

# The Routledge Companion to Disability and Media



Edited by Katie Ellis, Gerard Goggin, Beth Haller and Rosemary Curtis

# THE ROUTLEDGE COMPANION TO DISABILITY AND MEDIA

An authoritative and indispensable guide to disability and media, this thoughtfully curated collection features varied and provocative contributions from distinguished scholars globally, alongside next-generation research leaders.

Disability and media has emerged as a dynamic and exciting area of contemporary culture and social life. Media—especially digital technology—play a vital role in disability transformations, with widespread implications for global societies and how we understand communications. This book addresses this development, from representation and audience through technologies, innovations and challenges of the field. Through the varied and global perspectives of leading researchers, writers and practitioners, including many authors with lived experience of disability, it covers a wide range of traditional, emergent and future media forms and formats.

International in scope and orientation, *The Routledge Companion to Disability and Media* offers students and scholars alike a comprehensive survey of the intersections between disability studies and media studies.

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and Rosemary Curtis*

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**We dedicate this volume to those striving to ensure the involvement of people with disabilities in all aspects of the media—from inception to consumption.**



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# FOREWORD TO THE *ROUTLEDGE COMPANION TO DISABILITY AND MEDIA (OR: A COMPANION ON THE RAMP LESS TRAVELED)*

*Faye Ginsburg*

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*The Routledge Companion to Disability and Media* could not come at a more propitious moment. As this extraordinary compendium of 36 timely chapters makes clear, the experience of disability is intersecting with a broad reach of media practices that are burgeoning across the globe, demanding the kind of scholarly and activist attention that is richly evident in this groundbreaking volume. A companion, as we know, is a counterpart with whom one spends a lot of time, a welcome escort on a journey through territory that might be either familiar or novel. This ambitious landmark collection certainly lives up to the title of companion, escorting readers on an illuminating expedition.

The works gathered together here concern circumstances encountered in diverse locations, addressing sensory, cognitive and physical disability as these bodyminds<sup>1</sup> intersect with questions of representation, agency, authenticity/appropriate casting, access to media and the possibilities and foreclosures presented by new technologies. Most of the robust writing in disability and media studies has come from the Anglophone worlds where these fields first took shape. The inclusion of work from more than 12 countries—including a number of pieces from the too-often neglected global South as well as First Nations—is a welcome expansion and a reminder of the privileges that First Worlders too often take for granted. Additionally, the variety of media/practices encompassed in this collection ensures that this book will be widely used across many disciplines and attract diverse readers. Indeed, I can't think of an existing work in disability/media studies that speaks to such a broad spectrum of media worlds. The media forms addressed here include:

advertising  
books/print media  
digital storytelling  
digital/social media  
feature films  
graphic novels  
newspapers/journalism  
photojournalism

political cartoons  
robots  
speculative media  
sports reporting  
telephony  
television (including genres such as telenovelas, sitcoms, dramatic series, documentaries)  
video on demand

The wide-ranging writings that the editors have gathered open up new and exciting horizons that build on important earlier work in what Elizabeth Ellcessor and Bill Kirkpatrick dubbed in their 2017 volume, *Disability Media Studies*.<sup>2</sup> Indeed, the three editors—Gerard Goggin, Katie Ellis and Beth Haller—are well-known for creating the intellectual frameworks for scholarship on disability and media on which this collection builds. Their contributions include important foundational works that have framed the field: Gerard Goggin and Chris Newell’s *Digital Disability: The Social Construction of Disability in New Media* (2003); Beth Haller’s *Representing Disability in an Ableist World: Essays on Mass Media* (2010); Katie Ellis and Mike Kent’s *Disability and New Media* (2013); Katie Ellis and Gerard Goggin’s *Disability and the Media* (2015); and Katie Ellis and Mike Kent’s 2016 edited volume *Disability and Social Media: Global Perspectives*.<sup>3</sup> Underscoring the significance of the emergent interdisciplinary field of disability and media, American media scholars Ellcessor and Kirkpatrick’s aforementioned edited collection *Disability Media Studies* (2017), along with Ellcessor’s *Restricted Access: Media, Disability and the Politics of Participation* (2016),<sup>4</sup> are further testimony to the fact that neither disability or media studies are complete without consideration of the other field. Should anyone question the value of interdisciplinarity, a few hours perusing different chapters in this newest contribution to the field will yield convincing evidence of the liveliness of cross-pollination, not only across academic approaches, but also with respectful inclusion of the voices of activists and policymakers.

It’s exciting to see how rapidly disability media studies has expanded from the first important interventions by groundbreaking scholars who directed our attention to issues of textual representation. For example, the 2001 book, *Narrative Prosthesis* by David Mitchell and Sharon Snyder, is among the key works frequently cited by many of this collection’s authors.<sup>5</sup> There, Mitchell and Snyder powerfully demonstrate how disabled characters in literature and film have too frequently served as narrative prostheses, the neologism they use to describe how these figures become metaphors for either evil or for tragic loss, rather than as fully developed and complex characters living in the real world. While this approach is, alas, still with us, as several writers in the current collection remind us, the field has also moved along in terms of: what is getting produced and by whom; the rich portrayals of disabled characters (whether in fiction or documentary) including increasing appropriate/authentic casting; who has access to media viewing; and who is authoring texts or directing cameras. Recent films such as *Me Before You* (2016)<sup>6</sup> serve as reminders not only of the tenacity of narrative prosthetics in the cinematic imaginary, but also of the persistence of the too-long-standing tradition of having disabled characters played by normate actors (or what Tobin Siebers dubbed “disability drag”),<sup>7</sup> long considered Oscar-bait, but heavily critiqued by many in this volume and beyond. As activist, scholar and performer Lawrence Carter-Long wrote in his 2019 manifesto on disability and film for the journal *Film Quarterly*:

Once upon a time, disability was just a diagnosis. That’s all you got. Something to be fixed, cured, cut out, or gotten rid of. Through time, the definition has evolved to mean much more. Nearly three decades after the passage of the Americans with Disabilities Act, ask anyone with a disability who politically, culturally, or artistically embraces the rebellious act of being disabled what the word means to her or him, and you’ll most



likely hear back words like “community,” “constituency, and identity.” No handkerchief necessary. No heroism required. By any definition, that’s progress. But if we are to expand deeper meaning beyond the flock, these changes must be reflected in the movies we make, the films we watch, how we watch those movies, and perhaps most importantly, who gets to make them.<sup>8</sup>

Yet that older problematic approach is increasingly disrupted by exciting new works across the televisual, cinematic and online mediascape that are by, for and about those with disabilities and their allies. It seems that an embrace of the well-known disability rights slogan “Nothing About Us Without Us” (or “Nothing Without Us,” as Lawrence Carter-Long has rephrased it) is slowly but surely penetrating the disability media world.

Beyond the representational arena, the work in this volume addresses both very contemporary as well as long-standing concerns regarding the need for more inclusive technologies of mediation. Many of the articles in this volume fulfill the call generated by media scholars Jonathan Sterne and Mara Mills in their afterword to the aforementioned *Disability Media Studies*.<sup>9</sup> Entitled “Dismediation: Three Proposals, Six Tactics,” they offer a mild polemic emphasizing the need for broadening our approaches to media in relation to disability by theorizing media change and technical design from a disability studies perspective, suggesting that we use the neologism dismediation to capture this perspective. As they write:

Dismediation centers disability and refuses universal models of media and communication. It begins from a presumption of communicative and medial *difference* and *variety* rather than seeing media as either the tools to repair a damaged or diminished condition of human communication or themselves the cause of a fall from prior perfection ... dismediation appropriates media technologies and takes some measure of impairment to be a given, rather than an incontrovertible obstacle or a revolution.<sup>10</sup>

Without using the language of dismediation, the editors and many of the writers in this Companion are answering the call issued by Mills and Sterne. Their research attends to the intersection of disability and media both on-screen and off-screen conditions that “crip the media” through the affordances that enable those with sensory impairments access to print, television, film and other popular forms: these include (but are not limited to) closed captioning for d/Deaf audiences, audio description for those with low vision or who are blind, accommodations increasingly mandated by law in some locations, while embraced by disabled artists as an incitement to creativity.

As an anthropologist trained in one of the few disciplines not represented in this volume, I feel compelled to conclude with a few very recent examples drawn from the last month that offer a lively, ethnographic sense of the transforming place of media in a variety of growing disability media worlds.<sup>11</sup>

- In April, as part of an offsite screening at NYU for the Reelabilities Film Festival<sup>12</sup> that I have worked on since its inception over a decade ago, we showed the riveting Australian documentary *Gurrumul*, about the blind Indigenous musician of the film’s title whose traditional life as well as success on the world stage shape the arc of the film’s narrative.<sup>13</sup> Despite the fact that the film had a well-crafted audio description track and that we had excellent headphones, as well as a state of the art theatre, we could not get the technology to work to provide the additional track for blind audience members. As so often happens in settings where accommodations fail on more than one occasion, we improvised, setting aside a section of the theater, where people with limited vision who needed support could sit with sighted companions who quietly provided a whispered live audio description track.

- In the last class of my doctoral seminar last week, several students mentioned watching the season finale and last episode of *Speechless*, (discussed by Beth Haller in this volume) in which the central character JJ, who has cerebral palsy (played by the actor Micah Fowler who has cerebral palsy), graduates from high school.<sup>14</sup> He is selected to be the graduation speaker, communicating (as is his typical mode) with his laser pointer headgear to indicate words, on a board attached to his wheelchair, while his family steps up to read these aloud for him when his support person chokes up. JJ advises his classmates to “be unrealistic.” The final scene reveals him starting college at NYU, a plot twist that provoked discussion in the class. As it turned out, this last episode of this trailblazing show was followed by the disappointing announcement of its cancellation, a blow for fans of this thoroughly crippled sitcom. However, a new Netflix series, *Special*, hit the news cycle the same month, publicized as an unconventional comedy headlining Ryan O’Connell, a young gay TV writer and actor with cerebral palsy playing himself, launched first by eight 20-minute online episodes.<sup>15</sup> *Special* received widespread and positive press coverage. In one of his many interviews, O’Connell reminded his interlocutor of the potential size of the audience of viewers who identify as disabled:

[The show] changes the conversation surrounding those with disabilities and provides much-needed visibility for the estimated 61 million Americans who identify as having a disability ... You have a totally untapped demo[graphic] that is starving for stories like theirs, and we’re gonna ignore it? That doesn’t make sense. For so long, we’ve been ignored. I really hope that stops.<sup>16</sup>

- In May, I went to the opening of a brilliant gallery exhibit entitled *Crip Imponderabilia*,<sup>17</sup> curated by a terrific NYU MA student, Bojana Coklyat, an artist with low vision. The show was based on her thesis entitled “Beyond the Limits of Ocular-Centric Art Experience: Centering Disability in the Gallery.” The space filled with remarkable works by disabled artists addressing questions raised by their diverse experiences of disability. Additionally, each piece was hung at wheelchair height and many had tactile elements as well as a motion-activated sensor that provided a verbal description of the art for anyone who walked by; a creative alt-text walk-through of the show was produced by artist/contributor Shannon Finnegan. Bojana greeted visitors to the show dressed as her longstanding alter ego, Princess Leia from *Star Wars*, accessorizing the white costume and distinctive Princess Leia wig with her white cane. Coklyat used her presence as this character from “a galaxy far, far away” to good effect. She repurposed this heroic moxie-filled female rebel from popular media to remind us that a resistant, creative, alternative crip imaginary is indeed possible, demonstrating how a hacking aesthetic and assistive media can make that inclusive universe an actuality, at least briefly.
- A few days later, at what American television calls “the upfronts,” when major networks announce their anticipated projects for the fall season, a new comedy, *Everything’s Gonna Be Okay*, got attention as a new show in development, featuring a teen with autism who’s (finally!) played by an actress on the spectrum, Kayla Cromer. Kayla’s comments on a panel promoting the show make the essential point that resonates throughout this very welcome volume.

Honestly, people with a difference, we’re fully capable of portraying our own type and we deserve that right. With so many changes in the industry right now, why not now? Just give us our chance. Include us. We can do this.<sup>18</sup>

This *Companion to Disability and the Media* is a scholarly response to her call to action, taking us on “the ramp less traveled”<sup>19</sup> by reframing many of the taken-for-granted parameters of daily life, as thinking through the lens of disability media worlds so often does.

## Notes

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- 2 Elizabeth Ellcessor and Bill Kirkpatrick, eds., *Disability Media Studies* (New York: New York University Press, 2017).
- 3 Gerard Goggin and Chris Newell, *Digital Disability: The Social Construction of Disability in New Media*, Critical Media Studies (Lanham, MD: Rowman & Littlefield, 2003); Beth Haller, *Representing Disability in an Ableist World: Essays on Mass Media* (Louisville, KY: Advocado Press, 2010); Katie Ellis and Gerard Goggin, *Disability and the Media* (Basingstoke, UK: Palgrave Macmillan, 2015); Katie Ellis and Mike Kent, *Disability and New Media* (London: Routledge, 2013); Katie Ellis and Mike Kent, eds., *Disability and Social Media: Global Perspectives* (London: Routledge, 2016).
- 4 Elizabeth Ellcessor, *Restricted Access: Media, Disability and the Politics of Participation* (New York: New York University Press, 2016).
- 5 David Mitchell and Sharon Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2001).
- 6 *Me Before You*, directed by Thea Sharrock (London/Los Angeles, CA: Warner Brothers, 2016), motion picture.
- 7 Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008: 114–116).
- 8 Lawrence Carter-Long, “A Manifesto: Where Have You Gone, Stephen Dwoskin? On Disability Film,” *Film Quarterly* 72, no. 3 (Spring 2019): 26–29.
- 9 Mara Mills and Jonathan Sterne, “Afterword II: Dismediation—Three Proposals, Six Tactics,” in *Disability Media Studies*, ed. Elizabeth Ellcessor and Bill Kirkpatrick (New York: New York University Press, 2017), 365–378.
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- 11 See Faye Ginsburg, “Disability in a Digital Age,” in *Digital Anthropology*, ed. Heather Horst and Daniel Miller (London: Berg, 2012), 101–126; Faye Ginsburg and Rayna Rapp, “Disability Worlds,” *Annual Review of Anthropology* 42 (2013): 53–68.
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- 13 *Gurumul*, directed by Paul Damien Williams (Richmond, Vic: Madman Films, 2018), documentary, [www.madmanfilms.com.au/gurumul](http://www.madmanfilms.com.au/gurumul).
- 14 “U-n-r-Unrealistic,” *Speechless*, Season 3, Episode 22, directed by Bill Purple, aired April 22 (US: ABC, 2019), television series episode, <https://abc.go.com/shows/speechless>.
- 15 Naveen Kumar, “Ryan O’Connell Is Revolutionizing Queer, Disabled Representation on TV,” *them*, April 11, 2019, [www.them.us/story/ryan-oconnell-special-interview](http://www.them.us/story/ryan-oconnell-special-interview).
- 16 Ryan O’Connell quoted in Ilana Kaplan, “Ryan O’Connell Is Netflix’s Most *Special* New Star,” *GQ*, April 15, 2019, [www.gq.com/story/ryan-oconnell-is-netfixs-most-special-new-star](http://www.gq.com/story/ryan-oconnell-is-netfixs-most-special-new-star).
- 17 Crip Imponderabilia, accessed May 24, 2019, <http://cripimponderabilia.com>.
- 18 Kayla Cromer quoted in Shaun Heasley, “Actress with Autism Starring in New TV Show,” *Disability Scoop*, May 17, 2019, [www.disabilityscoop.com/2019/05/17/actress-autism-starring-tv-show/26641](http://www.disabilityscoop.com/2019/05/17/actress-autism-starring-tv-show/26641).
- 19 “The Ramp Less Traveled” (conference event, Getting Real ’18, Los Angeles, CA, September 27, 2018), <https://sites.grenadine.co/sites/documentary/en/gettingreal18/schedule/387/The+Ramp+Less+Traveled>.

# INTRODUCTION

## Disability and Media—An Emergent Field

*Katie Ellis, Gerard Goggin, Beth Haller and Rosemary Curtis*

### Introduction

The intersection of disability and mass media is resonating as a crucial topic in the modern world, against the backdrop of a vast expansion of research and publications on disability across many scholarly disciplines. Media, of course, is key to this overdue emergence of disability as central to academic research. Media and communication directly affect the lives of the approximately 15–20 percent of the world's population who live with disability.<sup>1</sup> In particular, the media help shape a range of economic, political, social, cultural, technological and attitudinal issues related to disability, something recognized internationally via the United Nations in the early 1990s:

The media can influence values and attitudes ... Generating awareness of the lives, experiences, talents and contributions of disabled persons in an integrated setting is important for providing disabled persons with highly visible role models and for changing negative stereotyping of disabled persons by the media where this happens.<sup>2</sup>

Subsequently, such international sentiments have been bolstered by the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), which provides a human rights framework and the potential of international law for encouraging deeper understanding and reforms of information, communication and media to underpin social participation, equality and justice for people with disabilities. A number of international organizations now recognize the key role of media in influencing the place of people with disability in the modern world. For example, the International Labour Organization has a media guide that reflects that:

How women and men with disabilities are portrayed and the frequency with which they appear in the media has enormous impact on how they are regarded in society ... Portraying women and men with disabilities with dignity and respect in the media can help promote more inclusive and tolerant societies ... and stimulate a climate of non-discrimination and equal opportunity.<sup>3</sup>

Thus, all forms of media are at the heart of an overdue and incomplete revolution underway in disability and society. Many aspects of the worldwide disability experience occur in mass media, whether via representation of disability in television, film, news or social media, via a disability

angle to participatory online cultures, crowd-sourcing or through the new attention paid to disability in media sport—to mention only a few of many areas. Disability in the media is now situated on a vibrant global stage, with much more access to media content and creation by citizens with disabilities worldwide. Extensive libraries of films/programs including fiction and non-fiction titles by and about people with disabilities can be accessed through subscription services such as Netflix, available in 190 countries; YouTube can be navigated in a total of 80 different languages (covering 95 percent of the Internet population). In addition to access to global content, video-making technology readily available in smartphones and lower-cost digital cameras allow people with disabilities to create and upload programs to YouTube or submit to the growing number of disability film festivals across the globe. What is evident is that how the media frames, circulates and enacts disability for news, entertainment and online audiences directly affects many of our central ideas and beliefs. In this sense, disability, like class, inequalities, race, sexuality, gender and other categories, potentially affects everyone.

### Disability and Media in Research and Teaching

The origin of work in disability and media stretches back some decades.<sup>4</sup> As a research topic, it appears in different disciplines and forms from the 1970s onwards. In some parts of the world such as the United States and United Kingdom, the emergence of research and teaching on disability and media has been documented and useful signposts and discussions exist. Early research can be found in a variety of journals and disability rights publications, everything from policy studies journals to the emerging disability studies-focused journals. Two major disability studies journals were founded in the United States and United Kingdom in the 1980s—*Disability, Handicap & Society* in 1986 in the United Kingdom (now called *Disability & Society*) and the US-based Society for Disability Studies academic journal *Disability Studies Quarterly* in 1986. The Kentucky-based disability rights publisher Advocado Press published early research on disability in the US news media in 1990.<sup>5</sup>

A variety of disciplines created disability and media/communication streams. The Media and Disability Interest Group of the Association for Education in Journalism and Mass Communication (AEJMC) in the United States began in 1990 and had its first interest group sessions in 1993 (it was in discontinued in 2007 due to falling numbers of conference submissions).<sup>6</sup> The US National Communication Association (NCA) started a Disability Issues Caucus in 1997, and it still exists today.

In terms of the use of media and disability scholarship in university classrooms, a number of disability studies courses that include media have been developed in the United States and Canada. Syracuse University in the United States keeps track of disability studies programs in North America and lists 42 that have disability studies programs (majors, minors, graduate programs).<sup>7</sup> Many of these programs now include courses focused on media and disability, either fully or partially. They range from “Understanding Disability through Mass Media” at Towson University (USA) to “Disability, Media and Madness” at Western University (Canada)<sup>8</sup> to New York University’s course “Disability, Technology and Media.”<sup>9</sup> British universities also offer several disability studies programs, such as the disability studies bachelor’s degree at the Sheffield Hallam University, where students are guided by scholar Rebecca Mallet, who researches disability in comedy and humor.<sup>10</sup>

The absence of the Internet and email meant little media and disability research was exchanged worldwide well into the 1990s (at least in the anglophone context). But some disability culture and media content did make it outside the United States in the 1990s through the David Mitchell and Sharon Snyder documentary, *Vital Signs: Crip Culture Talks Back*,<sup>11</sup> because it went to film festivals internationally. The film features conversations with disability studies scholars, disabled performers and disability activists, which allowed audiences to engage with a discussion of disability as a political and social identity.<sup>12</sup>

In the 2000s, disability and media work began to occur across various other scholarly and research traditions and groups, such as literature,<sup>13</sup> cultural studies,<sup>14</sup> performance studies,<sup>15</sup> socio-legal studies, sociology, anthropology,<sup>16</sup> Internet studies and many other areas. Digital technology has been an especially rich site of interdisciplinary work, crossing different fields and traditions, as well as articulating conversations and engagements across research and practice.<sup>17</sup> In one sense, this kind of variety and breadth is entirely characteristic of disability research and conversations, and supports and extends interdisciplinary and integrative scholarly work. Consider, for instance, various exciting works that have extended the range and repertoire and horizons of disability and media research, such as: Rosemarie Garland-Thomson's 1997 *Extraordinary Bodies* and 2009 *Staring*;<sup>18</sup> the work of Mitchell and Snyder, especially the 2000 *Narrative Prosthesis* and 2006 *Cultural Locations of Disability*;<sup>19</sup> various Petra Kuppers' books including her 2015 *Studying Disability Arts and Culture*;<sup>20</sup> Graham Pullin's 2011 *Design Meets Disability*;<sup>21</sup> Tanya Titchkosky's 2011 *The Question of Access*;<sup>22</sup> and, more recently, Bree Hadley and Donna McDonald's 2019 *Routledge Handbook of Disability Arts, Culture, and Media*.<sup>23</sup>

In a positive turn, we observe that in the media and communications associations with which we are familiar, there is more frequent appearance of disability-conceived and related work, and often dedicated panels and streams. In intersectional approaches, across gender, sexuality, race, class and other areas, disability increasingly finds a productive, if often challenging, set of alliances and combinations. At a variety of levels, most academic disciplines now embrace disability studies in their scholarly activities and teaching. Exciting, cutting-edge research is being undertaken that stands to transform the field. Despite such developments, for many years the place of disability work has been unclear in media and communication studies and associated disciplines such as cultural studies, sociology, Internet, digital media and mobile media studies. Papers on disability and media have increasingly appeared, published across a wide range of journals in the field. However, we have often felt that our work and that of other scholars working on media and disability falls between two areas: stranded between, on the one hand, the central focus of disability studies journals (where reviewer expertise in media and communications can be difficult to find and tap into) and, on the other hand, media and communications journals (where similarly knowledge of disability among editors, reviewers and readers has tended to be uneven). In other ways also in media and communication studies the emergence of disability has been slow to arrive on the research as well as teaching agenda. However, disability and media research has emerged with considerable momentum and richness in the past few years, indeed accelerating as this Companion has been underway.

Now we find books on disability and media regularly appearing, authored by emerging scholars of considerable talent, and established scholars have turned their attention to disability and media. All in all, we find hopeful signs that disability has finally "arrived" in the academic world and can now be accepted as an integral element of thinking about, and doing, media scholarship. In this context, we hope this Companion will be a useful guide to key areas in current and future research agendas, as well as showcasing a range of exciting international work in the field. Here this reference work can be read alongside key books that offer important perspectives on the field such as Beth Haller's pioneering *Representing Disability in an Ableist World: Essays on Mass Media* (2010),<sup>24</sup> Katie Ellis and Gerard Goggin's *Disability and the Media* (2015),<sup>25</sup> Elizabeth Ellcessor and Bill Kirkpatrick's *Disability Media Studies* (2017)<sup>26</sup> and Mike Kent and Katie Ellis' four-volume major works compilation, the 2017 *Disability and the Media*.<sup>27</sup> In addition, there are a wide range of other books and special issues of journals on aspects of disability and media that can provide specific itineraries, in-depth exploration and points of engagement and debate.<sup>28</sup>

## User's Guide to *Disability and Media Companion*

We are pleased to present this Companion as a balance between distinguished, established and leading scholars, with the emerging, next-generation researchers. In disability and media studies

especially, it is these emerging scholars who are often producing the cutting-edge and creative work, typically doing so in conditions of precarity and uncertainty in their careers and work and often with an uncertain sense of how their efforts will count or the impact their research will have.

In addition, a key aspect of the Companion is the inclusion of contributions from writers and practitioners, who have invaluable expertise and perspective on disability and media. Much of the knowledge resides with those deeply engaged in making, producing and interpreting media across industry, community, policy, professional, amateur, user and other settings.

Shaped by these ideas, and our own contexts, we were delighted to assemble a rich showcase of the state of the art in disability and media research and practice. Part I of this collection “Imagining and Representing Disability” addresses the discipline’s focus on representation across a variety of media forms including newspapers, advertising, television, film, magazine articles, political cartoons, literature and speculative media. Traversing Australian newspapers in the 1830s to traditional and digital media in Africa and India to contemporary US television programming and Hollywood drama, the chapters cover a wide range of both problematic and progressive disability representations.

The first three chapters address the news. Beginning with Tanya Titchkosky’s exploration of the ways readers of news media are invited into a *restricted imaginary* of disability as an inherently difficult life via newspaper headlines and taglines. Nookaraju Bendukurthi and Usha Raman’s chapter extends the notion of disability as newsworthy with a political economy reading of disability in Indian news media as having *use value* that translates as *exchange value* in the market. In the following chapter, John Gilroy, Jo Ragen and Helen Meekosha employ Martin Nakata’s Indigenous standpoint theory and decolonizing frameworks to deconstruct and analyze representations of “disabled” Indigenous people in mainstream newspapers during the first 100 years of the Australian press from 1830.

The focus shifts to advertising in Ella Houston’s chapter “Featuring Disabled Women in Advertisements: The Commodification of Diversity?” Drawing on the reactions from a small sample of women with mobility impairments, Houston analyzes the representations of women with impairments in UK and US advertisements from a feminist disability studies perspective. Following this Jonathan Bartholomy’s chapter offers a comparative analysis of different media imaginations of the key disability personality Mark O’Brien. The chapter examines the narratives about disability that are utilized in multiple media adaptations of O’Brien’s life: *The Sessions*, *Breathing Lessons* and “On Seeing a Sex Surrogate.”

The next two chapters maintain the focus on disability in film while incorporating interdisciplinary perspectives. Alison Wilde synthesizes disability studies, mad studies and film studies to examine and compare the narrative and visual techniques used in *Greenberg* and *Silver Linings Playbook*, while Sally Chivers examines the intersection between aging and disability in recent cinematic depictions of dementia, with *Still Alice* (2014) as a central focus.

Beth Haller then highlights authentic disability representation on US television as a social justice issue that pushes back against the aesthetic disqualification of disability. In the following chapter Tatiane Hilgemberg, Katie Ellis and Madison Magladry return the focus to the commercial potentials of disability representation in newspapers via a comparative analysis of representations of Paralympic athletes appearing in popular Australian and Brazilian newspapers during the 2012 Paralympic Games.

The final three chapters in Part I explore literary and visual representations of disability in particular genre imaginings. Focusing on characters Tyrion and Penny, Mia Harrison’s chapter investigates how George R. R. Martin’s fantasy series *A Song of Ice and Fire* is representative of both the weaknesses of fantasy literature and its potential as a champion of strong disability representation. Following this, Beth Haller investigates the intersection of disability metaphors within US newspapers political cartoon practices via analysis of selected US political cartoons from the

nineteenth century to 2015. Part I concludes with Sami Schalk's chapter that argues for a consideration of the non-realist context of speculative media when interpreting these representations in regard to (dis)ability and race.

Part II of the Companion, "Audience, Participation and Making Media," focuses on the ways people with disability can intervene as media researchers, teachers, producers and audiences. This section begins with Katie Ellis' investigation of social and cultural model approaches to disability in popular culture. Recognizing that these disciplines tend to approach the topic from a production perspective, Ellis foregrounds the role of consumption and critical engagement as a way to engage with the pleasures of popular culture. Extending the focus on consumption in the following chapter, Fiona Whittington-Walsh and her collaborators, Kya Bezanson, Christian Burton, Jaci MacKendrick, Katie Miller, Emma Sawatzky and Colton Turner, discuss the formation and activities of the Bodies of Film Club. This club, which comprises of a principal researcher, research assistant and five young adults who identify or have been identified with a developmental or intellectual disability, meet to analyze films with a disability theme by reflecting on their own lived experience, creating meaningful critical inquiry.

The next three chapters focus on disability media in developing countries. Taking Africa as its case study, Olusola Ogundola's chapter presents a comprehensive picture of *what* narratives shape disability stories when they make it onto the news agenda; *why* disability issues are being ignored; and *how* to make right the wrongs of several decades of "disability marginalization" in the news media. Patricia Chadwick's chapter adds to these debates with a focus on Afghanistan, China and Somalia. These case studies reveal the ways people with disabilities produce media to change attitudes about disabled people, advance disability civil rights and affect government policy in these countries. Kimberly O'Haver's chapter returns the focus to Africa with an exploration of the use of social media and digital technology by members of the African Youth with Disabilities Network (AYWDN).

Following this, Laurence Parent draws on her own experiences and observations as a disabled filmmaker, graduate student and activist in Montréal, Canada to explore some of the possibilities offered by mobile videos for challenging ableism and share some reflections on the pitfalls. Patricia Almeida's chapter then further investigates the potential for positive change via disability engagement in and with the media. The chapter explores how *Pages of Life* (*Páginas da Vida*), a Brazilian television telenovela (soap opera), used a plot about a child with Down syndrome to further the discussion of inclusion of children with disabilities in public education in Brazil.

Véro Leduc's chapter concludes Part II with an investigation of the production of *It Fell on Deaf Ears*, a graphic novel in Québec Sign Language. Reflecting on agency and digital media, Leduc asserts that the limits and uses of media technology must be pushed in order to foster the development of signed knowledge and Deaf becoming.

Media and communications have taken on a heightened importance in social life, especially with the advent of Internet, mobile and digital media and communications. Work on disability has especially developed in relation to these facets of the field, perhaps also because of the unique and generative ways that disability works in relation to media and communication technology. These concerns are taken up in Part III, "Media Technologies of Disability." Each of the nine chapters examines the notion that digital exclusion has significant social consequences for people with disability. Similarly that digital inclusion and accessibility has positive benefits. Jennifer Cole and Jason Nolan begin with an exploration of the genesis and maturation of the online community GimpGirl. The community that seeks to transcend the infantilizing oppression of medical and institutional models of disability has moved across many ICTs, from MOOs to Second Life, Blogs to Facebook, as the interest and needs of the community have grown and changed, charting paths for others to explore.



The next chapter turns to the issue of web accessibility. Using policy documents, web archives and interviews, Elizabeth Ellcessor traces the processes of negotiation that characterized the development of WCAG 1.0, the US Section 508 standards, WCAG 2.0 and recent related updates to situate accessibility standards as an infrastructure of possibilities. Following this, Jonathan Lazar and Brian Wentz join calls that the Web be fully accessible and usable for people with disabilities. Their chapter provides a framework for understanding technology accessibility, the challenges that are experienced by blind individuals as they use the Web and an overview of the international laws and policies that intersect with this topic. Mike Kent then explores the complicated relationship between social media and disability. Social media has provided opportunities for participation, commerce and political activism, as well as exclusion and inaccessibility.

Meryl Alper continues the focus on communication with an investigation of an augmentative and alternative communication system (AAC) as a form of mobile communications technologies. She calls for consideration of all mobile communication as existing along a spectrum between augmentations and alternatives to embodied oral speech. Lorenzo Dalvit furthers this argument via an investigation of mobile phone use by visually impaired people from different cultural, linguistic and socioeconomic backgrounds in Grahamstown, a small town in the Eastern Cape Province of South Africa. Dalvit finds that smartphones enable independent participation by disabled people as unobtrusive assistive devices and as popular symbols of social inclusion.

Wayne Hawkins then brings together the focus on accessibility and the influence of government policy in an analysis of the video-on-demand “streaming wars” taking place in Australia. Hawkins illustrates the ways hard-won access features across terrestrial broadcast platforms are being lost with these disruptive broadband-enabled services. Continuing the focus on accessible design, Jerry Robinson identifies cultural, political, economic and other disabling factors embodied in accessible technology products and services that have been rectified through self-directed life hacking activities. Finally, Eleanor Sandry’s chapter turns to the example of autonomous care robots and semi-autonomous assistive robots as technologies that have the potential to help support people with disabilities in their everyday lives. Sandry proposes an ethical approach, which acknowledges the importance of interdependence and relational autonomy, as well as flexible human–robot communication, relations and control as the key to realizing this potential.

The final part of the book, “Innovations, Challenges and Future Terrains of Transformation,” revisits several key themes and media addressed throughout the collection and looks to future research directions. Many of the chapters situate their research as an understudied area of disability media analysis and offer frameworks for future analysis.

Returning to the issue of news with which we started this Companion, Chelsea Temple Jones critically unpacks the taken-for-granted rationale that disability beats in journalism lead to positive, rights-based disability representation. Next, Josh Loebner addresses the inclusion of people with disabilities in advertising, offering a framework to bring disability inclusion into creative conversations and campaigns. Shawn Burns’ chapter uses the case study of the BBC’s *Ouch* and the ABC’s *Ramp Up* websites to explore the frail links between disability advocacy and mainstream media and the place of self-advocacy journalism in the changed media and journalism landscape. Following this, Carla Rice and Eliza Chandler interrogate how representation of disability informs understandings of disabled people through a reading of representations in and audience response to the social media account *Humans of New York*.

Filippo Trevisan’s chapter discusses how Internet-based media have become central to disability rights advocacy in recent years and provides useful pointers for further reading and research on this important yet under-studied topic. Katie Ellis and Melissa Merchant refocus analysis to address the issue of employing people with disability in media-related industries. The chapter argues that entering the media industry is challenging for people with disability, largely as a result of existing prejudices to disability and the notion that the media sector is fast paced. The final

chapter in the book, by David Adair and Paul Harpur, interrogates the way copyright law has supported a global publishing regime in a way that has delivered uneven levels of access to print materials. The chapter argues that innovations in public and non-profit sector strategic management can assist in a much-needed recalibration and build the required consensus.

## Conclusion

As mentioned, research in disability studies can be found in disciplines as diverse as literary studies, performance studies, sociology, social policy, education and social work. Disability often figures in interdisciplinary research and collaborations worldwide. Disability and media scholarship carries significant intellectual and cultural cachet, and capital disability has been attracting growing attention internationally<sup>29</sup> and this volume joins that vibrant trajectory.

As much as possible, we have aimed for the *The Routledge Companion to Disability and Media* to be international in its scope and orientation. We understand the barriers researchers and graduate students worldwide face when they are not nurtured and supported by their universities, national university and research innovation systems, or by international scholarly associations and research collaborations. The scholarly supports are many times inaccessible as well. Much of this amounts to, and is underpinned, by the geopolitics of research and knowledge—and the persistence of disabling relations of power among, within and transversally across countries. However, navigating differences in development of research, theory, university infrastructures and support for disability studies, research and engagement programs, we still found commonalities that solidify media and disability scholarship as its own sub-discipline within media studies.

We believe the work presented here registers many key trajectories and illustrates the momentum for more international work on disability and media in the future. This volume is part of a larger story about this scholarship finally being taken seriously by researchers, educators and those with a stake and interest in the area and its implications. Ultimately, the future of the field, its intellectual adequacy, research rigor and relevance will build from a volume like this one. For disability and media research vitality to continue, we know from working with this group of dedicated writers and researchers that a genuinely international constitution of the field will be essential.

## Notes

- 1 While dated, the most authoritative source providing an overview of international disability statistics remains the 2011 *World Report on Disability* published by the World Health Organization and the World Bank, [www.who.int/disabilities/world\\_report/2011/report/en](http://www.who.int/disabilities/world_report/2011/report/en). For discussion of the issues involved in measuring, defining and comparing disability data see WHO and World Bank, *World Report on Disability 2011*, 21–53, [www.who.int/disabilities/world\\_report/2011/report/en](http://www.who.int/disabilities/world_report/2011/report/en).
- 2 United Nations, Secretary-General, “Implementation of the World Programme of Action concerning Disabled Persons [A/49/435]: Part 2, Measures for the Medium Term” (United Nations, 1994–1995), 22.4, 22.7, [www.un.org/development/desa/disabilities/implementation-of-the-world-programme-of-action-concerning-disabled-persons-a49435-part-2.html](http://www.un.org/development/desa/disabilities/implementation-of-the-world-programme-of-action-concerning-disabled-persons-a49435-part-2.html).
- 3 International Labour Organization (ILO), *Reporting on Disability: Guidelines for the Media* (Geneva: ILO, 2015), [www.ilo.org/skills/pubs/WCMS\\_127002/lang-en/index.htm](http://www.ilo.org/skills/pubs/WCMS_127002/lang-en/index.htm).
- 4 Pioneering work on disability and media includes: Alan Gartner and Tom Joe, eds., *Images of the Disabled, Disabling Images* (New York: Praeger, 1987); Lauri E. Klobas, *Disability Drama in Television and Film* (Jefferson, NC: McFarland, 1988); Guy Cumberbatch and Ralph M. Negrine, *Images of Disability on Television* (London: Routledge, 1992); Jack A. Nelson, *The Disabled, the Media, and the Information Age* (Westport, CT: Greenwood Press, 1994); Martin Norden, *The Cinema of Isolation: A History of Physical Disability in the Movies* (New Brunswick, NJ: Rutgers University Press, 1994); the British Film Institute’s publication, *Framed: Interrogating Disability in the Media*, ed. Ann Pointon and Chris Davies (London: BFI, 1997); Paul Darke, “The Cinematic Construction of Physical Disability as Identified Through the Application of the

- Social Model of Disability to Six Indicative Films Made Since 1970” (PhD thesis, University of Warwick, UK, 1999), [www.outside-centre.com/darke/paulphd/content.htm](http://www.outside-centre.com/darke/paulphd/content.htm); and Dawn Braithwaite and Teresa Thompson’s edited collection, *Handbook of Communication and People with Disabilities: Research and Application* (Hillsdale, NJ: Lawrence Erlbaum Associates, 2000).
- 5 For more information, see [https://en.wikipedia.org/wiki/John\\_Clogston](https://en.wikipedia.org/wiki/John_Clogston).
- 6 Email correspondence between Beth Haller and Jennifer McGill at AEJMC headquarters, March 11, 2019.
- 7 Syracuse University, Disability Studies, “Academic Programs in Disability Studies,” accessed March 18, 2019, <http://disabilitystudies.syr.edu/programs-list>.
- 8 King’s University College, Western University, “Disability Studies Courses Offered,” accessed March 20, 2019, [www.kings.uwo.ca/academics/disability-studies/disability-studies-courses-offered](http://www.kings.uwo.ca/academics/disability-studies/disability-studies-courses-offered).
- 9 NYU Steinhardt | Media, Culture, and Communication, accessed March 20, 2019, “Disability, Technology and Media,” [https://steinhardt.nyu.edu/mcc/undergraduate/courses/MCC\\_UE\\_1026](https://steinhardt.nyu.edu/mcc/undergraduate/courses/MCC_UE_1026).
- 10 Sheffield Hallam University, “Disability Studies,” accessed March 20, 2019, [www.shu.ac.uk/research/specialisms/cultural-communication-and-computing-research-institute/what-we-do/projects/communication-media-and-culture/disability-studies-at-sheffield-hallam-university](http://www.shu.ac.uk/research/specialisms/cultural-communication-and-computing-research-institute/what-we-do/projects/communication-media-and-culture/disability-studies-at-sheffield-hallam-university).
- 11 *Vital Signs: Crip Culture Talks Back*, directed by David Mitchell and Sharon Snyder (New York: Fanlight Productions, 1995), <http://icarusfilms.com/fn-vital>.
- 12 Sharon L. Snyder and David T. Mitchell, “How Do We Get All These Disabilities In Here?’ Disability Film Festivals and the Politics of Atypicality,” *Revue Canadienne d’Études cinématographiques/Canadian Journal of Film Studies* 17, no. 1 (2008): 11–29.
- 13 See, for instance, the Modern Language Association (MLA) disability group, accessed March 20, 2019, [www.mla.org/About-Us/Governance/Committees/Committee-Listings/Professional-Issues/Committee-on-Disability-Issues-in-the-Profession](http://www.mla.org/About-Us/Governance/Committees/Committee-Listings/Professional-Issues/Committee-on-Disability-Issues-in-the-Profession).
- 14 See, for instance, the excellent *Journal of Literary & Cultural Disability Studies*, established in 2007.
- 15 Among other works noted elsewhere in this chapter, see Carrie Sandahl and Philip Auslander, eds., *Bodies in Commotion: Disability and Performance* (Ann Arbor: University of Michigan Press, 2005).
- 16 In anthropology and media, see the important work by Faye Ginsburg including her “Disability in the Digital Age,” in *Digital Anthropology*, ed. Heather Horst and Daniel Miller (London: Berg), 101–126, and her paper with Rayna Rapp, “Disability Worlds,” *Annual Review of Anthropology* 42 (2013): 53–68. See also the work by Tom Boellstorff, especially on disability in the virtual world Second Life in papers such as “The Opportunity to Contribute: Disability and the Digital Entrepreneur,” *Information, Communication & Society* 22 (2019): 474–490; Tom Boellstorff, “The Ability of Place: Digital Topographies of the Virtual Human on Ethnographia Island,” *Current Anthropology*, forthcoming; Faye Ginsburg and Rayna Rapp, “Disability/Anthropology: Rethinking the Parameters of the Human,” Introduction to a Special Supplement, *Current Anthropology*, forthcoming.
- 17 Among many studies of disability and technology, see Alan Roulstone’s pathbreaking *Enabling Technology: Disabled People, Work, and New Technology* (Buckingham, UK, and Philadelphia, PA: Open University Press, 1998), and his authoritative *Disability and Technology: International and Interdisciplinary Perspectives* (Houndmills, UK: Palgrave Macmillan, 2016); Gerard Goggin and Christopher Newell, *Digital Disability: The Social Construction of Disability in New Media* (Lanham, MD: Rowan & Littlefield, 2003); Paul T. Jaeger, *Disability and the Internet: Confronting a Digital Divide* (Boulder, CO: Lynne Rienner, 2010); Katie Ellis and Mike Kent, *Disability and New Media* (London and New York: Routledge, 2011); Edward Steinfeld and Jordana Maisel, *Universal Design: Creating Inclusive Environments* (Hoboken, NJ: Wiley, 2012); Peter Blanck, *eQuality: The Struggle for Web Accessibility by Persons with Cognitive Disabilities* (Cambridge, UK: Cambridge University Press, 2014); Meryl Alper, *Digital Youth with Disabilities* (Cambridge, MA: MIT Press, 2014); Jonathan Lazar, Daniel F. Goldstein and Anne Taylor, *Ensuring Digital Accessibility Through Process and Policy* (Waltham, MA: Morgan Kaufmann, 2015); Elizabeth Ellcessor, *Restricted Access: Media, Disability, and the Politics of Participation* (New York: New York University Press, 2016); Meryl Alper, *Giving Voice: Mobile Communication, Disability, and Inequality* (Cambridge, MA: MIT Press, 2017); Jonathan Lazar and Michael Stein, eds., *Disability, Human Rights, and Information Technology* (Philadelphia: University of Pennsylvania Press, 2017); Paul Harpur, *Discrimination, Copyright, and Equality: Opening Up the E-Book for the Print Disabled* (Cambridge, UK: Cambridge University Press, 2017); Mara Mills, *On the Phone: Deafness and Communication Engineering* (Durham, NC: Duke University Press, 2019).
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- 19 See Sharon L. Snyder and David Mitchell, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2000), *Cultural Locations of Disability* (Chicago: University of

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- 20 As well as *Studying Disability Arts and Culture* (London: Palgrave Macmillan, 2015), other books by Petra Kuppers include *Disability and Contemporary Performance: Bodies on Edge* (New York: Routledge, 2003) and *Disability Culture and Community Performance: Find a Strange and Twisted Shape* (London: Palgrave Macmillan, 2011).
  - 21 Graham Pullin, *Design Meets Disability* (Cambridge, MA: MIT Press, 2011). Design is a fertile and hotly debated area of interdisciplinary and engaged work, with other key texts including: Jos Boys, *Doing Design Differently: An Alternative Handbook on Architecture, Dis/ability, and Designing for Everyday Life* (London and New York: Routledge, 2014); Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (Minneapolis: University of Minnesota Press, 2017).
  - 22 Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning* (Toronto: University of Toronto Press, 2011).
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  - 25 Katie Ellis and Gerard Goggin, *Disability and the Media* (London: Palgrave Macmillan, 2015).
  - 26 Elizabeth Ellcessor and Bill Kirkpatrick, eds., *Disability Media Studies* (New York: New York University Press, 2017).
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  - 29 Everyone will have their own sense of what counts as theory, especially disability theory. We would include works such as: Michael Oliver, *Understanding Disability: From Theory to Practice* (Houndmills, UK: Palgrave Macmillan, 1996); Mairian Corker and Tom Shakespeare, eds., *Disability/Postmodernity: Embodying Disability Theory* (London: Continuum, 2002); Robert McCruer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York: New York University Press, 2006); Tobin Sieber, *Disability Theory* (Ann Arbor: University of Michigan Press, 2009); Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Aabledness* (London: Palgrave Macmillan, 2009); Dianne Pothier and Richard Delvin, eds., *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver and Toronto: UBC Press, 2006); Dan Goodley, Bill Hughes and Lennard Davis, eds., *Disability and Social Theory* (Houndmills, UK: Palgrave Macmillan, 2012); Teodor Mladenov, *Critical Theory and Disability: A Phenomenological Approach* (New York: Bloomsbury, 2014); Dan Goodley, *Dis/ability Studies: Theorising Disablism and Ableism* (New York: Routledge, 2014); Barbara Arneil and Nancy J. Hirschmann, eds., *Disability and Political Theory* (Cambridge, UK: Cambridge University Press, 2014); Elizabeth Barnes, *The Minority Body: A Theory of Disability* (Oxford: Oxford University Press, 2016); Ghosh Nandini, ed., *Interrogating Disability in India: Theory and Practice* (New Delhi: Springer, 2016); and Sarah Jacquette Ray and Jay Sibara, eds., *Disability Studies and the Environmental Humanities: Towards an Eco-Crip Theory* (Lincoln, NE: University of Nebraska Press, 2017).



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## PART I

# Imagining and Representing Disability



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# 1

## DISABILITY IMAGINARIES IN THE NEWS

*Tanya Titchkosky*

### Introduction

“Imagine disability; now imagine life with such a problem.” This trope, one that invites people to imagine disability as a problem, is an ordinary part of contemporary life. Making use of news articles and headlines that reproduce this trope, this chapter explores what it means to imagine disability in this way. Tracing how this disability imaginary is at work organizing how readers can expect disability and non-disability to fit together as newsworthy, the following pages will also explicate how “imagination” is best understood as a social phenomenon. While never totally alienated from the possibility of fantasy, imagination here refers to the interpretive character of perception as an “enworlded” phenomenon.<sup>1</sup>

Throughout, I will regard “imagination” as a complicated interpretive social action, potentially creative, but done always in relation to existing cultural conceptions and images; the products of imagination can be conceived as “imaginaries,” a kind of solidification of sense.<sup>2</sup> I will show how “disability imaginaries” are enworlded as alienation incarnate—full of unexamined and unbendable assumptions regarding disability that nonetheless serve to support flights of fancy regarding normalcy. Treating imagination as that social activity that operates between engagement and alienation, between creativity and constraint, I aim to reveal what the invitation to *imagine disability* both “marks and mirrors.”<sup>3</sup> By considering the grounds organizing the ordinary restrictive orders of perception, there arises the possibility of perceiving our lives with disability in new ways, perhaps breaking out of one way of finding disability newsworthy while breaking into others. Media representations of disability offers media producers and consumers an opportunity to reflect on the normative assumptions that ground these representations as well as a chance to perceive, know and do disability differently from how “society made us and believe us to be.”<sup>4</sup>

After revealing the contours of a disability imaginary common to Western news media, I end by exploring how to live with this imaginary in more vital ways. I do not, however, propose that a more realistic or normal imagery for disability be developed. As Eve Haque has shown, the “real” of media and its documented historical agents are full of imagined characters in need of explication.<sup>5</sup> Exploring the limits of an alienated and, even, pathological imaginary is a way to open up the cultural assumptions behind this disability representation. Indeed, by exposing the social imaginaries at play in media accounts of disability, this chapter aims to encourage media producers to want to gain access to those social imaginaries informing even their most “realistic” accounts of disability so that they might produce more vibrant, expansive and complex



representations of disability. To do so, however, requires that we first proceed with the assumption of *life* in disability and one way to do that is to regard media depictions of disability as a representational space that invites cultural critique. This chapter aims to reveal the products of imagination in new ways—representing a hybrid comingling of disability and non-disability reflective of the hope of an unexpected rupture of the ordinary in the social activity of media production and consumption.<sup>6</sup>

### Imagine Disability; Now Imagine Life with This Problem

Contemporary Western news media, invites readers, and not merely from time to time, to imagine disability. We read invitations such as *imagine being deaf, blind, a wheelchair user; imagine feeling anxious, depressed or confused; imagine losing an arm, your memory or the ability to speak*. This initial invitation serves to move the reader into another imaginative moment but one that can only read disability as the problem of normative disruption. Imagine disability while also imagining *raising a child, going on a trip, going to work, preparing dinner or getting out of bed*.

Versions of this invitation are extraordinary enough to be narrated and to regularly appear within Western news media:

Can you imagine changing a nappy with your TEETH? Disabled mother who can't use her arms or legs reveals how she copes with two young children.<sup>7</sup>

Imagine getting through the day with no arms. That's my life thanks to thalidomide.<sup>8</sup>

Can you imagine waking up every morning and doing what she did without being able to feel or move anything below your neck?<sup>9</sup>

Changing a diaper, washing dishes, getting through the day, are not the ordinary stuff of the news. Yet, such ordinary activities have suddenly and even dramatically become extraordinary and newsworthy. The reader, framed as non-disabled, is supposed to encounter disability as a problem that disrupts the flow of ordinary life and to find this interesting (even though it is easy and common to imagine that disability means only difficulty doing things). After all, these suppositions come into play and are at *work* in framing the request to “imagine disability as a problem, now imagine life as such.” Through this trope, readers are invited into a restricted imaginary—free to read disability, but only as a problem, a somewhat titillating disruption to the normal way of doing things. Ironically, restricted imaginaries have to restrict their own grounds of possibility (imagination) in order to operate. One way this is done is by imposing the fanciful belief in the singular view. But this is risky, for to imagine the singular meaning as all-encompassing risks the opposite, that we imagine disability as more and other than we make it and believe it to be.

Not only ordinary tasks such as washing dishes or changing diapers but also extraordinary ones, can be used to express a restricted imaginary. Readers are invited, for example, to imagine disability in the face of extraordinary feats, such as racing a car, running a marathon, skydiving, learning calculus, surviving in an inhospitable environment. Consider these examples:

Imagine your life if you had a disability. How many things might you have to give up on? Walking? Sports?

Now imagine you were a professional race car driver who suffered traumatic brain injuries. Medical professionals tell you, you will never recover, let alone drive again.

Rick Bye must not have received the memo.<sup>10</sup>

Calculus is never a picnic, but imagine if you couldn't see the numbers on the board.<sup>11</sup>

Even for the fully able-bodied, the world can be a cruel and challenging place to navigate. In northwest Michigan, we know all too well about low wages, unemployment, underemployment and the zigzagging path to providing enough for yourself or your family. Imagine if, through no choice of your own, you were dealt an even harder card to play. For people with developmental disabilities in this region—and every other, for that matter—often times the impediment to independence and happiness is a lack of opportunity.<sup>12</sup>

Racing cars and doing calculus, like surviving in a cruel and challenging world, are extraordinary feats. Add disability and the extraordinary is made spectacular, moving unique skills from the register of the exceptional to that of the almost magical. Still, this transformation also includes framing the presumed reader as a non-disabled person who regards disability as a problem that disrupts the accomplishment of extraordinary feats. While it may be difficult to imagine driving a race car or learning calculus, it remains easy to imagine that to do these things while disabled would be difficult, if not impossible.

Spectacular or ordinary, this trope posits disability as a condition that represents a lack of function; given this, things are difficult to do and given this, things will have to be done differently. This leads to what is perhaps the most perplexing matter of all—it hardly seems to be an imaginative act to call disability to mind as “difficulty doing things.”

This disability imaginary is so ubiquitous that it seems to put the activity of imagination out of play. Indeed so ubiquitous is this imaginary, that it seems realistic and true. Nation states as well as the World Health Organization, for example, structure their surveys of disability with exactly the same conception:

Do you or someone in your household have a physical condition or health condition ... that reduces the amount or the kind of activity that this person can do?<sup>13</sup>

Activities are limited because of a long-term condition or health-related problem.<sup>14</sup>

A disability is an impairment that has a long-term, limiting effect on a person's ability to carry out day-to-day activities.<sup>15</sup>

Any restriction or inability to perform an activity in the matter or within the range considered normal for a human being.<sup>16</sup>

Despite claims to using an updated and more social conception of disability—the International Classification of Functioning, Disability and Health—the *World Report on Disability* also makes use of the imaginary of difficulty doing things that results from a lack of function:

According to the *World Health Survey* around 785 million (15.6 percent) persons 15 years and older live with a disability, while the *Global Burden of Disease* estimates a figure of around 975 million (19.4 percent) persons. Of these, the *World Health Survey* estimates that 110 million people (2.2 percent) have very significant difficulties in functioning.<sup>17</sup>

Given the ubiquity of this restrictive disability imaginary, along with the simultaneous naturalization of the notion that it is found in individuals who are understood to possess an inability to function in a way considered normal for a human being, how are we to make sense of this news

media call *to imagine* disability? Perhaps, we can allow the lack of imagination involved in all this to disturb us a little while breaking into how disability figures in the social imaginary.

### Disability and the Social Imaginary

The cultural structuring of disability between the extraordinary and the ordinary has historically been given a detailed analysis by disability studies scholars.<sup>18</sup> They have revealed a variety of dichotomies through which contemporary society gives shape to disability. Rosemarie Garland-Thomson, for example, suggests that representations of disability can be understood through a four-part symbolic rhetoric making disability typically appear as the signifier of the wondrous, the sentimental, the exotic or the realistic.<sup>19</sup> Other theorists, such as Ato Quayson,<sup>20</sup> have suggested that disability is used to express nine categories of Othering, all the while producing what Michael Berube refers to as the “exceptional.”<sup>21</sup> Disability as an exceptional category of persons has, as Beth Haller et al. show, typically served to represent medical power, heroic spirit, charity acts or human rights within the news media.<sup>22</sup>

Whether it is two, four, nine or more categories, these scholars remind us that within mainstream media, disability is encapsulated as a sign of something readily obvious insofar as it can be easily noticed and deployed to express a rather restricted set of meanings. The sheer expanse of human variation is made to take shape in a few limited forms readily called upon by the news media through the trope: “Imagine disability, now imagine life with this problem.” Regulating sameness and difference, this trope makes both appear more simple than they are. Sameness, then, is what the community has come to expect; while difference, wrapped in the shape of disability, is the unexpected—nonetheless caught within the singular meaning of the problem of lack of function and the need to do things differently.

David Mitchell and Sharon Snyder tell us that the “ubiquitous presence of conventional disability narrative patterns tends to short-circuit public awareness about the social circumstances in which disability becomes enmeshed.”<sup>23</sup> Like a stock character, disability appears in the news, capable of making the ordinary wondrous or the wondrous exotic, but the circumstances in which disability is enmeshed, namely, as an invitation to readers by the news media to *imagine*, typically remains beneath notice. Insofar as repetitive patterns of recognition short-circuit awareness, what might these patterns have done to imagination itself? Recall that the representation of disability as lack of function is deployed by nation states to produce rates of disability in their populations followed by programmatic regimes and other daily practices that also carry the same meaning, namely, that disability is lack of function resulting in difficulty. This version of disability relies on an alienated form of imagination since only difficulty and not the fullness of life is admitted into disability. As Rod Michalko reminds us, it is often the case that the only included version of disability is a conventional one and this conventional way of patterning the recognition of disability short-circuits any need not only for awareness but, more critically, for imagination.<sup>24</sup> Instead, we encounter disability as a restricted set imaginary.

Monitoring misconceptions of disability and their subsequent misrepresentations perpetuated by the news media is not, however, the only possible response.<sup>25</sup> If “documenting damage” or “consciousness raising” are not alone sufficient to enact change,<sup>26</sup> perhaps another option is to discern how this repetitive cultural practice of requesting people to “imagine disability, and now imagine life with such a problem” teaches us something about the “human imaginary” itself. The news media represents a cultural production tied to a normative order produced by the contemporary neoliberal capitalist societal structures. This means that the news media is a site for engaging the human imaginary and its use of disability, a site that might invite us to theorize imagination. To this end, let us turn back to the media’s request to *imagine disability*.

## Human Imaginary

There are many theorists who draw out the social character of imagination and the production of human imaginaries.<sup>27</sup> One explicit in his sociological sense of imagination, is Charles Taylor who says of the “modern social imaginary”:

I am thinking rather of the ways in which people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations.<sup>28</sup>

Taylor is suggesting that there is a kind of social function at the heart of the imaginative productive process—the play of social imaginaries reflects a version of existence where people, things, events are made to fit together; where things are thought to go on in integrated ways; ways that meet social expectations. Earlier, I suggested that the invitation to imagine disability requires a non-imaginative, that is, a rigidly structured and taken-for-granted way of bringing disability to mind. This is a bio-pathological version of disability—lack of function that leads to difficulty doing things considered normal for a human being—the bio-pathological remains not only unimaginative but also strictly and repetitively ordinary. Still, this might reflect what Taylor means by *modern social imaginary* since it reduces the life of disability to a question of function and cuts off any other possibilities while ordering how it is we think we fit together.

*Imagine disability* materially inaugurates the reader’s expectation for an image of lack of function and functioning differently but, differently from what? Different from an imagined normalcy. Disability is made different from the norms and expectations that frame life as unconnected to difficulty pictured as normal life. *Imagine disability* can be read as actually an invitation to imagine normal life—its existence is imagined in contradistinction to a difficult life insofar as difficulty is continually symbolized by disability and vice versa.

What requires a much more fanciful form of imagination is how disability and non-disability “fit together” in a social existence imagined as basically without disability. We are invited to imagine a normative order that is regarded as not difficult. Disability, in this sense, is a quantitative departure from non-difficulty; the more difficulty the more disability.<sup>29</sup> Normalcy is “not difficult”—this is the imagined social existence, the mode by which things are meant to go on and through which people might fit together, and this is also how things are imagined for how they ought to be between people. But, what could be further from the truth! Not everything that is difficult is rooted in disability; not everything that is disability is rooted in difficulty. Still, the normative notion of existence as a smooth and easy relation between people might be the “deep” meaning behind the call to *imagine disability*. Placing all that can be imagined as difficult inside individuals with disabilities is reliant upon a taken-for-granted sense of everyday life as smooth, easy, trouble free, normal as it should be. Moreover, it is challenging to imagine disability as something other than difficulty in functioning and disability all but disappears if difficulty does.

This invites us into the heart of a paradox—*imagine disability*—relies on a notion of disability based in an alienated form of imagination where the reader is asked to separate disability from one’s self, from one’s life, from existence.<sup>30</sup> At the same time, *imagine disability* demands that we fit disability in as, and only as, the tumult of difficulty of doing things differently. *Imagine disability and now imagine life with such a problem* becomes an occasion to show the power of the normative fantasy that, at best, disability is the struggle to get back into the fold of doing things in an expected and smooth fashion. This struggle is conceived as detached from ordinary life lived by ordinary people since it is only individuals with impairments that need to do things in

extraordinary ways and with great difficulty. The ironic non-imaginative notion of *imagine disability* launches the reader pell-mell into the imaginative moment—imagine that existence is not difficult but is instead smooth but if, and only if, one is normal enough to imagine and expect it to be so.

These are the interpretive quandaries that come wrapped up in an invitation to *imagine disability*, quandaries that should make anyone involved in producing media depictions of disability want to uncover them further. Engaging this way of fitting disability and non-disability together is a new call on imagination. As Paul Gilroy puts it, “Our moral and political compass might profitably be reset by acts of imagination.”<sup>31</sup> Imagine disability and non-disability reflecting the meaning of each other, now imagine what this means for the human imaginary with its life of normalcy.

### Disability Imaginaries and Rethinking Normalcy

Through his analysis of disability supports, Dan Goodley suggests that we can treat our practices with disability as “mirrors to” and “markers of” humanity.<sup>32</sup> The folding of disability into a pathological imaginary becomes an invitation to gaze in the mirror and discern where the marks of humanity are made to (dis)appear, and to consider the confines of imagination that operate in a recognizably “human” way. Imagination is a term that can bring to mind the made up, the fanciful, the creative wanderings of individual psyches. However, the notion of imagination as an ephemeral individual creative wellspring needs to be conceived alongside the rather solid inescapable fact that imagination works through the already established words and deeds of culture, including its set imaginaries. Conceiving of imagination as a meeting point between the made and the really made up, as well as between alienation and engagement, permits us to encounter the invitation to imagine as an “enworlded phenomenon,”<sup>33</sup> potentially tied to the disruption of the same or, even, to making something new. This enworlded sense of imagination brings together things, people and events with expectations of the normative order while also pulling things or people or events apart since we can imagine a different social existence. As a particular form of assemblage, the invitation to *imagine disability* both mirrors and marks the intersection of the already made and the really made up in the simultaneity of what is both repetitive and productive in the human imaginary.

Given this, let us now return to the invitation to imagine: “Can you imagine waking up every morning and doing what she did without being able to feel or move anything below your neck?”<sup>34</sup>

The reader is asked to imagine something ordinary—waking up in the morning. But the reader is also invited to put this together with something extraordinary, namely, not being able to do things, to feel or move from the neck down. As we have already uncovered, the reader is invited to imagine waking up *as* lack of function causing difficulty. This serves to bring to mind the image that waking up and getting on with one’s day as disabled is filled with difficulty, which requires imagining that one should wake up to the day without a second thought. The reader is brought to this sense of normalcy by blocking the sense that getting on with one’s day always requires work, even while not disabled. Moreover, *producing* this image of disability required work: it required the work of re-presenting disability as such; to do whatever must be done in order to stay within the confines of this restricted social imaginary.

The taken-for-granted nature of the work of everyday life can be left unnoticed by focusing on the obviousness of work only by those who are depicted as disabled. While the type of work is undoubtedly different between disabled and non-disabled people, readers have been delivered into the normative expectation to understand some people as if they alone embody difficulty since they mark a radically alienated form of existence. This difference, imagined pathologically,

serves to alienate self from other, making difference into strangeness, while producing the sense that doing ordinary things is normally done without effort, without work.

Imagine your life if you had a disability. How many things might you have to give up on? Walking? Sports?

Now imagine you were a professional race car driver who suffered traumatic brain injuries. Medical professionals tell you, you will never recover, let alone drive again.

Rick Bye must not have received the memo.<sup>35</sup>

With the pathological imaginary at play, disability becomes a lack of function where things are not only difficult, but impossible to do. Once disabled, you will need to give things up insofar as this “you” is a non-disabled you who walks and does sports; but not now, now that medical professionals say that you will not recover. “Now imagine ...” something else: imagine what you are not, namely, disabled *and* a professional car racer (however, do so while not imagining that you are someone producing or consuming disability news). The disability imaginary is conceived as a parting of ways with the capacity to do things alongside the smooth ordinary flow of daily life that includes not only a lack of difficulty but also an abundance of possibility—walking, sports, racing cars and a capacity to imagine it all (while dis-attending to reading and/or producing the news). Normalcy conceived of *as* natural is made separate from disability conceived of *as* pathological and this separation is made prevalent and powerful through the underlying assumption that normalcy *is* possibility and *is* separate from disability since disability is imaged as nothing but limiting.<sup>36</sup> Non-disability is normal, natural and full of possibility; whereas disability is pathological, not natural and full of limitation. Struggling back into the fold of normalcy requires the almost superhuman invocation of the human spirit (which need not read the memo).

Even as this imaginary serves to aggrandize normal life it, nonetheless, can remind all people of the interpretive tensions that constitute existence, tensions that are kept alive even as a functional normalcy seems the be-all and the end-all of the modern era. Indeed, this particular “realist” notion of disability begins to seem key to the operation of normal everyday life. Is this tantamount to encountering disability as integral to the smooth workings of normalcy or, at least, as inviting the reader to imagine it as such?

Even for the fully able-bodied, the world can be a cruel and challenging place to navigate. In northwest Michigan, we know all too well about low wages, unemployment, underemployment and the zigzagging path to providing enough for yourself or your family. Imagine if, through no choice of your own, you were dealt an even harder card to play. For people with developmental disabilities in this region—and every other, for that matter—often times the impediment to independence and happiness is a lack of opportunity.<sup>37</sup>

Fully non-disabled, also through no choice of one’s own, pursuing, perhaps even achieving independence and happiness despite a relative lack of opportunity—this is the imagined underside to the “imagine if you had a disability.” Along with being a fanciful version of life, it is fascinating that normal life seems to need disability, needs it to be really far out and alienated, as this helps to make fanciful versions of normal life less noticeable. Fitting disability and non-disability together via the invitation to “imagine” relies on a dividing line between the pathological and the normal and on the assumed normalcy of not thinking about the work needed to produce all that gets configured as normal—ease, resources, doing things. Still, the reader is asked to imagine and this risks the possibility of doing so in ways that fall outside of the confines of the news article’s restricted imaginary. Could not the production of news media benefit from playing a bigger role in bringing to attention the sorts of disability imaginaries it puts into circulation? If