

Dis-eased: Critical Approaches to Disability and Illness in American Studies

Guest Editors: Gesine Wegner and Tanja Reiffenrath

Introduction

It is time to “Stand up and move a little for one minute,” one of Apple’s latest gadgets will remind its sedentary clientel, or, in more urgent tones, send pop-up notifications alerting users that it “detected a heart rate that rose above 120 BPM while you appeared to be inactive.” Casting technological and digital affinities and big data collections on health and fitness aside, we all are increasingly subject to a discourse on health, in which we are (held) responsible for our physical and mental well-being in ways unimaginable just a decade ago. American society in particular, Disability Studies scholar Thomas Couser argues, is at once disease and health conscious (*Recovering* 9). While any mention of illness and health would have conjured images of doctors, nurses, hospitals, drugs, or first aid thirty years ago, these associations are now supplanted by a wide variety of ideas ranging from nutrition and vitamins, exercise equipment, biking, walking, and jogging, to health check-ups, screenings, and alternative medicine (Nettleton 1). These are, Sarah Nettleton holds, emblematic of U.S. society’s “imperative for healthy living” (1). At the same time, this raises the question of what it means to be ill or disabled in a culture that so strongly values physical strength, beauty, and youth (Conway 4), a question that almost 20 percent of the U.S. population are compelled to pose.¹ This large number may on the one hand attest to the great capacities of medical science; however, it also reminds us of its limited power to cure—and of the fact that some bodily experiences fall beyond the purview of biomedicine and a medical cure.

With the title of this thematic issue, we intend to critically and productively engage with the sense of dis-ease—the frictions, anxieties, and discomfort—illness and disability may trigger in literary or (audio)visual works of art and their reception, as well as the irritations or gaps illness and disability may present in scholarly practice. Dis-ease, then, refers to both the social

¹ The Survey of Income and Program Participation conducted in 2010 by the U.S. Census Bureau on the 22nd anniversary of the Americans with Disabilities Act in 2012 found that 56 million Americans consider themselves disabled (Brault). A much greater, no doubt overlapping, rate of the U.S. population—49 percent—identify as chronically ill. Included in the statistics are twenty chronic conditions, among them cancer, asthma, hypertension, diabetes, coronary heart disease, and stroke (Ward, Schiller, and Goodman n. pag.).

construction and the materiality of the body. In our Call for Papers, we invited young scholars of American Studies to explore the socio-historical construction of non-normative bodies and minds in American culture and encouraged them to discuss the differences as well as overlaps and entanglements of social and physical disablement and the material reality of impairment. In line with Disability Studies scholarship, we purposefully decouple ‘impairment,’ a physical or psychological condition, from ‘disability,’ which arises from the physical and attitudinal barriers that the nondisabled majority has erected and that place constraints on the lives of people with impairments or exclude them altogether (Carol 38). While such a distinction between impairment and disability functions as important point of departure, the two notions can be best understood as working in close tandem, constantly influencing one another. Such an understanding is linked to ideas put forward by poststructuralist disability scholars who, via recourse to Foucault, read impairment and its materiality not as mere natural facts but as “naturalized *effects* of disciplinary knowledge/power” (Tremain 34). Demonstrating a range of shared yet also different Disability Studies approaches, the papers in this issue contribute to current Disability Studies research and offer new readings of both contemporary and historical texts from a variety of disciplinary strands in American Studies.

Disability in American Studies

Taking up Michael Bérubé’s speech at the 2012 MLA conference, Rosemarie Garland-Thomson concluded in 2014 that Disability Studies was no longer an emerging field but had left its adolescent years behind (“Disability Studies” 917).² Indeed, only half a year later the field officially established itself within American Studies with the formation of a Critical Disability Studies Caucus during the annual conference of the American Studies Association (“Critical Disability Studies Caucus” n. pag.). Similar to other identity-based interdisciplinary fields of studies, the emergence of Disability Studies had started in the 1980s and was now to be recognized as important part of current American Studies scholarship (Garland-Thomson, “Disability Studies” 915). This new prominence of Disability Studies materializes in a wide variety of cultural and literary studies texts that have been published since the mid-1990s. By

² At the Presidential Forum of the 2012 Modern Languages Association conference, Michael Bérubé declared that Disability Studies could no longer be described as an emerging field of study. Disability Studies has, Bérubé officially proclaimed, emerged (Garland-Thomson, “Disability Studies” 915).

now, groundbreaking books like Lennard J. Davis's *Enforcing Normalcy*, Rosemarie Garland-Thomson's *Extraordinary Bodies*, Tobin Siebers's *Disability Theory*, Robert McRuer's *Crip Theory* as well as David T. Mitchell and Sharon L. Snyder's *Narrative Prosthesis* have become widely recognized as foundational cornerstones of Disability Studies scholarship within the arts and humanities.³

The relative recency of such scholarship and events might seem surprising if we consider the important role that bodies marked by difference have played within American Studies research. Moreover, according to the latest census, Americans with disabilities make up over 56 million people and thus present the largest minority group in the United States (Brault 4). Although experiences of disability have thus been an integral part of American life, disability has traditionally been approached as a research object in applied health sciences, psychology, medicine, and social policy research. Yet, while social protection and assistance are important, traditional approaches frequently ignore that impairment is a shared experience that all of us will encounter and that such experience is shaped essentially by a person's socio-cultural surroundings (Fries 8; Waldschmidt 19).

To better grasp the heterogeneous experiences and understandings of disability and their positions within American culture, it is thus crucial to include various first-person perspectives in research on disability and illness. Well until the second half of the twentieth century, however, little attention had been devoted to individuals' perspectives on their bodies and selves, ignoring the crucial value their perspectives hold for academic investigations of disability and/or illness (Jurecic 2; Shakespeare 186). As a countermovement to such traditional approaches, Disability Studies frequently uses life writing and the "experiential knowledge" (Bolt 1) it contains as a productive epistemological tool, bringing new ideas to the forefront of the field. Indeed, first-person accounts shared within the disability rights movement serve as a vital ground upon which the term disability has been re-conceptualized in the U.S. As demonstrated by authors of the "new disability memoir" (Couser, *Signifying Bodies* 164-90), the premise of any Disability Studies related work is to question the causal link between the body and disability.

³ In light of this increase in literary and cultural Disability Studies, scholars such as Eleoma Joshua and Michael Schillmeier have announced a "cultural turn" in Disability Studies research (4). For a more extensive list of essential cultural Disability Studies work and for a general overview, please see Goodley 2017.

In cultural artifacts, illness and disability share a number of conventional scripts and metaphors which warrants their connection. Couser, for instance, writes about “the tyranny of the comic plot” and explains that due to the negative connotations that illness and disability hold, culturally preferred representations frequently follow a progressive narrative of triumph and a return to health (“Empire” 308). These narratives typically celebrate medical power and rely on the assumption that both illness and disability are tragedies or abnormalities to be corrected and normalized (Garden 73). In stark contrast to these medicalized and psychologized notions of disability and illness, Disability Studies relocates disability to social, cultural, economic, and political realms (Goodley, “Dis/entangling” 84). Disability is, as Brenda Brueggemann concludes, understood as a “culturally composed and shared narrative that resembles fictionalized categories of gender and race” (“Disability Studies” 283). At the same time, Lennard Davis cautions us to note that disability is a shifting, changing, morphing notion of identity that distinguishes itself from other identity categories in that it has not developed “a certain rigidity in definition” (*The End of Normal* 35). For Davis, disabled people are the ultimate intersectional subject, a universal image and important modality through which we can understand processes of exclusion and resistance.

Discourses on and around disability and illness often seem to reflect insecurities of the temporarily ‘able-bodied.’ By shedding light on the insecurities embedded in these discourses, Disability Studies have been able to challenge and deconstruct oppressive practices associated with the illusion of an able society (Goodley, “Dis/entangling” 84). In the practice of medical care, ‘disease’ and ‘impairment’ constitute the reasons for clinical intervention; in society, they carry immense weight, since they are not merely descriptive, but also normative notions (Engelhardt 41). While late twentieth century Disability Studies was very much occupied with a strict social model approach to disability, establishing the factors that foster the structural, economic, and cultural exclusion of disabled and chronically ill people, Disability Studies in the current century is eagerly working on finding nuanced theoretical responses to these factors (Goodley, “Dis/entangling” 81). Such critical Disability Studies does not only challenge direct practices of disablement but analyzes and highlights ableism as its underlying ideology.⁴ By questioning and redefining notions of ability, independence, and freedom, Disability Studies

⁴ Borrowing from feminist theory, David Bolt aptly remarks that disablement relates to ableism the way that sexism relates to patriarchy (12).

encourages Americanists of all disciplines to rethink a wide range of political, theoretical, and practical issues (Goodley, *Disability Studies* 157).

Indeed, notions of impairment and disability, as well as the very idea of normality, are not only being (re-)produced by mass media and everyday discourses but also by academic knowledge (Waldschmidt 24). The fact that disability is a cultural trope that spreads across all areas of society raises crucial questions about the materiality of the body and the social formulations that are used to interpret bodily and cognitive differences (Garland-Thomson, “Integrating Disability” 2). As Anne Waldschmidt asserts, “impairments and disabilities are structuring culture(s) and at the same time are structured and lived through culture” (21). Thinking about such cultural implications of disability implies a fundamental change of epistemological perspective. Disability is no longer an individualized research object at the margin of society but, instead, is used to utilize knowledge about the ‘center’ of society and culture (Waldschmidt 25). In Germany, such a cultural Disability Studies approach has been most famously picked up by scholars in sociology (e.g. Anne Waldschmidt) and pedagogy (e.g. Swantje Köbsell). At the same time, American Studies in Germany have been comparatively silent on the topic of disability. Yet as we aim to demonstrate with this special issue, Disability Studies has become an important field of investigation for postgraduate work done within German American Studies. Bringing together American scholarship on disability and Disability Studies projects pursued in German American Studies, this issue emphasizes the fruitful ways in which such a transnational collaboration can enrich our understanding of American history and culture.

Contributions

As editors of this thematic issue, we are delighted to have the opportunity of including not only scholarly “treatments” of disability and illness but also the creative contributions by Laura Passin and Kenny Fries. We encourage you to read both text genres side by side. Our aim is to create a space of communication in which first-person and third-person perspectives may become entangled, speak to one another, and jointly address questions of storying disability and states of dis-ease. Historically, knowledge about illness and disability has been divided into two categories, i.e., the subjective on the one hand and the objective on the other hand. Individuals’ qualitative perceptions have clashed and quarreled with data and ostensibly more

trustworthy observations about their bodies (Morris 39); yet all too often, they have been silenced and kept from the public and political realms. In this vein, we invite you to probe how knowledge about disability and illness is gathered and circulated.

Laura Passin's powerful artist's statement offers signposts for our reading of her poetry in which clear-cut distinctions between health and illness dissolve and the speaker straddles the divides of Susan Sontag's famous "kingdom of the sick and kingdom of the well" (3), as Passin locates herself "with one foot in both kingdoms, not certain in which one my center of gravity leans." Her work is at once deeply subjective, personal and intimate, as well as political. It prompts us to reflect on the role of the poet as interpreter—of others unable to speak for themselves and of one's own, at times fragile and utterly temporary, citizenship in Sontag's kingdom of the well. In doing so, it raises pivotal questions of authority.

The questions of who has the right and authority to write about disability—and what this writing could look like—echo, too, in the works which poet and disability scholar **Kenny Fries** contributes to this thematic issue. His artist's statement poignantly reminds us of the cultural cliché "where I am the only visibly disabled writer and if I don't bring up the subject nobody else will." His poems challenge us to move beyond the surface level and enter the very "microcosms" Fries discerned in *Japanese Gardens*. Purposefully, we included a wide array of poems, some specifically and explicitly about disability, others soliciting us to "excavate" and interrogate images and metaphors at work in both the representation and experience of disability.

In her paper "Sharing Autism through Metaphors," **Marion Schmidt** turns to the writing of Temple Grandin, an author, who, she holds, "has shaped and has been shaped by American discourse over autism as disability or valuable difference." By exploring an interconnected set of metaphors, namely the mechanical brain, visual thinking, and the animal mind, in Grandin's life writing, Schmidt probes the shifting notions of (dis)ability, difference, and diversity in her work as well as the ways in which definitions of autism and selfhood critically come to bear on autistic individuals' sense of identity. Autistic people, she shows, are located "outside of social spheres and apart from cultural influences," but partake in a shared discourse on the mind that eventually allows for the portrayal of Autistic individuals in non-pathological terms. However, Schmidt also unmask the normativity inherent in Grandin's agentic writing and her mastery of metaphors: "As her portrayal of autism skillfully caters to our yearning for unbiased

objectivity, for superior insight into ourselves, animals and machines, it takes part in an idealization that might not always benefit those living with autism.”

Shifting the gaze—quite literally—from the mind to the body, **Jason Dorwart** turns to representations of disability on stage and explores how these challenge “what everybody knows” about disabled bodies. He scrutinizes the mechanisms at work in the performances by two theater companies, the Denver-based Phamaly Theater Co. and the DisAbility Project from St. Louis. While physical disability is seldom staged and, in even rarer cases, performed by actors with disabilities, the two companies are particular cases in point and approach the representation of disability against the backdrop of different missions and visions and thus offer audiences different glimpses at disabled bodies. Dorwart argues that the two companies engage their audience’s expectations of disability and disabled actors. Putting Bertolt Brecht’s theater theory to work, he shows that Phamaly’s performances, in which disabled actors are cast in role traditionally reserved for able-bodied actors, employ the Brechtian alienation effect to deliberately cause discomfort and to call on audiences to rethink what they might know about disability. In the plays Dorwart discusses, familiar subjects are cast as unfamiliar sights and therefore help to initiate “a dialogue between actor/character and spectator which serves to underscore the theme of the actors’ and the audience’s vulnerability to accident, disease, and death.” In the performances of the DisAbility Project, on the other hand, Dorwart identifies strands of Augusto Boal’s ‘theater of the oppressed’ which have the potential of providing transformative visions of disability, such as the invitation to the audience to directly engage with what they witness on stage. Both approaches, Dorwart illustrates, challenge audiences to directly confront bodily difference and their own assumptions and expectations.

Scars constitute a particular form of bodily difference, marking a body once “whole” and healthy. **Jessica Stokes** reminds us that scars are more than reminders of loss. In this vein, she reads scars in the popular television series *American Horror Story: Freak Show* “for the presence of the unseen,” arguing that scars connect bodies and individuals both to the past and an unstoppable futurity, while also inextricably linking bodies to locales as well as places and instances of trauma. Discussing the roles of various freak show performers, Stokes illustrates how experiences of trauma and separation at once mark bodies and foster the creation of what she terms a “healing community,” when the scar’s potential for intimacy is taken into account. However, Stokes finds, disabled people of color are excluded from these

communities and from representation in the media, an observation that the authors of the following papers take upon their explorations of representations of blindness and deafness.

Tracing the intertext of Royall Tyler's *The Algerine Captive* (1797), **Andrew Sydlík** emphasizes the crucial relation between metaphors of blindness (and sight) and processes of meaning-making in the eighteenth century. Perpetuating ocularcentrism, metaphors of sight have traditionally been related to practices of knowing. The popularity of such metaphors has not only informed a false understanding of seeing *as* knowing but has also invoked the perception that seeing is necessarily the normal way of gathering knowledge (Bolt 18). In contrast, the word blind as used in everyday language has come to connote a lack of understanding or discernment, disregard or obliviousness, concealment or deception (Kleege 21). Sydlík demonstrates how Royall Tyler's novel draws from Denis Diderot's "Letter on the Blind for the Use of Those Who Can See" (1749) to investigate blindness and sight in relation to nationhood and foreignness. His close reading reveals that by engaging the medical and moral model of disability, "Tyler's novel suggests that just as the man cured of his blindness must learn how to use vision, so the American citizen must learn how to sympathetically bond with fellow white, non-disabled citizens to strengthen national identity." Sydlík interrogates the novel's problematic promotion of ablenationalism and sheds light on the different ways in which Tyler's text uses blindness to make this commentary on American citizenship.

Just as with blindness, notions of deafness are not always clearly or singularly defined. This is not only indicated by the constant struggle of activists and scholars alike to familiarize readers with the distinction between "deaf" and "Deaf" but is also mirrored by the uneasy position that the term disability has occupied in Deaf studies—with the field frequently distancing itself from Disability Studies and disability culture in favor of more distinct notions like Deaf culture and Deaf identity (Bruggemann, *Deaf Subjects* 12). Calling attention to the heterogeneity within the Deaf community and its rich and multifaceted history, **Anja Werner** shows that Deaf culture in general and the education of deaf people in specific do not occur in a socio-economic vacuum but have been shaped immensely by other identity categories such as race and class. With her analysis of nineteenth- and twentieth-century Black deaf history, Werner illustrates that Black deaf persons—whether they identified as culturally Deaf or not—have significantly contributed to American culture, although their contributions have gone largely unacknowledged. By examining multiple accounts from Black deaf history, Werner meets one

of Brenda Bruggeman's demands to go beyond the prominent historical scholarship on Alexander Graham Bell and his impact on deaf education and to look closely at the versatile historical interplays of speech, education and "normalcy" that have shaped public discourses about deafness throughout the nineteenth and twentieth century (Brueggemann, *Deaf Subjects* 23). Werner highlights that Black deaf people were sometimes able to undermine the racism of white hearing people and played a significant role in breaking down color lines. While Black deaf children had only limited access to education as their families faced greater difficulties to ensure that their children received an education, activism to improve educational opportunities on behalf of Black deaf children is viewed by Werner as an important driving force for the African American civil rights movement. The fact that Black deaf Americans have not resigned from voicing their concerns as a minority group within a minority group required, as Werner further concludes, particular efforts since, in comparison to their hearing Black peers, Black deaf Americans faced additional discrimination on account of their hearing status and communication even within the Black community.

It is in "keeping our eyes out for deaf commonplaces while also admiring ever-shifting capabilities of perspective (in both our "eyes" and our "I's")" that, as Brueggemann suggests, "the sites and sights of Deaf Studies promise us ever-enchanted explorations" (*Deaf Subjects* 24). While Werner provides us with new perspectives in her exploration of Deaf history, this special issue extends Brueggemann's claim in an attempt to account for Disability Studies as a whole. With its range of different perspectives on American negotiations of illness, neurodiversity, physical as well as sensory disabilities, its engagements with fictional as well as autobiographical texts, and its shifting focus between specific landmarks in American history and history's long arm, the following issue might serve as an encouragement to further keep our eyes out for the commonplaces of disability and/or illness and to explore the different perspectives as well as rigorous debates that the sites and sights of Disability Studies promise to bring to American Studies scholarship.

Acknowledgments

The seed for this special issue was sown at the PGF 2014 in Mainz and during an accompanying train ride home that gave us time to first meet and connect with someone else working within

American Studies and Disability Studies in Germany. Out of our excitement about this incidental meeting grew the wish to build a network of American Studies scholars specializing in Disability Studies and to connect within and beyond Germany. We are not only very thankful to the PGF for providing this very crucial space to first meet but would also like to express our gratefulness to COPAS for fostering our idea of a special issue. Next to acknowledging the entire COPAS team for their support, we would like to give special thanks to Johanna Heil, who, with much enthusiasm and patience, guided us in the editing process of this issue.

Works Cited

- Bolt, David. *The Metanarrative of Blindness: A Re-Reading of Twentieth-Century Anglophone Writing*. U of Michigan P, 2013.
- Brault, Matthew. "People with Disabilities." *Current Population Reports*. U.S. Census Bureau, 2012, pp. 70-131.
- Brueggemann, Brenda Jo. "Disability Studies/Disability Culture." *The Oxford Handbook of Positive Psychology and Disability*. Ed. Michael L. Wehmeyer. Oxford UP, 2013, pp. 279-99.
- . *Deaf Subjects. Between Identities and Places*. New York UP, 2009.
- Conway, Kathlyn. *Illness and the Limits of Expression*. U of Michigan P, 2007.
- Couser, G. Thomas. *Signifying Bodies: Disability in Contemporary Life Writing*. Ann Arbor: U of Michigan P, 2009.
- . "The Empire of the 'Normal': A Forum on Disability and Self-Representation." Introduction. *American Quarterly*, vo. 52, no. 2, 2000, pp. 305-10.
- . *Recovering Bodies: Illness, Disability, and Life Writing*. Madison: U of Wisconsin P, 1997.
- "Critical Disability Studies Caucus." American Studies Association.
www.theasa.net/communities/caucuses/critical-disability-studies-caucus. Accessed 12 Aug. 2017.
- Davis, Lennard J. *Enforcing Normalcy. Disability, Deafness, and the Body*. Verso, 1995.
- . *The End of Normal: Identity in a Biocultural Era*. U of Michigan P, 2013.
- Fries, Kenny. *Staring Back: The Disability Experience from the Inside Out*. Plume, 1997.
- Garden, Rebecca. "Disability and Narrative: New Directions for Medicine and the Medical Humanities." *Medical Humanities*, vol. 36, 2010, 70-74.

- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia UP, 1997.
- . Garland-Thomson, Rosemarie. "Integrating Disability, Transforming Feminist Theory." *National Women's Studies Association Journal*, vol. 14, no. 2, 2002, pp. 1-32.
- . "Disability Studies: A Field Emerged" *American Quarterly*, vol. 65, no. 4, 2013, pp. 915-26.
- Goodley, Dan. "Dis/entangling Critical Disability Studies" *Culture-Theory-Disability. Encounters between Disability Studies and Cultural Studies*. Ed. Anne Waldschmidt, Hanjo Berressem, Moritz Ingwersen. Transcript, 2017, pp. 81-109.
- . *Disability Studies: An Interdisciplinary Introduction*. Sage, 2011.
- Joshua, Eleoma and Michael Schillmeier. Introduction. *Disability in German Literature, Film, and Theater. Edinburgh German Yearbook*. vol. 4. Camden House, 2010, pp. 1-13.
- Jurecic, Ann. *Illness as Narrative*. U of Pittsburgh P, 2012.
- Kleege, Georgina. *Sight Unseen*. Yale UP, 1999.
- McRuer, Robert. *Crip Theory. Cultural Signs of Queerness and Disability*. New York UP, 2006.
- Mitchell, David T. and Sharon L. Snyder. *Narrative Prosthesis. Disability and the Dependencies of Discourse*. U of Michigan P, 2001.
- Morris, David B. *Krankheit und Kultur: Plädoyer für ein neues Körperverständnis*. Kunstmann, 2000.
- Nettleton, Sarah. *The Sociology of Health and Illness*. Reprint. Polity Press, 1999.
- Shakespeare, Tom. *Disability Rights and Wrongs*. Routledge, 2006.
- Siebers, Tobin. *Disability Theory*. U of Michigan P, 2008.
- Tremain, Shelley L. "On the Subject of Impairment." *Disability/Postmodernity: Embodying Disability Theory*. Continuum, 2002, pp. 32-47.
- Waldschmidt, Anne. "Disability Goes Cultural. The Cultural Model of Disability as an Analytical Tool." *Culture-Theory-Disability: Encounters between Disability Studies and Cultural Studies*. Ed. Anne Waldschmidt, Hanjo Berressem, Moritz Ingwersen. Transcript, 2017, pp.19-27.
- Ward Brian, Schiller Jeannie, and Richard Goodman. "Multiple Chronic Conditions among US Adults: A 2012 Update." *Preventing Chronic Disease*, vol. 11, 2014.
www.ncbi.nlm.nih.gov/pubmed/24742395. Accessed 29 Dec. 2017.