

# Disability Studies Quathe first journal in the field of disability

# Subversive Status: Disability Studies in Germany, Austria, and Switzerland

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#### **Abstract**

What activities facilitate the development of disability studies (DS)? What barriers hinder its (multi)disciplinary flourishing? We address these questions focusing on contemporary DS in Germany, Austria, and Switzerland—vibrant but challenging locales for DS. This multidisciplinary field engages intellectuals, activists, and stakeholders to subversively cross disciplinary, institutional, and political divides. Critical DS scholarship relies on collaboration among members of the disability (rights) movement, advocates, and academics to develop its subversive status. Within the academy, despite general barriers to transdisciplinary fields of study and persistent disability discrimination, more positions have been devoted to

research and teaching in DS. Intersectionality debates thrive and further disciplines discover the richness that the complex subject of dis/ability offers. The field, recognizing its subversive status and engaging insights from DS worldwide—across language and disciplinary boundaries—could better focus and unfold its critical powers. The potential of DS in the German-speaking countries continues to grow, with diverse conferences, teaching, and publications bolstering the exchange of ideas.

#### Introduction

As in North America, disability studies in Europe has gained recognition, engaged both academic and civil rights debates, and developed border-spanning scientific exchange over the past several decades. Gradually, it has also become part of university-based programs. However, disparities by language (community), country, and field persist, limiting the contribution that critical scholars of dis/ability have made in scholarly discourse or in establishing recognized training and research centers. Thus, in response to the theme of this Special Issue on "Growing Disability Studies," we ask what activities facilitate the development of disability studies' subversive status as well as which barriers hinder its (multi-)disciplinary flourishing. Given the diversity of languages, intellectual traditions and academic cultures as well as professional training and disciplinary recruitment pathways in Europe, we here concentrate on the German-speaking countries, especially Germany, Austria, and Switzerland. These cases provide vibrant but challenging locales to grow disability studies (DS).

Scholars and activists mainly in Great Britain and the United States have pioneered the field since the 1980s. Despite successes, scholars in Germany have struggled since the mid-1990s to fully develop all the necessary resource bases and features of a self-reproducing multidisciplinary field, as we will show. DS researchers in Austria and Switzerland have also accomplished crucial undertakings, balanced with on-going challenges. For example, the group "Disability Studies in Austria" (DiStA) networks individuals to establish DS in research, higher education, and continuing education (see dista.uniability.org). Formed in 2009, this working group, organized by Ursula Naue (2006), Volker Schönwiese, Christine Steger, and Angela Wegscheider, aims to develop egalitarian, positive understandings of disability in society. In Switzerland, Erich Otto Graf, Cornelia Renggli, and Jan Weisser (2011) join others in organizing "Disability Studies—the Forum for Transdisciplinary Projects" (www.disability-studies.ch) and conducting social and cultural analyses of disability at the intersections of the social, politics, art, and

bodies. In this century, DS in German-speaking countries has experienced a leap forward, though still not at the level witnessed in the Anglophone world. We provide an overview of the inroads and recent institutionalization of German DS, discuss major themes and important publications in the field, and identify pressing research gaps. In our contribution, we discuss developments mainly from 2000 onwards, thus updating Köbsell's (2006a) article on the history of the disability rights movement and scholarship in the special issue on DS in the German-speaking world (see Köbsell & Waldschmidt 2006). Then, we reflect on the problems of (global) language hegemony and the position of DS in the academy, exploring both potential facilitators of DS and contemporary barriers its scholars and advocates face.

### Contemporary Disability Studies In Germany, Austria, And Switzerland Between Academe And Activism

Asking how disability studies have been developed over the past ten years, we here sketch some of the most relevant institutions, events, and actors that have actively produced such knowledge. Just into the new century, the exhibition "The (Im-)perfect Human Being" was organized by Dresden's Hygiene Museum. Sponsored by a major disability-related philanthropic foundation, Campaign Human Being (*Aktion Mensch*), the exhibit also featured a watershed conference in Berlin. Considered as a foundational DS event in Germany, where German-speaking scholars connected with those from Anglophone Disability Studies, this led to the establishment of the network DS Working Group (*Arbeitsgruppe Disability Studies*; www.disabilitystudies.de (see Köbsell/Waldschmidt 2006) and further conferences (see Lutz/Macho /Staupe/Zirden 2003).

Many key actors of this network have been engaged in the fight for disability rights for years; even decades. For example, Network Article 3 (*Netzwerk Artikel 3*, www.nw3.de) battled successfully for inclusion of explicit protection against disability discrimination in Germany's constitution or Basic Law. The Community of Social Policy Working Groups (*Arbeitsgemeinschaft sozialpolitischer Arbeitskreise*, AG SPAK; www.agspak.de) has fought to promote and ensure progressive disability policymaking. Highly influential, the Forum of Disabled Lawyers (*Forum behinderter Juristinnen und Juristen*), has directed legal innovations in protecting the human rights of disabled people. Charting the development of these networks and associations as part of this growing new social movement, Swantje Köbsell (2012) shows that centers for independent living, ambulant caregiving service providers and self-help

organizations, and educational and scientific organizations join political action groups in this tapestry.

Over the past decade, a number of organizations have been founded to raise awareness, to represent disabled people, and to secure equal rights. The Institute on Personhood, Ethics and Science (*Institut Mensch, Ethik und Wissenschaft*, IMEW) provides a crucial forum for DS debates. Monitoring the implementation of the United Nations Convention on the Rights of People with Disabilities (UN 2006), the German Institute for Human Rights (*Deutsches Institut für Menschenrechte*, DIM) regularly charts progress. Recently, a network of disability organizations called the CRPD-Alliance (*BRK-Allianz*) collaborated to produce a report on the gaps between political rhetoric and lived experiences of people with disabilities throughout Germany (BRK-Allianz 2013, see www.brk-allianz.de). Such organizations have been enormously influential in providing opportunities for dialogue and coordination of political and social action and ensuring that issues of disability mainstreaming in policymaking are openly discussed.

Two notable academic centers that have stabilized the scientific activities of DS in Germany are the International Research Center on Disability Studies of the University of Cologne (Internationale Forschungsstelle Disability Studies, iDiS), led by Anne Waldschmidt, and the Center for Disability Studies (Zentrum für Disability Studies, ZeDiS) of Hamburg University. Günther Cloerkes long held a chair (discontinued) in "Sociology of Disabled People" at the University of Education in Heidelberg, pioneering the field. Other universities with active chairs in DS include the University of Dortmund (Markus Dederich), Rheinland Westfalen Lippe University of Applied Science (Theresia Degener; Sigrid Graumann), Landshut University of Applied Sciences (Clemens Dannenbeck), HAWK University of Applied Science and Arts (Gisela Hermes), Phillips University Marburg (Eckhard Rohrmann), and the University of Education Reutlingen (Jörg Michael Kastl). Newer professorships explicitly devoted to DS have been established at the Humboldt University of Berlin (Lisa Pfahl) and at Alice Salomon University of Applied Sciences (Swantje Köbsell). Mostly, these are within departments of (special) education, rehabilitation or social work. While several recently created posts in "inclusive education" and social work have DS affinities, this positioning highlights the dependence of DS on the professions serving disabled people to provide academic homebases. There are thus far no DS-dedicated positions outside these fields. On the one hand, this signals the difficulty of carving out a niche within the academy; on the other hand, the location within disciplines contributes to some measure of

cross-fertilization. Furthermore, the training of professionals who serve people with disabilities is a crucial area to affect change in dis/ability paradigms within disciplines and counteract discrimination in society. Active participation in DS debates includes individual scholars in the fields of cultural studies, education, history, philosophy, political science, psychology, public health, social work, and sociology, among others.

Until the turn of the century, the German-speaking field developed significantly along the lines of British critical social science, but over the past decade has grown to additionally embrace the progressive and postmodern humanities scholarship that has been a hallmark of DS in the United States. Receiving public recognition, the disability movement successfully institutionalized DS in both disability politics and academia. In 2004, a professorship devoted to Disability Studies was established at the University of Cologne. In Germany, as in Austria and Switzerland, many scholars engaged in studying the situation of disabled people, their stigmatization and their exclusion have been or are involved in the field of education and social work, as these fields have built their authority upon a century of professionalization addressing issues of dis/ability and disadvantage (Pfahl & Powell 2011) and expansive welfare states with social assistance and rehabilitation programs (Maschke 2008). However, special education and social policies do not yet systematically reflect or integrate the insights—or the critiques—of DS. Nevertheless, important exceptions include the addition of an anti-discrimination clause (§3) in Germany's Constitution (Grundgesetz) in 1994 and changes to the Social Code elaborated by disability activists and legal scholars.

For different reasons, critical DS scholars are not often warmly welcomed by their host faculties. Research on power relations within the professions, negative consequences of categorization, and segregation is rebellious to many researchers, because they often think *within* the system—largely congruous with the individual model of disability—and teach to serve existing systems. DS scholars challenge their colleagues by ideologically and practically bridging formerly separate worlds, for example, eliminating the divide between special and general education as they emphasize inclusive education for all. And they especially question the effects of policies and social services as they exchange, cooperate and work together with other disabled people underscoring the importance of subjective perspectives in research and counteracting everyday beliefs about impairment and disability. In the context of academic competition, especially for tenured positions, this leads to a form of ableism. Indeed, what was recently called "critical avoidance" (Bolt 2012)

can be found throughout the German-speaking academic world, exemplified by the reluctance to reduce barriers and provide accommodations. Despite its subversive status, both DS literature and its infrastructures have grown signficantly in recent years. Next, we discuss the major currents of scholarly development. Highlighting contemporary intellectual debates in German DS, this review emphasizes affinities with—as well as differences to—Anglophone DS. While it must remain selective, the following sketch shows discursive patterns that can be compared to discourses in other regions and language communities.

## Developing Disability Studies In The German-speaking Countries

Locating the Foundations and Entering the Field

For readers interested in German-speaking DS, we (a) locate the discourse in contemporary journals, (b) distinguish types of publication that provide introductions to DS, and (c) review empirical studies and contemporary scholarship. Those readers searching for an overview of cultural changes in disability in Germany over the last century written in English should read Carol Poore's authoritative Disability in Twentieth Century German Culture (2007). which provides a wide-ranging analysis of crucial phases of societal development with regard to disability, including both Germanies during the time of the country's division from 1945 until the fall of the Berlin Wall in 1989. Poore offers insights into the social, political, economic, and scientific processes that produce the tremendous range of disability definitions—and treatments—of disabled people. She shows the boundaries drawn around disability in the arts and state policies of the Weimar Republic to the eugenic nadir of Nazi Germany and to on-going struggles—and increasing victories—of people with disabilities for civil rights, self-determination, and social inclusion. Unfortunately, continuity and change in disability and disablement in Austria and Switzerland (even less so in Luxembourg) have not yet been fully reconstructed in the English language. Neither has the diversity of empirical studies in German yet been reviewed in English; thus we begin such a process here:

(a) Contemporary journals. Like central Anglophone DS journals that are open access (*Disability Studies Quarterly, The Review of Disability Studies*), already in 1997, a University of Innsbruck, Austria, project conceptualized and led by Volker Schönwiese

established the Internet database Disability, Inclusion, Documentation (Behinderung, Inklusion, Dokumentation; bidok.uibk.ac.at), providing a vital platform for researchers everywhere and from a range of disciplines to share their findings. Similarly, the journal Living Together—Journal for Inclusive Education (Gemeinsam Leben, Zeitschrift für integrative Erziehung) and the online Journal for Inclusion (Zeitschrift für Inklusion, www.inklusion-online.net) address mainly educators and advocates for the transformation of schools and societies. Numerous special issues on disability in an array of journals have appeared. For example, the weekly newsmagazine On Politics and Contemporary History (Aus Politik und Zeitgeschichte)—issues 8/2003 and 52/2010—has addressed themes of social recognition and equality, arts and history, inclusive education, and labor market participation. Claudia Franziska Bruner and Clemens Dannenbeck (2005) edited a Disability Studies special issue of Psychology and Societal Criticism (Psychologie & Gesellschaftskritik). A 2009 special issue of Pedagogy of Disabled People (Behindertenpädagogik) 48(3) provided an opportunity for DS scholars to showcase their perspectives on disability. Thus far, however, attempts to establish a full-fledged German-language scholarly journal dedicated to DS have not come to fruition.

(b) Introductions to DS. Beyond these special issues, a number of introductory textbooks and edited volumes provide a good overview of a diverse and comprehensive multidisciplinary field. The contemporary classic social science text is Soziologie der Behinderten (Sociology of the Disabled) by Günther Cloerkes (with co-author Reinhard Markowetz) (2007), now in a third, expanded edition. This comprehensive overview of more than 500 pages represents a keystone, as it summarizes sociological, educational, and psychological literature, explores the institutionalization of disability and socio-economic conditions, and contrasts attitudes about and reactions to disabled people. Educational, occupational, and social inclusion is analyzed, as is the family and everyday living. 1 Cloerkes also edited the 2003 volume Wie man behindert wird (How One Becomes Disabled) that provides a range of insights into the social categories of dis/ability. In 2004, Rudolf Forster edited Soziologie im Kontext von Behinderung (Sociology

in Disabling Contexts) that presents social theories that contribute to the sociology of disability. Walter Thimm's 2006 book Behinderung und Gesellschaft (Disability and Society) collects texts from a career devoted to that subject. More recently, Markus Dederich has written Körper, Kultur und Behinderung (Bodies, Culture and Disability) (2007), Anne Waldschmidt and Werner Schneider (2007) edited the first volume of the key DS book series "Body-Power-Discourse," and Jörg Michael Kastl authored an Einführung in die Soziologie der Behinderung (Introduction to the Sociology of Disability) (2010). Thus, several textbooks suitable for teaching DS in German universities exist, especially in sociology. The Bielefeld-based Transcript Verlag can be credited for contributing to the field by publishing foundational texts.

(c) Contemporary scholarship. As part of the European Year of Disabled People (2003), and building on the momentum of the original conference and exhibition "The (Im-)perfect Human Being," the DS Working Group (AG Disability Studies) organized an influential two-week "Summer University: Re-Thinking Disability" at Bremen University in which many (inter-)national DS scholars and students participated. The conference proceedings include the volumes DS in Deutschland: Behinderung neu denken (DS in Germany: New Thinking about Disability), edited by Gisela Hermes and Swantje Köbsell (2003), and Kulturwissenschaftliche Perspektiven der Disability Studies (Cultural Perspectives of Disability Studies), edited by Anne Waldschmidt (2003). The early history of DS in Germany through 2006 has been described by Swantie Köbsell (2006a) in a Disability Studies Quarterly special issue (Köbsell & Waldschmidt 2006). Diverse collections have been published, including Wie man behindert wird (How One Becomes Disabled), edited by Günther Cloerkes (2003), and Nichts über uns ohne uns (Nothing About Us, Without Us), edited by Gisela Hermes and Eckhard Rohrmann (2006), which features DS scholars active in shaping the field and introduces contemporary themes. The contributions explore the disability movement, cultural aspects of disability and DS, and disability in society and everyday life. These books exemplify the concerns and research priorities of those active in DS in the German-speaking countries and established the foundation for later publications such as

Waldschmidt and Schneider's 2007 Disability Studies. Kultursoziologie und Soziologie der Behinderung (Disability Studies, Cultural Sociology and Sociology of Disability). Aimed at an academic readership, this edited volume presents common theoretical foundations and methodological approaches simultaneously with documenting the diverse research interests in DS. In 2009, a collection of texts, Disability Studies: A Reader, was edited by Jan Weisser and Cornelia Renggli (2009), including translations of influential texts from Anglophone DS, enhancing their accessibility among German-speaking students and scholars. Newer contributions include the edited volume *Disability Studies*: Perspectives for Social Work (Rathgeb 2012). Building on a number of jointly authored books, Christian Mürner and Udo Sierck (2012) have recently published their synthesis of disability policy and the disability movement over the 20<sup>th</sup> Century, Behinderung: Chronik eines Jahrhunderts (Disability: A Century's Chronic), which addresses "normalization," eugenics, self-determination, and human rights, among other key topics. In the following, we further discuss a selection of works that manifest the field's establishment, sorted roughly along the lines of history and power relations, gender, theory, and policy, ending with life histories and everyday experiences.

### Major Themes in German-speaking Disability Studies

German DS is strongly concerned with two main issues. One is to examine the formation of medical, pedagogical, and welfare systems that classify and serve individuals, but also often stigmatize and segregate. These interlocking institutions establish powerful relationships through their myriad organizations, professional and power relations, and through specific representations of disability and modes of interaction with their "clients." The other concern is to reconstruct the life experiences of disabled people in order to manifest societal discrimination or oppression and then suggest necessary changes on multiple levels, from the local to the global. Shared concerns among all DS scholars lie in the emancipation of disabled people and enhancing accessibility, cultural and political participation, and improving living conditions in contemporary Germany.

Historically, Eckhard Rohrmann (2010) examines cultural contexts and their constructions of difference, from the demonization of being different during the

witch-hunts of several centuries ago up to current deliberations about disability. He also analyzes the on-going paradigm shift from paternalistic benevolence to the self-determination and social participation principles advocated, but not yet realized, in contemporary disability policy in Germany. Also using a comparative-historical approach, Austrian Volker Schönwiese (2003) presents the spectrum of societal pictures of disabled people from the pre-modern age to today. Exploring the question of disability's "visibility," Thomas Becker (2007) sketches the development of French natural and "human" sciences, arguing that the "neutral" perspective of science always assumes the point of view of the (usually male) observer, and shows how distinctions between "ab/normality" were reified in French psychiatry and in the establishment of asylums. As an active member in the movement of disabled women in Germany, Swantje Köbsell (2006b) discusses the crucial topic of disability and bioethics, historically comparing Germany, Great Britain, and the USA. She sketches critically the 20<sup>th</sup> century's darkest chapters: forced sterilization, "euthanasia," assisted suicide, (lack of) provision of health care, prenatal and pre-implantation diagnostics, and medical experiments carried out on patients without their permission.

Petra Fuchs (2001; 2010) analyses patient histories as medical history "from below" to reflect the historiography of disability in psychiatric and orthopedic fields. By contrast, Gabriele Lingelbach (2010) examines how the forerunner to "Campaign Human Being" (*Aktion Mensch*), namely the "Campaign Problem Child" (*Aktion Sorgenkind*)—a collaboration between public TV network (ZDF) and umbrella organizations in social welfare and care—constituted and changed the representation of disability. In her study "laughing at the other," Claudia Gottwald (2009) deconstructs comical representations of disability in history as she considers the idea of representing "otherness" and "embodied difference".

In the edited volume *Disability History*, social historical approaches are synthesized as an independent research perspective. Here, Elsbeth Bösl, Anne Klein, and Anne Waldschmidt (2010) argue that in the espoused "cultural" model of disability, bodies are to be seen as socially constructed and that all ascriptions of disability are simultaneously descriptions of bodies. Waldschmidt also discusses the distinction between humanities and social science approaches in DS, suggesting that the cultural approach questions our understandings of categories themselves, whereas social sciences generally are satisfied to analyze the effects of categorical membership. Of course, data

collection efforts say as much about the state of science and politics as about the individuals surveyed. A strong critique of the social model of disability was provided by the editors of *Gendering Disability*, Jutta Jacob, Swantje Köbsell, and Eske Wollrad (2009), as they underscore the intersection of gender, class, and ability differences. Köbsell, providing an historical overview of gender-related disability research, emphasizes that gender, like impairment and disability, is embodied. Focusing on bodies, DS researchers should serve to locate relational inequalities that occur at the individual level. Disability then appears to be a gendered experience, connected to psychological processes and feelings as much as to cultural beliefs.

In her work, Anne Waldschmidt (2007) shows the relevance of working with Foucault in DS (see also Tremain 2005) to extend critical research on disability, discussing historical, genealogical, and governmentality studies as well as her own approach of the "flexible-normalistic" dispositive of disability. She not only criticizes both the "individual" and "social" models of disability as both subscribing to an essentialist core of pre-social, "natural" impairment and conceiving disability as primarly an applied "problem" that demands "solutions," but also she argues that the body must be studied as a social phenomenon established by discursive strategies and power. Robert Gugutzer and Werner Schneider (2007) orient the reader in the spectrum of social scientific theories of the body, especially which conceptions are legitimated via powerful discourses of medicine, statistics, and rehabilitation sciences as "normal" and how these are reflected in which bodies are considered disabled. In a pragmatism-based approach, Michael Schillmeyer (2007, 2010) explores questions of the relationship between nature and culture, in order to conceptualize disability as an "event and experience" and to introduce into DS the pragmatic "assumption of multiple objects of the social/non-social" (2007: 84f; translation by authors).

Developing further theoretical research perspectives, Clemens Dannenbeck (2007) as well as Heike Raab (2007) establish links between disability, gender, and queer studies. Dannenbeck recounts multiple traditions in theorizing disability in Great Britain, the US, and Germany, arguing that a "cultural turn" of DS would broaden the field, increase its transdisciplinarity and support DS as a scientific and political project understanding people not only through their "disability" but through their "social, cultural and gender differences" (2007: 112). This emphasizes inclusive principles to support each individual and meet needs. Addressing "intersectionality," Raab discusses the interaction of class, ethnicity, gender, and disability as categories of difference to extend analyses

of social structural, cultural, and gender-specific inequalities.

Highlighting the interrelation of inclusion and exclusion, Gudrun Wansing (2005) questions the constraints on societal participation of people with disabilities even as they receive welfare state benefits. Michael Maschke (2008) theorizes disability as a central issue of all welfare states, providing a broad social structural analysis of disability and its complex social and political dimensions, illuminating the links to phenomena such as poverty, social exclusion, and discrimination throughout Europe. In his comparative neo-institutional analysis of "intraschool separation" in the US and "interschool segregation" in Germany, Justin Powell (2011) explains the institutionalization of self-referential systems of segregated special schooling as the key barrier to inclusion. Although outright exclusion from schooling has been eliminated, both countries struggle to provide inclusive education for all, taking incremental steps toward this elusive goal. Elsbeth Bösl (2009) charts the discursive and socio-political foundations of the "politics of normalization" in Germany's disability policies, especially the vocational rehabilitation system. over the twentieth century. Cornelia Renggli (2003) argues for a paradigm shift in the media via her analysis of pity and wonderment in contemporary representations of disability in Swiss poster campaigns.

Some research reconstructs the life histories and experiences of people with disabilities in Germany. Examining how barriers are experienced in everyday life, Hans-Günter Heiden (2006) contrasts the problematic fiction of the "average" human being with concepts of accessibility and universal design or design for all. Based on his lengthy and varied experiences as a vocal member of both the German and American Independent Living movements, Ottmar Miles-Paul (2006) emphasizes self-determination as the foundation of DS. Josef Ströbl (2006), as a member of the "People First Network of Germany" writes about disability and societal participation from the perspective of people with learning difficulties and names major claims of equal rights, including "easy language" (leichte Sprache), learning and working together, self-determined living, and participation in learning and research. Significant gender aspects of DS and the role model of the feminist movement are discussed by Martina Puschke (2006) as she analyzes the living situations of disabled women. Sigrid Arnade (2006), concerned with employment and especially with gender aspects thereof, presents a differentiated picture of conditions and constraints that disabled women face in labor markets. In her study Body Tracks (KörperSpuren), Claudia Franziska Bruner (2005) analyzes the intersection and the relative importance of disability and gender for

employment careers of women, showing how the meanings of disability shift and how gender solidifies throughout the life course.

Applying Goffman's theory of discredited and discreditable people, Maren Möhring (2007) asks how bodily deviance is recognized in everyday interactions in the case of returning wounded and disabled soldiers at the beginning of the 20<sup>th</sup> Century. Bodily experiences and self-determination are intricately connected, as Siegfried Saerberg (2007) discusses in his study of the styles of perception of blind and seeing people that challenge interactions. In a genealogical study of the nexus of scientific discourses and biographical narratives, Walburga Freitag (2005) gives voice to people as she connects the power of medical-orthopaedic discourses and their influence on the self-descriptions and lived experiences of persons that were affected by thalidomide (Contergan) in the womb: Over the life course, their feelings of being different and disabled shifted, especially through unemployment in adulthood. Similarly, Lisa Pfahl's (2011) study Techniken der Behinderung (Technologies of the Disabled Self) reconstructs the key category of "learning" disability" over the 20<sup>th</sup> century and pairs this with longitudinal biographical research to show how the medicalization of the effects of poverty occurred and how the experience of these ascriptions of learning disability affect youth and young adults in Germany as they transition from compulsory schooling.

Overall, these studies demonstrate the processes of differentiating or homogenizing people into groups, situated in hierarchies and subject to normative societal demands. Relying in large measure on historical and discourse analyses, they provide useful methodological and theoretical foundations for DS. These studies describe more than they fully explain these processes, and some lack sufficient emphasis on the ways being disabled was and is experienced in particular contexts. Among the key objects of study is the dichotomy of ab/normalcy and classifications of dis/ability, reflecting strong continuities as well as considerable contemporary changes—and vast cultural differences in meanings ascribed to dis/ability across the globe (Richardson/Powell 2011). People classified in psychic, intellectual, emotional or cognitive categories have long been underrepresented in research (but see Schramme 2003); however, this situation is gradually changing, especially in the growing subfield of DS in Education.

**Current Subjects: The UN-CRPD Implementation and Disability Studies in Education** 

The most significant change relating to disability in recent years has been the worldwide ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD). DS protagonists have been crucial in leveraging the Convention for political and social change. Theresia Degener, herself a key figure in the global disability movement though her role in the United Nations (see Human Rights and Disability, Quinn & Degener 2002), was instrumental in legal developments solidifying disability equality in Germany (Degener 2009). Deliberations about the implementation of the UN-CRPD continue about legal aspects, standards, and fundamental principles and their interpretation. And society-wide debates now include the quality of inclusion, especially in education and employment, as in health, accessibility, and political and social participation. The most encompassing debates have been about schooling. This is because of the lack of equality and excellence in education, reflecting the persistent segregation of the vast majority of students classified as having special educational needs. The change required to meet the UN-CRPD's objectives and to equalize educational opportunities and life chances requires a complete transformation of stratified and highly-differentiated education systems (Pfahl & Powell 2011; Powell 2011). The minority and human rights perspectives that have long been dominant in Anglophone DS have only recently—via the concerted efforts of those in the disability movement and influential Germans who have lived in the US—become commonplace. The UN-CRPD ratification (2008) has fostered awareness and debate in both academic discussions and policy debates on the topics of inclusion and participation of children in schooling and issues of accessibility and anti-discrimination. As mentioned above, the disability movement and the BRK-Allianz have vigilantly emphasized the gaps between political rhetoric and ratification of the UN-CRPD and the living conditions and situations of disabled people in Germany.

Relatedly, a significant contemporary subject is DS in Education, defined here loosely as education research that explicitly addresses issues of dis/ability and inclusion, which has grown strongly over the past decade. While school integration and inclusive education have been important topics since the 1980s, these have recently gained salience in general debates (e.g., Prengel 1993; Feuser 1995; Schnell 2003). With implementation of the CRPD, awareness and debate about issues of exclusion and inclusion have risen. Questions of rights and standards of implementation continue to be contested, as do questions of how to measure the qualities and quantities of inclusion, especially relating to education, work (Aichele 2010; Pfahl & Powell 2010), public life and health. Studies in German analyze the WHO International Classification of Functioning, Disability and Health (ICF)

(Hirschberg 2009) or discuss fundamental questions regarding recognition (Rösner 2002) or the legal status of people with impairments and their participation (Graumann 2011). Such topics have only gradually reached the educational system, which in the German-speaking countries has traditionally not been oriented to human rights, but rather to status reproduction.

The goal of inclusive education has received substantially more attention, from general media as well as in the training of teachers and other professionals (Seitz 2011). Debates about the role(s) of special educators in inclusive settings have become vitriolic (see Hinz 2009), especially because learning environments that embrace diversity call the stratified and homogeneity-oriented educational systems into question (Powell 2011). Research on schooling often includes DS themes and perspectives; however, these often remain implicit (Schwohl & Sturm 2010). Petra Flieger and Volker Schönwiese (2011) provide an overview of contemporary studies in their edited volume Menschenrechte—Integration—Inklusion (Human Rights, Integration, Inclusion). In 29 contributions, German and Austrian authors present theories, models for practice, and education policy strategies on the inclusion of disabled children and youth. The emphasis mainly on theories of the body seems to somewhat limit German-speaking DS, as issues surrounding learning and cognitive abilities remain underrepresented. This is especially problematic given that invisible and non-physical forms of disability are of increasing significance in "knowledge societies," whether in education or employment. Based on life experiences of disabled people in "pedagogic" organizations, participatory research strategies have been (re-)introduced to German-speaking countries that challenge elitist knowledge production on disability and emphasize self-advocates carrying out their own research projects (Buchner & Koenig 2011). Similarly, in public health research, strategies of active participation in the scientific process are emphasized (von Unger 2014). Further, DS scholarship must address the institutional conditions and causes of exclusion and inclusion, thus contributing to the direct critique of clinical and individual-deficit models a strategy for enhancing capability and ensuring qualification. Especially as 138 countries ratified the UN-CRPD by the end of 2013 (www.un.org/disabilities /index.asp), the academy, as other institutions, must accept the responsibility to make education and employment more inclusive by reducing barriers, enhancing accommodations, and emphasizing diversity and universal design (e.g., Klein & Heitzmann 2012). Durable inequalities (Tilly 1999) that cause impairment and poverty and mechanisms of social reproduction are closely related to the causes and consquences of disability in education.

### **Research Gaps in Contemporary German Disability Studies**

Our synthesis of contemporary DS in Germany must be selective, but it does show that disability has been approached mainly with discursive and power-based approaches that emphasize the state and its influential policies and programs and the professions, such as medicine and education, that (re)define disability. Although intersectionality perspectives have grown, DS continues to struggle to influence mainstream disciplines. Further life histories that show the impact of discourses, policies, and practices are needed, and throughout DS the importance of participatory research is acknowledged, but still comparatively rare. Social structures that determine access, participation and the distribution of privileges require examination. Research on everyday life and the influence and practices of the professions on people with disabilities must embed such analysis in broader social and political dynamics. Here, further studies of the life course, of families (e.g., Engelbert 2003; Thimm/Wachtel 2003), and of individual educational and employment careers are needed, especially longitudinal research. Crossdisciplinary syntheses of cultural, sociological, psychological, and educational approaches should clarify the structures and processes leading to disablement.

Thus far, too few studies explicitly apply theory developed in DS 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 continues to be a key debate in DS. The social model has been criticized as essentialist by connecting disability to bodily impairment. Today, differentiated theoretic models help to explain the causes and consequences of disability as a social and cultural construction at the micro level of the individual life course, the meso level of organizations, and at the macro level of society. Thus, DS has the important task to reconstruct subjective experiences and thus complement—and to a certain extent replace—"expert" knowledge about disability. The perspective "nothing about us—without us" has yet to be everywhere acknowledged.

These gaps in German DS research relate to the relatively weak institutionalization of the field in both universities and in extra-university research institutes, which contribute most research in many fields. With only a few exceptional universities devoting resources to DS, research project proposals to the German Research Foundation (DFG) and other third party sources become all the more important. In this competitive context, reputable journals and other high quality publication outlets become even more important. Without an independent journal devoted to the above themes, collaborators across disciplinary boundaries face particular

challenges. While in some fields, critical disability research has advanced, for example, in education and in public health, these developments often are not explicitly connected or do not refer to DS scholarship, even when they advance similar goals, such as in participatory and/or emancipatory research. Furthermore, within Europe, the dominant locale and language in DS remains Great Britain and English. With some exceptions, the translation of key texts in DS into other languages has been modest and vice versa, which makes the accumulation of research and scientific advance more challenging. Therefore, the issue of language hegemony is ever-present.

From this focus on contemporary contexts, themes, and gaps of DS scholarship, we conclude by analyzing significant barriers and facilitators of DS in the German-speaking world.

## Analysis Of Barriers To And Facilitators Of Disability Studies

Barriers include language hegemony, disciplinary dominance, lack of academic infrastructure, and ableism in the academy. These are counteracted by a number of significant facilitators that support and sustain the subversive status of DS: from the linkages between academics, advocates, and activists to the use of international networks (exemplified in the discourse among the German-speaking countries), and the dedication of members of the field to make connections and contribute to DS.

If the reception of Anglophone debates in German DS has been important, with reference made to key studies, the disciplinary heterogeneity of DS also challenges the development of an accepted canon, whether in English or in German. Few journals in languages other than English contribute to bring the research results and perspectives of DS into (sub-)national discourses. Several decades after the first social scientific and humanities-based attempts to wrest control over interpretations and analyses of dis/ability from the clinical and rehabilitation disciplines, across Europe disability continues to be understood as primarily an individual deficit (see the Academic Network of European Disability Experts, www.disability-europe.net). Despite the notable developments of disability activism, antidiscrimination legislation, and the rise of intersectionality as a theoretical approach to human differences, DS remains in a marginal position with regard to mainstream social science disciplines, such as sociology, economics, or political science. Even professionals, in such fields as (special) education, rehabilitation or social work

that are most connected to disability, despite their good intentions, seem to rarely reflect upon their roles in reproducing institutional power dynamics. Yet most DS scholarship has been produced by scholars whose homebase is one of these departments that reproduce these structures and relationships. This makes the paucity of intellectual homes that are genuinely multidisciplinary and devoted to (critical) DS even more problematic. Questions of power, language and discipline are thus paramount for achieving the potential of DS.

As in the US, Great Britain, and elsewhere, the founding and development of DS in Germany has been strongly linked to the disability movement. International conferences, like the Society for Disability Studies annual conference, serve to connect scholars and activists—and span boundaries between communities. However, in contrast to the US or UK, the relatively weaker institutionalization of Gender Studies and, later, LGBT or Queer Studies, in the German-speaking countries did not provide spaces within higher education and science in which the origins of social categories and their effects could be deconstructed. Universities in the German-speaking world remain discipline-bound. Joint research on questions of gender, sexuality, and disability relies to a large extent on networks devoted to these topics, with a few university centers providing organizational support. Indeed, those larger universities that have established courses of study in Gender Studies are most likely to have stronger DS, not least because of the considerable overlap in research interests, theories, and methodologies.

Whether in sociology or education, history or political science, significant studies of disability exist. However, the lack of positions for many scholars (let alone activists) in the academy, insufficient career perspectives, and the weak (independent) institutionalization of DS in universities and research institutes has limited the development of sustained DS scholarship in Germany, Austria, and Switzerland. Our analysis suggests that, despite increasing numbers of dissertations written in the field, the position of DS in the academy remains tenuous. There are no simple solutions to this problem, given the fact that the vast majority of academic positions (except for full professorships) are untenured; indeed, most are fixed-term contracts of several years' duration. Of course, this produces considerable biographical insecurities among young scholars planning scientific careers, especially for those with family (care) responsibilities and those most affected by barrier-filled environments. The often-criticized German academic career model assumes financial and temporal independence and thus must be considered heavily ableist, especially when it glorifies "genius" and "autonomy." Not only disabled people

or those with chronic illnesses, but other minorities as well as women face disadvantages, often institutionalized discrimination. Quota regulations and anti-discrimination laws have succeeded little in ensuring equality of these groups in science; they are highly underrepresented, especially at the tenured professorial level.

Due to the dearth of positions—not to mention professorships—many young scholars are forced to leave DS behind to seek success in more mainstream disciplinary-based careers or to move abroad. Yet those DS researchers who switch to other fields or institutions represent vital potential to implement progressive policies and programs in state administration, not-for-profit organizations, and in research and guidance centers. DS has a central role to play, particularly in the areas of education, employment, and health, just as its scholars should accompany the training of experts and professionals in these fields to ensure critical reflection and awareness of subjective perspectives of people with disabilities themselves. Clearly, a focus on disablement (a phenomenon rising over time) and ableism (a persistent feature of cultural contexts around the world) provides a most significant and challenging topic for a range of disciplines.

An open, multidisciplinary network that brings together those working on key DS topics—both within and outside the disability movement—is needed. DS, like Gender and Queer Studies and other academic fields that arise within and grow in relationship to new social movements, raises crucial questions about problems of representation and giving voice. Because direct or personal representation can never be complete and individuals always have multiple memberships in social groups, it is time for DS in the German-speaking countries to revisit questions and conditions of participation in DS and its intellectual, political, and social agendas. Advocacy in social policy and in science will of course occur mainly through affected interest groups and their representatives, increasing on global, national, and local levels simultaneously. At the same time, DS could potentially achieve more empowerment through a shift in science policy, especially via the translation and coordination of scholarship at higher levels and across fields that it could spearhead. The struggles described above, of establishing structures and expanding dialogue both within DS and within mainstream disciplines, need to be shouldered by as many people as possible. This implies providing access to the members and advocates of many different groups to participate in the academic debates and on-going legal initiatives to enhance accessibility through reducing barriers, securing human rights, and eliminating discrimination.

Thus far, feminist and queer approaches to difference seem to be farther along the path to academic "status". The subversion and decentering that DS has begun to accomplish across Europe continues to face a number of barriers, including the artificial (or at least temporary) dichotomy of "disabled"/"non-disabled"; the heterogeneity of a multidisciplinary field that includes a diversity of theories, methodologies, levels of analysis, and empirical databases; the aforementioned simultaneous language hegemony and diversity; the relative paucity of data, especially longitudinal, that is not based on individual deficit(s) or clinical principles; the continued dominance of clinical professions and medical models, exacerbated by the recent growth of the new eugenics (genetics and biomedicine); and finally, the lack of stable career opportunities for scholars in DS, whether self-identified as disabled or not.

Focusing especially on Germany—among the largest language communities of Europe—we here identified facilitators of DS that should be further strengthened. In the coming era of a maturing multidisciplinary field, networks of DS scholars, activists, and stakeholders will subversively cross disciplinary, institutional, and political divides. The activities of the alliance among dozens of disability activist groups (BRK-Allianz) to monitor and critique the slow implementation of the UN-CRPD in Germany exemplifies the power of networking and coordination among activists, academics, and advocates. In the academy, there will be more professorships devoted to research and teaching in DS, as the debates surrounding intersectionality flourish and other disciplines and newer fields discover the richness that the complex subject of dis/ability offers, especially related to cognition and learning in the "knowledge society." With the continued growth of the Internet, open access journals and databases will gain further relevance, reducing structural barriers. Prominent conferences and book series will solidify the exchange of ideas and offer opportunities to broaden and deepen the conversation. The potential of disability studies in the German-speaking countries continues to develop. While the field is appropriately wide open, recognizing its subversive status and engaging the insights from DS worldwide—across language and disciplinary boundaries—would help to focus and unfold its critical powers.

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#### **Endnotes**

 Despite the important index and literature review provided by Günther Cloerkes, the findings of international DS could only be selectively represented.

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