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Normalcy, Bio-Politics and Disability: Some Remarks on the German Disability Discourse

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Abstract: In Germany the perspectives of disabled people have a special weight in the public discourse on new genetics. This paper concentrates on the critique developed by activists of the disability rights movement. It focuses on the discourse's patterns and regularities which show a rough historical structure, and on the main and most influential arguments. As a first step, a theoretical framework is sketched. It draws on the work of French philosopher Michel Foucault as well as that of German literary scientist Jürgen Link. The concepts of "governmentality," "bio-power," and "normalism" help to understand that normalcy and eugenics are modern apparatuses of power/knowledge. In analyzing the discursive patterns of the German disability discourse on bioethics, in particular the "historical argument" and the "feminist argument," it can be shown that the disability rights discourse still considers power mainly as a disciplining, repressive force. The paper concludes with a plead for a renewal of the critique in order to better understand the bio-political matrix of neoliberal society which not only provides risk-oriented programs and policies, but also governs our subjective ways of thinking.

Introduction[i]

In the discourse on the new genetics, disabled people's perspectives have a special weight, especially in Germany. When the discourse began in the 1980s (Köbsell & Strahl, 1986; Köbsell & Waldschmidt, 1989; Sierck & Radtke, 1984), post-war Western German society showed little willingness to even listen to people with disabilities. Over the last two decades, the public — in part assisted by application of certain discourse strategies — has gradually become more attentive to and aware of the issue of disability in the context of genetic engineering and reproductive technologies. At present, it seems that German people with disabilities have been quite successful in the discourse strategies they have applied. As reprogenetics has grown more and more routine in everyday life, they have received more and more opportunities to voice their views — in scientific debate and public campaigns, in official commissions and hearings at the German parliament, in conferences and in the mass media (Aktion Mensch & Zirden, 2003; Deutscher Bundestag, 2002; Die Zeit, 2001; Dörr, Grimm, & Neuer-Miebach, 2000; Graumann, 2003; Graumann, Grüber, Nicklas-Faust, Schmidt, & Wagner-Kern, 2003).

In considering disability in the context of new genetics, one must remember that disabled people tend to be characterized rather arbitrarily and are not a clearly defined social group. Consequently, they do not speak with a single voice about the potentials and risks of genetic engineering. And, of course, positions on crucial issues such as the use of prenatal or preimplantative diagnostics — and abortion — vary from person to person. They tend to vary by gender and parental status and, in the case of people with disabilities, they tend to depend on specific impairment. While opinions thus of course differ, Germans with disabilities are generally inclined to be suspect of genetic engineering. More than other segments of the German population, disabled people and their organizations are likely to view the new technologies and the experts' promises with a skeptical eye. I should add that this is my impression, not the result of empirical analysis, as representative studies on disabled people's attitudes to reprogenetics and bioethics have not yet been carried out in Germany (c.f. case studies Hönniger, 2000; Köbsell, 2003; Volz, 2003; Waldschmidt, 1992, 1995, 2003b). At present, the best way to learn what disabled people think in this country is to consult papers and statements issued by disability organizations and leading authors on disability issues. For this reason, I will concentrate on such materials in the following.

In particular, this paper concentrates on a specific field of the discussion: the argumentation developed by activists of the disability rights movement. In other words, I do not consider sources issued from the official interest groups of and for people with disabilities, as Hönniger (2000) does. Nor do I take into account self-help groups of people with chronic diseases and genetic impairments, as such groups normally focus on a single anomaly, impairment or illness. Instead, I consider sources written by disabled people committed to the cross-disability rights movement. In the following discussion, a history of nearly twenty years is covered (c.f. Köbsell, 2003; Waldschmidt, 1992, 1995, 2003b). Needless to say, one could apply a chronological approach and analyze the historical development — how the discourse started, how it evolved over the years and how certain arguments were advanced, changed, forgotten and rediscovered. But in this paper special attention is being paid to discursive patterns and regularities (which actually show a rough historical structure), and on the main or basic arguments that have been most influential.

I will start with an overview of my theoretical perspective that draws on Michel Foucault (1983; 1991; 1999) as well as on the German literary scientist Jürgen Link (1998). It was Link who at the end of the nineties developed the concept of so called "normalism" that helps understand the relevance of normalcy (and disability) in modern societies. And it was Foucault who in the seventies outlined the concepts of "governmentality" and "bio-power", in which context he pointed out the weight of the statistical conception of normalcy that contrasts distinctly with the juridical and disciplinary norms which earlier forms of sovereign power have employed. He also called attention to a power that governs by freedom, not repression, and which reigns over people by regulating and positioning them, not excluding and institutionalizing them. (for a review of Foucauldian disability studies see Waldschmidt, 2006)

I will come back to this last point when in the second part of this paper I discuss the discursive patterns of the German disability discourse on bioethics. In the following, the focus will be laid on the two central arguments that have been put forward by disability rights activists against the new reprogenetics over the last two decades. I call the first of these the "historical argument" and the second the "feminist argument." As it happens, each of these two basic arguments is linked with a certain phase of the discussion. The historical argument was formulated in the beginning, whereas the feminist viewpoint dominated the discussion during the nineties. In each case, I first describe the argument by way of taking one typical discursive fragment as example, and then analyze it theoretically with the concept I am now going to explain in more detail. Before turning to the disability discourse, let us first explore the relationship between society and normalcy (Waldschmidt, 2004). Of course, normalcy and its critique is an issue of constant debate in disability studies; yet it seems to me, as if "the tyranny of the norm" (Davis, 1995, p. 13) is too often too readily accepted. Can — one feels compelled to ask — the phenomenon of the normal truly be boiled down to social conformity or individual behavior oriented to dominant norms? Is the omnipresence of "normalcy" which we are witnessing in current society really such a simple fact?

Normalcy and Society

When one takes a close look at contemporary societies, especially those belonging to the western hemisphere of the world, it cannot be doubted that they do function in a different way than in former times, for example, than during the 19th century. And this functioning seems to rely a great deal on "normalistic" patterns (Link, 1998). Significantly, societies, which are dynamic, individualistic and pluralistic, orient themselves less and less to penal laws, sanctions and external conformity, but again and again, to diversity, statistical normalcy and internal self-control. Social norms have receded into the background. Instead, the normalcy of the majority or average seems to be the putty that holds society together in the face of flexibility requirements, disorientation and atomization. Of course, there are still social norms that we must obey if we do not want to be penalized. And yet in the course of the 20th century statistical normalcy has become a special phenomenon that now, like normativity, aims at influencing human behavior.

In short, with Link (1998), I am claiming that there are now two different types of norms, namely "normative norms" and "normalistic norms." The differences between these two norm concepts can roughly be described as follows: "Normativity" refers to the power of social and legal norms, of social rules that are imposed on people. Normative norms orient people to external rules that they must follow or conform to. Controlling mechanisms ensure conformity with social norms; deviation and disobedience are subject to penalties and sanctions. A "normative norm" can also be described as a "point norm," as a regulation that is externally set and prescribed for individuals. In terms of its social function, normativity is aimed at the production of stability and conformity. Its purpose is to generate conformity, prevent deviation and protect society from upheaval and chaos.

On the other hand, normalcy in the narrower sense, i.e. average normalcy, involves comparing people with each other in light of a standard. Normalistic norms confront each person with the question: who or how am I, or how do I behave, *in comparison with others*? This question refers to regular behavior rather than to rule-conforming behavior. Normalcy in this modern sense means the experience that social behavior or human characteristics that are seen as customary and that are statistically documented can become guidelines and standards. The conformity demanded by normalistic norms is not conformity with external rules; it is conformity with other people. Statistical normalcy, as an ordering category, implies the ongoing production of a mean or an average, i.e. the symbolic or factual production of normal distribution curves. In contrast to the "normative norm," the "normalistic norm" is a "range norm," a spectrum grouped around an average. While the normalistic norm also has external power over some people, all people are continually involved in its formation. We are all always involved in establishing Gauß' curves, i.e. the normal mean, the relevant transition zones and the relevant periphery. Normalistic norms, in contrast to normativity, are less static and less oriented to stability; they are based on change and dynamics. In addition, since they are supported by statistics, they exist only in highly data-oriented societies.

In short, these days we find ourselves living in a normalization society. This normalization society no longer exerts repressive forces on us in the narrow sense. Instead, by way of normalistic norms it "solely" calls on us to orient our behavior to that which the majority demands of us; only in this way does it discipline. Perhaps we no longer even notice the subtle, dominating character of the normalization society. Completely voluntarily, in line with ideals of autonomy and self-determination, we orient ourselves to the middle of society, to average norms. We want to live the way other people do; most importantly, we want to be "normal." And when we feel enjoyment in deviation, then all we want is to "march to the beat of a different drummer" — but only for a while. By no means do we want to be permanently localized at a negative pole.

In my view, the normalization society has become so influential, especially over the past two decades, because it has been able to redefine the concept of normalcy and to enforce it in social practice via discourse, strategic procedures and identity policies. In order to better understand the functional power of the normalization society, I would like to follow Jürgen Link (1998) by differentiating two strategies: protonormalism and flexible normalism.

Protonormalistic normalization strategies can be characterized as follows: They are oriented to normativity, build on the strict separation between the normal and the pathological and permanently ostracize all that is deviant. Protonormalistic procedures function wherever disabled people are isolated and institutionalized, wherever the homeless are police-ejected from public facilities, wherever asylum seekers are interned far from society, wherever homosexuality is seen as a sin and slower learning pupils are considered naturally dumb. Flexible normalization strategies, on the other hand, are gentler and more permeable. Flexible normalistic procedures begin with the ideal of a "well-mixed" distribution of people within the social environment, a distribution that can always change. They follow the assumption that people reach the periphery by chance, that they can leave boundary areas or the realm of the abnormal again and return to the center of society. Flexible normalism also separates the normal from the abnormal, but its separation is only temporarily valid and can always be redrawn. It does not constrict the normal spectrum; but permits it to be expanded out to the boundaries if necessary. The flexible-normalistic field contains a continuity of "normalities" and movable normalcy boundaries. For example, flexible normalism permits cognitively disabled people, who have been ostracized for centuries, to move into normal apartments situated in normal communities. It permits homosexuals, long stigmatized, to maintain normal, open relationships. It provides special counseling and therapy programs that help drug addicts to re-integrate themselves into society.

But let us be cautious. The tendency toward flexible normalization is not simply positive for it does not eliminate all ostracizing categories, all mechanisms that divide people into hierarchical groups. Instead, the imperative of "rearward binding" (Rückbindung) applies (Link, 1998, p. 340). Graphically, this mechanism can be described as follows: in expanding, in moving outward toward abnormalcy, the band that binds the normal center with its boundary zones must not break. Any danger that the entire normal field could dissolve would spark a backlash, a return to strategies that emphasize narrow normalcy zones and fixed boundaries. One example of such a recourse to normativity and its pertinent sanction options is provided by the present worldwide "war on terrorism" in which the "zero tolerance" policy for persons suspected of being involved in terrorist acts clearly outweighs liberal values. In other words, the normalizing society is tolerant and accepts many escapades, but normalcy boundaries continue to exist and may not be heedlessly crossed.

Normalcy and Disability

A look around today's normalization society reveals that normalistic norms play important roles in many areas. For example, normalcy has become the decisive orientation point in disability policies, rehabilitation programs and special education concepts (Waldschmidt, 1998, 2003a). In Germany some years ago, in 1997, a publicity campaign was carried out in support of equal status for people with disabilities. In a major poster campaign, an alliance of the most important associations for the disabled, working under the name "Equal Rights Campaign" ("Aktion Grundgesetz"), called for the recognition of disability as a normal mode of life. The campaign comprised a number of slogans that all utilized the concept of the normal:

"Sport with a handicap - completely normal. - Who is really normal, anyway? - In the U.S., disabled people are a normal part of life. Why not here as well?"[ii]
And:
"Do you really think you're normal? - Being cognitively disabled is also normal.[iii]

A closer look at these pithy formulations reveals that they contain different concepts of normalcy. For example, the question, "do you really think you're normal?" and the claim, "being cognitively disabled is also normal" are based on rather contrary perceptions of "normal." The somewhat rhetorical question, "do you really think you're normal?," is an appeal to people's wishes for individuality and uniqueness. It assumes that no one really wants to be just normal, as average as the man or woman on the street. It equates normalcy with the bourgeoisie and emphasizes the joys of eccentricity. On the other hand, the claim, "being cognitively disabled is also normal," is oriented to a positive concept of normalcy and claims this concept for cognitively disabled people. It assumes that cognitively disabled people are in the minority but are not unusual, and thus are normal people. This slogan also seems to assume that normalcy is something desirable, something that should also be possible for people with cognitive disabilities. This view could also be formulated in ways such as "people with learning difficulties are people like us."

The disabled associations' campaign obviously saw no problem in simultaneously propagating different perceptions of the normal. How was this possible? Clearly, the different normalcy concepts involved are based on basic assumptions that are implicit in flexible normalism. All slogans imply that normalcy provides choices and room for change. Another common feature is the assumption that each society is free to define normalcy. The line between normalcy and handicap is no longer rigid or naturally given; it is shifting and variable and may even be unnecessary. In today's society of flexible normalization, normalcy is no longer considered an immutable, permanent fact. It is instead seen as a challenge, as something that can be designed and produced, as a "landscape" that changes with time. It is no longer an external constraint that society imposes on its members — it is formed and shaped by the acting subjects themselves. In other words, policies for the disabled clearly use a normalcy concept that, according to Link (1998), could be termed "flexible-normalistic."

In the second part of this paper I will turn to the bio-political discourse and examine the positions that were developed by people with disabilities in this context. And of course, the question of normalcy will guide me again: Does the issue of flexible normalization play any role in this discourse?

Normalcy, Disability and Bio-Politics

From the late 1970s, when the German disability rights movement was just emerging, until now in the early 21st century, the effects of genetic engineering and reproductive technologies on the lives of disabled people have continued to be important issues and areas of intensive debate (Graumann, 2003; Köbsell, 2003; Waldschmidt, 1992, 1995, 2003b). Female activists have figured especially prominently in this discourse, and thus feminist arguments have played, and continue to play, a significant role in it. However, the debate began not with the formulation of a feminist position, but with a look back at the blackest period of German history — national socialism, to be precise: Nazi eugenics and racial hygiene. It was definitively not a coincidence that the first argument put forward by disability activists was a historical one.

a) The historical argument

The historical argument was developed in a small but influential book called "The Mafia of Benefactors" ("Die Wohltäter-Mafia"). It was first published in 1984 by the authors themselves, Udo Sierck and Nati Radtke, a man and a woman who were both disabled and involved in the German disability rights movement. In the years that followed, the book met with a remarkable reception and went into several editions. In 1989, the fifth edition was published by a left-leaning publisher known in Germany for its policy of publishing critical texts on medicine, public health and nursing.

In their book, Sierck and Radtke (1984) focus on the history of human genetics counseling. They seek to identify the traditions which National-Socialist racial hygiene and human genetics have in common. Their approach is centered on these questions: Is there a relationship or a so-called "continuity" between National-Socialist racial hygiene and post-war human genetics, or, in other words, are there links between the old, authoritarian eugenics and the new, liberal eugenics? Needless to say, these questions are answered in the affirmative. In their book, which is one of the first sources of the disability rights discourse on the new genetics, Sierck and Radtke (1984) posit a close continuity between eugenics, racial hygiene and human genetics. Their criticism can be summarized as follows:

First, both eugenics and human genetics are concerned with the same object, namely research into genetic inheritance and hereditary disease. Both scientific disciplines attempt to find out the causes and identify the symptoms of congenital impairments and aberrancies. In the past, techniques were based on Mendel's genetic theory; today, research is carried out on the level of chromosomes, gene products, and molecular structures. Secondly, there is a strong continuity on the biographical level. The same generation which was actively involved in the racial hygiene program built up human genetics in post-war Germany. That earlier generation of scientists had no qualms about what it had done during the Third Reich, and it felt it had instead been misused by the Nazis. Without a second thought, then, the old guard made use of their former scientific works to formulate a modern approach. Thirdly, human genetics and eugenics share the same paradigm, which is the principle of selection. The scientific intention, in former times and today, is to systematically apply findings with a view to preventing hereditary disease and eradicating their causes. The purpose, then and now, is to reduce the number of so-called unhealthy genes and to pass on healthy genes to the next generation. And the principle of selection is still all-important. In the past, human beings were selected and classified according to socially justified quality characteristics; today, unborn life is so selected and classified. In short, both eugenics and human genetics apply "quality" criteria to human life. Fourthly, both eugenics and human genetics are part and parcel of population policy. Their underlying basis is the fear that the population will decline in numbers and deteriorate in quality, as the number of overall births continue to decline, as medical science progresses and as ecological damage and industrial hazards increase. For these reasons, cost-benefit-analyses are undertaken to characterize certain minority groups as burdens on the welfare system. For the same reasons, bans on childbearing are enacted for some populations and obligations to have children for others are imposed. Bans on childbearing affect disabled women, whereas incentives to have children are directed at women without disabilities. Furthermore, the population approach inherent in human genetics requires the systematic recording of genetic data in which masses of people are being registered and thus controlled. In an article written in 1986 Sierck concludes:

"In sum, human geneticists are upholding a social-strata model of society based on the premise that some people are biologically inferior." (p. 19)[iv]

For years, this pattern of argumentation has dominated disabled people's discussion on human genetics in Germany. The old eugenics and today's new preventive genetic strategies have been seen as largely equivalent. Today's human genetic counseling and prenatal diagnostics have been regarded as disciplinary technologies operated by a dominant cartel of science, medicine, industry and the state. The assumption has been that the racial hygiene concept was transformed directly into post-war policies, and that human genetics is being used to achieve population policy targets. The scientific discipline has been considered as an instrument of coercion, executed by "those at the top" against those "at the bottom," and as an anti-disability strategy for controlling, disciplining and standardizing the deviant.

This "repression model," as I would like to call it with reference to Foucault (1983), although very successful within the discussion, was already an anachronism at the time it was formulated. It relied on an obsolete political theory, as it did not take into account that in post-war Germany, as in other countries, democratization and liberalization had fundamentally changed relationships between the state, society and the individual. Today's new eugenics relies on individual autonomy and self-responsibility. Nowadays, human geneticists act not on their own authority, but on the authority and wishes of their clients. Genetic selection is based on the seemingly objective concept of "risk" and is practiced with the active participation of the individuals concerned — after they have been duly informed and have given their consent (Waldschmidt, 1996, 2005). Eugenics has shed its authoritarian roots and developed a democratic and individualistic approach. Coercion and pressure, open repression and control are no longer applied; they are, in fact, no longer necessary. The state and society no longer need to urge people to do their eugenic duty. People obey their individual genetic risks; they are voluntarily adhering to eugenic reasoning, without expressly being told to do so.

The central issue thus is not one of a specific governmental policy, but of a eugenic matrix that is gradually invading all areas of everyday life. The new eugenics has its own dynamics, as it is supported and practiced by the woman and the man on the street, and is not enforced by the police and the official authorities. As a result, genetic selection appears to be something "quite normal." Only 70 years ago, eugenics was a crude instrument of social management that was forcibly imposed upon individuals against their will. Today, it is granted to individuals in accordance with their wishes, and it seems to have become part and parcel of modern identity policies. In short, we are witnessing an "eugenics of risk" (Lemke, 2002, p. 288) and its normalization.

b) The feminist argument

Should we worry about the new eugenics, rather than the old? Perhaps the big problem is not human genetics as a science, but the participation of so many people in the search for genetic perfection and normalcy in our liberal societies. Why did genetic testing during pregnancy become routine practice so quickly — not only in Germany, but all over the world? What makes a great number of women want to use genetic diagnostics and reproductive technologies despite the health hazards for themselves and their babies? Why are so many women prepared to accept invasive diagnostic techniques during pregnancy and to submit to potentially dangerous surgeries, such as amniocentesis and chorion villi sampling, and risk a miscarriage only to ensure that their embryo or fetus is not disabled?

These questions were raised by women with disabilities, especially by women who were active in both the disability rights movement and the women's liberation movement (Barwig & Busch, 1993; Bradish, Feyerabend, & Winkler, 1989; Ewinkel et al., 1985; Faber, 2002). Sensitized by what they had experienced at the hands of medicine and gynecology, disabled women came to see human genetic diagnostics not as a way to achieve greater women's self-determination, but as an instrument of control over women and their bodies. From the disabled women's perspective, genetic diagnostics is not only "ableist," but "anti-women," too.

The main problem for the disabled feminist position, however, has been that the issue of prenatal genetic selection is closely tied up with the highly emotionalized issue of abortion.[v] The German women's liberation movement has been busy fighting for a woman's right to choose, while ignoring the problem of genetic selection. Women with disabilities finally brought this issue forward for debate in the 1980s. The position of disabled women within the abortion discourse can be described as "sitting on all fences." On the one hand, they stand up for women's reproductive freedom and the right to abortion. On the other hand, they criticize a politically naive feminist self-determination concept that accepts dominating ideological norms, such as the expectation that women should bear healthy children. At the same time, disabled women also have to make clear that the solution of the eugenic dilemma cannot lie in obliging conservative antiabortionists by forbidding abortion in general or even installing a women's "duty to bear disabled children" — a demand brought forward by some male disability rights activists at a heated stage of the discussion (see for a critique Degener, 1989).

In 1992, a book appeared which proved to be a landmark in the emotionalized debate between non-disabled feminists, male activists of the disability rights movement and women with disabilities (Degener & Köbsell, 1992). This contribution to the discussion, which was written by two activists of the feminist disability movement, Theresia Degener and Swantje Köbsell, both summarized the discussion to-date and developed it further. The authors also formulated the position of the German disabled women's movement, a position that is inspired by both the feminist disability perspectives.

Degener and Köbsell (1992) do not question women's right to abortion in general, but they question the right to abortion on selective grounds. They deny that the use of genetic diagnostics enhances female self-determination (ibid., pp. 67-82). From their point of view, decisions for prenatal diagnostics are not part of reproductive autonomy. The authors thus call for a new look at the old feminist slogan "the private is the political." They argue that if women try to achieve individual self-determination by using selective abortion, they participate in eugenics, whether they intend to or not. Prenatal diagnostics is confronting women with the eugenic dilemma, a dilemma which is not easy to escape. Degener and Köbsell also argue that there is a fundamental difference between abortions after prenatal diagnostics and abortions in the case of unwanted pregnancy.

They claim that selective abortion is in fact directed against an unborn child which was actually wanted in the first place (Degener & Köbsell, 1992, pp. 82-84). The genetic quality assessment of the fetus turns a heartily welcomed pregnancy into an undesirable one. In the contrasting case of a nonselective abortion for social or personal grounds, the pregnant woman may also see her fetus as a burden, as something she wants to get rid of. In such cases, the fetus is seen as a burden not because of its own fetal characteristics, but because of the woman's personal situation and living conditions. The fetus as such is unwanted, and his or her genetic traits do not play any role, whereas in the case of a selective abortion the woman's desire to have a "normal," non-disabled child is crucial for the decision to terminate the pregnancy. Of course, the woman's decision against a disabled child can be attributed to social constraints and pressures, but nevertheless, when one looks for the logic of genetic diagnostics during pregnancy, one has to admit that the decision against a fetus on the ground of a disability has a qualitative dimension — in fact, a eugenic dimension.

With such arguments, women with disabilities touch an open wound of feminist philosophy, as generally one can find great acceptance of eugenic thinking amongst feminists (Degener & Köbsell, 1992, pp. 84-90). They call attention to the fact that women without disabilities often fight for their own rights while ignoring basic principles of equality. Middle-class, educated, white and healthy women — in short, "normal" women — demand rights that are solely in their own interest and that may result in discrimination against other groups of women. If, for instance, the women's liberation movement argues for a concept of self-determination that entails the right to a non-disabled child, it implicitly calls for a population policy that is directed against disabled people's right to life. Even in liberal societies, reproductive freedom is granted to women only under the condition that they adhere to genetic selection and the prevention of the disabled. Freedom and self-determination are made available to those who are willing to orient their actions towards a selective model of procreation and to submit themselves to "ableist" conditions of living.

In connection with this argument, disabled feminists raise the question of the society model applied by the women's movement, which they see as closely linked to the principle of self-determination (Degener & Köbsell, 1992, pp. 91-93). The issue at stake is whether disabled people have a place in a feminist utopia. Most women would not want a disabled child even if society were more supportive of the needs of disabled people. Both the feminist movement and mainstream society tend to associate disability with pain, suffering and burdened lives. Even feminists often regard disabled people only as "Auch-Menschen" ("also human beings"). For these reasons, Degener and Köbsell (1992, p. 93) plead for a change in feminist utopian thought. Disability and "non-disability" should be thought of as neutral states; that is the only possible way to accord disabled and non-disabled people equal value as human beings. Feminist concepts of freedom should be connected with the utopia of an inclusive society in which disabled people are fully accepted. The two feminist authors summarize their position as follows:

"We consider it possible to argue both for women's rights to abortion and against any supposed rights to non-disabled children (…). And we also think that the concept of self-determination (…) is increasingly being instrumentalized as a social weapon…." (Degener & Köbsell, 1992, p. 9)[vi]

This contribution to the discussion has played a central role in the feminist discussion on self-determination. It has spurred a new mode of thinking. Until the early 1990s, German feminists tended to ignore the viewpoints of disabled feminists. This book has attracted their attention and has helped to change the discourse profoundly. Women with and without disabilities have begun talking with each other and exchanging views. In 1995, a common network against selective measures during pregnancy ("Netzwerk gegen Selektion durch Pränataldiagnostik") was established; another forum for critical analysis of reproductive technology was founded in 1999 (Reprokult - Women's Forum for Reproductive Medicine, 2002). And yet, at least in my view, the disabled feminists' analysis does not go far enough in connection with the implied society model. Of course, it makes sense to link female self-determination with social living conditions, to point out its relativity, and to note that the mainstream women's liberation movement has a problematic liberalistic tradition. It is also valuable, however, to demonstrate that the feminist battle for recognition can create new barriers for women and men with disabilities. With such insights, the disabled feminists' criticism of the new eugenics is convincing, but at the same time one has to concede that obsolete instruments for the analysis are being used.

Apparently, postmodern power relationships and dynamics in neo-liberal and postmodern society are not understood, since in the essay of Degener and Köbsell one finds continual references to "external control," "restraints" and "discipline," while simultaneously the authors admit that eugenic measures are now carried out not by the state, but by practitioners of reproductive medicine and bio-ethics. However, is it really true that female self-determination is being used as a new "social weapon" (Degener & Köbsell, 1992, p. 107)? Does a woman really only want a "Normkind" ["norm child"] (ibid., p. 82)? What are the reasons for the deeply rooted "ableism" in the population, and how did the prevailing acceptance of new genetics and widespread willingness to cooperate develop in the first place?

It seems to me that instead of searching for agents that are about to develop social weapons against the population, it would be more helpful to analyze neoliberal eugenics as a power apparatus or — as Foucault (1978) has named it — as a "dispositive" that consists of discursive, institutional and identity policies that structure social power relationships and form new ways of self-representation. In our day, women are not instrumentalized (in traditional ways) by an external authority, but they voluntarily act in certain ways, seduced by promises and suggestions of a better life. While the resulting eugenics may differ from many women's individual intentions, most women still want what they are obliged to do. Very few women have the courage to decide against abortion and in favor of a disabled child. Perhaps women are not prejudiced against disabled people, but are simply afraid that a disabled child will cause them to be regarded as "abnormal." They become clients of genetic diagnostics not because they fear disability but simply because they want normalcy in their own lives.

Conclusion

More than a decade ago, it was myself who wrote this passage:

"We refuse to allow our right to life to be questioned, because we are afraid of the normalization of eugenics (…) It is conceivable that disabled people may soon be considered as 'waste products' or 'accidents' in a genetically screened, technically engineered reproductive process that is designed to prevent sickness and suffering (…). Genetic therapy would be the only assistance offered to them. They would no longer receive any financial or social support. There would be cuts in social security and rehabilitation systems. The living conditions of the disabled would deteriorate (…). Before long, disabled people themselves could be held accountable for their fate and left to cope with life on their own. After all, they would only be people who should never have been allowed to be born anyway. In the long term, they would have no essential right to existence any more in an age of applied human genetic engineering (…). Yet, even if they had no right to a decent human life, disabled children would still be born, and a large number of people would still become disabled at some time in their lives as a result of health injuries caused by traffic accidents, industrial accidents, or environmental contamination. They would all face the dilemma of being alive but irrelevant factors according to the technocratic logic of the year 2000. The disabled would become the human 'garbage' of a future society." (Waldschmidt, 1992, p. 166)

Rereading this gloomy prospect in the year 2006, I now have to state that the negative utopia which I designed over fourteen years ago has not yet been realized, and probably never will be. The current situation of disabled people in Germany is not characterized by overt repression and blunt discrimination. Instead, a complex dynamic process is in progress, one which I now identify as a somewhat complicated combination of flexible normalization and rigid "normification," as I would like to call it with reference to Erving Goffman (1963, p. 30f.), who in his study "Stigma" distinguishes between the normalizing strategies of relevant others and the efforts of the stigmatized person to submit to dominant norms. In the past few decades, the disability arena has been fundamentally restructured not only in Germany, but in other Western societies as well. At present, one can witness a so-called "paradigm shift" in disability policies. Great efforts are being undertaken to increase general acceptance of disabled people, to make participation and self-determination possible for them and to build up an inclusive society. Normalization has become the decisive orientation in social and health policies, rehabilitation programs and special education concepts. At the same time, discrimination continues, and mechanisms of exclusion and segregation are still in force — especially in schools and the workplace, but also at the level of face-to-face interactions. Strategies of normification, that is to say, the building of strict barriers between the normal and the disabled, are still in operation.

A similar combination of normalization and normification is apparent in the field of human genetics. Today, human geneticists use not paternalistic guidance, but the concept of "high risk" to assist their clients in making appropriate decisions in their particular cases (Waldschmidt, 2005). Normalistic landscapes have been developed that are based on fluctuation ranges, transition zones and variably defined boundaries. These landscapes serve as a framework for seemingly autonomous decisions. Nowadays, human genetics counselors seek to counsel non-directively so that they will avoid any suspicion of engaging in eugenics. They instead use mean values and comparative figures and aim to establish neutrality, objectivity and rationality within the counseling context. Explicit advice is no longer offered; because the suggestive power of flexible normalcy is at work. At the same time, selection through genetic diagnostics has increasingly become an unquestioned routine practice in Germany as well as in other countries. With pre-implantative diagnostics, the selective approach will become even more deeply rooted in the technological procreation process.

As to the disability rights discourse on reprogenetics, recent moves towards liberalization and normalization, in both society and genetic science, have not yet been adequately reflected, at least in the discursive fragments I have analyzed in this paper. In her edition on the "government of disability," Canadian philosopher Shelley Tremain (2005) points out that the international disability rights critique of bio-power still needs to understand that neoliberal power operates not primary as a repressive apparatus by the hand of an external sovereignty, but as an omnipresent matrix which structures policies and programs and at the same time provides techniques of self-regulation. Obviously German disability rights activists as well have not yet fully recognized that we live in a normalization society and not under authoritarian rule. Perhaps it is easier to analyze the effects of disciplinary repression than those of flexible normalization, as the former are more clear-cut than the latter, which can be somewhat blurred. Traditional identities, as outcomes of normalization, are being challenged. The conventional boundaries between the disabled and the normal are about to vanish, but new categories are not yet in sight. What about those "genetically at risk" — do they still belong to the normal or do they already belong to the disabled? In other words, the dispositive of normalization is questioning the fundamentals of the disability identity policy that the disability rights movement has adopted over the last two decades. What do "disability" (and "normalcy") mean in the age of genetic engineering? That is the crucial question which needs discussing. The disability rights discourse with respect to genetic engineering and reproductive technologies has not yet ended — apparently, it needs to start all over again.

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Endnotes

[i] The first draft of this paper was translated by Eric Allen. Unless otherwise noted, all quotes are also translated by him.
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[ii]. "Sport mit Handicap — Total normal. - Wer ist schon normal? - In den USA sind behinderte Menschen normaler Teil des Lebens. Warum nicht bei uns?"
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[iii] "Sind Sie etwa normal? - Geistig behindert ist auch normal."
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[iv] "Festzuhalten bleibt: Humangenetiker sind dabei, ein Schichtenmodell der Gesellschaft fortzuführen, das auf der Basis ruht, daß eine biologische (Minder-)Wertigkeit der Menschen existiert." (Sierck, 1986, p. 19)
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[v] Some additional information on the abortion laws may be helpful for those who are not familiar with German history and law: In the German Democratic Republic, abortion within the first twelve weeks of pregnancy was allowed even since 1968. In contrast, in Western Germany abortion was generally forbidden until 1976, and only when a disabled fetus was diagnosed could the woman get an exemption from the legal ban. A disabled child, it was argued, was a danger to the mother's mental health; it was accepted as a medical indication and could legitimatize the termination of a pregnancy. Between 1976 and 1995 the Western German law permitted abortion only on four main grounds: high risks to the woman's health and life, rape, proven social predicament, and genetic diagnosis. Remarkably, the pregnancy-duration limits for abortion were made to vary in accordance with the basic justifications: abortion for medical reasons could be performed at any time, abortions after a rape and for social grounds were permitted only during the first twelve weeks of pregnancy and abortions on the basis of a so called "child", "eugenic" or "embryo pathological" indication were allowed until the 22nd week. In 1995, the abortion law was again changed, this time in connection with German re-unification. Since then, as clarified by a constitutional court ruling, abortion is to be regarded as "unlawful", but not forbidden. Within the first twelve weeks of pregnancy, women are permitted to have abortions — without having to provide specific reasons, but only after undergoing mandatory counseling from certain authorized institutions. And abortion is no longer financed by national health insurance. There are two exemptions from this rule: First, if the pregnancy results from a rape and is carried out within the first twelve weeks of pregnancy, the woman is not obliged to undergo counseling, and will get nation health insurance coverage. Secondly, accepted genetic indications have been fused with medical indications. As a consequence, the conditions for an abortion for genetic reasons also differ from those for a "normal" abortion. In the case of a disabled fetus, no counseling advice is needed, either, national health insurance is granted as well, and additionally no time limits apply. In fact, the current law even allows selective abortions to be carried out until shortly before birth.

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[vi] "Wir meinen, daß es möglich ist, für das Recht von Frauen auf Abtreibung und gegen ein vermeintliches Recht auf ein nichtbehindertes Kind zu streiten (...). Und wir meinen auch, daß der Selbstbestimmungsbegriff (...) zunehmend als soziale Waffe instrumentalisiert wird... ." (Degener & Köbsell, 1992, p. 9)

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