of the concept of self-determination more clearly in the following proposition: "There is no self-determination without domination over others" (Mies, 1989, pp. 111–116). Her historical and philosophical analysis traces the path that led to the division of vital relationships (mind/body, nature/civilisation, freedom/life, transcendence/immanence, etc.). In her view, the historical processes of self-determination prove to be processes of division and domination over others:

The rise of men is based on the decline of women. Europe's progress is founded on the retrogression of the colonies. The development of the productive forces is founded on plunder, war and violence. . . . The self-determination of the bourgeois individual, the subject, is based on domination over others, over women and other colonized populations, in particular. (Mies, 1989, p. 116)

Austrian sociologist Susan Zimmermann has also studied the history of women's self-determination and come up with some astonishing discoveries. In her analysis of the concept of self-determination used by the sexual reformers around the turn of the century, she traces how zealously the feminists of the day participated in establishing an ideology of race hygiene. The focal perspective of these sexual reformists, Zimmermann reports, was "the comprehensive reform of 'sexual life' and motherhood in line with the utopia of a society of free and equal individuals of both sexes" (Zimmermann, 1988, p. 54). However, Zimmermann describes this utopia of free and equal individuals as being closely linked to a

theory of subjectivity, according to which becoming a subject or developing one's individuality was essentially based on self-responsibility by means of controlling the body as well as birth and health patterns. As a result, women were divided into two categories, those who had become subjects and

. . . not-yet-subjects: Anyone who did not treat her/himself self-responsibly was behaving irresponsibly. Anyone who did not in her/himself embody the "new ethics" of self-responsibility had consequently forfeited their claim to individual freedom, subjectivity. (Zimmermann, 1988, pp. 56–57)

At the time, feminists openly advocated a social utopia based on the "higher development of the race" which was to be achieved by means of standardization, surveillance, and the legal sanction of responsible birth behaviour. The race-hygienic dimensions of this sexual reform debate are exemplified by a number of quotations cited by Zimmermann:

The "barbarians of chance, unplanned breeding" manifests itself, among other things, "in the alarming encumbrance of our society with incurable sickness and harmful elements" (Schreiber, 1912, p. 202). The utopia of the "higher development of the race," on the other hand, was to be realized in the new motherhood of the "new woman" or in a new style of parenthood altogether that would enable children to become "productive individuals" (Mayday-Hentzelt, 1912, p. 186), "strong and joyful people" (Stöcker, 1906, p. 81), individuals on the path to "super-humans" (Carpenter, undated, p. 158), equipped with a "healthy and vigorous constitution" (Müller-Lyer, 1912, p. 151)—in brief: they should be "high-quality products" (Goldscheid, 1909, p. 87), "individuals of striking originality—not just the masses of people like herds of sheep" (NG, 1905, p. 130).

The reformers called for the compulsory sterilization of the "irresponsible" and "inferior." Zimmermann quotes a resolution dated 1916 in which it is stated that:

. . . in the interests of society the sick, the

mentally, morally and physically inferior (should) be prevented from breeding. (Zimmermann, 1988, p. 66)

With regard to those who were accessible to reason, however, it was a matter of establishing the “imperative of responsibility” (Zimmermann, 1988, p. 65):

“The people must be brought to understand that breeding diseased hereditary factors is one of the worst crimes and almost worse than murder . . .” (Müller-Lyer, 1912). If a woman is not in possession of the means to “bring up (children) to become proper people” she is committing “not only a folly but almost a crime” in having them. (NG, 1905)

The conclusion Zimmermann draws from her historical analysis is that radicalizing the “demand for women’s liberation in the line with ‘self-determination’ as an abstract and objectified substantial right” ultimately leads nowhere. For the notion of freedom underlying this concept both historically and theoretically precludes “effectively dealing with fertility in a way that is liberating for all women” (Zimmermann, 1988, pp. 67–68).

Thus, the debate on the concept of self-determination within the West German women’s liberation movement has led some to want to drop the concept altogether, while others speak out in favour of retaining it. Ute Annecke, editor of “beiträge zur feministischen theorie und praxis,” for instance, describes the concept as a concept of resistance that is indispensable to women’s liberation owing to its antihierarchical direction. In view of the negative implications historically and currently associated with the concept, it falls to the women’s liberation movement to give it “a new positive definition.” A definition:

that sees self-determination as the opportunity for a self, an individual “to determine something by name, prescribing her/his own terms,” in the sense of casting a vote, making a decision for or against something in terms that are prescribed by others. (Annecke, 1989, pp. 89–92)

She considers it essential to fight for self-determination in this positive sense precisely because of the new technologies:

It is all the more imperative for women to fight for true freedom of decision and choice precisely because the diversity of technological methods of diagnosis and treatment offered by medicine, by reproductive technology, takes acceptance of the ruling societal expectations for granted and does not give women any real choice . . . Women must consciously fight for this freedom of choice, for women’s right to reject the so-called force of facts and social norms, the right to not know (the sex of a fetus, for instance), the right to say no, and the right to organize practical alternatives of their own. Our only chance for (self-) conscious action, strengthening our common resistance, lies in leading an enlightening feminist dialogue which addresses the material conditions, the interests and scope of choice needed for the expression of women’s self-determination, poses the question of potential contradictions between the individual and collective needs of women and discusses the problem of structural responsibility—including that of women. (Annecke, p. 98)

Dorothea Brockmann, another West German sociologist, also advocates retaining the concept of self-determination. However, she opposes a new “general concept of self-determination” that would make it all too easy to forget the negative implications. She favours a new approach to the concept of self-determination under the premise “the private is political.” This new approach should also embrace the hitherto unreflected contradictions inherent in the concept of self-determination. She mentions two contradictions in particular. On the one hand, a concept “that bases becoming a subject on body control” turns “self-determination . . . into a precarious tightrope walk between the liberating and repressive aspects of body-self-control” (Brockmann, 1989, p. 105–109). The second contradiction, as she sees it, arises from self-determination, as a subject-related concept, being necessarily based on individualism:

According to the concept of individualism, however, the subject is considered asocially in the sense that s/he becomes a subject in the private sphere, in the apparently non-societal pursuance of her/his interests while at the same time competing to assert them, whereby the collective consequences of asserting them are

disregarded. (Brockmann, 1989, p. 114)

She arrives at a conclusion similar to Maria Mies. Self-determination and self-realization always also imply an element of domination and suppression of others:

Namely in the sense that self-determination as a private category implicitly means disregarding the conflicting vital interests of others, meaning the vital interests of the disabled in the case of reproductive medicine. (Brockmann, 1989, p. 115)

Thus, she accepts the protest of the disability movement against prenatal diagnosis and selective abortion as being justified because “the use of these techniques and the acceptance of selective abortion means that women participate in commonplace eugenics at the cost of the disabled, the physical and mental misfits” (Brockmann, 1989, p. 113), yet she rejects a ban on these techniques or even so much as “heroically abstaining” from their use:

This would only reinforce the very same unconscious repressive mechanisms that lead to the use of technology; it would discriminate against the often desperate attempts made by women who hope to make it easier to lead a life according to plans of their own individual choosing by resorting to technological solutions to their problems; it would also prevent the dialogue that could perhaps accommodate this solitary desperation. (Brockmann, 1989, p. 115)

In addition to initiating a dialogue of this kind that is free of guilt feelings, she also advocates establishing a responsible rule of conduct under the premise that “the private is political.” In the final analysis, however, this rule of conduct she is talking about boils down to nothing more than being fully conscious of all that we do:

The awareness that whatever we do we are responding and we should have the courage to do so consciously. To act consciously even if we refuse to respond, if we make use of reproductive medicine, although we know (or could know) that it amounts to eugenics, that it violates the dignity of the disabled. (Brockmann, 1989, pp. 115–116)

A rule of conduct which she obviously sees as opening up a way to enlightenment:

Perhaps we will only be able to see clearly and relate our own individual conduct to the collective, the social network, once we accept responsibility and face up to what has been so violently repressed, i.e., respond to it, and acknowledge our complicity as a refusal to accept responsibility. (Brockmann, 1986, p. 116)

The persons and opinions cited here reflect only one—albeit essential—part of the current discussion among German-speaking feminists.<sup>5</sup> The opinions outlined here suffice to show that the discourse of self-determination involves many different aspects, such as the relationship of feminism to the state, body to mind, nature to technology, individual to society, productive and reproductive relations on a national and international scale, as well as resistance and conformity.

#### **THE PRIVATE IS POLITICAL**

The question of female self-determination in relation to prenatal diagnosis is very substantially one of the relationship between the individual and the collective, that is, of the social implications of individual self-determination. Dorothea Brockmann illustrates this particularly clearly with her notion that “the private is political.” If women want to exercise their self-determination by means of selective abortion, they are actively participating in promoting the acceptability of eugenics, quite irrespective of whether they are themselves supporters of eugenics or not. The fact that nondisabled feminists now also realize and accept this is, in my opinion, one of the greatest achievements of the self-determination debate to date. To prevent my being misunderstood, I underline that I am not concerned with the question of whether women have a right to abortion in general. As a feminist my answer is unequivocal: Of course they have!

Selective abortion, however, is a matter of deciding to terminate a pregnancy that was originally desired. It becomes undesired because of a potential qualitative characteristic of the fetus, because a possible disability is valued as being worthy or unworthy of life or as a reasonable or

unreasonable burden for the woman. Of course, the nonselective abortion of a pregnancy that was undesired from the start also views the fetus as a burden, but this evaluation is not based on an individual characteristic of the potential child, but on aspects that are unrelated to the fetus, such as the women's living conditions and the way she wants to lead her life. The special character of selective abortion lies in wanting to opt for a so-called norm(al) child and reject a disabled child. At numerous meetings, disabled women like myself have attempted to point out that this attitude is greatly influenced by societal conditions and that these can even assume coercive dimensions. However, this fact does not alter the qualitative aspect of the decision. Nor am I interested in personalizing the fetus the way the pro-life mafia does, for this runs counter to the interests of nondisabled people just as much as disabled people (see Degener, 1989b). The question I am trying to raise in this discussion is whether a decision in favour of prenatal diagnosis is a part of *feminist* self-determination or reproductive autonomy as we see it.

This question arises automatically when Dorothea Brockmann calls for self-responsibility, meaning that we should become aware of the repressed implications of the feminist concept of self-determination, that we should aim to act consciously and have to stand up for what we do. This question also raises the question of feminist ethics, that is, the rule of conduct governing women's self-determination. Women's self-determination, however, cannot be defined by societal conditions alone, for this would be tantamount to viewing our actions as a purely mechanistic reflection of societal conditions for which it would be impossible to assume responsibility.

According to the principle of *dialectic determinism*, people never act entirely voluntarily, that is, independently of societal conditions, nor entirely involuntarily, that is, totally dependently on these conditions. Within the given conditions, people can choose to behave in one way or another in accordance with specific social needs and necessities or in contradiction to them (Klaus & Buhr, 1976, p. 382). Whether or not women oppose the conditions of prenatal diagnosis, whether or not they reject selective abortion because this implies that women are controlled by

an external agency, (men or women) doctors, as well as their own active participation in a policy of eugenic population control, will depend to a large extent on their own feminist ideals and their vision of the future. Thus, raising the question of the rule of conduct governing women's self-determination leads to the question of the (feminist) utopia of the individual and the collective and whether disabled people have a place in this utopia or not.

To put it another way, it is evident that it would be easier to decide to have a disabled child if there were no discrimination of disabled persons and their families, if the mothers of disabled children were not separated from society. But the question is whether the women who are talking about self-determination today can at least imagine saying yes to having a disabled child if the conditions were tailored to the needs of the disabled. The question not only arises because there always have been and always will be disabled people all over the world.<sup>6</sup> It also arises because inseparably linked to it is the question of the feminist concept of humanity.

#### FEMINISTS AND DISABILITY

In their publications to date, nondisabled feminists have primarily associated disability with unbearable suffering and stress, especially for the mothers. There have been some outlines of a utopia, such as the utopia of "living relationships" formulated by Maria Mies (Mies, 1989, p. 121) which potentially, though not expressly, includes acceptance of disability and otherness. Ute Annecke also describes the scope of self-determination to be fought for in terms which encompass the "dimensions of the 'other', the excluded, negated and debased" (Annecke, 1989, p. 100).

Yet, a utopia of differences in a collective freed of capitalist and patriarchal norms of merit always seems to stop short at the thought of disability. This is clearly illustrated by the fact that disability is generally mentioned in one and the same breath with sickness, suffering, and death (Kontos, 1986, p. 141), the consequence being that disability is inevitably seen as involving an element of disaster. A utopian future will have to find "other ways of dealing with" this kind of disaster (Kontos, 1986, p. 141) than those practised under the present

societal conditions, but in any event it remains a disaster. According to Silvia Kontos, societal conditions prevent

a realistic discussion of the specific problems of specific disabilities and kindle the irrational fear of bearing a disabled child shared by all pregnant women. (Kontos, 1986, p. 141)

She identifies the specific problem of a specific disability as follows:

In the past a child with water on the brain would often die in the womb and the woman could ascribe this to God or Nature or Fate, while today she has to decide whether or not to agree to fetal surgery or else to abort the child. (Kontos, 1986, p. 142).

It is interesting that she should only think of these two alternatives. There are two other alternatives that also come in to question: immediate postnatal surgery or to live with water on the brain.

She similarly only seems to be acquainted with two attitudes towards disability, the so-called rational fear of disability and the irrational or even hysterical fear of disability. It is the latter forms of fear she wishes to see eliminated in her attempt to define a utopia of reproductive autonomy. Not even in her wildest dreams does it appear to occur to her that it is possible to have no fear of disability.

Dorothea Brockmann's outlook is also limited to nondisabled lifestyles when she describes the disabled child as being capable "of independent life only in a limited sense" or "possibly restricted in its ability to shape its own life autonomously" (Brockmann, 1989, p. 113). It is precisely this definition of autonomy and independence in life, geared as it is to nondisability, that we in the disability movement have been trying to change for decades. For some years now personal assistance service centres—or "Centres for Independent Living," as the latest projects are called—have begun to create or help fight for the conditions required by disabled people and their relatives to lead an autonomous life.<sup>7</sup> It may be that Dorothea Brockmann is simply referring to the material conditions in our society today which prevent the vast majority of disabled individuals from even beginning to think of living a self-determined life. However, her final remark, in

which she quotes Gisela Wülffing (co-founder of the alternative *Tageszeitung*, and now member of the Executive Committee of the GREENS), indicates that according to her concept of humanity disability is purely negative:

We will doubtlessly only become socially orientated, self-assured subjects if we stop walking around the place as victims, as "itinerant invalids" [Gisela Wülffing] . . . (Brockmann, 1989, p. 116)

Does this mean that being disabled and being subject are mutually exclusive?

I have no wish to split hairs and Dorothea Brockmann is trying to say something else, but language is revealing and in this case it reveals exactly what most people, feminists included, just cannot imagine: disability as a neutral condition which—no different from a person's sexual status—is in itself neither necessarily linked with suffering nor with happiness. After all, this is the argument behind the disability movement's slogan: "It's not disability that makes life difficult, it's the discriminating conditions of society!"

#### **WANTING A NONDISABLED CHILD-A "PRIMAL WISH"?**

Discussions on selective prenatal diagnosis show just how little this slogan has been understood and accepted. At a recent meeting, I asked women who justified their right to selective abortion with the social conditions if they would also want the right to selective prenatal diagnosis and subsequent abortion in a society that was disabled-friendly. The disabled-friendly conditions I quoted were the following: no special schools, homes, or other special institutions; every woman who had a disabled child receives financial aid and the assistance of a nurse or social worker; the child is entitled to a place in every creche and kindergarten; there is an accessible network of remedial centres that are able to develop individually tailored orthopaedic appliances as required; there are no accommodation problems for the disabled; there is an adequate number of centres offering special care at home under autonomous conditions; there is an adequate supply of places for disabled people who wish to move away from home and need shared accommodation; there are enough jobs for the



disabled in the regular production process; streets, buildings, and public transport are accessible to wheelchair users; there are no more pitying looks when a woman pushes her disabled child across the road in the pram or when the disabled show themselves in public.

It took some time for the women to reply to the question whether they would still want a right to prenatal diagnosis under conditions such as these. The majority said yes, although they found it difficult to give their reasons or argue their case. During a heated debate on prenatal diagnosis and disability organized by the magazine *Konkret*, German sociologist Susanne von Paczensky spontaneously supplied an explanation. She described wanting a “healthy” child as a “primal wish of humanity” that has existed from the beginning of time “right across the ages and continents and has nothing to do with false ideologies or eugenics” (*Konkret* 4, 1989, p. 46). This was said spontaneously when she was under attack and should not be given too much weight. Nevertheless, I dare say that there are many nondisabled people who would have spontaneously said exactly the same. I would go even further to say that there is a biologicistic line of reasoning at the back of this primal fear of disability. For disability is seen here as a condition that is incompatible with a natural human wish, and therefore incompatible with human nature too. But who has defined human nature?

Much thought has been given to the question of why we want children and much has been written on the subject as well, particularly in connection with the new reproductive technologies. Children fulfill different functions in different cultures and economic systems. Children represent social security in countries with poorly developed social security systems. In the Western industrial (technological) countries, children fulfill several different functions—they are needed to complete the basic unit or germinal cell of the state, they are a status symbol, they put a premium on womanhood, etc. In particular, however, wanting to have children is motivated by the desire to reproduce oneself. That is why nondisabled women experience the birth of a disabled child as a “narcissistic trauma.” It is also why some disabled women wish to have a similarly disabled child (Degener, 1989b).

However, to a certain extent Susanne von Paczensky may be right when she says that wanting to have a nondisabled child has nothing to do with false ideologies or eugenics. She is right inasmuch as wanting nondisability need not necessarily be based on eugenic ideology. It would be wrong to conclude this since eugenics is essentially based on the notion of elimination and selection. Thus, there is as little harm in wanting to have a nondisabled child as there is in wanting to have a disabled child. The danger lies in *implementing* that wish and in the political consequences of doing so. It is only when this wish for a nondisabled child is declared universal and it becomes mandatory to resort to supposedly infallible technological means to ensure that it is fulfilled that it becomes a danger and a duty. That is also why any concept of self-determination that implies one has a right to a nondisabled child is dangerous. It is dangerous not only because it implies that certain embryos should be aborted, but because it can only be implemented within the context of a politically motivated population control programme that potentially militates against the vital interests of the disabled as well as nondisabled women (and men). Peter Singer, a bioethicist living in Australia who has gained publicity in the West German media since June 1989, is only one example of someone who carries this kind of policy to its logical conclusion. In June 1989, the *Bundesvereinigung der Le-benshilfe*—the largest association of parents of mentally handicapped children in West Germany—planned to hold an international symposium at which Singer had been invited to present his argument in favour of euthanasia for severely handicapped children. The symposium ultimately had to be cancelled as a result of the massive protest from the disability movement combined with other progressive forces, among them various women’s groups and antifascist organisations. Singer demands that newborn babies should be killed if they are severely handicapped, a policy he justifies by declaring them nonpersons. In his hierarchical classification of life forms, disabled people rank below chimpanzees and pigs because they allegedly do not possess the fundamental characteristics of human beings, that is, the faculties of “rationality, autonomy and self-consciousness.” (Singer & Kuhse, 1985, p. 122).

It would be too simple to denounce Singer as a neo-Nazi. He is undoubtedly a prominent supporter of the neo-eugenics mentioned above. Yet this lethal mentality did not first emerge under National Socialism—its history goes back over 100 years, at least as far as the Western industrial hemisphere is concerned.

Klaus Dörner has called this history the “medicalization of the social question,” the brutal culmination of which so far was the Nazi policy of “the final solution of the social question” (Dörner, 1988). His work on the subject is particularly relevant to the discussion of prenatal diagnosis because he also examines the concept of self-determination historically. He comes to the conclusion that the ideology of self-determination has always implied an ideology of inequality and that this is true of German history in particular. Economically and philosophically, self-determination became a vehicle to justify the freedom of certain sections of the population at the cost of equality for all. And, indeed, with potentially lethal consequences for all concerned:

The general acceptance of submitting to the capitalist laws of the free market and the social Darwinist imperative of “the survival of the fittest” had to have its consequences. Having already sacrificed the right to equality for all with the aid of the concept of inferiority and thus paid the price of further magnifying the right to free self-determination . . . and did one wish . . . to have a society made up of ever “better, socially more useful, healthier and happier people,” not only did it follow that the inferior, socially less useful, sicker and unhappier sections of society had to be eliminated, it also followed that one had to have a personal right to one’s own death if one felt bad, asocial, ill or unhappy. (Dörner, 1988, p. 36)

Dörner also points to the close connection between self-determination through suicide and the right to kill others in their best interests:

This is the birth of a logic and an ethic which is irrefutable once its assumptions have been accepted and which has persistently kept us busy up to the present day: for if we want a society that consists of ever better, socially more useful, healthier and happier people, then

we must at some point concede people a right to their own death if they temporarily feel that they do not fit the bill, and it also follows that people who are incurably inferior, socially less useful, sicker or unhappier must also at some point be granted the right to death, indeed they must be placed under a certain obligation to exercise this right for they would otherwise disturb the world order that has been defined in such terms. We would be entitled to expect their death. And if we are dealing with people who are incurably inferior, asocial, disabled, mentally dead anyway, old or dying and incapable of speaking or deciding for themselves, we must be able to speak and decide for them in their own best interests so as to release them from their worthless, inhuman, and undoubtedly agonizing state of vegetation; for according to the above logic and ethic it is a law of nature and scientifically proven that, if they could speak and decide for themselves, they would wish for their own death. (Dörner, 1988, p. 37)

#### **SELF-DETERMINATION AND THE PRINCIPLE OF EQUALITY**

Self-determination has never been defined purely as freedom in the sense of the absence of (state, social) compulsion. The historical analyses conducted by Klaus Dörner, Susan Zimmermann, and many others show that this concept has always been based on a specific concept of humanity that sacrificed the idea of equality. Even today it is still the case that the right to self-determination is only granted to those who are prepared to be guided by this selective concept of humanity and accept the social conditions as they are. This also influences the discussion of female self-determination and prenatal diagnosis. However, the feminist concept of self-determination is superior to other concepts of self-determination inasmuch as it is always guided by a utopia based on the equality of the sexes and thus embodies at least one element of equality.

In demanding rights that only addressed the problems of a certain section of women, the old and new women’s liberation movement has often unwittingly renounced the principle of equality. Our approach to the question of abortion and contraception is a clear example of this. In the

western part of the world we fight for contraception and abortion because we see them as liberating us from an obligation to bear children, as essential instruments of female self-determination. Yet we overlook the fact that for many women in Third World countries, and for many disabled women in our own countries, this right only exists in the form of a ban on having children in the interests of population control. Angela Davis comes to similar conclusions in her analysis of the pro-choice movement in the United States:

The ranks of the abortion rights campaign did not include substantial numbers of women of color. Given the racial composition of the larger Women's Liberation Movement, this was not at all surprising. When questions were raised about the absence of racially oppressed women in both the larger movement and in the abortion rights campaign, two explanations were commonly proposed in the discussions and the literature of the period: women of color were overburdened by their people's fight against racism, and/or they had not yet become conscious of the centrality of sexism. But the real meaning of the almost lily-white complexion of the abortion rights campaign was not to be found in an ostensibly myopic or underdeveloped consciousness among women of color. The truth lay buried in the ideological underpinnings of the birth control movement itself. . . . This movement, for example, had been known to advocate involuntary sterilization—a racist form of mass “birth control.” If ever women would enjoy the right to plan their pregnancies, legal and easily accessible birth control measures and abortions would have to be complemented by an end to sterilization abuse. (Davis, 1981, pp. 203–204)

Even today in the United States women of colour can only expect the costs of voluntary sterilization to be covered, while they almost always have to pay for an abortion themselves. Angela Davis feels that up to now white feminists have paid too little attention to this sorry state of affairs:

Over the last decade the struggle against sterilization abuse has been waged primarily by Puerto Rican, Black, Chicana and Native American women. Their cause has not yet been

embraced by the women's movement as a whole. Within organizations representing the interests of middle-class white women, there has been a certain reluctance to support the demands of the campaign against sterilization abuse, for these women are often denied their individual rights to be sterilized when they desire to take this step. (Davis, 1981, p. 221)

### **SELF-DETERMINATION ON THE BASIS OF OVERCOMING DIVISION**

The current discussion of female self-determination will only be able to overcome this division if greater attention is paid to the notion of equality. On the one hand, this means that we must “place the abortion issue in a more global context” as proposed by one of the feminist activists of the West German GREENS, Verena Krieger (Krieger, 1987, p. 239):

The global context is characterized by the worldwide expropriation of the woman's reproductive capacity. The fact that some women are compelled to bear children while others are prevented from doing so is based on one and the same rationale. The right to freely choose abortion is dependent on the right to freely choose motherhood—and vice versa. White and colored women, crippled women and prostitutes, foreign women and local women will only have a common interest if both aspects are embraced. (Krieger, p. 239)

As far as the discussion of prenatal diagnosis is concerned, however, this also means saying no to a right to a nondisabled child along with the bogus biologicistic remedies of selective technology.

This, however, presupposes that women too redefine their utopia. Disability must no longer be automatically equated with suffering, and nondisability must no longer be seen as the precondition for happiness. Only when disability and nondisability can be thought of as equal—or perhaps neutral—conditions will there be a utopia in which disabled people are not merely regarded as being also-people, but in which disabled and nondisabled people are equal. The feminist concept of self-determination must be guided by this goal.

This demand does not give much guidance for dealing with prenatal diagnosis in everyday practice. It will no doubt be criticized for failing to

address the realities confronting women today. In my defence, it should be said that however attractive realistic political demands and rules of conduct may be, they are no substitute for (utopian) thinking. After all, you have to be able to think of something before you can fight for it.

### ENDNOTES

1. For selected further reading on the continuity between race hygiene and human genetics see Sierck, & Radtke Nati, 1984; Kaupen-Haas, 1986; and Weingart et. al., 1988.

2. In Sierck & Radtke Nati, 1984.

3. Judgement of January 1983, Bundesgerichtshof, W. Ger., 86 Bundesgerichtshof in Zivilsachen <BGHZ> 240.

4. American sociologist Barbara Katz Rothman, whose book is now also available in German, has made a valuable contribution to the feminist debate with her investigation into the effects of amniocentesis on pregnancy and motherhood (Katz Rothman, 1989).

5. It should also be mentioned that the positions taken up by Maria Mies and Dorothea Brockmann were not the only aspects to be discussed during the debate on self-determination at the 2nd Federal Congress in Frankfurt. For other analyses, see for example Theresia Degener (1989) and Paula Bradish et al. (1989). The extent to which the understanding of self-determination is influenced by material, geographical, cultural, and economic conditions was clearly illustrated at the last International Feminist Congress on Genetic and Reproductive Engineering in Bangladesh. See Degener (1989) and Bradish (1989).

6. Moreover, this proves how far removed from reality human genetics is.

7. Recommended reading on this subject is Mayer & Rütter, 1988.

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