Literature and Contemporary Thought

LITERATURE AND

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ALICE HALL

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Literature and Disability

Literature and Disability introduces readers to the field of disability studies and the ways in which a focus on issues of impairment and the representation of disability can provide new approaches to reading and writing about literary texts. Disability plays a central role in much of the most celebrated literature, yet it is only in recent years that literary criticism has begun to consider the aesthetic, ethical and literary challenges that this poses. The author explores:

- key debates and issues in disability studies today
- different forms of impairment, with the aim of showing the diversity and ambiguity of the term "disability"
- the intersection between literary critical approaches to disability and feminist, postcolonial and autobiographical writing
- genre and representations of disability in relation to literary forms including novels, short stories, poems, plays and life writing.

This volume provides students and academics with an accessible overview of literary critical approaches to disability representation.

Alice Hall is a Lecturer in Contemporary and Global Literature at the University of York, UK.

Literature and Contemporary Thought

Literature and Contemporary Thought is an interdisciplinary series providing new perspectives and cutting edge thought on the study of Literature and topics such as Animal Studies, Disability Studies and Digital Humanities. Each title includes chapters on:

- why the topic is relevant, interesting and important at this moment and how it relates to contemporary debates
- the background of and a brief introduction to the particular area of study the book is intended to cover
- when this area of study became relevant to literature, how the relationship between the two areas was initially perceived and how it evolved

A glossary of key terms and annotated further reading will feature in every title.

Edited by **Ursula Heise** and **Guillermina De Ferrari** this series will be invaluable to students and academics alike as they approach the interdisciplinary study of Literature.

Also available in this series:

Literature and Animal Studies
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For Lucy

Series Editors' Preface

Since the turn of the millennium, literary and cultural studies have been transformed less by new overarching theoretical paradigms than by the emergence of a multitude of innovative subfields. These emergent research areas explore the relationship between literature and new media technologies, seek to establish innovative bridges to disciplines ranging from medicine, cognitive science, and social psychology to biology and ecology, and develop new quantitative or computer-based research methodologies. In the process, they rethink crucial concepts such as affect, indigeneity, gender, and postcolonialism and propose new perspectives on aesthetics, narrative, poetics, and visuality.

Literature and Contemporary Thought seeks to capture such research at the cutting edge of literary and cultural studies. The volumes in this series explore both how new approaches are reshaping literary criticism and theory, and how research in literary and cultural studies opens out to transform other disciplines and research areas. They seek to make new literary research available, intelligible and usable to scholars and students across the Humanities and, beyond the university, to a broader public interested in innovative approaches to art and culture across different historical periods and geographical regions.

Literature and Contemporary Thought highlights new kinds of scholarship in the literary and cultural humanities that are relevant and important to public debates, and seeks to translate their interdisciplinary analyses and theories into useful tools for such thought and discussion.

Ursula Heise and Guillermina de Ferrari

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Disability Demands a Story

This study takes as its starting point an understanding of politics, ethics and aesthetics as fundamentally intertwined, connected through the concept of representation. It argues that it is important to explore disability in terms of character, metaphor and theme in literary narratives, both inside and outside of the traditional literary canon, across the ages. Disability perspectives can transform understandings of structure, genre and narrative form. These perspectives can destabilise established theoretical paradigms in literary criticism and provide a fresh, often provocative approach to analysing all literary texts. Literary representations of disability open up discussions about some of the most pressing issues of our age: about austerity, empathy, minority status, social care and citizenship. They provide creative opportunities for close reading, but they can also initiate a re-imagination and a re-writing of literary and cultural history.

A contemporary example of this process of re-writing and re-imagining can be found in the opening short story of Anne Finger's collection, *Call Me Ahab* (2009). It begins with two female icons of disability: Frida Kahlo and Helen Keller. Finger uses the imaginative licence of the short story form to bring together two figures from different backgrounds and to stage a series of conversations between Keller and Kahlo. "Helen and Frida" is creative in aesthetic terms: the sensuous language, shifting time-frames, and mutability of the narrative perspective endow the story with an air of delirium. This aesthetic experimentation is intimately connected to the complex, often transgressive approaches to authorship and the politics of representation explored in the story. Finger uses her narrative to give voice to Kahlo, a figure known predominantly for her silent self-portraits; she focuses on the relationship between speech and silence, on processes of communication, and multisensory experience. Then, at its climax, the flow of the narrative is ruptured by a moment of direct address in which the narrator calls upon readers to try to imagine deafblind experience for themselves: "Try it right now. Finish reading this paragraph and then close your eyes, push the flaps of your ears shut, and sit" (Finger 12).

"Helen and Frida" introduces many of the major concerns of this book. In the story, Frida communicates with Helen through finger spelling. The narrative emphasises the physicality and the idiosyncrasies of this mode of communication: Frida takes particular pleasure in writing the letters "j" and "z" and she searches for a vocabulary that uses these letters as much as possible, often to comic effect. This personal moment in the story suggests questions about textual representation more generally and the ways in which form, content and structure are shifted when considered from a disability perspective. The moment also re-inserts the body as a site of knowledge into the debates about communication and representation that underpin the story. Readers are reminded not only of the physicality of this imagined communication between Helen and Frida, but also of their own bodies which mediate their experience of the text: "Feel the press of hand crossed over hand: without any distraction you feel your body with the same distinctiveness as a lover's touch makes you feel yourself. You fold into yourself, you know the rhythm of your breathing, the beating of your heart, the odd independent twitch of a muscle..." (Finger 12). In this moment, the story calls for an embodied perspective on disability, a perspective which introduces debates about gender identities, sexuality, expression and materialist aesthetics. Finger seeks to represent in narrative the visual qualities of film with colours and timeframes that fade in and out. The form of the story itself therefore invites readers to think across the boundaries of traditional disciplines and genres as it invokes characters and narrative strategies not only from film, but also from canonical literary texts, and Finger's own autobiographical experience.

Call Me Ahab, Finger's short story collection, features Vincent Van Gogh, Velazquez's dwarf, Shakespeare's Gloucester, the Biblical Goliath, and Melville's Ahab. The stories draw attention to the wealth of representations of disability in the history of western literature and culture, but they also adopt an ironic critical distance that allows the author to re-write this history from a twenty-first-century perspective. The impetus is neither towards straightforward historical recuperation of disability nor documentary social realism. Instead, Finger appropriates historical figures and re-imagines them, not as easy metaphors, tragic victims or medical case studies, but as complex, active and embodied author figures inhabiting distinctly everyday settings. *Call Me Ahab* draws together a web of intertextual threads from a rich literary and cultural history of representation. Nevertheless, Finger insists, through the fragmented structures, transgressive comedy and moments of direct address, that readers confront pressing contemporary issues about disability.

Literature and Disability seeks to introduce readers to the wealth of work done so far in cultural disability studies, with a particular focus on literary theory and fictional representations. It maps out existing debates and recent new directions in the field. Kenzaburō Ōe, a Nobel Prize-winning Japanese writer and disability activist, is one of a number of authors whose works are used to anchor some of these debates in key examples and to highlight the international range of contemporary writing about disability. Ōe's understanding of the relationship between literature and imagination, drawn originally from William Blake, is fundamental to the thinking in this book. For Ōe, who writes about his cognitively impaired son, Hikari, literary forms allow him the freedom to imagine a perspective that is radically different from his own. The imaginative dimensions of fiction offer neither a clear reflection of, nor an escape from, the contemporary world; instead they complicate and intensify his ability to narrate and think critically about his immediate familial, social and political environment. Ōe proposes that: "imagination is at the core of the function of language in fiction and is critical to observing the circumstances of the contemporary world" (127).

Critical disability theorists have frequently suggested that disability sparks imagination and narration. Michael Bérubé states simply: disability "demands a story" ("Disability and Narrative" 570). For David Mitchell and Sharon Snyder, it is disability's "very unknowability that consolidates the need to tell a story about it" (6). This "demand for explanatory narrative" works on a crude level in everyday life: people with disabilities are often expected to describe and even explain their bodies and histories in ways that those perceived as normal are not: "the scar, the limp, the missing limb, or the obvious prosthesis – calls for a story" (Couser 457). This demand for story also inspires literary narratives about disability. For Lennard Davis, narrative reconfigures the relationship between disability and time: "When one speaks of disability…[it] immediately becomes part of a chronotope, a time-sequenced narrative, embedded in a story" (*Enforcing Normalcy: Disability, Deafness, and the Body* 3–4). The use of disability as a trigger for narrative is evident in stories ranging across literary history from blind Oedipus to the scarred, physically impaired slaves in Toni Morrison's *Beloved*. For some scholars, such as Ato Quayson, disability in literature is so common that it can be seen as the defining feature of literary narratives per se: "I want to suggest that we consider the plot of social deformation as it is tied to some form of physical or mental deformation to be relevant for the discussion of all literary texts" (22).

Disability studies is founded on a commitment to challenging the social marginalisation of people with disabilities. Many of the humanities scholars affiliated to this field insist that disability is not a marginal issue in literary and cultural study either: it is a central and transformative critical category for thinking about literature and literary theory. Far from replicating the absences of people with disabilities in social and political life, therefore, literary writing can be seen to obsessively return to the topic of disability. In some cases, representations of disability are used as a metaphorical shortcut, signifying wider societal anxieties and propping up definitions of the norm. Couser points out that "the unmarked case – the 'normal' body – can pass without narration" (457). In the same way, one might assume that a character in a literary narrative, like a "normal" American or European citizen, is necessarily white, non-disabled, heterosexual, physically and economically self-supporting, unless it is explicitly stated otherwise. Certain novels, plays, short stories, and poems reinforce oppressive ideas of normalcy, sentimentalise, and solidify stereotypes about disability. Identifying, challenging and exploring examples of these characters, metaphors, themes and discriminatory attitudes is important cultural work, particularly when this work contributes to social and political campaigns for acceptance and equality for people with disabilities. Literary writing has the potential to reach large and diverse populations; it serves a pedagogic function in the sense that it not only documents but also shapes attitudes towards disability. After all, as Snyder and Mitchell suggest, classics such as *Of Mice and Men* (1937), *Catcher in the Rye* (1951), *To Kill a Mockingbird* (1960), and *One Flew Over the Cuckoo's Nest* (1960) remind us that citizens often learn about disability "from books more than policies" ("Disability Haunting in American Poetics" 6).

This book also sets out to explore formal and theoretical questions about disability representation in literature and culture. It considers modern literary writing by disabled and non-disabled authors that is innovative and, at times, experimental and resistant to normative representations. These imaginative works and critical approaches invite us to think deeply about complex intersectional identities and to test the boundaries of literary form and the definition of "disability" itself.

Definitions: Disability at a Critical Juncture

Chapter Two of this book charts the history of disability studies and the critical distinction between the "medical" and the "social" models of disability. In addressing the topic of "disability studies now", this chapter examines another tension between different understandings of disability.

Disability theory currently finds itself at an important critical juncture, in its negotiation of the tension between minority identity-based models and highly flexible rights-based definitions of disability.

In the wake of the 2008 financial crisis, cuts to welfare and aid budgets, long-term unemployment and poverty have accentuated the economic disparities and social inequalities that already existed for the majority of people with disabilities. In this context, the definition of "disability", from a legal-administrative point of view, is highly politicised and hotly contested. In the United Kingdom, for example, the former general secretary of the Trades Union Congress, Brendan Barber, identified an "ideological austerity" in his address to the 2012 Disabled Workers Conference. The narrative framework through which the government and media were choosing to construct disability was not, he suggested, merely a convenient form of rhetoric for justifying financial cuts to disability budgets, but it was, in itself, an act of aggression and violence. Barber pointed to a "dichotomy between rhetoric and reality" in the UK government's promotion of the "language of fairness" alongside the perpetuation of "demeaning myths about workshy scroungers" (Association). From "bedroom taxes" to disability benefits, the question of whether a person is deemed "disabled" or indeed "disabled enough" to qualify in an official capacity often makes a very direct impact on his or her material living conditions and quality of life.

Yet, despite this recent economic and administrative policing of the boundaries of disability, in the last two decades there has been a rapid expansion in both legal and popular conceptions of what "disabled" might mean. This is, in part, linked to the broad definitions of disability established in legislation such as the Americans with Disabilities Act (ADA) which was passed in 1990 (and is discussed further in Chapter Two). This landmark act put forward a rights-based model of disability; it recognised the socially constructed dimensions of physical, cognitive and sensory disabilities and extended existing civil rights legislation by declaring that there are certain essential and inalienable rights that people with disabilities share with all other human beings. Disability is understood in the act as an impairment that limits at least one life activity, or is perceived as doing so. The ADA employs a wide-ranging definition of disability in which shared rights between all citizens, rather than distinct minority identities, are emphasised. The more recent 2006 UN Convention on the Rights of Persons with Disabilities seeks to extend this rights-based approach on an international scale.

This widening of the legal definitions of disability is connected to a demographic explosion in the number of people with disabilities, a trend that looks set to be maintained as life expectancies increase. The World

Health Organisation's "World Report on Disability" (2011) estimates the number of people with disabilities around the world at one billion, about 17 per cent of the global population. As the baby boomer generation ages in the west, there is an increasing number of people for whom the idea that everyone is "temporarily able-bodied" (TAB) or not yet disabled, has a powerful personal resonance. Like the rights-based legislation, activist labels such as "temporarily able-bodied" suggest a democratisation of disability: being disabled, or having the potential to become disabled, is an aspect of identity and embodiment that all human beings share. Unlike the categories of race and gender, disability is fluid: a person can become disabled suddenly, temporarily, and at any time in their lives. Disabilities can be invisible and most disabilities are acquired over the course of a lifetime rather than from birth. If we all occupy a position on a multidimensional gradient of ability, some of the linguistic distinctions between "disabled" and "non-disabled" become less certain; the critic Mark Osteen, for example, argues that they are often arbitrary (2). As age-related disabilities become incorporated into the category, the prevalence and perceived relevance of disability issues and identification looks set to expand even further.

These universalising legal and social definitions are also evident in literary and cultural studies of disability. Recent scholarly works, for example, explore scars, obesity, cancer and Alzheimer's disease under the banner of cultural disability studies criticism. The "neurodiversity" movement provides a striking example of the impact of the changing conceptions and growing public awareness of certain disabilities: this progressive social and political campaign seeks to bring together and represent a variety of atypical cognitive styles and neurological differences, including autism, intellectual disabilities, learning disabilities, attention deficit hyperactivity, epilepsy, bipolar disorder, Tourette's syndrome, and schizophrenia (Antonetta; Baker). New conceptions of neurodiversity have, in turn, led to the analysis of diverse texts on these topics, which were traditionally viewed as entirely separate and perhaps not even as about disability at all, alongside each other. Criticism of the so-called "neuronovel" genre, for example, discusses topics from Asperger Syndrome to post-traumatic stress disorder (Gaedtke).

This flexible view of disability also extends to some recent conceptions of the field itself. Disability theory has been put in dialogue with gender and feminist theories, queer theory, critical race theory and postcolonial studies. In asserting the importance of these "intersectional" approaches, scholars argue that disability studies has important insights for better understanding a huge range of identities and different forms of cultural production. For Davis, the person with disabilities has the potential to become "the ultimate example, the universal image, the modality through whose knowing the postmodern subject can theorize and act" ("Introduction" xvii). These examples pose questions about the definition of "disability", but also of "disability studies" as a discipline. Intersectional, interdisciplinary approaches can cause difficulties in practical, methodological and pedagogical terms: provoking debates about the location of the field in relation to academic institutions and activist movements, who teaches it, and which texts are included in the ever-evolving canon of disability theory and literature. As Bérubé suggests, "it does not seem coincidental that the potential universalization of the field of study should be accompanied by fresh emphases on the potential universalization of disability" ("Afterword: If I Should Live So Long" 338).

For other scholars and activists, this highly malleable view of disability, and the range of the field itself, risks diminishing the power of disability as a political, social, and critical category. If disability is understood in universal terms, as affecting or potentially affecting all bodies, then how can people with disabilities demarcate and celebrate a distinct collective identity? A collective conception of identity is strategically important in terms of disability activism. As Siebers argues, a clearly defined and distinctive disabled community is important for thinking about, and fighting for, "fundamental democratic principles such as inclusiveness and participation" (93). Similarly, in *Claiming Disability* (1998), Simi Linton argues that disabled people in America represent a "solidified" group. She sees disability as a distinct social, rather than medical or legal, identity: "We are everywhere these days…We are all bound together, not by this list of our collective symptoms but by the social and political circumstances that have forged us as a group" (*Claiming Disability: Knowledge and Identity* 4). For Linton, disability is a distinctive identity but it is not somatised or essentialist; instead it is a socially constructed, public position that a person actively "claims". Her choice of language is key here: the frequent use of the collective "us" identifies people with disabilities as a distinctive group who share a sense of solidarity. Linton also employs the identifier "nondisabled" in her descriptions of people in order to make disability the norm in her critical account. The Deaf community, discussed in Chapter Five of this book, can be seen to act as a powerful example of such a group, who share a commitment to alternative systems of communication and have a strong political presence, though the celebration of Deaf identity is often linked to a rejection of the label "disabled" entirely.

This idea of a unifying language, identity or disability culture is put under pressure when disability is explored in a global context. Michael Davidson invokes an idea from architecture, of "universal design", to critique the idea of a "universal" disability identity. Disability theory has, he suggests, been guilty in the past of assuming that models of disability which are appropriate in the Euro-American settings that dominate the field can be easily transported elsewhere (172). Instead, Davidson argues for a porous, historicised, and culturally specific understanding of disability that takes into account economics, politics and poverty, and the fact that the most people with disabilities live in the non-western "majority world". In this context, a malleable definition of disability is necessary in order to account for the fact that what might be perceived as a disability in one culture, or time period, may not be identified as a disability in another.

These debates feed into the language through which scholars construct disability in their critical and theoretical writing. The tension between the rights-based model and the minority identity definition is encapsulated, for example, in the use of different terminologies. "People with disabilities" is often used by activists and academics to suggest a "people-first" approach, in which the shared qualities of personhood are given prominence. "Disabled people", by contrast, is often favoured by British social model advocates, who celebrate disability as an affirmative identity and a distinct collective movement. This book employs both terms but tends more towards "people with disabilities" as a model that is appropriate for the discussion of the ways in which disability intersects with race, class, nationality and gender.

Literature and Disability is underpinned by a commitment to the sense that disability not only "demands a story", but also that language matters. The language through which disability is discussed is inevitably shifting, and this will no doubt render some of the terms used in this book outdated or problematic as time passes. However, language matters not merely as a question of political correctness, but because it shapes expectations and it conveys models and conceptions of disability that are fundamental to how disabled identities and agency are experienced. Self-consciousness about language and anxiety about causing offence can be obstacles to important and necessary debates about disability. The language of disability can evoke visceral reactions and fear (Stiker 3). But the commitment to thinking, writing, theorising and imagining disability is essential. As Lucy Burke suggests, the field of cultural disability studies is founded on a "suspicion" about the "uses and abuses of language" that is hardly surprising given the history of oppressive representations and stigmatising labels imposed upon people with disabilities (i). Yet, this makes these debates more important rather than less so: language is necessary in order to critique, challenge and re-write the stories and structures through which disabilities have been traditionally understood.

Technologies of Writing and the Body

Davidson suggests that the "first-world" texts from the global north that have dominated disability studies so far "may very well have narrative closure as their telos, but regarded in a more globalized environment, the social meaning of both disability and narrative may have to be expanded" (176). As discussed above, the definition of disability has, in certain contexts, been expanding in the twenty-first century. Alongside greater critical attentiveness to the ways in which disability is constructed according to local languages, beliefs, social attitudes and cultures, there is also a growing sense of disability as located within a globalised world system. The interconnectedness of global and local, of public and private is illustrated in the title of Linton's 2006 memoir, *My Body Politic* (2010). Snyder and Mitchell draw on discussions about the role of disability in the nation state, critiquing assumptions about non-disabled citizenship in globalised capitalist systems through their notion of "ablenationalism" (2010). Philosophers such as Martha Nussbaum and Anita Silvers highlight the ways in which certain dominant models of citizenship, structured around John Rawls's social contract theory, have failed to take account of people with disabilities. For Nussbaum, contrarian thinking often considers "severe mental impairments and related disabilities as an afterthought, after the basic institutions of society are designed" (98). In this context, a specific focus on disability issues highlights the exclusions in theories of justice and citizenship that are often assumed to be universal. As the definitions of disability are expanded, contested, and theorised, narratives of disability are also reconfigured.

Technology plays an important role in shaping these changing conceptions of both disability and narrative. Like disability, the boundaries of literature are being increasingly destabilised in contemporary contexts, with some authors and cultural commentators pronouncing that the novel is a "dying animal" and that, in a technological age of constant distraction from newsfeeds, images and updates from around the world, readers exhibit a form of attention deficit when it comes to sustained engagement with traditional literary forms (Roth; Self). New technologies bring with them new narrative forms and new modes of reading. These technologies have also revolutionised access to reading and writing for people with disabilities: from talking books and electronic reading machines developed for blind populations over the course of the twentieth century to rapidly advancing computerised assistive technologies such as voice synthesizers for those who are non-verbal in the present day. Autistic authors such as Tito Mukhopadhyay and Naoki Higashida, whose works are discussed in Chapter Seven of this book, simply would not have been able to write their poems, short stories or memoirs in an earlier age.