

Literature and Contemporary Thought

LITERATURE AND

LITERATURE AND

# DISABILITY

ALICE HALL



 ROUTLEDGE

# 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.

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# Literature and Disability

Alice Hall

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# 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

# 1 Disability Studies Now

## 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

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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).

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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

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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 "neuro-novel" 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



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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.

Mukhopadhyay's experience in particular, as a young man who was sponsored by the Cure Autism Now organisation to travel from India to the United States, highlights the ways in which access to technologies is bound by global economic inequalities as well as localised politics and campaigns.

The boom in disability life writing exemplifies the blurring of the line between the autobiographical and the fictional in contemporary writing. Blogs, websites, YouTube videos and Twitter feeds allow new voices to be heard and provide far-reaching, low-cost platforms that allow people who have historically been silenced to tell their stories. Online self-publishing bypasses the traditional publishers who have been the gatekeepers of the literary establishment. Digital technologies serve as a vehicle both for the wider distribution of disability narratives but also for the production of new genres, forms of writing and types of language. For example, these forms bring together words, images and physical performances in new configurations, such as in sign language poetry or Amanda Baggs's autobiographical, "In My Language" (2007), accessible on YouTube. Chapters Seven and Eight of this book discuss the recent explosion in disability life writing and some of the work, both online and in print, which adopts an experimental approach to genre and, through its form, highlights some of the creative possibilities of new technologies of writing. The use of new digital technologies to create new archives, such as the BBC's 2013 radio series, "Disability: A New History", which features sound clips that re-create voices from the eighteenth and nineteenth centuries, also serve as a reminder about the challenges of preserving valuable digital forms of writing for future generations (White).

For Davis, disability studies provides a new perspective not only on specific experiences of impairment, genres, and texts, but also on the ways in which *all* bodies in the twenty-first century have a flexible sense of identity and are dependent on technologies. He proposes the idea of "dismodernism", as a subject position that is intimately connected to postmodernism: a new category that acknowledges the partial, incomplete nature of human subjects and focuses on dependency and interdependence rather than autonomy (*Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions*). Discussions about disability frequently focus on technology, economics, and dependency, he suggests, but these issues are often overlooked when it comes to critical thinking about bodies that are deemed "normal". So disability perspectives provide a productive means to destabilise the neoliberal fiction of the definitive self-sufficient, independent citizen of modernity (and the global north in particular); a figure who, Christopher Bell and Robert McRuer remind us, is often assumed to be white and heterosexual too.

This association between narratives of disability, citizenship and technology was striking in the media coverage of the London 2012

Paralympic Games. Celebrated for both the achievements of the participants and the scale of the public interest that it generated, the London 2012 Paralympics conveyed, from the opening ceremony speech by Stephen Hawking, a celebratory message of disability pride. Media coverage focused on technologies, such as the “Cheetah limbs” of Oscar Pistorius and the superlative achievements of the athletes. UK Channel 4’s national television and billboard campaign to promote coverage of the games, called “Meet the Superhumans”, featured, among other clips, a highly physical game of basketball played by muscular men using high-tech wheelchairs set on a darkened court to a backdrop of drum and bass music. Some critics suggested that this “superhuman” view simply replaced one unrealistic set of cultural assumptions about people with disabilities as subhuman with its polar opposite, the superhuman.

These superhumans and “supercrips”, whose technologised and superhuman power eclipses any sense of human vulnerability, are examples of a recurring figure or narrative template often identified by cultural disability studies critics. In her “Cyborg Manifesto”, for example, Donna Haraway depicts the cyborg as a figure of feminist empowerment whose transgressive body disrupts boundaries between organism and machine, male and female. Haraway makes explicit the comparison with disability, and particularly prostheticised bodies, explicit, focusing on modes of communication: “Perhaps paraplegics and other severely-handicapped people can (and sometimes do) have the most intense experiences of complex hybridization with other communication devices” (178). Disability studies scholars such as Siebers have taken issue with Haraway, accusing her of being “so preoccupied with power that she forgets what disability is” and pointing out that for the cyborg, prostheses always increase abilities, whereas in daily life they are often a source of problems (Siebers 63).

Following the revelation of Oscar Pistorius’s shooting of his partner, Reeva Steenkamp, several months after his paralympic success, sensationalised media coverage returned to the idea of the “superhuman” or “supercrip”. In the week after the shooting, on 11 March 2013, the front cover of *Time* magazine in the United States featured an image of Pistorius staring intently in semi-darkness, bare-chested, muscular and wearing only his prosthetic legs. The three-word headline, emblazoned in bold vertically over his body, suggested an association between Pistorius’s prosthetic legs, his attachment to guns, and his superhuman ego:

Man.  
Superman.  
Gunman.

Yet, alongside this media coverage, contemporary artists and museums were also exploring representations of the “superhuman”. Timed to coincide with the London Paralympic games in 2012, the “Spare Parts” exhibition in London’s Rag Factory gallery exhibited second-hand prosthetic limbs that had been turned into works of art through the paintings, drawings and narratives that were inscribed on every surface to emphasise their aesthetic and personal value. Over the same period, the Wellcome Trust in London ran an exhibition, “Superhumans”, that displayed technologies designed for people with disabilities, such as ancient Egyptian prosthetic toes or early hearing aids, alongside modern-day items that visitors might not usually consider to be prostheses, such as reading glasses or the latest iPhone. These more everyday examples return us to Davis’s sense of dismodernism: the idea that all bodies in the twenty-first century are dependent on technology and are deemed incomplete without consumer products from deodorant and hair gel to contact lenses, hearing aids, breast implants, pacemakers and birth control implants. These normalising technologies and practices, through which the idea of an average “normate” is constructed and sustained, are negotiated and often reinforced in literary and cultural spaces: novels, comics, magazines, films and the media (Garland-Thomson 8). Chapter Four of this book, on physical disability and the novel, takes up these questions about normalising discourses, the representation of physical prostheses, and “prosthesis” as a common metaphor in critical discourse, through a reading of J.M. Coetzee’s 2005 novel, *Slow Man*.

This powerful fiction of the average citizen, in cultural and scientific discourses, is not a twenty-first-century phenomenon. Much recent disability theory is influenced by Michel Foucault’s idea of biopower. Foucault takes a historical approach, pinpointing the late eighteenth century as the moment in Europe and the United States at which “a technology of human abnormality, a technology of abnormal individuals appears precisely when a regular network of knowledge and power has been established” (61). Cultural disability studies scholars such as Davis, Mitchell and Snyder, and Bérubé, among others, have drawn on this work to trace the strategies through which the state subjects citizens to regulatory and normalising strategies which include the use of statistics, demographics, eugenics and sterilization, in industrialised and post-industrialised societies. For Snyder and Mitchell, for example, disability is not merely another identity to add to the “theoretical matrices of other marginalized peoples”, but instead it is “the keystone in the edifice of bodily based inferiority rationales built up since the late eighteenth century” (*Cultural Locations of Disability* 12). Davidson focuses in particular on the Modernist period when, he argues, the increasing influence of the technologies of “statistics,

comparative anatomy, and racial science” directly paralleled the emergence of a modernist artistic aesthetic that, in contrast to the quantification and regularisation of bodies, “shattered ideas of sculptural integrity, single-point perspective, narrative coherence, and tonal harmony” (xvii). In this context, literary and cultural production are understood as potential sites of resistance, subverting the state’s desire to standardise bodies and measure citizens through experimental, often fragmented aesthetics and a focus on individual interior lives. In Chapter Seven of this book, we take up the example of William Faulkner’s modernist classic, *The Sound and the Fury* (1929), to consider in more detail how this relationship works.

### **The Structure of the Book**

Faulkner is just one of the authors discussed in this book who was denounced in his time for writing about disability. His works, that deal with disability, race and class in the American South, polarised opinion: they were celebrated through the award of the Nobel Prize near the end of his life in 1949, yet they were also publicly derided for their depiction of African Americans and people with cognitive impairments (Hall 20–48). Today, we may question whether works such as *The Sound and the Fury*, published before the main disability rights movement, should be considered simply as literature about disability or whether they can be classified according to a more narrowly defined notion of “disability literature”. Recalling earlier debates about flexible definitions of disability as opposed to minority-identity models, some scholars suggest that “disability literature” includes only those texts that actively convey a progressive disability politics. The title of this book, *Literature and Disability*, aims to acknowledge the importance of these debates, but also to suggest that there are a broad range of texts and authors for whom a cultural disability studies perspective can be productive. Even if the texts themselves are problematic when viewed from the perspective of twenty-first-century disability politics, it is possible to read them for their historical value and even for moments of disruption or resistance. *Literature and Disability* engages with theoretical frameworks that have at their centre a sense of solidarity with people with disabilities, a desire to critique ableism, and to explore disability consciousness. The chapter titles highlight questions of genre, including the novel, the short story, and life writing, in order to draw attention to the fact that genre is often overlooked in a disability studies context, but also because disability perspectives can reconfigure the ways in which we think about the form of literary texts as well as their content. Disability can have a defamiliarising effect on the basic categories of identity and of literary criticism, from nationality and normality, to genre and narrative form.

*Literature and Disability* therefore joins other recent cultural disability studies texts in suggesting that disability has the potential to be a transformative critical category for the humanities (Garland-Thomson; Bérubé “Afterword: If I Should Live So Long”; Davidson). In these works, there is a striking sense of disability as an active critical position, one from which a subject might “act” or “theorize”, rather than function merely as a passive object of research (Davis “Introduction” xvii). A key aspect of this is making higher education more accessible for disabled students and academics, as well as promoting and engaging closely with literary works by authors with disabilities. At the same time, we note Georgina Kleege’s objection to “any inference that the mere fact of my disability augments my teaching qualifications or that there is a pedagogical value in exposing my disability to nondisabled students. This practice smacks too much of the freak show and casts me in the role of goodwill ambassador sharing the quaint beliefs and customs of my alien world” (311–12). Following this, the frequent engagement with works by authors with disabilities in this book, including Tomas Tranströmer, Naoki Higashida, Stephen Kuusisto, Simi Linton and Jim Ferris, among others, focuses specifically on the aesthetic qualities and the ethical complexities of the works themselves rather than treating the authors as “native informants” who “explain” their personal experiences of disability to a non-disabled audience.

The location of cultural disability studies, both inside and outside of academic institutions, means that the field is propelled forward by a productive tension between art and activism. Powerful recent cultural examples of this crossover can be found in films such as *Gattaca* (1997) and *Million Dollar Baby* (2004). Following the release of the critically acclaimed *Million Dollar Baby*, activists from the disability rights “Not Dead Yet” campaign protested at university campuses in California and Chicago, objecting to the way in which the film portrays the assisted suicide of a quadriplegic man (Berger 2). This example helps to remind us of the ways in which cultural representations of disability provide a space in which some of the most pressing debates of our day are played out: about assisted suicide, care, neonatal testing, genetic engineering, and body modification. Disability studies returns us to fundamental debates about the boundaries of the human but also, in an age in which these disciplines are increasingly under threat, about how and why we value and practise the humanities.

The book is structured around several key questions which connect across the diverse range of materials covered in the chapters that follow:

- i What is the relationship between activism and art?
- ii How can literature help us to better understand changing relationships between technology and the body?

- iii How do literature and theory represent and challenge ideas of the normal?
- iv What can the study of literature and disability contribute to debates about the value of the humanities?
- v How does the representation of disability change ideas about literary form and metaphor?

Each chapter aims to take up some, or all, of these questions in relation to a specific disability identity and genre, using the close reading of particular exemplary texts in order to illuminate and complicate these discussions. The focus is, primarily, on twentieth- and twenty-first-century literature, and particularly texts that have been produced since the advent of the disability rights movement. The aim, however, is to introduce readers to theoretical frameworks and key figures in the field whose work is valuable for studying other historical periods and for thinking about texts that are not covered in this book. Areas that have often been overlooked in disability studies, such as cognitive impairment and the relationship between literature and life writing, have been afforded the most space in this book. The increasingly global focus of cultural disability studies is reflected in the choice of fictional and theoretical texts from America, the UK, South Africa, India, Japan and Scandinavia, though a greater proportion of the critical writing discussed here is necessarily from Euro-American contexts because that has been the main hub for cultural disability studies work in the academy so far. Through the specific focus on literature and disability, it is hoped that the dynamic and reciprocal relationship between literary criticism and disability theory will come to the fore: each enriches the other, and disability perspectives invite a reconsideration of some of the boundaries and assumptions of traditional literary criticism.

While this book seeks to bring together and showcase the pervasiveness of disability representation in modern and contemporary literature and the richness of the theoretical work that has been produced so far, it also acknowledges that there remain many “publication, curricular and epistemological absences” in the field and a troubling “silence” about disability issues in mainstream literary criticism (Bolt iii; Murray 244). Much remains to be written in this growing field. This book echoes Bérubé’s hope that disability studies will one day be understood as “one of the normal – not normalizing – aspects of study in the humanities, central to any adequate understandings of the human record” (“Afterword: If I Should Live So Long” 343). Literary writing provides an important way into the wider field of disability studies because of its potential to reach diverse populations and to locate narratives of



disability in particular familial and social networks, historical and geographical locations, and political contexts. Fictional works represent disability in a public forum; they invite readers to think about processes of empathy, identification, and the ways in which disability reconfigures our relationship to the materiality of texts and forms literary writing. The study of disability in the context of the humanities is, in itself, a way of resisting the idea that disability is a personal tragedy or a pathologised medical issue. Literary and theoretical writing about disability provides a fresh critical category, access to new forms of knowledge, and a means of examining the narratives through which we give shape and meaning to our lives.

### Further Reading

- Roland J. Berger. *Introducing Disability Studies*. Boulder: Lynne Rienner, 2013.
- Michael Bérubé. "Afterword: If I Should Live So Long." *Disability Studies: Enabling the Humanities*. Ed. Snyder, Sharon L., Brenda Jo Brueggemann, and Rosemarie Garland-Thomson. New York: The Modern Language Association of America, 2002. 337–343.
- Michael Davidson. *Concerto for the Left Hand: Disability and the Defamiliar Body*. Ann Arbor: University of Michigan Press, 2008.
- Lennard J. Davis. *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions*. New York: New York University Press, 2002.
- Anne Finger. *Call Me Ahab: A Short Story Collection*. Lincoln: University of Nebraska Press, 2009.
- Simi Linton. *My Body Politic: a Memoir*. Ann Arbor: University of Michigan Press, 2006.

### Bibliography

- Antonetta, Susanne. *A Mind Apart: Travels in a Neurodiverse World*. New York: Jeremy P. Tarcher/Penguin, 2005. Print.
- Association, Press. "Ministers Accused of Dishonesty over Disability Cuts." *The Guardian*. 30 May 2012. Print.
- Baker, Dana Lee. *The Politics of Neurodiversity: Why Public Policy Matters*. Boulder, Colo.: Lynne Rienner Publishers, 2011. Print.
- Bell, Christopher M. *Blackness and Disability: Critical Examinations and Cultural Interventions*. East Lansing: Michigan State University Press, 2011. Print.
- Berger, Roland J. *Introducing Disability Studies*. Boulder: Lynne Rienner Publishers, 2013. Print.
- Bérubé, Michael. "Afterword: If I Should Live So Long." *Disability Studies: Enabling the Humanities*. Ed. Snyder, Sharon L., Brenda Jo Brueggemann, and Rosemarie Garland-Thomson. New York: The Modern Language Association of America, 2002. 337–343. Print.

- Bérubé, Michael. "Disability and Narrative." *PMLA* 120.2(2005): 568–576. Print.
- Bolt, David. "Introduction." *Journal of Literary & Cultural Disability Studies* 1.1(2007): i–vi. Print.
- Burke, Lucy. "Introduction: Thinking About Cognitive Impairment." *Journal of Literary Disability* 2.1(2008): i–iv. Print.
- Coetzee, J. M. *Slow Man*. New York: Secker and Warburg, 2005. Print.
- Couser, G. Thomas. "Disability, Life Narrative, and Representation." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 2013. 456–459. Print.
- Davidson, Michael. *Concerto for the Left Hand: Disability and the Defamiliar Body*. Ann Arbor: University of Michigan Press, 2008. Print.
- Davis, Lennard J. *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions*. New York: New York University Press, 2002. Print.
- Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995. Print.
- Davis, Lennard J. "Introduction." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 2006. xv–xviii. Print.
- Finger, Anne. *Call Me Ahab: A Short Story Collection*. Lincoln: University of Nebraska Press, 2009. Print.
- Foucault, Michel. *Abnormal: Lectures at the Collège de France*. New York: Picador, 2003. Print.
- Gaedtke, Andrew. "Cognitive Investigations: The Problems of Qualia and Style in the Contemporary Neuronovel." *Novel: A Forum on Fiction* 45.2(2012): 184–201. Print.
- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997. Print.
- Hall, Alice. *Disability and Modern Fiction: Faulkner, Morrison, Coetzee and the Nobel Prize for Literature*. Basingstoke; New York: Palgrave Macmillan, 2011. Print.
- Haraway, Donna. *Simians, Cyborgs and Women: The Reinvention of Nature*. New York: Routledge, 1991. Print.
- Kleege, Georgina. "Disabled Students Come Out." *Disability Studies: Enabling the Humanities*. Ed. Snyder, Sharon L., Brenda Jo Brueggemann, and Rosemarie Garland-Thomson. New York: The Modern Languages Association of America, 2002. 308–316. Print.
- Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York University Press, 1998. Print.
- Linton, Simi. *My Body Politic: A Memoir*. Ann Arbor: University of Michigan Press, 2006. Print.
- McRuer, Robert. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press, 2006. Print.
- Mitchell, David T., and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press, 2001. Print.
- Morrison, Toni, *Beloved: a Novel*. New York: Penguin Books, 2000. Print.

- Murray, Stuart. "From Virginia's Sister to Friday's Silence: Presence, Metaphor, and the Persistence of Disability in Contemporary Writing." *Journal of Literary and Cultural Disability Studies* 6.3(2012): 241–258. Print.
- Nussbaum, Martha Craven. *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge, Mass.: The Belknap Press: Harvard University Press, 2006. Print.
- Ōe, Kenzaburō. *Rouse up O Young Men of the New Age!* 1st ed. New York: Grove Press, 2002. Print.
- Osteen, Mark. *Autism and Representation*. Routledge Research in Cultural and Media Studies. New York: Routledge, 2008. Print.
- Perry, Alex. "Man, Superman, Gunman." *TIME*. 11 March 2013. Print.
- Quayson, Ato. *Aesthetic Nervousness: Disability and the Crisis of Representation*. New York: Columbia University Press, 2007. Print.
- Roth, Philip. "The Novel Is a Dying Animal." 2009. YouTube. Web. 14 March 2011.
- Self, Will. "The Novel Is Dead (This Time It's for Real)." *The Guardian*. 2 May 2014. Print.
- Siebers, Tobin. *Disability Theory*. Ann Arbor: University of Michigan Press, 2008. Print.
- Silvers, Anita, David Wasserman and Mary Mahoward. *Durability, Difference, Discrimination Perspectives on Justice in Bioethics and Public Policy*. Lanham: Rowman and Littlefield, 1998. Print.
- Snyder, Sharon L., and David T. Mitchell. *Cultural Locations of Disability*. Chicago: University of Chicago Press, 2006. Print.
- Snyder, Sharon L., and David T. Mitchell. "Disability Haunting in American Poetics." *The Journal of Literary Disability* 1.1(2007): 1–12. Print.
- Snyder, Sharon L., and David T. Mitchell. "Introduction: Ablenationalism and the Geo-Politics of Disability." *Journal of Literary & Cultural Disability Studies* 4.2(2010): 113–125. Print.
- Stiker, Henri-Jacques. *A History of Disability*. Ann Arbor: University of Michigan Press, 1999. Print.
- White, Peter. *Disability: A New History*. BBC Radio 4. 2014. Radio.
- World Health Organisation. *World Report on Disability*. Geneva, 2011. Print.

## 2 An Introduction to Disability Studies

This chapter traces the activist roots of disability studies and explores its development as a discipline in the late twentieth and early twenty-first centuries. The relationship between different models of disability, particularly the distinction between the social and the medical models, extends debates outlined in Chapter One about the complex and shifting politics of defining “disability”. Resistance to the medical model of disability and the theorisation of an alternative social model underpinned political and social campaigns of the late 1960s, the 1970s and 1980s, and informed legislative changes in the 1990s in the UK, the US, and elsewhere. From the 1980s onwards, disability studies began to gain increasing recognition as an academic field in its own right.

Today, scholars continue to probe the relationship between medical and social models, between activism and intellectual activity, and between “disability as a subject position” and as a location of “academic knowledge-production” (Garland-Thomson “Disability Studies: A Field Emerged” 917). Disability studies is now an established field with its own institutional history; it is a history that is perhaps best conceived of in terms of overlapping waves rather than a straightforward linear progress narrative. The diversity of the field, in terms of disciplinary scope, methodological approaches and cultural range, is at once a strength and challenge: disability studies continues to pose questions that are difficult, complex but also enriching for social policy campaigns, political movements, and engaged academic scholarship in the social sciences and the humanities.

### Early Activism: Social Campaigns and Environmental Barriers

In 1966, Paul Hunt introduced his edited collection, *Stigma: The Experience of Disability*, with a bold declaration: “This is an uncomfortable book” (i). “The problem of disability”, he continued, “lies not only in the impairment of function and its effects on us individually, but

also, more importantly, in the area of our relationship with ‘normal people’” (Hunt 146). This early disability studies text sets out some key questions that dominated activism of the 1960s and 1970s. Hunt distinguishes between his own functional impairment and the social process through which he is disabled by discrimination. The problem, he suggests, lies not in the individual but in their surrounding social environment. The idea of a norm is, he argues, a damaging fiction. Hunt insists upon the importance of raising the profile of disability issues and bringing these concerns, previously conceived of as private medial matters, into the public sphere. This call to make disability more visible is echoed by later texts that similarly combine personal experiences with a strong activist agenda. Simi Linton, for example, insists that: “We have come out, not in those brown wool lap robes over our withered legs, or dark glasses over our pale eyes, but in shorts and sandals...straightforward, unmasked, and unapologetic” (6). Linton’s uncompromising declaration of “coming out” echoes the productive discomfort that Hunt insists upon in his account.

Both Hunt and Linton are part of ongoing campaigns that focus on challenging environmental barriers and building a sense of collective identity for people with disabilities. Hunt, a former resident of the Lee Court Cheshire Home in the United Kingdom, became a founding member of the advocacy organisation, the Union of the Physically Impaired Against Segregation (UPIAS). In the United States, Linton strongly supports campaigns for independent living, calling for disabled people to be liberated from “the institutions that have confined us, the attics and basements that sheltered our family’s shame” (3).

These disability rights campaigns can be traced back to the period after World War II when returning wounded soldiers called for healthcare and compensation for their injuries (Davis “Crips Strike Back: The Rise of Disability Studies” 507). The return of disabled Vietnam war veterans in the United States in the late 1960s and the wider “grand examination” of gender, race and sexuality in the 1970s, added impetus to these campaigns and provided a civil rights model for thinking about disability rights. In the United States, the first major legislation in this area was the Architectural Barriers Act (1968), which required all buildings constructed with federal funds to be accessible to people with disabilities. This legislation, a direct response to the burgeoning Disabled People’s Movement, sought to tackle barriers to access on the most literal, physical level. This language of barriers, and barrier-removal, was also taken up in a more wide-ranging sense by other campaigners in this period. Frank Bowe’s *Handicapping America* (1978), for example, identifies six major barriers to the social inclusion of people with disabilities: architectural, attitudinal, educational, occupational, legal and personal, including

everyday problems ranging from a lack of resources to the stigma of having an impairment.

## The Medical and Social Models

By the late 1980s and the 1990s, these social and political rights-based campaigns and legislative changes had triggered a greater awareness of disability in academic circles. In disciplinary terms, disability had traditionally been the preserve of medicine, psychology, and social work. In the 1980s and 1990s, however, scholars in sociology, social policy, education, cultural studies and the humanities began to draw on recent campaigns and civil rights paradigms in order to put forward an alternative model of disability. Many explicitly defined themselves in opposition to a medical model in which disability was understood as a deficit residing in the individual; they refused to see disability as a pathology or to treat it as a problem that is necessarily in need of cure, rehabilitation or concealment. Instead, activists and scholars put forward a social model, sometimes called the “social-constructionist” model, of disability. This model emphasised the public, structural aspects of disability and highlighted the status of people with disabilities as a historically oppressed group. The social model makes a key distinction between “impairment” and “disability”, summarised by UPIAS in 1976 as:

**Impairment:** Lacking part or all of a limb, or having a defective limb, organ, or mechanism of the body.

**Disability:** The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

(Barnes and Mercer 11)

Under this model, first proposed by Irving Kenneth Zola, impairment is a functional limitation (Davis “Crips Strike Back: The Rise of Disability Studies” 506). Disability, by contrast, is created through a social process: through the relationship between an individual with an impairment and the society in which they live. Society “disables” individuals by excluding or discriminating against them and creating affective, sensory, cognitive or architectural barriers. Put in stark terms, a social model view suggests that wheelchair users might have a mobility impairment, but they are disabled by the lack of provision of ramps and appropriate access facilities. Similarly, a person with a hearing impairment only becomes disabled when no-one else in the room can communicate using sign language.

Erving Goffman's sociological study, *Stigma: Notes on the Management of a Spoiled Identity* (1963), provides an early example of this approach and is often seen as a founding text in disability studies. For Goffman, "stigma" is created through the interaction between a person and their social context, in the relationship between the stigmatiser and the stigmatised. Goffman traces the idea of stigma across a wide period from the ancient Greek practice of physically marking those that society wanted to brand as different, through to discrimination against physical abnormalities in contemporary culture. Goffman's flexible definition of stigmatized people, including the blind, deaf, "crippled", "deformed", "disfigured", "mentally ill", and people with speech impediments, reinforces his argument that stigma is a fluid and historically contingent (128). As a social category and an affective state, stigma can be transferred to different groups at different times, depending on the hierarchies and prejudices of a particular society. This view feeds into later social model thinking: it suggests that disability is not a fixed, essentialised condition located in the individual, but rather a product of the social attitudes and practices of the society that they inhabit.

This social model perspective, adopted against a backdrop of feminist, black and gay rights movements in the 1960s and 1970s, is a powerful weapon in the fight for disability rights. It represented a paradigmatic leap offering a new vision of disability as a topic that could not be dismissed as a minority concern (Goodley 11). For Tom Shakespeare, the articulation of the social model – at once an academic theory and an activist tool – had a complex and wide-ranging impact. It acted, he argues, as a force for change on three levels: through its *political* potential to build a social movement of disabled people; through its *instrumental* power in placing an emphasis on the need for society to adapt to remove barriers; and through a *psychological* shift that facilitated the development of a communal identity among people with very different physical and mental impairments (199).

These socio-political campaigns for barrier removal and anti-discrimination policy contributed to striking legislative changes. In response to pressure from disability activists, for example, The World Health Organisation brought out an official Classification of Impairment, Disability and Handicap (ICIDH) in 1980. This recognised the distinction between "impairment" and "disability", offering a further term, "handicap", defined as a disadvantage, resulting from an impairment or disability, which prevents the fulfilment of a role, depending on age, sex, social and cultural factors (29). The Americans with Disabilities Act (1990), a landmark act that extended the civil rights legislation of 1964 to protect disabled people from discrimination, was widely celebrated as a victory for

campaigns based on the social model of disability. Like the distinction made between impairment and disability, the act acknowledges that “disability depends upon perception and subjective judgement rather than on objective bodily states...The law concedes that being legally disabled is also a matter of ‘being regarded as having an impairment’” (Garland-Thomson *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* 6). This was followed by the Disability Discrimination Acts of 1992 and 1995, in Australia and the UK, respectively. The UK act, since replaced by the Equality Act of 2010, also took its lead from civil rights law and made it illegal to discriminate against disabled people in relation to employment, education, transport and provision of goods and services.

### **The Rise of Disability Studies as a Discipline**

The formation of disability studies as an academic field is intimately bound up with these activist campaigns and social changes. Lennard J. Davis, writing in the introduction to *The Disability Studies Reader* in 2006, emphasises the importance of understanding the formation of the field in historical terms, and in dialogue with other interdisciplinary fields concerned with rights and social justice:

It is not as if disability studies has simply appeared out of someone’s head at this historical moment. It would be more appropriate to say that disability studies has been in the making for many years, but, like people with disabilities, has only recently recognized itself as a political, discursive entity. Indeed, like the appearance of African-American studies following rapidly on the heels of the civil rights movement, there is a reciprocal connection between political praxis by people with disabilities and the formation of a discursive category of disability studies.

(“Introduction” xvi)

This intersectional approach, which views the emergence of disability studies in the 1980s alongside the increasing institutional recognition of fields such as African American studies and Women’s Studies, highlights the very close alliances between activism and academia, particularly in this “first wave” of scholarly work. Garland-Thomson, for example, suggests that the growing cluster of “identity-based fields” in the 1980s including disability studies, “theorized as well as actualized greater inclusion and equality in the academy” (“Disability Studies: A Field Emerged” 916). For Garland-Thomson, academic scholarship is itself a



form of activism. Dan Goodley, writing in 2011, echoes this view of disability studies as an extension of movements that seek to celebrate positive minority identities and protest against discrimination:

Disability culture is rich in creativity and proud slogans of liberation, including “Piss on Pity”, “Disabled and Proud” and “People First”. A key task of disability studies is to tap into these affirmative understandings of the productive impaired body and mind, while examining how disablism is enacted at the level of psyche, culture and society. (10)

This view, in which disablism is “enacted” as a social and psychological process, suggests that in disciplinary terms disability is an important area of concern for education, sociology, social policy, literary and cultural studies, rather than just its traditional disciplinary home of applied health sciences. These interdisciplinary approaches are linked through their commitment to the social model and to privileging the voices of people with disabilities.

The first wave of disability studies was highly politicised and particularly concerned with processes of “recuperation” and “revelation” (Garland-Thomson “Disability Studies: A Field Emerged” 916). Recuperative scholarship sought to trace the often-overlooked history of people with disabilities in history, literature and culture, or to analyse social constructions of disability and ability across time. These works often focused on exposing discrimination and damaging stereotypes in historical settings and past cultural representations while, at the same time, seeking to re-value disability as an important critical category and a positive, collective identity in the present. The sense of revelation lay in the idea that disability was everywhere once you knew how to look for it and in the rich possibilities that disability as an area of study opens up.

The 1980s and 1990s also saw an increasing institutional acceptance of disability studies. In 1982, the Society for Disability Studies was founded in the United States and since then there have been special interest groups established in the Modern Language Association (MLA), the American Anthropological Association (AAA) and the American Educational Research Association (AERA) (Goodley 10). Other networks have been formed in Japan, the UK, Canada, New Zealand and South Africa (see Further Reading below for links to some of these). In the introduction to the first edition of *The Disability Studies Reader*, a defining critical collection in the field published in 1997, Davis proclaimed the “birth” of the discipline. The second edition, published almost a decade later in 2006, documents the rapidly changing nature of the field in the intervening period:

When I wrote the introduction to the *Disability Studies Reader* about ten years ago, I was announcing the appearance of a new field of study...It is gratifying to note that after less than a decade, all that has changed. Disability studies is taught throughout the United States, the United Kingdom, and the world...And disability courses are taught in departments throughout the university. The efforts of many scholars and activists have come to fruition in the birth of a fully legitimate area of study and discussion.

(Davis "Introduction" xiii)

Davis's bold progress narrative for the field acts as a manifesto or rallying call for a very diverse group of scholars and activists. Although the spread of disability studies has been uneven across different countries and disciplines, new levels of institutional, structural support and acceptance since the turn of the millennium have led to a widening of the scope of disability studies to encompass interdisciplinary areas such as law, performance, life-writing, design, bioethics, and material culture. In line with this, methodologies have also diversified to include close readings of texts, ethnographies, archival work, and an engagement with theories of visual culture.

Announcing the theme of "access" at the 2012 Modern Language Association convention, the president Michael Bérubé argued that disability studies could no longer be seen as an emerging field of study. It has, he declared, "emerged!" (Garland-Thomson "Disability Studies: A Field Emerged" 915). In the twenty-first century, interdisciplinary, intersectional understandings of disability studies, as "both an academic field of inquiry and an area of political activity" and a "matrix of theories, pedagogies and practices" raise complex but highly productive questions about the future development of the field (Davis "Introduction" xv; Goodley 10). A recent sub-section of the discipline, "critical disability studies", seeks to address precisely these issues: it recognises and theorises the diversity of disability as "a civil and human rights issue, a minority identity, a sociological formation, a historical community, a diversity group, and a category of critical analysis in culture and the arts" (Garland-Thomson "Disability Studies: A Field Emerged" 917).

### **Beyond Binaries: New Challenges for Disability Theory**

In contemporary disability theory, these diverse definitions of both disability and the field of "disability studies" are coming under scrutiny. Disability historian Paul Longmore understands the history of disability studies in terms of "waves", the first wave being of activism, a struggle

for civil rights culminating in the 1990 Americans with Disabilities Act. The second wave, in which Longmore locates his own work, saw the emergence of disability studies as an academic field that remained closely linked to collective identity and disability culture campaigns. More recently, scholars have suggested that disability theory is entering a third, overlapping wave or phase in which the field has begun to “fissure” around certain key debates (Adams 496).

One of these fissures exists around the dichotomy at the heart of the social model, between “disability” and “impairment”. While recent scholars have acknowledged the political power of the social model as a memorable and striking way of highlighting environmental barriers and the socio-cultural dynamics of disability, they also have begun to critique the limits of social-constructionist perspectives. Scholars such as Mark Osteen have observed the “field’s neo-Cartesian duality – its separation of body from mind, of impairment from disability” (3). For Osteen, the crude separation of the social (disability) from the physical (impairment) has meant that disability studies has, so far, failed to adequately theorise suffering, impairment and pain. There has, of course, been an understandable resistance to medical models of disability that focus predominantly on the body. Yet, this resistance has led, Hughes and Paterson argue, to a strangely “disembodied notion of disability” (330). For these scholars, the intense focus on sociocultural constructions of identity in disability studies has eclipsed important discussions about the physical realities faced by people with physical disabilities.

The social model of disability has also been criticised for the way in which it presents people with disabilities as having minimal agency in their own self-representation (Osteen 3; Shakespeare 201). The social model borrows heavily from Foucault’s understanding of the role of the state in regulating and normalising bodies, through a process of “subjection” and the techniques of biopower such as statistics, demographics, sterilisation and eugenics (Siebers 55). The social constructionist view positions disabled bodies as, to use Foucault’s language, “docile bodies” (Foucault 135); it can be seen to minimise the potential for advocacy, self-representation and resistance through an emphasis on processes of subjection to the overarching powers of the state.

These arguments about the limits of the social model may seem to call into question the scope of the field itself. For Osteen, the failings of the social model have “in short, disabled disability studies” (Osteen 3). Shakespeare suggests that while valuable and important in the past, the social-constructionist model “has now become a barrier to further progress” (202). In fact, these critiques illustrate the power of disability studies to trouble and destabilise even its own most basic assumptions. Scholars

are responding to new challenges: calling for alternative theories of the body, pain and suffering that take account of impairment and forms of embodied knowledge (Shakespeare 200; Siebers 61). At the same time as this call for a return to bodily concerns, there is also an increasing focus on issues of cognitive impairment, an area which has been traditionally side-lined in disability studies (Osteen 3). Focusing on issues of cognitive impairment, such as autism or Down Syndrome, challenges understandings of disability as simply a mismatch between the social environment and an individual's physical impairments. In this context, "disability" might be re-framed: seen not as a damaging social process but instead as an alternative way of being in the world.

Some of the most recent theories of disability have therefore self-consciously rejected splits between mind and body, and between the medical and the social. Instead, they have started from an assumption that "while identities are socially constructed, they are nevertheless meaningful and real precisely because they are complexly embodied" (Siebers 30). This "interactionist" perspective suggests that disability is produced through the interaction between individual bodies and social environments (Shakespeare 201). Drawing on theorists such as Judith Butler and on Foucault's writing on the materiality of bodies, they argue that disability cannot exist apart from, or indeed pre-exist, the linguistic sign systems or social forces that shape our understanding of it (Stiker 14; Siebers 56).

This shift, described by Siebers as being "from social constructionism to the new realism of the body" (Siebers 53), is just one set of perspectives on a rapidly changing and diversifying field. Disability studies continues to be animated by its fissures and the productive tensions between medical, social and interactionist models, and between academic activity and activism. The next chapter takes up some more of these key contemporary debates: about the category of "cultural disability studies", intersectionality, and the relationship between disability studies, gender studies, postcolonial and queer theory.

## Further Reading

- Rachel Adams. "Disability Studies Now." *American Literary History* 25.2 (2013): 495–507.
- Lennard J. Davis, ed. *The Disability Studies Reader*. 4th edn. New York: Routledge, 2013.
- Lennard J. Davis, "Crips Strike Back: The Rise of Disability Studies." *American Literary History* 11.3 (1999): 500–512.
- Rosemarie Garland-Thomson, "Disability Studies: A Field Emerged." *American Quarterly* 65.4 (2013): 915–926.

## 28 *An Introduction to Disability Studies*

- Erving Goffman. *Stigma; Notes on the Management of Spoiled Identity*. Englewood Cliffs, N.J.: Prentice-Hall, 1963.
- Dan Goodley. *Disability Studies: An Interdisciplinary Introduction*. Los Angeles; London: SAGE, 2011.
- Paul K. Longmore. *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple University Press, 2003.
- Joseph Shapiro. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Three Rivers Press, 1994.

### Useful Links

- Society for Disability Studies (USA): <http://www.disstudies.org>
- Disability Studies Association (UK): <http://www.disabilitystudies.net>
- Nordic Network on Disability Research: <http://www.nndr.org>
- Canadian Disability Studies Association: <http://www.cdsa-acei.ca>
- African Journal of Disability*: <http://www.ajod.org/index.php/ajod>
- Disability Studies Quarterly*: <http://dsq-sds.org>
- The Journal of Literary and Cultural Disability Studies*: <http://liverpool.metapress.com/content/121628>

### Bibliography

- Adams, Rachel. "Disability Studies Now." *American Literary History* 25.2(2013): 495–507. Print.
- Barnes, Colin, and G. Mercer. *Disability*. Cambridge, UK: Polity Press, 2003. Print.
- Bowe, Frank. *Handicapping America: Barriers to Disabled People*. 1st ed. New York: Harper & Row, 1978. Print.
- Davis, Lennard J. *The Disability Studies Reader*. 1st ed. New York: Routledge, 1997. Print.
- Davis, Lennard J. "Crips Strike Back: The Rise of Disability Studies." *American Literary History* 11.3(1999): 500–512. Print.
- Davis, Lennard J. "Introduction." *The Disability Studies Reader*. 2nd ed. New York: Routledge, 2006. xv–xviii. Print.
- Foucault, Michel. *Abnormal: Lectures at the Collège de France*. New York: Picador, 2003. Print.
- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997. Print.
- Garland-Thomson, Rosemarie. "Disability Studies: A Field Emerged." *American Quarterly* 65.4(2013): 915–926. Print.
- Goffman, Erving. *Stigma; Notes on the Management of Spoiled Identity*. Englewood Cliffs, N.J.: Prentice-Hall, 1963. Print.
- Goodley, Dan. *Disability Studies: An Interdisciplinary Introduction*. Los Angeles; London: SAGE, 2011. Print.

- Hughes, Bill and Kevin Paterson. "The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment." *Disability & Society* 12.2(1997): 325–340. Print.
- Hunt, Paul. *Stigma: The Experience of Disability*. London, Dublin, etc.: G. Chapman, 1966. Print.
- Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York University Press, 1998. Print.
- Longmore, Paul K. *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple University Press, 2003. Print.
- Osteen, Mark. "Autism and Representation: A Comprehensive Introduction." *Autism and Representation*. Ed. Osteen, Mark. New York: Routledge, 2008. 1–47. Print.
- Shakespeare, Tom. "The Social Model of Disability." *The Disability Studies Reader*. Ed. Davis, Lennard J. 2nd ed. New York: Routledge, 2006. 197–204. Print.
- Siebers, Tobin. *Disability Theory*. Ann Arbor: University of Michigan Press, 2008. Print.
- Stiker, Henri-Jacques. *A History of Disability*. Ann Arbor: University of Michigan Press, 1999. Print.
- WHO. *International Classification of Impairments, Disabilities and Handicaps*. Geneva: World Health Organisation, 1980. Print.

### 3 Literature and Disability

#### The Cultural Model and the Rise of “Literary Disability Studies”

Writing in her 1926 book on cognitive impairment, *The Almosts*, Helen MacMurphy commented:

Sometimes the poet sees more than the scientist, even when the man is playing his own game. The novelist can give a few points to the sociologist, and the dramatist to the settlement worker.

(1)

In the book, MacMurphy calls for a multidisciplinary model of disability that places social sciences and the arts alongside medical understandings. *The Almosts* fuses activism and literary criticism as it calls for better treatment of so-called “feebleminded” people in institutions in the United States in the 1920s. MacMurphy uses examples from fiction such as Dickens’s Tiny Tim, a character narrated entirely from an external perspective, to argue that state authorities and individuals should pay more attention to the interior lives and emotional well-being of people with disabilities living in state institutions. In doing so, MacMurphy highlights a paradox that modern disability studies scholars have only recently begun to respond to: the gap between the prevalence of representations of disability in literature and culture and the social marginalisation of people with disabilities.

In the 1970s and 1980s, disability studies was dominated by social science perspectives, exemplified by the political and sociological focus of some of its leading organisations and publications such as The Society for Disability Studies, and journals including *Disability Studies Quarterly* and *Disability and Society*. It was not until the late 1980s and 1990s that, given a boost by the growth of cultural studies, disability studies was taken up in a sustained way by scholars in the humanities (Davis “Crips

Strike Back: The Rise of Disability Studies” 508–9). Since then, scholars including Rosemarie Garland-Thomson, Lennard Davis, Brenda Brueggemann, David T. Mitchell and Susan L. Snyder have put literature at the heart of their critical examinations of disability and the “normal” body, analysing works by authors with disabilities, cultural works that depict disabled characters, and texts that deal with disability on a level of metaphor. In the UK, David Bolt and Lucy Burke have argued that literary and cultural disability studies is not a marginal “decorative discipline”, but rather a key framework for analysis that contributes significantly to the overall project of disability studies and deserves greater institutional recognition (Goodley 15; Bolt 1). Following Tobin Siebers’s definition of disability studies, literary and cultural texts are seen as providing rich material for analysis, and a humanities training is valued for teaching scholars valuable analytic skills, theoretical frameworks and methodologies:

Disability studies does not treat disease or disability, hoping to cure or avoid them; it studies the social meanings, symbols, and stigmas attached to disability identity and asks how they relate to enforced systems of exclusion and expression.

(*Disability Theory* 4)

This work, sometimes referred to as the “cultural model” of disability, or more specifically “literary disability studies”, is the focus of this chapter. The chapter provides an overview of shifting approaches to literary disability studies and considers some of the key, ongoing debates that bind scholars together: debates about empathy, the status of disability as a metaphor, and the intersections between cultural disability studies and postcolonialism, feminism, gender and queer theory. The cultural model destabilises the traditional distinction between “disability” and “impairment” made by social model theorists. For these cultural critics, social identities and even the materiality of the body cannot pre-exist or be separated off from systems of language and culture (Stiker 14; Siebers *Disability Theory* 2).

Many recent scholars have echoed MacMurphy’s sense that although there has been a proliferation of representations of disability across different cultures and periods, literary and cultural critics have often failed to analyse or even acknowledge the presence of disability. How often, for example, has *King Lear* been discussed with no specific mention of disability? Or, to take more recent examples, how can the significance of the impairments represented in Steinbeck’s *Of Mice and Men* (1937) or Beckett’s *Endgame* (1957) be overlooked? Stuart Murray draws attention



to the persistent representations of disability in modern and contemporary writing (241); David Mitchell, in his Foreword to Stiker's *A History of Disability* (1999), takes a wider, cross-period perspective to suggest that the segregation and marginalisation of disabled people in many societies has coexisted with literary and cultural representations that make "difference into a paramount trope of the human condition" (ix).

The first wave of writing in literary and cultural disability studies therefore focused on revealing and recuperating this wealth of works by disabled authors and intellectuals, and on analysing fictional characters and existing works of literary or cultural theory that engage with disability. Davis, for example, takes a biographical approach to the recuperative project as he asks his readers to consider whether they had ever previously thought of John Milton, Sir Joshua Reynolds, Alexander Pope, Harriet Martineau, John Keats, George Gordon Byron, Henri de Toulouse-Lautrec, James Joyce or Virginia Woolf as disabled. He goes on to retrospectively "claim" some classic works of cultural theory for disability studies, including work by Sander Gilman on disease, David Rothman on asylums, and Leslie Fielder on freaks (Davis "Introduction" xvi–xvii).

This project of identifying disability, rooted in the original activist foundations of disability studies, brings with it a commitment to challenging stereotypes of disability in cultural representations. The recuperative agenda can therefore be seen as having an impulse towards historical revisionism. Scholars have critiqued the ways in which fictional characters with disabilities have so often been invoked as straightforward symbols of evil, exoticism, weakness or ugliness (Garland-Thomson *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* 9). They have identified the ways in which disability is used as a defining trait, as either a "moral index" for the characters themselves, or as a kind of barometer to account for how other characters choose to treat those perceived to be of lesser standing (Bérubé 569–70). This is important cultural criticism that complements and extends social campaigns to change attitudes towards disability. These critics explore recurring stereotypes perpetuated by literary texts and argue that archetypal disability narratives are often misrepresentations which fail to do justice to the complexities of disability as an identity, a way of being in the world, or an embodied, lived experience. Stereotypical narrative scripts have the potential to reinforce ableist conceptions of disability as an absence; disabled characters are, these scholars argue, often used merely as a tool to reveal something about the non-disabled protagonists (Murray 249).

Lennard Davis suggests that this idea of disability functioning merely as a means of illuminating or reinforcing the norm works not only on the level of character, but also at the level of genre and form. He suggests that

the novel is an inherently normative, conservative form which has the potential to directly inform an individual's world view:

I am not saying that novels embody the prejudices of society towards people with disabilities. That is clearly a truism. Rather, I am asserting that the very structures on which the novel rests tend to be normative, ideologically emphasizing the universal quality of the central character whose normativity encourages us to identify with him or her. Furthermore, the novel's goal is to reproduce, on some level, the semiologically normative signs surrounding the reader, that paradoxically help the reader to read those signs in the world as well as the text. The middle-ness of life, the middle-ness of the material world, the middle-ness of the normal body, the middle-ness of a sexually gendered, ethnically middle world is created in symbolic form and then reproduced symbolically.

(“Constructing Normalcy” 11)

Davis views the novel as one of a number of “public venues” in which the “abnormal” is represented in order to bolster hegemonic ideas of the normal in terms of race, class, gender and dis/ability – a theory he refers to as “enforcing normalcy” (“Constructing Normalcy” 12). In particular, Davis makes a compelling case for the “normalcy” of the novel form as a means of reinforcing ideas of the norm in relation to bodies and social identities.

However, this view fails to acknowledge the potentially diverse range of forms of novels themselves and the agency of critics in bringing different critical models of reading to a particular text. While other literary disability studies critics, like Davis, have looked to novels for examples of oppression and misrepresentation, they have also found alternative figures of empowerment that challenge dominant discourses and prejudice. Garland-Thomson's seminal work, *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (1997), for example, celebrates a genre of “black women's liberatory novels” about disability that includes works by Toni Morrison and Audre Lorde (6). Garland-Thomson focuses on figures of resistance such as Eva Peace, a poor African American female amputee who is a mesmerising presence at the centre of Morrison's novel, *Sula* (1973): powerful, sexually attractive and a great storyteller in her own right (*Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* 124).

Reading and analysing cultural texts from a disability studies standpoint can itself be seen as providing a way of disrupting assumptions and critiquing ideology; these critical readings can be productive and

sometimes progressive, even if the fictional texts analysed contain very restricted understandings of disability. Recently, therefore, scholars have sought to qualify and complicate approaches in which literature is used as a tool to either “search for a more ‘positive’ story of disability”, or to “spot” examples of prejudice and injustice (David T. Mitchell and Sharon L. Snyder “Narrative Prosthesis and the Materiality of Metaphor” 212; Murray 249). This is not, they suggest, to deny or ignore the valuable project of documenting and exposing examples of social oppression and the role that literature plays in both reflecting and perpetuating damaging myth-making processes about disability. Rather, it is to push the discipline further, challenging approaches that have tended to treat fictional characters as “real people” or have overlooked the potential for literature to act as a site of resistance or creative re-imagining (Bérubé 570). Murray, for example, acknowledges the “continuous and highly problematic” use of disability in fiction in ways that “emphasize values that negate the presence and meaning of disability” but, at the same time, he looks at other literary writing that generates a sense of the “productive presence” of characters with disabilities (241).

Contemporary critics continue to debate how disability studies, as a discipline that is committed to engaging with the lived experiences and social campaigns led by people with disabilities in the present, can best engage with close textual analysis and theoretical framings of literary works from across different settings and periods. Literary critical language and strategies have informed some of the most ambitious cross-disciplinary work in disability studies. In his *History of Disability*, Stiker places examples from literature alongside historical case studies. The project is, he suggests, best conceived of as a “semiotics of cultures”, which is methodologically rigorous and historically astute precisely because it acknowledges its own status as a constructed narrative of the past, as a “fiction” (Stiker 20; 19). Siebers, whose work sits at the intersection of cultural theory and studies in visual culture, echoes this sense of the importance of thinking about processes of reading in the broadest methodological sense. “Oppression”, he argues, “is driven not by individual, unconscious syndromes but by social ideologies that are embodied, and precisely because ideologies are embodied, their effects are readable, and must be read” (*Disability Theory* 30). For Siebers, focusing on texts and culture does not distract from concerns of material embodied experience; instead, the material, textual, and cultural are all closely interwoven.

This emphasis on productive processes of critical reading, and the potential for some literary representations to offer complex, even radical, non-normative characterisations of disability, has endowed the field with a striking critical energy in recent years and has opened up exciting new challenges. Some of these challenges and key concerns in recent literary

disability writing are introduced below; they also inform the analysis in the chapters that follow.

## Empathy

Debates about the ethics and aesthetics of empathy and the role that literature can play in processes of identification are central to the recent “ethical” or “affective” turn in literary and cultural studies (Attridge; Nussbaum; Keene). These debates take on a particular significance in the context of literary disability studies where terms such as empathy, pity, fear and abjection are highly politicised and hotly contested. These debates are often conceived of in terms of the relationship between reader and text, or between disabled and non-disabled individuals. Sue Halpern, for example, argues that while sympathy is a possibility, “empathy for the disabled is unavailable for most able-bodied persons” because their attempt to project themselves into another condition is always mediated by their knowledge of their own body’s ability (3). Feminist philosopher Susan Wendell takes a similar but subtly different perspective on this debate. She suggests that it is absolutely possible for people to imagine other states of being: “women can identify with a male protagonist in a story”, for example (Wendell 248). But, she argues, disability constitutes a special case: the barrier is not an inability to imagine disability but rather a deep-rooted desire not to do so because of the fear, pity and even revulsion that is often associated with disability in contemporary cultural life. Both Wendell and Halpern share a strong sense of the failure of identification, and particularly the failure of non-disabled people to make the “imaginative leap” into the skins of those who are physically or cognitively different from themselves. While the uneven dynamic of pity is possible, the reciprocal relationship of empathy remains, they argue, unavailable.

By contrast, some literary disability scholars have argued that literature provides a unique location in which imaginative identification may be possible. Mitchell and Snyder do not underplay the difficulty of the task of imaginative identification, but they suggest that narrative can play a key mediating role:

To represent disability is to engage oneself in an encounter with that which is believed to be off the map of “recognizable” human experiences. Making comprehensible that which appears to be inherently unknowable situates narrative in the powerful position of mediator between two separate worlds.

*(Narrative Prosthesis: Disability and the Dependencies of Discourse 5)*

This view suggests that narrative acts as a bridge between individuals. In a later article, Snyder and Mitchell elaborate: “by definition, literature makes disability a social, rather than a medical phenomenon” (“Disability Haunting in American Poetics” 6). Literary narrative allows, they suggest, an “intimacy” with disabled characters that is a “rare exception” amid the social marginalisation of people with disabilities (Snyder and Mitchell “Disability Haunting in American Poetics” 6). These arguments connect to debates outside of disability studies about the ethical value of literary writing, and even the wider value of the arts, as ethically significant “other-directed” acts (Attridge). They draw readers, as well as scholars, into a dialogue about their own role in actively constructing a narrative and the characters within it.

### Disability and Metaphor

The debates about empathy and the focus on the problems and possibilities of narrative as a mediator, a means of understanding an apparently “unknowable” or alien position in terms of something else, are closely linked to debates about the ethics of using disability as a metaphor. If metaphor is understood according to its etymology, as a vehicle for “carrying” meaning from one place to another, then it may itself be seen as a mediating device that has the potential to bridge gaps in empathetic understanding or communication. The use of disability metaphors in literature has, however, been viewed with suspicion by many cultural disability studies theorists. Many “first wave” scholars highlight the tendency for disability to be invoked in literature as an easy metaphorical shortcut: a marker of pity, vulnerability or, less frequently, the heroic “supercrip” (Davis *Enforcing Normalcy: Disability, Deafness, and the Body* 106). They emphasise how distant these metaphors are from the actual lives of disabled people or the embodied experiences of disability. They condemn them for misrepresenting disability and attracting attention away from material concerns. For example, in his seminal essay, “Disability as Metaphor in Literature” (1988), Leonard Kriegel argues that literary representations tend to depict disability as either a source of pity or a threat, and “in the history of Western literature, both before and after Shakespeare, there is little to be added to these two images” (7). Shari Thurber sees the metaphoric use of disability as “a most blatant and pernicious form of stereotyping” (12). The title of Kathleen Tolan’s article for *American Theatre*: “We Are Not a Metaphor: A Conversation about Representation” (2001) encapsulates this wholesale rejection of metaphor.

The most influential theorisation of this resistance to metaphor is found in David T. Mitchell and Sharon L. Snyder’s *Narrative Prosthesis*:

*Disability and Dependencies of Discourse* (2001), which is discussed further in Chapter Four of this book. The concept of “narrative prosthesis” is used to articulate the sense in which disability is used as a shorthand or stand-in to signify stereotypical notions of pity and moral or social disorder. Literary narratives and films, Mitchell and Snyder argue, frequently depend on disability as a device of characterisation; disability is, they suggest, a “crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight” (49). Disability is represented not for its own sake, but is instead used to shore up and stabilise ideas of the normal or to tell readers something about the plot and deepen understandings of central, non-disabled characters. Mitchell and Snyder offer close readings of works of fiction and drama, including Melville’s *Moby Dick* (1851) and Katherine Dunn’s *Geek Love* (1989), in order to create an overarching theory that is, itself, highly metaphorical, despite their condemnation of the use of disability as an “opportunistic metaphorical device” (47).

Nevertheless, the theory of narrative prosthesis provides a powerful framework through which literary disability studies critics have challenged the ways in which disability metaphors are used to aestheticise and depoliticise disability issues. The theory encourages critics to draw attention to metaphors and stereotypical narrative scripts that might otherwise be taken for granted. It invites a close reading of the details of the text in political terms. The theory is also important in the sense that it emphasises the striking presence of disability across literary history on a level of metaphor as well as a level of character.

Recently, however, some scholars have reassessed the ways in which disability has been represented as a metaphor in literary texts, but also the ways in which disability theory itself frequently employs certain metaphors. Vivian Sobchack, for example, discusses the ways in which “prosthesis” has become a strikingly popular critical metaphor; though it is regularly invoked in both disability and postmodern theory, it has remained distant from the material realities of prosthetics (see Chapter Four for a more detailed discussion of this). Garland-Thomson and Michael Bérubé both comment on the ways in which the common resistance to metaphor in disability studies might seem to run counter to the basic impulses and training of literary critics. Garland-Thomson suggests that there is a tendency to read disabled characters “metaphorically or aesthetically” rather than politically, with an emphasis on the ways in which they correspond to “conventional elements of the sentimental, romantic, Gothic or grotesque traditions” (*Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* 10–11). Bérubé takes this observation a stage further, suggesting that to be asked to

reject disability metaphors and figurative readings, seems “queer”, “counterintuitive” and even “incompatible with the enterprise of professional literary study” (570). Disability studies does not, he insists, mark a new era of literalism in literary studies, but rather requires fresh reading strategies that leave space for the interpretation of both the figural and the material presence of disability alongside each other.

These arguments are also taken up by Amy Vidali. She argues that rather than rejecting or “policing” damaging disability metaphors, scholars should engage more closely with theories of metaphor in order to find ways of “working critically, ethically, transgressively, and creatively at the edges of disability metaphor” (51). This approach marks a shift away from a view of disability as a resource to be “used” by authors or critics. Instead, Vidali argues that scholars and artists need to employ a diverse vocabulary in order to actively, “artistically create and historically reinterpret” metaphors of disability (42). This sense of the productive possibilities of disability metaphor has been echoed recently by other contemporary critics. Murray, for example, argues that the idea of “narrative prosthesis” is useful but that it can also be damaging in the sense that it risks limiting the ways in which literature is discussed. Narrative prosthesis, he suggests, has the potential to be reductive because it can lead scholars to overlook the rich variety of literary representations of disability and the creative uses of metaphor that exist alongside material concerns in cultural texts (249).

These recent debates about literary metaphor suggest the vitality of literary disability studies and its increasing scrutiny of the reading practices that are brought to bear on interwoven aesthetics, politics and ethics of disability metaphors. These metaphors deserve critical attention in part because they have social implication in terms of their cumulative effect in shaping cultural discourses and perceptions of disability. Recent scholarship insists that disability metaphors can be productively reinvented and reinterpreted by artists, writers and cultural critics. Metaphors cannot be simply stripped away: they are an integral part of the way in which narratives and even cognitive processes are structured (Lakoff and Johnson).

### **Intersectionality**

Some of the recent work on metaphor, such as Vidali’s article discussed above, considers arguments made in disability studies in relation to philosophy, politics, linguistics, and literary theory. This intersectional approach is a feature of much recent literary and cultural criticism on disability, both at a methodological level and in terms of the models of identity proposed in the criticism. The activist roots of disability studies,

discussed in detail in Chapter Two, mean that the history of the discipline is closely connected to a variety of rights campaigns and, by extension, other interdisciplinary identity-based academic fields.

Rachel Adams traces the history of disability studies back to Irving Zola, a pioneer in the field and founding member of the Society for Disability Studies. Adams highlights the way in which Zola's memoir, published in 1982, describes the study of disability as "an unravelling of a social problem in the manner of *Black Like Me*" ("Disability Studies Now" 496–97). This reference to white journalist John Howard Griffin's account of his journey across America in which he "passed" as an African American man in 1959, underlines Zola's concerns with prejudice, socially constructed identities, and the relationship between writing and activism. It invites direct parallels, for example, between the civil rights campaigns for racial equality in the United States in the 1960s and 1970s and the disability rights movement of the 1980s and 1990s. The disability rights movement has a long history of connections with the civil rights, the women's and trades union movements (Goodley 33). The academic disciplines, such as feminism, queer theory, postcolonial and critical race studies, which came out of these movements and campaigns have given generations of scholars theoretical training that can sensitise them to the intersecting social, political, and cultural concerns of disability studies. Methodologically, this commitment to intersectionality can be seen in recent studies such as Kim Q. Hall's *Feminist Disability Studies* (2011) and Christopher M. Bell's *Blackness and Disability: Critical Examinations and Cultural Interventions* (2011).

In terms of identity, intersectional approaches enable activists and scholars to explore the ways in which individuals who identify themselves as "disabled" will also be raced, gendered, trans/nationally sited, aged, sexualised and classed (Goodley 33). Social oppression is constructed through a complex web of these intersecting identities and cultural conditions. The argument is not that these facets of identity can simply be mapped onto each other, or that the complex histories of very different activist and protest movements can be conflated. Siebers, who in his study *Disability Theory* (2008) maintains a commitment to intersectionality, suggests that the approach is productive precisely because it highlights both points of divergence as well as convergence:

The presence of disability creates a different picture of identity – one less stable than identities associated with gender, race, sexuality, nation, and class – and therefore presenting the opportunity to rethink how human identity works.

(*Disability Theory* 5)



Siebers argues for a reciprocal, mutually enriching relationship between “adjacent fields”. He maintains that disability studies can both draw on and radically transform basic assumptions about identity, ideology, politics, meaning, social justice, and the body in fields such as cultural studies, literary theory, queer theory, gender studies, and critical race studies (*Disability Theory* 1). Siebers’s notion of “adjacency” is useful in that it suggests points of overlap and proximity, whilst allowing different critical approaches to be distinguished from one another.

Susan Schweik also explicitly searches for appropriate and nuanced models of intersectionality in her book, *The Ugly Laws: Disability in Public* (2009). Divided into separate chapters on race, gender, national and ethnic difference, the book examines literal points of intersection, such as the street corners in countless American cities where homeless “unsightly beggars” were forced to take refuge, criminalized and discriminated against through municipal “ugly laws” in the late nineteenth and early twentieth centuries (143). Schweik argues against the use of analogy, such as the idea that a disabled person can be read as “like” an African American. She challenges what she sees as a damaging logic of equivalence that can overemphasise likeness, undermine alliances between social movements, and elide potentially productive intersections (143). Instead, Schweik suggests an alternative term, “confluence”, to suggest a more fluid “as with” model of intersecting differences (143). She considers the ways in which different identities are mutually constitutive, and recognises that a person may identify more strongly with others on the basis of shared race or gender, rather than with people who happen to be assimilated into the diverse, historically and politically contingent category of “disabled”.

Siebers argues that disability has been and still is used as a “lever to elevate debate” in adjacent fields in fresh and productive ways (*Disability Theory* 2). The sections that follow introduce some of the critical intersections work between disability studies and feminism, queer theory and postcolonial studies.

## **Disability and Feminism**

There are striking convergences between feminism and disability studies. Both are rights-based movements that are committed to drawing attention to the power structures and social conventions through which sexism and ableism are reinforced. Intersecting activist agendas have a particular urgency for women with disabilities who are more likely than non-disabled and disabled men to be poor, unemployed, and to experience sexual abuse (Goodley 35). These pressing material questions of injustice

demand a strong connection between activism and scholarly work in both inter-related fields. Diane Price Herndl, for example, suggests that feminist disability studies is defined by the ways in which it “works with and toward feminist disability rights”; she uses analysis of literary and cultural representations, ideology, and public policy in order to further these aims (188). In their important sociological work on women with disabilities, Michelle Fine and Adrienne Asch identify the double negative of female disability, as defined by normalising social expectations: “[e]xempted from the ‘male’ productive role and the ‘female’ nurturing one, having the glory of neither, disabled women are arguably doubly oppressed” (13). Both feminists and disability scholars have used dualistic models of identity in order to highlight the ways in which oppressive roles are socially constructed. Just as early feminists called for a distinction between biological “sex” and cultural assumptions about “gender”, first wave disability scholars often distinguished between physical “impairment” and the socially constructed category of “disability”. More recently, however, theorists such as Judith Butler and Tom Shakespeare have begun to question the possibility of making such a stark distinction between the physical and the social in both fields.

Despite these points of convergence, the aims, agendas and approaches of feminism and disability studies cannot be easily mapped onto each other. Many feminist disability studies scholars have sought to probe the areas in which feminism diverges from a disability studies agenda. In his article, “Disability and the Justification of Inequality in American History”, for example, Douglas C. Baynton highlights the ways in which some suffragettes draw a contrast between non-disabled women and physically and cognitively impaired men as a means of arguing for the vote. More recently, campaigns for equality have often been framed in terms that emphasise ability and the individual autonomy of women. In *The Second Sex* (1952), for example, Simone de Beauvoir asks: “How can a human being in a woman’s situation attain fulfilment? How can independence be recovered in a state of dependency?” (35). By contrast, scholars such as Susan Wendell argue that a collective acknowledgement of mutual interdependency is key to a feminist disability studies approach precisely because of the cultural climate in which “Dependence on the help of others is humiliating in a society which prizes independence” (273). A disability studies perspective here reveals the ways in which traditional arguments about autonomy and independence are often predicated on an assumed, compulsory able-bodiedness.

Feminists have attacked the pathologisation of “female” conditions such as hysteria, premenstrual tension and postnatal depression (Goodley 35). Philosophers such as Iris Marion Young trace a conflation between

femaleness, illness and disability in western thought; women's bodies, like disabled bodies, are frequently understood as lacking, burdensome and fragile (27–45). This rejection of a medicalised view of some bodies as inherently wounded, passive or even deformed, creates a clear link between feminism and disability studies. Yet, in some cases, feminist arguments for women's rights and a more equal understanding of embodiment have relied on ableist discourses that reinforce damaging conceptions of disability. Sami Schalk, for example, closely examines works by leading feminists such as bell hooks and Tania Modleski to suggest that both employ extended disability metaphors in ways that promote an ideology of impairment as a negative form of embodiment. This has led scholars such as Quinlan to suggest that disabled women have, far too often, been silenced and shut out by the feminist mainstream.

A key aspect of feminist disability studies is, therefore, to put the two fields of feminism and disability studies in self-conscious, productive dialogue with each other. Through their shared concerns, feminist disability studies engage with some of the most powerful and significant medical, ethical and cultural debates of our day: about social care, the politics of appearance, normalizing standards of beauty, and reproductive technologies. While some traditional feminist writing already engages with these topics, disability perspectives can transform these debates. How, for example, might a classic feminist pro-choice campaign for the right to have an abortion fit with the widespread objections to prenatal genetic testing among disability activists? How are debates about obesity, genetic engineering and cosmetic surgery re-focused when they are explicitly reconsidered as disability issues? Feminism, in turn, confronts disability studies and activism with its own gaps, such as the tendency to focus campaigns on property rights, employment and changes to the built environment, all of which are areas in which decisions are traditionally dominated by men.

In critical terms, one of the most influential figures in articulating this rich, reciprocal relationship between feminism and disability studies is Rosemarie Garland-Thomson. In an article published in 2005 in the journal *Signs*, Garland-Thomson explicitly sets out to define feminist disability studies as a field. She charts a disciplinary and institutional history of feminist disability studies, dividing it into three waves, “retrievals”, “reimaginings” and “rethinkings” (Garland-Thomson “Feminist Disability Studies” 1560), suggesting a tripartite structure that is reminiscent of Showalter's 1982 account of feminist literary history. “Retrievals” involves searching for writings that might not engage with disability, but that capture disabled experience in some way. The second wave, “reimaginings” incorporates works that directly resist and rewrite oppressive scripts and often includes works by women with disabilities. The third, “rethinkings”, suggests an

intersectional approach that views feminist disability studies in relation to poststructuralism, materiality and phenomenology. Literary critical strategies are central to Garland-Thomson's methodology:

Language about "figuring" and "representing" or "narratives" can dislodge the pervasive notions we all learn about disability and shake up our assumptions about what constitutes happiness, attractiveness, suffering, dignity, or a livable experience. Feminist disability studies thus reveals both the cultural work and the limits of language.

("Feminist Disability Studies" 1559)

Garland-Thomson suggests that literary representations feed directly into cultural perceptions of disability; she is highly attuned to the power of literary criticism to carry out important social and political work by highlighting the socially constructed nature of disability as a set of representations, narratives or figures. In this context, Garland-Thomson uses close readings of literary and cultural texts to challenge conventional deterministic disability metaphors and scripts such as the biomedical, sentimental, or catastrophe narrative ("Feminist Disability Studies" 1568). At the same time, she acknowledges the potential for new forms of cultural production, including literary writing, to offer re-readings and re-writings of disability. This sense of the potential for literary critical perspectives to "re-frame" disability is also exemplified in Kim Q. Hall's edited collection, *Feminist Disability Studies* (2011), in a section titled "Refiguring Literature".

A commitment to the close reading of both literary texts and images is central to much recent work in feminist disability studies. Garland-Thomson's *Extraordinary Bodies*, and her later book, *Staring: How We Look* (2009), use close reading strategies to introduce another key area of intersection and interest in the field: the visual politics of appearance and its interaction with ideas about beauty. Disability and feminism offer vantage points from which normalising, regulatory practices to do with looking and appearance can be scrutinised: for example, the "westernizing" of Asian eyes, the use of leg braces to "correct" scoliosis, the use of breast prostheses after surgery for breast cancer, or the stapling of stomachs. Feminist disability historians have explored these contemporary practices in the context of earlier beauty norms and histories of display. In *Sideshow USA: Freaks and the American Cultural Imagination* (2001), for example, Adams recuperates the history of the display of "freaks" at sideshows and circuses in the nineteenth and twentieth centuries and argues that the freak show has enjoyed a disturbing resurgence in contemporary America. In *Extraordinary Bodies*, Garland-Thomson takes a similar cross-period

approach, drawing implicit parallels between the case of Saartje Baartman, the South African so-called “Hottentot Venus” displayed in nineteenth-century Europe for her shapely buttocks and sexual organs, and the damaging white beauty ideals that are explored in African American author Toni Morrison’s novel, *The Bluest Eye* (1970). These and other examples illustrate the ways in which certain forms of bodily display reinforce narrow sets of ideas about beauty, at once fetishising and denigrating disability and difference.

This concern with beauty norms and the display of female disabled bodies underpinned debates about Marc Quinn’s statue, *Alison Lapper Pregnant* (2005), the image of which is used on the cover of the third edition of *The Disability Studies Reader* (2010). First unveiled in Trafalgar Square in London in September 2005, the sculpture is a portrait of Alison Lapper, naked and pregnant. The image of Lapper, an artist born without arms and with shortened legs, is sculpted in smooth, white marble; the statue measures over 3 metres tall and 13 tons in weight. This uncompromising display of a naked, pregnant disabled body in public provoked uproar in the British media, where it was dismissed as “repellent”, “political correctness gone mad”, and a subject matter that “falls short of being art” (Simon; Moulard; Jones). This initial negative response has since been countered by a feminist disability studies discourse that specifically seeks to read the statue in terms of its aesthetic, as well as political, value (Millett-Gallant; A. Hall). In historical terms, the statue highlighted the often unrecognised prevalence of disability in aesthetic works; Lapper’s portrait was, for example, displayed diagonally opposite the disabled war hero, Lord Nelson, a permanent fixture in Trafalgar Square. For Millett-Gallant, the statue acted as an “anti-monument”, subverting the significance of neo-classical ideals of wholeness and heroism in the sense that it represents an alternative to traditional subjects of public monuments (51–83).

The debate about Quinn’s statue connects to other cultural disability studies analyses that seek to read art history from a different perspective: as Siebers asks, “Would the *Venus de Milo* still be considered one of the great examples of both aesthetic and human beauty if she still had both her arms?” (*Disability Aesthetics* 65). Siebers uses his analysis to argue for a “disability aesthetics” that fundamentally challenges the normalised definitions of beauty in terms of “harmony, bodily integrity and health as standards of beauty” (*Disability Aesthetics* 71–71). Feminist disability studies perspectives, which seek to balance material, aesthetic and political concerns, therefore pursue a recuperative agenda of historical “retrieval”, but also provide productive approaches for rethinking and re-reading social settings, cultural representations, critical theories and normalising discourses in the present.

## Queer Theory

In her essay in the *Plaintext* collection (1986), feminist critic Nancy Mairs names and claims her identity as a “cripple” (9). Self-consciously evoking a “wince” from non-disabled people, she declares that “as a cripple”, “I swagger” (Mairs *Plaintext: Essays* 9). Mairs suggests that there is something productive, transgressive and powerful about her off-kilter position. By combining feminist and disability approaches and subjectivities, she takes a unique perspective, proposing a “feminist sitpoint theory” as opposed to a more conventional, situated feminist standpoint theory (*Waist-High in the World: A Life among the Nondisabled*). Mairs’s physical disability is at once material and metaphorical here: it is an embodied reality for her as an individual and a critical metaphor that she uses to articulate her intersectional theoretical approach.

In adopting this position, Mairs recuperates and appropriates the word “cripple” in the same way that gay and lesbian activists have reclaimed the word “queer”. In both cases, the traditionally negative associations are rewritten as transgressive, empowering identities. Moreover, “crip” and “queer” are used not only to describe individual identities, but they are also invoked as verbs to describe a critical process. “To crip” or “to queer” is to question and to subvert dominant cultural expectations about heteronormativity and/or able-bodiedness in fresh new ways. This appropriation of and sensitivity to different forms of language, including the language of prejudice, abuse and political correctness, is central to these approaches and to the creation of a new critical vocabulary. Literary and cultural texts also provide the material through which these fluid critical approaches are explored and articulated, such as in Robert McRuer’s queer theory analysis of the film *As Good as it Gets* (1997), or Barounis’s article on “cripping heterosexuality” and “queering able-bodiedness” in the films *Murderball* (2005) and *Brokeback Mountain* (2005).

McRuer, a leading exponent of queer theory, argues that there is a clear alliance between queer theory and critical disability studies: “queering entails rejecting cultural devaluation and reshaping heterosexist norms, and claiming disability entails bringing out the multiple differences that are compelled to pass under the sign of the same” (96–97). Despite a parallel history of oppression and pathologisation, the powerful intersections between queer theory and disability studies have not, until recently, been considered. This is even more surprising given that, McRuer suggests, disability is often seen as a form of feminised “queerness” and there has been a frequent conflation of disability and queer identities.

Like disability studies, queer theory emerged from an activist movement, particularly the HIV and LGBT rights movements. Concepts of “passing” can be applied in both contexts and “coming out” narratives, in which an identity is positively claimed, offer another important point of intersection, encapsulated in examples such as Eli Clare’s memoir, *Exile and Pride: Disability, Queerness and Liberation* (1999). Ellen Samuels argues that we should not try to escape the analogy between disability and “queerness” but that it requires close critical analysis (318). Through his critical approach, McRuer establishes what he describes as a “parallel” and an “alliance” between the two fields, but at the same time he suggests that straightforward analogical thinking is problematic. He echoes the wider suspicion of metaphor in disability studies in his assertion that while both movements should remain “attuned to how queerness and disability are metaphorized”, “queers and people with disabilities should insist, inflexibly, that we will not serve as metaphors for each other” (McRuer 98–99).

In addressing the relationship between disability and sexuality, McRuer, Clare, Barounis and others challenge a cultural taboo about acknowledging the sexualisation of disabled bodies and subjects. Crip theory and queer theories are concerned with the politics of visibility in the sense that they privilege discussions of topics and people who are often overlooked; they share a resistance to the perception of white non-disabled heterosexual masculine identities as simply transparent. In this sense, queer theory draws strongly on what Lennard Davis has termed “normalcy studies” as a field of scholarship complementary to “disability studies”. Queer theory explores and exposes the ways in which definitions of heterosexuality and able-bodiedness, just like whiteness, maleness and normalcy, are inextricably bound up with, and dependent upon, the reinforcement of certain ideas of the homosexual, disabled, racial and gendered otherness. “To queer” is, therefore, to actively disrupt “the performance of able-bodied sexuality” but also to theorise the intersections between disability and homosexuality (McRuer 373).

The language of identity and performance used in queer theory draws directly on other gender studies writing, particularly Judith Butler’s *Gender Trouble* (1990). Butler’s work contains within it the idea of a productive critical process of “troubling” dominant binary assumptions about gender which is akin to “queering” or “cripping”. These dialogues between disability studies, gender studies, feminism and queer theory illustrate the ways in which the fields overlap but can also radically reformulate one another. The challenge to “compulsory able-bodiedness” is at the centre of queer theory as it seeks to expose the ways in which being non-disabled is seen as a default, “invisible” identity; it draws on

Adrienne Rich's feminist critique of "compulsory heterosexuality", made in her 1986 collection, *Blood, Bread and Poetry*. McRuer extends Rich's concept to suggest that the status of 'able-bodiedness' as a naturalised identity is even more deeply embedded than assumptions about heterosexuality as the norm. For feminists, queer and disability theorists, this interaction between different identities and critical positions is often both uneasy and productive, providing as it does a transgressive critical platform from which social expectations can be subverted and new cultural identities are rewritten.

### Disability and Postcolonial Theory

Disability studies and postcolonial studies share a concern with silenced populations. Since the 1990s, disability theorists have emphasised the ways in which disability issues have been left out of mainstream political discourses and academic criticism, just as people with disabilities have often been socially marginalised (Shakespeare *Disability Rights and Wrongs*; Bolt; Garland-Thomson *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*). Similarly, Toni Morrison's cultural critique, *Playing in the Dark: Whiteness and the Cultural Imagination* (1992), suggests a "paucity of critical material", stemming from a parallel history of racial discrimination: "in matters of race, silence and evasion have historically ruled literary discourse". In a postcolonial context, the issue of silence and voicelessness, specifically the problem of narrating experiences or theorising from a marginalised, colonised subject position are raised by Gayatri Chakravorty Spivak's famous challenge: "Can the subaltern speak?"

Critical race studies, postcolonial criticism, and disability theory have begun to address some of these silences. Despite the fact that these fields have remained largely separate until recently, the borrowing of language and metaphors between them is striking. In postcolonial writing, images of wounded and impaired bodies proliferate. Frantz Fanon, for example, in *Black Skin, White Masks* (1952), describes in highly physical terms the process of objectification that he experiences under colonialism:

In the company of the white man who unmercifully imprisoned me, I took myself far off from my own presence...and made myself an object. What else could it be for me but an amputation, an excision, a haemorrhage that spattered my whole body with black blood?

(112)

Amputation figures here as a symbol of the loss of identity and agency, but also as a striking reminder of the material history of the physical and



psychological violation of colonised black populations. Elleke Boehmer points out that the “silenced and wounded body of the colonized is a pervasive figure in colonial and postcolonial discourses”, while Ashcroft, Griffiths and Tiffin take a cross-cultural view to suggest that “the body has ... been the literal ‘text’ on which colonization has written some of its most graphic and scrutable messages” (Boehmer 268; Ashcroft 290). As in Fanon’s work, disabled, colonised bodies are figured here as passive objects or texts, inscribed with violence, damaged by dominant discourses.

Postcolonial theory informs the critical language and frameworks of disability theory, often as a means through which the ethical and aesthetic challenges of “speaking for others” are brought to the fore (Alcoff). In some cases, this is primarily a matter of using shared language and concepts. The title of Leonard Kriegal’s 1969 essay, for example, suggests an easy equivalence between race and disability: “Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro”. Harlan Lane in *The Mask of Benevolence: Disability and the Deaf Community* (1992), draws parallels between the narration of “native” experience by colonial rulers and the ways in which deaf people often find themselves spoken for by the mainstream hearing establishment. Other disability theorists draw more explicitly on postcolonial theory as a guiding framework for their analysis. Barker and Murray, for example, engage with Said’s notion of “democratic criticism” in their theorisation of disability in contemporary postcolonial fiction (219). And Tom Shakespeare cites Fanon, Edward Said and Albert Memmi in his discussion of care as a potentially invasive relationship that replicates the unequal power dynamics of the colonial/“native” relationship (*Help*).

These shared metaphors and theoretical frameworks clearly relate to parallel and intersecting histories of the social, economic, cultural and physical oppression of colonised and disabled peoples that cannot be ignored. The experience of cultural imperialism is, according to Anita Ghai’s definition, one that connects those who have and who continue to be discriminated against on the basis of race, disability, national or ethnic identity: “[it] means to experience how the dominant meanings of society render the particular perspective of one’s group invisible at the same time as they stereotype one’s group and mark it out as other” (40). In Europe and the United States, people with disabilities and people from ethnic minorities were displayed alongside each other as examples of human oddity and exoticism in nineteenth- and early twentieth-century freak shows (Rachel Adams; Garland-Thomson *Freakery: Cultural Spectacles of the Extraordinary Body*). In the twentieth century, people with disabilities, foreigners and non-white populations were all judged to be physically and intellectually inferior according to the pseudo-scientific

logic of eugenics (A. Hall). In the Global South, exploitation and cultural imperialism associated with racism and colonial legacies co-exist with higher rates of impairment in poorer, formerly colonised countries. A larger proportion of disabled people live in the Global South; Goodley cites this number as 400 million (between 66 and 75 per cent of disabled people depending on the source of the statistics) (39). Helen Meekosha, a global disability theorist, suggests that a “multiplicity of phenomena” cause this, including “war and civil strife, nuclear testing, the growth of the arms trade, the export of pollution to ‘pollution havens’ and the emergence of sweatshops” (667). In many cases, therefore, colonised and disabled identities intersect, not only as a critical metaphor for thinking about the experience of colonialism or disability, but also in terms of actual embodied experiences, specific material conditions, and debates about economic and political injustices.

There is, however, a danger that this intertextual borrowing between disability theory and postcolonial studies conflates important debates in both fields, even perhaps leading to an over-emphasis on disability as a metaphor that can eclipse shared material histories of discrimination and injustice. Mark Sherry, Clare Barker and Stuart Murray, for example, all argue that although the “rhetorical connections” between disability studies and postcolonial theory are undeniable, the relationship between the two fields has not yet been theorised in a way that does justice to its complexities (Sherry 10; C. Barker 219). Christopher Bell, in his collection *Blackness and Disability: Critical Examinations and Cultural Interventions* (2011), argues that disability studies criticism is overly focused on white bodies as the model for the archetypal disabled body. Similarly, postcolonial and critical race theory rarely engage explicitly with disability and, by failing to do this, they implicitly reinforce a model of independent, self-supporting citizenship based on a non-disabled vision of the wider body politic. When they do address each other, Sherry argues, disability and postcolonial conditions are treated merely as metaphors for each other, “rhetorically employed as a symbol of the oppression involved in a completely different experience” (10).

In the literary domain, Murray identifies a tendency for postcolonial critical readings to “simply *reinforce* the prosthetic uses of texts”, using them “only in a manner that fetishizes disability in seeking to ‘explain’ postcolonial cultures” (*JLCDS* 253). A key literary example of this tendency is the critical response to the character of Friday in J.M. Coetzee’s novelistic re-writing of Defoe’s *Robinson Crusoe* (1719), entitled *Foe* (1986). Friday, a silent and apparently tongue-less African slave, acts as an absent presence at the centre of the text. The presence of Friday as a character has generated a variety of readings among postcolonial critics: Friday has

been interpreted as a metaphor for silenced populations in Apartheid South Africa, as a visual reminder of the unspeakable history of slavery, and as a symbol of the ethical challenges of speaking from a subaltern subject position. Yet, as some disability theorists have pointed out, these highly metaphorical readings of Friday in postcolonial criticism often fail to engage with the material presence and embodied knowledge of Friday as a physically disabled figure at the centre of the text (Quayson; A. Hall; Murray).

These criticisms suggest that the complex relationship between postcolonialism and disability theory not only requires greater attention, but also that a close analysis of this dynamic could radically transform key assumptions and critical models in both fields. Scholars working at the intersection of postcolonial and disability theory suggest that a postcolonial perspective can help to “globalise” disability studies and to challenge universal models of identity. Michael Davidson, in a chapter entitled “Universal Design”, argues that definitions of “normalcy” need to be understood as culturally contingent and fluid according to time period and geographical location (168–96). Meekosha critiques the Euro-American bias of disability studies and radically challenges the tendency for scholars to assume that capitalist conceptions of citizenship developed for the Global North are applicable to populations in the Global South (667). Barker and Murray suggest that in order to “decolonise” disability studies, scholars need to move away from the implied universalism of the “modelling” that dominates the field at present, and particularly the straightforward investment in the social model, so that the focus can be more specifically on the nuances of cultural difference (225). All of these scholars remind readers that there is not a clear line between impairment and disability: what it means to be disabled is flexible and determined by specific social and political contexts. Postcolonial perspectives can therefore help to challenge the binary between disabled and non-disabled that is entrenched in some disability theory, and to highlight the ways in which an individual’s impairments may be seen radically differently, indeed perhaps not as a disability at all, depending on the community in which they live.

The call to globalise disability studies by extending it beyond Euro-American settings and universalised models leads, paradoxically, to a return to the local. This theoretical move towards a focus on the cultural *location* of disability has been a feature of some humanities-based disability theory for a while (Snyder and Mitchell *Cultural Locations of Disability*). In postcolonial theory, sensitivity to disability issues is increasing but remains quite rare. In recent years, a greater number of texts have sought to combine approaches, for example, in works such as Anita Ghai and Renu Addlakha’s multicultural approach to disability studies in India, Patrick Devlieger’s analysis of disability in African proverbs,

and Swartz's autobiographical account of whiteness and non-disabled experience in South Africa.

In literary studies, one of the most influential books to emerge in this area is Ato Quayson's *Aesthetic Nervousness: Disability and the Crisis of Representation* (2007), which adopts a comparative approach to engaging with representations of disability in Irish, African American, South African and Nigerian literature. For Quayson, the texts from these disparate settings are connected by the ways in which they exhibit a form of "aesthetic nervousness". He argues that this unease functions primarily at the level of character, but it also permeates the form of the text and the reader/text relationship: disability brings about a "crisis" in representation that "short-circuits" representation itself (Quayson 15). Other recent works that engage with postcolonial theory and disability, such as Barker's *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality* (2011), explicitly challenge this view of a "crisis" in disability representation. Her book, which reads literature from colonial and postcolonial settings including Nigeria, India, Zimbabwe and Māori New Zealand alongside each other, focuses on the everyday experiences and empathetic representations of disability (20). In this context, the disabled body is shifted from being a passive text written on by a critic with a predetermined agenda or by the hegemonic discourses of society, to become an active subject position from which theorising and creative re-imaginings of disability can take place.

Debates about disability and postcoloniality therefore encapsulate a key set of issues that underpin disability studies. For Quayson, disability is associated with loss, trauma and oppression: a crisis of language, social marginalisation and an "interpretive difficulty or impasse" (14). Barker and Murray, by contrast, seek to go beyond a tradition of literary disability analysis that identifies "prosthetic" metaphors and pinpoints oppressive forms of representation (219). In doing so, there is a danger that yet another framework, this time of the positive and politically progressive disability narrative, is mapped onto complex and often contradictory texts drawn from radically different time periods and settings yet grouped together under the label "postcolonial". As Meekosha suggests, "the experience of colonisation and colonialism in the global South was both disabling and devastating for the inhabitants...Yet the agendas of disability pride and celebration in the metropole may appear to stand in stark contrast to the need to prevent mass impairments in the global South" (667). The desire to celebrate disability as a positive identity, or to read a progressive political message into certain texts may, she argues, conflict with the need to recognise and act upon histories of violence and current material injustices.

For Meekosha, this clash of models and the failure to take account of the Global South represents “an intellectual crisis of disability studies on the periphery” (667). Yet, these tensions between celebratory identity-based models of disability, and those that seek to campaign against disabling forms of oppression, are productive in the sense they both unsettle and energise contemporary social, political and academic debates. The intersection between postcolonial, race and disability theories offers a welcome diversification of disability studies, calling into question fixed models of identity and citizenship on both sides. It also opens up materialist, context-specific approaches to analysis that insist on the importance of ordinary details, everyday experiences and situated perspectives. These approaches resist the usual trajectory of reading from the metropolitan centre to the periphery, emerging instead from distinct local settings and offering an opportunity for the field to open up to new populations and to challenge and disrupt its own assumptions as it grows in the future.

## Conclusion

Discussions about the ethics of empathy and the politics of disability metaphor are divided into separate sections in this chapter but they extend across and connect to the concerns of literary disability criticism, feminism, queer theory, critical race and postcolonial theory. Despite the debates and divergences between different approaches, all disability theory and criticism shares a commitment to raising the profile of disability issues and to exploring the complexities of disabled experience. However, the main purpose of this chapter has been to probe critical intersections, analogies and tensions between disability studies and other theories and models of identity. Because of its often close ties to sociology, psychology and politics, disability theory in the humanities is driven by a need to think in interdisciplinary ways and to continually question its own parameters and its social, cultural and political value. The history of criticism in these fields contributes to an understanding of the complex roots of disability studies. But it also suggests the ways in which cross-disciplinary conversations have enriched and reciprocally developed disability studies and other adjacent fields. As the field of disability studies grows, cross-disciplinary connections with newer critical fields, such as ecocriticism, memory studies, medical and digital humanities, are also becoming increasingly productive.

At times, the so-called “linguistic turn” in disability studies, towards the humanities, may be seen to have distracted attention away from direct political campaigns in the last two decades, encouraging scholars to focus instead on abstract theoretical approaches in which issues of

embodiment are overlooked or lost in a maze of linguistic signification (Siebers *Disability Theory* 2). Yet, the analysis of literary and cultural texts has contributed significantly to the understanding of politics, aesthetics, ethics and social attitudes towards disability that has emerged. Theoretical work can offer perspectives that actively challenge and reformulate understandings of some of the key questions of our age about global citizenship, knowledge production, discrimination, notions of the normal, genetic testing and social care.

Theorists writing in the literary domain share a marked sense of the critical potential of the field. For Davis, disability perspectives have the power to invigorate the whole field of literary theory and criticism:

The study of literature, literary history, and theory have only begun to fall under the sway of disability studies. The grotesque, the gaze, the dialogic, visual theory, the law, and so on – all are beginning to be broached by interrogations of disability. The exciting thing is the emergence of a whole new field in literary studies at the moment when many felt there was nothing new under the hermeneutic sun. The survival of literary studies may well belong not to the fittest, but to the lame, halt, and the blind, who themselves may turn out to be the fittest of all.

(“Crips Strike Back: The Rise of Disability Studies” 510)

Theories of gender, sexuality, race and postcoloniality all call into question naturalised identities and expose the fluid and culturally constructed nature of the boundaries of the normal. Sometimes seen from the outside as a peripheral – as yet another sub-genre in a growing list of identity studies – disability theory in fact has the potential, as Siebers suggests, “to transform critical and cultural theory all over again” (*Disability Theory* 3). Whereas Garland-Thomson positions herself as a critic at the margins, moving towards the centre: “I probe the peripheral so as to view the whole in a fresh way” (*Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* 5–6), for Davis, literary analysis of disability representations challenges the basic centre/peripheral binary: “Over time many scholars have come to see the ‘them’ of these identity studies is ultimately the social collectivity of ‘us’ ... Seeing what appears to be a narrow subject expand to include almost all of literary studies” (“Crips Strike Back: The Rise of Disability Studies” 500).

Davis’s critical commentary on the rise of disability studies was written on the eve of the millennium. The chapters that follow seek to convey a sense of the critical energy and the diversity of literary and cultural theories of disability in a twenty-first-century context, exploring current theoretical

debates and specific literary examples with particular reference to questions of genre and in dialogue with the frameworks and critical perspectives introduced in this chapter.

### Further Reading

- Clare Barker and Stuart Murray. "Disabling Postcolonialism: Global Disability Cultures and Democratic Criticism." *Journal of Literary and Cultural Disability Studies* 4.3 (2010): 219–236.
- Michael Bérubé. "Disability and Narrative." *PMLA* 120.2 (2005): 568–576.
- Lennard J. Davis. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995.
- Rosemarie Garland-Thomson. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997.
- Michelle Fine and Adrienne Asch. *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Philadelphia: Temple University Press, 1988.
- Kim Q. Hall. *Feminist Disability Studies*. Bloomington: Indiana University Press, 2011.
- Diane Price Herndl. "Politics and Sympathy: Recognition and Action in Feminist Literary Disability Studies." *Legacy: a Journal of American Women Writers* 30.1 (2013): 187–200.
- Helen Meekosha. "Decolonising Disability: Thinking and Acting Globally." *Disability and Society* 26.6 (2011): 667–682.
- David T. Mitchell and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press, 2001.
- Stuart Murray, "From Virginia's Sister to Friday's Silence: Presence, Metaphor, and the Persistence of Disability in Contemporary Writing." *Journal of Literary and Cultural Disability Studies* 6.3 (2012): 241–258.
- Robert McRuer. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press, 2006.
- Mark Sherry. "(Post)Colonising Disability." *Wagadu* 4 (2007): 10–22.

### Bibliography

- Adams, Rachel. *Sideshow U.S.A: Freaks and the American Cultural Imagination*. Chicago: University of Chicago Press, 2001. Print.
- Adams, Rachel. "Disability Studies Now." *American Literary History* 25.2(2013): 495–507. Print.
- Addlakha, Renu. *Disability Studies in India: Global Discourses, Local Realities*. New Delhi: Routledge India, 2013. Print.
- Alcoff, Linda Martín. "The Problem of Speaking for Others." *Cultural Critique* 20(1991–1992): 5–32. Print.
- Ashcroft, Bill, Gareth Griffiths and Helen Tiffin, ed. *The Postcolonial Studies Reader*. London: Routledge, 2005. Print.

- Attridge, Derek. *The Singularity of Literature*. London; New York: Routledge, 2004. Print.
- Barker, Clare. *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality*. Basingstoke; New York: Palgrave Macmillan, 2011. Print.
- Barker, Clare and Stuart Murray. "Disabling Postcolonialism: Global Disability Cultures and Democratic Criticism." *Journal of Literary and Cultural Disability Studies* 4.3(2010): 219–236. Print.
- Barounis, Cynthia. "Crippling Heterosexuality, Queering Able-Bodiedness: *Murderball*, *Brokeback Mountain* and the Contested Masculine Body." *The Disability Studies Reader* Ed. Davis, Lennard J. ed. New York: Routledge, 2013. 381–397. Print.
- Baynton, Douglas C. "Disability and the Justification of Inequality in American History." *The New Disability History: American Perspectives*. Ed. Longmore, Paul K., and Lauri Umansky. New York: New York University Press, 2001. 33–57. Print.
- Beauvoir, Simone de. *The Second Sex*. New York: Vintage Books, 1974. Print.
- Bell, Christopher M. *Blackness and Disability: Critical Examinations and Cultural Interventions*. East Lansing: Michigan State University Press, 2011. Print.
- Bérubé, Michael. "Disability and Narrative." *PMLA* 120.2(2005): 568–576. Print.
- Boehmer, Elleke. "Transfiguring: Colonial Body into Postcolonial Narrative." *Novel: A Forum on Fiction* 26.3(1993): 268–277. Print.
- Bolt, David. "Introduction: Literary Disability Studies in the UK." *Journal of Literary and Cultural Disability Studies* 3.3(2009): 1–4. Print.
- Butler, Judith. *Gender Trouble: Feminism and the Subversion of Identity*. New York: Routledge, 1990. Print.
- Clare, Eli. *Exile and Pride: Disability, Queerness, and Liberation*. Cambridge, MA: SouthEnd Press, 1999. Print.
- Davidson, Michael. *Concerto for the Left Hand: Disability and the Defamiliar Body*. Ann Arbor: University of Michigan Press, 2008. Print.
- Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995. Print.
- Davis, Lennard J. "Crips Strike Back: The Rise of Disability Studies." *American Literary History* 11.3(1999): 500–512. Print.
- Davis, Lennard J. "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century." *The Disability Studies Reader*. Ed. Davis, Lennard J. 2nd ed. New York: Routledge, 2006. 3–16. Print.
- Davis, Lennard J. "Introduction." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 2006. xv–xviii. Print.
- Davis, Lennard J. *The Disability Studies Reader*. 3rd ed. New York: Routledge, 2010. Print.
- Devlieger, Patrick. "Frames of Reference in African Proverbs on Disability." *International Journal of Disability, Education and Development* 46.4(1999): 439–451. Print.
- Fanon, Frantz. *Black Skin, White Masks*. London: Pluto Press, 1993. Print.



- Fielder, Leslie A. *Freaks: Myths and Images of the Secret Self*. New York: Simon and Schuster, 1978. Print.
- Fine, Michelle, and Adrienne Asch. *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Philadelphia: Temple University Press, 1988. Print.
- Garland-Thomson, Rosemarie. *Freakery: Cultural Spectacles of the Extraordinary Body*. New York: New York University Press, 1996. Print.
- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997. Print.
- Garland-Thomson, Rosemarie. "Feminist Disability Studies." *Signs: Journal of Women in Culture and Society* 30.2(2005): 1557–1587. Print.
- Garland-Thomson, Rosemarie. *Staring: How We Look*. Oxford; New York: Oxford University Press, 2009. Print.
- Ghai, Anita. *(Dis)Embodied Form: Issues of Disabled Women*. New Delhi: Shakti Books, 2003. Print.
- Gilman, Sander. *Disease and Representation: Images of Illness from Madness to Aids*. Ithaca: Cornell University Press, 1988. Print.
- Goodley, Dan. *Disability Studies: An Interdisciplinary Introduction*. Los Angeles; London: SAGE, 2011. Print.
- Hall, Alice. *Disability and Modern Fiction: Faulkner, Morrison, Coetzee and the Nobel Prize for Literature*. Basingstoke; New York: Palgrave Macmillan, 2011. Print.
- Hall, Kim Q. *Feminist Disability Studies*. Bloomington: Indiana University Press, 2011. Print.
- Halpern, Sue. "Portrait of the Artist: A Review of *Under the Clock* by Christopher Nolan." *The New York Review of Books*. 1988: 3–5. Print.
- Herndl, Diane Price. "Politics and Sympathy: Recognition and Action in Feminist Literary Disability Studies." *Legacy: A Journal of American Women Writers* 30.1(2013): 187–200. Print.
- Jones, Jonathan. "Bold, Graphic but Bad Art." *The Guardian*. 16 March 2006. Print.
- Keene, Suzanne. *Empathy and the Novel*. Oxford: Oxford University Press, 2007. Print.
- Kriegal, Leonard. "Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro." *The American Scholar* 38.3(1969): 412–430. Print.
- Kriegel, Leonard. "Disability as a Metaphor in Literature." *Kaleidoscope* 17(1988): 6–14. Print.
- Lakoff, George, and Mark Johnson. *Philosophy in the Flesh: The Embodied Mind and Its Challenge to Western Thought*. New York: Basic Books, 1999. Print.
- Lane, Harlan L. *The Mask of Benevolence: Disabling the Deaf Community*. 1st ed. New York: Knopf, 1992. Print.
- MacMurphy, Helen. *The Almosts: A Study of the Feeble-Minded*. Boston: Houghton Mifflin, 1926. Print.
- Mairs, Nancy. *Plaintext: Essays*. 1st ed. Tucson: University of Arizona Press, 1986. Print.

- Mairs, Nancy. *Waist-High in the World: A Life among the Nondisabled*. Boston: Beacon Press, 1996. Print.
- McRuer, Robert. "As Good as It Gets: Queer Theory and Critical Disability." *GLQ: A Journal of Lesbian and Gay Studies* 9.1–2(2003): 79–105. Print.
- Meekosha, Helen. "Decolonising Disability: Thinking and Acting Globally." *Disability and Society* 26.6(2011): 667–682. Print.
- Millett-Gallant, Ann. *The Disabled Body in Contemporary Art*. 1st ed. New York: Palgrave Macmillan, 2010. Print.
- Mitchell, David T. and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press, 2001. Print.
- Mitchell, David T. and Sharon L. Snyder. "Narrative Prosthesis and the Materiality of Metaphor." *The Disability Studies Reader*. Ed. Davis, Lennard J., 2nd ed. New York: Routledge, 2006. 205–216. Print.
- Morrison, Toni. *Playing in the Dark: Whiteness and the Literary Imagination*. Cambridge, Mass.: Harvard University Press, 1992. Print.
- Morrison, Toni. *The Bluest Eye*. 1st Knopf ed. New York: Knopf: Distributed by Random House, 1993. Print.
- Mouland, Bill. "Nelson Looks Down as Statue of Disabled Mother Is Unveiled in the Rain." *The Daily Mail*. 16 September 2005. Print.
- Murray, Stuart. "From Virginia's Sister to Friday's Silence: Presence, Metaphor, and the Persistence of Disability in Contemporary Writing." *Journal of Literary and Cultural Disability Studies* 6.3(2012): 241–258. Print.
- Nussbaum, Martha Craven. *Poetic Justice: The Literary Imagination and Public Life*. Boston, Mass.: Beacon Press, 1995. Print.
- Quayson, Ato. *Aesthetic Nervousness: Disability and the Crisis of Representation*. New York: Columbia University Press, 2007. Print.
- Quinlan, K., L. Bowleg, and S. Faye Ritz. "Virtually Invisible Women: Women with Disabilities in Mainstream Psychological Theory and Research." *Review of Disability Studies* 4(2008): 4–17. Print.
- Rich, Adrienne. *Blood, Bread, and Poetry: Selected Prose, 1979–1985*. 1st ed. New York: Norton, 1986. Print.
- Rothman, David J. *The Discovery of the Asylum: Social Order and Disorder in the New Republic*. Piscataway: Aldine, 2009. Print.
- Samuels, Ellen. "My Body, My Closet: Invisible Disability and the Limits of Coming Out." *The Disability Studies Reader*. Ed. Davis, Lennard J., New York: Routledge, 2013. 316–332. Print.
- Schalk, Sami. "Metaphorically Speaking: Ableist Metaphors in Feminist Writing." *Disability Studies Quarterly* 33.4(2013). Print.
- Schweik, Susan M. *The Ugly Laws: Disability in Public*. New York: New York University, 2009. Print.
- Shakespeare, Tom. *Help*. Birmingham: Venture Press, 2000. Print.
- Shakespeare, Tom. *Disability Rights and Wrongs*. New York: Routledge, 2006. Print.
- Shakespeare, Tom. "The Social Model of Disability." *The Disability Studies Reader*. Ed. Davis, Lennard J., 2nd ed. New York: Routledge, 2006. 197–204. Print.

- Sherry, Mark. "(Post)Colonising Disability." *Wagadu* 4(2007): 10–22. Print.
- Showalter, Elaine. *A Literature of Their Own: British Women Novelists from Brontë to Lessing*. London: Virago, 1982. Print.
- Siebers, Tobin. *Disability Theory*. Ann Arbor: University of Michigan Press, 2008. Print.
- Siebers, Tobin. *Disability Aesthetics*. Ann Arbor: University of Michigan Press, 2010. Print.
- Simon, Robin. "Alison Lapper, the New Icon of Trafalgar Square." *The Evening Standard*. 15 September 2005. Print.
- Snyder, Sharon L., and David T. Mitchell. *Cultural Locations of Disability*. Chicago: University of Chicago Press, 2006. Print.
- Snyder, Sharon L., and David T. Mitchell. "Disability Haunting in American Poetics." *The Journal of Literary Disability* 1.1(2007): 1–12. Print.
- Sobchack, Vivian. "A Leg to Stand On: Prosthetics, Metaphor and Materiality." *The Prosthetic Impulse: From a Posthuman Present to a Biocultural Future*. Ed. Smith, Marquard and Joanna Morra. Cambridge, MA: MIT Press, 2005. 17–41. Print.
- Spivak, Gayatri Chakravorty. "Can the Subaltern Speak?" *Colonial Discourse and Postcolonial Theory: A Reader*. Ed. Williams, Patrick and Laura Chrisman. New York: Columbia University Press, 1994. 66–111. Print.
- Stiker, Henri-Jacques. *A History of Disability*. Ann Arbor: University of Michigan Press, 1999. Print.
- Swartz, Leslie. *Able-Bodied: Scenes from a Curious Life*. Cape Town: Zebra Press, 2010. Print.
- Thurber, Shari. "Disability and Monstrosity: A Look at Literary Discourses of Handicapping Conditions." *Rehabilitation Literature* 41.1(1980): 12–15. Print.
- Tolan, Kathleen. "We Are Not a Metaphor: A Conversation About Representation." *American Theatre* (2001): 17–21, 57–59. Print.
- Vidali, Amy. "Seeing What We Know: Disability and Theories of Metaphor." *JLCDS* 4.1(2010): 33–54. Print.
- Wendell, Susan. "Towards a Feminist Theory of Disability." *The Disability Studies Reader*. Ed. Davis, Lennard J., 1st ed. New York: Routledge, 1997. 260–278. Print.
- Young, Iris Marion. *On Female Bodily Experience: "Throwing Like a Girl" and Other Essays*. Oxford: Oxford University Press, 2005. Print.

## 4 Physical Disability and the Novel

Scholarship on physical disability has dominated literary and cultural disability studies so far. Brenda Jo Brueggemann points out that physical disability is “the category that most people imagine when they think of ‘disability’” (12) and, in everyday life, the image of the wheelchair remains the most frequently used symbol of disability in all of its diverse forms. Although disability studies scholars and activists have argued for an understanding of disability as a social, political and cultural identity, rather than a fixed set of physical characteristics, in a literary context, imaginary works that deal with highly visible physical disabilities have remained at the centre of disability studies criticism. Founding critical works in the field have taken wide-ranging historical perspectives on representations of physical disability in literature. For example, Diane Price Herndl’s *Invalid Women* (1993) explores works between 1840 and 1940 and Rosemarie Garland-Thomson’s *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (1997) draws examples from mid-nineteenth- to late twentieth-century literature.

There has been a focus on the novel form in disability studies scholarship. This can be attributed in part to the “recuperative” project discussed in the previous chapter: the desire to establish the significant presence of disability in some of the most canonical and celebrated literary writing, from Swift’s *Gulliver’s Travels* (1726) to Dickens’s *A Christmas Carol* (1843), Brontë’s *Jane Eyre* (1847) and Toni Morrison’s *Sula* (1973). Altschuler describes Melville’s *Moby Dick* (1851), for example, as the “ur-text” of American cultural disability studies criticism (264).

More recent scholarly works have modified their critical focus to look, in some cases, beyond Euro-American contexts or at narrower historical timeframes and specific sub-genres of the novel. For example, Michael Bérubé has suggested that science fiction is a genre “as obsessed with disability as it is with space travel and alien contact” (568), and Ria Cheyne takes up a text that is frequently written about in science fiction

scholarship, Anne McCaffrey's *The Ship Who Sang* (1969), and reads it through an explicitly disability studies framework, focusing on the ways in which it reinforces ableist ideologies and addresses contemporary ethical debates about euthanasia. Clare Barker and Siobhan Senier have explored Indian, Zimbabwean, Nigerian, Pakistani and Native American novels through the lens of disability. Senier's work on Aids-related novels by indigenous people in North America connects discourses of "rehabilitation", discussed later in this chapter, to the culturally specific and multi-layered understandings of "reservations" in Native American texts such as Tomson Highway's *Kiss of the Fur Queen* (1998). The intersection between physically disabled and ageing bodies has also provided a rich vein in recent fiction and in theoretical and literary critical work, as the undeniable significance of disability issues in greying twenty-first-century societies is brought to the fore (Wendell 263; Siebers 60; Small).

This chapter introduces some of the key debates in relation to physical disability and the novel, including various theories of "narrative prosthesis" and several moments that scholars have identified as significant turning points in the literary and cultural history of physical disability. The chapter argues that disability is not only significant on a level of character and theme but that it can transfigure understandings of both the history of the novel and contemporary theoretical accounts of the form. As Davis argues, disability perspectives can provide a rich and productive way of thinking about *all* novels, even those that do not explicitly represent impairment ("Constructing Normalcy" 12). The chapter ends with a discussion of J.M. Coetzee's *Slow Man* (2005), a novel written and set in Australia by a South African author. This discussion of *Slow Man* is used to illuminate some recent debates about care, dependency and materiality.

## Historicising Disability and the Novel

Tracing early examples of physical disability in literature is a topic fraught with debates about the definition of the novel and of disability itself. Literary scholars have understood the history of disability in the novel according to a number of significant turning points. Arguing for a more nuanced and historically specific approach to disability in literary history, Altschuler suggests that extraordinary bodies "began to make their way into the American novel after 1815", after the end of the War of 1812 (260). The absence of impaired bodies in pre-1815 American fictional works was not, she argues, because of any lack of people with disabilities in society; indeed, in an age before institutionalisation, disability would have been part of everyday social life. Representations of

disability did not, Altschuler suggests, suit the generic conventions and political purposes of the American novel in the pre-1815 period in the United States. With their didactic and overtly political forewords and footnotes, the early-national novel did not need to “route its social and political critique through disability” (Altschuler 246). When impaired bodies did begin to enter works of fiction in the 1810s and 1820s, they were more often a source of pride and patriotism rather than stigmatisation. In this sense, Altschuler takes up the example of a particular national literary tradition in order to argue against universal claims made in some disability studies scholarship that literary representations always use disability as a “master trope of human disqualification” (Mitchell and Snyder 3). Instead, she suggests, disability representation, like the form of the novel, is fluid, uneven, and tied to idiosyncratic local contexts and national histories.

Lennard J. Davis also focuses on the nineteenth century as a transitional moment in the history of disability representation in the novel. For Davis, the turning point came with the introduction of the statistical concept of the “norm” which entered the English language in 1855, and led to a paradigm shift towards ideas of normalcy in the period 1840–1860 (“Constructing Normalcy” 3). The novel is, for Davis, a social construction that arose as part of the project of middle-class hegemony, alongside democracy, ableism and industrial capitalism (*Enforcing Normalcy: Disability, Deafness, and the Body*). Drawing on Foucauldian scholarship on eighteenth- and nineteenth-century culture in Europe, he suggests that this was a period obsessed with categorising, measuring and reinforcing ideas of the norm through statistics, eugenics, demographics and fiction. “For example”, Davis writes, “most characters in nineteenth-century novels are somewhat ordinary people who are put in abnormal circumstances, as opposed to the heroic characters who represent the idea in earlier forms such as the epic” (“Constructing Normalcy” 11). In this context, he suggests that disability is used by novelists in an instrumental way, to tell readers something about the “average” protagonist. Once the character with disabilities has played this role, they are quickly removed in order to re-establish control over disruptive, unruly bodies and enact a triumph of normality at the end of the novel. It is, Davis suggests, necessary to represent the abnormal in public forums such as the novel in order to reinforce a sense of the norm through a process of negation.

This is not, however, merely a question of character and theme. Instead, Davis suggests that the form of the novel itself promotes and symbolically produces normative structures:

I am asserting that the very structures on which the novel rests tend to be normative, ideologically emphasizing the universal quality of

the central character whose normativity encourages us to identify with him or her. Furthermore, the novel's goal is to reproduce on some level, the semiologically normative signs surrounding the reader, that paradoxically help the reader to read those signs in the world as well as the text. The middleness of life, the middleness of the material world, the middleness of the normal body, the middleness of a sexually gendered, ethnically middle world is created in symbolic form and then reproduced symbolically.

(“Constructing Normalcy” 11)

Somewhat paradoxically, this insistence on “middleness” can only be shored up through the creation and fictional representations of groups deemed “abnormal”, such as people with disabilities, “natives” and colonised subjects. This view of the novel as an inherently conservative and normative form has been challenged by some scholars recently through readings of particular texts as sites of resistance to these norms (Hall; Senier). It is, nevertheless, a powerful theoretical paradigm in the sense that it uses a disability perspective to make a statement about *all* novels in that Davis suggests that even in texts that do not appear to be about disability, the issue of normalcy is a structuring principle.

This sense of the novel as a normalising force is also articulated by Rosemarie Garland-Thomson in her seminal work, *Extraordinary Bodies*. Like Altschuler and Davis, Garland-Thomson roots her analysis in a very specific set of cultural and historical conditions, this time to do with the visibility of disability in the United States from the mid-nineteenth to early twentieth century. Garland-Thomson draws on the history of the freak show and the beauty pageant as interconnected locations in which exclusionary, polarised beauty ideals were displayed and reinforced. She draws a direct line between these spectacles and literary representations: “Like *tableaux vivants*, beauty pageants, and freak shows – all related forms of representation grounded in the conventions of spectacle – literary narratives of disability usually depend on the objectification of the spectacle that representation has created” (12). Garland-Thomson suggests that there is a direct and mimetic relationship between literature and social attitudes towards disability: “Stereotypes in life become tropes in textual representation” (11). This is, in part, a means of arguing for the importance of literary writing and literary criticism as a valuable repository in which social attitudes towards disability can be made visible, and therefore be used in support of disability rights campaigns and activism.

However, like Susan Schweik, Garland-Thomson is also interested in historical moments at which disability was hidden from the public gaze. The so-called “Ugly Laws” or “Unsightly Beggar Ordinances” in the United

States, for example, legislated to control the rights of “any person who is diseased, maimed, mutilated, or in any way deformed” to occupy public spaces between the 1860s and the 1970s (Schweik 4). This public and legal refusal to see the disabled was accompanied by the gradual decline in public displays of “freaks”; it formed part of a wider shift towards institutionalisation, medicalisation and the segregation of people with disabilities. In the same period, when disability was becoming less visible in public places and in spectacles, representations of impairment became hyper-visible in novels. Garland-Thomson argues that the sensationalised, fetishising gaze of the freak show became transposed into narrative form: “literary texts...necessarily make disabled characters into freaks, stripped of normalizing contexts and engulfed by a single literary trait” (11). In the context of this analysis, the questions posed by novels are ethical, aesthetic and highly topical: dilemmas about how to look at disabled bodies on the level of character, but also through formal choices such as narrative style and perspective. Novels provide a space in which both the desire to look, and to look away, can be satisfied within the same safely delineated fictional framework.

### **Narrative Prosthesis**

In a twentieth-century context, these debates about normalising gazes and the visibility of disability were crystallised in discussions of rehabilitation and prosthetics. Henri-Jacques Stiker, in his wide-ranging *History of Disability* (1999), suggests that the 1920s marked an important turning point in the social and cultural history of physical disability. The end of the First World War saw huge numbers of injured and physically impaired soldiers returning from battle and trying to re-assimilate into their communities. This sudden increase in the visibility of disability in everyday life was, Stiker argues, met by a new conception of rehabilitation. This “integrationist ideal” was distinct from existing medical conceptions of cure: “Cure is a removal and relates to health. Rehabilitation is situated in the social sphere and constitutes replacement for a deficit” (Stiker xii; 124). According to this deficit model of rehabilitation, disability is a lack that needs to be covered up and made to disappear. The widespread development of prosthetics in the same period represented a “technology of absorption” that was part of the same desire to restore injured men to an non-disabled ideal, or at least to sustain a fantasy of completion in the public sphere (Stiker 164). In *Replaceable You: Engineering the Body in Postwar America* (2004), David Serlin argues that this expansion of the prosthetics industry sought to prop up both injured male bodies and a damaged national economy. Gary Albrecht’s *The Disability Business:*



*Rehabilitation in America* (1992) also emphasises these interconnections between capitalist imperatives to be economically self-supporting and discourses of physical capability.

These debates about rehabilitation, reintegration and the complex role of prosthetics were also examined in a boom of fictional writing about disability after the First World War. Disabled war veteran novels such as William Faulkner's *Soldier's Pay* (1926) and Dalton Trumbo's *Johnny Got His Gun* (1939), describe shattered bodies and minds using experimental, fragmented narrative forms. Faulkner's short narrative sketch, "The Leg" (1934), displays this fascination with war veterans through an engagement with prosthetics that is rendered in both viscerally physical and richly symbolic terms. Like Trumbo's novel, "The Leg" begins with a wounded First World War soldier lying in a hospital bed in the darkness:

And my nights were filled too, with nerve- and muscle-ends chafed now by an immediate cause: the wood and leather leg. But the gap was still there, and sometimes at night, isolated by invisibility, it would become filled with the immensity of darkness and silence despite me.  
(Faulkner 311)

Here, Faulkner's narrator conveys a powerful impression of disorientation and physical discomfort, related from a claustrophobic first-person perspective. Yet, in the story the narrator also hints at the multi-layered metaphorical significance of David's prosthetic leg. This sense of the symbolic potential of prosthesis connects to the insistence in Stiker's historical account that "prosthesis is not only the pieces of wood, iron, now plastic that replace the missing hand or foot. It is also the very idea that you can *replace*...Replacement, re-establishment of the prior situation, substitution, compensation – all of this now becomes possible language" (123–24). In "The Leg", Faulkner puts these assumptions about physical and linguistic substitution under scrutiny. Just as David, Faulkner's narrator, describes the physical challenges of adapting to his prosthesis, the leg comes to symbolise the difficulties of narrating psychological loss and the impossibility of a return to his prior bodily or mental state. David's prosthesis becomes, paradoxically, a symbol for all that is absent and irreplaceable in this surreal story: his leg, his memory, his former identity, and his dead companion George.

This richly figurative power of prosthesis, alongside its material importance and presence in war narratives of the twentieth century, has led to a proliferation of critical works that engage with "prosthesis" as a theoretical concept as well as a fictional construction. Tim Armstrong's *Modernism, Technology and the Body: A Cultural Study* (1998) puts

forward the concept of “Prosthetic Modernism”. Marquand Smith and Joanna Morra’s collection, *The Prosthetic Impulse: From a Posthuman Present to Biocultural Future* (2006), explores the “point of prosthetic contact – and the dialectic of the edges in such contact” in order to think about ways in which the prosthetic is integral to understandings of the human (7). Donna Haraway, in her “Cyborg Manifesto” suggests that “Prosthesis is semiosis...the making of meaning and bodies, not for transcendence but for power-charged communication” (277). In these studies, prosthetics are considered in largely metaphorical terms as a means of thinking through the relationship between modernity, technology, the body, and shifting definitions of the human.

In cultural disability studies scholarship, this figurative use of prosthetics has often been criticised for the ways in which it fetishises prosthetics and distances discussions from embodied, material experiences (Siebers 63; Sobchack). Vivian Sobchack in her essay, “A Leg to Stand On”, suggests that she is both “startled” and “amused” by the prominence of prosthetics in contemporary cultural criticism. She challenges the notion prosthetics should be read as “sexy” or “exotic” (19; 32). Sobchack’s work takes a first-person perspective in order to explicitly challenge the tendency for prosthetics to be narrated from an external perspective, as a rhetorical or poetic figure “located *elsewhere*”; instead, she suggests that these “parts” become, in her experience, incorporated into an individual’s body (20). Like many of the recent works on prosthesis in disability studies scholarship, including David Wills’s *Prosthesis* (1995) and Mark Jeffreys’s “The Visible Cripple (Scars and Other Visual Displays Included)” (2002), Sobchack’s work fuses various genres and draws upon her own autobiography, in this case her experience of using a prosthetic leg, as a means of introducing and complicating her critical insights.

Sobchack denounces the “scandal of the metaphor” of prosthesis as an “unfleshed-out” catchword in contemporary cultural theory (21). Yet, disability scholarship also regularly invokes prosthesis in metaphorical terms. In one of the most influential theories of literature and disability, David T. Mitchell and Sharon L. Snyder put forward the idea of “narrative prosthesis”. They argue that disability is “a crutch upon which literary narratives lean for their representational power, disruptive potentiality and analytic insight” (49). This means that literary writing necessarily depends upon disability, using it as a “stock feature of characterisation” and an “opportunistic metaphorical device” (Mitchell and Snyder 47). As in Davis’s theory of the novel, Mitchell and Snyder therefore view literary representation as necessarily normative and conservative. They argue that disabled characters shore up normalcy in a narrative; they are temporarily invoked as figures of tragedy, disruption or

deviance but then, once they have fulfilled this one-dimensional function, they are rapidly removed from the narrative frame in order to allow for the restoration of a newly reinvigorated sense of normality at the end. In this context, disability representation or characterisation is never *about* disability, it is always a quick metaphorical shortcut to convey social disorder or a means of telling readers something about the main, non-disabled protagonists. For Mitchell and Snyder, therefore, prosthesis becomes a key term for thinking about narrative structure, even when it is not actually present in narratives about disability: “Our notion of narrative prosthesis evolves out of this specific recognition: a narrative issues to resolve or correct – to ‘prostheticize’ in David Wills’s sense of the term – a deviance marked as improper to a social context” (53).

Here, Mitchell and Snyder set up a dialogue with Wills’s *Prosthesis*, a theoretical text that also focuses on the ideological assumptions about deviancy contained within the concept of prosthesis and the underlying desire to erase difference by encouraging a kind of “passing”. “Prosthesis” is, for Wills, “inevitably about belonging” (15). Mitchell and Snyder suggest that there is a sharp distinction between the physical and the textual: “While an actual prosthesis is always somewhat discomforting, a textual prosthesis alleviates discomfort by removing the unsightly from view” (8). Wills, by contrast, revels in the fluid movement between literal and metaphorical understandings of prosthesis in his lyrical, playful and experimental writing that is at once highly personal – “a narrative of a father’s stance” – and highly theoretical: a “critical posture” (9). Both critical texts share a concern with the “prosthetic relation of body to word”, as an “artificial contrivance” and an “imperfect supplement” (Mitchell and Snyder 8). For Snyder and Mitchell, this dynamic is explored by way of a literary analogy, through an example from *Moby Dick*:

“Reality” is merely an effect of the duplicity of language, a false leg that cannot quite replace the lost original. In this way, Ahab’s prosthetic leg serves doubly as both the organizing trope of the novel’s myriad substitutions and the mechanism of the obsessive captain’s own undoing.

(12)

This widening of the definition of prosthesis, to use it as a way of talking about processes of linguistic substitution and as a metaphor for literary forms, also extends into the area of technology. For Wills, the act of writing itself reminds us of our prosthetic relationship to language and to technologies: “One cannot simply write about prosthesis when one is automatically, just by virtue of writing, writing prosthesis, entering into

prosthetic relations, being prosthetic” (30). His highly metatextual, self-reflexive theoretical writing therefore paradoxically returns readers to the materiality of their bodies, reading or writing in the present moment. As human beings become increasingly dependent upon digital and communication technologies, bodily modifications and enhancements, and medical interventions, prosthesis emerges as an important concept for theorising the relationship between bodies, technologies and their cultural representations.

### Care, Dependency and Coetzee’s *Slow Man*

These theoretical debates about metaphor and processes of linguistic substitution have led some scholars to warn that the body, the starting point for discussions of prosthetics, is paradoxically sometimes at risk of becoming absent from theoretical accounts of physical disability (Sobchack; Siebers; Jeffreys). Jeffreys, for example, acknowledges that the focus on social constructionism in disability studies has been a “liberation epistemology” in activism, but there is a danger of an “erasure of the body by culture” if we invest too heavily in the idea that “the body that is a fiction cannot be false or falsely represented, all representation being equally fiction” (33). This has led to a turn back towards “a new realism” of the body for some disability scholars. Siebers, a leading proponent of this perspective, suggests that the desire to celebrate disability and to provide a counter-narrative that challenges dominant ideas of passivity and dependency can lead to a problematic level of theoretical abstraction:

Pain is most often soothed by the joy of conceiving the body differently from the norm. Frequently, the objects that people with disabilities live with – prostheses, wheelchairs, braces, and other devices – are viewed not as potential sources of pain but as marvellous examples of the plasticity of the human form or as devices of empowerment ... Rare is the theoretical account where physical suffering remains harmful for very long. The ideology of ability requires that any sign of disability be viewed exclusively as awakening new and magical opportunities for ability.

(62–63)

In his novel *Slow Man*, Coetzee offers not a theoretical, but rather a fictional account that is deeply concerned with the physical, with the representation of pain, and with how a “realism” of the body might work in terms of literary writing and form. Coetzee’s narrator, Paul, is involved in a road accident on the very first page of the book. The

accident is related from an intimate first-person perspective in visceral detail, and then re-played again and again over the course of the novel: “What”, Paul asks, “do you think life has consisted in ever since Magill Road but being rammed into the physical day after day?” (Coetzee *Slow Man* 235). Following what he describes as “the gross butchery of amputation”, Paul experiences his own body as “a lump of all too solid flesh” (Coetzee *Slow Man* 99; 198). He is plagued by a sense that his body is “too solid” and inflexible yet, at the same time, cannot escape a sense of its fragile vulnerability and missing parts.

*Slow Man* can be seen as a book about the process of becoming disabled. In her memoir about her life as a disability rights activist, Simi Linton describes this process of becoming disabled as distinct from the moment at which she became impaired:

The new shape and formation of my body were set on that April day; the meaning this new body would have for me took years to know...The injury was a sudden cataclysmic event, and the paralysis in my legs was instant. Becoming disabled took much longer.

(3)

*Slow Man* refuses to conform to the narrative template of a progress narrative that moves towards either assimilation or the awakening of a progressive political consciousness. With shocking physicality, Paul describes how part of his own body was reduced to waste after the accident: “You anaesthetised me and hacked off my leg and dropped it in the refuse for someone to collect and toss into the fire” (Coetzee *Slow Man* 10). This discourse of waste seeps into the imagery of the novel, such as in Paul’s conception of his life as “a waste”, and time itself as “like a wasting disease...gnawing away at him, devouring one by one the cells that make him up” (Coetzee *Slow Man* 10; 12). This cultural conflation of disability, dependency and waste is, itself, a recycled intertextual reference from Samuel Beckett’s play, *Endgame* (1957): Paul is one of “four people in four corners, moping, like tramps in Beckett, and myself in the middle, wasting time, being wasted by time” (Coetzee *Slow Man* 141). This web of intersecting references to waste also provides an indirect critique of the ways in which definitions of citizenship often exclude people with disabilities; to use Nussbaum’s terms, Paul’s situation disrupts the “idealising fiction” of an average citizen capable of “fully cooperating ... over a complete life” that is at the centre of traditional social contract theory (141).

Instead, *Slow Man* explores the complex dynamics of care in a twenty-first-century, Australian context. Following his accident, Paul receives professional care from a hired immigrant nurse, Marijana, and

informal offers of care from Elizabeth Costello. He differentiates carefully between these different caring roles: “We do not need love, old people like us. What we need is care: someone to hold our hand now and then when we get trembly...Care is not love. Care is a service that any nurse worth her salt can provide, as long as we don’t ask for more” (Coetzee *Slow Man* 154). Once again, Paul’s reductive readings – including his dualistic, almost Cartesian split between love and care, between body and mind – are complicated and undermined by the action of the narrative. As the novel progresses, Paul becomes sexually attracted to Marijana and is increasingly embroiled in the politics of her family life.

In this way, *Slow Man* pits different understandings of care against each other. These debates are also articulated in a recent wave of writing about care and care ethics in contemporary feminist and disability theory. Eva Feder Kittay and Ellen K. Feder suggest that, as in Coetzee’s novel, conceptions of care and dependency go well beyond the physical: “the notion of dependency leaves the relatively narrow domain of caring labour that is associated with the fulfilment of basic needs and enters a wider social domain in which our social dependencies become important in the constitution of our identities” (4). In this context, dependency becomes relevant to all human identities. Davis also suggests that considering “care of the body” reveals the ways in which all bodies in a consumer society are deemed incomplete in some sense: “the contemporary body can only be made completed by means of consumption” (*Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions* 27). He insists on a “dismodernist ethics” that is based on a multidimensional understanding of care: “care of the body” and “care for the body”, including the dependent care industry, but also “caring about the body” through a commitment to taking on debates about poverty, unemployment and education (Davis *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions* 28). This widened and more complex understanding of care in many different senses can be linked back to literary critical practices through Murray’s claim that an awareness of different understandings of care can not only encourage social change, as Davis suggests, but also reconfigure ways of reading:

It is only by reading with a holistic sense of care, that is, with an alertness to the narrative possibilities offered by metaphor as well as to the materiality of disability’s social presence, that we can get past a simple notion of the disposability of disabled characters and towards a more complex engagement with the nuances of contemporary disability narratives.

(Murray 256)

This is a matter of close and careful reading, but also of caring *about* disabled bodies through an ethically informed theoretical approach. Coetzee's text poses an important question for disability studies scholars: can a piece of literary writing be classified as "disability literature" simply because it engages in detailed ways with enduring and everyday conditions of disability? On one level, *Slow Man* seems to offer an unrelentingly bleak view of impairment and the disabling process of ageing, as Paul articulates a deficit model of disability: "A man without sight is a lesser man, as a man without a leg is a lesser man, not a new man" (113). Yet, these are the words of Coetzee's fictional narrator; on a macro level, *Slow Man* provides a complex and nuanced commentary on many pressing disability issues: the professionalisation of care in western societies, pain, intimacy, sexuality and the formation of alternative identities. Paul's sometimes reductive reading of disability, and his authority as narrator, are contested by a number of counter-voices in the text, including that of writer Elizabeth Costello, an uncanny author figure who enters the text part of the way through and seeks to re-frame and narrate Paul's own life story in alternative ways.

The action of *Slow Man* is, in some senses, structured around Paul's struggle to wrestle back control as narrator of his own body and his own disability: from the medicalised discourses of the healthcare professionals who consistently patronise, infantilise, and speak for him, but also from the author Elizabeth Costello. As the narrative draws to a close, Elizabeth seeks to foreclose Paul's narrative by imposing a comforting closure that is reminiscent of the narratives of progress, of overcoming, or sentimental resolution that have been critiqued by cultural disability studies scholars (Cheyne). Coetzee provides a bathetic, fleeting possibility of a fairy-tale ending in a rare moment of intimacy between Paul and Elizabeth:

Ever so gently, he lifts her and slips a cushion under her head.

In a fairy story, this would be the moment when the foul hag turns into a fair princess. But this is not a fairy story, evidently.

(*Slow Man* 237)

The moment of narrative reversal, from ugly duckling to swan, is punctured. In Snyder and Mitchell's terms, Coetzee's *Slow Man* refuses to "remove the unsightly from view" (8). At the very end, Coetzee raises expectations of a possible reconciliation with Marijana, Paul's nurse, when he is invited to her family home and given a recumbent bicycle made for him by her son, Drago. However, just as Paul refuses the prosthetic leg offered to him at the hospital, he vows never to use the recumbent

bicycle. His refusal to try to “pass” for his former non-disabled self suggests a shift in Paul’s approach to his disability over the course of the novel and even a move away from his earlier sense of disability as deficit. Like Paul’s body, the novel remains “incomplete” in normative terms: rather than an easy metaphorical “shortcut” or narrative of overcoming, the story of disability offered is open-ended, enduring, and suffused with an everyday realism of the body. It is, in the senses discussed by Wills and Mitchell and Snyder, a novel that refuses to be “prostheticised”. In this way, Coetzee’s *Slow Man* explores the slippages between physical and metaphorical and insists on the importance of telling stories about disability in a twenty-first-century context; it is a novel that aesthetically, ethically and politically, stubbornly refuses to remove disability from the narrative frame.

## Conclusion

In *Crip Theory* (2006), Robert McRuer describes a “rehabilitative contract” which stipulates that “in return for integration, no complaints will be made, no suggestion for how the world, if not the disabled body or mind, might be molded differently. No complaints will be made even if the contract in effect relegates disabled people to the margins” (121; 13). Novels provide one space in which this rehabilitative contract can be renegotiated and disability is brought centre-stage. Writing about physical disability, prosthetics, and rehabilitation has the potential to serve a “prosthetic” function in the sense described by Mitchell and Snyder: propping up normative discourses through traditional bodily and narrative forms, stock characters and reductive metaphors. However, as examples such as *Slow Man* demonstrate, novels can also provoke thinking about the relationship between physicality and textuality, and explore pressing concerns about ageing, care and interdependency. In the process, the basic forms of the novel, the conventions of realism, and the “contract” between reader and writer come under scrutiny. The novel form necessarily raises questions about empathetic identification, multiple coexisting viewpoints on and stories about disability, and who is given the authority to narrate. In Coetzee’s *Elizabeth Costello* (2003), the novel that precedes *Slow Man*, Elizabeth’s son entertains the possibility that fiction could, perhaps, invite readers to engage in productive imaginative processes: “ask[ing] us to imagine our way into that way of moving, to inhabit that body” (96). The theoretical accounts of the novel and fictional works discussed in this chapter insist that the struggle to imagine and to inhabit other bodies and minds is difficult and complex and yet it remains ethically, aesthetically and politically important.



## Further Reading

- Sari Altschuler. “‘Ain’t One Limb Enough?’: Historicizing Disability in the American Novel.” *American Literature* 86. 245–274 (2014). Print.
- Lennard J. Davis. “Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century.” *The Disability Studies Reader*. Ed. Davis, Lennard J. 2nd ed. New York: Routledge, 2006. 3–16.
- Rosemarie Garland-Thomson. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997.
- David T. Mitchell and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press, 2001.
- Vivian Sobchack. “A Leg to Stand On: Prosthetics, Metaphor and Materiality.” *The Prosthetic Impulse: From a Posthuman Present to a Biocultural Future*. Ed. Smith, Marquard and Joanna Morra. Cambridge, MA: MIT Press, 2005. 17–41.
- Henri-Jacques Stiker. *A History of Disability*. Ann Arbor: University of Michigan Press, 1999.
- David Wills. *Prosthesis*. Stanford: Stanford University Press, 1995.

## Bibliography

- Albrecht, Gary L. *The Disability Business: Rehabilitation in America*. Newbury Park: Sage Publications, 1992. Print.
- Altschuler, Sari. “‘Ain’t One Limb Enough?’: Historicizing Disability in the American Novel.” *American Literature* 86. (2014): 245–274. Print.
- Armstrong, Tim. *Modernism, Technology, and the Body: A Cultural Study*. Cambridge; New York: Cambridge University Press, 1998. Print.
- Barker, Clare. *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality*. Basingstoke; New York: Palgrave Macmillan, 2011. Print.
- Bérubé, Michael. “Disability and Narrative.” *PMLA* 120.2(2005): 568–576. Print.
- Brueggemann, Brenda Jo. *Arts and Humanities*. Sage Reference Series on Disability: Key Issues and Future Directions. Thousand Oaks: SAGE Publications, 2012. Print.
- Cheyne, Ria. “‘She Was Born a Thing’: Disability, the Cyborg and the Posthuman in Anne McCaffrey’s *The Ship Who Sang*.” *Journal of Modern Literature* 36.3(2013): 138–156. Print.
- Coetzee, J. M. *Elizabeth Costello: Eight Lessons*. London: Vintage, 2004. Print.
- Coetzee, J.M. *Slow Man*. New York: Secker and Warburg, 2005. Print.
- Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995. Print.
- Davis, Lennard J. *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions*. New York: New York University Press, 2002. Print.
- Davis, Lennard J. “Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century.” *The Disability Studies Reader*. Ed. Davis, Lennard J. 2nd ed. New York: Routledge, 2006. 3–16. Print.

- Faulkner, William. *Dr Martino and Other Stories*. London: Chatto and Windus, 1965. Print.
- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997. Print.
- Hall, Alice. *Disability and Modern Fiction: Faulkner, Morrison, Coetzee and the Nobel Prize for Literature*. Basingstoke; New York: Palgrave Macmillan, 2011. Print.
- Haraway, Donna. *Simians, Cyborgs and Women: The Reinvention of Nature*. New York: Routledge, 1991. Print.
- Herndl, Diane Price. *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840–1940*. Chapel Hill: University of North Carolina Press, 1993. Print.
- Jeffreys, Mark. “The Visible Cripple (Scars and Other Disfiguring Displays Included).” *Disability Studies: Enabling the Humanities*. Ed. Snyder, Sharon L., Brenda Jo Brueggemann and Rosemarie Garland-Thomson. New York: The Modern Language Association of America, 2002. 31–39. Print.
- Kittay, Eva Feder, and Ellen K. Feder. *The Subject of Care: Feminist Perspectives on Dependency*. Lanham, MD: Rowman & Littlefield Publishers, 2002. Print.
- Linton, Simi. *My Body Politic: A Memoir*. Ann Arbor: University of Michigan Press, 2006. Print.
- McRuer, Robert. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press, 2006. Print.
- Mitchell, David T., and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press, 2001. Print.
- Murray, Stuart. “From Virginia’s Sister to Friday’s Silence: Presence, Metaphor, and the Persistence of Disability in Contemporary Writing.” *Journal of Literary and Cultural Disability Studies* 6.3(2012): 241–258. Print.
- Nussbaum, Martha Craven. *Frontiers of Justice: Disability, Nationality, Species Membership*. The Tanner Lectures on Human Values. Cambridge, MA: The Belknap Press: Harvard University Press, 2006. Print.
- Schweik, Susan M. *The Ugly Laws: Disability in Public*. New York: New York University, 2009. Print.
- Senier, Siobhan. “Rehabilitation Reservations: Native Narrations of Disability and Community.” *Disability Studies Quarterly* 32.4(2012). Print.
- Serlin, David. *Replaceable You: Engineering the Body in Postwar America*. Chicago: University of Chicago Press, 2004. Print.
- Siebers, Tobin. *Disability Theory*. Ann Arbor: University of Michigan Press, 2008. Print.
- Small, Helen. *The Long Life*. Oxford: Oxford University Press, 2007. Print.
- Smith, Marquard, and Joanne Morra. “Introduction.” *The Prosthetic Impulse: From a Posthuman Present to a Biocultural Future*. Ed. Smith, Marquard and Joanna Morra. Cambridge, MA: MIT Press, 2006. 1–16. Print.

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- Smith, Marquard, and Joanne Morra. *The Prosthetic Impulse: From a Posthuman Present to a Biocultural Future*. Cambridge, MA: MIT Press, 2006. Print.
- Sobchack, Vivian. "A Leg to Stand On: Prosthetics, Metaphor and Materiality." *The Prosthetic Impulse: From a Posthuman Present to a Biocultural Future*. Ed. Smith, Marquard and Joanna Morra. Cambridge, MA: MIT Press, 2005. 17–41. Print.
- Stiker, Henri-Jacques. *A History of Disability*. Ann Arbor: University of Michigan Press, 1999. Print.
- Wendell, Susan. "Towards a Feminist Theory of Disability." *The Disability Studies Reader*. Ed. Davis, Lennard J., 1st ed. New York: Routledge, 1997. 260–278. Print.
- Wills, David. *Prosthesis*. Stanford, CA: Stanford University Press, 1995. Print.

## 5 Deafness and Performance

Mark Medoff's 1980 play, *Children of a Lesser God*, probes the linguistic, cultural, emotional and social distances between Sarah, a profoundly deaf woman who works at a deaf residential school, and James, a hearing teacher at the school who becomes her lover and husband. The characters communicate through speech and American Sign Language. The play ends as it begins:

*Silence. Close by each other. James reaches to touch her. She bolts away. They're in the same positions they were at the beginning of the play.*

(87)

The stage directions create a striking visual metaphor: they insist on a highly physicalised sense of distance between the two leading characters, an uneasy yet powerful impasse.

*Children of a Lesser God*, which was inspired by Phyllis French's complaint about the dearth of roles for deaf actors, was a striking critical and popular success. The play version, which featured French in the lead role as Sarah, was performed over eight hundred times on Broadway and swept the board at the 1980 Tony theatre awards. In 1988, a film version was released in which ten of the sixteen main characters were played by deaf actors. The film's widespread popularity was crowned when Marlee Matlin won the Best Actress Oscar for her performance as Sarah.

Many critics, while praising *Children of a Lesser God*, emphasised the romantic dimension of the plot in their initial responses to it. Edwin Wilson in *The Wall Street Journal*, for example, saw deafness as a "powerful" symbol of "the difficulties a man and a woman have in communicating with each other" (Spirko 17). The director of the Hollywood film version of *Children of a Lesser God*, Randa Haines, echoed this highly metaphorical, universalised reading: "It is difficult for any

two people to really reach each other across the barriers that separate them...In this movie, the metaphor for what separates James and Sarah is her deafness. But, in some ways, he is also deaf” (Norden 289). In line with this, the film version shifts the relationship between Sarah and James from being a subplot to the centre of the action.

These reductive, “prosthetic” readings, in which deafness is understood as an easy metaphorical shortcut for the difficulty of communication between the sexes, fail to take account of the nuances of performance and the complex, culturally specific context and politics of the original play. Medoff’s theatrical version of *Children of a Lesser God* is concerned with processes of translation and interpretation between oral communication and sign language and the ethical problems that arise when certain populations speak for others. In a meta-theatrical moment, Sarah, whose sign language is “translated” into speech and repeated for hearing audiences by James throughout the play, draws attention to the artificiality of this theatrical device and the limits of communication in the play itself: “I can’t say what I feel about being deaf through a hearing person” (83). The dialogue plays and puns on linguistic slippages and idiosyncrasies, including the problematic literal translation of an idiom such as “you’d think I was a scream” (Medoff 9). It also focuses on the nuances of bodily, tactile modes of perception, such as Sarah’s sensation of music as a set of vibrations through her nose (Medoff 62). Medoff has commented that the play seeks to create an alternative dramatic space: “another place; not in silence or in sound but somewhere else” (90).

The hybrid form of *Children of a Lesser God* paved the way for a wave of experimental performances that combined manual and oral forms, and creatively explored the tensions between them. But *Children of a Lesser God* was a seminal work in many ways, and so it is used as the main focus of this chapter, and a vehicle through which to introduce key debates in Deaf Studies, on definitions of D/deafness, the history of deaf education, pedagogies and activism.

## Definitions

Miss Klein, the lawyer, hired to represent the students at the deaf residential school in *Children of a Lesser God*, articulates a common stereotype about people with hearing impairments: “As I understand it,” she says, “Sarah is deaf *and* dumb” (Medoff 69). Until linguists such as William C. Stokoe Jr. began to recognise and revalue American Sign Language (ASL) as a language in its own right in the late 1950s and 1960s, assumptions about sign language as a simplified, inferior form of communication abounded. Sign language was equated with “broken English” and, in turn, with

“broken intelligence” (Brueggemann “Deafness, Literacy, Rhetoric: Legacies of Language and Communication” 123). In the decades that followed this re-evaluation, deaf organisations and populations, often connected through residential schools and deaf clubs, became increasingly politically engaged, organising to contest stereotypes and build strong communities. A key aspect of this growing political consciousness was the distinction made between “deafness” as a physical hearing impairment, and the capitalised concept of “Deafness”, as a social and cultural identity. In this latter context, scholars such as Paddy Ladd, MJ Bienvenue, Tom Humphries, and Carol Padden resisted a previously dominant medical model of deafness as a biological deficit, a problem to be cured or corrected. Instead, they celebrated the unique identity of Deaf populations, often translated from ASL as “Deaf World”, as a linguistic minority who are characterised by a rich sense of a shared culture and their use of sign language.

Harlan Lane’s influential work in the 1990s provided a framework for understanding the uneven power dynamics between hearing and deaf communities in terms of national and colonial identities. In *The Mask of Benevolence: Disabling the Deaf Community* (1992), Lane writes: “like the paternalism of colonizers, hearing paternalism...sees its task as ‘civilizing’ its charges: restoring deaf people to society” (37). Arguing that, “hearing paternalism fails to understand the structure and values of deaf society” (37), Lane aimed to oppose the oppressive dominance of the “audist” state to provide a vocabulary for critique and to create a form of “postcolonial” resistance among the “native” deaf community. Lane’s influential paradigm continues to underpin many theoretical discussions in Deaf Studies and activist campaigns today. Writing from a literary perspective, for example, Cynthia Peters takes up this model to draw a parallel between Deaf American literature and the vernacular storytelling traditions of other minority populations in the United States: “Like Native Americans, Deaf Americans have their own language and their own vernacular stories and art forms” (3). In an American context, other scholars have suggested analogies with the biculturality of Asian Americans and Latinos in the United States; they argue that the only “dysfunction” of these ethnic minority groups, like Deaf populations, is their inability or their choice not to communicate in English (Davis *Enforcing Normalcy: Disability, Deafness, and the Body* 78).

Deafness is therefore viewed as a cultural difference rather than a disability. In line with the social model of disability, the process of representation itself becomes a key concern: Deaf studies is concerned with “reframing representations of deafness from sensory lack to cultural diversity” (Bauman and Murray 246). The use of the social model of disability links Deaf scholars to many other disability studies theorists. Yet, despite this

connection, many Deaf scholars and activists have rejected the term “disabled” entirely. Lane, for example, specifically criticises the disability movement for assimilating such radically different conditions as deafness, paraplegia and autism into the same category in its activism and rhetoric (“Construction of Deafness”). Recently, other scholars, notably Lennard Davis, have countered this view, suggesting that a collective disability movement is more politically effective and less likely to mimic the exclusionary principles that it purports to oppose. Davis argues that in the twenty-first century, postmodernism and globalisation have destabilised all unified categories of identity, including Deafness. Moreover, he specifically takes issue with Lane’s “idea of an ethnic group or minority” which, he suggests, “is tinged with the brutal history of racial politics” and has echoes of “racial profiling” in its insistence upon the identification of “pure” deaf populations (“Deafness and the Riddle of Identity”). The linguistic minority model of Deafness can lead to some paradoxical exclusions. It includes “CODAS”, “Children of Deaf Adults”, who can hear but have used sign language from birth, but excludes people with hearing impairments who lip read and use speech, those who have not had the opportunity to learn sign language, individuals who became hard of hearing later in life, and people with cochlear implants.

These debates provide an important historical and cultural context for the representation of d/Deafness in *Children of a Lesser God*. The play dramatises the tensions between characters with different levels of hearing impairment, such as Orin, who is partially deaf and uses both speech and sign language; Lydia, who uses hearing aids; and Sarah who has been profoundly deaf since birth and chooses to communicate exclusively through ASL. The conflict between a celebration and an exploitation of “pure Deaf” identity is suggested by Orin’s desire to use Sarah, the only profoundly deaf member of the group, as a figurehead for his activist “revolution”. Orin insists that it is Sarah who should represent them when they bring their case to the employment commission and seek to overturn the school’s resistance to employing deaf teachers. This strand of the plot, minimised in the Hollywood film version, references Deaf rights activism in educational institutions throughout the 1980s and 1990s. The most high profile example of this occurred at Gallaudet University in 1988, just a year after the film version of *Children of a Lesser God* was released. The student protests, which came to be known as “Deaf President Now”, centred on resistance to the appointment of Jane K. Fernandes, a candidate who was not a native signer, as college president. The result was a shutdown of the university, the appointment of the college’s first Deaf president, and a level of media coverage that brought issues about Deaf identity and education into the American national consciousness. Davis

commented that these protests “did more to launch deafness and deaf culture onto the national scene than any event since the release of the 1986 film *Children of a Lesser God*” (Davis “Deafness and the Riddle of Identity”).

This activist resistance to dominant models of deafness, perpetuated even within deaf education systems, is articulated in the sense of Deaf pride that underpins Sarah’s speech to the commission in *Children of a Lesser God*. She insists upon, and indeed *performs* through the physical act of signing, the importance of understanding sign language as a valid and rich form of communication: “Well, my brain understands a lot; and my eyes are my ears; and my hands are my voice; and my language, my speech, my ability to communicate is as great as yours” (Medoff 84). After a lifetime of being spoken for and of occupying the position of a pupil, Sarah reverses the pedagogic dynamic here as she seeks to educate her hearing audience. In line with the idea of “Deaf Gain” prominent in Deaf studies and activism, Sarah suggests that Deafness is not a matter of hearing *loss*, but instead it has the enriching potential to facilitate the acquisition of a different language, a greater awareness of the nuances of tactile relations, and a shared sense of history and community. Sarah’s speech to the commission can also be read as a manifesto for “manualist” forms of education. Throughout *Children of a Lesser God*, she resists attempts by the teachers in the residential school, and James in particular, to encourage her to conform to an “oralist” model of education by learning to lip read and to speak. The pedagogic practices depicted in the fictional American residential school in *Children of a Lesser God* are typical of the privileging of aural/oral forms of communication in many educational institutions for deaf people in the same period. These practices, which focus on lip reading and speech training, were frequently allied with a suspicion of, and even an explicit opposition to, the use of sign language, which was often restricted and even banned.

Models of deaf education are defined by their relationship to these debates about language. The first schools specifically for the deaf in Europe, which often took the form of “institutions” or “asylums” that were separate from mainstream education, date back to the Enlightenment (Brueggemann “Deafness, Literacy, Rhetoric: Legacies of Language and Communication” 119). In late eighteenth- and early nineteenth-century Europe, there was a rapid growth in the number of schools for “special education” of the deaf, from a dozen schools in 1780 to sixty by 1822 (Davis *Enforcing Normalcy: Disability, Deafness, and the Body* 52). In the United States, the first permanent school, the American Asylum for the Deaf and Dumb, was founded in 1817 (Sánchez 133). The formation of residential institutions offered new possibilities for deaf individuals to form



communities like never before. Early deaf education in America was dominated by the teaching of sign language. There was, however, a shift from manualist forms of education in the eighteenth century towards oralism in late nineteenth- and twentieth-century schooling. Douglas Baynton argues that, in an American context, the civil war marked a decisive rupture in these pedagogic practices. In the post-war period, he suggests, increased nationalism and fears about American disunity meant that the separation of deaf communities came to be seen as a threat to the project of nation-building. In this context, sign language itself took on a significant and subversive symbolic value as the ability to speak English came to be understood as a key defining feature of citizenship. In this context, then, Baynton argues that a paternalistic insistence on speech-based pedagogies became necessary in order to weave together the fabric of the body politic (1–11). His argument suggests the ongoing and far-reaching significance of these debates about education in terms of national identity. It also underlines the importance of studying the construction of D/deafness within specific historical and cultural contexts.

In the twenty-first century, these hotly contested debates have continued to play out in educational settings, Deaf Studies scholarship, and activism, particularly where a civil-rights model of Deafness is adopted. Brenda Brueggemann, for example, considers that she enters “charged minefields” in her works on deafness and literacy (“Deafness, Literacy, Rhetoric: Legacies of Language and Communication” 116); Bauman and Murray employ powerful language to dismiss what they see as the “neo-eugenic drive towards normalization” that underpins oralist pedagogies (247). The climactic scene in *Children of a Lesser God* brings these two models of deaf education, of oralism and manualism, into direct confrontation, embodied in the figures of James and Sarah. James, a model of paternalistic oralism, equates speech with independence: “You want to talk to me, then *you* learn *my* language!...You’ve probably been reading lips perfectly for years...You always have to be dependent on someone, and you always will for the rest of your life until you learn to speak” (Medoff 86). His violent injunction, “Speak! Speak! Speak!” (86), provokes the first and only words that Sarah vocalises in the play: “Speech! Speech! Is that it? No! You want me to be your child! You want me to be like you. How do you like my voice...*What about me? What I want?*” (Medoff 87). However, this eruption of speech, “like a volcano” (Medoff 86), is more significant for the way in which it is performed rather than the content of the words themselves. The stage directions at this point in the play are very detailed: “*She can’t be sure how this sounds except by his reaction to it. It is clearly sentences, the sense of it intelligible but it is not a positive demonstration of speech – only of passion. Only a few*

words are even barely understandable” (Medoff 87). The scene challenges the logic of James’s argument that speech should be privileged over signs and creates a climactic moment in which, paradoxically, the primacy of oral communication is subverted through a speech act. By demonstrating that she can speak, Sarah highlights the fact that using sign language is an active and positive choice for her. For hearing audiences, Sarah’s largely unintelligible words call into question the phonocentric model of understanding through which they would conventionally construct meaning in a play. *Children of a Lesser God* uses its theatrical form to highlight the uniquely performative nature of sign language and the general importance of paying attention to visual and kinetic forms of knowledge and communication.

Kenny Lerner and Peter Cook’s hybrid performance, *I am Ordered Now to Talk*, is structured around a similar eruption of speech. Lerner and Cook make up the collaborative “Flying Words” duo whose performances combine speech and sign with mime, ventriloquism, storytelling and dance. Their works grow out of an ASL deaf poetry tradition that began in the 1980s and grew in the 1990s through works by performers such as Debbie Rennie, Ella Mae Lentz and Clayton Valli (Davidson 82). However, Lerner and Cook go against the grain of this sign language poetry tradition in the sense that they incorporate speech into their performances, featuring vocalisations and signs by both Deaf performer, Peter Cook, and the hearing half of the Flying Words duo, Kenny Lerner. In this way, the hybrid form of the works by the Flying Words collaboration trouble the boundaries through which Deaf Theatre has been interpreted in the past. Jessica Berson, for example, defines “inside performances” as “those by Deaf artists for Deaf artists, or that privilege the theatrical experience of Deaf viewers”. “Outside” performances, by contrast, include “interpreted theater and productions in which hearing actors ‘shadow’ Deaf actors”. Cook and Lerner’s shows fit into Berson’s category of “inside” performances in the sense that they “are intended for audiences that are both hearing and deaf” (43). However, both the content and the form of many of their performances are borne of the tensions between the inside and outside; *I am Ordered Now to Talk* explores the creative possibilities that come out of occupying the indeterminate space in between these two traditions and languages.

As in *Children of a Lesser God*, the spatial positioning of the two protagonists at the opening of *I am Ordered Now to Talk*, at either end of the stage, serves as a striking visual metaphor for the distance between the different forms of oral and manual communication that are used in the performance. The poem, performed by both Lerner and Cook, deals with similar issues to Medoff’s play: it tells the story of Cook’s

education at the Clarke School for the Deaf in Northampton, Massachusetts and it contains a strong critique of the oralist education that he received there. Yet it is the form of the performance itself, rather than either the spoken or signed words of the poem, that articulate this point most powerfully. The poem is spoken aloud by Cook, who is deaf, and it is signed by Lerner, who can hear. Whereas *Children of a Lesser God* stages a gradual reversal of the pedagogic dynamic, as James comes to realise that he, as a hearing teacher, has much to learn from his signing student and wife, Sarah (Medoff 89), *I am Ordered Now to Talk* reverses the traditional dynamics between interpreter and interpreted, speaker and spoken for. The effect of Cook and Lerner's performance is, for Davidson, "unsettling" (84). Cook's voice is "garbled" and Lerner's signing is "clumsy" (Brueggemann "Delivering Disability, Willing Speech" 23). This stilted delivery, Cook insists, is "part of the point". In a short, spoken aside at the beginning, Lerner announces: "Peter will now sign something to the deaf audience only, and he will be focusing on the hearing people so please – feel paranoid" (Cook and Lerner). This is intended to have the effect of jolting the hearing audience members out of their position of privilege and knowledge, to confront them with the limitations of the spoken form and their own monolingualism. Audience members also receive the poem that is performed onstage in written form, printed in the play's programme. However, once again, the form that this takes destabilises conventional hierarchies of communication: the written version does not provide a definitive version of the poem in standard English, instead it is written in "Deaf English", a sign language gloss that is "not very smooth or articulate" (Brueggemann "Delivering Disability, Willing Speech" 24).

*I am Ordered Now to Talk* therefore emphasises the difficulties of interpretation, the intricate nuances of different forms of communication, and the ways in which sign language, speech and writing cannot be easily transposed onto each other. At one point in the performance, Cook and Lerner move together, so that Lerner's arms are over Cook's head, signing and acting out the words that he is vocalising. Yet, even at this moment of spatial proximity, the divide between the different forms of communication remains distinct. In fact, the apparent physical intimacy of this moment is undercut by the violence of the imagery of the words that they deliver: the interventions of Cook's childhood speech teacher, who insists that "B is not P", "D is not T", are figured as the incisions made into his skull by a lobotomist. Moreover, the phonemes, B and P, D and T, serve as an example of a case in which the manual communication of ASL makes a much clearer distinction between words and letters than in the lip-reading method favoured in oralist education. Through the hybrid form of the performance itself, therefore, Cook

subverts the script that was imposed upon him as a child, and resists models of Deaf individuals as either passive patients or as puppets whose strings are pulled by a hearing master. The urgency of the teacher's refrain that runs throughout the poem, "you / must / now / talk", is called into question by the polyglossic forms of communication that make up the performance.

Both *Children of a Lesser God* and *I am Ordered Now to Talk* explore fundamental questions which are articulated by another sign language performer, Terry Galloway: "how to have a voice in theatre. How to be heard...[How to] make a claim on that empty space" (Beach and Pasternack 51). For some scholars, the theatre itself provides a space in which the voices and perspectives of disabled people can be heard. Thomas Fahy, for example, suggests that the stage invites audiences to see the bodies on display as "individuals, not objects", creating a sense of "intimacy and community" that challenges stereotypes about disability (x). For Petra Kuppers, performance is a form of political activism: "a place where cultural uncertainties can find expression" within distinct social and aesthetic boundaries: "the unknown is framed by the conventions of the stage or the gazing scenario" (3).

In America, the foundation of the National Theater for the Deaf in 1967 helped to create opportunities for Deaf actors and sought to insert Deaf theatre into a mainstream theatrical tradition. In particular, there was an emphasis on producing new versions of classic plays in which speaking and signing actors occupied the stage at the same time (Kochhar-Lindgren 3). Through productions like these, which are often characterised by their attention to visual, spatial and kinaesthetic modalities, Deaf theatre has cast new light on the histories of mime and theatrical tableau, including on works by celebrated modern playwrights such as Antonin Artaud, Robert Wilson and Samuel Beckett (Bauman and Murray 252). More recently, attention has turned to performances written and produced by Deaf individuals for hearing-impaired audiences. Peters, for example, identifies an emerging canon of ASL literature, highlighting a long tradition of vernacular performances by the Deaf community, including "literary nights" and festivals such as Deaf Way. Drawing on Mikhail Bakhtin's theory of the carnivalesque, Peters argues that these vernacular performances are spaces in which ASL literature have been shared, performed and renegotiated for decades. Like the carnivalesque "trickster" figure, Deaf performers are characterised by their ability to jump between and invert the relationship between "high" and "low" cultural forms and different languages (Peters 11–13).

*Children of a Lesser God* and *I am Ordered Now to Talk* both draw on this subversive energy of Deaf theatre and use their theatrical forms

to foreground the performative power of sign language itself. They also explore the complex and often difficult processes of interpreting and visually representing disabled bodies on stage. The representation of people with disabilities in theatre recalls, on one level, deeply problematic histories of staring at and displaying disabled bodies for commercial gain both in medical contexts and in popular culture. For some scholars, theatrical productions risk reproducing this dynamic, valorising a form of “gentrified freak show, allowing audiences to look at disabled bodies metaphorically and voyeuristically” (Fox 234). Yet, unlike many other disabilities, deafness becomes visible only when an individual or character comes into contact with language or begins to communicate.

Debates about deaf pedagogies in the works by Medoff, Cook and Lerner are closely connected to a long and intertwined relationship between deaf education and performance. For example, Jean Nicolas Bouilly’s play about the Abbé Charles-Michel de l’Épée, a founding father of deaf education in Europe, ran to over a hundred performances in Paris at the end of the eighteenth century and was one of the greatest dramatic successes of the period. This play, in turn, drew on a history of public displays of deaf students organised by the Abbé de l’Épée himself. In these public displays, deaf students answered theological questions and did written translations in front of hundreds of visitors, including dignitaries such as European emperors, British parliamentarians and the Pope, who came daily to watch the shows (Davis *Enforcing Normalcy: Disability, Deafness, and the Body* 53–54). In the twenty-first century, Deaf theatre and performances about deafness are using new aesthetic forms to confront audiences with debates about deaf identities and complex, everyday experiences of deafness. Spectators are invited to become active participants, considering how deaf identities have been performed in the past both on-stage and off it, but also in creatively reimagining cultural understandings of Deafness in the present.

### **Deafness as a Critical Metaphor and Modality**

The intersections between deafness and performance in the examples discussed above works on different levels: as metaphors, in drama, as a way of categorising works by Deaf artists, but also as a means of thinking about and theorising the performative nature of deaf communication and identity. In literary terms, deafness on stage reminds us that theatre, and indeed all literary production, is a dialogic “event” in which the audience or reader play an active role in constructing meaning (Peters 11; Attridge 2). No single reading of a text or theatrical performance is ever exactly the same.

Davis proposes using deafness, and specifically the notion of the “deafened moment”, as a critical metaphor for “a contextual position, a dialectical moment in the reading/critical process that is defined by the acknowledgement on the part of the reader/writer/critic that he or she is part of a process that does not involve speaking or hearing” (Davis *Enforcing Normalcy: Disability, Deafness, and the Body* 100–01). This use of deafness as a critical metaphor aims to challenge the traditional association between blindness and insight and, as an alternative, introduces deafness into the critical lexicon in order to destabilise the ways in which “reading/writing has been unproblematically thought of as a process that involves hearing and vocalizing” (Davis *Enforcing Normalcy: Disability, Deafness, and the Body* 101). Critics such as Davis are part of a wave of scholars who seek to go beyond understandings of deafness in literature as simply a theme or a catalogue of deaf characters, which in Anglophone writing is often dated back to Daniel Defoe’s *Life and Adventures of Duncan Campbell* (1720). These scholars also see deafness as a critical metaphor or modality that transfigures understandings of what literature is and how it works. Understanding literary production from this stance invites productive connections with existing theories and traditions, from reconfigurations of Roland Barthes’s notion of “readerly” and “writerly” texts to new insights into the physical performances of feminist and Beat generation spoken word poetry. It also helps to establish the significance of Deaf literature as a category with a place in the literary canon in its own right.

Postmodern theories of “performativity”, theorised by Goffman and Judith Butler as a means of understanding the ways in which all of us are engaged in performing identities in our everyday lives, take on a striking physicality in Deaf theatre. Spectators come face to face with the power of the body as a signifying mechanism through the use of sign language, gesture and facial expression by the actors on stage, but also with a model of language and identity that is flexible, changing and constantly renegotiated before their eyes. Bruce Henderson and R. Noam Ostrander, in their 2008 introduction to *Text and Performance Quarterly’s* special issue on Disability Studies/Performance Studies, suggest that performance provides a productive framework through which to understand the entire discipline of disability studies:

The premise of this special issue is not simply that disability studies is always in some sense a form of performance studies – although what is commonly known as the “social model” of disability would affirm that – [but that] disability is something that we do, rather than we are.

(1–2)

In a twenty-first-century context, in which the mainstreaming of deaf students in education and technological changes such as the use of cochlear implants are becoming more common in the western world, the conception of what Deaf studies or a culturally Deaf identity mean is hotly contested. Moreover, in an age increasingly driven by digital forms of communication and media, the definition of Deaf literature is also being redefined. The internet can be seen as a threat to the unique physicality and intimacy which, for some, are defining features of Deaf communication and performance. Sites such as YouTube make resources in dominant forms of sign language such as ASL or BSL (British Sign Language) worldwide phenomena, often at the expense of sign language systems used by smaller communities that go largely undocumented or have even begun to disappear (Bauman and Murray 247).

Yet, digital platforms also make Deaf literature, theatre and sign language poetry far more accessible than ever before. For example, the works by Cook, Lerner and Williamson, discussed in this chapter, are all freely available online. This physical relationship between bodies and machines has, recently, become incorporated into the aesthetics of some Deaf performances. For example, Deaf British artist Aaron Williamson uses a computer with speech recognition software that interprets sounds as written text as the basis for his performance-installation, *Hearing Things*. Visitors to the installation space become part of this interactive, collaborative process, as the noises that they make in the gallery, from footsteps to coughs, are incorporated into an unreadable text that is projected onto one side of a glass screen. As in *Children of a Lesser God* and *I am Ordered Now to Talk*, Williamson's installation uses language that is difficult to comprehend, or indeed unintelligible, in order to alienate spectators and to challenge basic assumptions about communication. Instead, Williamson himself re-enters the installation space periodically in order to re-interpret the text through physical performances and visceral vocalisations that also become part of the installation. The body, rather than text, speech, or signs, becomes the central signifying mechanism in this installation performance. Notions of knowledge, authority and the dynamic between interpreter and interpreted come under scrutiny as Williamson brings together past and present in his references to the computerised speech recognition system as an electronic "oracle".

All of the works discussed in this chapter use performance to pose questions about communication, interpretation and the construction of d/Deaf identities through acts of performance. Deafness is addressed not only on a level of character and theme, but also through experimentation with hybrid forms, particularly in the examples of works by Cook, Lerner and Williamson. Close analysis and the process of historically contextualising these performances helps to remind us that "hearing" is much more than

a process of registering the presence or absence of sound. Hearing is a cultural process, both reflected in and shaped by performances that take place on stage, as well as in the interactions that make up everyday life. Kochhar-Lindgren points out that hearing and deafness cannot be fully understood without also “unpacking the trope of deafness” (4–5). Hearing and deafness are also central to the vocabulary through which communication and social and ethical relationships are understood. The relationship between Deaf studies and disability studies, and the place of Deaf performances and literature in the literary canon, are still very much in flux.

The final moments in *Children of a Lesser God* weave together hearing and deaf forms of communication, as the words are simultaneously spoken and signed. Yet, the final communicative act, a sign, is given to Sarah. The play ends not with an act of easy linguistic communion or romantic resolution, but rather with an invitation to spectators to engage in the ongoing cultural, pedagogic and ethical debates and dilemmas raised by the performance itself: “Join” (Medoff 91).

### Further Reading

- H. Dirksen, L. Bauman, Jennifer L. Nelson, and Heidi M. Rose. *Signing the Body Poetic: Essays on American Sign Language Literature*. Berkeley: University of California Press, 2006.
- Brueggemann, Brenda Jo. “Deafness, Literacy, Rhetoric: Legacies of Language and Communication.” *Embodied Rhetorics: Disability in Language and Culture*. Ed. Wilson, James C. and Cynthia Lewiecki-Wilson. Carbondale and Edwardsville: Southern Illinois University Press, 2001. 115–134.
- Michael Davidson. *Concerto for the Left Hand: Disability and the Defamiliar Body*. Ann Arbor: University of Michigan Press, 2008.
- Lennard Davis. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995.
- Petra Kuppers. *Disability and Contemporary Performance: Bodies on Edge*. New York: Routledge, 2004.
- Harlan Lane. “Construction of Deafness.” *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 1997. 153–171.
- Cynthia Peters. *Deaf American Literature: From Carnival to the Canon*. Washington, D.C.: Gallaudet University Press, 2000.
- Carrie Sandahl and Philip Auslander (eds). *Bodies in Commotion: Disability and Performance*. Ann Arbor: University of Michigan Press, 2005. 42–55.

### Bibliography

- Attridge, Derek. *The Singularity of Literature*. London; New York: Routledge, 2004. Print.
- Bakhtin, M. M. *Rabelais and His World*. Cambridge, Mass.: MIT Press, 1968. Print.



- Barthes, Roland, and Honoré de Balzac. *S/Z*. 1st American ed. New York: Hill and Wang, 1974. Print.
- Bauman, H-Dirksen L. and Joseph J. Murray. "Deaf Studies in the 21st Century: 'Deaf Gain' and the Future of Human Diversity." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 2013. 246–260. Print.
- Baynton, Douglas C. *Forbidden Signs: American Culture and the Campaign against Sign Language*. Chicago: University of Chicago Press, 1996. Print.
- Beach, Maria, and Leslie Pasternack. "Making a Claim on the Empty Space: An Interview with Terry Galloway." *Theatre InSight* 9.1(1998): 50–54. Print.
- Berson, Jessica. "Performing Deaf Identity: Toward a Continuum of Deaf Performance." *Bodies in Commotion: Disability and Performance*. Ed. Sandahl, Carrie and Philip Auslander. Ann Arbor: University of Michigan Press, 2005. 42–55. Print.
- Bienvenu, MJ. "Queer as Deaf: Intersections." *Open Your Eyes: Deaf Studies Talking*. Ed. Bauman, H. and L. Dirksen. Minneapolis: University of Minnesota Press, 2008. 264–273. Print.
- Brueggemann, Brenda Jo. "Deafness, Literacy, Rhetoric: Legacies of Language and Communication." *Embodied Rhetorics: Disability in Language and Culture*. Ed. Wilson, James C. and Cynthia Lewiecki-Wilson. Carbondale and Edwardsville: Southern Illinois University Press, 2001. 115–134. Print.
- Brueggemann, Brenda Jo. "Delivering Disability, Willing Speech." *Bodies in Commotion: Disability and Performance*. Ed. Sandahl, Carrie and Philip Auslander. Ann Arbor: University of Michigan Press, 2005. 17–29. Print.
- Butler, Judith. *Gender Trouble: Feminism and the Subversion of Identity*. New York: Routledge, 1990. Print.
- Cook, Peter and Kenny Lerner. "I Am Ordered Now to Talk." [americandeafculture.com](http://americandeafculture.com). Web. 12 October 2013.
- Davidson, Michael. *Concerto for the Left Hand: Disability and the Defamiliar Body*. Ann Arbor: University of Michigan Press, 2008. Print.
- Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995. Print.
- Davis, Lennard J. "Deafness and the Riddle of Identity." *The Chronicle Review* 53 (January 12 2007): 19, 86. Print.
- Fahy, Thomas. "Peering Behind the Curtain: An Introduction." *Peering Behind the Curtain: Disability, Illness and the Extraordinary Body in Contemporary Theater*. Ed. Fahy, Thomas and Kimball King. London and New York: Routledge, 2002. ix–xiii. Print.
- Fox, Ann M. "'But, Mother – I'm – Crippled!': Tennessee Williams, Queering Disability, and Dis/Membered Bodies in Performance." *Gendering Disability*. Ed. Smith, Bonnie G. and Beth Hutchinson. New Brunswick: Rutgers University Press, 2004. 233–250. Print.
- Goffman, Erving. *The Presentation of Self in Everyday Life*. London: Allen Lane, 1969. Print.
- Henderson, Bruce and R. Noam Ostrander. "Introduction to Special Issue on Disability Studies/Performance Studies." *Text and Performance Quarterly* 28.1–2(2008): 1–5. Print.

- Kochhar-Lindgren, Kanta. "Between Two Worlds: The Emerging Aesthetic of the National Theater of the Deaf." *Peering Behind the Curtain: Disability, Illness and the Extraordinary Body in Contemporary Theater*. Ed. Fahy, Thomas and Kimball King. London and New York: Routledge, 2002. 3–15. Print.
- Kuppers, Petra. *Disability and Contemporary Performance: Bodies on Edge*. New York: Routledge, 2004. Print.
- Ladd, Paddy. *Understanding Deaf Culture: In Search of Deafhood*. Clevedon; Buffalo: Multilingual Matters, 2003. Print.
- Lane, Harlan L. *The Mask of Benevolence: Disabling the Deaf Community*. 1st ed. New York: Knopf, 1992. Print.
- Lane, Harlan L. "Construction of Deafness." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 1997. 153–171. Print.
- Medoff, Mark. *Children of a Lesser God*. Ambergate: Amber Lane Press, 1982. Print.
- Norden, Martin F. *The Cinema of Isolation: A History of Physical Disability in the Movies*. New Brunswick, N.J.: Rutgers University Press, 1994. Print.
- Padden, Carol, and Tom Humphries. *Inside Deaf Culture*. Cambridge, Mass.: Harvard University Press, 2005. Print.
- Peters, Cynthia. *Deaf American Literature: From Carnival to the Canon*. Washington, D.C.: Gallaudet University Press, 2000. Print.
- Sánchez, Rebecca. "'Scenes in the History of the Deaf and Dumb': Angeline Fuller's Strategic Sentimentality and the Development of an American Deaf Identity." *American Literary Realism* 45.2(2013): 133–145. Print.
- Spirko, Robert C. "Better Me Than You": Children of a Lesser God, Deaf Education and Paternalism." *Peering Behind the Curtain: Disability, Illness and the Extraordinary Body in Contemporary Theater*. Ed. Fahy, Thomas and Kimball King. London and New York: Routledge, 2002. 16–23. Print.
- Williamson, Aaron. "Hearing Things." Vimeo.Web. 2 April 2013.

## 6 Blindness and the Short Story

This chapter explores the representation of blindness in short fiction in relation to ideas about empathy, intimacy and touch. It considers some examples from the wealth of twentieth-century short stories about visual impairment, introducing debates about competing understandings of blindness and processes of reading and writing about it. The focus is on two stories in particular: D.H. Lawrence's "The Blind Man" (1920) and, "Cathedral", Raymond Carver's 1981 re-writing of Lawrence's story. These stories deal with everyday encounters, domestic settings, and understated marital tensions which might seem initially insignificant yet both ask fundamental questions about the imaginative relationship between blind and sighted characters, readers and writers. For sighted readers they raise questions of whether we feel *for*, or *with*, the blind writer. As Paterson asks: "is the mechanism one of sympathy, the sharing of feelings of another (feeling-with), or the more specific projective identification of putting oneself in the place of another, empathy (feeling-for)?" (95).

Before the discussion of these more conventional short stories, the first section of this chapter draws on the experiential knowledge of autobiographical writing by the writers, Stephen Kuusisto and Georgina Kleege, both of whom are blind. Their works, *Sight Unseen* (1999) by Kleege, *Planet of the Blind* (1998) and *Eavesdropping: A Life by Ear* (2006) by Kuusisto, are memoirs which challenge the boundaries of the chosen genre; their descriptions of the experience of blindness are at once lyrical and analytical. Kleege and Kuusisto's memoirs are interwoven with literary critical analysis and a rich variety of references to works of poetry, drama, novels, essays, letters and short fiction about blindness from across the ages. This focus on imaginative and fictional works within the memoir form suggests the significance of the long literary history of blind characters, from Oedipus to King Lear to Coetzee's barbarian girl, in forming conceptions of blindness that contribute to the construction of social and cultural identities in the present day.

Central to this chapter is a consideration of the importance of blindness as a metaphor, often for writing itself. Visual impairment foregrounds and reconfigures the physical and phenomenological aspects of reading processes through the engagement with technologies such as Braille, computer scanners, audiobooks, and through the attention to representations of sound, texture, and smell in textual forms. Short stories, alongside literary memoirs, offer a form that often encourages writers to experiment with radical ideas and innovative narrative techniques that might not seem viable over a more extended piece of writing, though this is not to suggest that the short story necessarily disrupts common stereotypes or “the underpinning hierarchies of normativism” that are common in novels and other literary representations of blindness (Bolt 271).

### **Blindness and Literary Tradition**

The figure of the blind writer or the writer with impaired or degenerating vision is a familiar one in literary history, from Homer and Milton to Joyce and Borges. Blindness as a topic or a metaphor has also been a source of fascination for writers, dramatists and myth-makers working with many different oral and narrative forms across the ages. Landmark studies such as Edward Larrissy’s *The Blind and Blindness in Literature of the Romantic Period* (2007) and Mary Klages’s study of *Woeful Afflictions: Disability and Sentimentality in Victorian America* (1999), survey the range of literary writing about blindness in the eighteenth and nineteenth centuries. Klages considers a range of genres alongside one another, including fiction, biography, domestic and popular cultural representations. She argues that, even within a disability studies context, this material has received “comparatively little attention” (7). David Bolt’s study of twentieth-century literature, *The Metanarrative of Blindness: A Re-Reading of Twentieth Century Anglophone Writing* (2014), also comments on the array of literary writing about blindness by some of the most high profile modern authors, including Joseph Conrad, Rudyard Kipling, Stephen King and José Saramago, and the relative lack of analytical writing or literary criticism on issues of blindness and visual impairment in works by these writers. He suggests that a dominant social and cultural metanarrative of blindness which reduces the agency of blind people is invoked and explored nowhere more than in twentieth-century Anglophone writing (4).

The focus on twentieth-century short fiction in this chapter is based partly on the confines of space but it also seeks to respond to a very particular intersection between the popularity of the short story form and a proliferation of writing about blindness at the beginning of the

twentieth century. This can be attributed in part to the greater visibility of disability in the period following the First World War. Lawrence's "The Blind Man" was written in the months leading up to the Armistice and completed a few weeks after it (Clausson 123). The protagonist's experience of the Great War remains the unspoken presence at the heart of the text. Faulkner's novella, *Soldier's Pay* (1926) focuses on similar issues but in an American context, as a blinded soldier tries to assimilate back into his community on his return from war.

Alongside these historical incidences of blindness caused by wartime injuries, there was also an aesthetic focus on questions of vision and sight by Modernist writers in the same period. "Ocularcentric" epistemologies were being challenged through radical experiments with narrative technique; fragmented narratives were seen as representing an implicit rejection of the certainties of realist equations between vision and truth. Much Modernist writing, including Lawrence's, is marked by a multisensory aesthetic, an attempt to write from and about the body in new ways. Virginia Woolf, in her essay "On Being Ill" (1930), suggests that the ill person is "forced to coin words for himself, and, taking his pain in one hand, and a lump of pure sound in the other...so to crush them together that a new word drops out" (7). High Modernism therefore acknowledges bodily experience in new ways which chime with autobiographical writing, particularly the autobiographical writing of people with illness and disabilities. Virginia Woolf's description of language as malleable and textured, needing to be moulded according to the individual's subjective experience, resonates with Helen Keller's 1908 description of her experience of language as a deafblind woman:

The hand is my feeler with which I reach through isolation and darkness and seize every pleasure, every activity that my fingers encounter. With the dropping of a little word from another's hand into mine, a slight flutter of the fingers.

(10)

These representations of blindness in works by twentieth-century short stories, including works by H.G. Wells, Rabindranath Tagore, Henry James, V.S. Pritchett, G.K. Chesterton and Jorge Luis Borges, connect back to much older traditions of writing about visual impairment in other short forms such as biblical parables, ancient Greek myths and letters. There is, for example, a strong epistolary tradition of writing about blindness from William Molyneux's famous letter to John Locke written in 1693 and Denis Diderot's 1749 "Letter on the Blind for the Use of Those Who See" to the philosophical exchange of letters between Martin

Milligan, the blind philosopher, and his sighted colleague, Bryan Magee published in 1995.

These literary traditions of letters, myths, parables, and modernist short stories feed into contemporary representations of blindness in works by Kleege, Kuusisto and Carver. Kleege draws on the epistolary tradition, blending it with historical fiction, in *Blind Rage: Letters to Helen Keller* (2006). In this unconventional text, she reconstructs different periods from Keller's life and imagines challenging her, through letters, to reveal a more complex self beyond her public image as a secular saint. Kuusisto describes his memoir, an account of travel and sightseeing through sound, in terms that blur the boundaries of genre, as "auditory postcards" or "tone poems" (*Eavesdropping: A Life by Ear* xi). In *Planet of the Blind*, Kuusisto reminds readers that the nature of his visual impairment means that, on a practical level, he necessarily consumes literary texts in short chunks: "College is brutally difficult for me. One poem must take the place of the bulky novel I cannot read, or at least not read in a week. I often go home from the library with the few words I've been able to see and absorb still vivid in my imagination" (66). His descriptions of the reading process are full of both pain and lyricism: "My spastic eye takes in every word like a red star seen on a winter night. Every syllable is acquired with pain" (*Planet of the Blind* 66). Reading is not a passive act, it is a multisensory experience in which Kuusisto is an active and embodied reader, memorising and imaginatively reconstructing words and stories: "Alone, I take apart and rearrange them...Exploring what words can do when placed side by side, I'm starting to build the instrument that will turn my blindness into a manner of seeing" (*Planet of the Blind* 66). The resonances with Woolf are striking.

Kleege, whose macular degeneration leads her to consume texts in a similarly atomised form, describes the acute level of attention she bestows on each word: "For me, reading visually means deciphering every word, syllable by syllable...It is impossible for me to do a cursory visual reading" (*Sight Unseen* 169). Her description of viewing a painting, through "peripheral vision", scanning it "systematically" in sections with an intense awareness of "the details of texture, depth and illumination", provides a powerful analogy for the mode of reading texts that she employs in *Sight Unseen* (93–94). This analogy also reminds us that a blind "reading" of a short story, whether in text form, through audiobook, or Braille, might have more in common with experiencing a painting, a piece of music, or a sculpture, than a novel or poem. Both Kleege and Kuusisto insist in their autobiographical accounts on the importance of understanding reading as an embodied process. The result is a

reconfigured approach to language and to literary form which experiments with genre and develops multisensory perspectives within the writing.

### The Language of Blindness

In *Sight Unseen*, Kleege declares: “I find it easy to imagine what it’s like to be sighted. I had to write this book to learn what it means to be blind” (3). This immediately destabilises the idea of blindness as a fixed physical or cultural category. Similarly, Beth Omansky describes the experience of being legally blind as living in the “borderlands of blindness”, inhabiting a liminal space between sightedness and blindness which means that she can never fully identify with either category. Statistics suggest that these are common experiences: only about 10–20 per cent of people labelled legally blind, in places where this category is in use, are without any visual perception at all (Kleege “Blindness and Visual Culture: An Eyewitness Account” 453). “Legal blindness” means visual acuity of 20/200 or less (seeing at 20 feet away what a fully sighted person sees at 200 feet), and/or a peripheral visual field of 20 degrees or less, in the better eye with corrective lenses (Berger 149). Blindness can, therefore, be more accurately understood as a spectrum of variation in visual acuity, rather than in binary opposition to sightedness.

This flexibility of blindness as a category is explored in literary accounts: Emily Dickinson and Jacques Derrida have written poetry and literary criticism in response to their own experiences of temporary conditions of visual impairment; Borges describes his progressive hereditary blindness as a “slow nightfall” (474). Borges’s description reflects his own gradual process of going blind, but he also calls into question a common equation between blindness and complete darkness in a physical, metaphorical and moral sense:

One of the colours that the blind – or at least this blind man – do *not* see is black... I, who was accustomed to sleeping in total darkness, was bothered for a long time at having to sleep in a world of mist, in the greenish or bluish mist, vaguely luminous, which is the world of the blind. I wanted to lie down in darkness. The world of the blind is not the night that people imagine.

(Borges 474)

The autobiographical essay on blindness from which this quotation is taken is written as a didactic piece in the form of a lecture. In the essay, Borges argues that, having lost “the beloved world of appearances”, the

task of the artist is to create something new (Borges 477). He himself drew on literary resources that were new to him (Anglo-Saxon poetry and Norse mythology) which enabled him to replace the visual with the aural. Appointed as the director of Argentina's National Library in the same year that he became blind, Borges was confronted with the necessity of finding new ways of reading, writing and engaging with literary texts. In this reflective essay, Borges ultimately comes to think of blindness as "a gift", a "style of living" and an "instrument" that he and other blind artists use in the creation of their work (483).

Both Kleege and Kuusisto make reference to cultural objects, such as novels and paintings, to convey and creatively re-imagine their experiences of visual impairment and to subvert rigid medical definitions. In her reading of J.M. Coetzee's novel, *Waiting for the Barbarians* (1980), a reference to a blur on the window allows Kleege to articulate her own experiences of light and darkness more precisely (*Sight Unseen* 82). The form and style of Kuusisto's writing, which depicts a sensorium that is at once "magical and disturbing...lovely and terrible", specifically challenges stereotypes that equate visual impairment with darkness and understandings of blindness as a "a profound misfortune, a calamity" that were dominant in his own childhood (*Planet of the Blind* 7; 13). Kuusisto's prose has a striking kaleidoscopic quality; he attends to subtle changes in the quality of light and explores the creative possibilities of his impaired vision:

It's like living inside an immense abstract painting. Jackson Pollock's drip canvas *Blue Poles* comes to mind, a tidal wash, an enormous, animate cloud filled with light. This is glacial seeing, like lying on your back in an ice cave and staring up at the cobalt sun.

(*Planet of the Blind* 7)

These contestations about what it means to be blind are played out in debates about the naming of the condition. For some, it is important to reject the sense of deficit implicit in many understandings of blindness. John Hull, for example, in his autobiographical account, *Touching the Rock: An Experience of Blindness* (1991), avoids the label: "Increasingly, I do not think of myself as a blind person, which would define me with reference to sighted people and as lacking something, but simply as a whole-body seer" (164). Bolt, adopting a similar stance, advocates the use of "person-first" language in his literary critical writing, favouring the terms "people with" or "people without visual impairments" to invert normative notions of blindness as a lack. By contrast, the American National Federation of the Blind refuses to avoid "such straightforward,



respectable words as *blindness, blind, the blind*" (Jernigan). In line with models of Deaf pride or "Crip" theory, they suggest that blindness is a label that should be actively appropriated and defined by blind people themselves as a social and cultural identity.

Kirtley argues that debates about language and terminology can ring hollow. Changing the words we use is not "likely to be effective", he suggests, unless attitudes have already improved because "without change, the older, prejudicial meanings would simply become reattached to the liberalized vocabulary" (41). It is difficult, however, to see how the process of changing attitudes can be entirely separated off from challenging dominant assumptions about blindness that are embedded in everyday language and influential cultural narratives. As the self-absorbed narrator of Carver's "Cathedral" suggests, "My idea of blindness came from the movies. In the movies, the blind moved slowly and never laughed. Sometimes they were led by seeing-eye dogs" (196). These stereotypical associations between physical slowness, dependency and blindness, given voice by the narrator in Carver's story, connect to frequent everyday metaphorical usages of blindness as a synonym for ignorance, limitation, concealment and a lack of control. In the *Collins English Language Dictionary*, for example, only four of the thirty-three entries relate to medical definitions of visual impairment. Abstract and metaphorical meanings predominate, from the use of blindness to connote a kind of stupor, such as being "blind drunk" or love-struck, to its use as an adjective describing restricted knowledge, such as a blind corner or blind spot. In these contexts, blindness becomes a "problem of knowing" (Michalko 5). If, as the maxim suggests, to see is to believe, then the inverse is also implied: blindness becomes linked to uncertainty, to a state of not believing or knowing, and a lack of clarity or rationality.

"The metaphor of blindness", Naomi Schor reminds us, "is inscribed in a critical genealogy that links Rousseau to Derrida and Derrida to de Man" (79). Sight-centred epistemologies are embedded in literary critical language that "focuses on" or "illuminates" a text and seeks critical enlightenment and insight. Foundational myths about the supposed connection between blindness and insight are explored in literary works from the clairvoyant prophet Tiresias in ancient Greek mythology to the fortune-telling Thérèse in Toni Morrison's *Tar Baby* (1981). The fluid and often unquestioned movements between conceptions of seeing as a physical and a cognitive or critical activity are underpinned by a normative conception of the able body. However, as Schor points out, in many literary texts and everyday contexts blindness is a "devalued metaphor" (78). Yet, these ingrained narratives and metaphorical associations cannot be simply stripped away; decisions have to be made about language and

terminology. Helen Keller in *The World I Live In* (1908) addresses this in a forthright manner. After telling the story of how she was “taken to see a woman”, Keller adds a footnote saying: “The excellent proof-reader has put a query to my use of the word ‘see’” (19). She politely but sharply rejects the proof-reader’s misgivings, pointing out that “If I had said ‘visit’ he would have asked no questions, yet what does ‘visit’ mean but ‘see’ (*visitare*)?” (19). She adds that her intention was to “us[e] as much of the English language as I have succeeded in learning” (19).

Keller refuses to allow her visual impairment to limit the range of her linguistic expression. She argues that when writing her books, which are clearly addressed to a sighted majority, she has to make use of the language system that she finds herself within. Kleege, reflecting on Keller’s works in *Blind Rage*, extends the point: “no special vocabulary exists to represent deaf-blind experience, and even if you could invent such a vocabulary, it would be incomprehensible to seeing-hearing readers” (102–3). Kleege and Kuusisto’s twentieth-century memoirs, written in dialogue with Keller, but also in the era of the disability rights movement, self-consciously lack “the requisite trauma and drama” or indeed the sentimentality of many traditional narratives about blindness; their accounts of everyday life refuse to conform to the stereotypical templates of the blind mystic or what Kleege calls the “blind whiner” (*Sight* 5). Like Keller, they remain highly attuned to the assumptions about visuality embedded within everyday language, metaphors and many canonical narratives, but they also explore the possibility of challenging these sensory hierarchies through the process of writing itself.

### **Embodied Sightlessness**

Both Lawrence’s “The Blind Man” and Carver’s “Cathedral” build up to climactic scenes in which sighted characters are temporarily deprived of their sight and, as a result, experience their surroundings in a radically new way. In this sense, both short stories represent a form of thought-experiment on the part of the authors who use fictional settings to explore alternative modes of consciousness. The title of Lawrence’s story, “The Blind Man”, introduces the protagonist in anonymous terms; he is presented as the kind of “hypothetical blind man” that recurs as a stock character in the western philosophical tradition (Kleege “Blindness and Visual Culture: An Eyewitness Account” 450). This “blank figure upon whom the epistemological theories and assumptions of the sighted author were projected” can be traced back to Descartes’s *Dioptrique* (“On Optics”, 1637) and through works by Locke and Diderot (Paterson 97).

The primary function of the hypothetical blind man is, Kleege argues, to serve merely as a prosthetic “prop for theories of consciousness”, to “highlight the importance of sight and to elicit a frisson of awe and pity which promotes gratitude among the sighted theorists for the vision they possess” (“Blindness and Visual Culture: An Eyewitness Account” 447–48). In Lawrence’s short story, the narrator’s third-person perspective creates a striking sense of distance: “He had been home for a year now. He was totally blind. Yet they had been very happy” (46). When Bertie, a visitor to the house, arrives, the narrative itself becomes permeated by a sense of unease: “The blind man was silent...Bertie made her conscious of a strangeness” (Lawrence 57). However, “the blind man” is soon named; as “Maurice”, he acquires an identity and an embodied presence that complicates the idea of him as an entirely abstract philosophical construct or a pitiable figure. In fact, before Bertie’s arrival, the couple, Maurice and Isabel, share an “unspeakable intimacy”, a “dark and palpable joy” and a life that is “very full” and “strangely serene” (Lawrence 46). Since Maurice returned from war with his visual impairment, they have enjoyed a “newly and remotely happy” life together (Lawrence 46). At this early stage, the narrative has a multisensory quality to it; the sighted figure of Isabel is attuned to the nuances of sound and touch: “the sound of wheels on the drive...the noise of her husband’s footsteps in the hall” (Lawrence 46). When she seeks out Maurice as he works in the darkened cattle shed, it is Isabel, rather than Maurice, who finds herself in a position of sensory deprivation and dependency, guided only by the “smell of horses, and ammonia”, “the sound of his voice seemed to touch her” (Lawrence 51; 52).

Yet, as it progresses, Lawrence’s story slips into binary forms of representation: Maurice’s silence and “blood-contact” with the earth is represented in stark opposition to Bertie who is lofty, cerebral, and associated with language: he is a man of letters, a “*litterateur*” (Lawrence 54; 58). Bertie introduces into the text, and into the home of Isabel and Maurice, an alternative model of blindness as a deficiency to be lamented (Lawrence 59). The story’s climactic scene, in which Maurice impels Bertie to trace his eyebrows, to touch his face and to feel his scar, results not in a unifying shared experience, but rather a complete breakdown of communication between them: while Maurice proclaims their new-found friendship, Bertie feels nothing but “revulsion” (Lawrence 62). This fracturing of their relationship and of their communication is endowed with a distinctly visual quality in the stark final image of Bertie as a “mollusc whose shell is broken” (Lawrence 63).

Lawrence’s “The Blindman” is experimental in the sense that it introduces a connection between disability and pleasure, and also in the way

that the author places different social models of blindness, as a source of “rich positivity” or dependent deficiency, alongside each other (Lawrence 54). The narrative hints at an alternative, “new way of consciousness” on Maurice’s part (Lawrence 54). Yet, even as this alternative mode of consciousness is described, it is conceived in purely binary terms as a negation of the visual: “He did *not* think much or trouble much...he wanted *no* intervention of visual consciousness....He did *not* try to remember, to visualise. He did *not* want to” (Lawrence 54; my italics). Nevertheless, the fleeting encounters in the darkness between Isabel and Maurice, and between Bertie and Maurice, do, albeit momentarily, invite readers to think differently about perception and alternative ways of experiencing the world.

Traditional critical readings of Lawrence’s story tend to minimise the distinctly physical, embodied aspects of the narrative. Clausson, for example, reads “The Blind Man” as “an allegory of (partial) authorial blindness: the blindness of Lawrence’s blind man, then, is a figure for the blindness of Lawrence to those meanings that escape his conscious control” (110). In one sense, this metaphorical reading reduces Maurice to the status of a one-dimensional “hypothetical blind man”. But the idea of exploring cultural representations of blind people in order to reflect on the creative process itself is a recurring critical trope. Derrida, for example, in *Memoirs of the Blind* (1993), takes portraits of blind people in the Louvre art gallery as his starting point. As in Lawrence’s story, Derrida suggests that there is a mixture of discomfort and fascination involved in the act of looking at the blind. Derrida uses the figure of the blind draftsman to explore the way in which whenever someone writes, draws or paints, they necessarily look away from their subject and instead re-create the image from the one that is in their mind’s eye. In this sense, memory always “supplements” sight:

A hand of the blind ventures forth alone or disconnected...it feels its way, it gropes, it caresses as much as it inscribes, trusting in the memory of signs and supplementing sight...This eye guides the tracing outline; it is a miner’s lamp at the point of writing, a curious and vigilant substitute, the prosthesis of a seer who is himself invisible.

(Derrida and Musée du Louvre 3)

For Derrida, therefore, creative and aesthetic processes are intimately bound up with moments of not seeing. The hand that gropes in the dark represents a movement *towards* knowledge, a struggle to remould an image or an idea through creative invention rather than a direct process of mirroring.

Carver's short story, "Cathedral", also explores this act of translating an idea from one form into another, both as an abstract concept and as a physical process. Like Lawrence's "The Blind Man", "Cathedral" dramatizes the tensions between a trio of characters: Robert, a blind visitor to the house, the husband (and narrator), and his wife, who remains nameless throughout. Like the climactic scene between Bertie and Maurice in Lawrence's story, the final moments in "Cathedral" feature an encounter between the narrator and Robert, the blind visitor, in which touch substitutes for sight. Sitting watching a television documentary, the narrator is confronted with the limits of visual and verbal forms of communication: "I stared hard at the shot of the cathedral on the TV. How could I even begin to describe it? 'I can't tell you what a cathedral looks like. It just isn't in me to do it. I can't do any more than I've done'" (Carver 212). Robert encourages the narrator to close his eyes and to use his imagination to draw out the shape of a cathedral; he places his hands on top of the narrator's as he sketches. The result is a moment of unexpected intimacy. Up until this moment, the narrator's prejudices about blind people have been extremely close to the surface: he does not want his wife's blind friend in the house, he is surprised to see him smoking, joking, wearing a beard but no dark glasses and displaying a "spiffy" dress sense (Carver 202). In this climactic scene, the savage cynicism that dominates his narration in the rest of the story is replaced with a moment of genuine revelation. In contrast to the breakdown of communication at the end of Lawrence's story, the two men are united in a moment of shared imagination and creativity: "His fingers rode my fingers as my hand went over the paper. It was like nothing else in my life up to now" (Carver 214). Closing his eyes, the narrator tries to imagine, for the first time, his companion's perspective; touch, rather than visual or verbal perception, becomes the primary means of sensation and communication: "My eyes were still closed. I was in my house. I knew that. But I didn't feel like I was inside anything... 'It's really something,' I said" (Carver 214).

Through their representations of blindness, Lawrence and Carver invite both blind and sighted readers to think in alternative ways about perception and, briefly, to attempt to inhabit another form of consciousness. Through their engagement with visual impairment on an empathetic and aesthetic level they provide a way into these complex debates.

## Conclusion

The depiction of everyday epiphanies in the short stories by Lawrence and Carver resonate with the description of creative imagining and

reinvention in Kuusisto's work. In *Eavesdropping*, Kuusisto observes that "as things happen around us we reinvent what we hear like courtroom artists who sketch as fast as they can" (xi). Like Derrida's blind draftsman, Kuusisto insists that "in reality I cannot see the world by ear, I can only reinvent it for my purposes" (*Eavesdropping: A Life by Ear* xi). The result is a reconceptualised experience of sound, space and architecture:

Alone in unfamiliar hotel lobbies, we survey our surroundings and hear in the ambient curves of architecture a hundred oddities. We hear the movements of strangers; hear their laughter; hear pennies dropped in the Hilton's fountain; the bristles of a shoeshine brush; the wings of a pigeon that has made its way indoors. The blind hear all this while they're locating the chiming bells of the elevators.

(Kuusisto *Eavesdropping: A Life by Ear* xi)

These alternative approaches to the experience of space, architecture and other cultural objects, rooted in the experience of blindness, have been explored by artists in museum settings. Blind visual artist Carmen Papalia, for example, runs "blind field shuttle" walking tours of north American cities and guided routes around museum spaces including the Whitney Museum of American Art, the Solomon R. Guggenheim Museum and the Museum of Modern Art in New York. Like the protagonists in the stories by Carver and Lawrence, sighted participants are invited to close their eyes in order to experience familiar spaces and architectural shapes through their non-visual senses. Art objects are often described by a partner who leads the collaborator-participant around the gallery. The emphasis is on sensory discovery and alternative ways of mapping public and institutional spaces; the experiences raise questions about art but also about access.

The examples discussed in this chapter, from Kleege and Kuusisto to Lawrence, Carver and Papalia, share a common concern with destabilising the relationship between sight and knowledge and exploring the creative possibilities of visual impairment. Underpinning the analysis is a sense of the fundamental ways in which disability studies approaches can shift understandings of the body and the process of representation itself. As Siebers argues:

Blind hands envision the faces of old acquaintances. Deaf eyes listen to public television. Tongues touch-type letters home to Mum and Dad. Feet wash breakfast dishes. Mouths sign autographs. Different bodies require and create new modes of representation. What would

it mean for disability studies to take this insight seriously? Could it change body theory if it did?

(54)

As the Papalia example suggests, literary writing is just one of the forms grappling with the challenge to create new modes of representation. An embodied, phenomenological approach to analysis requires us to flesh out our metaphors, to challenge established aesthetic and sensory hierarchies, and to think through the ways in which bodily representations are mediated through text. Now and in the future, this requires scholars and readers to think about literature in its very widest sense, to consider how new technologies such as voice synthesisers and computer scanners open up access to texts and also create new forms that offer powerful models for the participatory, collaborative reading practices and imaginative processes that we are all engaged in whenever we read or write.

### Further Reading

- David Bolt. *The Metanarrative of Blindness: A Re-Reading of Twentieth-Century Anglophone Writing*. Ann Arbor: University of Michigan Press, 2014.
- Mary Klages. *Woeful Afflictions: Disability and Sentimentality in Victorian America*. Philadelphia: University of Pennsylvania Press, 1999.
- Georgina Kleege. *Sight Unseen*. New Haven, CT: Yale University Press, 1999.
- Stephen Kuusisto. *Planet of the Blind*. New York: Dial Press, 1998.
- Mark Paterson. "Blindness, Empathy, and 'Feeling Seeing': Literary and Insider Accounts of Blind Experience." *Emotion, Space and Society* 10(2014): 95–104.
- Naomi Schor. "Blindness as Metaphor." *Differences: a Journal of Feminist Cultural Studies* 11.2 (1999): 76–105.

### Bibliography

- Berger, Roland J. *Introducing Disability Studies*. Boulder: Lynne Rienner Publishers, 2013. Print.
- Bolt, David. "The Blindman in the Classic: Feminisms, Ocularcentrism and Charlotte Brontë's *Jane Eyre*." *Textual Practice* 22.2(2008): 269–289. Print.
- Borges, Jorge Luis. "Blindness." Trans. Allen, E., S.J. Levine, E. Weinburger. *Selected Non-Fictions*. New York: Viking, 1999. 473–483. Print.
- Carver, Raymond. "Cathedral." *Cathedral*. London: Vintage, 2009. 196–214. Print.
- Clausson, Nils. "Practicing Deconstruction, Again: Blindness, Insight and the Lovely Treachery of Words in D.H. Lawrence's 'The Blind Man'." *College Literature* 34.1(2007): 106–128. Print.

- Coetzee, J.M. *Waiting for the Barbarians*. London: Secker & Warburg, 1980. Print.
- “Collins English Dictionary.” Web. 16 June 2014.
- Derrida, Jacques and Musée du Louvre. *Memoirs of the Blind: The Self-Portrait and Other Ruins*. Chicago: University of Chicago Press, 1993. Print.
- Diderot, Denis. *Diderot’s Early Philosophical Works*. New York: AMS Press, 1973. Print.
- Faulkner, William. *Soldier’s Pay*. Harmondsworth; New York: Penguin, 1976. Print.
- Hull, John M. *Touching the Rock: An Experience of Blindness*. London: Arrow Books, 1991. Print.
- Jernigan, Kenneth. “The Pitfalls of Political Correctness: Euphemisms Excoriated.” *Braille Monitor* 36.8(1993). Web. 6 June 2014.
- Keller, Helen. *The World I Live In*. Ed. Shattuck, R. New York: NYRB Classics, 2003. Print.
- Kirtley, D. D. *The Psychology of Blindness*. Chicago: Newlson-Hall, 1975. Print.
- Klages, Mary. *Woeful Afflictions: Disability and Sentimentality in Victorian America*. Philadelphia: University of Pennsylvania Press, 1999. Print.
- Kleege, Georgina. *Sight Unseen*. New Haven, CT: Yale University Press, 1999. Print.
- Kleege, Georgina. *Blind Rage: Letters to Helen Keller*. Washington: Gallaudet University Press, 2006. Print.
- Kleege, Georgina. “Blindness and Visual Culture: An Eyewitness Account.” *The Disability Studies Reader*, Ed. Davis, Lennard J., 4th ed. New York and London: Routledge, 2013. 447–455. Print.
- Kuusisto, Stephen. *Planet of the Blind*. New York: Dial Press, 1998. Print.
- Kuusisto, Stephen. *Eavesdropping: A Life by Ear*. 1st ed. New York: W.W. Norton, 2006. Print.
- Larrissy, Edward. *The Blind and Blindness in Literature of the Romantic Period*. Edinburgh: Edinburgh University Press, 2007. Print.
- Lawrence, D.H. “The Blind Man.” *England, My England and Other Stories*. Ed. Steele, Bruce. Cambridge: Cambridge University Press, 1990. 46–63. Print.
- Magee, Bryan, and Martin Milligan. *On Blindness: Letters between Bryan Magee and Martin Milligan*. Oxford; New York: Oxford University Press, 1995. Print.
- Michalko, Rod. *The Two in One: Walking with Smokie, Walking with Blindness*. Philadelphia: Temple University Press, 1999. Print.
- Molyneux, William. “Letter to John Locke, 2 March 1693.” *The Correspondence of John Locke (9 Vols.)*. Ed. de Beer, E.S. Oxford: Clarendon Press, 1979. vol. 4, no. 1609. Print.
- Morrison, Toni. *Tar Baby*. New York: Knopf, distributed by Random House, 1981. Print.
- Omansky, Beth. *Borderlands of Blindness*. Boulder, CO: Lynne Rienner, 2011. Print.
- Papalia, Carmen. “Long Time No See.” 2013. Web. 2 August 2014.



Paterson, Mark. "Blindness, Empathy, and 'Feeling Seeing': Literary and Insider Accounts of Blind Experience." *Emotion, Space and Society* 10(2014): 95–104. Print.

Schor, Naomi. "Blindness as Metaphor." *Differences: A Journal of Feminist Cultural Studies* 11.2(1999): 76–105. Print.

Siebers, Tobin. *Disability Theory*. Ann Arbor: University of Michigan Press, 2008. Print.

Woolf, Virginia. "On Being Ill." Ed. Lee, Hermione. Ashfield: Consortium, 2002. Print.

## 7 Cognitive Difference and Narrative

William Faulkner described his 1927 novel, *The Sound and the Fury*, as “the most gallant, the most magnificent failure” of all of his books. “I couldn’t leave it alone, and I could never tell it right”, he continued, “though I tried hard and would like to try again, though I’d probably fail again” (*Faulkner in the University: Class Conferences at the University of Virginia, 1957–1958* 61).

The novel’s title recalls the final soliloquy from Shakespeare’s *Macbeth* which compares life to “a tale / Told by an idiot, full of sound and fury / Signifying nothing” (105). The first section of the novel is narrated by Benjamin Compson, a character labelled an “idiot” by other characters. Far from “signifying nothing”, scholars have, until recently, read Benjy’s presence in the narrative as signifying everything from a curse on a morally corrupt family to a symbol of the decaying powers of the American south (Mellard 239; Morris and Morris 136). Everything, that is, except as being about the relationship between narrative and cognitive difference itself.

Faulkner’s “magnificent failure” represents an attempt to capture what has been seen as an unknowable ontological position (Halliwell 18). His sense of failure may stem from a recognition of the barriers to his own understanding: writing from his privileged subject position as a white American man of “normal” intelligence, how could Faulkner even begin to imagine the inner thoughts of a cognitively impaired character who was excluded from education, state institutions and even from his own family? Alternatively, Faulkner’s sense of failure could be attributed to a typically Modernist questioning of the possibility of narrative representation itself: his struggle to represent cognitive difference reminds readers of the impossibility of ever “reading” another person’s mind or accurately capturing their point of view in writing. In this sense, the depiction of Benjy’s complex, fragmented thought processes exposes the workings of narrative itself and challenges the idea that literary

representation acts as a window into the mind of another. As Michael Bérubé suggests: “Mindedness is so obviously a necessary condition for self-representation and narration that it should be no surprise to find various depictions of damaged mindedness serving neither as moral barometers nor as invitations to pity or horror but as mediations of the possibility of narrative representation” (“Disability and Narrative” 572).

This chapter takes up three examples of texts that explore, in complex ways, the possibilities of narrative representation in relation to cognitive impairment and difference: Faulkner’s *The Sound and the Fury* (1929), Mark Haddon’s *The Curious Incident of the Dog in the Night-Time* (2003) and Naoki Higashida’s *The Reason I Jump* (Japanese, 2005; English, 2013). The texts are from strikingly different contexts: Faulkner was writing in the 1920s in the American south, Haddon in London at the turn of the millennium, and Higashida in twenty-first-century Japan. The books engage with very different conditions or ways of being in the world. The works by Faulkner and Haddon are novels by non-disabled authors who imagine characters with cognitive impairments and Asperger Syndrome; Higashida is a teenage author with autism who interweaves autobiography and fiction. What connects these texts is their experimental, often radical approach to narrative. Through first-person perspectives they explore the potential for writing to render a disabled perspective normal and to explore “insider” narratives about cognitive difference.

Faulkner, Haddon and Higashida all engage with conditions that were or are widely perceived as constituting “epidemics” in their day. Through his writing, Faulkner taps into a climate of fears about “feeble-mindedness” at the beginning of the twentieth century; Haddon and Higashida write against a backdrop of a huge explosion of diagnoses and writing about autism at the beginning of the twenty-first century. Analysing these literary examples can help us to think through “feeble-mindedness” and autism as shifting categories with distinct representational histories, as powerful cultural metaphors, and as embodied, individual ways of being in the world, which represent an important area of critical study in their own right.

### **Labelling Cognitive Impairment**

In recent years, disability studies has been criticised for its lack of engagement with cognitive, intellectual or neurological disabilities. Mark Osteen suggests that this disciplinary gap has replicated a wider social avoidance, “thereby excluding the intellectually disabled just as mainstream society has done” (3). “These missing discursive pieces have”, he continues, “disabled disability studies, preventing the field from achieving

sturdier and more sophisticated theoretical groundings” (3). For Osteen, the field’s “neo-Cartesian duality”, which posits a split between body and mind, and between impairment and disability, is rendered problematic by an area of study that requires scholars to think about the brain as both a bodily organ and a source of consciousness (4). Stuart Murray also notes an emphasis on questions of the body in disability studies, particularly physical and sensory impairments (“Autism and the Contemporary Sentimental: Fiction and the Narrative Fascination of the Present” 25). Like Osteen, Ralph Savarese argues that the “discomfort” with which disability studies has taken up questions of cognitive difference is connected to the fact that the social constructionist models of disability fit more easily with physical disabilities in which “disabling” environmental factors and social attitudes can be clearly located outside of the individual with impairments.

Many disability rights campaigners have therefore promoted self-advocacy and have argued that the voices of people with disabilities should be privileged. The issue then, as Joseph N. Straus puts it, is in part a “problem of narration: the member of the minoritized social group should be able to resist medicalized discourse by speaking for him or herself” (462). This idealised model of independent self-representation and self-reflection is, however, complicated by the question of how the rights, preferences and stories of people with, for example, nonverbal autism can be articulated. As Higashida asks in *The Reason I Jump*, “Can you imagine how your life would be if you couldn’t talk?” (40). In the fictional realm, what are the ethical, political and aesthetic implications of depicting characters who cannot narrate their own experience or seem unable to understand the narrative that they inhabit? These complex questions require an innovative approach to storytelling and to disability studies criticism since they challenge conventional notions of authorship and narration.

The commitment to privileging the voices and perspectives of people with disabilities must not, Bérubé argues, come at the cost of subscribing to a narrow, normalising understanding of narrative:

I am not suggesting that all the characters in a narrative should in principle be able to narrate themselves and that any narrative involving a character who cannot narrate themselves is somehow exploitative. On the contrary, the dynamics of disability compel us to recognize that there will always be among us people who cannot represent themselves and must be represented.

(“Disability and Narrative” 572)

This close attention to the power dynamics involved in “speaking for” or “speaking with” others can work on many different levels: writers such

as Faulkner and Haddon put words into the mouths of fictional protagonists who are read as, in some ways, representative of a condition. For some, these fictional “thought-experiments” might be seen as acts of sensationalist exploitation in which the author is “passing” as disabled and using the veil of fiction to provoke shock or sympathy (Bérubé, “Disability and Narrative” 575). Burks-Abbott argues that fictional representations can undermine autobiographical work because they imply that people with autism or cognitive disabilities need their stories to be mediated by non-disabled “professional” writers (295). Yet even Higashida’s autobiographical “insider” account, implicitly claims to “speak for” people with autism in a collective sense that could be seen as problematic. These complex ethical and aesthetic debates about voice, and the power dynamics involved in storytelling, pose questions that are difficult but important for the future of disability studies, and for thinking through the status of narrative in the discipline.

There is, therefore, a tension between attending to the dangers of speaking for certain groups in a collective sense, and the need – critically, politically, aesthetically – to find a way of talking about cognitive difference, in the academy and in society in general. In her introduction to a special issue of *The Journal of Literary and Disability Studies* on cognitive impairment (2008), Lucy Burke wonders: “whether *cognitive difference* or *cognitive disabilities*, would have been better terms. Perhaps the key point is that we have a political and ethical obligation to recognize the very fact that this kind of terminology is never adequate” (i). The terminology in this area is in a constant state of flux: the American Association on Intellectual Development and Disabilities shifted from using “mental retardation” to “intellectual disability” in 2007, a definition which stresses limitations in intellectual functioning and adaptive behaviour but also acknowledges the significance of social and environmental surroundings (Meyer 268). Margaret Price offers a gloss which highlights the problems of labelling conditions of the mind: “mental illness (madness), cognitive disabilities (mental retardation, intellectual disabilities), autism spectrum disorder (neuroatypicality), and learning disabilities (learning difficulties)” (Price 118). C.F. Goodey, in a study of intelligence and “intellectual disability”, looks to literary history to highlight the cultural contingency of the category: “The medieval fool may have had outlandish characteristics, but his description bears no resemblance at all to any modern psychological diagnosis”. This chapter uses the term “cognitive difference” in an attempt to capture both the breadth of this shifting category, and to acknowledge the recent activist argument that autism in particular is just a different way of interacting with and being in the world, rather than an identifiable impairment.

The rapidly changing, culturally contingent nature of these categories is evident in the literary examples discussed in this chapter. Faulkner was writing at a point when the Binet Scale, an early version of the IQ test introduced in the United States in 1908, fuelled widespread anxiety about the “intelligence” of American citizens and the threat of the so-called “feeble-minded in our midst” (Cincinnati 18). Taken up by a growing eugenics movement, labels such as “idiot” and “moron” were recognised as legitimate medical categories in this period. The intelligence of US citizens became a matter policed by the state through organisations such as the National Committee for Mental Hygiene, which resulted in the widespread institutionalisation of those regarded as being below the desired norm. In 1927, just two years before *The Sound and the Fury* was published, a landmark case in the US Supreme Court, *Buck vs. Bell*, legitimised the sterilisation of those deemed to be “feeble-minded”. Idiocy became a “symbolic repository for that which defies categorization” (Halliwell 4), as paupers, prostitutes, criminals and people with physical disabilities were assimilated with so-called idiots and morons into a homogenised category of “defective delinquents” (Cincinnati 22). The apparent coherence of these categories became a convenient fiction that supported the implementation of policies of segregation and the institutionalisation of those who were different. This policy context figures in the text through the frequently repeated threat to Benjy that he will be “sent to Jackson” (Faulkner *The Sound and the Fury* 45).

The tendency to conflate very different conditions into a single category can also be seen in early discussions of autism. As a diagnostic category, autism was identified by Blueler in 1911 but further definition of the condition did not happen until the 1940s when it was theorised in more detail by Leo Kanner and Hans Asperger. Kanner, writing in 1943, describes observing a group of children who he came to label as autistic: “Several children of our group were introduced to us as idiots or imbeciles, one still resides in a state school for the feeble-minded, and two have been previously considered as schizophrenic” (242). Many years later in the twenty-first century, the definition of autism remains fluid and subject to debate. This fluidity of definition has led Ian Hacking to argue that the autistic spectrum itself can be seen as a “moving target” in that it has distinct biogenetic origins but it is also culturally contingent (“Autistic Autobiography” 1467).

The fact that the protagonists, Benjy in *The Sound and the Fury* and Christopher in *The Curious Incident of the Dog in the Night-Time*, are never specifically labelled with a particular condition has led certain readers and scholars to attempt to “diagnose” these characters themselves. Bérubé suggests that “Faulkner based his portrait of Benjy

Compson on a local Mississippi man with Down Syndrome” (xv) while others have read the character as “severely retarded” or “autistic” (Churchwell). Disability studies scholars such as Murray have identified contemporary novels such as Simon Armitage’s *Little Green Man* (2001) and Nick Hornby’s *About a Boy* (1998) as texts that assert an “autistic presence” even if they do not explicitly refer to autism (“Autism and the Contemporary Sentimental: Fiction and the Narrative Fascination of the Present” 29). Other critics have engaged in a more controversial process of retrospective diagnosis, identifying fictional characters from literary history such as Conan Doyle’s Sherlock Holmes or Dickens’s Barnaby Rudge as “autistic”, thereby attributing labels to them that would certainly not have existed in the period (Frith 43; Grove 139).

This precarious process of labelling is parodied in Haddon’s *The Curious Incident*. With characteristic directness, the narrator and protagonist Christopher declares:

All of the other children at my school are stupid. Except I’m not meant to call them stupid, even though that is what they are. I’m meant to say that they have learning difficulties or that they have special needs. But this is stupid because everyone has learning difficulties because learning to speak French or understanding Relativity is difficult, and everyone has special needs.

*(The Curious Incident of the Dog in the Night-Time 56)*

The reference to learning languages and understanding relativity here exposes another form of cultural relativism: since the ways in which intelligence is defined constantly shift, the establishment of a “norm” requires the delineation of a group that fails to match up to the current definition. Haddon parodies the political correctness of 1990s Britain, but also highlights the ways in which the details of language can segregate and mask more subtle understandings of intelligence as a complex continuum or spectrum. As Higashida suggests early in *The Reason I Jump*, “When I was small, I didn’t even know that I was a kid with special needs. How did I find out? By other people telling me that I was different from everyone else, and that was a problem” (15). Language takes on a performative function in this example: labelling and inducting Higashida into an identity which has more to do with social interactions than biological determinism.

### ***The Sound and the Fury: Memory and Multisensory Narrative***

*The Sound and the Fury* challenges conventional modes of expression and hierarchies of the senses. Thirty-three-year-old Benjy is described

from the outside by other characters in terms that are infantilising and even dehumanising, “slobbering and moaning”, a “baby”, a “damn looney”, and a “big foolish dog” (Faulkner *The Sound and the Fury* 43; 5; 8; 298). Yet, the first section of the novel is narrated from Benjy’s interior, first-person perspective. Despite the striking simplicity of the syntax and punctuation, his narrative is notoriously difficult to read. Timeframes dissolve into each other, images provoke floods of associations and, as a narrator, Benjy does not distinguish where the boundaries of his body end and the outside world begin. The regularly repeated refrain, “*Caddy smelled like trees*” (Faulkner *The Sound and the Fury* 36), exemplifies this coexistence of past and present in the narrative. It signals, for example, the physical presence of Caddy but also triggers a childhood memory in which the Compson children watch their sister as she climbs a tree. This memory is related as a vivid present tense experience: “We looked up into the tree where she was” (Faulkner *The Sound and the Fury* 36).

Benjy’s unedited memories draw on Modernist stream of consciousness techniques that defy conventional linear narrative structures through the depiction of unedited memories. This has led many scholars to read Benjy, who appears unable to communicate verbally with other characters in the text, as a passive “textual vehicle” (Halliwell 21). For example, Wesley Morris and Barbara Alverson Morris view Benjy as a deficient narrator, capable only of echoing other people’s words: “Language is associated with lacking (‘he can’t talk’)...Surrounded by words he cannot use... Benjy’s narrative is predominantly the voices of others he hears” (136). Mellard also emphasises Benjy’s passivity as a narrator who reflects the words of others: “His instinctive responses...permit him to serve accidentally as a mirror of moral conscience, in which the various members of the family can see their own actions...and [are] implicitly evaluated” (239).

However, the idea that either characters or language fulfil a straightforward mimetic function in *The Sound and the Fury* is completely disrupted by a close reading of the text itself. The first section of the novel is full of literal mirror moments, but these serve only to destabilise the certainties of realist modes of viewing and to highlight the power that Benjy has as a narrator to determine what is seen by readers. His description of everyday domestic settings is rendered in multiple different dimensions, giving it an almost kaleidoscopic quality: “*There was another fire in the mirror*” (50); “Father put me down and went into the mirror” (Faulkner *The Sound and the Fury* 50; 53).

The reductive, stereotypical views of the “feeble-minded” from the period in which *The Sound and the Fury* was written are evident in the text. Luster, for example, conflates different forms of disability and sees Benjy as being in complete sensory isolation: “He deaf and dumb”



(Faulkner *The Sound and the Fury* 40). *The Sound and the Fury* occupies a place in a long and often illustrious literary tradition of work about “idiots”, which includes Shakespeare’s fools and Dostoevsky’s *The Idiot* (1869). Conrad’s 1896 text “The Idiots” offers an external perspective on the protagonist whose glance was “unseeing and staring”, surmising that “probably the image passed before the eyes without leaving any trace on the misshapen brain of the creature”. At the turn of the twentieth century, there were a flurry of texts that similarly depicted “the idiot” as a figure of comic alienation, such as W.C. Morrow’s *The Ape, the Idiot and Other People* (1897). John Kendrick Bangs’ comic illustrated novel from the same period, *The Idiot* (1895) ran to a sequel, the domestic comedy of manners, *The Idiot at Home* (1900).

Although *The Sound and the Fury* represents these stereotypical images through the voices of certain characters, the first section of the novel also attempts something radically different. Faulkner presents Benjy’s perspective from the *inside*, through a first-person narrative that gains implicit authority and power from its position at the start of the novel. The primacy of the visual, traditionally associated with truth, enlightenment and realism, is challenged through Benjy’s attention to smell. The scent of Caddy’s perfume, for example, signals her sexual awakening and a change in Caddy that Benjy is aware of before any other character. The smell of trees represents a comforting return to the past which subtly suggests moments of calm, pleasure, and apparent innocence. To borrow a phrase from Christopher in *The Curious Incident*, Benjy’s memory has “a smelltrack” (96). In contrast to the unseeing eyes and unresponsive bodily surfaces depicted in Conrad’s “The Idiots”, Faulkner’s Benjy has a heightened sensitivity to his surroundings, a powerfully detailed memory, and a striking sensory acuity. The hierarchy of the senses, and of narrative chronology, are destabilised in favour of an impressionistic account that blurs the boundaries and emphasises the importance of smell and touch:

*She smelled like trees. In the corner it was dark, but I could see the window. I squatted there, holding the slipper. I couldn’t see it, but my hands saw it, and I could hear it getting night, and my hands saw the slipper but I couldn’t see myself, but my hands could see the slipper and I squatted there hearing it get dark.*

(Faulkner *The Sound and the Fury* 59–60)

Benjy’s narrative highlights the subjective nature of all first-person narration. Like everyone, he experiences his own body in glimpses, fragments and in a multisensory way. In this example, Benjy acknowledges that, as

the light fades, he cannot see himself in a literal sense but other forms of perception are privileged instead.

Churchwell has commented that *The Sound and the Fury* is, in a sense, a “*reductio ad absurdum* of the act of reading itself” in that it highlights the way in which we are always inferring meanings from small details. Like *The Curious Incident*, *The Sound and the Fury* follows the structure of detective fiction, in which readers are given clues but left to actively interpret and piece the fragments together for themselves. Through the use of an intimate first-person perspective that includes memories stretching over a thirty-year period, Faulkner strips away the illusion of a coherent, stable narrative identity. By refusing to provide a frame through which to analyse the story, Faulkner challenges the idea that any narrator can really narrate themselves from the outside. Bérubé argues that, in this way, *The Sound and the Fury* can be seen as a novel that “disables” the conventions of narrative itself and, in doing so, reveals Benjy as an “ideal narrator” rather than a deficient one, due to his richly associative memory and vivid storytelling (“Disability and Narrative” 575). For Kartiganer, the novel is therefore “not too jumbled but too clear”: it “makes sensation” rather than sense (623).

There are undoubtedly moments of fear and frustration linked to Benjy’s inability to verbalise his wishes. His interest in the schoolgirls passing by the fenced garden, for example, read from the outside, appears to contain a sexual threat. Readers, with the benefit of an inside point of view, are party to the more complex emotions and memories of Caddy that the view of the two girls provokes in Benjy. The layered clauses and repetition capture the rising panic and rapid pace of this moment of miscommunication:

I could hear them talking. I went out the door and couldn’t hear them, and I went down to the gate, where the girls passed with their book satchels. They looked at me, walking fast, with their heads turned. I tried to say but they went on, and I went along the fence, trying to say, and they went faster. Then they were running and I came to the corner of the fence and I couldn’t go any further, and I held to the fence, looking after them and trying to say.

(Faulkner *The Sound and the Fury* 42)

Surrounded by barriers – literal fences and verbal failures of understanding – Benjy is depicted as a character caught in the condition of “trying to say”. Through the creative licence of fiction, Faulkner imagines an interior life that includes a strong communicative impulse, deep emotional bonds, a hyper-vigilant awareness of his surroundings and moments of intense

pleasure. Written at a time when people like Benjy would typically have been seen as possessing no interior life at all, Faulkner documents contemporary anxieties about the increasing numbers of “feeble-minded” people in the American south but ultimately rejects the simplistic deficit models of cognitive difference. The lyrical beauty of the language in *The Sound and the Fury* acts as a powerful early example of the ways in which first-person representations of cognitive difference can inaugurate a radical, experimental approach to language, narrative and the shifting categories of identity.

### **Autism as Metaphor: *The Curious Incident of the Dog in the Night-Time***

The stereotypical depictions of the “idiot” in the nineteenth and early twentieth centuries connected cognitive impairment to sensory and social isolation. For example, Edward Seguin’s *Nervous Diseases* (1869), describes the “blunted surfaces of the idiot”, labelling “feeble-minded” adults as “inert children” (19). This emphasis on isolation can also be found in early definitions of autism. The term autism was coined by Eugen Bleuler in 1911 in his book, *Dementia Praecox*. In 1912, he elaborated:

Autistic schizophrenics [have] turned away from reality; they have retired into a dream life...a world of subjective ideas and wishes, so that to them reality can bring only interruptions.

(20)

This description established a conflation of autism and schizophrenia in the early twentieth century, and set a trend for thinking about autism as a condition that is defined by “blunted” senses and isolation. The term was not taken up again until the 1940s when, in 1943, Leo Kanner, working at Johns Hopkins University in Baltimore, defined “autism” in his article “Autistic Disturbances of Affective Contact”. Just a year later, Hans Asperger working at the University Paediatric Clinic, Vienna, published a paper entitled “Autistic Psychopathy in Childhood”. This historical coincidence adds another dimension to these ideas about autism and isolation. These two doctors – Kanner and Asperger – working independently with no knowledge of each other’s work, both highlighted a condition that had been largely ignored before and gave it the same label. What links the works by Kanner, Asperger and Bleuler together, is their characterisation of the condition in terms of a “profound aloneness”, not only an inability to relate to other people but also a failure to “relate to oneself” (Kanner 242).

Patrick McDonagh argues that the fascination with autism at this particular historical moment was influenced by intersecting medical and cultural movements (101). The rise of modern psychiatry and psychoanalysis coincided with aesthetic Modernism; all three movements shared a fascination with idiosyncratic language, fragmented models of the self, and processes of exclusion (McDonagh 101). The dynamic and reciprocal relationship between medical and cultural discourses that McDonagh identifies highlights the importance of critically analysing representations of cognitive difference in their cultural context. This point is strengthened further by Hacking's suggestion that autism can be seen as both an "indifferent" and an "interactive" condition (*The Social Construction of What?* 115). It is "indifferent" in the sense that its neurological and physiological aspects are not affected by being measured or classified. Yet, it is also interactive in that, Hacking argues, being labelled autistic affects behaviour and this then "loops" back to change the classification itself. According to this view, films, novels and autobiographies might not only reflect a particular view of autism in the period, but they could also play a role in constituting the condition itself. The texts have the potential to shape collective expectations and understandings, which then "loop back" to change an individual's own experience of autism.

*The Curious Incident of the Dog in the Night-Time* may be seen as one such text. Murray, for example, considers that the publication of the novel in 2003 represents an "event" in the history of autism just as Barry Levinson's film *Rain Man* did in 1988 (*Representing Autism: Culture, Narrative and Fascination* 12). *Rain Man*, which narrated autism from the outside, helped to influence a particular popular cultural view of the condition in terms of extraordinary savant skills in mathematics, mapping and memory. Like *Rain Man*, Haddon's fictional text was greeted with huge critical claim and international success in terms of sales. Published in the wake of an explosion in the number of autism autobiographies written since the mid-1980s, *The Curious Incident*, narrated from the first-person perspective of Christopher Boone, coincided with rapid increases in the number of children being diagnosed with forms of Asperger's in the US and the UK. Some scholars greeted the novel enthusiastically: Osteen considered it "by far the best novel with an autistic character yet published" (40); Bérubé judged that it depicted autism "without a whiff of pity or horror – or maudlin sentimentality" ("Disability and Narrative" 574). For other scholars, the novel was part of "the incredible increase in autism narratives in contemporary culture", but the impact of this wave of writing was limited since it had "not led to a profitable revision of public knowledge of what autism is" (Murray *Representing Autism: Culture, Narrative and Fascination* 4). Nevertheless, the vast majority of

commentators agree that, perhaps in part because of the lack of scientific consensus on autism, *The Curious Incident* has been “profoundly influential” (McDonagh 113). Hacking’s notion of “looping” is exemplified in his observation that *The Curious Incident*:

is now taught in the special education segment of teacher training and so, for better or worse, it is having more effect on how autism is conceptualized than most theoretical texts. This is a striking but by no means unusual example of how the genre of autism narrative is helping to shape the very way that autism is understood.

(Hacking “Private Thoughts in Public Language” 12)

Murray argues that *The Curious Incident* is, in this sense, one of a number of fictions that “almost achieve the status of sociological documents in the ways in which their presentation of the condition was received” (*Representing Autism: Culture, Narrative and Fascination* 12). Burks-Abbott suggests that “*The Curious Incident* is the new *Rain Man*, the new definitive, popular account of the autistic condition. Back in the early nineties when I was first diagnosed with autism, the only way I could counter the blank stares when I disclosed my condition was to mention the 1988 movie” (295).

On one level, then, *The Curious Incident* joins company with novels such as Karin Fossum’s *Black Seconds* (2002), Elizabeth Moon’s *The Speed of Dark* (2003), Margot Livesey’s *Banishing Verona* (2004), Camie McGovern’s *Eye Contact* (2006), Claire Morrall’s *The Language of Others* (2008), Jodi Picoult’s *House Rules* (2010), and Sabina Berman’s *Me, Woman Who Dove into the Heart of the World* (2012), all of which draw on and contribute to a public fascination with autism in the late twentieth and early twenty-first centuries. Autism has powerful resonance as a metaphor in twenty-first-century culture. Couser considers autism “the paradigmatic developmental disability” of the postmodern period (*Signifying Bodies: Disability in Contemporary Life Writing* 5); McDonagh asks: “Could not autism be, in part at any rate, an expression of our secret (and very modern) fear of and fascination with isolation, alienation and disintegration?” (113). Straus argues that as an “emblematic psychiatric condition of the late twentieth and early twenty-first centuries”, autism is “simultaneously a medical diagnosis and a cultural force” (461). “Is it”, he asks, “a medical condition (syndrome, disorder, pathology) or is it a social group (an identity, a shared culture)?” (Straus 461).

In this context, the recurring association between autism and isolation in medical discourses may mean that it provides a useful “prosthetic” shorthand or plot device for authors, film-makers and journalists who

want to explore the modern condition of urban isolation and the breakdown of the family and community. There is, for example, a striking association made between autism and terrorism, specifically the 9/11 attacks in the US, in two popular films, one from Hollywood and the other from Bollywood. The 2012 Hollywood film, *Extremely Loud and Incredibly Close*, starred Tom Hanks and Sandra Bullock in Stephen Daldry's adaptation of Jonathan Safran Foer's novel of the same title. The film tells the story of Oskar, a boy with Asperger Syndrome whose father has been killed in the 9/11 attacks in the US. The Bollywood film, *My Name is Khan*, which made it into the top ten highest grossing Bollywood films ever after its release in 2010, tells the story of Rizwan, a boy with Asperger Syndrome, who is falsely accused by the FBI of being a terrorist sympathiser (Johar). Both films draw on the metaphorical potential of autism as a vehicle for thinking about an unspeakable act of terrorism. Both films employ stereotypical notions of autism as a condition with an unexplained cause which limits expression and disrupts the stability of the family unit from within. In a similar vein, this metaphorical flexibility of autism was also invoked in a now infamous article by controversial right wing commentator Niall Ferguson in the UK's *Telegraph* newspaper in 2004. Ferguson argued that "America has got Asperger's": he connected autism and danger, offering a mock-diagnosis of George Bush as a vehicle for critiquing a nation whose citizens, he argued, had become emotionally detached from each other and isolated from the political realities of the rest of the world.

A close reading of *The Curious Incident*, however, suggests a more complex, subtle relationship to metaphor than the sensational or sentimental examples cited above. Christopher, the main character, specifically articulates a preference for simile over metaphor: it is, in his view, a more honest, solid form of expression (*The Curious Incident of the Dog in the Night-Time* 20). He treats "proper novels", like jokes, with similar suspicion, branding them "lies" (*The Curious Incident of the Dog in the Night-Time* 20). Like Benjy in *The Sound and the Fury*, Christopher is sharply attuned to non-verbal forms of communication (gestures, sounds, ways of looking and even smells); as he puts it, "people do a lot of talking without words" (Haddon *The Curious Incident of the Dog in the Night-Time* 19). Murray suggests that the very fact of Haddon's choice of a first-person perspective implies a resistance to treating autism simply as a metaphor: "Making such agency a possibility involves placing the autistic character at or near the centre of the fiction, a process which is at odds with the metaphorical usefulness of autism so common to the majority of narratives that employ representations of the condition" (*Representing Autism: Culture, Narrative and Fascination* 47).

Early in the book, Christopher is shown a series of cartoon faces depicting different expressions and is told by Siobhan, his teacher, that he is likely to find it difficult to read and interpret them: a view that he internalises and repeats later (Haddon *The Curious Incident of the Dog in the Night-Time* 3). Later in the narrative, Christopher suggests that he not only has difficulty interpreting metaphors and faces, but also imagining other perspectives. Discussing strangers he says, “I can’t tell what they’re thinking. It is like being in a room with a one-way mirror in a spy film” (20). Haddon’s portrayal of Christopher’s autism here chimes with Simon Baron-Cohen’s theory of autism as a form of “mindblindness”, a theory which was influential in the period when Haddon was writing. Baron-Cohen suggests that people with autism often lack a “theory of mind”, a phrase that “has come to be shorthand for the capacity to attribute mental states to oneself and to others and to interpret behaviour in terms of mental states” (55). In basic narrative terms, this view might be understood as a failure to imagine another character’s perspective. Since the 1990s, this view of autism has been contested by scholars and activists. For example, Rachel Adams summarises the view that theory of mind is “an outdated and inaccurate description of a condition that, in fact, is often characterized by an enhanced understanding of figurative language .... Instead, it is we neurotypicals who fail to read their – often coded, highly figurative – responses accurately”.

Like *The Sound and the Fury*, the status of *The Curious Incident* as a novel means that it is problematic to read it straightforwardly in terms of accuracy or realism. Many critics, not least Haddon himself, suggest that imaginative licence allows him to create a narrative that is not necessarily consistent with Christopher’s self-proclaimed dislike of metaphor (Haddon “The Curiously Irresistible Debut of Mark Haddon: Author Interviews”). Yet, Christopher’s first-person perspective does seek to render an autistic point of view normal; as readers, we are complicit with his way of seeing the world. *The Curious Incident* is as much a novel about a son’s relationship with his parents, the death of a dog, or post-Thatcherite Britain, as it is about Asperger Syndrome.

As a character on the high-functioning end of the autistic spectrum, Christopher has a sophisticated sense of his narrative as an edited piece of work; he frequently reminds his readers that his story has been edited, polished and produced in collaboration with his teacher, Siobhan. Through Christopher’s self-consciousness, Haddon draws attention to the complex layers of authorship and mediation; it is a crafted piece of work necessarily shaped by the conventions of genre: “This is a murder mystery novel” (Haddon *The Curious Incident of the Dog in the Night-Time* 5). In *The Curious Incident*, meaning is produced in the gaps: in

the gap between author and narrator and in the ironic distance between Christopher's apparent literalism and the invitation to read metaphorically that the form of the novel constantly invites (Quayson 157). This distance can be a source of comedy, such as when Christopher insists that his decision to hit the policeman was not an "accident" (23), but it is also a stark reminder of the gap between different people's perspectives which neither literature nor autobiography can bridge in a straightforward way.

### **Making Connections: *The Reason I Jump***

Like *The Curious Incident of the Dog in the Night-Time*, *The Reason I Jump* begins from the starting point that autism is the norm. The first-person perspectives adopted in both books mean that the individual, autistic point of view is the default position; it is represented as an everyday way of seeing the world rather than an exceptional case to be narrated from outside. *The Reason I Jump* is autobiographical, written by thirteen-year old Higashida. As Hacking points out,

Our instinct is to treat the words of the autobiographies as literal descriptions, albeit tinged with metaphor and coloured by art. That is to say that they are true (or false) according to some pre-existing criteria for describing experiences and sensibilities.

("Autistic Autobiography" 1467)

Reading autobiographical writing alongside first-person fiction about cognitive difference highlights the ways in which they cross-fertilise each other and can also "loop" back to influence ways of imagining and understanding autism in contemporary society. As Hacking asks: "Are the autobiographies and other stories less telling what it is like to be autistic than constituting it, both for those who inhabit the autistic spectrum, and for those who do not?" ("Autistic Autobiography" 1467). Clearly autobiography is more than a "window" into the mind of another person. Instead, there is a complex interplay between life writing, novels, films, media and other cultural representations: stories, metaphors, and tropes are circulated, borrowed, and reconfigured in the dialogue between the different forms. Metaphors and narratives are not merely decorative or vehicles for conveying meaning, they constitute influential shifting, culturally contingent understandings of the condition.

Higashida himself suggests that literature, film, and the media not only provide a rich repository for contemporary understandings of cognitive difference, but they can also play an active role in constructing a sense of a cultural, cognitive "norm": "Via TV, books and just tuning in to the



people around me, I'm constantly learning about how ordinary people are supposed to feel in given situations" (114). Higashida challenges the implicit power dynamic in which an autobiography about autism may be seen to represent an opportunity for the individual to "explain" their autism or to educate a neurotypical audience about their experiences.

The act of narration is depicted as a challenge. Language is, for Higashida, a valuable tool but also something slippery and overwhelming: "It's as if I'm drowning in a flood of words" (36). Like Christopher, Haddon's fictional narrator, Higashida remains highly aware of what has been edited out of his narrative, as well as the ways in which storytelling and language are necessarily subject to imprecisions, inaccuracies, rhetorical and generic conventions. Written using a cardboard alphabet grid and a computer, Higashida's text complicates simplistic models of independent authorship. *The Reason I Jump* is a first-person, single-authored yet collaborative, technologically aided piece of writing that, through its form, acknowledges its own status as a piece of "negotiated knowledge" (Jurecic 16). Early in the book, Higashida foregrounds these material, practical questions of writing and the production of the text by reproducing a copy of his alphabet grid including western letters and Japanese characters (18).

These innovative, rapidly changing forms of writing that are associated with representations of cognitive difference are particularly significant for a genre that has been seen as paradoxical because autistic modes of thinking are perceived as particularly resistant to conventional narrative forms with their implicit linearity, coherent characterisation and structure. Belmonte, for example, argues that: "In autism...failures of neural connectivity impede narrative linkage" (11) and Osteen suggests that "one would expect that narrative, which demands links, linearity and global coherence, would present a problem for autistic people" (16). Osteen continues:

Most autistic people crave sameness. ... How does one craft a tale about events that never seem to change? ... In other cases, autism strikes family members as an inexplicable interruption. ... But how do you tell a cohesive narrative about continual interruption?

(17)

The fragmented first section of *The Sound and the Fury*, or the self-conscious digressions of Haddon's *The Curious Incident*, could be seen as attempts to imagine first-person, fictional narratives that incorporate the experience of continual interruption.

These debates about storytelling and metaphoric capacities are bound up with questions about self-reflection and imagination. Oliver Sacks

suggests that, traditionally, an autobiography by a person with autism would have been seen as a “contradiction in terms” (253). In his foreword to Temple Grandin’s *Thinking in Pictures* (1996), Sacks writes that Grandin’s earlier autobiography, *Emergence: Labeled Autistic*, was “unthinkable” when it was published “because it had been medical dogma for forty years or more that there *was* no ‘inside’, no inner life, in the autistic” (xiii). Grandin’s works represent early examples of a wave of autobiographical writing by people with autism published since the mid-1980s. Later examples in this rapidly growing genre of so-called “autie-biographies” or “spectrum publishing”, such as Donna Williams’s *Nobody Nowhere: The Extraordinary Autobiography of an Autistic Girl* (1992), challenge the notion of an absence of interiority by asserting a distinct and complex individual autistic presence (Couser “Disability, Life Narrative, and Representation” 457).

*The Reason I Jump* takes an ambitious approach to these challenges associated with rendering interior perspectives through narrative and autobiographical forms. Like *The Curious Incident*, Higashida’s book places images and text side by side. *The Reason I Jump* also challenges the boundaries of the autobiography as a genre by including fragments of his memories, anecdotes, answers to questions, and ending with a short story. Through its structure, therefore, *The Reason I Jump* implicitly recognises autism as a social, relational condition which is constructed through a dialogue with the surrounding environment. Each section begins with a question, such as “What are your flashback memories like?”, followed by an extended answer (Higashida 62). This form might be problematic in the sense that Higashida presents himself as a kind of interpreter who, through his writing skills, is able to mediate between people with autism and so-called neurotypicals. Indeed, metaphors of translation recur both in David Mitchell’s commentary on *The Reason I Jump* and also in Higashida’s own writing: “To make myself understood, it’s like I have to speak in an unknown foreign language every minute of the day” (Higashida 26). These notions of translation echo other fictional, autobiographical and theoretical texts about autism. Temple Grandin, for example, called her 2005 book *Animals in Translation: Using the Mysteries of Autism to Decode Animal Behaviour*. She describes the way in which “I think in pictures. Words are like a second language to me” (3). In *The Curious Incident*, Christopher likens his hatred of strangers to the linguistic isolation of being abroad: “I do not understand strangers ... They are hard to understand. It is like being in France” (45). Oliver Sacks famously titled his book that looks in part at the life of Temple Grandin *An Anthropologist on Mars* (1995), thereby likening his clinical position as an observer to being on another planet, rather than merely in

another country. Higashida appropriates this metaphor for his own purposes in *The Reason I Jump*. In the short fictional aside, “Earthling and Autisman”, he positions himself not as a passive subject of observation, but an active communicator, capable of imagining movement between two different realms (74). This metaphorical concern with distance and translation has a very literal significance in the publication history of *The Reason I Jump*, which was first published in Japanese in 2005 and did not appear in English until 2013. The book was translated by novelist David Mitchell and his wife Keiko Yoshida, who are parents of an autistic son. The trajectory of the text therefore itself highlights the way in which cultural representations of cognitive difference in the twenty-first century can to be understood in terms of a global circulation of stories and texts. Technology not only permits writers like Higashida to produce texts, it also facilitates new kinds of writing mediated and shared through online networks and virtual communities in chat rooms, blogs and shared film uploads.

The internet provides a particularly useful way of fostering connections and communities for some of those who find face-to-face interactions or conventional modes of expression difficult (Hacking “Autistic Autobiography” 1468–69). Metaphors of technology, like images of translation, are a common motif in recent writing about autism. In Haddon’s *The Curious Incident*, Christopher likens his cognitive processes to a “machine” and insists that human beings are distinguished from animals by the fact that “they can have pictures on the screens in their heads of things which they are not looking at” (8; 147). Higashida describes his imagination as like a “computer graphics program” and his “library of video memories” (5; 6). This echoes Grandin’s declaration that: “I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures” (3). In these ways, technology provides a language through which autism can be conceptualised for a contemporary reader, as writers attempt to translate what has been perceived as a deeply private condition into public discourse (Hacking “Private Thoughts in Public Language” 12).

This recurring association between autism and technology, embedded in the text on the level of metaphor, may however perpetuate damaging stereotypes about autistic behaviour as “mechanical” or unemotional. Yet, as the activist Amanda Baggs so powerfully demonstrates in her YouTube video, “In My Language”, technology can also be a tool of translation for groups whose voices have not traditionally been listened to. Like *The Reason I Jump*, Baggs’s video is structured as a dialogue. The first part, which features her humming, singing, making sounds, touching everyday

objects, and moving around her home is described as being in her “native language”. The second part, titled “Translation”, insists that far from being detached and isolated “in her own world”, Baggs’s way of thinking and interacting with the world is rich and deeply engaged with sensations of smell, touch, vision, taste and sound. Her short film challenges the conventional view of people with autism as “non-communicative if they do not speak the standard language”. New technologies, in this sense, create opportunities for bilingualism, offering alternative modes and forms of communication and visual languages that reframe the stories that are told about autism.

## Conclusion

In the blurb that goes alongside her YouTube video, Baggs argues that her clip is not a “freakshow” but a “statement about what gets considered thought, intelligence, personhood, language, and communication, and what does not”. Although cognitive difference remains an under-theorised area of disability studies, existing works often echo Baggs’s argument that exploring cognitive difference requires us to re-think fundamental assumptions and categories. For Murray, these are questions of ontology and the definition of humanity (“Autism and the Contemporary Sentimental: Fiction and the Narrative Fascination of the Present” 25). For Mills, the rise in auto/biographical narratives about autism requires us to “rethink past paradigms that oppose typical/normal with atypical/abnormal imaginative processes” in order to “begin to refund an understanding of the imagination in relation to autism” (118). Bérubé also articulates this need for creative rethinking, arguing for a paradigm-shift that is framed as a re-reading:

Rereading narrative from the perspective of disability studies, then, leads us to reread the role of temporality, causality, and self-reflexivity in narrative and to reread the implications of characters’ self-awareness, particularly in narratives whose textual self-awareness is predicated on the portrayal of cognitive disability. The point of learning to reread in this way is to try to learn what makes all reading and self-representation possible: it a question literary texts cannot fail to address and to which literary scholars in disability studies will not fail to attend.

(“Disability and Narrative” 576)

Bérubé’s sense of the urgency of this task is striking. Across the disciplines, scholars are beginning to respond with critical approaches that

make new connections, such as the one between first-person perspectives in fiction and, since the turn of the century, the explosion in autobiographical writing about autism and cognitive difference. Eva Feder Kittay, for example, adopts a critical approach in which politics and autobiography are fundamentally connected in her article: “The Personal is Philosophical is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield”. Richard Grinker explores experiences of autism in a globalised context through a cross-cultural study of France, South Africa, Korea and India published in 2007, *Unstrange Minds: Remapping the World of Autism*. David Wright’s *Downs: The History of a Disability* (2013) traces shifting understandings of the condition and ethical debates across a long timescale, from the early twentieth-century eugenics movement to twenty-first-century prenatal testing. The questions that many of these critical examples raise about personhood, speaking for or with others, and finding new modes of telling stories, also intersect with key debates in other related fields, from the aesthetics and ethics of dementia narratives to digital forms of storytelling.

In his introduction to *The Reason I Jump*, David Mitchell observes that “the three characters used for the word ‘autism’ in Japanese signify ‘self’, ‘shut’ and ‘illness’” (xii). “My imagination”, he continues, “converts these characters into a prisoner locked up and forgotten inside a solitary confinement cell waiting for someone, anyone, to realise he or she is in there” (xii). The first-person perspective narratives discussed in this chapter, both fictional and autobiographical, challenge these straightforward associations between cognitive difference and isolation. They may all represent, in Faulkner’s words, “magnificent failures” in the sense that their attempt to imagine cognitive difference and disability is shaped by the conventions of genre, processes of mediation, and culturally contingent understandings of cognitive difference that will necessarily be superseded, critiqued and re-written by the generations that follow. As works of fiction, *The Sound and the Fury* and *The Curious Incident* may tell us more about a particular culture’s approach to cognitive difference, or its power as a metaphor, than they do about actual conditions. All three texts, through their use of experimental forms, require us to think beyond conventional scripts, such as the narrative of overcoming or the restitution narrative (Frank 98), to consider different ways of being in the world. As texts, they require us to think carefully about the role of language and story in shaping cultural understandings of cognitive difference. They help us to see how acts of self-expression might inaugurate a shift away from deficit models and encourage us to embrace alternative ways of knowing. Literary and cultural criticism involves “debat[ing] the meaning of words like

‘normal,’ ‘retarded,’ ‘disability,’ and, underwriting all these, ‘justice’” (Bérubé 264). *The Sound and the Fury*, *The Curious Incident*, and *The Reason I Jump* also encourage readers to think in new ways about representations of time, the ethics of metaphor, ways of knowing and being, and the workings of narrative itself.

## Further Reading

- Amanda Baggs. “In My Language.” YouTube 2007. Web. 2 March 2014.
- Michael Bérubé. “Disability and Narrative.” *PMLA* 120.2 (2005): 568–576. Print.
- William Faulkner. *The Sound and the Fury*. London: Vintage, 1995. Print.
- Temple Grandin. *Thinking in Pictures: And Other Reports from My Life with Autism*. 2nd Vintage Books ed. New York: Vintage Books, 2006. Print.
- Mark Haddon. *The Curious Incident of the Dog in the Night-Time*. 1st ed. New York: Doubleday, 2003. Print.
- Martin Halliwell. *Images of Idiocy: The Idiot Figure in Modern Fiction and Film*. Aldershot; Burlington: Ashgate, 2004. Print.
- Naoki Higashida. *The Reason I Jump*. Trans. Yoshida, K.A. and David Mitchell. New York: Random House, 2013. Print.
- Stuart Murray. *Representing Autism: Culture, Narrative and Fascination*. Liverpool: Liverpool University Press, 2008. Print.
- Mark Osteen (ed). *Autism and Representation*. New York: Routledge, 2008.
- James W. Trent. *Inventing the Feeble Mind: A History of Mental Retardation in the United States*. Berkeley and Los Angeles: University of California Press, 1984.
- Donna Williams. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*. New York: Times Books, 1992. Print.

## Bibliography

- Adams, Rachel “A World Where We Are All Autistic.” Public Books 2013. Web. 2 April 2014.
- Asperger, Hans. “‘Autistic Psychopathy’ in Childhood.” Trans. Frith, Uta. *Autism and Asperger Syndrome*. Ed. Frith, Uta. Cambridge: Cambridge University Press, 1991. 37–92. Print.
- Baggs, Amanda. “In My Language.” YouTube 2007. Web. 2 March 2014.
- Bangs, John Kendrick. *The Idiot*. New York: Harper & Brothers, 1895. Print.
- Bangs, John Kendrick. *The Idiot at Home*. New York and London: Harper & Brothers, 1900. Print.
- Baron-Cohen, Simon. *Mindblindness: An Essay on Autism and Theory of Mind*. Cambridge, Mass.: MIT Press, 1995. Print.
- Belmonte, Matthew K. “Human, but More So: What the Autistic Brain Tells Us About the Process of Narrative.” *Autism and Representation*. Ed. Osteen, Mark. New York: Routledge, 2008. 166–180. Print.

- Berman, Sabina. *Me, Woman Who Dove into the Heart of the World: A Novel*. 1st U.S. ed. New York: Henry Holt and Co., 2012. Print.
- Bérubé, Michael. *Life as We Know It: A Father, a Family, and an Exceptional Child*. 1st ed. New York: Pantheon Books, 1996. Print.
- Bérubé, Michael. "Disability and Narrative." *PMLA* 120.2(2005): 568–576. Print.
- Bleuler, Eugen. *Dementia Praecox*. New York: International Universities Press, 1950. Print.
- Burke, Lucy. "Introduction: Thinking About Cognitive Impairment." *Journal of Literary Disability* 2.1(2008): i–iv. Print.
- Burks-Abbott, Gyasi. "Mark Haddon's Popularity and Other Curious Incidents in My Life as an Autistic." *Autism and Representation*. Ed. Osteen, Mark. New York: Routledge, 2008. 289–296. Print.
- Churchwell, Sarah. "Rereading *The Sound and the Fury* by William Faulkner." *The Guardian*. Web. 4 June 2014.
- Cincinnati, The Juvenile Protective Association of. *The Feeble-Minded or the Hub to Our Wheel of Vice, Crime and Pauperism, Cincinnati's Problem: A Study*. 1915. Print.
- Conrad, Joseph. "The Idiots." The Literature Network. Web. 2 February 2014.
- Couser, G. Thomas. *Signifying Bodies: Disability in Contemporary Life Writing*. Ann Arbor: University of Michigan Press, 2009. Print.
- Couser, G. Thomas. "Disability, Life Narrative, and Representation." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 2013. 456–459. Print.
- Daldry, Stephen. *Extremely Loud and Incredibly Close*. Warner Bros. Pictures. 2011. Film.
- Faulkner, William. *Faulkner in the University: Class Conferences at the University of Virginia, 1957–1958*. Charlottesville: University of Virginia Press, 1959. Print.
- Faulkner, William. *The Sound and the Fury*. London: Vintage, 1995. Print.
- Ferguson, Niall. "America Has Got Asperger's." *The Telegraph*. Web. 23 March 2013.
- Foer, Jonathan Safran. *Extremely Loud and Incredibly Close*. Boston: Mariner Books, 2005. Print.
- Fossum, Karin and Charlotte Barslund. *Black Seconds*. 1st ed. Orlando: Harcourt, 2007. Print.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995. Print.
- Frith, Uta. *Autism: Explaining the Enigma*. 2nd ed. Malden, MA: Blackwell Pub., 2003. Print.
- Goodey, C.F. "Social Mobility, Education and Intelligence: The Emperor's Old Underpants." New Left Project. Web. 16 September 2012.
- Grandin, Temple. *Thinking in Pictures: And Other Reports from My Life with Autism*. 2nd Vintage Books ed. New York: Vintage Books, 2006. Print.
- Grandin, Temple and Catherine Johnson. *Animals in Translation: Using the Mysteries of Autism to Decode Animal Behavior*. 1st Harvest ed. Orlando: Harcourt, 2006. Print.

- Grinker, Roy Richard. *Unstrange Minds: Remapping the World of Autism*. New York: Basic Books, 2007. Print.
- Grove, Thelma. "Barnaby Rudge: A Case Study in Autism." *Dickensian* 83 (1987): 139–148. Print.
- Hacking, Ian. *The Social Construction of What?* Cambridge, Mass.: Harvard University Press, 1999. Print.
- Hacking, Ian. "Autistic Autobiography." *Philosophical Transactions of the Royal Society: Biological Sciences* 364.1522(2009): 1467–1473. Print.
- Hacking, Ian. "Private Thoughts in Public Language." *Literary Review of Canada* (April 2009): 12–13. Print.
- Haddon, Mark. *The Curious Incident of the Dog in the Night-Time*. 1st ed. New York: Doubleday, 2003. Print.
- Haddon, Mark. "The Curiously Irresistible Debut of Mark Haddon: Author Interviews." Powells Books Blog. Web. 29 June 2014.
- Halliwell, Martin. *Images of Idiocy: The Idiot Figure in Modern Fiction and Film*. Aldershot; Burlington: Ashgate, 2004. Print.
- Higashida, Naoki. *The Reason I Jump*. Trans. Yoshida, K.A. and David Mitchell. New York: Random House, 2013. Print.
- Hornby, Nick. *About a Boy*. New York: Riverhead Books, 1998. Print.
- Johar, Karan. *My Name Is Khan*. Fox Searchlight Pictures. 2010. Film.
- Jurecic, A. "Mindblindness: Autism, Writing, and the Problem of Empathy." *Literature and Medicine* 25.1(2006): 1–23. Print.
- Kanner, Leo. "Autistic Disturbances of Affective Contact." *Nervous Child* 2(1943): 217–250. Print.
- Kartiganer, Donald M. "The Sound and the Fury and Faulkner's Quest for Form." *ELH* 37.4(1970): 618–639. Print.
- Kittay, Eva Feder. "The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield." *Metaphilosophy* 40.3–4(2009): 606–627. Print.
- Livesey, Margot. *Banishing Verona*. 1st ed. New York: Henry Holt, 2004. Print.
- McDonagh, Patrick. "Autism and Modernism: A Genealogical Exploration." *Autism and Representation*. Ed. Osteen, Mark. New York: Routledge, 2008. 99–116. Print.
- McGovern, Cammie. *Eye Contact: A Novel*. New York: Viking, 2006. Print.
- Mellard, James M. "Caliban as Prospero: Benjy and *The Sound and the Fury*." *Novel: A Forum on Fiction* 3.3(1970): 233–248. Print.
- Meyer, Abbye E. "'But She's Not Retarded': Contemporary Adolescent Literature Humanizes Disability but Marginalizes Intellectual Disability." *Children's Literature Association Quarterly* 38.3(2013): 267–283. Print.
- Mills, Bruce. "Autism and the Imagination." *Autism and Representation*. Ed. Osteen, Mark. New York: Routledge, 2008. 117–132. Print.
- Mitchell, David. "Introduction." Trans. Yoshida, K.A. and David Mitchell. *The Reason I Jump*. Ed. Higashida, Naoki. New York: Random House, 2013. vii–xvii. Print.



- Moon, Elizabeth. *The Speed of Dark*. 1st ed. New York: Ballantine Books, 2003. Print.
- Morrall, Clare. *The Language of Others*. London: Sceptre, 2008. Print.
- Morris, Wesley and Barbara Alverson Morris. *Reading Faulkner*. Madison: University of Wisconsin Press, 1989. Print.
- Mukhopadhyay, Tito Rajarshi. *How Can I Talk If My Lips Don't Move? Inside My Autistic Mind*. 1st ed. New York: Arcade Publishing; Distributed by Hachette Book Group USA, 2008. Print.
- Murray, Stuart. "Autism and the Contemporary Sentimental: Fiction and the Narrative Fascination of the Present." *Literature and Medicine* 25.1(2006): 24–45. Print.
- Murray, Stuart. *Representing Autism: Culture, Narrative and Fascination*. Liverpool: Liverpool University Press, 2008. Print.
- Osteen, Mark. "Autism and Representation: A Comprehensive Introduction." *Autism and Representation*. Ed. Osteen, Mark. New York: Routledge, 2008. 1–47. Print.
- Picoult, Jodi. *House Rules: A Novel*. New York: Atria Books, 2010. Print.
- Price, Margaret. "Mental Disability and Other Terms of Art." *Profession* 11(2010): 117–123. Print.
- Quayson, Ato. *Aesthetic Nervousness: Disability and the Crisis of Representation*. New York: Columbia University Press, 2007. Print.
- Sacks, Oliver W. *An Anthropologist on Mars: Seven Paradoxical Tales*. 1st ed. New York: Knopf, 1995. Print.
- Savarese, Emily Thornton and Ralph James Savarese. "The Superior Half Speaking: An Introduction." *Disability Studies Quarterly* 30.1(2010). Print.
- Seguin, Edward. *Nervous Diseases*. New York. 1869. Print.
- Shakespeare, William. *Macbeth*. London: Penguin, 1984. Print.
- Straus, Joseph N. "Autism as Culture." *The Disability Studies Reader*. Ed. Davis, Lennard J. 4th ed. New York: Routledge, 2013. 460–484. Print.
- Williams, Donna. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*. New York: Times Books, 1992. Print.
- Wright, David. *Downs: The History of a Disability*. Oxford; New York: Oxford University Press, 2011. Print.

## 8 Disability Life Writing

Stephen Kuusisto, writing in his 1998 memoir *Planet of the Blind*, laments the lack of available writing about disability during his childhood in 1950s and 1960s America. His striking use of the present tense suggests a painful sense of immediacy, even as he looks back in time:

In our town there are no discernible men or women with disabilities, with the exception of World War II veterans. A disabled child is without a category: one simply doesn't see them...There are no books about blind children or how to bring them up, no associations of parents or support materials, at least not in rural New Hampshire. Instead there are assumptions: blindness is a profound misfortune, a calamity really, for ordinary life can't accommodate it.

*(Planet of the Blind 13)*

For Kuusisto then, the fundamental lack of available writing and talk about disability in the community in which he grew up renders him invisible, a child “without a category”. Anne Finger’s autobiography, *Elegy for a Disease: A Personal and Cultural History of Polio* (2006), also suggests that the lack of writing about disability contributed to her childhood isolation: “I had a sense that my problem was a social one, not an individual one ... I lacked both a history and a community” (236). Drawing on a social model of disability, Finger suggests that she was disabled in part by the lack of an available history or language through which she could situate her personal experiences and tell her story.

In the last twenty-five years, by contrast, there has been an explosion in the number of memoirs and auto/biographical accounts of disability. Indeed, the memoirs by Kuusisto and Finger themselves contribute to the boom in life writing in which ordinary people’s stories, rather than those of renowned public figures, have been written, marketed and widely consumed in far larger numbers than ever before. Disability life writing

is a highly flexible category; it includes first-person and third-person accounts, as well as collaboratively written works about a wide range of experiences of disability. New critical vocabularies have emerged in response to this phenomenon, from the bodily emphasis of the “auto/somatography” (Couser *Signifying Bodies: Disability in Contemporary Life Writing* 15) to the accounts of autism offered by the “autie-biography” (Couser “Disability, Life Narrative, and Representation” 457), and the disparaging catch-all labels of “misery literature” or the “nobody memoir” which often include stories of impairment, trauma and abuse (Hall and Hall 111; Adams). In recent years, the growing accessibility and decreasing costs of self-publishing technologies have extended the reach of disability life writing and significantly widened its definition, arguably to incorporate new condensed forms such as the blog post, tweet, or the newsfeed.

This radical change, from the large-scale under-representation of the life stories of people with disabilities in the mid-twentieth century to their “hyper-representation” in life writing in the last twenty-five years, suggests a significant cultural shift in attitudes towards the public representation of disability at the end of the twentieth century (Couser “Disability, Life Narrative, and Representation” 456). An awareness of this explosion in life writing is significant for thinking about literary representations and theories of disability in the sense that it represents a key example of the ways in which texts and print media can raise the public profile of disability and, crucially, offers the opportunity for self-representation through new narrative and linguistic forms.

This chapter argues that literary critical approaches are a productive way of analysing disability life writing, in part because they draw attention to the nuances of language, genre and narrative perspective, but also because thinking through the reciprocal relationship between literature and life writing can help us to question and to complicate claims about authenticity, objectivity and the web of cultural associations and narrative conventions through which both life writing and literary works are constructed. This literary critical approach seeks to recognise the power of disability life writing as a resource for protest and/or self-expression for marginalised groups, while at the same time highlighting the richness and complexity of much of this writing. The argument here, then, is that debates about empathy, identification and imagination are enriched by reading and critically analysing life writing alongside literary works.

The first part of this chapter considers a brief history of disability life writing, drawing primarily on recent works that might be classified under the title of the “new” disability memoir in the sense that they were written at the end of the twentieth or beginning of the twenty-first centuries (Couser *Signifying Bodies: Disability in Contemporary Life Writing* 164).

A reading of Kenzaburo Ōe's works in the second part of the chapter seeks to provide a more developed example of the valuable exchange between literature and life writing and to extend discussions beyond the focus on Anglo-American texts that dominates much current cultural disability studies writing.

### Autobiography and Activism: The Roots of Disability Life Writing

The flexibility of the term, "disability life writing", means that its roots are difficult to disentangle from debates about genre and definition. Two key texts highlight some of the features of the genre. The first of these is Helen Keller's influential series of autobiographical works which, while traditional and direct in their style, provide a model for a form of collaborative, process-oriented writing and re-writing. Keller wrote different versions of her autobiography at various stages of her life: *The Story of My Life* (1903), *The World I Live In* (1908) and *My Religion* (1927). In these works, the act of writing is central to the action of the narrative as Keller documents her struggle to gain the right to education, to learn Braille and to express herself in the context of prejudice and the material hardship that she faced as a deafblind woman born in America in 1880. The second key text is Christy Brown's *My Left Foot*, published as an autobiography in 1954 and then released as a film featuring an Oscar-winning performance by Daniel Day Lewis in 1989. *My Left Foot* also focuses on the materiality of writing. As in Keller's works, the narrative focuses on the difficulties of self-expression, this time from the perspective of a man with cerebral palsy born into a working-class family in Dublin in 1932. The scene that depicts Brown's childhood "discovery" of his ability to write, to literally make his mark on the floor with a piece of chalk using his left foot, is pivotal: it marks the moment when he gains recognition from his father and enters the wider community as he is carried out of the house and into the local pub. For both Brown and Keller therefore, the process of writing is itself associated with overcoming obstacles, disrupting stereotypes of dependency and vulnerability; it becomes an act of defiant and triumphant self-inscription.

More recent examples of the new disability memoir often exhibit a reflexive awareness of this history of disability life writing. Anne Finger, for example, begins her autobiography from a position of ironic self-abnegation rather than self-inscription. In an opening section entitled "Stories I'm Not Going to Tell" she writes:

I'm not going to tell the story of the plucky little cripple stepping gamely forward on two crutches ... This won't be the elegiac story

with its expected arc beginning with normalcy...then ascending into crisis....And then hard-won ending, with its return to the empire of the normal...I do not want to give you just my story. ... I also want to write about the social experience of disability.

(7–8)

Finger suggests an explicit critique here of the pathologising, individualising tendencies of some early disability life writing. Like the “prosthetic” stereotypes identified by disability studies scholars in certain literary representations (Mitchell and Snyder), Finger suggests that disability life writing is also often informed by conventional narrative scripts such as the triumphant recovery story or narrative of overcoming. Like Finger, Georgina Kleege defines her memoir, *Sight Unseen* (1999), in opposition to prevailing models of disability life writing about blindness: “When I looked for models in memoirs and other personal writing about blindness, what I read was distressing” (3). Existing works, she suggests, “fall into two categories. There were the blind whiners...[and] the blind mystics” (3). In Kleege’s own memoir, these polarised notions of either disastrous vulnerability or compensatory second sight are replaced by an account of everyday experience that self-consciously “lacks the requisite trauma and drama” (3) of traditional disability life writing and incorporates literary and cultural analysis alongside the personal narrative.

These works by Finger and Kleege typify the wave of disability life writing in the latter stages of the twentieth and the beginning of the twenty-first centuries which, in line with the social model of disability, seeks to tell personal stories of disability in wider social and cultural contexts. Physical or cognitive impairments are not the primary focus for these authors; instead they document the everyday relationships, prejudices, friendships, legal changes and cultural representations through which a complex sense of identity is constructed and maintained in a wider social context. This has encouraged scholars to adopt a broader historical frame of reference in looking at the work. Couser, for example, comments:

It is safe to say there was not much in the way of published autobiographical literature before World War II. War both produces and valorizes certain forms of disability; not surprisingly, then, disabled veterans produced a substantial number of narratives after the war. Polio generated even more narratives...In the 1980s and 1990s, HIV/AIDS and breast cancer provoked significant numbers of narratives; many of these challenge the cultural scripts of the conditions.

(“Disability, Life Narrative, and Representation” 457)

Couser sees life writing as a form of resistance that can be closely connected to civil and human rights movements. In this context, life writing is used to educate and to protest but can also celebrate certain minority identities, in line with movements such as gay or deaf pride. The disability rights slogan “Nothing about us without us” highlights the importance of self-representation by people with disabilities as a source of empowerment and as part of a call to collective action. The boom in disability life writing can therefore be understood as being in direct dialogue with, and part of, social movements agitating for cultural and legal change, such as campaigns leading up to the passing of the Americans with Disabilities Act in the United States in 1990. The aim of increasing the accessibility of public spaces for people with disabilities extended to claiming higher profile space in conventional publishing and online communities as well.

Activism and protest provide, for example, the frame for Simi Linton’s celebrated autobiography, *My Body Politic* (2006). The story of her life begins not with her birth, but with her involvement in a protest, as she hitches a lift to an anti-Vietnam war demonstration in Washington. The chronology is not that of a conventional memoir; it is cyclical in the sense that the memoir ends as it began but twenty-six years later, with Linton setting out to take part in another protest in Washington. The nuances of Linton’s linguistic choices, and her reconfiguration of the autobiographical “I”, are bound up with her self-conscious insistence that disability is not a private matter of individual impairment but rather a question of social prejudices and cultural representations that we all participate in. The memoir’s title, *My Body Politic*, suggests an individualised account, but by the final chapter this has been transformed into a collective call to action: “Our Body Politics” (Linton 223).

### **The Literary Memoir and the “Coming Out” Narrative**

Since many recent works of disability life writing are closely aligned with activist aims, they challenge both the status quo and the conventions of the genre of life writing itself. These accounts often shift the focus from a view of auto/biography as an individualistic endeavour, as “the acme of independent, liberal, individual self-expression in literature” (Coogan 42), to create narratives that chart the recognition of a collective identity. The motif of the “coming out narrative”, suggested by Kleege as a defining feature of her memoir (5), recurs in much recent disability life writing. The notion of “coming out” is fitting in the sense that it suggests a shift from private to public but also because it borrows a vocabulary from lesbian and gay activism in a way that highlights the intersections

between the two movements. The need to “come out” could be seen as oppressive in that the individual is required to account for their sexuality or impairment in a way that a heterosexual and/or non-disabled person would not be expected to do. Yet it can also be viewed in both cases as an empowering act of celebration, of proudly naming and claiming a positive identity that counters histories of enforced silence. Stephen Kuusisto suggests that his childhood sadness was “compounded by my mother’s militant refusal to use the words ‘blind’ or ‘blindness’” (*Planet of the Blind* xii). Lucy Grealy, in *Autobiography of a Face* (1994), describes her own “lifelong refusal to learn *how* to name the person in the mirror” (221). In these cases, the act of “coming out” through their autobiographies rests not only on a view of life writing as an instrumental or didactic tool for activism, but also asserts the performative potential for language itself to enact change on a personal level.

Albie Sachs, author of the powerful disability memoir *The Soft Vengeance of a Freedom Fighter* (1990), also acknowledges the importance of this performative function of language in shifting his own sense of identity. Writing in the preface to another auto/biographical work about disability, an inventive fusion of essays, interviews and photography called *Zip Zip My Brain Harts* (2006), Sachs highlights his own initial inability to name disability, despite his long history of involvement with protest movements and his enduring commitment to social and legislative reform:

It was two years after I lost my arm in a bomb blast that I discovered I was disabled.

I had known, of course, that with a short right arm I looked different, even freaky. I had battled, with some success, to get medical professionals to engage with me as a whole person and not just someone with an instrumental defect to be hidden or minimised. I had even written a memoir on the process. But it was only when I met with the leaders of Disabled People South Africa (DPSA) that I began to call myself disabled. It was 1990 and they had asked me to advise on how to advance the rights of the disabled in the new Constitution. “What you must do...” I said. “What we must do...” I continued. In shifting from “you” to “we”, I quietly joined what I have come to call the “great democracy of the disabled.”

(Buckland et al. vii)

As in Linton’s autobiography, the shift from individual to collective identity is important here, as is the recognition of the overlaps between the human and civil rights protests that Sachs is involved in fighting for.

His “coming out” is not realised by the act of writing a memoir, but rather through dialogue. For Sachs, claiming a disabled identity is a collaborative as well as a linguistic act that requires renewed imaginative engagement with other marginalised people.

Another striking example of a performative act of naming comes in the opening line of Kleege’s memoir, *Sight Unseen*. Kleege highlights the gap between impairment and disability; she opens her memoir with the declaration that: “Writing this book made me blind” (1). In the paragraph that follows, she explains that her visual impairment has not changed but, in part as a result of writing the book, she has started to identify herself as disabled: “today I am likely to identify myself as blind; five or six years ago I would have been more likely to use the less precise phrases, such as ‘visually impaired’ or ‘partially sighted’” (1). Kleege challenges the binary opposition between blind and sighted populations by narrating her experiences of partial vision. Like Sachs, she highlights the ways in which the naming of disability requires for her an almost literary process of imaginative identification, of re-imagining her own identity and experience from an alternative perspective which comes to her through the process of writing itself: “I find it easy to imagine what it’s like to be sighted. I had to write this book to learn what it means to be blind” (Kleege 3).

For Kleege, however, the process of recognition and naming is not only about the individual act of writing, emphasised to such a great degree in the narratives of Keller or Brown; it is also related to her reading. Kleege reads and critically analyses life writing and literary texts alongside each other in her memoir in order to locate herself in a community of blind people across history and to think deeply about cultural perceptions of blindness. At the opening of *Sight Unseen*, she identifies an important physical shift in her own mode of reading both texts and the surrounding landscape: “Since I began this book I have learned to use Braille and started to carry a white cane” (Kleege 1), but an attention to literary critical modes of reading is also central to the process through which she tells her life story. Kleege explicitly resists the conventional structure of an autobiography through “the arrangement of material [that] maps a thought process...cyclical rather than linear. It spirals round its subject in ever-smaller circles” (5). First-hand experiences of blindness are juxtaposed with cultural essays on, for example, blindness in language, film and literature. The striking range of literary references which include Rudyard Kipling, Graham Greene, H.G. Wells, J.M. Coetzee, D.H. Lawrence, F. Scott Fitzgerald and Raymond Carver, are employed not as passing asides or illustrative metaphors. Literary and cultural references are interwoven into the fabric of the text itself; they play a



part in constructing both Kleege's own personal understandings and experience of blindness and the wider public understandings she encounters in her everyday life. "Reading", she insists, "is essential to my life as a writer and to my life as a blind person" (Kleege 5).

Kuusisto echoes this focus on the importance of critically reading literary works as part of the process of producing life writing. For Kuusisto, poems are not only "wholly necessary" but also enriching and nourishing: "the words of poetry are onions, garlic, fennel, basil, the book itself is an earthenware vessel" (*Planet of the Blind* 64–65). Like Kleege, he suggests that the physical difficulties of reading do not detract from its importance: "My spastic eye takes in every word like a red star seen on a winter night. Every syllable is acquired with pain. But poetry furnishes me with a lyric anger, and suddenly poems are wholly necessary" (Kuusisto *Planet of the Blind* 65). Like Kleege, his work is interwoven with literary references, from Homer to Robert Frost, which not only deepen his understandings but also infuse his autobiographical prose with a lyrical quality. The experimental structures of Kuusisto's autobiographical works, from the kaleidoscopic *Planet of the Blind* to the "auditory postcards or 'tone poems'" of *Eavesdropping: A Life by Ear* (xi), are intimately bound up with the ways in which his visual impairment necessarily creates a different relationship to language: "I often go home from the library with the few words I've been able to see and absorb still vivid in my imagination. Alone, I take them apart and rearrange them...Exploring what words can do when placed side by side" (*Planet of the Blind* 66). In *Planet of the Blind*, he not only takes apart and rearranges binary understandings of blindness and sightedness, but also challenges the conventional structure and dominant visual mode of literary autobiography. For Kuusisto, aesthetic representations animate the imagination; literary references are important because they provide an alternative language or way of thinking about disability but also because they offer an aesthetic style and experimental structure through which a rich interior life of imagined landscapes can be articulated.

### **Kenzaburo Ōe's Life Writing: Dialogues with Literary Representations**

For Kenzaburo Ōe, a Nobel Prize-winning author who writes in forms that blur the boundary between literature and life writing, the works of other literary writers are a key resource for thinking about everyday ethics and disability. Ōe's work stands at the intersection of Japanese and European traditions. Throughout his career, his writing has centred on two key concerns, both of which relate to disability: the first is the

experiences of victims of the Hiroshima atomic bomb attack, and the second is his life with his cognitively impaired son, Hikari. Ōe's memoir, *A Healing Family: A Candid Account of Life With a Handicapped Son* (1995), was his first book to be published after he won the Nobel Prize for literature in 1994. In the book, he looks back at his writing and family life, acknowledging the central importance of his son Hikari in shaping his understandings of compassion, humanism, imagination and his own life story.

The marketing blurb on the dust jacket of *A Healing Family* suggests a highly reductive view of the book as a straightforward narrative of overcoming in which Hikari has been successful "despite" his disabilities:

Hikari was born in 1963 with a growth on his brain so large it made him look as if he had two heads. His parents were told he might never be more than a "human vegetable" requiring constant care; but they took the decision to raise him. Today, despite autism, poor vision and a tendency to seizures, their son is an established composer with two successful CDs to his credit.

(Ōe)

In fact, the text that follows within the dust jacket is a deeply nuanced account of Ōe's family life that disrupts this triumphalist blurb at every stage. Divided into separate episodic sections that work as stand-alone essays and were clearly written (and initially, published) separately, *A Healing Family* defies the chronology of a narrative of overcoming on a structural level. Ōe is not concerned with documenting his son's exceptionality, either in terms of his special needs or his outstanding skills as a composer, but rather with exploring the ordinary everyday challenges and pleasures of their lives together: eating meals as a family, watching television quiz shows and listening to the radio, as well as approaching difficult issues that affect any parent-child relationship such as sex education and the ageing of the older generation. For Ōe, looking back on his career, the processes of reading and writing fiction – which have dominated his life – have served not as an escape from his everyday existence with his family, but rather as a new lens through which he has focused his experiences and developed his thinking:

I experienced an identity crisis of my own at the age of twenty-eight, in the year Hikari was born ... It was in the midst of this crisis that my son's birth burst like a bombshell; and it was through the pain of this experience that I somehow regained my equilibrium. My son was operated on and welcomed home, and in the act of fictionalizing

those events in the form of a novel, I was finally able to synthesize them, to make some kind of sense out of a senseless situation.

(*A Healing Family* 28)

*A Healing Family* also reveals Ōe's deep engagement in activism and his sense of interconnection between public and personal concerns. The research for his book *Hiroshima Notes*, for example, led him to consider "the cataract-clouded eyes of the elderly victims...the deformities and handicaps suffered by [the] children...the elevated levels of cancer throughout the region, and other lingering effects of radiation" (Ōe 22). In *A Healing Family*, Ōe self-consciously connects the writing of this non-fiction text, *Hiroshima Notes*, published in 1965, to the fictionalised story of his own son's birth, *A Personal Matter*, published in 1964. For Ōe, the act of writing about his own experiences in a novel allowed him to fuse or "synthesise" the personal and the public, and to engage his imagination to try to make sense of the experiences of other Japanese people with disabilities:

I must acknowledge the fact that the central theme of my work, throughout much of my career, has been the way my family has managed to live with this handicapped child. Indeed, I would have to admit that the very ideas that I hold about this society and the world at large – my thoughts, even, about whatever there might be that transcends our limited reality – are based on and learned through living with him...Essentially, in writing a novel about a handicapped child one is building a model of what it means to be handicapped, making it as complete and comprehensive as possible yet also concrete and personal. Nor is the model confined to the handicapped person alone, but something that encompasses the world around him, and by extension, the world we live in.

(*A Healing Family* 44)

In *A Healing Family*, Ōe directly connects both his life writing and his fiction to his protests as a public intellectual in Japan against nuclear weapons, his anti-imperial stance, and his participation in disability rights activism such as events to promote "World Disabled Person's Day" (47). A novel, he suggests, can include "concrete and personal" autobiographical details, but also has the potential to allow readers and the writer to think imaginatively beyond the life story of a single individual (Ōe 44).

Ōe is highly conscious of the fact that he is "speaking for" his largely non-verbal son. Yet, this fiction allows a level of experimentation with

representing scenes from his own life without a claim to a single truth or authenticity. Novelists are always, in a sense, “speaking for” their imagined characters; fiction allows Ōe the space to imaginatively reconstruct a complex interior life for his son. For Ōe, ethics and aesthetics are intertwined: reading and writing are not merely didactic, instrumental tools for articulating his political ideas, but rather they provide a space in which the public and the personal are fused. Ōe extends the scope of *A Healing Family* beyond their family home, and even beyond Japan, through his readings of a range of literary works from across different times and places that engage with illness, disability and imagination, from Flannery O’Connor, to William Blake, Nadine Gordimer, Shiki Masaoka and Jean-Jacques Rousseau. To borrow Kuusisto’s metaphor, fiction and poetry serve here not only as a “vessel” through which ideas about disability are stored and carried to different settings, but also as a means of enriching understandings of fundamental questions about identity, disability and the limits of ethical or imaginative identification.

### Ōe’s Fiction: Renegotiating Endings

The exchange between life writing and fiction is a defining characteristic of Ōe’s highly autobiographical novels and short stories. Many of his works explore the relationship between a father and his disabled son, including: *A Personal Matter* (1964); the two short novels collected in his *Teach Us to Outgrow Our Madness* collection: “Aghwee the Sky Monster” (1964) and “Teach Us to Outgrow Our Madness” (1969); *The Pinch Runner Memorandum* (1973); *Rouse Up O Young Men of the New Age!* (1983); *A Quiet Life* (1990); and *The Changeling* (2000). These narratives occupy an ambiguous space between life writing, the Japanese “I-novel” tradition, and fictional invention. The narratives are undoubtedly triggered by the birth of Ōe’s own son, Hikari, in 1963. The recurring father figures bear a strong resemblance to Ōe, down to the smallest detail; they are born in the Japanese countryside, educated in Tokyo, and, like the author himself, are lovers of literature, whiskey and Korean-style pig’s trotters. Yet, through naming, Ōe also retains a level of distance between his family and his fictionalised creations. The father figures are, for example, known as “Bird” or merely “the fat man”, while the sons are known as Mori, Jin, or, most commonly, Eeyore. Once again, this suggests a level of fictionalised doubling with Ōe’s own life, as it recalls the affectionate name, “Pooh”, which Ōe calls Hikari. This reflexive quality to the works is made explicit in the scenes of naming that run throughout the fiction. In both “Teach Us to Outgrow Our Madness” and *A Personal Matter*, the father figure delays naming his son following the discovery

of his impairments. The question of what to call his son, as well as how to put the story of his birth into language, is one that the fictionalised young male protagonist grapples with on many levels: “Could such existence be given a name?” (Ōe *Teach Us to Outgrow Our Madness: Four Short Novels* 86). This parallels Ōe’s own belated decision to name his own son “Hikari”, a name that has associations of both “light” and “enlightenment” in Japanese.

In *A Personal Matter* and *Rouse Up O Young Men of the New Age!*, Ōe blurs the boundaries between fiction and life writing to return to the scene of his son’s birth, a scene that is perpetually re-written in his fictional works:

When my son was born with a bright-red lump the size of a second head attached to the back of his skull, I found myself unable to reveal the true situation to either my wife or my mother, and, having installed the baby in critical care for infants at Nihon University Hospital, I wandered around in a daze. Meanwhile, not only the actual head but also the lump appeared to be well nourished and growing ... Two and a half months later, I asked Doctor M, who had been caring for my son – and looking after me as I struggled unavailingly to recover from the shock of his birth – to perform surgery.

(*Rouse up O Young Men of the New Age!* 42–43)

This scene powerfully replays the dilemma that Ōe faced in his own life when Hikari was born with a brain hernia. Ōe’s choice to write about his own experiences through such a thinly veiled fictional form has a documentary and activist value to it: it records the discrimination and cruelty towards babies with disabilities in 1960s Japan; the complete lack of support for parents; and a wider social context in which “it was considered shameful to even take a handicapped child out in public” (Fay and Ōe). Like the father figures in *A Personal Matter* and “Aghwee the Sky Monster”, Ōe, at the age of twenty-eight, was presented with a child viewed by all of those around him as a “monster baby” (Ōe *Teach Us to Outgrow Our Madness: Four Short Novels* 260), and advised by doctors to allow the hospital to starve the child to death, without the knowledge of his mother, by feeding him sugar water rather than milk. In interviews since, Ōe has said that he made his decision to go ahead with the operation to save his son quickly, against the advice of many of the doctors (Fay). Yet, the period of indecision and doubt is one that Ōe never allows his readers, or himself, to forget. While it is unclear whether the period of time that Ōe refers to in *A Personal Matter* reflects his own

experience, the personal resonance makes this fictionalised self-reproach all the more powerful: “No powerful detergent has allowed me to wash out of my life those disgraceful five weeks, nor do I expect to succeed at this as long as I live” (*Rouse up O Young Men of the New Age!* 90–91). This quotation highlights the way in which Ōe’s writing frequently reconfigures its relationship to time: in *Rouse Up O Young Men of the New Age!* the decision-making process took two months, in *A Personal Matter* it took five weeks, and in his interviews Ōe states that the decision was made in a matter of hours. The haunting scene remains the same but the details of time and character are subjected to the instability of memory and the imaginative licence of fictional processes. The simple “healing” of his family implied in the title of Ōe’s memoir is subverted by the frequent re-writing and re-living of his earlier decisions and experiences through fictional forms.

By fictionalising the story, rather than writing it as an “authentic” autobiographical account, Ōe is able to imaginatively explore the possible consequences of the choices he was forced to decide between. In *A Personal Matter*, the action of the novella is based entirely on the young protagonist’s need to make a decision about the future of his son. With relentless, ferocious intensity and a level of grotesque realism that characterises all of his writing, Ōe extends the period of the father’s indecision about his son’s operation and slows it down to dominate the entire narrative. Instead of a chronological narrative arc or timeline, readers are trapped in a series of static, claustrophobic interiors: the hospital, the darkened room of his lover, Himoko, and inside Bird’s own agonised, sleepless consciousness. It is only in the last few pages of *A Personal Matter* that Bird makes his decision to allow the operation to save his son to go ahead.

Ōe’s short story, “Aghwee the Sky Monster”, by contrast, imagines the consequences for a father who has decided to allow his son to die. Aghwee tells the story of a young man who is hired to take care of a composer, a “sentimental madman”, who suffers “delusions about living with a monster” (*Ōe Teach Us to Outgrow Our Madness: Four Short Novels* 224–45). This “monster” it emerges, appears to be the vision of the composer’s dead child, visible only to him in a bizarre kangaroo-shaped form that emerges periodically from the sky. This odd, almost comic image, reminiscent of a children’s fairy story, is tinged with intense sadness as the mother’s account halfway through the narrative reveals that the name “Aghwee” turns out to be the only sound ever uttered by the child. The father, who has “fled from reality into a world of phantoms”, declines “to live his own life, just as he declined to let the baby go on living” (*Ōe Teach Us to Outgrow Our Madness: Four Short Novels* 242)

and ultimately commits suicide at the end of the story. The narrator's description of the father figure as being "like a traveller who had arrived here in a time machine" (*Teach Us to Outgrow Our Madness: Four Short Novels* 245) provides a fitting metaphor for Ōe's own relationship to his narrative: through the creative licence of fiction he imagines himself transported to a different time in his life, living with the consequences of a very different decision about his son's future.

Ōe's writing sets up innovative and powerful intertextual dialogues with rich literary traditions of Japanese, Korean, English, French and American literature, but also suggests dialogues between his own life writing and fiction. Wilson, in the only English-language book-length study of Ōe published to date, suggests that: "We must not dismiss the presence of this 'obsessive metaphor' of the father and the idiot son merely as a repetition of an old theme, but rather must consider the five works as one large narrative in progress" (Wilson and Ōe 83). In fact, far from treating his son's disability merely as a metaphor, Ōe is obsessively concerned with considering the material and very real social challenges his son faces growing up in twentieth-century Japan, as well as the ways in which his relationship with his son has reconfigured his own world-view. In an interview, Ōe provides a more nuanced way of thinking about the complex dynamic between his works, drawing a parallel between the processes of Hikari's musical composition and his own literary compositions: "I am the kind of writer who writes and rewrites. So one of my main literary methods is 'repetition with difference'...Through elaboration...composers create new perspectives" (Fay and Ōe). Through this aesthetic of improvisation around a recurring theme, Ōe uses fictional forms to challenge narrative scripts and fixed endings such as the miracle recovery, triumph-over-adversity, or narrative of overcoming. "Aghwee the Sky Monster" and *A Personal Matter* represent a "repetition with difference" of his own life story. Ōe's fiction not only retrospectively draws on his autobiography but also prefigures his actions and informs his future decision-making processes in practical ways. In an interview, he recalls: "In this case, it's actually backwards. Having written about the actions of both Aghwee's father and Bird, I steered my life toward those of Bird. I didn't intend to do this but afterward I realized that this was what I'd done" (Fay and Ōe).

Rebecca Garden suggests that renegotiated endings are a significant feature of contemporary disability life writing. Garden cites the relationship between the positive ending of Lucy Grealy's *Autobiography of a Face* and Ann Patchett's much darker afterword to the text as a key example of this potential for endings to be renegotiated or rewritten (130). In his hybrid generic forms, Ōe's experimental writing provides a

complex and early example of this: he perpetually re-writes and renegotiates his own life story, imagining different versions of himself, his son and very different narrative endings. Patchett's Afterword claims to tell the "real" story of Lucy's life, while Grealy acknowledges that life writing is always only one version of events: "I didn't remember it...I wrote it, I'm a writer" (Patchett 231). Ōe's autobiographical life writing also strips away the reassurance of any claim to realism. Instead, he uses his life story as a point of departure, using fiction, in line with Laura Marcus's definition, as "a space for more general identification, or the trying out of potentialities and possibilities – what might have been, what could have been, what might yet be" (280).

In this sense, Ōe's writing is important because it reminds readers that life writing cannot be discussed as an "unmediated voice of the author" or a straightforward record of memory (Garden 126); it draws on many of the same culturally resonant structures, predecessors and conventions as literary writing. The recurring scenes of naming and doubling in Ōe's fiction complicate responses and encourage readers to guard against the "assumption that the speaker or narrator of autobiography is the author her- or himself" (Garden 123–24). Ōe's works jolt readers out of easy assumptions about authenticity of the narrative voice and, instead, present a view of life stories as necessarily subjective, provisional and in a constant state of flux. Ōe uses fiction to insist on the importance, as well as the difficulty, of active imaginative engagement with his subject; how, he asks, can he articulate the story of his largely non-verbal son without "speaking for" him in a straightforward or oppressive way? Rather than merely telling readers about the decision he had to make following the birth of his son, *A Personal Matter* and "Aghwee the Sky Monster" enact the decision-making process and so, with a stark combination of bathetic humour and emotional complexity draw them into this ethically charged debate. Ōe uses fiction as a powerful mode of exploring the possible consequences of the different choices he could have made, as a father in relation to his son's future but also as a cultural and social figure living in a particular place at a particular moment in history.

### Conclusion: Ōe, Bérubé and the Imaginative Imperative

The relationship between fiction and life writing in Ōe's works sets up a complex model of identity as shifting and necessarily constructed in relation to others: both family members and the wider sociocultural context. Ōe's anxiety about speaking for his son is refracted in the many different voices and versions of their lives together that he creates. His short novel, "Teach Us to Outgrow Our Madness" explores the potential



for life writing to act as a form of self-delusion rather than enlightenment. Throughout the narrative, the central character, “the fat man”, is engaged in a failed attempt to write a biography of his father. He also creates a sense of his own life narrative and identity by telling a particular story of his son’s disability: “The fat man had structured a life unique to themselves. And that the structure demanded his bondage to his idiot son had long been his secret belief” (Ōe *Teach Us to Outgrow Our Madness: Four Short Novels* 183). The protagonist revels in the power that narrating his nonverbal son’s interior life gives him, positioning himself as a vital mediator: “a window into his son’s mind”, “the touch of his hand infused the fat man with the essence of his son’s entire experience” (Ōe *Teach Us to Outgrow Our Madness: Four Short Novels* 186–87). The crisis point in Ōe’s story comes when this fantasy of complete identification and transparent communication is shattered: the protagonist is forced to recognise that “the maintenance of this extraordinary structure had been most ardently desired by himself” (*Teach Us to Outgrow Our Madness: Four Short Novels* 183). He experiences this recognition of his son’s independence as an individual as a painful wound: “his son began to peel away from his consciousness like a scab” (*Teach Us to Outgrow Our Madness: Four Short Novels* 183).

This short narrative highlights the dangers of a “one-sided dialogue” between father and son and explores the potential for the position of narrator to reinforce an unequal and damaging relationship of dependency (Ōe *Teach Us to Outgrow Our Madness: Four Short Novels* 204). Here, Ōe uses a fictional form to raise and work through difficult ethical debates about speaking for another person that are pertinent to all third-person accounts of disability (Alcoff). Fiction provides the space in which Ōe imagines a worst-case scenario through a grotesque portrait of a father who fails to recognise his son’s right to his own self-expression. At the end of “Teach Us to Outgrow Our Madness”, the father’s fantasy of narrating the world as “the composite of the son and himself” becomes untenable (193); his son is institutionalised as his father descends into madness.

Michael Bérubé articulates similar anxieties in his memoir about his life with his son Jamie, who has Down Syndrome. He writes: “[I wondered whether] I would always be able to understand what Jamie wants and needs, and whether our ability to imagine his desires will be commensurate with his ability to imagine ours” (Bérubé xviii). In contrast to the one-sided dialogue and assumed omnipotence of Ōe’s fictionalised narrator in “Teach Us to Outgrow Our Madness”, Bérubé suggests that imagination is a reciprocal relationship that is difficult to achieve yet ethically important. Nevertheless, the challenges involved in trying to

imagine or represent another person's point of view are countered by a drive to make these personal, familial stories public. Bérubé suggests that imagining and representing his son's story and wishes are on-going processes, just as Ōe perpetually re-writes his son's life story. In *A Healing Family*, Ōe insists that imagination is an essential part of everyday life with his son: "Hikari, for example, particularly when he was younger, never expressed a desire for anything...And realizing this only increases my admiration for my wife's patience and compassion in the task of imagining his needs" (40). In his memoir, Bérubé suggests that this process of imagination is not only a practical necessity and a thought-experiment that is of personal interest, but that it also has a wider ethical value in the public sphere: "It is part of my purpose, in writing this book, to represent Jamie as best I can – just as it is part of my purpose, in representing Jamie, to ask about our obligations to each other, individual and socially, and about our capacity to imagine other people" (xix). As part of his attempt to locate his family's individual story in a collective, cultural context, Bérubé draws on a wide range of literary resources including William Faulkner, Richard Powers, Marcel Proust, W.E.B. Du Bois and Dostoyevsky, alongside recent life writing by people with Down Syndrome such as Chris Levitz, Jason Kingsley and Mitchell Levitz.

Bérubé suggests that he has "no sweeter dream to imagine – aesthetically and ethically and parentally – that Jamie will someday be his own advocate, his own author, his own best representative" (264). The recent rise in disability life writing, as well as literary writing by people with disabilities, allows people to tell their stories who might, until very recently, have been rendered voiceless, including those with aphasia, locked-in syndrome and nonverbal autism. Examples such as Jean-Dominique Bauby's best-selling memoir, *The Diving Bell and the Butterfly* (1997) and Naoki Higashida's *The Reason I Jump: One Boy's Voice from the Silence of Autism* published in English translation in 2013 (and discussed in Chapter Seven of this book), complicate traditionally individualistic ideas about authorship and highlight the ways in which digital technologies open up the act of writing to a far wider section of the population, making possible a new range of literary and autobiographical forms. Expanding the notion of life writing to include diverse forms such as photography, dance, sign language, and music, leads to the creation of new critical vocabularies that are not based exclusively on narrative or linguistic frameworks (Woods; Louvel; Siebers).

Ōe's works exemplify this recent widening of the conception of life writing. They blur formal boundaries between literature and autobiography and draw on a wide range of fiction, poetry, essays, lectures and music. In an interview, Ōe suggests that his son, through the

fictional alter egos of Eeyore, Jin and Mori, is not only the inspiration for his Nobel Prize-winning works but also, in a sense, a co-writer of them: “I copy the words of Hikari in the exact order he says them. What I add is the context and situation and how others respond to him. Through this process Hikari’s words become more comprehensible. I would never reorder his words to make them understandable” (Fay and Ōe). Yet, Ōe ultimately suggests that it is through music, rather than either literature or life writing, that Hikari is able to find a form of self-expression and communicate with his family: “[Music is] the principal way in which he can express himself ... had he never taken up composing, my family and I would have remained forever ignorant of the delicate existence that was locked away deep inside him” (*A Healing Family* 56).

So, Ōe’s life writing can perhaps be best understood in dialogue with Hikari’s musical compositions and his wife Yukari’s illustrations (included in *A Healing Family*). The wide-ranging forms of his own works include a play that he co-wrote with Hikari, a documentary that they made together, the introductory blurb that he has written for Hikari’s records, his essays, interviews, and his Nobel Prize lecture. Ōe’s works, written over almost half a century, maintain an on-going commitment to representing disability and, like many recent disability memoirs, invite readers to think critically about the process of life writing itself. Borrowing from a musical vocabulary, Ōe suggests that Hikari’s disability has led him and his family to “improvise creatively” in the ways in which they live their lives and to think in new ways about communication and self-expression (*A Healing Family* 95). Ōe’s works, in turn, encourage his readers to critically analyse narratives of the past in ways that acknowledge their complexity and narrative richness, and to think creatively about the ways in which life stories are understood and conceptualised in the future.

### Further Reading

Michael Bérubé. *Life as We Know It: A Father, a Family, and an Exceptional Child*. 1st ed. New York: Pantheon Books, 1996. Print.

Christy Brown. *My Left Foot*. New York: Simon and Schuster, 1955. Print.

Tom Coogan. “Me, Thyself and I: Dependency and Issues of Authenticity and Authority in Christy Brown’s *My Left Foot* and Ruth Sienkiewicz-Mercer and Steven B. Kaplan’s *I Raise My Eyes to Say Yes*.” *The Journal of Literary and Cultural Disability Studies* 1.2 (2007): 42–54. Print.

G. Thomas Couser. *Signifying Bodies: Disability in Contemporary Life Writing*. Ann Arbor: University of Michigan Press, 2009. Print.

Lucy Grealy. *Autobiography of a Face*. Boston: Houghton Mifflin, 1994. Print.

- Helen Keller. *The Story of My Life*. New York: Norton, 2003. Print.
- Georgina Kleege. *Sight Unseen*. New Haven, CT: Yale University Press, 1999. Print.
- Stephen Kuusisto. *Planet of the Blind*. New York: Dial Press, 1998. Print.
- Simi Linton. *My Body Politic: A Memoir*. Ann Arbor: University of Michigan Press, 2006. Print.
- Kenzaburō Ōe. *A Healing Family: A Candid Account of Life with a Handicapped Son*. Trans. Synder, Stephen. Tokyo: Kodansha International, 1995. Print.
- Kenzaburō Ōe. *A Personal Matter*. 1st Tuttle ed. Tokyo: C. E. Tuttle, 1969. Print.

## Bibliography

- Adams, Lorraine. "Almost Famous: The Rise of the 'Nobody' Memoir." *Washington Monthly*. Web. 28 August 2013.
- Alcoff, Linda Martín. "The Problem of Speaking for Others." *Cultural Critique* 20(1991–1992): 5–32. Print.
- Baubly, Jean-Dominique. *The Diving Bell and the Butterfly*. 1st U.S. ed. New York: A.A. Knopf: Distributed by Random House, 1997. Print.
- Bérubé, Michael. *Life as We Know It: A Father, a Family, and an Exceptional Child*. 1st ed. New York: Pantheon Books, 1996. Print.
- Brown, Christy. *My Left Foot*. New York: Simon and Schuster, 1955. Print.
- Buckland, Angela. *Zip Zip My Brain Harts*. Cape Town, South Africa: HSRC Press, 2006. Print.
- Coogan, Tom. "Me, Thysself and I: Dependency and Issues of Authenticity and Authority in Christy Brown's *My Left Foot* and Ruth Sienkiewicz-Mercer and Steven B. Kaplan's *I Raise My Eyes to Say Yes*." *The Journal of Literary and Cultural Disability Studies* 1.2(2007): 42–54. Print.
- Couser, G. Thomas. *Signifying Bodies: Disability in Contemporary Life Writing*. Ann Arbor: University of Michigan Press, 2009. Print.
- Couser, G. Thomas. "Disability, Life Narrative, and Representation." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York: Routledge, 2013. 456–459. Print.
- Fay, Sarah and Kenzaburō Ōe. "Kenzaburō Ōe, the Art of Fiction." *The Paris Review*, No. 183(2007). Web. 2 August 2013.
- Finger, Anne. *Elegy for a Disease: A Personal and Cultural History of Polio*. 1st ed. New York: St. Martin's Press, 2006. Print.
- Garden, R. "Telling Stories About Illness and Disability: The Limits and Lessons of Narrative." *Perspectives Biology and Medicine* 53.1(2010): 121–135. Print.
- Grealy, Lucy. *Autobiography of a Face*. Boston: Houghton Mifflin, 1994. Print.
- Hall, Alice and C.J. Hall. "Reading Real Life Writing." *Teenagers and Reading: Literary Heritages, Cultural Contexts and Contemporary Reading Practices*. Ed. Manual, Jacqueline and Sue Brindley. Kent Town: Wakefield Press, 2012. 111–127. Print.

- Keller, Helen. *The World I Live In*. New York: The Century Co., 1908. Print.
- Keller, Helen. *My Religion*. New York: Swedenborg Foundation, 1962. Print.
- Keller, Helen, et al. *The Story of My Life*. New York: Norton, 2003. Print.
- Kleege, Georgina. *Sight Unseen*. New Haven, CT: Yale University Press, 1999. Print.
- Kuusisto, Stephen. *Planet of the Blind*. New York: Dial Press, 1998. Print.
- Kuusisto, Stephen. *Eavesdropping: A Life by Ear*. 1st ed. New York: W.W. Norton, 2006. Print.
- Linton, Simi. *My Body Politic: A Memoir*. Ann Arbor: University of Michigan Press, 2006. Print.
- Louvel, Liliane. "Photography as Critical Idiom and Intermedial Criticism." *Poetics Today* 29.1(2008): 31–48. Print.
- Marcus, Laura. *Auto/Biographical Discourses: Theory, Criticism, Practice*. Manchester; New York: Manchester University Press, 1994. Print.
- Mitchell, David T. and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press, 2001. Print.
- Ōe, Kenzaburō. *A Personal Matter*. 1st Tuttle ed. Tokyo: C. E. Tuttle, 1969. Print.
- Ōe, Kenzaburō. *The Pinch Runner Memorandum*. Armonk, N.Y.: M.E. Sharpe, 1994. Print.
- Ōe, Kenzaburō. *A Healing Family: A Candid Account of Life with a Handicapped Son*. Trans. Snyder, Stephen. Tokyo: Kodansha International, 1995. Print.
- Ōe, Kenzaburō. *Teach Us to Outgrow Our Madness: Four Short Novels*. 1st ed. New York: Grove Press: distributed by Random House, 1977. Print.
- Ōe, Kenzaburō. *Rouse up O Young Men of the New Age!* 1st ed. New York: Grove Press, 2002. Print.
- Ōe, Kenzaburō and Deborah Boliver Boehm. *The Changeling*. 1st ed. New York: Grove Press, 2010. Print.
- Ōe, Kenzaburō and David L. Swain. *Hiroshima Notes*. Tokyo: YMCA Press, 1981. Print.
- Ōe, Kenzaburō, Kunioki Yanagishita and William Wetherall. *A Quiet Life*. 1st ed. New York: Grove Press, 1996. Print.
- Patchett, Ann. "Afterword." *Autobiography of a Face*. New York: Harper Perennial, 2003. 227–236. Print.
- Sachs, Albie. *The Soft Vengeance of a Freedom Fighter*. Cape Town: D. Philip, 1990. Print.
- Sheridan, Jim (dir.). *My Left Foot: The Story of Christy Brown*. 1989. Film 24. February 1989. Film.
- Siebers, Tobin. *Disability Aesthetics*. Ann Arbor: University of Michigan Press, 2010. Print.
- Wilson, Michiko N. and Kenzaburō Ōe. *The Marginal World of ŌE Kenzaburō: A Study in Themes and Techniques*. Armonk, N.Y.: M.E. Sharpe, 1986. Print.
- Woods, A. "The Limits of Narrative: Provocations for the Medical Humanities." *Medical Humanities* 37.2(2011): 73–78. Print.

## 9 Voice and Poetry

Act II, Scene IV of Shakespeare's *Titus Andronicus* (1588–93) opens with a young woman, Lavinia, in a condition of voicelessness and vulnerability. She is, according to the stage directions, “ravished”, “her hands cut off, and her tongue cut out” (89). After they rape her, Demetrius and Chiron taunt Lavinia mercilessly:

DEMETRIUS: So, now go tell, and if thy tongue can speak,  
Who 'twas that cut thy tongue and ravish'd thee.

CHIRON: Write down thy mind, bewray thy meaning so,  
And if thy stumps will let thee play the scribe.

(Shakespeare 89)

They confidently declare that their acts of physical and sexual violence have entirely deprived Lavinia of the chance to speak or to “play the scribe”. Later in the play, however, Lavinia reclaims her voice through alternative means: first through gesture and then by writing the names of her perpetrators in the ground using her mouth. The play itself gives voice to a shocking story of male violence through grotesque imagery and shocking on-stage action that pushes the boundaries of performance. Through Lavinia, Shakespeare suggests that “playing the scribe” goes far beyond conventional notions of physical voice: it is a complex process that requires spectators and readers to become attuned to the nuances of different forms of embodied communication. Textual and verbal certainties are destabilised by a disabled female character at the centre of the play who “dost talk in signs” and refuses to be read as a victim (Shakespeare 102).

The character of Lavinia is part of a long poetic tradition that extends well before, and long after, Shakespeare's sixteenth-century play. Ovid's *Metamorphoses*, a key source for Shakespeare, tells the story of Philomela, who is raped and has her tongue cut out by Tereus. Like Lavinia, Philomela bears witness to the crime by alternative means: she weaves

her story into a tapestry and is then turned into a nightingale by the gods. This myth of the shift from silenced speech to a beautiful singing voice has transformed Philomela into a resonant symbol of feminist resistance but also, in the form of the nightingale, a symbol of the muse and of poetry itself. Philomela's prediction, immediately following the rape, that "My mournful voice the pitying rocks shall move, / And my complainings echo through the grove" are borne out in the poem through her transformation into a nightingale (Ovid 62), but also in the echoing of the myth across literary history, from Shakespeare's *Titus Andronicus* to Keats's "Ode to a Nightingale" (1819) and T.S. Eliot's "The Waste Land" (1922).

In a disability studies context, Davis suggests that the Philomela myth is important because of the connection that it establishes between "poetry, dumbness, and writing" (119). "Poetry", he concludes, "issues from the throat of the nightingale – the repressed other of dumbness" (Davis 120). The myth is also significant because it introduces an understanding of poetic voices as intimately bound up with the politics of gendered power relations and the social silencing of certain populations. The visceral physicality of the story in all of its different iterations, with its connections between sexual violation with amputation, serves as a powerful reminder that writing, singing or reading poetry are embodied acts. The alternative forms of communication depicted in the poems and stories, from Lavinia's mouth writing to Philomela's weaving, broaden the definitions of voice and writing.

Davis points out that there is not necessarily a connection between speech and writing and that it is only through "a false chain of metonymy" that "the writing process comes to reside in the throat and the mouth" (119). This point is borne out in some of the examples discussed earlier in this book, including Cook and Lerner's sign language poetry, the attention to the expressive potential of touch in lyrical works by Kuusisto and Kleege, or the works composed using voice synthesizers by ASD poets such as Tito Mukhopadhyay. In the landmark disability poetry collection, *Beauty is a Verb* (2011), Raymond Luczak's poem, "Hummingbirds", describes how:

My fingers were only  
 hummingbirds in a small cage.  
 I sat up and freed  
 my deaf voice, my hearing hands.  
 They fluttered under my chin, in  
 front of my chest, everywhere.

(227)

Rewriting Ovid's nightingale, Luczak's image of hummingbirds allows him to render through text the liberating experience of manual communication: "My voice faltered as I felt / their fierce wings beating" (227). In *Cripple Poetics: A Love Story* (2008), Kuppers picks up on this idea that a voice which might be seen as faltering in a conventional sense in fact opens up multisensory forms of communication: "THE MUTE SPEAKS in many tongues / Art / Touch / Whispers / Tones" (66). While speech may seem "garbled" to the "untrained ear", Kuppers's poem suggests that synesthetic experiences of "feelsmellstaste" – amalgamated into a single word and a combined set of perceptions in the poem – are strikingly "clear" (Kuppers and Marcus 66). Like *Titus* or the Philomela myth, the poems by Luczak and Kuppers suggest that eyes, ears and hands need to be re-trained to read differently: they insist on diverse embodied and multisensory approaches to communication and voice. There are, Kuppers's poem suggests, "so many languages to talk in" (66).

By focusing on poetry and voice, this chapter addresses an area in which disability studies criticism, with its close attention to narrative, has often remained surprisingly silent (Schweik 49). Recently, scholars such as Michael Davidson, Susan Schweik, Jim Ferris and Petra Kuppers have sought to emphasise the importance of attending to the presence of disability in poetic traditions and to celebrate contemporary works by poets with disabilities through their scholarship. Kuppers, for example, is both a poet and a critic; she suggests that poetry can be socially valuable as a creative and pedagogic practice in its own right: "poetry can perform the binding of community *and* the singularity of experience" ("Performing Determinism: Disability Culture Poetry" 90). In an image resonant of the tapestry in *Titus Andronicus*, she suggests that "reading poetry and weaving myself into myth rehearse these pleasures of texts for me ... an undoing and doing that binds me to a story, to a people, to a land. In that land, I can lose myself, unbind, and gather again" ("Disability Culture Poetry: The Sound of the Bones. A Literary Essay"). Here, Kuppers seeks to celebrate a sense of collective identity through the recuperation of shared myths, stories and poetic traditions relating to disability, but she also celebrates her own capacity to actively reinvent them in the present day.

The poetic examples discussed in this chapter are connected through their concern with questions of voice and voicelessness. The poets discussed draw on different intertextual threads, recalling a long concern with categories of disability and ability in poetry from Milton's "On Blindness" (1655) and Walt Whitman's "I Sing the Body Electric" (1867) to Wilfred Owen's "Disabled" (1917) or Emily Dickinson's embodied aesthetics. The first section of the chapter explores conditions of physical and social voicelessness in poetry, particularly in relation to the frequent



representation of the natural world. The second part focuses on the ways in which the “crip poetry” movement can be understood as a means through which poets with disabilities can find a voice through an interconnected body politics and poetics. Thinking about disability poetics adds to the existing rich tapestry of scholarship about poetry, but it also has the potential to unpick some of the fundamental structures through which poetry is traditionally interpreted and understood.

### **Silence and Voicelessness: Interior and Exterior Landscapes**

Norma Cole’s poetry complicates ideas about voice by exploring the process of “crooked translation” between language and thought, between interior and exterior. For Cole, this process is, in part, rooted in her own physical and mental condition. In a short autobiographical aside before her poem, she describes how, following a stroke, “speech production was knocked out of the brain. Therefore I couldn’t talk at all. And I’ve had to refigure, little by little, how to make speech occur with mouth, teeth, tongue” (“Why I Am Not a Translator – Take 2” 258). The poem that follows, “Speech Production: Themes and Variation”, therefore has a highly personal, physical and a performative significance to it. The poem is formed of words that Cole finds particularly difficult to enunciate: “ribbons / vandals / the ribbons of vandals, the vandals / of ribbon, scissors of ribbon, / ribbons of scandal” (“Speech Production: Themes and Variations” 260). On one level, this repetition of language hollows it out almost to the point of meaninglessness; letters and sounds appear arbitrary as they are disconnected from concepts or ideas. The rhyming, most notably of “vandal and scandal”, emphasises this sense of the interchangeability of words. Language slips away from the author and then returns; words are substituted for each other. In this highly personal piece of writing, then, Cole experiments with poetic form in order to articulate some of the ways in which her approach to language has been radically reconfigured as a result of her stroke. The sense of the fluidity and interchangeability of language, underpinned by a threat of meaningless repetition, also call into question conventional models of reading poetry, particularly the ways in which literary students and scholars are often trained to read the unique significance and symbolism of each individual word choice in a poem.

However, “Speech Production: Themes and Variation” also suggests Cole’s commitment to engaging with systems of language: the repetition is also resonant of speech exercises in which participants are asked to retrain their mouths, tongues, and voices by practising words that they find difficult to articulate. The fragmented structure of the poem, in

which words hover on individual lines in isolation from each other, suggests a peculiarly modern process of cutting and pasting. The “scissors” cut the smooth flow of the rhythm and the connecting structural thread of the “ribbon” as words are re-arranged and readers are expected to string together meanings for themselves. These are not, however, abstract words on the page: they are animated by Cole’s own physical struggle to articulate them in her public performances. Her “slurred speech” is played for laughs yet also acts as a reminder of the “utterly wrenching” situation of “a poet losing words” (Bartlett 15). The result is not only an experimental form of poetry but also a reconceived conception of the relationship between language and thought: “I am here to tell you that one has ideas even before one has the words to say them. Ideas or image. No tabula rasa” (Cole “Why I Am Not a Translator – Take 2 ” 258).

Processes of “crooked translation” and the challenges of speech production following a stroke also permeate the later writing of Swedish Nobel Prize-winning poet, Tomas Tranströmer. Originally written in his native Swedish, Tranströmer’s works have been translated into more than fifty languages and come to Anglophone readers through Robert Bly’s translations. Like Cole, Tranströmer’s poetry collections such as *Sorrow Gondola* (1996), written after he had a stroke in 1990, explore processes of translation between interior and exterior spaces and challenge the idea that language is a precondition of thought. Partially paralysed and largely unable to speak, Tranströmer depicts a rich interior life through written poetry. His writing plays on the permeability of the relationship between interior and exterior, physical and mental landscapes through a recurring representation of the archipelago of islands where he lives in Sweden. In “Midwinter”, this porous relationship between internal and external worlds is conveyed through images of physical boundaries, such as the “clattering tambourines of ice” that give access to the water below and trigger a stream of thought: “I close my eyes” (Tranströmer and Fulton Macpherson *New Collected Poems* 177). There is a fluid movement between physical and imaginative landscapes in Tranströmer’s writing: “There is a soundless world / there is a crack / where dead people / are smuggled across the border” (177). In a muted poem set in “Midwinter”, this cracking of the ice represents a rare sonic, musical reference in a largely still and silent landscape; it suggests an understated yet highly significant moment of entering another consciousness or world. In this moment, the poem recalls mythic associations of the River Styx but also returns readers to a very particular Swedish landscape and the author’s own physical condition. Like the broken ice, poetic structures are pared down and language is rendered crooked, even jagged, by the speaker’s physical condition of voicelessness.

This concern with depths and textures of the natural world is also conveyed in the sumptuous “velvet-dark ditch” and gleaming “yellow flowers” of Tranströmer’s poem, “April and Silence”, from the same collection (*New Collected Poems* 165). Written in the first person, the poem lends itself to an autobiographical reading. Yet, like Tranströmer’s imagery, the language of the poem remains translucent, condensed and far too fluid to tie down to a single narrative. The silence of the title is played out in a striking image of personal enclosure: “I’m carried in my shadow like a violin in its black case” (Tranströmer and Fulton Macpherson *New Collected Poems* 165). In contrast to the generous depths and expanses of the natural world, the poem’s narrator articulates a claustrophobic sense of physical limitation through the “black case”. The untouched violin also hints at the difficulty of expression through sound; the musical instrument, a symbol of poetry like the lyre, a nightingale or muse, remains silent. The final line of the poem extends this sense of unattainable expression, paradoxically rendered through language: “The only thing I want to say / gleams out of reach / like the silver / in a pawnshop.” (Tranströmer and Fulton Macpherson *New Collected Poems* 165). The end-stop, in the context of a poem with sparse punctuation and pared-down language, creates an abrupt sense of finality. Verbal expression, and the words needed to externalise internal experiences, remain “out of reach”. On one level, the poem represents a crisis of communication: the pawnshop silver image evokes a sense of language itself as emptied of value, used by multiple different owners and reduced to a commodity through the process of circulation. By contrast, the imagery of the natural world provides a way in which, paradoxically, Tranströmer articulates a sense of unspeakability through language itself and allows readers momentary gleams of insight into the interior life of another consciousness.

The fertile possibilities of the natural world as a subject for disability poetry are also conveyed through the section titles in Kuppers’s poetry collection, “Cripple Poetics: A Love Story”: “Seeds”, “Landscape”, “Biology” and “Echoes” (3). In contrast to the spare end-stopped lines and broken systems of circulation in Tranströmer’s writing, Kuppers’s titles suggest fluid progression and growth. Kuppers employs natural imagery as a means of explicitly challenging taboos about disability and sexuality and contesting a medicalised model in which disability is viewed as unnatural, warranting a clinical intervention or cure. The first poem in the collection opens with a challenge: “How can I speak of cripple and not mention the wind / How can I speak of cripple and not mention the heart / Heart, wind, song, flower....To leave / these absent is to leave cripple in stark terms. / As if we were made of medical parts and not flesh and bone”

(Kuppers and Marcus 7). In this moment, Kuppers aligns herself with a growing group of disability poets, including Mark O'Brien, Stephen Kuusisto, Floyd Skloot and Jim Ferris, who write nature and landscape poetry yet refuse the model of "heroic individuality" that is often associated with it (Kuppers "Outsides: Disability Culture Nature Poetry" 31). In this new brand of "ecological poetry", Kuppers finds "little triumphant or melancholic masculinity, conquering and conquered, wrestling with mountains and awe", but rather an understanding of bodies and voices as embedded in an interconnected, interdependent natural world ("Outsides: Disability Culture Nature Poetry" 31).

This image of interconnectedness is captured on a formal level in Kuppers's untitled poem in *Cripple Poetics* in which the words are arranged as a spiral on the page. This innovative use of spacing recalls earlier examples of work by experimental disability poets, notably the gaps and gulfs between words in Larry Eigner's poetry (Davidson 125). Addressed to her lover, Neil Marcus, the spiralling form of Kuppers's poem on the page is such that bodies and images are "curled" around each other and intertwined like a "gnarled nautilus / shell" (Kuppers and Marcus 104). The shell-like poem on the left-hand page is held in dialogue with the photograph displayed opposite it, which portrays Kuppers and her lover naked and curled up in each other's arms in a forest. The structure of the book as a whole means that their voices also merge together: poems by Kuppers and Marcus co-exist and are not differentiated. For Tranströmer, the natural world is vast, icy and hauntingly quiet; it provides a powerful metaphor for his own isolation from social life and speech. Kuppers's poetry, by contrast, takes a more intimate focus on particular details of the natural environment. Through the spiral of the shell and the intertwined bodies, natural imagery permeates the form and language of the poem, giving voice to Kuppers's exploration of sexuality, fertility, disability and aesthetic creativity.

### **Finding a Voice: Body Poetics**

In his poem, "Disabled Country", Neil Marcus suggests that "Crip culture offers me another land and language". Marcus embeds himself in a particular social context and environment, re-situating conventional understandings of his disabled body through a distinctive linguistic agency and identity. Like Kuppers, Marcus engages with contemporary "crip" poetry, a movement that is often traced back to the publication of *Towards Solomon's Mountain: The Experience of Disability in Poetry* by A.J. Baird and D.S. Workman in 1986 (Northern 18). Since the passing of the Americans with Disabilities Act in 1990, there has been a

flourishing of disability poetry in the United States including works by Petra Kuppers, Neil Marcus, Tom Andrews, Floyd Skloot, Jim Ferris, Stephen Kuusisto, Nicole Markotic, Kenny Fries, Dara McLaughlin, Johnson Cheu, Karen Fisher and Mark O'Brien. Jim Ferris, author of a series of essays that explicitly seeks to define the movement, suggests that key features of this new disability poetry include the desire to challenge stereotypes, to celebrate disabled experience, and to explore the possibilities of the new poetic forms that are generated from the perspectives of "abnormal" bodies and minds, for example "Against Rhythm: Poetry in Uncommon Time" and "The Enjambed Body: A Step Towards a Crippled Poetics". Disability poetry is, he argues, also characterised by a kind of edginess, a transformative capacity to push the boundaries of language, form and social expectations in order to make the world "roomier" and more appreciative of diverse poetic forms and a range of different physical bodies (Ferris "Crip Poetry, or How I Learned to Love the Limp"). In this context, the re-mapping that Marcus undertakes in "Disabled Country", in which he describes an on-going project of "making myself / At home in my country", is at once a personal, political and an aesthetic process.

This insistence on situating bodies and identities within particular cultural and political settings is a key concern for many disability poets. It is a logical extension of the concerns of social models in which disability is understood in terms of the social construction of impairments within a particular cultural context. The first person defiance of Cheryl Marie Wade's writing, for example, is captured in the staccato rhythms of her verse: "I'm a sock in the eye with a gnarled fist / I'm a French kiss with a cleft tongue" (526). She refuses the euphemistic language of the "differently abled" and instead actively re-appropriates terms that traditionally have derogatory associations such as "gimp", "cripple" and "crazy". The title of her poem emphasises the voice of the first-person speaker as central to the process of self-definition: "I am Not One of The" (Wade 526).

However, some poets and scholars have expressed reservations about the label "crip poetry", suggesting that it can lead disability poetry to be read in purely autobiographical terms or to be seen as representative of some sort of definable and essentialised "disability experience" (Weise 138–39). Like Wade, Daniel Simpson opens his poem, "Broken Reverie", with a defiant statement of what he is not going to do: "I am not going to write a political poem" (125). Yet, in the very next line, the poem performs a U-turn: it turns back to the material details of the local environment and the politics of the everyday: "But in my neighbourhood, a truck is in reverse" (125). Similarly, Ferris invokes Virginia Woolf's celebrated essay, "A Room of One's Own" (1929), in his poem, "Poet of Cripples": "we carry within, our hidden void, / a place for each to

become full, whole, / room of our own” (540). Like Woolf, Ferris and Simpson suggest that while their works should not be read in exclusively political terms, bodies and poems cannot exist as purely aesthetic objects in isolation from the very real material needs for money, support, recognition and a space in which to write. They suggest a fundamental interconnection between interior and exterior landscapes that necessarily informs the language, imagery and construction of the poem itself.

This sense of being embedded in a particular body or environment also extends to an embodied conception of aesthetics. In “Crip Poetry, or How I Learned to Love the Limp”, Ferris cites Emily Dickinson’s description of poetry as that which “makes my whole body so cold no fire can ever warm me...[I] feel physically as if the top of my head were taken off” as a key inspiration for his own creative processes. This echoes Tobin Siebers’s materialist conception of aesthetics as “the sensations that some bodies feel in the presence of other bodies”; the human body, he argues, “is both the subject and object of aesthetic production” (1). In contrast to early disability poets, such as Eigner and Josephine Miles, who tended to ignore or displace their bodies even within their more autobiographical poetry (Northern 20–21), many more recent critical and poetic works put corporeal experience at the centre of their writing. Ferris’s poem, “Facts of Life”, addresses the question of looking at the body. He confronts external gazes with a direct defiance that is reminiscent of Wade’s refusal of euphemistic language: “This is my body. Look if you like” (544). Yet, the “meat, substance” of his flesh is not, he goes on to insist, his “essence”; instead, his body becomes a starting point to open up a wealth of different interpretations of the world and the self in a “cosmos of possible ontologies” (Ferris “Facts of Life”). Bodily concerns are explored on the level of the poem’s subject matter, but they also influence approaches to form and processes of reading and writing. To inhabit a disability consciousness is to be open to different readings of rhythm and non-standard forms of bodies or poems: Koppers celebrates a community of people who “read a halting step meter differently than those of someone who strides straight and full” and are “attuned to the small shifts of pain, breath or fluttering fingers” (“Disability Culture Poetry: The Sound of the Bones. A Literary Essay”). This fine attunement to the rhythms of the body is manifested in poems in the *Beauty is a Verb* collection, for example, through the incorporation into the form of the poems themselves of the beating hearts, limping gaits, tapping canes and the humming of a respirator.

The body emerges, therefore, not only as an important image “*in* poetry” but also “an important image *of* poetry” (Ferris “The Enjambed Body: A Step Towards a Crippled Poetics”). Scholars discuss “bodies of work” and poetic forms are conceptualised in terms of certain

standardised, often symmetrical forms: a sonnet, limerick, prose poem or villanelle. Deviating from a conception of the standardised body, of either an individual person or a poem, is an important part of the off-beat challenge that disability poetry can pose. Ferris's "Apologia", for example, which appears initially as a number of fragments of text scattered across the page, is a poem that determinedly "does not explain / its shape" and provides a metatextual commentary on its own resistance to formal conventions: "This poem / does not need / to march / across/ the page. / This poem / is free / to lean / and limp / and lurch" (546).

Yet, for others, the rigid shapes of traditional poetic forms provide an empowering structure through which complex and chaotic experiences, often deemed "unspeakable" in everyday discourse, can be articulated. Discussing her series of poems about the experience of MS and seizure, Laurie Clements Lambeth describes a paradoxically liberating process of "formal containment": "fitting form to the poem, lending it shape and order, granted me a tremendous sense of power" ("Reshaping the Outline" 176). Like other disability poets such as Ferris, who self-consciously locates his works within a poetic tradition stretching back to Whitman and Dickinson, Lambeth draws on and re-imagines traditional poetic forms. Her villanelle, "The Shaking" challenges taboos by combining disability and sexuality in its very first line, comparing the night-time shaking of a sudden seizure to her regular love-making. The measured rhythms of the end-stopped lines early in the poem, in which she sets the scene, break off as it reaches its climax with the enjambed line: "my body shows us our lives breaking / apart." (Lambeth "The Shaking" 179). In this moment, the container or "cage" of the poem's form seems to be at breaking point; lives and lines are spilling over and become fragmented (Lambeth "Reshaping the Outline" 175). For Lambeth, the poetic form allows her to give voice to an experience that is not autobiographical in a straightforward sense. Instead, her imagery recalls the translucent images and the porous boundaries of Tranströmer's writing:

MS entered my poetry – not in subject, but in the ways it altered my perception of the body's place in the world, as though the outline of what I could call "me" was a broken line, permeable and wavering, and what was inside that perimeter was a shimmering transparency, at once me and not me.

("Reshaping the Outline" 175)

Disability permeates Lambeth's writing: not merely in terms of subject matter but also in the sense that it reconfigures her approach to poetic form and the way in which she understands her body's place in the

world. Like many of the examples discussed in this chapter, her poetry is not necessarily confessional, autobiographical or defined exclusively by her own personal disability; instead, a distinct and complex disability consciousness informs the interconnected aesthetic, political, formal and linguistic aspects of her writing.

### Conclusion: Speaking For and With Others

Davidson argues that a theoretical engagement with literary writing about disability cannot be dismissed as merely a decorative adjunct to the political aims of disability studies: “[This] is why a poetics – as much as a politics – of disability is important: because it theorizes the ways that poetry defamiliarizes not only language but the body normalized *within* language” (118). Poetry in particular, with its attention to the textures, sounds and nuances of linguistic expression, plays with this process of defamiliarisation and challenges standardised conceptions of bodies, minds and literary forms. For Kuusisto and Koppers, poetry is an “art of intelligent dislocations” (78). Ferris creates experimental, fragmented forms in his own writing and draws on diverse bodies of work by poets across history. For Lucy Burke, poetic texts can help in imagining experiences outside the “physical constraints” of institutional settings, but they can also support the creative re-imagining of mental spaces and conditions, such as cognitive impairment caused by Alzheimer’s disease. Poems, Burke argues, can operate “as a form of prosthetic subjectivity reconstructing lost selves and perspectives that can only be imagined rather than ‘known’” (69).

In this sense, writing labelled “disability poetry” opens up the problems and the possibilities of speaking for others. These problems and possibilities extend throughout literary writing about disability. Burke’s work on audio-visual poetry about Alzheimer’s, for example, draws attention to ethical dilemmas about how to give voice to cognitively impaired individuals who cannot articulate their own wishes. But these debates also extend to questions about how individual authors or activists might be seen to “speak for” diverse disabled communities, particularly when those communities have been, or still are, silenced in mainstream social settings and official discourses. Koppers, for example, suggests that a definable “disability culture” is still “more a horizon of desire than lived reality for most disabled people” (Koppers “Outsides: Disability Culture Nature Poetry” 22). Uncritical claims that poetry necessarily represents or humanises a uniquely accurate or intimate experience of disability should, Burke reminds us, be viewed with suspicion (68).



However, literary and theoretical analysis of poetry and other cultural representations of disability is important precisely because it allows us to explore the various layers, narrators and complex dynamics that are at play in these works. Theorising and engaging in reading practices that are attuned to the nuances of language and are committed to setting representations within specific cultural and political contexts, helps to open up understandings of disability as a concept that is constantly shifting, culturally constructed and created from an interplay of different voices. While they may not “humanise” experience in a straightforward sense, the poetic, fictional and theoretical works discussed in this book engage, ultimately, with the question of what it means to be human. They insist that this is not only a question for the disciplines of medicine or the biological sciences, but also a valuable and potentially reinvigorating way to approach the study of the humanities at a time when these disciplines are often undermined or under threat in institutions.

The choice to close this book with a chapter on poetry was made because it represents an area of writing by people with disabilities, and by scholars in disability studies, that is flourishing and rapidly growing, yet – like the field as a whole – deserves greater attention. As with many of the literary texts discussed in *Literature and Disability*, the poetry explored in this chapter is concerned with pressing contemporary issues and the aesthetics and politics of everyday experience. Through the content and form of their works, many disability poets engage with technologies and systems of communication that destabilise the idea of poetry as emanating directly from the mouth, throat or voice, whether this is through the use of American Sign Language, multimedia poetry and video art, or voice synthesizers and electronic e-readers. They encourage us to consider poetry and reading as living things, “connective tissue” (Kuppers “Scars in Disability Culture Poetry: Towards Connection” 148), and to re-think the metaphors, conceptual frameworks and forms through which poetry and literature are often understood. Many of these works negotiate the blurred boundaries between art, activism and autobiography and, through these connections, give rise to new types of theoretical writing and alternative methodological approaches.

*Literature and Disability* began with a discussion of Anne Finger’s writing and, in particular, the ways in which her short stories re-write literary traditions as voices from the past are transposed into a contemporary setting. In arguing for disability as an important and potentially transformative category for the study of literature and for the humanities more widely, this book has tried to bring together various voices from disability studies that speak *with*, rather than for, disabled communities and help to both demonstrate and complicate some of the ways in which

disability approaches can reconfigure understandings of literary history and shift modes of reading in the present. Poetry is, Ferris suggests, “a conversation, not a monologue” (“Against Rhythm: Poetry in Uncommon Time” 84). Above all, *Literature and Disability* aims to provoke conversations that contribute to the ongoing dialogues in cultural disability studies and to give a sense of the rich variety of genres and theoretical works encompassed by the field.

## Further Reading

- Jenifer Bartlett, Sheila Black and Michael Northern, eds. *Beauty Is a Verb: The New Poetry of Disability*. El Paso: Cinco Puntos Press, 2011. 260–261. Print.
- Jim Ferris. “Crip Poetry, or How I Learned to Love the Limp.” *Wordgathering* 1.2 (2007). Print.
- Jim Ferris. “The Enjambed Body: A Step Towards a Crippled Poetics.” *The Georgia Review* 58.2 (2004): 219–233. Print.
- Petra Kupperts. “Disability Culture Poetry: The Sound of the Bones. A Literary Essay.” *Disability Studies Quarterly* 26.4 (2006). Print.
- Petra Kupperts and Neil Marcus. *Cripple Poetics: A Love Story*. Ypsilanti: Homofactus Press, 2008. Print.
- Susan Schweik. “Josephine Miles’s Crip(t) Words: Gender, Disability, ‘Doll’.” *Journal of Literary Disability* 1.1 (2007): 49–60. Print.
- Tomas Tranströmer and Robin Fulton Macpherson. *New Collected Poems*. Tarsset, Northumberland: Bloodaxe Books, 2011. Print.

## Bibliography

- Bartlett, Jennifer. “Preface.” *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 15–17. Print.
- Burke, Lucy. “The Poetry of Dementia: Art, Ethics and Alzheimer’s Disease in Tony Harrison’s *Black Daisies for the Bride*.” *Journal of Literary Disability* 1.1(2007): 61–73. Print.
- Cole, Norma. “Speech Production: Themes and Variations.” *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 260–261. Print.
- Cole, Norma. “Why I Am Not a Translator – Take 2.” *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 257–259. Print.
- Davidson, Michael. *Concerto for the Left Hand: Disability and the Defamiliar Body. Corporealities*. Ann Arbor: University of Michigan Press, 2008. Print.
- Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. London; New York: Verso, 1995. Print.
- Eliot, T.S., and Frank Kermode. *The Waste Land and Other Poems*. Penguin Twentieth-Century Classics. New York: Penguin Books, 1998. Print.

- Ferris, Jim. "The Enjambed Body: A Step Towards a Crippled Poetics." *The Georgia Review* 58.2(2004): 219–233. Print.
- Ferris, Jim. "Crip Poetry, or How I Learned to Love the Limp." *Wordgathering* 1.2(2007). Print.
- Ferris, Jim. "Against Rhythm: Poetry in Uncommon Time." *Journal of Literary Disability* 1.1(2007): 81–86. Print.
- Ferris, Jim. "Apologia." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York and London: Routledge, 2013. 546. Print.
- Ferris, Jim. "Facts of Life." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York and London: Routledge, 2013. 544. Print.
- Ferris, Jim. "Poet of Cripples." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York and London: Routledge, 2013. 540. Print.
- Keats, John "Ode to a Nightingale." *John Keats: Complete Poems*. Ed. Stillinger, Jack. Boston: Harvard University Press, 2003. 279–283. Print.
- Kuppers, Petra. "Disability Culture Poetry: The Sound of the Bones. A Literary Essay." *Disability Studies Quarterly* 26.4(2006). Print.
- Kuppers, Petra. "Outsides: Disability Culture Nature Poetry." *Journal of Literary Disability* 1.1(2007): 22–33. Print.
- Kuppers, Petra. "Performing Determinism: Disability Culture Poetry." *Text and Performance Quarterly* 27.2(2007): 89–106. Print.
- Kuppers, Petra. "Scars in Disability Culture Poetry: Towards Connection." *Disability and Society* 23.2(2008): 141–150. Print.
- Kuppers, Petra and Neil Marcus. *Cripple Poetics: A Love Story*. Ypsilanti, Mich.: Homofactus Press, 2008. Print.
- Kuusisto, Stephen and Petra Kuppers. "Auto-Graphen or 'the Blind Man's Pencil': Notes on the Making of a Poem." *Journal of Literary Disability* 1.1 (2007): 74–80. Print.
- Lambeth, Laurie Clements. "Reshaping the Outline." *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 174–177. Print.
- Lambeth, Laurie Clements. "The Shaking." *Beauty Is a Verb: The New Poetry of Disability* Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 179. Print.
- Luczak, Raymond. "Hummingbirds." *Beauty Is a Verb: The New Poetry of Disability* Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 237. Print.
- Marcus, Neil. "Disabled Country." Smithsonian Museum Web Exhibition. Web. 16 March 2014.
- Milton, John. "On His Blindness." *The Poetical Works of John Milton* Ed. Montgomery, James. Vol. 2. Hartford: S. Andrus and Sons, 1748. 233–234. Print.
- Northern, Michael. "A Short History of American Disability Poetry." *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 18–24. Print.
- Ovid. *Metamorphoses: Translated from the Latin*. Trans. Garth, Samuel and Others. Vol. 1. London: Suttaby, Evance and Fox, 1812. Print.

- Owen, Wilfred and John Whitehead. *Disabled and Other Poems*. Munslow, Shropshire: Hearthstone, 1995. Print.
- Schweik, Susan. "Josephine Miles's Crip(T) Words: Gender, Disability, 'Doll'." *Journal of Literary Disability* 1.1(2007): 49–60. Print.
- Shakespeare, William. *Titus Andronicus*. Cambridge: Cambridge University Press, 1994. Print.
- Siebers, Tobin. *Disability Aesthetics*. Ann Arbor: University of Michigan Press, 2010. Print.
- Simpson, Daniel. "Broken Reverie." *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 125–126. Print.
- Tranströmer, Tomas and Robin Fulton Macpherson. *Sorgegondolen = Sorrow Gondola*. Dublin: Dedalus Press, 1997. Print.
- Tranströmer, Tomas and Robin Fulton Macpherson. *New Collected Poems*. Tarsset, Northumberland: Bloodaxe Books, 2011. Print.
- Wade, Cheryl Marie. "I Am Not One of The." *The Disability Studies Reader*. Ed. Davis, Lennard J. New York and London: Routledge, 2013. 526. Print.
- Weise, Jilian. "From the Disability Rights Movement and the Legacy of Poets with Disabilities." *Beauty Is a Verb: The New Poetry of Disability*. Ed. Bartlett, Jennifer, Sheila Black and Michael Northern. El Paso: Cinco Puntos Press, 2011. 138–144. Print.
- Whitman, Walt. "I Sing the Body Electric." *Leaves of Grass: The First (1855) Edition*. London: Penguin Books, 2005. 129–136. Print.
- Woolf, Virginia. *A Room of One's Own/Three Guineas*. Oxford: Oxford World's Classics, 2008. Print.

# Glossary

**Ableism** Ableism is a form of prejudice against people with disabilities. Ableist perspectives value “normal” or “able” bodies and minds above all others. It is a systematic form of discrimination that subjects people to economic, social or cultural degradation. In this sense, ableism is a source of oppression comparable to sexism, racism and heterosexism. Disability studies works in opposition to ableism and sets out to critique it.

**ADA** The Americans with Disabilities Act was passed in 1990. It is a landmark piece of legislation which set out to mandate civil rights for people with disabilities and to eliminate discrimination against them in the United States. The act defines disability broadly to include individuals who have a “record of” an impairment or are “regarded as having” an impairment that limits at least one life activity. It therefore recognises the significance of the ways in which disability is perceived and the social contexts in which it exists. The definition of disability employed in the act encompasses physical, sensory, and cognitive impairments, illnesses, congenital and acquired differences and psychological disabilities.

**Crip** The word “crip” is used as an adjective and a verb in disability studies contexts. “To crip” is to question and to subvert dominant cultural expectations about disability and able-bodiedness in fresh new ways. In a literary context, a “crip” reading suggests a subversive reading of text that emphasises the presence of disability, the potential for interpretations and representations that deviate from a rigid norm, and the transgressive power of this critical position. By re-appropriating a term that traditionally has derogatory associations, “crip theory” draws attention to the significance of linguistic choices and turns traditional meanings inside out to make “crip” a term with a positive value. In this sense, “crip” or “to crip” is comparable to the use of “queer” or the verb “to queer” in queer and gender theory.

**Crip Poetry** This is a modern poetry movement which is often traced back to the publication of *Towards Solomon's Mountain: The Experience of Disability in Poetry* by A.J. Baird and D.S. Workman in the United States in 1986. It is founded on a desire to challenge stereotypes, to celebrate disabled experience, and to explore the possibilities of the new poetic forms that are generated from the perspectives of "abnormal" bodies and minds. The movement has flourished since the passing of the Americans with Disabilities Act in 1990. It encompasses works by Petra Kuppers, Neil Marcus, Floyd Skloot, Jim Ferris, Stephen Kuusisto, Nicole Markotic, Johnson Cheu and Mark O'Brien. Many scholars emphasise the transformative potential of this movement and how it invites new ways of thinking about diverse poetic forms and physical bodies. It is underpinned by a sense of the ways in which the personal, aesthetic and political aspects of poetry are intertwined.

**Dismodernism** This concept is introduced in Lennard Davis's book, *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions* (2002). Davis suggests that we have entered a dismodern era in which identities are malleable and technology has become part of the body. In this context, difference and (inter)dependence are what all of us have in common. He suggests that postmodernism has been replaced with "dismodernism", a new category that is based on the partial, incomplete subject. Davis argues that disability can be seen as the identity that both inspires and connects a broader re-examination of gender, race, sexual orientation and body politics in contemporary culture.

**Extraordinary bodies** This term is used in Rosemarie Garland-Thomson's seminal study, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997). Garland-Thomson uses the term to introduce a very flexible definition of disability, incorporating people who are sick, ageing, and deemed to be ugly or abnormal. Her study acknowledges the significance of visual display and the role of public spectacles in constructing "extraordinary bodies" in nineteenth- and twentieth-century America. Garland-Thomson engages with the ways in which exoticising discourses of race and gender intersect with understandings of disability in this period.

**Legal blindness** The medical criterion for legal blindness is that a person has visual acuity of 20/200 or less (seeing at 20 feet away what a fully sighted person sees at 200 feet), and/or a peripheral visual field of 20 degrees or less, in the better eye, with corrective lenses. To be legally blind does not necessarily mean that the person

is without some visual perception. In places where the category exists, only about 10–20 per cent of people designated “legally blind” are without any visual perception at all.

**Medical model** The model of disability tends to consider disability as a deficit: a problem or pathology that needs to be treated, concealed or dealt with through rehabilitation. Disability is understood as residing in an individual’s body or mind, rather than in the organisation of society. Processes of medicalisation are often connected to the institutionalisation of people with disabilities in asylums and hospitals in Europe and the United States at the beginning of the twentieth century. This model is often contrasted with “social” or “social-constructionist” models put forward by disability studies scholars.

**Minority model** The model highlights and seeks to celebrate disability as a distinctive minority identity. It is often associated with identity politics in the sense that it delineates a specific definition of disability as a group identity. According to the minority model, disability is not a set of physical or cognitive characteristics but rather a social identity that an individual actively takes up. Some adherents of minority models suggest that broad definitions of disability, such as the one found in the Americans with Disabilities Act, can undermine collective movements that unite disabled people through their shared minority status.

**Narrative prosthesis** The term was coined in David T. Mitchell and Sharon L. Snyder’s study, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2001). A “prosthetic” use of disability in narrative is one that employs representations of disability as a shorthand or stand-in to signify stereotypical notions of pity and moral or social disorder. Mitchell and Snyder argue that literary narratives and films often depend on disability as a device of characterisation or a “crutch” to lean on for its disruptive power and analytic insight. In this sense, disability is not represented for its own sake but, instead, it is used to shore up and stabilise ideas of the normal, telling readers something about the plot or deepening understandings of central, non-disabled characters. This theory encourages scholars to draw attention to metaphors and stereotypical narrative scripts that might otherwise be taken for granted.

**NLP** This acronym stands for “No Light Perception”. It is a medical model for measuring total blindness.

**Normate** This term was coined in Rosemarie Garland-Thomson’s *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997) and it has been widely used by disability studies scholars since then. It draws attention to the socially

constructed nature of the term “normal”. The term *normate* describes what is considered to be a normal human being in a particular society. For example, in a contemporary Euro-American context, these characteristics might relate to heterosexuality, whiteness, non-disabled status, and a certain height and weight. Garland-Thomson suggests that *normate* status is connected to both bodily configurations and cultural capital, and that these ideas are often reinforced through representations in literary and cultural texts. She emphasises the irony that only a small minority of people actually meet these criteria.

**Normalcy** This term is explored in Lennard Davis’s study, *Enforcing Normalcy: Disability, Deafness, and the Body* (1995). Normalcy is understood as a culturally specific standard or set of characteristics through which “normal” human beings are defined in a particular society and period. Norms are “enforced” through a variety of normalising technologies and practices, including the representation of norms as positive traits in books, films, television shows and works of art.

**Not dead yet** This is both a campaign slogan and the name of a grassroots international disability rights movement that oppose the legalisation of assisted dying.

**Nothing about us, without us** A disability rights slogan frequently used in activist campaigns. It asserts the rights of people with disabilities to be heard, to be involved in decision and policy-making, and to represent themselves wherever possible.

**Neurodiversity movement** The term *neurodiversity* is used to refer to a range of atypical cognitive styles due to neurological differences, including autism, intellectual disabilities, learning disabilities, attention deficit hyperactivity, epilepsy, post-traumatic stress disorder, bipolar disorder, Tourette’s syndrome, and schizophrenia. It brings together a wide range of cognitive impairments and conditions that have, until recently, been thought of separately in an attempt to gain greater recognition and empowerment for people who experience these conditions. As a collective social and political campaign, the *neurodiversity* movement seeks to raise the public profile of these cognitive differences and to give individuals better opportunities for self-representation.

**People-first language** This term features in hotly contested debates about the correct terminology and language to describe different types of disability. Proponents of *people-first* language use the term “people with disabilities” rather than “disabled people”. This *people-first* idiom, often used by disability studies scholars in the United States, seeks to emphasise the individual rather than their disability. By



contrast, the term “disabled people”, often favoured in the United Kingdom, Canada, Australia, and in languages other than English, emphasises an affirmative sense of group identity and minority status.

**Social constructionist model** This model emphasises the role that social, political and cultural contexts play in constructing disability. It is underpinned by a distinction between “impairment”, which might be a form of functional limitation such as missing a limb, and “disability”, which is a disadvantage or an exclusion from mainstream social activities caused by the environment in which a person lives. For example, a wheelchair-user is “disabled” by a lack of a proper access ramp through which to enter a building. Barriers can be sensory, affective and cognitive as well as architectural. Disability is, therefore, a social process, constructed through the relationship between an individual with an impairment and the society in which they live. This model emphasises the public and structural aspects of disability and, since the 1970s, has been an important part of activist campaigns to highlight the status of people with disabilities as an oppressed group.

**Supercrips** This term is used by disability studies scholars to describe the stereotype of the “superhuman” person with disabilities whose technologised body and power eclipses any sense of human vulnerability. Examples of this narrative template can be found in media, literary and other cultural representations. Critics suggest that these representations, while potentially empowering, often simply substitute problematic traditional perceptions of people with disabilities, as subhuman, for an equally unrealistic image, of the superhuman.

**TAB** This acronym stands for “temporarily able-bodied”. Disability scholars and rights activist use this term to highlight the flexibility of disability as a category which, unlike gender or race, any human being can join at any stage in their lives. It emphasises the fact that able-bodied status is temporary and, if we live long enough, most of us will become disabled in some way. Disabilities can be invisible and short-lived; most disabilities are acquired over the course of a lifetime rather than from birth. The term “not yet disabled” is used to similar effect.

**Universal Design** This term is explored in Michael Davidson’s *Concerto for the Left Hand: Disability and the Defamiliar Body* (2008). Davidson invokes the term “universal design” from architecture and, in this context, it is used to describe changes to design spurred on by the passage of the Americans with Disabilities Act. These changes include dropped kerbs, readable signs, wheel-chair accessible bathrooms and ramps. These designs are “universal” in the sense that

they facilitate access to the built environment for all people, disabled and otherwise. In his study, Davidson extends the concept of “universal design” and uses it 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 that are appropriate in the Euro-American settings that currently dominate the field can be easily transported elsewhere. 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 most people with disabilities live in the non-western “majority world”.

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