

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

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Abstract

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 which the movement emerged and describes its subsequent development. From the very beginning, the goals of the movement were the medicalization of disability, self-determination, anti-discrimination 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 shifted its focus to everyday issues of disabled people. Concrete and practical like like counseling and welfare services, services individuals tried to get involved in themselves, 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, 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 social power, whose nature is a question of consciousness. (Fodor-Katza, in: N.N., 1989, p. 5)
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Preconditions

When the Nazi regime was abolished in 1945, about 300,000 disabled people had been killed in the course of the so-called "euthanasia program." Infrastructure for disabled people was virtually non-existent. 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."^[3] Even though the disease itself was paid much more attention in the media, the same could not be said for the disabled people, especially those in need of assisted breathing,^[4] were kept indifferently in specialized hospital units.

This was different than the situation of the children who were impaired because of Thalidomide. The so-called "sea-babies" (born 1957 to 1961 under the brand name "Contergan") was produced and prescribed for relieving the symptoms of pregnancy sickness. 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 withdrawn from the market. In these clubs young disabled people and their parents, of whom approximately 2800 survived,^[5] the 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 decisively involved in the political and social life of their parents. In 1968, "Club 68" was founded, which became the model for the so-called "Clubs of Disabled People and their Friends," which in the next few years sprang up all over Germany. In these clubs young disabled people and their parents 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 in the 1970s: inaccessible public transport, lack of accessibility to public places — or bus depots, access 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 "helplessness." Only a few voices existed already in the 1970s that the term "disabled" or "disability" as a social 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 the way society, which had to be changed (Köbsell and Frehe 1993, p. 7). Presently 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... and other disabled people were denied access to public transport by their own... issues and trains were jammed, built for others. 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 which were the result of the existing situation on the one hand, and

In 1974 the perception that this situation was politically caused, led Steiner to hold seminars at the Frankfurt adult education center for disabled and non-disabled participants, together with the non-disabled journalist Ernst Klee. The aim of these courses was on the one hand to make non-disabled people more sensitive towards 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.

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 the 1970s the two of them had been active in the "Cripples' Group" in Bremen. It comprised a reduction of the societal suppression of disabled people and the forced conformity to the values, ideals and aesthetics of non-disabled people as a form of cultural enslavement. The best way to develop a "cripples' consciousness" was through a partnership, but opposition to oppressors (Frehe, 1997, p. 14). The choice of the provocative name "cripple" was part of this opposition.

Often we are asked why we call ourselves cripples [...] For us, the term disability only masks the real social conditions whereas the name cripple highlights the distance between ourselves and non-disabled people. Through the word "cripple" we are seeking activities, special schools and rehabilitation centers where we are being kept almost dependent and isolated. On the other hand parental overprotection destroys our possibilities for self-development. This is also true that we are not only being disabled (i.e. by clubs) but systematically by the society. Consequently, the term "cripple" is not a self-accusation, but 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 the establishment of the well-known power-structures to the advantage of presentable people.^[6] Of course, the Cripples' Groups' approach to disability-related issues was much debated by 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 Germany.

Birth of a Movement

This changed dramatically on February 25, 1980 as a result of a court decision that made history as the "Frankfurt Judgment" (Frankfurter Urteil) and ruffled a lot of feathers. In this highly debated decision, the Frankfurt District Court granted 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 protesters from all over West Germany demonstrated in front of the court building. A lot of them disabled people, who were in Germany. Attention was not only drawn to the abled 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 the 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 in German history, the resistance of disabled people made it into the national news.

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 time a platform for German disabled people. In the afternoon, the activists disrupted 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 delivering his speech. The protesters' actions instead, which called for "No to the Federal State" and "violations of human rights" (N.N., 1981). The Federal President eventually had to speak in a side room, proving with his speech what the protesters had anticipated. There was no mentioning of rights or self-determination, but of interpersonal relationships, charity to one's neighbor and responsibility (Steiner, 1983, p. 47).

Though the taking of the stage had drawn a lot of media attention, not many really understood what the protesters 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 Day of 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 taking the future and present of disabled people as a "symbol of the Federal State" would have had to face fingerprinting, photographing, and a prison sentence, he was merely banned from the premises.

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 and Degener, 1995, p. 42). Charges were brought against 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 the fact that at the end, the UN year had proved itself as a very effective "midwife" for the emerging Disability Rights Movement in Germany.

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 on local conditions, the movement focused on different issues, but the overall goal was the same: "Cripples" intertwined and inspired each other. The next section will more fully explore these developments.

Self-determined Living with and without (Personal) Assistance

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 the problem of independent living. 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 introduced by conscientious private citizens (COs) rather than by the state. Through the help of 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 a first step. Through the following years 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 1980 the first center for self-determined living (Zentrum für Selbstbestimmtes Leben) was opened in Bremen. Today, there are more than 20 such centers throughout Germany. In Bremen, the center was founded by a group of people founded in 1990 (Interessengvertretung Selbstbestimmtes Leben). Although each center has its own main focus, the unifying philosophy is to provide "political services" to disabled people and their relatives, improving the situation of their individual through counseling, and improving the situation of all disabled people through political involvement against discrimination. Through the help of the German government 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 their political 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 provided by COs who had certain disadvantages: They were not providing the services voluntarily, they were not always male (constriction in Germany being for males only), and they were 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 (Tobiasen 1999) — a decision that overnight thousands of young disabled people were left without disabled people who 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 and women experienced to become employers of their own services. 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 co-operatives (Assistenzkooperativen) was also developed (Köbsell and Frehe 1993, p. 7). 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 disability community in 1982, the traditional term "help" was very persistent. It was only in the 1990s that they were more and more conceptually replaced by "(personal) assistance."

Besides counseling and assistance, the issues of mobility and a barrier-free environment are moved that were not taken into account by the state. 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.

The Struggle for Legal Equalization

When in 1983 the group piece was elected, the first time that 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 (Länder). The most successful outcome of the co-operation between members of the movement and the Green Party was a law on legislation on the funding of care and assistance. This bill aimed to abolish all institutions by 1995, at which time a nationwide network of independent living centers would 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 1984 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 was necessary to pursue this goal, and further interaction with the organization 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 violation of the European Convention on Human Rights and the UN "World Charter." 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 and equalization of disabled people should be included in the amended Constitution. This was achieved in 1994 with the insertion of the sentence: "No person shall be disadvantaged because of disability."^[7] Unfortunately this Constitutional prohibition of discrimination 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 targeted the general public and policy-makers. The result was a "symbol of the Federal State" 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 the people to lead the self-determined living and Disabled Lawyers' Movement was Franz Christoph, who 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 federal ministry. And an absolute novelty in German law was introduced: For the first time these competences of a law were given in its making! Two lawyers from the movement helped to write the relevant Act on the Equalization of Disabled Persons (Behindertengleichstellungsgesetz), which eventually came into force on May 1, 2002. This Act regulates the competences of the federal state in terms of accessibility of federal buildings and committees of federal authorities, but also access to the media and to the judiciary, 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 national discrimination law. The bill did not protect disabled people from discrimination by airlines, restaurants or hotel owners and the like. This bill did not make it through the old government, but it remains to be seen if chancellor Angela Merkel and the new government will manage this task.

The Right to Live — No Matter of Course

From the very beginning, the discussion of eugenics — a legacy from the Third Reich — and, later on, bioethics were central to the movement. The "distinction of life" was a topic that was 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 at the end of the 1970s and women experienced a "symbol of the Federal State" in genetic engineering and its promises were already being talked about, which generated fears in many disabled people.

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 have dealt with all that 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 Sierek and Nati Raffaele, both founding members of the Bremen 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 on disability that had laid the ground for the disability developments.

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, came into being. Even though the law was repealed after the end of the Second World War, involuntarily sterilization, mainly of congenitally disabled young 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, 1997). This scandal was made public on TV in 1984 and it became obvious that new laws were needed. In 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 who were not able to consent was made more difficult because of certain legislative periods to achieve this goal. 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