

## AGAINST SELECTION OF HUMAN LIFE-PEOPLE WITH DISABILITIES OPPOSE GENETIC COUNSELLING

ANNE WALDSCHMIDT

Elsa Brändströmstrasse 33a, 5300 Bonn 3, Germany

**Synopsis** – It is impossible to understand why people with disabilities criticize human genetic counselling without some knowledge of the history of human genetics and the German disabled movement. Something new occurred at the beginning of the 1970s – disabled people developed a sociopolitical concept of disability and commenced serious research into the National Socialist race-hygiene policies between 1933 and 1945. Disabled women publicly exposed how they are subjected to special discrimination by the imposition of a “ban on childbearing,” and developed their own feminist-oriented standpoints with respect to human genetic counselling. Undoubtedly, the fundamental principles underlying today’s human genetic counselling date back to ancient times, but the “eugenics” of the 19th century expanded these principles to a scientific doctrine, and the National Socialists implemented eugenics as a political policy that held human life in total contempt. The eugenics of ancient times and today’s human genetics have enough in common to justify speaking of them as one and the same concept. There is a crucial difference, however. Today, eugenics is practised with the cooperation of the individuals concerned, with their willing consent. In times that require everyone to function as smoothly as possible, the Utopia of perfect health is extremely seductive. So it is no surprise that people with disabilities are afraid they will be classed as society’s human “garbage” and join forces to defend themselves.

**Synopsis** – Um zu verstehen, warum Behinderte die humangenetische Beratung kritisieren, muß man die Geschichte sowohl der Humangenetik als auch der deutschen Behindertenbewegung kennen. Zu Beginn der siebziger Jahren dieses Jahrhunderts geschah etwas Neues: Behinderte entwickelten einen gesellschaftspolitischen Behindertenbegriff und begannen, sich mit der nationalsozialistischen Rassenhygiene der Jahre 1933–1945 auseinanderzusetzen. Behinderte Frauen deckten ihre spezifische Diskriminierung, von einem “Gebärverbot” betroffen zu sein, auf und entwickelten bezogen auf die humangenetische Beratung ihre eigenen, feministisch geprägten Positionen. Zwar sind die Grundprinzipien, die in der heutigen humangenetischen Beratung stecken, uralte, doch die “Eugenik” des 19. Jahrhunderts hat diese Überlegungen zu einem wissenschaftlichen Konzept ausgebaut. Die Nationalsozialisten haben die Eugenik auf menschenverachtend radikale Weise in konkrete Politik umgesetzt. Die alte Eugenik und die heutige Humangenetik haben genug Gemeinsamkeiten, die berechtigen, von dem gleichen Konzept zu sprechen. Gegenwärtig allerdings – und das ist der entscheidende Unterschied – findet Eugenik unter Beteiligung der Individuen statt, mit ihrer bereitwilligen Zustimmung. In einer Zeit, in der jeder möglichst reibungslos funktionieren muß, besitzt die Gesundheitsutopie große Faszination. Kein Wunder also, daß Behinderte Angst haben, künftig zum menschlichen “Müll” der Gesellschaft zu gehören und sich deshalb zur Wehr setzen.

**A LONE CRY**

“We reject human genetic counselling. We

know that this is an isolated position in the Federal Republic of Germany” (Sierck & Radtke, 1984, p. 5). This minority opinion is supported by an entire movement, the “crippies’ movement”—a movement formed by people with disabilities who call themselves “cripples” with the intention to provoke. The “cripples’ groups” have formulated a number of precise demands derived from their clearcut point of view. They demand the closure of counselling centres, the improvement of living conditions for the disabled, the setting up of a support network for families with disabled children, and information campaigns to enlighten the public on human genetic selection procedures. The list ends with an appeal to the public to boycott the human genetic counselling services (cf. for instance Köbsell & Strahl, 1988 P.4).

It may seem unrealistic to reject human genetic counselling and go so far as to demand its abolition at a time in which waiting rooms are full and the laboratories for prenatal diagnosis are being stretched almost beyond capacity. It is anachronistic, to be sure. Indeed, it cannot help but run counter to the *Zeitgeist*. But is it that unrealistic? The cripples’ groups are virtually forced to take up this position. They have no alternative but to oppose genetic counselling and diagnosis because it is a matter of their right to life, disabled people’s right to life, that is being negated daily by human genetics. In order to understand why people with disabilities come up with such radical demands, why they concern themselves with genetics, prenatal diagnosis, and gynaecology at all, one has to have some

my own history as a disabled woman, as an opponent of genetic and reproductive engineering.

“BETTER ALIVE THAN NORMAL!”

As with so many of the opposition and protest movements, our movement began in the 1970s. At this time of awakening and rebellion, social work was thriving and, along with it, work with the so-called marginal groups of society. The individuals thus declared marginal soon responded and began to organize themselves. They were no longer prepared to have their affairs managed for them by the professionals (as if they were incapable of speaking for themselves) or to be treated as “a field of research.” They began to rehearse their own “uprising from the bylines” and to discover their own history and identity. Following decades of silence, of being locked away behind the walls of institutions and homes, the physically handicapped and mentally sick finally set up their own interest groups. “Self help” was the key concept of these and following years. Undoubtedly, the disabled can look back on a long tradition of self help, yet these years saw the emergence of something new. So-called cripples’ groups sprung up all over the country.<sup>1</sup> The members of these new organizations were not brought together by the cause of their disability (i.e., as the “victims of an industrial accident” or as “war victims”) or by virtue of their being parents of disabled children. Nor did the specific disease or disability play any role in the “cripples” getting together to organize themselves. This is the crucial aspect in which the “cripples’ groups” differ from other disabled organizations. Most of these regard invalidity to be the root cause of their difficulties in life. They see disability first and foremost as a problem of medical technology. Resentment of the suffering caused by their disability, the experience of pain and the hardship of everyday life that is often fraught

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fascism and eugenics or link it with sterilization, abortion, and euthanasia. In relating this history, I am relating aspects of

with struggle, practical and bureaucratic hurdles, and poverty and loneliness move many disabled people to long for a life free of disability and suffering. This is why they often welcome genetic counselling as a means to prevent disease and disability (i.e., to prevent lives as burdensome as theirs from beginning at all).

The cripples' groups vehemently oppose this point of view. They have developed a totally different and extremely radical position: the "cripples' standpoint" (Christoph, 1980; *Psychologie und Gesellschaftskritik*, 1980). It is directed against the professionals and pedagogues; against the power of the helpers, who take charge of their affairs and oppress them; and against the do-gooders and their denigrating compassion. It is full of angry protest against the ideologies of partnership and integration expressed in slogans such as "The disabled are humans too." That little word *too* makes the sentence mean exactly the opposite of what it claims to mean.

We "cripples" challenge this and angrily reverse the equation – we the disabled, the marginal group, are not the problem; it is the society in which we live and the nondisabled who have difficulties with us – whether it is because they feel repulsion and rejection towards "cripples" and wish to avoid being confronted with us for this reason, because we remind them of their own vulnerability, or because we do not match up to the values of society. The "cripples' groups" are different from other disabled associations, whose declared object it is to bring the disabled and nondisabled together, in that they are places where "cripples" only meet "cripples," to the exclusion of the nondisabled. In this, they follow the example set by the women's liberation movement and women's consciousness-raising groups. Our aim is to accept and value disability as a form of life. We also demand radical changes in living conditions as a natural right, and not as charity. We have no desire to be "disabled

showcases" – pressed into pattern, dear and well-behaved little things, isolated and normalized. We want to be "cripples" – proud of our distinctiveness, bold and fighting, "better alive than normal!" (Sierck & Radtke, 1982).

For me and many others, the concept of "cripple" is linked to the beginnings of our movement when we, who are supposed to be bound to the wheelchair, helpless on crutches, and not quite right in the head, finally and enthusiastically became active. The action groups were infused with a sense of awakening, an exhilarating "coming out." At that time, it shocked people when we called ourselves cripples – and it was intended to do so. But today – 10 years later – the term is no longer ours as a battle slogan. It has also been taken up by the nondisabled, who either use it opportunistically, proclaiming themselves to be advocates and supporters of the "cripples," or because they need a progressive synonym for the word *disabled*. And, of course, *cripple* is still being used in its customary sense as a derogatory term, a deliberate stigmatization of disabled people – indeed, to my mind this is becoming more frequent again.

#### DISABILITY AND DISCRIMINATION ARE SOCIAL PHENOMENA

Even now – after a period of working more within the various social institutions (i.e., pragmatic political lobbying, founding associations, working within the job creation schemes and counselling services) – the "cripples' standpoint," a clearly defined concept of disability, still remains the mainspring of our activities. As I see it, our rejection of human genetic counselling derives from this concept of disability, and I would like to explain it in more detail. What exactly is meant by the cripples' standpoint? It defines disability as the result of a process of social discrimination and attribution based on a person's physical, mental, or emotional

impairment. There has to be some kind of legitimation, a diagnosis based on certain – and this is the crux of it! – social criteria for people to be degraded and segregated out of society. In this way, a more or less objectively verifiable impairment becomes the material precondition for the social category of disability and for the process of disablement, which always encompasses being disabled by others. The ruling norms determine whether or not this process is set in motion and how much importance is attached to it. In our society, these norms apply first and foremost to the following sectors: employment and education, independence and mobility, and aesthetics and communication. Disability is thus equated with economic and social inferiority (i.e., with an inability to perform and compete, which, unlike sickness, is assumed to be chronic, permanent, and irremediable). Seen as such, as “deficient beings,” we are prevented from unfolding and developing our capabilities. Because the disabled are solely and immutably defined on the basis of “deficiencies,” and not on the basis of their abilities and talents, they are effectively barred from participating in and partaking of society and from mapping out their own lives. In other words, anyone whose educational ability is rated low, whose work potential cannot be marketed, anyone who cannot move quickly, anyone who is considered ugly, or anyone who cannot communicate verbally or cope with the demands of everyday life on their own is regarded as disabled. Thus, disability is born in the process of interacting and dealing with others, and reinforced over and over again with each of these interactions. It becomes a permanent, formative experience of the individual.

Here, at this point in the argument, we can already find a reason for the cripples’ groups’ opposition to genetic counselling. Anybody who sees disability as a social and political problem cannot help but find it cynical if the problem is to be solved by preventing the very

people concerned – and this is precisely the rationale underlying today’s human genetic practices. Moreover, there are hard historical facts that provide evidence for the structural links between degradation and discrimination that lead to segregation and selection and the final extermination of people with disabilities. After all, social isolation does not only take place subtly in the form of rejection and disparaging remarks, but also quite concretely and forcibly in the form of homes, institutions, and special units. For centuries “cripples,” “idiots,” and “freaks” have been locked away, segregated, banned, and kept in custody behind walls and doors. It is this common experience that unites and welds us “cripples” together.

Segregation has a double aspect. The people who have been defined as disabled are, at one and the same time, both hidden away and exposed to view. On the one hand, they disappear from daily life and the streets and become almost invisible, so that normal people can ignore them and deny their existence. On the other hand, segregation makes them more conspicuous than ever. They are rounded up in special units and asylums, where they form a mass and become a social institution, the result being that they have become a “social problem.” So the next question is: Where did this all start? How were the disabled treated in the past? The cripples’ groups very soon began to delve into history to find the answers. Unavoidably, our interest was focused on the years of German fascism (Romey, 1982; Sierck, 1982).

Under fascism, treatment of the disabled was so brutal and inhuman that, especially for “cripples,” the question immediately arises: Could it have been me? Could I have been sterilized, tormented, or gassed by the Nazis? It is all the more horrifying to realize that the answer must probably be yes! Yet the previous centuries of discrimination and segregation had created the conditions necessary for the mass extermination of the disabled between

1933 and 1945. After all, the Nazis had little difficulty in laying their hands on defenceless “cripples” and “idiots” who had already been separated from their families and rounded up in special homes. The more we learned about what had happened under fascism, the greater our horror – and our fear that it might happen again.

#### NATIONAL SOCIALIST RACE HYGIENE POLICY

To enable you to gain an understanding of our feelings and reactions I would like to proceed by giving a brief summary of the Nazi’s race hygiene policy. However, I can only very roughly sketch what happened in an article of this length (for more details, cf. Aly, 1987; Kaupen-Haas, 1986; Klee, 1983; Müller-Hill, 1984; Osnowski, 1988; Weingart, Kroll, & Bayertz, 1988; Wunder, 1988). What did happen?

Immediately after the Nazis seized power in 1933 they began the systematic “extermination” of people they defined as “ballast existences not worthy of life” – first preventing their reproduction by compulsory sterilization and then murdering them within their “euthanasia” programmes.

A “Commission of Experts for Population and Race Policy” had already been established in the Reich Ministry of the Interior within the first half of 1933 to draft the laws legalizing compulsory sterilization. The result was the notorious “Law to Prevent Congenitally Diseased Offspring” that was passed in July 1933 and effective from January 1, 1934. From then on, compulsory sterilization was permitted for the following diagnoses: congenital idiocy, schizophrenia, manic-depressive lunacy, hereditary epilepsy, Huntington’s chorea, severe physical deformity, and severe alcoholism.

The opportunities for carrying out compulsory sterilization were rapidly extended in the following years. Initially, it was mainly

the institutionalized disabled and sick who were subjected to this treatment, but from 1935 onwards compulsory sterilization was also performed on healthy family members. Moreover, in the same year, compulsory abortions were permitted up to the 6th month of pregnancy and could be combined with subsequent compulsory sterilization. The law was also amended to allow male castration. In 1936, the 5th amendment permitted the use of X-ray and radium treatment (methods that were highly disputed and potentially damaging to health) for the purposes of sterilization and castration. More and more decrees were issued to expand the concepts of “hereditary disease” and “idiocy.” They soon covered “the value of the sufferer to the *Volksgemeinschaft* [community],” as well as his or her “productive capacity.” With general clauses of this kind, practically anybody could be compulsorily sterilized.

By the end of the war at least 300,000 people throughout the Reich had become victims of the “Law for the Prevention of Congenitally Sick Offspring’s – mutilated for the rest of their lives and burdened with a trauma from which the majority of them were never able to fully recover. Yet sterilization was only the first step. As war started, the second stage of the Nazi extermination policy was launched, the stage that was intended to achieve the “final solution” of the disabled question – mass extermination. Cynically, this programme was called “euthanasia” (Greek: easy death).

Its first victims were newborn babies. Following a secret decree circularized by the Reich Ministry of the Interior in August 1939, midwives and doctors were required to report the birth of “misshapen” babies. A “Reich Commission for the Scientific Documentation of Severe Hereditary and Congenital Disease” in Berlin examined the reports and passed them on to medical experts, whose verdicts resulted in the admittance of the “scientifically interesting cases” to 30 special pediatric

wards. Here, the infants were subjected to medical experiments and then killed. Soon after the beginning of the child euthanasia programme, the political and bureaucratic machinery for the eradication of all the disabled and hereditarily diseased throughout the Reich was set up. An informal letter of authorization from Hitler to Reichsleiter Bouhler and his health policy adviser Brandt (which he consciously predated September 1, 1939, the first day of the Second World War) set the machinery of death in motion. The message of the Führer's letter: war abroad and war at home. The murder of thousands of people on the grounds of "race hygiene" was coordinated and carried out with military precision from a central office in Tiergartenstraße 4 in Berlin (whence the abbreviation "Aktion T4"). Registration of institutionalized patients was begun at the end of 1939. Questionnaires were sent to the directors of the institutions requiring information as to the "type of disease," "length of stay," and "productive capacity" of each individual inmate. After the questionnaires had been returned, three medical inspectors added their "crosses," by which they passed sentence over life and death. Lists with the names of the patients who were to be removed were then sent back to the institutions. The victims of the euthanasia programme were loaded into inconspicuous grey busses belonging to an undercover firm, the "Gemeinnützige Krankentransportgesellschaft" (Welfare Transport for the Sick), and transported via intermediate establishments that served to cover their traces and that continued selection – singling out those who were fit to work and those who were "interesting cases" – before delivering them to the extermination centres.

Efforts were made to keep the extermination of the disabled secret. However, public unrest spread. In a few cases there was opposition to this operation. On August 3, 1941, the bishop of Münster, Graf von Galen, delivered his famous sermon in which he

publicly condemned the euthanasia programme. Three weeks later, following a verbal order by Hitler, the Aktion T4 was officially discontinued. But the unofficial euthanasia programme that followed continued to claim large numbers of victims, among them psychiatric patients, consumptives, "racially undesirable" children, forced labourers, and concentration camp prisoners who were no longer fit for work. Barbarous and sadistic human experiments, conducted by doctors and scientists, were common practice in the extermination camps. Today's estimates of the number of people murdered on the grounds of race hygiene range between 100,000 and 275,000.

Can history be repeated? It is this question that is always at the heart of our facing up to and discussing the inconceivable, the Nazi policy of race hygiene. Even today, it still remains a taboo topic. The major establishments that were the centres of the extermination programmes were not closed down after the war. They still exist. The system of segregation has not been dropped over the last 40 years. On the contrary, it has been expanded and perfected. We now have new, modern methods and new establishments in addition to the traditional closed institutions. There is no sphere of life in which people with disabilities are not subjected to special treatment, whether it be in special kindergartens or special schools, in special training schemes, in special sheltered workshops (when it comes to the job market), in specially designed residential ghettos for the disabled on the outskirts of town, or in special entertainment clubs set up just for them. The latest and, in the eyes of the cripples' groups, the most sinister of these new institutions is the practice of human genetic counselling that has been set up over the last 15 years. Not only does it involve selection for special treatment, it (again?) pursues the policy of elimination of the disabled, only this time it is practised before conception, by means of genetic

counselling, or before birth, by means of prenatal diagnosis and abortion on eugenic grounds: Only those who are certified as “healthy” or “normal” are given a chance to live. A diagnosis of “disabled” is equivalent to prenatal death. Before elaborating on this line of argument put forward by the cripples’ movement, I would like to say something about the “crippled women.” For the disabled women active within the cripples’ movement have drawn up their own positions with regard to human genetic counselling that are determined by the woman’s role and specific experience as childbearer, and that are influenced by the feminist viewpoint.

“WOMEN WITH DISABILITIES –  
LET US CONQUER THE DAY!”

Soon after the cripples’ movement came into being, we “crippled women” felt we also needed to get together on our own without nondisabled women and without men (Ewinkel et al., 1985; Radtke, 1982; Strahl & Waldschmidt, 1983). The issue under discussion was and still is the specific problem we have in being regarded as sexless beings, although we are not. Living as a disabled woman in this society means being subjected to several kinds of discrimination at one and the same time (Schildmann, 1988). Disabled women rank right down at the bottom end of the social hierarchy. On the job market we are threatened by unemployment to a far greater extent than (disabled) men or nondisabled women. If we do find work it hardly ever corresponds to our qualifications, is extremely badly paid, and offers next to no opportunities for promotion. And yet we are dependent on employment to a far greater extent than nondisabled women. It is as good as impossible for us to settle for a life as wife, housewife, and mother. We are usually brought up to expect this from a very early age, for it is the common belief that “no man will want us anyway.” Not attractive enough in

conventional terms to even be considered as future wives and lifelong partners, disabled women raise strong doubts as to whether they are physically or mentally capable of fulfilling their role as a housewife. And, to cap it all, we are faced with the question as to whether we are capable of bearing and bringing up healthy children at all. Whichever way you look at it, “crippled women” are hopeless losers when it comes down to competing with nondisabled women. If we do manage to find a satisfying job, if we do fall in love and have children, we do so not in fulfillment of, but in defiance of the expectations and values that have been handed down by society. “Crippled women” are faced with no other alternative but to arduously work out their life perspectives on their own if they are unwilling to settle for a life in the isolation of those who have been cast out of society. And this necessarily also involves joining issue with so-called normal women and the women’s liberation movement.

Nondisabled women fight for self-determination and, in doing so, concentrate their efforts on opposing the abortion laws and the implicit duty to bear children, while we have to fight against another (unwritten) law – the ban on childbearing. For although society might not use force, it takes precautionary measures to prevent us from giving birth to the children we are perfectly capable of having. We are to be prevented from having children because they might be disabled too, or because we might not be able to care for them ourselves. The ban on childbearing we are confronted with may not be expressly formulated in legal terms, but it is extremely effective on an informal, ideological, and moral plane. And we have been taught by experience over and over again that it is the medical practitioners who are the agencies through which this ban is enforced. Almost every “crippled woman” has a story to tell. One of them may have been pressed into sterilization far too quickly, another may have been advised by her gynaecologist to solve all

her problems at once and have a hysterectomy, and yet another may have been urged to have an abortion on the grounds of her disability. And, again, this is where human genetic counselling comes into play. Its express task is to prevent disabled children from being born. We “crippled women” are among the first to be addressed as clients of the genetic family planning services.

### **JULIANE’S DIARY**

As women and potential mothers, general practitioners and gynaecologists more or less automatically focus their special attention on us once we have been diagnosed as disabled (i.e., as “genetically suspect”). Juliane’s case is an example that shows what effects human genetic counselling can have on an individual’s personality and sense of identity, and how it can intrude into the family and permanently change life perspectives. I met Juliane at university. She was born disabled in 1960 and grew up in Hesse in a small town near Marburg, where the first human genetic counselling centre in the Federal Republic of Germany was to be established 12 years later. Juliane told me that her father is a worker and her mother a housewife. Her parents and her nondisabled younger brother had never attached any great importance to Juliane or her disability. In 1976 her doctor advised her to go to the genetic counselling centre for regular routine tests. He had a very high opinion of the service and hoped to be able to learn more about the cause of Juliane’s impairment. Above all, he wanted to know whether the diagnosis at birth had been correct. He considered it essential for Juliane to be examined in case she wanted to have children. Her parents wanted to serve their daughter’s best interests, and so they made an appointment at the Human Genetics Institute in Marburg.

At this time Juliane was in midpuberty – no longer a child and not yet a woman. She has

been kind enough to allow me to quote from her diary, and the notes she made on the examination and the advice she was given clearly illustrate this dichotomy.

*May 17th, 1976*

On Wednesday, May 12th, we went to Marburg, to the Human Genetics Institute. I suspect Mum and Dad were rather anxious because they were afraid of being told that my disability was hereditary. The woman doctor we saw was awfully nice and normal (the professor was not there, as I had thought, but I was quite glad). First of all we had to list all our relatives, when they were born, what they had died of, whether or not they had had any particular illnesses. When we got round to granny, Mum and Dad said nothing, as if there were something to be ashamed of. I was rather embarrassed, but I had expected that something like this might happen and was just about to say “Yes, wasn’t she menta . . . “ when Mum started to talk about it, scaling it down rather. The doctor wanted to have the records sent from the hospital granny had been in, to which my parents willingly and understandingly immediately gave their consent, and said with a smile, “If we’re going to have the tests done anyway, we might as well find out everything at once, mightn’t we?” This sounded sensible to me too. In other words, we’ll discover whether mental illness runs in the family at the advisory meeting in the summer. It’ll be a shock for Dad if the answer is positive. I found it rather embarrassing the way he kept saying “Perfectly healthy! We’re all perfectly healthy!”, adding that we had actually always been assured that my disability was not hereditary and indirectly implying that he had nothing to do with the tests. I was ashamed when Dad said “Yes, well, that’s the way it is in life: some die young and



others grow old” and stopped anyone else from saying any more. Later I was photographed and blood was taken for tests. An American woman doctor was there during the consultation and the tests, she looked very sweet in her dress and didn't understand a word of German.

*April 20th, 1977*

I was in Marburg on April 15th, at the Human Genetics Institute to discuss the results of my chromosome analysis. The doctor told me that I had a 50:50 chance of having a healthy baby, in other words, I was strongly advised not to risk getting pregnant and I guess I seemed to take the news surprisingly calmly. So if I contemplate the future and weigh up the facts rationally this means that I will never have a child of my own. At first I was absolutely determined to have one all the same, knowing that it would most probably be just as disabled as I am or even more so. But I have now realized that this is just selfish egoism on my part and, if I am ever forced to make the decision at all (which is still very doubtful), I will decide against having children. But I am absolutely determined to adopt some, which is far more useful than giving birth to new life in this child-hostile, inhuman world with its tendency towards totalitarianism. What probably hit me harder was the new and disturbing fact that you only have to look at my face to see what's wrong with me. My exceptionally thick lower lip, only unusual to nongeneticists, the creases next to my eyelids (when I looked more closely I felt I must be mongoloid!) are not signs of my individuality, they're abnormal, pathological. What this means is that any good doctor or geneticist can tell what's wrong with me just by looking at me(!) . . . I was awfully shocked at the thought. When Dad tried to comfort me at lunch and said

“Well, not everybody who gets married has children,” I thumped on the table and said: “I don't want to hear another word about it.” It sounded so banal and stupid, the idea of me and a husband, all on our own and most likely bored with each other, so forbidding and insufferably dull that I could only react by getting aggressive.

Today, 15 years after visiting the Human Genetics Institute, Juliane can talk about it fairly objectively. The blood tests revealed that her chromosomes were normal. It took a long process of studying the medical textbooks and comparing her symptoms with other cases before a diagnosis could be made. So the investigation took almost a whole year. Yet the results are more than unsatisfactory. Solely on the evidence of her symptoms, her disability was classified as a “systemic disorder.” The diagnosis was based on a total of a mere 50 similar recorded “cases.” And yet the medical report stated that Juliane had a dominant hereditary disability. Juliane still remembers with horror the photographs of other cases she was shown to console her that she herself was only suffering from a mild form of this particular disorder. Juliane is now 32 years old, unmarried, and has no children. All her love affairs are overshadowed by the knowledge that she might be the carrier of a hereditary disease. Dubious medical information forced upon her by the genetic counselling service has made it impossible for her to make unburdened choices concerning her life as a woman. If she wants to have children of her own she has to have them in spite of the diagnosis. She could also get pregnant with the intention of giving birth to a disabled child. If she decides to remain childless, she will never know whether she has done so because of the medical findings or for quite different reasons.

Juliane was obliged to experience for herself how genetic counselling exercises a controlling influence on her reproductive

behaviour and sex life. She was confronted with this institution, which now propagates childbirth bans and guidelines to women at large, at a very early age. Sensitized by what we have experienced in the hands of medicine and gynaecology, there is no way we “crippled women” can see human genetic counselling and diagnosis as a way to achieve greater women’s self-determination; we can only see it as an instrument of control over women and our bodies (Degener, 1986; Köbsell & Strahl, 1986; Köbsell & Waldschmidt, 1989; Willeke, 1986). Women’s reproductive capacity is exploited in order to achieve a specific goal – to obtain healthy, “qualitatively sound” offspring. The methods of control have reached technical perfection in prenatal diagnosis. It serves to select fetuses, and only those diagnosed as normal are deemed worthy of life. Human genetic counselling is thus the most advanced instrument of discrimination and selection: “The good into the pot, the bad into the . . .”

Its underlying logic fundamentally opposes people with disabilities, and it is anti-women too, since it is only possible to achieve the objective of allowing as few disabled people to be born as possible by means of total control over women during pregnancy. Currently, however, there is a heated controversy between representatives of the cripples’ movement and feminists. The point at issue is the extent to which the woman’s right to self-determination is levelled against the disabled if women make use of prenatal diagnosis and abortion for eugenic reasons. The stance adopted by “crippled women” in this debate can only be described as “falling between all stools.” Along with others, “crippled women” also strongly criticize an unhistorical feminist concept of self-determination that ends up as nothing more than ideology and that honours the ruling dictates, such as one’s duty to bear healthy children. But this does not mean we have to drop the concept entirely, it just needs redefining. After all, the solution of the

eugenic dilemma cannot lie in obliging the conservative antiabortionists and making it women’s “duty to bear disabled children.”<sup>2</sup>

#### FROM REPRODUCTIVE HYGIENE TO HUMAN GENETICS

In the last part of this article I would like to deal with the roots of today’s human genetics, the concepts of reproductive hygiene and the science of eugenics, to show that the history of the idea of selection is centuries old. These ideas and Utopias were inhumanly and radically put into political practice by the Nazis. They opened floodgates that will never be completely closed again. Yet history does not go round in circles. If it is repeated, it is repeated in a different way. We are continually being confronted with uncharted territory, and new situations and structures. Rather than stress the continuities and traditions, I would like to concentrate on the new dimensions of human genetics and eugenics. But, first, let us take a look back.

The basic principles underlying today’s human genetic counselling are age-old (Bayertz, 1987; Weingart et al., 1988). Time and again, ever since Plato (380 B.C.), people have come up with new Utopias and programmes to control and plan reproduction of the human race. Common to all of them is the idea of breeding high-quality people, “the best of the human race.” In other words, the aim is to rationalize, to scientifically control human sexual behaviour, and ultimately, to transform it into a highly developed technology. More and more it is being governed by utilitarian principles and product orientation; quelling fears also plays an important role in the emergence of the ideology of race hygiene – fear of the sexual instinct as well as fear of crippled and sick people. The idea of breeding, perfected with animals, is simply transferred to humans. In the past it was invariably linked to the concept of a strong state, which was needed to control

the reproductive behaviour of its subjects and to conduct the necessary selection procedures – however, this is where there is a significant difference in today's practices.

“Eugenics” embraced all these ideas and expanded them into a scientific concept. The creation of the term, which is of Greek origin and means “wellborn,” is attributed to a cousin of Darwin, Francis Gallon (1883). The 19th century was the century of eugenics, and also the age of rising capitalism and industrialization. In those years, the advances of science and technology were greeted with great optimism and enthusiasm and yet – quite understandably in view of the social conditions – there was also a sense of doom and lack of faith in the process of civilization. Around the turn of the century, in particular, there was simmering discontent, especially in the cities, which were rife with poverty caused by industrial exploitation and deplorable living conditions. The state of health of the working population was extremely poor; infant and child mortality rates were high. Under these circumstances, a scientific approach that explained social conditions in biologicistic terms as the result of civilization's abolishing “natural selection” and allowing tainted stock to be passed down through the generations was bound to fall in fertile soil. All the more so as it promised rectification by means of planned intervention. On the one hand, this meant artificially reducing the incidence of defective genes by preventing carriers from reproducing (“negative eugenics”), and on the other hand, it meant introducing special incentives to encourage the carriers of healthy genes to have more children (“positive eugenics”),

The rediscovery of Mendel's laws around 1900 and exhilarating scientific advances in the field of genetics contributed to the rapid spread and popularization of eugenic ideology. Not only did eugenics establish itself as a science of the future, it also assumed the dimensions of a social and political movement. Countless associations with eugenic aims

sprung up. They were invariably in close touch with racist-oriented anthropology and soon developed strong leanings towards radical right-wing politics. The majority of German eugenicists and geneticists actively collaborated with the Nazis when it came to the practical implementation of what had by then come to be called “race hygiene.”

After the collapse of the Third Reich, the same men (there were only a few women among them) set to work to establish and expand genetic science, now called human genetics, in the Federal Republic of Germany. Biographical continuities reestablished the tradition of this scientific discipline (Kaupen-Haas, 1986; Müller-Hill, 1984). Initially, the old guard kept a low profile, working silently in the academic genetics institutes that had been set up in Berlin, Münster, and Marburg, for instance. Then, towards the end of the 60s, the time had come, and they ventured into the public arena. In 1969, at a congress entitled “Genetics and Society” held in Marburg, plans were discussed to open the first human genetic counselling centre in the Federal Republic of Germany. Applications for the funding of a pilot programme were submitted to and granted by the Federal Ministry of Health and the VW-Stiftung (a foundation primarily financed by the German car corporation Volkswagenwerk). The counselling scheme began in 1972 (Bundesministerium für Jugend, Familie und Gesundheit [Federal Ministry for Youth, Family, and Health], 1979). It is interesting to note that the counselling centre in Marburg was attached to the university and not to the Public Health Authority because – as it was put by the director of the Marburg centre, Wendt – it was feared that otherwise the public might not find their way to the counselling service “for emotional reasons” (Wendt, 1976). So we see that the human geneticists are fully aware of their roots! It was in this institute that Juliane was examined in 1976, at the time they were still using the traditional methods of ancestral research and

chromosome analysis. With the “Marburg model” as precursor and trailblazer, it has only taken 20 years to successfully build up a nationwide network of counselling centres. The advances in prenatal diagnosis have given human genetics an enormous boost. Amniocentesis and chorion villi sampling are only two of a number of methods of collecting fetal tissue, which can then be tested in many different ways. The availability of molecular genetic analysis is growing. Clinical genetics is sure to experience a further boom as a result of the international projects to decipher the entire human genome.

#### THE NEW GRASSROOTS EUGENICS

Human genetics and eugenics have enough in common to justify speaking of them as one and the same concept.<sup>3</sup> They are both concerned with research into hereditary disease. They both attempt to find out the causes and identify the symptoms of hereditary disease. In the past, procedures were based on Mendel’s genetic theory, today they have reached the level of chromosome, gene product, and molecular analysis. The intention of eugenics and human genetics has always been to systematically apply their findings with a view to preventing hereditary disease (i.e., for prophylactic and selective purposes). The aim is to reduce the number of so-called unhealthy genes and to pass on healthy genes. The principle of selection is all-important here. In the past it was born life, and today it is unborn life that is being subjected to a process of selection, classified according to socially justified quality characteristics. They also share a common background, having developed in social conditions that were rocked by crises in times of transition. The question of quality has been raised and will continue to be raised time and again and ever more frequently in the fierce struggle for existence and the competition for resources.

Moreover, the setting up of a counselling

service – the history of eugenics and human genetics illustrates this too – is a well-proven method of establishing a new branch of science and its application. Counselling services create a demand and imply the existence of problems that may not have existed in this form before, or may even not exist at all. They represent the linchpin between theory, research, and applied science, and provide access to the desired clientele. They permit invasions and insights under the guise of medical services. Put bluntly, they provide the materials required for experimentation – that is, the human individuals and genes needed for research on genetic processes and hereditary characteristics, and for the accumulation of clinical experience and the testing of medical techniques. Counselling was also employed to this end in the early days of eugenics, although not so successfully. As early as 1864, the authorities enjoined the press to warn the population of the dangers of marrying “unhealthy partners.” The first “eugenic advisory centre” was set up under the directorship of the zoologist Ernst Häckel in Dresden. Later, genetic counselling mainly took place in the marriage guidance bureaus that were founded in the 1920s, and which numbered roughly 100 in 1927. However, these bureaus do not seem to have attracted very many visitors. One advisory centre in Dortmund was closed again because so few people were seeking advice (Sierck & Radtke, 1984, p. 9). Was the time not yet ripe?

The lack of public resonance and the lack of technical know-how to perform prenatal selection may have characterized eugenics in the past, but herein lie the crucial differences with today’s human genetics. In the past, counsellors could only draw on Mendel’s laws of heredity. They could only make probable diagnoses, and they were unable to offer any practical assistance. It was still impossible to perform the prenatal tests needed to make a firm statement about the embryo or fetus. The

first invasive method of testing the unborn child within the womb, amniocentesis, was not developed until the 1960s. Today, human genetics has developed a whole array of methods to diagnose hereditary disease before conception and before birth. Prenatal diagnosis generally ends with the abortion of a fetus that has been diagnosed as “pathological.” Although it is not a therapy in any conventional sense, it is widely accepted as a medical treatment. Apparently, it is ethically more acceptable to consent to the abortion of a deformed unborn baby than to the murder of disabled adults as practised by the National Socialists. The earlier selection takes place, the sooner it is condoned. Yet both women and men often refuse to acknowledge this fact. It may be true that abortion and the Nazi mass-murder are not the same, but in both cases it is a matter of judging the “worth” of life, making a quality assessment.

Today, amniocentesis, genome analysis, and, if indicated, abortion are among the doctors’ services that can be claimed for under the statutory health insurance schemes. By this token, eugenic practices have been redefined as a medical treatment or cure. This is clearly illustrated by the arguments put forward by human geneticists to legitimize these procedures. As doctors, they argue, it is their duty to prevent people from suffering. The unborn child is spared a painful fate involving life-long therapy, the success of which cannot even be guaranteed, and parents are spared the burden of having to care for a disabled member of the family. This contrasts with the tradition of eugenics that was closely bound up with “race doctrine,” both in theory and in practice, and that was seen as an instrument of state population control – that is, as something that was decreed from above and, if necessary, could be carried out against the will of the people concerned.

Today, eugenics is practised with the active participation of the individuals concerned – after they have been informed of the facts and

given their consent. It has shed its authoritarian roots and developed an apparently democratic approach. In a historical context, one might say it has grown out of its nappies. Coercion and pressure, open repression, and control are no longer applied today; they are not even necessary anymore. The state and society no longer need to step in to urge people to do their eugenic duty. People are already “voluntarily” adhering to this line of reasoning individually, without having to be expressly told to do so.

Other than under the Nazis, eugenics is no longer upheld as a theory of its own (Enquete-Kommission, 1987, p. 150). We are no longer dealing with a specific governmental policy, but are now confronted with eugenic practices that are gradually invading all areas of everyday life. On the surface of it, neoeugenics may appear to be more humane than traditional eugenics, but looking more closely, it becomes apparent that it is just a perfected form of the same thing. It has its own dynamics and functions almost automatically precisely because it is supported and practised “from below,” by the woman and the man on the street, and not enforced by the police and the authorities. Even the human geneticists no longer appear to be acting on their own authority, but merely according to the wishes of their women clients. Eugenics has been given a new suit of clothes; methods have been brought up to date. Having reached maturity, it has long since almost imperceptibly established itself behind our backs, and by employing a strategy that relies on the force of circumstances, it now influences our way of life without our noticing it. As a result, genetic selection appears to be something quite normal. This transforms eugenics into a duty that is technically performed by the individual, by way of parental selection, with the doctor figuring as an intermediate agency and executor (or executioner!). Only 50 or 60 years ago, eugenics was a crude instrument of social

management that was forcibly imposed upon individuals against their will. Today, eugenics is practised with the aid of these very individuals.

### NEGATIVE UTOPIAS

We people with disabilities say, "We refuse to allow our right to life to be questioned," because we are afraid of the normalization of eugenics. We are afraid of what I call a "genetic dilemma." 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. The tendency to reduce them to a diagnosis based purely on hereditary factors would be stronger and more one-sided than ever before. 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. There is also a danger that disability will increasingly come to be regarded as an individual affair. 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, once gamete line therapy grows out of the experimental stage and becomes fully established. 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.

On a moral and ideological plane, the portents of these visions of the future can already be found in the current political and social climate in Germany<sup>4</sup> and many other countries. Genetic counselling and diagnosis are already instilling public and personal awareness with an erroneous faith in technological feasibility. They already create the illusion that disability can be abolished, and thus prevent the growth, development, and cultivation of experience, methods, and traditions of coping with suffering, pain, disability, and disabled people. In times in which everybody, both male and female, must function daily as smoothly as possible, the idea of complete health, a whole and happy life, obviously holds a great attraction. But in view of what has become technologically feasible with regard to invalids, people with damaged health, and the disabled, this is a fatal attraction. The current trend is against us, against the disabled and the sick.

### ENDNOTES

1. A summary of the various disabled organisations and their various aims can be found in Waldschmidt, 1987.

2. Here I am referring to a discussion on this subject in "Krüppelschläge," 1989, and the reply by Degener, 1989.

3. Although it is an important factor in common to both eugenics and human genetics, I do not discuss the unspeakable cost-effectiveness analyses in this article. They have been thrown into the debate with foreseeable regularity ever since eugenics was thought of. Here, there really is an unbroken continuity. Details of how bookkeeping attitudes are at the back of both the old and the new eugenics can be found in Sierck & Radtke, 1984, and Weingart, Kroll, & Bayertz, 1988.

4. Especially since 1989, the heated public controversy in Germany surrounding the Australian philosopher and bioethicist Peter Singer, who vehemently advocates euthanasia, prenatal diagnosis, and infanticide, illustrates that views of this kind are again within reach of finding a majority even in this country with its history of National Socialism. Compare the series of articles published in the renowned weekly

newspaper *Die Zeit* ("Exzeß der Vernunft oder Ethik der Eriösung?," 1989; "Läßt sich Euthanasie ethisch begründen?," 1989; "Der Streit um Leben und Tod." 1989).

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