2. Disabled Women Fighting for Equality

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For a long time, disability was regarded as an individual or medical problem, a stroke of fate that had to be endured. “The disabled” were perceived as a needy, asexual, and genderless mass of people who were expected only to express occasional gratitude for the benefits granted to them. Over a considerable amount of time, however, a disability rights movement developed. The disabled women’s movement subsequently became a movement within that larger movement. While the German women’s movement was influential in this process, the women’s movement itself was not concerned with disabled women’s interests. This chapter outlines the development of the German disability movement since the 1980s before focusing on the challenges that disabled women in Germany were and are facing (see box 2). Moreover, the gendered perspective on disability, which was initiated by disabled women from the movement, also has great potential to enrich the field of gender studies in Germany, as it has in the Anglo-American context (see Garland-Thomson 2004; Hall 2011; Kafer 2011). The chapter explores the accomplishments recorded by German disabled women and their organizations as well as notes their shortcomings, failures, and prospective challenges.

The fact that disabled women no longer are only the object of scientific research but are actively involved might be their most important and hardest-won success. Their experiences and knowledge have become a research subject within the emerging German field of disability studies in such areas as their life courses and sexuality and reproduction. Such studies
have highlighted the importance of researching the intersection of gender and disability. The research on women’s biographies (Bruner 2005; Freitag 2005) as well as on sexuality, self-determination, and reproduction (Waldschmidt 1996; Köbsell 2006a, 2006b) has provided important support for the movement’s agenda and demands. In addition, disabled women themselves increasingly act as researchers (Pfahl and Powell 2014). Furthermore, the newcomer in the German social sciences and the humanities, disability studies, pushed gender studies toward the question of how disability, gender, and class intersect and cause inequality among women and marginalize disabled women’s interests.

This chapter describes and analyzes processes of extraparliamentary
policymaking by disabled women, who use their own organizations to pressure the government from the “bottom up”. German disabled women were also instrumental in challenging the United Nations to include women’s issues into the Convention on the Rights of Persons with Disabilities (UN-CRPD). Against the backdrop of the history of the disability rights movement and the women’s movement of the twentieth century, we describe disabled women’s involvement in the policymaking processes of nongovernmental organizations (NGOs), disabled persons organizations (DPOs), and other associations in Germany. Disabled women have been involved in public policymaking processes by contributing to the amendment of (constitutional) law, other crucial interventions in German socio-political culture, and the twin track approach in the UN-CRPD to make disabled women visible within the convention. Nevertheless, disabled men and women have not been equally represented in the German disability (rights) movement or disabled people’s organizations, leading to the development of the Weibernetz e.V., an umbrella group for German disabled women’s associations, to engage in political lobbying. The examination of the agenda-setting activities of NGOs, DPOs, and other associations reveals that the interests of women with learning difficulties or mental health problems and of disabled women of color are still widely ignored, a situation that not only diminishes their stake in political interventions but renders them invisible.

Theoretical Perspectives

In 2006, the United Nations passed the UN-CRPD, and by the beginning of 2017, 172 states had ratified the convention (UN OHCHR 2017). Disability activists from many countries have leveraged the convention for political and social change, although deliberations continue about its legal aspects, standards, and fundamental principles as well as their interpretation and implementation. In Germany and other countries that have ratified the convention, debates have focused on the quality of inclusion, especially in education and employment, as well as in health, accessibility of public buildings and spaces, and political and social participation. The minority and human rights perspectives that have long been dominant in anglophone disability studies have only recently—via the concerted efforts of those in the disability movement—become common.

The development of the disabled women’s movement was also instrumental in creating awareness in Germany of multidimensional discrimi-
nation, a concept internationally addressed as intersectionality. Intersectionality originated from gender, queer, and postcolonial studies in the 1990s with a focus on the interaction of dimensions of inequality. Kimberlé Crenshaw (1989), a U.S. lawyer, was one of the first to look at the interwoven nature of categories—in her case, race, class, and gender—and how they strengthen or weaken each other. The attribute of being (non) disabled has not yet been extensively considered, since the intersectional research approach has only just been adapted for disability research. Disability studies researchers have nevertheless analyzed disability as a social phenomenon since the 1980s, when the international disability movement first developed. The medical model of disability was criticized by disability activists and a social model of disability subsequently was formulated. The most often quoted definition of it, developed by the Union of the Physically Impaired Against Segregation in 1976, reads: “Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (quoted in Oliver, 1996, 3). This understanding of disability frames it as a result of social, legal, and cultural facts: “The social model considers disability the result of physical, social, economic, political, and cultural barriers that limit opportunities for people with biological impairments” (Mirza 2014, 421). In the 1980s, feminist disability studies started to analyze the intersection of gender and disability, exploring how heterosexist stereotypes and ability expectations influence—historically as well as presently—the social conceptualization of disabled men and women (Fine and Asch 1988; Garland-Thomson 2004). To look at the intersection of disability and gender means to gender disability—that is, to analyze differences among disabled women as well as to analyze the inequalities between men and women with disabilities and between women with and without impairment (Jacob, Köbsell, and Wollrad 2010).

Our analysis takes an emancipatory social science research approach that understands disability as a question of who can(not) gain agency via social, legal, and cultural circumstances. By describing (social) barriers and facilitators (e.g., legal privileges, rights, and resources) and analyzing disabling stereotypes, people with impairments sought to create a social understanding of disability that included the intersection of gender, sex, race, and class (for examples of debate from English-speaking countries, see Campbell 2009; Kafer 2011).
Sources of Evidence and Data on Women with Disabilities

To trace the growing influence of disabled women, both at the domestic level in Germany and at the international level through the United Nations, we draw on several primary sources of information. First, we look to the statements made by disabled activists themselves, both in personal memoirs and in journals or on websites put out by the disability rights movement. Second, we examine the texts of government and international organizations’ documents, including UN conventions and reports issued by the German Parliament (Bundestag) and federal ministries. Third, we draw on German-language disabilities studies publications, much of them written by disabled scholars.

The German government is required to deliver basic data on women and men with disabilities every legislative period. As of 2013, almost ten million persons in Germany lived with some kind of impairment, while another seven million are living with a chronic illness. Accordingly, as much as 25 percent of the population is considered to have disability experiences (BMAS 2013, 44). About twenty million working-age persons struggle to obtain full inclusion in society, and women with impairments face significantly more barriers to social participation than their male peers. For example, women with disabilities are more often unemployed than other women and disabled men (BMAS 2013, 18). Women with impairments also still face more stigmatization and exclusion than disabled men and have more issues with family, domestic violence, and reproductive rights. Disabled women more often live on their own, have fewer children, and have a much higher risk of becoming victims of (sexual) violence at the hands of caregivers, therapists, and partners. The situation of disabled women who immigrated to Germany is more or less a black box but is probably even worse. In addition, women with impairments face additional problems because of heterosexist stereotypes, gender-related social expectations, and a lack of political representation.

Tracing the German Disability Rights Movement

The disability movement in West Germany came into being some time later than the students’ and the women’s movements. The new movement posed a radical challenge to century-old foundation of the German disability care system. Even though many material structures had been destroyed
in World War II and the Nazis had killed many disabled people, no attempt to reform the system had subsequently occurred. In fact, the old segregating structures based on the idea that disabled people had little worth were reconstructed and were even expanded. Thus, disabled people either lived with their families, sometimes even hidden, or in institutions. From the 1950s well into the 1970s, these “total institutions” (Goffman 1968) treated the disabled as inmates whose entire lives were subjected to the logic of the institution, a situation often compared to prisons (Klee 1980b, 53). Moreover, conditions inside the institutions, most of which were built during the nineteenth century, were often degrading, as a 1975 federal report noted. Psychiatric hospitals, where many disabled people were placed, often featured big dorms that lacked privacy, exhibiting poor hygienic conditions, untrained staff, and insufficient therapeutic and medical provisions (BT-Drucksache 7/4200, 25.11.75, 11–12).

In the late 1950s, parents began founding impairment-related associations to provide relief for themselves, to offer support for their disabled children, and to lobby for a better infrastructure for families with disabled children. At that time, concepts of integration and inclusion were not even considered, so special kindergartens, schools, and workshops for the disabled were established. The decade between 1964 and 1975, saw the creation of an extensive system of vocational rehabilitation with specialized institutions in response to a shortage of skilled labor. From the beginning, the rehabilitation system discriminated against women: courses and trainings were offered mostly to men, and the social security system was modeled on a typical male labor biography. The rehabilitation system did produce skilled workers, but they had difficulty finding gainful employment (Heiler 1984, 86).

Until the late 1970s, disabled people could not gain self-determination or participate in society; they had to live their lives within the confines of families and special institutions. Germany lacked an accessible infrastructure that would have allowed for participation: housing, public transportation, and public buildings and cultural venues were not designed for barrier-free access, and assistance with everyday activities was not available. The predominant perception of disability attributed disabled people’s exclusion from participation in mainstream society to their personal medical-biological problem, which was equated with suffering (Poore 2007). This medical model of disability locates the problem in “faulty biological equipment,” and accordingly the problem must be solved on an individual level by either finding a cure or accepting one’s fate (Garland-Thomson 2004).
Disability was defined by individual rather than social factors, with a focus on deficits rather than on rights, competencies, or potential. People with impairments were perceived as inevitably facing barriers, a quasi-natural consequence of their biological “shortcomings.” As a consequence of this perception of disability, medical and rehabilitation experts wielded extensive power over people with impairments: “experts” had the skills to “fix” faulty bodies and minds and were presumed to know what was good for the persons concerned (Köbsell 2006a). Special education also focused primarily on biological defects (Pfahl and Powell 2014). Disability overruled other identity positions, especially gender, which was neutralized. “The disabled” were a pathetic group in need of pity and professional support, not a gendered group of people like the rest of society. Only a few voices attributed the phenomenon of “disability” to social factors.

First Steps toward a Movement

In the late 1960s and 1970s, when the disabled children of the parent-association founders reached puberty, West German society was shaken up by the student movement. The women’s movement emerged at the same time, as did the self-help movement. Many disabled adolescents were caught up in the general mood of social change and began to distance themselves from the expert-dominated parent organizations. Club 68, founded in 1968, became the model for other “Clubs of Disabled People and Their Friends” that sprang up all over the country in the next few years. Young disabled and nondisabled people met to reduce prejudices through “co-operation in partnership” (Waldschmidt 1984, 31). The clubs emphasized leisure activities but found that physical barriers hampered these activities, leading members to become increasingly involved in local politics as they sought to eliminate these barriers. More and more disabled people began to realize that the reason for their exclusion was not their physical condition but a segregating society and that they had to fight it. One of West Germany’s earliest disability activists explained his “awakening”:

I was denied access to buildings by steps and staircases that had been planned and built by others who were in power. I and other disabled people were denied access to public transportation by the way that buses 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 en-
ergy to self-confidently draw attention to the problems and change the disabling situation. (Steiner n.d.)

Disabled young people took on the challenge of fighting everyday discrimination and exclusion. Some groups staged public actions to call attention to excluding and discriminatory conditions—for example, building a temporary ramp in front of an inaccessible post office or blocking tram rails—that the general public perceived as outrageous, ungrateful, and provocative. Even though these activities targeted physical barriers, disabled people who challenged the disabling society were an absolute novelty. Beginning in 1978, cripples’ groups (Krüppelgruppen) took a more political approach to disability. Their “cripples’ position” viewed disability as the result of the societal oppression of disabled people and perceived 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 1984, 105). The choice of the provocative term 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 term cripple highlights the distance between us and the so-called nondisabled. Through segregation in institutions, special schools, and rehabilitation centers, we are kept utterly dependent and isolated. . . . This shows that we are being not only dis-abled (e.g., by curbs) but systematically destroyed. Consequently, the term cripple seems to be more straightforward to us, because nondisabled people with their bogus integration (“disabled people are people too”) can’t hide behind it. (Mürner and Sierck 2009, 17)

In another provocation, nondisabled people were excluded from the cripples’ groups to allow participants to analyze discrimination without the discriminators being present, a situation analogous to the exclusion of men from women’s groups. Exclusion also prevented the groups from replicating the well-known power structures that disadvantaged disabled people. The disabled community debated the approach taken by the cripples’ groups to disability-related issues, and that viewpoint always remained in the minority. And despite the growing concern regarding the disadvanta-
geous social situation of disabled people, at the end of the 1970s, (West) Germany still had no significant disability movement.

A Movement Is Born

The situation changed dramatically after a historic and controversial 25 February 1980 court decision, the Frankfurt Judgment (Frankfurter Urteil). The Frankfurt District Court agreed that a vacationer should receive a refund of some of her travel expenses because her travels had been marred by the sight of severely disabled persons (Klee 1980a). The decision generated numerous protests, and on 8 May, five thousand demonstrators from all over West Germany, including many disabled persons, converged on Frankfurt. Such a gathering was unprecedented in Germany. The demonstration drew attention not only to the ruling 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. This demonstration did not lead to a reversal of the court’s decision but nevertheless provided an enormous boost to the fledgling disability rights movement, creating a spirit of fighting together, of common strength. For the first time in German history, the resistance of disabled people made it into the national news.

The United Nations had proclaimed 1981 the International Year of Disabled Persons (IYDP), and the demonstration galvanized preparations for that event. Certain that disability officials would use the platform to sing their own praises without making any actual changes, a coalition of disability activists decided to act. Disabled people traveled from all over (West) Germany to the IYDP opening event on 24 January to disrupt non-disabled politicians’ speeches and draw attention to the dismal situation faced by disabled people. Several activists chained themselves to the stage, preventing the West German president from speaking, and demanded “no speeches, no segregation, no violations of human rights” (anon. 1981). The president eventually delivered his address in an adjoining back room, making no mention of rights or self-determination and discussing only interpersonal relationships, neighborly charity, and responsibility (Steiner 1983, 82). The activists staged several other quite spectacular events that received media coverage and that culminated with the “Cripples’ Tribunal” (Krüppeltribunal) on 13 December. Modeled on Amnesty International’s “Russell Tribunals,” which drew attention to human rights violations,
the Cripples’ Tribunal focused on the violation of disabled people’s human rights. The organizers challenged government policies that promoted the segregation of disabled people and called for massive and radical resistance (Daniels, Degener, and Jürgens 1983, 9). The Cripples’ Tribunal examined living conditions in institutions, arbitrary use of power by authorities, restriction of mobility, sheltered workshops, discrimination against disabled women, psychiatry, and the pharmaceutical industry. By and large, the IYDP proved a very effective midwife for the emerging German disability rights movement.

The year was also important for the networking of disability rights movements around the globe. Founded in 1981 in Singapore, Disabled Peoples’ International (DPI) became “the world’s first successful cross-disability endeavor to convert the talk about full and equal participation of persons with disabilities into action,” and it remains “the world’s ONLY cross-disability Global Disabled People’s Organization” (DPI n.d.). DPI now represents disabled peoples’ organizations from more than 140 countries and has consultative status with the UN. It is headquartered in Canada, with regional offices covering Asia and the Pacific, the Middle East, Europe, Africa, Latin America, North America, and the Caribbean. “DPI’s goal is to achieve full participation of ALL persons with disabilities in the mainstream of life, through promotion and protection of their human rights” (DPI n.d.). DPI explicitly seeks to encourage involvement by disabled women, especially those from developing countries.

By the end of the IYDP, several subdivisions had developed in the disability movement, mainly in two directions. The first was basically concerned with the establishment of infrastructure for disabled people, such as assistive services and accessibility of public transportation and public buildings; 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 focus was placed on different issues, and in the process, these different branches of the movement intertwined and inspired each other.

Analyzing the Movement within the Movement:
Women with Disabilities

During this era, disabled women and girls were invisible, swallowed up by the amorphous group “the disabled.” They were neither mentioned in specialist literature on disability nor present in the literature from the women’s
movement. Even authors who were already thinking and writing critically about disability referred to “the disabled” as a group—as a male-connoted singular in German. Likewise, the evolving male-dominated disability movement had no interest in dealing with gender issues, having adopted unchallenged mainstream society’s male-centered, heterosexist worldview. The women’s movement, too, was not open to the issues and concerns of disabled women: disability overruled the identity position woman.

Disabled women realized that the intersection of disability and gender meant that their actuality differed in various aspects from those of disabled men as well as from nondisabled women, and since neither movement was available to them, they began founding “women’s cripple groups” (Krippelfrauengruppen) in the late 1970s to create a space free of male as well as nondisabled perspectives to enable the open exchange and theorization of disabled women’s specific situation (Ehrig 1996, 297). These groups laid the cornerstone for the movement inside the movement, the disabled women’s movement. Women’s cripple groups sprang up across West Germany, with national meetings held at least once a year from 1982 on. Participants sought not only to discuss and theorize among themselves but also to bring the “double discrimination” of disabled women, as the situation was referred to then, to the attention of the broader public.

On several occasions during the IYPD, the women drew attention to their situation and clarified the aspects in which their experiences differed from those of nondisabled women and disabled men. At the Cripples’ Tribunal, issues such as the ideal of beauty, gynecology, rape, and abortion were used to explicate what it meant to be female as well as disabled (Daniels, Degener, and Jürgens 1983). In 1983 the first research on the situation of disabled women in Germany was published, albeit by a nondisabled researcher. The work proved what disabled women had always known: the increase in social oppression that women who deviate from “female normality” face in a patriarchal-capitalist-structured society (Schildmann 1983, 41). Two years later, disabled women published their first book, Geschlecht: Behindert—Besonderes Merkmal: Frau (Gender: disabled—Special Characteristic: Female) (Ewinkel et al. 1985). It not only explored the issues of the Cripples’ Tribunal in more depth but also dealt with issues such as motherhood, sterilization, socialization, education, and rehabilitation, illustrating the diversity of disabled women’s experiences and the differences in the treatment of disabled women and of disabled men and nondisabled women. The authors declared, “We are women who are disabled, but we are treated as disabled persons who happen to be women” (8). Henceforth,
topics related to double discrimination became the leitmotif of the literature, and despite the changes that have occurred over the past three decades, the discussion remains dominated by these issues.

A central issue for disabled women was the denial of their femininity throughout their socialization by being told that they were not “real” women and could not expect or aspire to lead a woman’s life. They were not seen as attractive or desirable and therefore not considered “marriage material.” They could try to compensate for these shortcomings only through performing well in school, but even such achievements could not guarantee gainful employment: at the time (as well as today), disabled women have the highest rate of unemployment and are thus most likely to live in poverty (BMAS 2013, 142). And the denial of femininity led to the denial of sexuality. The assumption of disabled women’s genetic inferiority made them targets for “voluntary” sterilization and abortion (both of which were difficult for able-bodied women to obtain). Instead of facing pressure to procreate, as able-bodied women did, disabled women were effectively banned from giving birth, particularly if they were labeled developmentally disabled (Pixa-Kettner, Bargfrede, and Blanken 1996). And even though they are not perceived as potential sex partners, disabled women experience the highest rates of sexual violence, a fact that was ignored for a long time (BMAS 2012). The activities of disabled women brought this taboo inside a taboo to public attention. The Cripples’ Tribunal had drawn attention to the fact that their presumed helplessness turns disabled women into easy victims. Moreover, disabled victims of sexualized violence had difficulty persuading people that they had been attacked, frequently receiving responses along the lines of “You wish” or “No normal man would touch someone like you,” and were often physically dependent on the perpetrator. As a consequence of such attitudes and such dependence, incidents of sexualized violence against disabled women rarely were reported to the authorities. Further, the law granted reduced sentences when victims were “incapable of resistance” on the grounds that less criminal energy was needed to commit the crime. When charges were filed, offenders usually were acquitted.

Disabled women subsequently began creating local interest groups whose members became involved in local and national women’s issues. The emerging feminist criticism of the new genetic and reproductive technologies led these disabled activists to confront nondisabled critics with the connections between eugenics, genetic counseling, and selective abortion, thus initiating discourse regarding the political nature of personal deci-
sions in the reproductive sector (Degener and Köbsell 1992). Here the conflict arose between members of the women’s movement, who upheld freedom of choice as the highest value, and disabled women, who differentiated between the general right to choose to bear a child and the selective abortion of so-called defective fetuses from previously accepted pregnancies. The disabled women’s opposition to the latter was strongly inspired by the historical experience of Nazi eugenics (Köbsell 2006b; Poore 2007).

Active, self-confident women became sought-after speakers on the question of eugenics/human genetics. Despite the increasing visibility, their problems persisted: the women’s movement had not become more receptive to their issues, while the disability rights movement remained resistant to gender issues. The early 1990s saw an intense battle of the sexes within the disability rights movement. The linchpin was the use of the term *double discrimination* to signify the special situation of disabled women. Male activists denounced it as a strategy for double approval by nondisabled people, thus implying that the women had not grasped the meaning of discrimination (Christoph 1993, 149). The male activists were annoyed by the women’s public and political success, viewing them as having stepped out of line by increasingly presenting themselves primarily as *women* rather than as disabled and thus threatening to split the movement. Despite this debate, the term *double discrimination* became the trademark with which many disabled women identified (Hermes 1994, 3). It is still used today to describe the specific situation of disabled women despite the recent development of an intersectional approach to gendering disability.

*Shaping Public Policy from Below: The Fight for Equalization and Antidiscrimination*

The 1990s were characterized by German unification and the process of reconciling the political objectives of the women’s movements in the two parts of the country. As Myra Marx Ferree has pointed out, “Overall, the story of unification is one of disunity, and it theoretically leads to the reflections on what this brief period reveals about the bigger picture of struggles over differences among women in Germany and globally” (2012, 146). In their drive to make the state, women’s organizations continued to ignore disabled women’s interests. With a very high risk of unemployment on the one hand and numerous problems in balancing work and family life on the other, disabled women in several German states started to build networks. The decade was dominated by the struggle for legal equalization, a process
inspired by developments in the United States. A German delegation visited the United States in 1986 and came back highly impressed by the U.S. antidiscrimination legislation. Nevertheless, support for this issue was not forthcoming in Germany. The 1990 passage of the Americans with Disabilities Act reignited the German discussion and led to several initiatives for legal change.

A milestone of political acknowledgment of the aims of the disability movement as such was the 1994 amendment of Article 3 in the German Basic Law (*Grundgesetz*), for which the Association of Disabled Lawyers (Bund behinderter JuristInnen, founded in 1992) had campaigned along with other disability organizations and activists. Created in 1949, the Basic Law initially did not mention people with disabilities as a vulnerable group. The 1994 amendment added the words “No person shall be disfavoured because of disability.” Though the public debates on constitutional change did not highlight gender issues, they increased awareness among (female) lawyers inside and outside the disability movement regarding gender-related legal issues concerning disability as well as regarding continuing social inequality among disabled men and women.

In 1996, almost one hundred disabled women from all parts of Germany gathered in Munich for a conference on disabled women’s political interests. The conference demonstrated the need for a national network to represent disabled women’s interests. Putting employment, family, and (sexualized) violence against disabled girls and women on the top of their agenda, disabled women started to advocate on their own behalf in state and national politics. Founded in 1998, the Federal Network of Women, Lesbians, and Girls with Impairments (Weibernetz—Bundesnetzwerk von Frauen, Lesben und Mädchen mit Beeinträchtigungen) has become the biggest lobbying organization for disabled women’s interests. Moreover, the group’s name draws attention to the fact that the disabled women’s movement initially had not challenged the heterosexual norm, thus leaving disabled lesbians on the margins. The organization permitted disabled women to involve themselves actively in the debate on equality laws. They formulated their own demands for such laws, which were fed into the equalization debate (see Ruhm 1997, 25).

For the first five years, Weibernetz worked with neither paid staff nor state funding. Between 2000 and 2002, the group intervened in the pending changes to the Social Security Code (Sozialgesetzbuch), which covers regulations on rehabilitation and participation. The reforms to the code took into account various groups, disabled women among them. This
involvement and the wording of the new law exemplified the paradigm change from welfare to participation in German disability politics. Disabled people are no longer considered objects of care but subjects of equal rights for participation and independent living. The new Social Security Code includes several mentions of the needs of disabled women, although not all of their demands were met. For example, they still are not permitted to choose the gender of their personal assistants or care providers, and traveling expenses and child care costs for women in medical rehabilitation or participating in work are not covered (Arnade 2005, 2–4).

Aiming for self-determined sexuality, family relations, parenting, and protection from sexual abuse, the disabled women’s network then sought to reform the Sexual Crime Legislation (Sexualstrafrecht). Reforms enacted in 2004 by a SPD/Green majority in the Bundestag maintained the reduced penalty for sexual crimes against “nonresistant” or “delicate” persons. However, the reform increased the penalties for sexual crimes involving children or persons with (learning) disabilities. In 2016, the CDU/CSU/SPD government oversaw another reform to the Sexualstrafrecht that finally granted disabled women equal treatment with other women, an enormous success for the disabled women’s movement. Weibernetz remains the biggest and most influential German disabled women’s organization, lobbying for changes in legislation and other regulations that affect the lives of disabled women.

Many of disabled women’s other demands have also found their way into the law, which now takes into account the particular needs of disabled women. In addition to triggering the debate over selective abortion, the disabled women’s movement has brought attention to the issue of the sexual abuse of disabled girls and women and has obtained measures for preventing such abuse and increased the punishments meted out to the perpetrators. Other successes have been less tangible but nevertheless important. Since 2003, the European Year of Persons with Disabilities, Weibernetz has received government funding to represent disabled women’s interests in a variety of forums. It is a member of the German Disability Council as well as the German Women’s Council, a genuine sign of growing political and social recognition.

While the implementation of the 2006 German General Equal Treatment Act (Allgemeines Gleichstellungsgesetz) was heavily influenced by the European Commission’s mandate to standardize European antidiscrimination regulations, the 2002 German Equal Opportunities for People with Disabilities Act (Behindertengleichstellungsgesetz) constitutes
another unequivocal triumph for the German disability movement. Disabled activists have also sought and obtained changes in laws at the state level. Berlin introduced an Equal Opportunity Law for disabled people in 1999, with the rest of the states following by 2007. These laws were passed by governments of varying political orientations: conservative as well as liberal, social democratic, and green (see the Introduction, table I.1). Paralleling these legal changes, German disability politics shifted toward more self-determination and independent living.

*Shaping Public Policy from Above: Recent Debates on Women’s Issues in the UN-CRPD*

The widespread support for legal reform in Germany was driven in part by disabled women acting at the international level, the same strategy pursued by intersex citizens and women seeking inclusion in the military. During this time, the disability movement experienced Europeanization and internationalization. In the German disability movement, as in the women’s movement,

strategies, organizations, alliances, and concerns . . . were being enriched not only by a flow of ideas expressed by non-German authors . . . but also by being drawn into organizational engagement with global institutions. This growing transnational strategic effort was evident not only in formal organizations, networks, and alliances, but in political discourses, strategies and tools. The UN and the EU in particular provided new frameworks of discursive opportunity and key material resources for this work in Germany. (Ferree 2012, 183–84)

Founded in 1999, the International Disability Alliance (IDA) took part in the genesis of the UN International Convention on the Rights of People with Disabilities (UN-CRPD) as part of the UN Commission (Köbsell 2012: 90). The IDA’s participation indicates a paradigm shift in disability politics insofar as representatives were directly involved in the regulatory process, resulting in the first globally acknowledged document proposing a broader definition of disability: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations
2006, 4). This definition is akin to what academics call the social model of disability.

The 2006 passage of the UN-CRPD constitutes the most significant change relating to disability in recent years. Disability activists from all over the world have leveraged the convention for political and social change. Representatives of the Weibernetz as well as Theresia Degener and other individuals from the German and global disability movement played instrumental roles in formulating the UN-CRPD. Degener, the UN-appointed moderator, has been especially instrumental in solidifying legal equality for disabled people all over the world (Quinn and Degener 2002; Degener 2009). Although the German government signed and ratified the UN-CRPD in 2009, deliberations about its implementation continue, especially with regard to legal aspects, standards, and fundamental principles.

Disabled German women played a crucial role in making disabled women visible in the negotiations that led to the UN-CRPD. In 2004, Sigrid Arnade, a Weibernetz representative, asked the UN ambassadors to recognize women’s issues in the CRPD. Back in Germany, Network Article 3 started the international campaign “Toward Visibility of Disabled Women in the UN Convention” (Netzwerk Artikel 3 n.d.).

As Arnade has written,

We worked with a trilingual homepage (German/English/Spanish), collected signatures for our issues, and published them on the website. Within a very short time, the campaign was supported by almost 500 persons and approximately 100 organizations from roughly 30 countries. All organizations of the German Disability Council [Deutscher Behindertenrat] had signed, and also the European Women’s Lobby, the association of women’s organizations on the European scale, and the German Women’s Council [Deutscher Frauenrat] supported the campaign. Furthermore, we came up with amendments to the convention and did public relations work. We received ideological and financial support from the Federal Ministry of Family, Seniors, Women, and Youth, so we could expand our network. (Arnade 2010, 224)

In 2005, DPI appointed Arnade and her colleague, Sabine Häfner, to report on how to deal with the issue of disabled women in the UN convention. They produced 

Toward Visibility of Women with Disabilities in the UN-
CRPD, which consisted of three parts: “First, we discussed the situation of women with disabilities, and second, we checked existing UN documents for their relevance for disabled women. In the third part, we presented proposals for amendments, whereby we partially adopted ideas of other states and partially suggested new formulations” (Arnade 2010, 224–25). The report established that disabled women throughout the world are disadvantaged compared to disabled men and nondisabled women. As consequence, the United Nations took a two-track approach, with separate women’s articles and gender references in other important articles. Together with other activists, mostly from East Asia and South America, representatives of Germany’s disabled women fought at the UN meetings for the acknowledgment of their situation and for the inclusion of an independent article on disabled women’s interests. Initially meant to be a compromise between the interests of disabled women in the global South and the global North, this approach became a strategy. The two-track approach now guarantees not only that women’s interests are mainstreamed in the convention but also that their special situation is considered in the CRPD’s Article 6:

1. States Parties recognize that women and girls with disabilities are subject to multiple discriminations, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention. (UN 2006, 7)

Further references to women and gender appear in the preamble as well as in Articles 3 (General Principles), 8 (Raising Awareness), 16 (Freedom from Exploitation, Violence, and Abuse), 25 (Health), 28 (Adequate Standard of Living and Social Protection), and 34 (Committee on the Rights of Persons with Disabilities). However, disabled women’s activists also lost fights to include gender references in the articles on education, labor, and employment as well as regarding statistics and data collection. Despite the acute need, these articles do not contain references to women (Arnade 2010, 228). In 2015, the United Nations committee reviewed the German government’s first official report on the implementation process. A broad network of German NGO experts and supporters, the UN-CRPD-Alliance (BRK-Allianz), published a parallel report on the implementa-
tion of the UN-CRPD.\textsuperscript{14} The members of this network of disability organizations collaborated to produce a report on the gaps between political rhetoric and the lived experiences of people with disabilities (BRK-Allianz 2013), resulting in a list of issues for the thirteenth session of the CRPD committee. These international organizations have been enormously influential in providing opportunities for dialogue and coordination of political and social action and in ensuring that issues of disability mainstreaming have entered policymaking debates. The disability movement and the BRK-Alliance have emphasized the gaps between political rhetoric and ratification of the UN-CRPD and the living conditions and situations of disabled people in Germany, especially women.

\textbf{Avenues for Future Research and Activism}

For decades, many different German actors—male and female—have worked to increase the visibility and codification of the rights of disabled people. They have argued for the inclusion of explicit protection against disability discrimination in Germany’s Grundgesetz, mainly by organizing. Weibernetz, Netzwerk Artikel 3, the Centers for Independent Living, and the Community of Social Policy Working Groups (Arbeitsgemeinschaft sozialpolitischer Arbeitskreise) have fought to promote and ensure progressive disability policymaking through public discussion, public relations, policy monitoring, lobbying, and occasionally occupations of public buildings and demonstrations. The Forum of Disabled Lawyers (Forum behinderter Juristinnen und Juristen) has been influential in initiating legal protections for the human rights of disabled people on the state and national levels. These committees, associations, and activities combine to constitute the more or less institutionalized result of the earlier disability movement. Despite increases in formalization and institutionalization, many actors in the field still describe themselves as part of this movement, partially through identification, partially as a symbolic strategy.

The network of individual and collective actors that is succeeding the disability movement should be distinguished from organizations in the welfare sector (e.g., ambulant care/assistance service providers and self-help organizations) and the political sector (e.g., parties and lobbying groups), which have been enlisted as dialogue partners and are at least partially motivated by their own public relations strategies or by opportunities to profit from the provision of care and assistance. Welfare organizations and individual contributors have founded, financed, and supported the In-
stitute on Personhood, Ethics, and Science (Institut Mensch, Ethik, und Wissenschaft), which provides a highly public forum for disability studies debates. Monitoring the implementation of the UN-CRPD, the German Institute for Human Rights (Deutsches Institut für Menschenrechte) charts progress.

Since 2002, another organization, Disability Studies in Germany—We Do Research on Our Own (AG Disability Studies in Deutschland—Wir forschen Selbst) has organized workshops for researchers with disabilities (Köbsell and Waldschmidt 2006). The exclusivity of such forums is an important part of retaining a degree of self-representation, although it can hardly be maintained when establishing an academic discipline, which necessarily involves a separation of identity questions from the production of scientific discourse on disability in different fields of studies. The interdisciplinary German academic field of disability studies is growing but mostly still claims a subversive status (Pfahl and Powell 2014) while striving for further institutionalization at institutions of higher learning. Such double strategies entail enormous contradictions and difficulties, including tense discussions about the legitimacy of less or nondisabled people within academia.

Thus far, too few studies explicitly apply theory developed in disability studies to explore and explain the living conditions and lived experiences of people with disabilities in Germany. Yet the contrast of bodily impairment versus disablement as the consequence of social barriers and oppression remains a key debate. The social model has been criticized as essentialist by connecting disability to bodily impairment. Today, differentiated theoretical models help to explain the causes and consequences of disability as a social and cultural construction at the level of the individual life course, at the level of organizations, and at the level of society. Thus, disability studies has the important task of reconstructing subjective experiences and thus complementing—and to a certain extent replacing—“expert” knowledge about disability. However, feminist and queer approaches to difference seem to be farther along the path to academic status. The subversion and decentering that disability studies has begun to accomplish across Europe continues to face a number of barriers, including the artificial (or at least temporary) dichotomy of the “able / nonable divide” (Campbell 2009); the heterogeneity of a multidisciplinary field that includes a diversity of theories, methodologies, levels of analysis, and empirical databases; the relative paucity of data, especially longitudinal, that is not based on individual
deficit(s) or clinical principles, and the continued dominance of clinical professions and medical models, exacerbated by the recent growth of the new eugenics (genetics and biomedicine).

Debates that resonate broadly—and accordingly provoke broad resistance—now include the quality of inclusion, especially in education, employment, health, accessibility, and political and social participation. The most encompassing and fierce debates have involved schooling. Disability organizations and scholars have pointed out the lack of equality and excellence in education for disabled children, reflecting the persistent and ongoing segregation of the vast majority of students classified as having special educational needs. Critical disability studies scholarship has used comparative research to formulate far-reaching demands for changes designed to enable the educational and welfare system to meet the UN’s objectives and to equalize educational opportunities and life chances. The implementation of these demands is seen as requiring a complete transformation of stratified and highly differentiated educational systems (Powell 2011). These claims are not readily accepted even within academia: competing organizations, professions, and scholars challenge these assumptions and rally against inclusive education and disability politics (Pfahl and Powell 2011).

In the broader public as well as in the academia, the ratification of the UN-CRPD has fostered both academic awareness and debate and policy debates on the topics of inclusion and participation of children in schooling as well as discussions regarding issues of accessibility and anti-discrimination (Pfahl and Powell 2014). The minority and human rights perspectives that have long dominated anglophone disability studies have only recently—via the concerted efforts of those who agree and sometimes identify with the disability movement—become commonplace, while their implementation is burdened by the structural conservatism of professions, entrenched interests, and a general reluctance to give up privilege.

As in other cases depicted in this volume, members of an intersectional group initially found themselves overlooked by the women’s movement as well as by their male peers. Organizing at home and abroad and working through the United Nations has given disabled women’s organizations leverage to obtain a voice in policymaking, at times cross-party support for legislation, and a seat at the table in Germany’s main women’s (Deutscher Frauenrat) and disabled (Deutscher Behindertenrat) umbrella organizations.
Notes

1. For an excellent and detailed English-language overview of German disability culture in the twentieth century, see Poore 2007.

2. In this paper, disability is understood as a social construction: it is not a natural, unchangeable phenomenon, but the result of a social power relation, in which persons with impairments are being disabled by physical, structural and attitudinal barriers. As a consequence of this, disabled people find themselves in marginalized positions with little or no access to rights and social participation.

3. There was no disability movement in the sense of a social movement in the German Democratic Republic, since political organizations other than those run by the state were forbidden.

4. All translations by the authors.

5. From 1979 to 1985 the cripples’ groups published Cripples’ Magazine (Kruppelzeitung). See Mürner and Sierck 2009.

6. The title refers to entries in German passports concerning gender and special/distinctive characteristics.

7. BGB, Art. 3, 3, http://www.gesetze-im-internet.de/englisch_gg/englisch_gg.html. The liberal-conservative government allegedly only added the clause after Chancellor Helmut Kohl had approved it. The amendment required a two-thirds majority to pass the Bundestag.

8. In 1997, exclusion from both the disabled women’s network and the nondisabled lesbians’ network led disabled lesbians to found the Network of Crippled Lesbians. In 2010, another network, Queerhandicap, was founded to include gay, bisexual, and transgender persons with disabilities.

9. The statute also specified that the five-year statute of limitations for crimes such as sexual abuse or rape committed by offenders against victims in residential facilities or ambulant care commences when the victim turns eighteen, irrespective of the date when the offence was committed.

10. For a discussion of the 2006 German antidiscrimination law, see Ferree 2012, 196–99.

11. The IDA is a network of global and regional organizations of disabled people and their families, an umbrella group for other organizations such as DPI and Inclusion International.

12. Netzwerk Artikel 3 is a nationwide association created during the implementation of the 1994 Basic Law amendment and is crucial to disability activism despite lacking a genuine perspective on women. The name relates to the article of the Basic Law that prohibits discrimination because of disability.

13. For a discussion of similar problems obtaining data regarding the needs of another intersectional group, migrant schoolboys and schoolgirls, see Bale, chapter 5, this volume.

14. German intersex advocates followed a similar strategy (see von Wahl, chapter 1, this volume).
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