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**Towards Self-Determination and Equalization:** A Short History of the German Disability Rights Movement

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Having gradually emerged during the late 1970s the (West) German Disability Rights Movement was "born" with a big bang in 1981, the UN Year of the Disabled. This paper explores the background from

**Abstract** 

which the movement emerged and describes its subsequent development. From the very beginning, the goals of the movement were the de-medicalization of disability, self-determination, antidiscrimination and equalization, securing disabled people's right to life, integration into the community, and as much control as possible over services for disabled people. After the action-packed year of 1981, the movement settled down to everyday business: A lot of groups started to organize practical help like counseling and assistance services, some individuals decided to get involved in politics, and even others did research on eugenics and bioethics. Quite early in the movement's history disabled women began to form their own "sub-movement," which was quite successful. Recently, Disability Studies and their implementation in the German academic field have become an issue. These "branches" of the movement have sometimes crossed and intertwined, thus forming a strong national Disability Rights Movement. After the reunification of East and West Germany in 1990, disabled people from the former German Democratic Republic (GDR) joined the already existing movement. Keywords: German Disability Rights Movement history, self-determination, Krüppelgruppen, Initiative

for the Legal Equalization of Disabled People, German women with disabilities Disability is not a matter of fate, not a medical problem, but a matter of political and personal power; above all a question of consciousness (Adolf Ratzka, in N.N. 1989, p. 5).

**Preconditions** 

consciousness, so, successively a nationwide web of special kindergartens, schools and sheltered workshops was established.

When the Nazi-regime was abolished in 1945, about 300,000 disabled people had been killed in the course of the euthanasia-program. Infrastructure for disabled people was virtually non-existent. On the other hand, the war and its aftermath had produced a lot of impaired people who had to be dealt with. Consequently, organizations for disabled war-veterans were the first to be (re-)established in the young German democracy, "civilian" disabled persons were of no importance. This began to change in the 1950s, when parents got together to form impairment-related associations, which were to provide relief for the parents as well as assist their children with disabilities. At that time, concepts of integration or inclusion were not evident in the political

In the late 1950s and early 1960s two causes for physical impairment were predominant in the public perception: Poliomyelitis and Thalidomide. Until the introduction of oral vaccination in 1962, each year several thousand people fell victim to a polio infection. In 1961, for example, West Germany reported

305 deaths due to polio, as well as 4461 persons left with physical impairments. [2] These people were seen as tragic victims of a cruel virus as demonstrated by the slogan for the campaign for oral vaccination which read: "Polio is cruel — oral vaccination is sweet." Even though the disease itself was paid much public attention, the same could not be said for the survivors. Most of them, especially those in need of assisted breathing, were kept indeterminately in specialized hospital units. This was different than the situation of the children who were impaired because of Thalidomide. The

soporific, sold in Germany from 1957 to 1961 under the brand name "Contergan," was predominantly

prescribed for pregnant women, as it additionally helped with morning nausea and was allegedly not teratogenic. In 1960, however, reports about the potential of Thalidomide-related birth deformities accumulated. In 1961 the connection between the drug and the deformities was proved; and the drug was subsequently phased out. In Germany about 4000 Thalidomide-impaired children had been born, of whom approximately 2800 survived. [4] These so-called "Contergan-children" got a lot of public attention, causing an alleged shift in the perception of disability — from that of personal (tragic) fate to social challenge (Aktion Mensch, 2005).

Coming alive In the late 1960s and 1970s, as the disabled children of the parent-association founders reached puberty, West German society was shook up by the students' movement. The women's movement also emerged during this time, as well as the self-help-movement. Many disabled adolescents got caught in the maelstrom of societal decampment like everybody else and were seeking activities outside the parent- and expert-dominated organizations. In 1968, "Club 68" was founded, which

in the 1970s: unsatisfactory supply of aids, lack of accessibility to almost all public buildings as well as to public transport, no accessible housing, and no assistance services, to name but a few. Disabled people in need of help on a regular basis had either to stay with their families or live in an institution, often in nursing homes for the elderly. Disability was viewed from a medical perspective, often equated with illness. Even though a few voices existed already that attributed a social factor to the phenomenon "disability," societal reality was far from recognizing this. More and more disabled people began to realize that the reason for their segregation was not their physical condition but a segregating society, which had to be fought. Gusti Steiner, one of Germany's first-hour activists, has explained his process of awakening: I was denied access to buildings by steps and staircases which had been planned and built by others who were in power. I and other disabled people were denied access to

public transport by the way in which busses and trains were planned, built and used. And this had consequences for our self-confidence! We had to go to the places where these conflicts were evident. There we had to use our creative energy to self-confidently draw attention to the problems and change the disabling situation (Steiner, 2003). In 1974 the perception that his situation was politically caused, led Steiner to hold seminars at the Frankfurt adult education center for disabled and non-disabled participants, together with the nondisabled journalist Ernst Klee. The aim of these courses was on the one hand to make non-disabled people more sensitive to the problems of disabled people. Disabled people, on the other hand, should learn not to resign in the face of discriminations but to take them as a challenge. The participants of

these courses performed some public actions that, at that time, were perceived as being outrageous and provocative. Even though these activities were basically aimed at physical barriers, the fact of

disabled people who answered back was an absolute novelty.

Often we are asked why we call ourselves cripples [...]. For us, the term disability only masks the real societal conditions whereas the name cripple highlights the distance between us and the so-called non-disabled. Through the segregation in institutions, special schools and rehabilitation centers we are being kept utmost dependent and isolated. On the other hand parental overprotection destroys our possibilities for selfdevelopment. This shows that we are not only being dis-abled (i.e. by curbs) but systematically destroyed. Consequently, the term cripple seems to be more straightforward to us, because non-disabled people with their bogus integration ('disabled people are people too') can't hide behind it (N.N., 1982, p. 2).

Non-disabled people were excluded from the Cripples' Groups — another provocation. This exclusion was, on the one hand, analogous to the women's groups from which men were excluded to allow for mutual analysis of discriminations. On the other hand, it was a means for preventing the repetition of the establishment of the well-known power-structures to the disadvantage of disabled people. [5] Of course, the Cripples' Groups' approach to disability-related issues was much debated among disabled people as well. And even though a lot of people were concerned with the disadvantaged societal situation of disabled persons, at the end of the 1970s there was no movement to speak of in

This changed dramatically on February 25, 1980 as a result of a court decision that made history as the "Frankfort Judgment" (Frankfurter Urteil) and ruffled a lot of feathers. In this highly debated decision, the Frankfort District Court granted a vacationer a reduction in travel expenses because she had to bear the sight of severely disabled persons on her well-earned travels (Klee, 1980). Immediately after the decision had been published, numerous protests arose and a nationwide demonstration was announced for May 8. On this day, 5000 demonstrators from all over West Germany gathered in Frankfort, a lot of them disabled. A gathering like this had no predecessor in Germany. Attention was not only drawn to the ableist court decision but also to the extensive discrimination against disabled people. Disabled speakers also maintained that they were perfectly able to speak for themselves and to stand up for their rights. Even though this demonstration did not

lead to a reversal of the court's decision, it served as an enormous boost for the fledgling Disability Rights Movement because of the spirit of fighting together, of common strength. And for the first time

The positive feelings gleaned from this demonstration inspired the preparations for the next event: the UN International Year of the Disabled 1981. Being well aware that disability officials would only use it as a platform to sing their own praises without actually making any changes, a coalition of disability activists had decided to use the UN year for their own purposes. The official opening event on January 24 offered the first opportunity to do so. From all over Germany, disabled people traveled to Dortmund to disrupt the official speeches and to draw attention to the actual dismal situation of disabled people. Several activists chained themselves to the stage, thus preventing the Federal President from

in German history, the resistance of disabled people made it into the national news.

This year's final event from the movement's side was the "Cripples' Tribunal." (Krüppel-Tribunal) It was held in analogy to Amnesty International's "Russell-Tribunals" which drew attention to human rights violations, in this case the violation of disabled people's human rights. The organizers wanted to charge the government with their segregative disability politics and call for massive and radical resistance (Daniels et al. 1983, p. 9). Charges were brought against the following: the living conditions in institutions, arbitrary use of power by authorities, lack of mobility, sheltered workshops, discrimination of disabled women, psychiatry, and the pharmaceutical industry. Activities at the beginning of the UN year had been supported by a wide range of groups, from the "Clubs of Disabled People and their Friends" to the Cripples' Groups. But during the preparatory process for the tribunal a conflict arose over the participation or non-participation of non-disabled persons. This conflict could not be solved and eventually led to the splitting up of the group, which meant that the Cripples' Groups did not take part in the tribunal. Despite this note of conflict in the end, the UN year had proved itself as a very effective "midwife" for the emerging Disability Rights

With the end of the UN year, the everyday life of the movement started in which several subdivisions developed, mainly in two directions. The first was basically concerned with the establishment of infrastructure for disabled people like assistive services; the other was focused on the political representation of disabled people. Depending on the specific groups and people involved as well as

From the start, non-segregation, self-determination and being the expert of one's own life were the central issues of the German Disability Rights Movement. Soon it was not simply enough to point to the segregating structures, but it was time to get actively involved in their dismantling. One of the most pressing issues was to establish conditions that allowed disabled people to live independently, which meant the provision of help outside institutions. In 1978 the first of these services was established in Munich, and soon more followed nationwide, many of them inspired and/or led by disabled people. Most of the actual help (the term "assistance" was yet unknown in the German disability community) was performed by conscientious objectors (COs). [6] Their help, while it allowed for a life outside of

on local conditions, focus was placed on different issues, and in the process, these different "branches" intertwined and inspired each other. The next section will more fully explore these

Self-determined Living with and without (Personal) Assistance

Rehabilitation Fair. Before he could do so, however, he was approached by Franz Christoph, who first asked him whether he had not learned anything from the Dortmund experience and then hit him slightly twice with his crutch. In doing so, Christoph impressively proved that the resistance of disabled people was not taken seriously. Whereas any other person hitting a "symbol of the Federal State" would have had to face fingerprinting, photographing, and a prison sentence, he was merely banned

self-determined living (Zentren für Selbstbestimmtes Leben) was opened in Bremen. Today, there are more than 20 such centers throughout Germany, now united under their own umbrella organization founded in 1990 (Interessenvertretung Selbstbestimmt Leben). Although each center has its own main focus, the uniting philosophy is to provide "political services" to disabled people and their relatives, improving the situation of the individual through counseling, and improving the situation of all disabled people through political involvement against discrimination and for equalization. To ensure that all decisions made in the self-determined living context are in the interest of disabled people, all member organizations of the umbrella organization have to make sure that only disabled people have the right to vote and that all decisive positions are held by them. Public representation as well must be performed by disabled people.

The emergent field of assistive services also continued its development. As mentioned above, a lot of these services were performed by COs who had certain disadvantages: They were not providing the services voluntarily, they were by definition always male (conscription in Germany being for males only), and they always left after their period of service. The disadvantages of the CO-System became evident in 1990 when politicians shortened the period of service drastically from 20 to 15 months (Tobiassen 1999) — the result being that overnight thousands of young men were off duty and many disabled people were left without services. But sometimes something good develops from desperate situations, for since then, service providers have been employing regular employees for assistive services thus making more self-determination possible for the service-users. Also in the wake of the "CO-crisis" some disabled people decided to become employers of their assistants (Bartz, 2001). However, this is not an option for everyone because not everyone can or dares to assume the responsibility for hiring, firing, and the subsequent financial transactions. In order to relieve people of these burdens while still ensuring the most possible self-determination, the idea of assistance cooperatives (Assistenzgenossenschaft) was also developed (Köbsell and Frehe 1993, p. 7f). Presently there are two co-operatives in Germany, one in Bremen and another in Hamburg, and another one in Vienna, Austria. It should be added that even though the term "(personal) assistance" was already introduced into the German discussion in 1982, the traditional terms of "care" and "nursing" were very

persistent. It was only in the 1990s that they were more and more consequently replaced by

Besides counseling and assistance, the issues of mobility and a barrier-free environment are

important ingredients of a self-determined life. From its start, the German Disability Rights Movement was involved in those areas. This 25-year long fight has not yet achieved country-wide accessible transportation, but most regions come close. An accessible environment is also still an issue, but one that is at least nowadays covered by several laws on legal equalization and anti-discrimination.

When in 1983 the Green Party was elected for the first time into the German parliament, they offered themselves as mouthpiece for social minorities, an offer that was taken on quickly by the Disability Movement in the hope to push ahead disability issues. Several activists got involved actively in Green politics and subsequently were elected into the parliaments of several Federal States (Laender). The

most successful outcome of the co-operation between members of the movement and the Green Party was a bill for legislation on the funding of care and assistance. This bill aimed to abolish all institutions by 1995, at which time a nationwide net of in-house help agencies should have been established. Unfortunately, this legal initiative was not crowned with success. In the following years, the discussion was sometimes more, sometimes less, dominated by another legal project: anti-discrimination. In the summer of 1986 a few activists had visited the United States and came back absolutely thrilled by their legal framework against discrimination. As a result of this visit, the demand for similar regulations in Germany arose, even though it was acknowledged that the attitudes of the non-disabled majority towards disabled people would not be changed simply by passing a law. Still, it seemed worthwhile to pursue this goal, and there was even talk of co-operation with the traditional disability organizations on this issue. But, the time was not yet ripe for this. It took some years and the reunification of East and West Germany to bring a new drive into this project. In the meantime, the United States had passed the ADA and the traditional disability organizations in Germany had developed interest in legal anti-discrimination. 1990 saw the founding of the "Initiative for the Legal Equalization of Disabled People," which subsequently started lobbying.

Anti-discrimination was to be achieved by amending the German Constitution, which had become necessary due to the unification anyway, and through equalization laws on the federal and the states' level. In 1992 the Forum of Disabled Lawyers was founded, whose members came mostly from the Disability Movement. In coalition with the traditional disability organizations they managed to convince politicians that protection from discrimination against disabled people had to be included into the amended Constitution. This was achieved in 1994 with the insertion of the sentence: "No person shall be disfavored because of disability."[7] Unfortunately this Constitutional prohibition of discrimination

thus giving deaf people the right to an interpreter when dealing with federal authorities. Because the Act only deals with the competences of the federal state it was clear from the beginning that further legislation would be needed on the states' level — most of which have respective laws — as well as a civil anti-discrimination law which would protect disabled people from discrimination by insurances, airlines, restaurant or hotel owners and the like. This bill did not make it through the old government; however, it remains to be seen if chancellor Angela Merkel and the new government will manage this The Right to Live — No Matter of Course From the very beginning, disabled people's right to life was a major issue for the German Disability Rights Movement. The discussion of eugenics — a legacy from the Third Reich — and, later on, bioethics were central to the movement. The "destruction of life unworthy to live" had not been reviewed at the end of the 1970s along with the investigation of Nazi practices, although many people knew what had happened to disabled people during the Nazi era. Disabled people felt that they had been left out in the review of the past, and realized that their history had yet to be written.

At that time, some activists were survivors of the Nazi regime, others had encountered talk like "Under Hitler you would have been gassed," and others had already had experiences with human genetic counseling — so eugenics was still an integral part of the life of disabled people. Prenatal diagnostics was already available, albeit still on a small scale, and was viewed as being ableist. In addition, genetic engineering and its promises were already being talked about, which generated fears in many

On this background, members of the movement started to deal with their own past, one question always remaining in the back of their heads: "How would I/we been dealt with at the time?" They researched, made connections between facts and published their findings. Besides the review of the past, the focus was on continuities and topical developments, like the emerging discussion on assisted suicide. In 1984 Udo Sierck and Nati Radtke, both founding members of the Hamburg Cripples' Group, published "The Mafia of Benefactors" (Die Wohltätermafia). In this book, which in hindsight can be called an early product of German Disability Studies, the authors proved continuities from the beginnings of the Nazi-ideology to the present. Explicitly criticized was the individualized view

Disabled people from the movement researched how the Nazi "Law on the Prevention of Offspring of People with Hereditary Diseases," which caused the compulsory sterilization of about 400,000 people,

involuntarily sterilization, mainly of cognitively disabled underage girls and young women, remained an issue. Although the performance of the operation constituted willful bodily harm, it was estimated to be performed about 1000 times per year (Köbsell, 1987). This scandal was made public on TV in 1984 and it became obvious that clear legal regulations were needed. It took a lot of discussion and several legislative periods to achieve this goal. On January 1, 1992, a law came into power that regulated the sterilization of so-called persons unable to consent. It outlawed the sterilization of persons under age, and the sterilization of persons of age was made more difficult because now one had to adhere to certain regulations. But still the freedom from bodily harm was not guaranteed, a fact that caused

came into being. Even though the law was repealed after the end of the Second World War,

on disability that had laid the ground for the deadly developments.

2002. This Act regulates the competences of the federal state in terms of accessibility of federal buildings und communication with federal authorities. It also acknowledges German Sign Language,

With Singer, not only the term "bioethics" had arrived in Germany, but also the denial of basic human rights for disabled people. This became evident again in 1994 when the draft of the "European Convention on Human Rights and Biomedicine," dubbed the "Bioethics-Convention," was published. The purpose of this document was to protect the human rights of individuals against the arising desires of biomedicine. But actually something else happened: Being trapped within bioethical philosophy, instead of protecting human rights the document relativized them. The universality of human rights was denied and individual rights equaled with research requirements. In the bioethical context, then, human rights are not something that people own because they are human beings, but they have to earn them by proving certain qualities or abilities. Following this logic, disabled or otherwise incapacitated persons become "humans of lesser value" who can be used for research or as transplant donors. In response, however, an alliance like the one against Singer's appearance in 1989 was able to develop enough political pressure to prevent the German government from signing the convention. Recently, the movement has lost a bit of its "punch." When, in 2004, Singer was once more invited to Germany; there were protests again, but no nationwide alliance to prevent his presentation. Unsurprisingly, Singer remained true to himself in stating once more that in his opinion only those individuals with self-awareness and a sense of future had the right to life (Kobinet-Nachrichten Web site, 2004). Another bioethical issue was and is still very important for the German Disability Movement: prenatal testing and selective abortion. Here the roots go back even to pre-Nazi times, the continuity going from the early eugenics movement, to the racial hygiene of the Nazis to modern human genetics (Degener and Köbsell, 1992). This issue has accompanied the German movement from its very beginning. During the years the overall stance — with few exceptions — has always been the general acceptance of abortion as part of women's right to self-determination whilst simultaneously disapproving of selective abortion of "defective" fetuses as prenatal discrimination against disabled life. For an in depth exploration of this topic, see Anne Waldschmidt's article in this issue of DSQ.

Women, respectively the women's movement, played a crucial part in the young movement insofar as the women's groups were viewed as a model for the Cripples' Groups. "We have to act like the women who have joined together in women's groups to become more aware of their oppression, to empower themselves and fight against their oppressors. Let's learn from the women, let us join

cripple-tribunal at the end of the UN year became the first major occasion to make public what it means to be female and disabled, using the ideal of beauty, gynecology, rape and abortion as

In 1983 the first research on the situation of disabled women in Germany was published, albeit by a non-disabled researcher. With her work she proved what disabled women had known all along: the increase of social oppression for those in a patriarchal-capitalist structured society who deviate from "female normality" (Schildmann, 1983, p. 41). Two years later, disabled women themselves published their first book "Sex disabled — special characteristic female" (Ewinkel et al., 1985). The book explores the issues of the cripple-tribunal in more depth, additionally dealing with motherhood, sterilization, socialization, education and rehabilitation to show how differently women experience disability and how they are treated in comparison with disabled men and non-disabled women: "We [disabled women S.K.] are women who are disabled but we are treated as disabled persons who are incidentally female." (ibid, p. 8). Despite the fact that it was published more than 20 years ago, the

In the following years more local groups of disabled women were founded, their members involving themselves in local and national women's issues. In the context of the emerging feminist criticism on the (then) new genetic and reproductive technologies, they confronted the non-disabled critics with the connection between eugenics, genetic counseling, and selective abortion, thus setting in motion the discourse on the question how political private decisions in the reproductive sector were. These selfconfident women became increasingly asked-for speakers on the issue of eugenics/ human genetics;

Despite the increasing visibility of disabled women, the basic problems remained the same: the women's movement had not become more receptive to disabled women's issues and the Disability Rights Movement proved to be very resistant to gender issues. The early 1990s saw an intense "battle of the sexes" within the movement. The linchpin was the use of the term "double discrimination" to signify the special situation of disabled women. Franz Christoph, conveniently forgetting that he had first brought up the term, "unmasked" the use of this term as a strategy for "double approval" by nondisabled people (Christoph, 1993, p. 149). The "male-stream" of the movement obviously was annoyed that the women had stepped out of line and presented themselves more and more as women, and being successful with this. "I confess to being peeved by the way disabled women deal

book is still the classic on the situation of disabled women, which makes evident that the

contemporary discussion is still characterized by the same issues.

they themselves also organized events on this topic.

A Movement within the Movement: Women with Disabilities

with their issues in public" (Christoph, 1993, p. 149). But there were also some disabled women who criticized the usage of the term, because it supposedly led to the perception of disabled women as double victims (Hanna, 1995, p. 42). It was feared that the propagation of this term would slow down the movement in general — an implicit allegation of disruption (Hanna, 1995, p. 43). Despite this controversial debate, the term continued to be used, and it has long since become the trademark with which many disabled women could identify (Hermes, 1994, p. 3). It is still used today to describe the specific situation of disabled women. Also in the early 1990s, disabled women started to build networks on the federal states' level. In 1996 the national disabled women's network "Weibernetz — Bundesnetzwerk von Frauen Lesben und Mädchen mit Beeinträchtigungen" (Federal network of women, lesbians and girls with impairments) was founded. The name draws attention to the fact that the disabled women's sub-movement initially also had not challenged the heterosexual norm, thus leaving disabled lesbians on the margins (Ruhm,

numerous governmental and non-governmental bodies, so it can well be spoken of as a genuine,

The German Disability Rights Movement has been pronounced dead already many times. In 1993 Franz Christoph stated "our movement is in a sorry state" (Christoph, 1993, p. 145); and another author claimed in 1999 the degeneration of the Movement from "a roaring lion" to a "yapping lap dog" (Rohrmann, 1999, p. 52). Certainly, the loosely organized "small radical minority" has developed into

organization or to cooperate on certain issues with the traditional disability organizations. But despite not having achieved everything one had aimed for — like the co-representation of cognitively disabled people — the political claim to denounce and challenge ableist structures continues to exist. Even though the Movement has become more adapted and well-behaved, confrontation has given way to cooperation and actions are no longer as spectacular as they used to be. The Movement has,

however, remained true to itself in essential matters. Until today the aim was and is to enable disabled people to lead a self-determined life and to have control over this life (Frehe, 1984, p. 122), as well as to challenge the individual, medicalized perspective on disability, segregation, and discrimination.

Thus, the German Movement may well look proudly on its successes: Presently there are more than 20 centers for self-determined living, where disabled people make all the decisions. More and more of them organize their life with personal assistance, representatives of the Movement hold seats in several (states') parliaments and political bodies, and German disability politics have performed a much quoted "paradigm shift" — from welfare recipients to equal participation in society (Haack, 2003). Yet, it remains to be seen which effect this shift will have on the actual lives of disabled people in present times of empty coffers. Here, the Disability Rights Movement has to remain vigilant towards

institutions or the challenges to disabled people's right to life. In the face of these manifold challenges, the German Disability Rights Movement has to be wished a long life and a lot of stamina. It also has to be wished that more young people with disabilities acquire the initially mentioned consciousness and

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supporting or respectively preventing other developments like the increasing segregation into

not only reap the benefits from their "forefathers" and "foremothers."

in der Bundesrepublik. die randschau (2)3, pp. 21 – 22.

established organizations. Back then, it would have been unthinkable to have an umbrella

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<sup>2</sup> http://www.polio-berlin.de/schluck1.htm, retrieved August 16, 2005. back to text

<sup>3</sup> http://www.chiron-behring.de/cont\_76.kinderlaehmung\_poliomyelitis.php, retrieved January 10, 2006. back to text <sup>4</sup> http://www.emergency-management.net/pdf/contergan\_brd.pdf, retrieved January 24, 2006. back to text <sup>5</sup> From 1979 to 1985 the Cripples' Groups published their own magazine called Krüppelzeitung (Cripples' Magazine). back to text <sup>6</sup> Conscientious objector: "a person who refuses to serve in the armed forces or bear arms on moral or religious grounds", (http://www.m-w.com/cgibin/dictionary?book=Dictionary&va=conscientious+objector&x=21&y=17, retrieved January 25, 2006). In Germany, these young men perform an alternative social service (Zivildienst) instead of military service.

<sup>7</sup> http://www.bundestag.de/htdocs\_e/info/030gg.pdf, retrieved January 25, 2006. back to text <sup>8</sup> Peter Singer — among other things — divides people into "persons" and those who are not persons.

The "Cripples' Groups" (Krüppelgruppen), which were founded from 1978 on by activists Horst Frehe and Franz Christoph, had a more political approach to disability. In 1977 the two of them had developed the "cripples' position" on disability. It comprised a perception of disability as the societal suppression of disabled people and the forced conformity to the values, ideals and aesthetics of nondisabled people as a form of cultural enslavement. The best way to develop a "cripples" consciousness" appeared not to be partnership, but opposition to the oppressors (Frehe, 1997, p. 14). The choice of the provocative name "cripple" was part of this opposition:

Germany.

Birth of a Movement

delivering his speech, holding their own instead, which called for "No speeches, no segregation, no violations of human rights" (N.N. 1981). The Federal President eventually had to speak in a side room, proving with his speech what the protestors had anticipated. There was no mentioning of rights or selfdetermination, but of interpersonal relationships, charity to one's neighbor and responsibility (Steiner, 1983, p. 82). Though the taking of the stage had drawn a lot of media attention, not many really understood what the protestors wanted. The next public demonstration was even less understood: The Federal President was about to make another speech on behalf of disabled people at the Federal

from the premises.

Movement in Germany.

developments.

institutions, still rarely offered a self-determined life, because the users often had no say in who would perform which service when or where. Disabled women had no choice but to accept male COs as help providers. The only other possibilities were to find a user-controlled service or become employer of one's own helpers, both of which were quite difficult. With the advent of home help services, another need became evident: counseling. In order to make use of all their possibilities disabled people had to be informed about their rights. The Bremen Cripples' Group very early developed a system of "peer counseling" even though neither concept nor term were yet known in Germany. But it was only after a congress in Munich in 1982, that the ideas of independent living and peer counseling gathered momentum by introducing them to a broader public. The uplifting spirit of this congress led to the development of a pilot program with the aim of establishing Centers for Independent Living in five German cities. For several reasons this plan never became reality, but the seed was at least sown, and the interest in the concept of independent living was awakened, albeit under the "brand name" of self-determined living. In 1986 the first center for

'(personal) assistance."

The Struggle for Legal Equalization

had no noticeable effect on the everyday situation of disabled people. For this, more specific laws were needed. To support the efforts of translating the Constitutional claim into actual legislation, the biggest German charity, Aktion Mensch (Campaign Human Being) — after changing its name and allocation policy to be more compatible with the demands of the Disability Movement — created a large media campaign. This campaign, together with the additional publicity created by the disability organizations, developed so much pressure that the 1998 newly elected government had to include the aim of a federal law for the equalization of disabled people into their coalition agreement. Unfortunately, this did not move anything, and even more activities on the part of the Disability Rights Movement were needed. One of these was the "gift," which the Forum of Disabled Lawyers gave to the government: a bill for an equalization law (Forum, 2000). With the committed support of the Federal Commissioner for Persons with Disabilities, in 2001 a working group was established in the relevant ministry. And an absolute novelty in German legal history occurred: For the first time those concerned by a law were involved in its making! Two lawyers from the movement helped to write the Federal Act on the Equalization of Disabled Persons (Behindertengleichstellungsgesetz), which eventually came into force on May 1,

disabled people.

criticism from the Disability Movement, which had been part of the campaign "No New Law on Sterilization in Germany" (Arbeitskreis, 1987, p. 21). Even though there is still criticism concerning the general attitude towards the procreation of persons with disabilities, this issue is rarely considered in contemporary discourse. As already mentioned above, "euthanasia" and assisted suicide were at first mostly important in their historical dimension, especially as trials of Nazi doctors that had been part of the Euthanasia program were still in process. That changed soon when new campaigns for the legalization of assisted suicide were launched, all heavily protested against by the Disability Movement because of the Nazi experiences. For those born after the Third Reich, these experiences were always a reminder of the consequences of a conception of humankind that declares certain people as "not worth living." With the advent of the Australian bioethicist Peter Singer and his "Practical Ethics," this theme became more dynamic. In 1989 Singer, not yet widely known in Germany, was invited to talk about "The Right to Life of Severely Disabled Newborns" by the biggest German organization for cognitively disabled people. [9] Singer's extreme positions concerning the right to life of disabled people became known nationwide practically overnight and caused an immediate outcry of protest. The massive protest campaign of the Disability Movement, disability organizations and their allies under the motto 'Our right to life is indisputable" (Sierck, 1989, p. 7), eventually led to the cancellation of Singer's invitation. Nevertheless, the genie was out of its bottle: What had until then been inconceivable due to the Nazi experience with "euthanasia" became now possible again — the denial of disabled people's

right to life.

together in groups without non-disabled people!" (Christian, 1979, p. 8). It is not only noteworthy that a movement which was initiated by men recurred to the women's movement, they also seemed to be aware of the fact that men and women experience disability differently, as committed to paper in the first issue of the Cripples' Magazine: "Unfortunately there has not been much consideration of disabled women's double discrimination. We hope that some will join us disabled in the editorial collective and represent disabled women's opinions." (Horst and Franz, 1979, p. 52). Despite this progressive declaration, the movement remained male-dominated, and further reactions to the women's "coming out" from 1981 onwards allow for the conclusion that the claim to acknowledge their "double discrimination" was merely paying lip service to the zeitgeist of the time. The UN Year of the Disabled offered disabled women a platform as well. Their dilemma was that at the time their interests were not represented either by the emerging Disability Movement or by the women's movement: the former being dominated by men and thus structured patriarchally, the latter being of the opinion that these were just social problems that were not on their agenda. So the Disability Movement's women had to find their own way to draw attention to their situation, which is characterized by belonging as one person to two socially marginalized groups: women and disabled people. At the time, women and girls with disabilities were invisible. In expert literature and elsewhere they were subsumed under the neutral — but in German still male-connotated — term "the disabled." The Disability Movement had simply adopted the general male-centered, heterosexist world view without questioning. But the women soon did some questioning which led to the founding of women's Cripples' Groups in order to analyze and make public their special experiences of discriminations. The

examples (Daniels et al., 1983).

1997, p. 25). The quandary of not being represented in neither the disabled women's nor the nondisabled lesbians' network led them to found their own network in 1997. Thus, being properly organized, disabled women involved themselves in the debate on equalization laws. They met to phrase their own demands against such laws, producing a substantial list of claims (Hermes, 1994, p. 93), which was fed into the equalization debate. Meanwhile, many of these demands have found their way into laws; most of the new laws that are concerned with disability allow for a provision for the particular needs of disabled women. Besides the triggering of the dispute on selective abortion, one of the major merits of the disabled women's movement is having brought to public attention the issue of the sexual abuse of disabled girls and women and having successfully demanded measures for prevention as well as for a more severe punishment of perpetrators. Other successes of the disabled women's movement are not as "tangible" but nevertheless important: The "Weibernetz" now represents disabled women's interests in

continuing story of success.

The State of Affairs

Bartz, E. (2001). Der lange Weg zur Selbstbestimmung – der Anfang eines anderen Lebens. Retrieved August 18, 2005 from http://www.forsea.de/projekte/20\_jahre\_assistenz/bartz\_e.shtml. Christian (1979). Rehabilitation – Integration – Partnerschaft. Krüppelzeitung 1/1979, pp. 6 – 8. Christoph, F. (1993). Pädagogische Betroffenheit. In Mürner, C. and Schriber, S. (Eds.). Selbstkritik der Sonderpädagogik? Stellvertretung und Selbstbestimmung (pp. 137 – 153). Luzern: Edition SZH.

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Unterdrückung. Gießen: focus.

Ruhm, K.. Krüppel-Lesben-Netzwerk. die randschau (12)4, p. 25.

Humangenetischen Beratung. Hamburg: private publishing venture.

January 25, 2006 at www.zentralstelle-kdv.de/presse23.htm

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A person in Singer's meaning must possess the properties of autonomy, self-consciousness, an orientation towards the future and perceptiveness. People who don't possess — or allegedly don't possess — these properties have, according to this philosophy, only a restricted right to live. back to text <sup>9</sup> Lebenshilfe für Menschen mit geistiger Behinderung. back to text <sup>10</sup> The book's title refers to entries in German passports concerning sex and special/distinctive characteristics. back to text

became the model for the so-called "Clubs of Disabled People and their Friends," which in the next few years sprang up all over the country. In these clubs young disabled and non-disabled people met, their main objective being the reduction of prejudices through cooperation in partnership (Waldschmidt, 1984, p. 31). Even though their emphasis was on leisure activities, in order to reduce physical barriers, the clubs became more and more involved in local politics. Barriers were numerous