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Digital Media Economy Through a Disability Lens

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INTRODUCTION

Nothing like sex to grab attention. So how could the world's media resist the story of a deaf man suing a pornography site over its failure to caption its videos? When Yaroslav Suris sued Pornhub in 2020 under the Americans with Disabilities Act (ADA), the risqué stories practically wrote themselves. Many outlets went for the double-entendre (like TMZ's "Pornhub: You make it hard for deaf to enjoy!!!"); others ridiculed the value of captions on porn in the first place: "According to [Suris], it is impossible to enjoy a video like 'Hot Step Aunt Babysits Disobedient Nephew' if you can't hear the dialog" (Ozdemir, 2020; *Pornhub sued*, 2020). Although the suit against Pornhub was consistently the lede, much of the coverage emphasized Suris's other lawsuits against major websites, from the Weather Channel to Columbia University, thereby painting him as a litigation-happy gadfly rather than a citizen legitimately seeking equal access under the law.¹ Whatever the legal merits of the case, this coloration of Suris's suit was its own form of ableism, denying the importance of accessibility rights in the online realm of sex that are well established elsewhere; as Celeste Reeb (2019) notes, "Since closed captioning is a space coded as disabled or linked to disability, sex scene closed captioning highlights the tension between concepts of bodies, pleasure, sex, and identity" (n.p.).

Nothing like sex to grab attention for an academic essay too, but the Suris-Pornhub case opens this chapter primarily because it vividly illustrates a range

of profound questions about disability and digital media economies as we move deeper into the 21st century. What new issues of access, representation, and participation arise with the growth of digital media? What is “access” anyway, and who decides how much and which kinds of access are sufficient? Is the rights-based approach to “accommodation,” like that represented by the ADA, capable of securing meaningful participation in the digital media economy by persons with disabilities, and what would “meaningful participation” even look like? How do digital media reveal ongoing forms of ableism, and how do the structures, affordances, and uses of digital media work to regulate and enforce “normalcy”? Thus, the Suris suit goes far beyond “I want to know what the pool boy said” to reveal how a critical disability studies lens can shed new light on the technological, cultural, economic, and political dimensions of digital media.

Unfortunately, in contrast to race, class, gender, and sexuality, the value and power of disability perspectives (and of understanding the intersection of disability/able-bodiedness with those other phenomena) remain poorly understood within media scholarship. As Elizabeth Ellcessor and I have pointed out, scholars of disability media studies are not focused solely on representations of persons with disabilities, despite what many of our colleagues seem to think:

We are not simply looking for “the cripple in the text”; we are interrogating the dynamics of power and normalization that produce certain kinds of bodies, sensoriums, and cognivities as “able, normal, better” and others as “disabled, abnormal, worse.” A disability perspective, then, is about decentering the physically and cognitively “normal” character, the “normal” viewer, the “normal” producer, and so on; this has profound consequences for the study of media texts, industrial practices, social relations, media policies, modes of reception, and the design of technologies and spaces (Ellcessor & Kirkpatrick, 2019, p. 140).

With that broad, critical approach in mind, this chapter will explore the relevance of a disability lens to a range of questions central to the study of digital media economies, including access, cultural access, and universal design; the problem of algorithms and “code”; privacy and surveillance; employment and the reorganization of work; representation and representational justice; the production of disability through digital media; and the politics of communication rights. I argue that thinking beyond ableism and the constraints of bodily and cognitive normativity allows us to better perceive the possibilities and challenges of the digital media economy. Within that, I hope to reveal the constructedness of certain taken-for-granted dimensions of digital media economies and demonstrate the larger issues of social justice at stake in our understanding of unfolding media landscapes.

I begin by offering a quick primer on critical disability studies; although this is well-trodden ground for scholars of disability (Corker & Shakespeare, 2002; Garland-Thomson, 2018; McRae, 2018; Meekosha & Shuttleworth, 2009; Titchkosky, 2003; Tremain, 2005), it will remain necessary to continue rehearsing this theoretical background until more media scholars come to be familiar with it. Following this, I use critical disability studies to explore core concepts

in the study of digital media, prominently including “access.” Next, I turn to specific issues in the digital media economy, then close, as I began, with issues in law and policy.

METHODOLOGICAL APPROACHES

To the average person (and sadly to many media scholars even now), “disability” still denotes what it meant in the charity drives and telethons of the mid-20th century: a medical abnormality, disorder, or trauma debilitating an individual’s body and/or brain. In disability studies, this is called the “medical model,” and it regards disability as both ontological and inherently problematic. People with non-normative bodyminds are seen above all as sad or even tragic cases who need to be cured by medical science, perhaps made more “normal” by miraculous technologies like robotics or cochlear implants, or, failing that, provided assistive technologies like wheelchairs or voice synthesizers. That’s the “bright side” of the medical model; the darker consequences of seeing disability as deficiency include discrimination, exclusion, eugenics, institutionalization, involuntary sterilization, and euthanasia. Without questioning the value of medical intervention for many people, we can oppose the medical model as an inherently stigmatizing approach to bodily and mental variation in so far as it defines disability as abnormality, locates that abnormality in individual bodies, and then scripts those individuals into disempowering processes, institutions, and logics of medicalization and normalization.

Although the medical model has long come in for criticism, the most politically effective critique of medicalization emerged from disability activists in the 1970s with the “social model” (Finkelstein, 1980; Oliver, 1996). This approach distinguishes between “impairment” as an underlying ontological physical or mental condition and “disability” as the socially constructed disadvantages (political, economic, environmental, etc.) that ensue. People with impairments thus become “disabled” not by their non-normative bodies or minds, but rather by a society that is (at best) not designed with them in mind and (at worst) eugenically opposed to their very existence. To give an oversimplified example, paraplegia may be an “impairment,” but it only becomes a “disability” in the absence of ramps, elevators, and curb cuts that allow wheelchair users to access physical spaces, as well as in the presence of widespread discrimination in jobs, housing, education, and public services. The social model, as a rights-based articulation of the social production of disability, is the animating philosophy of laws like the ADA that provide legal remedies to disabled persons for violations of their civil rights.

In contrast to the medical and social models, a critical disability studies approach does not take as its starting point an ontology or underlying reality of either disability or impairment, but rather interrogates the normalizing systems of power through which certain physical and mental variations are marked as

“abnormal” and come to be constructed as “disabilities,” with all the effects of medicalization, stigmatization, and marginalization that entails. This is not to deny the existence of variation itself, much less the lived experience of difference (frequently including chronic pain), the phenomenology of encountering the world as a “disabled person,” and the reality of ableist oppression. But it *is* to question the ways that social norms – norms of how bodies *should* look and function, how minds *should* work, how sensoria and communicative capacities *should* interface with the external world – produce some bodyminds as problematic, defective, and inferior.

The shift in perspective offered by critical disability studies offers new insights into how power works in the realms of physical and mental normativity. For example:

- If we do not assign ontological status to the category of “impairment/disability,” we are better positioned to understand how bodily and mental variations are constructed as “disabling” in various contexts. On the one hand, “disability” itself is far from a universal concept, with different cultures and historical moments defining, explaining, and valuing variation differently (see, e.g. Livingston, 2006). Even within Western cultures, “disability” is usually overstretched to include everything from paraplegia to Down syndrome to blindness to spina bifida to schizophrenia. On the other hand, moving beyond ontology allows us to see disability as a site of struggle. For example, the Deaf community has long resisted the construction of deaf/hard-of-hearing people as “disabled,” arguing that deafness is linguistic a minority status, not a disabling condition that requires repair (Holcomb, 2012). Critical disability studies thus allows us to see impairment and disability as contingent, contextual, relational, and contested.
- If disability is not ontological, then it follows that the “disabled person” is socially constructed as well. Just as Foucault (1990) could claim that the homosexual was “invented” in the early 19th century, so too can we understand the contemporary Western disabled subject as, say, a product of the industrial revolution and the rise of capitalism, when new variations entered the category of disability, and the concept of disability became increasingly articulated to productivity and labor. This coincided with the rise of the modern medical profession and the medicalization of contemporary life: the person designated as disabled now became inserted into systems and logics of patienthood and rehabilitation/cure, and/or systems and logics of institutionalization, forced sterilization, and extermination, a constellation that allowed one study to plausibly claim, “Before World War I disability was not considered a medical or a social problem in America” (Gritzer & Arluke, 1985, p. 38). Issues of identity, rights, and personhood thus unfold within social contexts that become constitutive of disability statuses.
- The construction of certain bodily and mental variations as “disability,” “loss,” or “deficiency” – and of disablement as inherently tragic and undesirable – mostly serves to valorize normalcy and legitimize exclusion and oppression. Robert McRuer (2010) calls this valorization “compulsory able-bodiedness,” i.e. the social, economic, and political forces on subjects to identify with and perform able-bodiedness to the greatest extent possible. However, a critical perspective challenges this negative valuation of disability, as disability activists call for recognition of their bodyminds as not tragically broken but rather as different ways of being in the world, with challenges and benefits. For example, a range of scholars and activists have flipped the script on “hearing loss” and “vision loss” to discuss instead “Deaf gain” and “Blind gain,” calling our attention to the abilities, capacities, epistemologies, and phenomenologies that emerge thanks to “disability” (Bauman & Murray, 2014; Kleege, 2018).

- Finally, critical disability studies calls attention to the social, cultural, economic, political, and material systems that inform the subjectivity and structure the lived experience of persons designated as “disabled” *as well as* persons designated as “normate,” a term coined by Rosemarie Garland-Thomson (1997) to make visible the unmarked bodyminds and identities of non-disabled persons (analogous to “cis” in queer theory). What follows from this is “cripping” and “crip politics”: analogous to queering, criping “spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects” (Sandahl, 2002, p. 37; see also Hutcheon & Wolbring, 2013; McRuer, 2006; Price, 2015). Crip politics allows us to recognize disability and able-bodiedness as relational and intersectional, including the role of disablement as part of the enormous “normate privilege” with which non-disabled persons move through the world, largely oblivious to the countless range of unearned advantages that “normalcy” provides.

These and other core insights from critical disability studies provide an understanding of disability not as a sad fact about some unlucky persons but as a socio-cultural construct inseparable from power: the power to know and naturalize, to normalize and discipline, to value and devalue, to include or marginalize, to seize and act on bodies and minds, to justify and perpetuate oppression, to let live or kill. They also provide the framework for a crip politics of social justice that intervenes in the structures and practices of ableist oppression.

The relevance of critical disability studies specifically to digital media economies, as will be elaborated in the rest of this chapter, is its ability to help us recognize the ableism that continues to shape digital media industries, technologies, practices, and politics, as well as to identify positive trends and opportunities for social change.

CORE CONCEPTS

Ableism

As the above unpacking of hegemonic understandings of disability suggests, much work remains to grapple with the ways in which normate people participate in and perpetuate the production of disability as a set of social, economic, political, and material relations. There remains a pervasive disavowal of complicity in ableist systems, both evidenced and reinforced by the widespread (if often grudging) embrace of accessibility as the solution to the “problem” of disability: a few parking spots here, some Braille on the elevator buttons there, and we as a society have done what we can or need to for people with disabilities.

For critical disability studies, unsurprisingly, ableism is a far more complex issue. While many insightful definitions of ableism exist,² Arseli Dokumaci’s (2018) understanding of “ableism as habitus” is especially generative, building on Bourdieu’s emphasis on the *embodied* experience of living in a particular milieu in order to “expose the possibilities that a seemingly neutral world of

supports affords the normate body, while putting other bodies out of place” (n.p.). The ableist habitus encompasses the built environment and the structure of social relations as organized around and for normative bodyminds, normative communicative capacities, and normalizing power-knowledges. In this sense, and echoing Sara Ahmed (2007) on race, Dokumaci argues that ableism is a “bad habit” that “puts certain affordances within easy reach of some bodies at the expense of their availability to others” (n.p.).³

As with structural racism, ableism does not require conscious intent; instead, ableism forms and informs daily life as we move habitually through social and material environments that appear to be simply neutral even as they advantage normate bodies. A quick example from digital media: if you are a sighted person, how consistently do you add or edit text descriptions to the images you post to social media? Socially, the practices of most people in your network probably don’t reinforce text description as a norm, and the broad potential benefits of description are rarely explained. Technologically, many platforms (including Facebook and Instagram) use image-recognition software to automatically generate text descriptions, but the user is not prompted to correct or improve them; indeed, those descriptions are hidden by default from anyone not using a screen reader, thereby limiting their potential usefulness for sighted people while obscuring the existence of non-sighted people altogether. Even well-intentioned practices can bring about additional exclusions. For example, Trevisan and Reilly (2014) have shown how classifying persons with disabilities as *ipso facto* “vulnerable” for the purposes of ethics-board research approval works to exclude disabled voices from scholarship. In such ways, the ableist habitus reinforces the norms and perspectives of able-bodiedness, and to the extent that normate persons feel “at home” in such a world, calls for changes to the technologies, practices, and logics of ableism from persons who do *not* feel at home in this world will likely appear as external, exceptional, and extraneous.

Access and Universal Design

This brings us to “access,” perhaps the most crucial and contested word in disability studies. From within the dominant normate/ableist habitus, access most commonly refers to the provision of physical/sensorial tools, adjustments, and affordances that enable the usage of spaces and technologies by persons otherwise excluded by dint of their bodily or cognitive variation. This widely held definition signals an approach by which the normate world “accommodates” persons who require “special” equipment and adaptations to participate in public life and culture. (The tools, adaptations, and affordances that normate persons require to participate in public life and culture do not, of course, count as accommodations at all.) In law and social policy, access often reduces to mandated modifications to the “normal” way of doing things and takes bureaucratic form in the guise of additional burdens on normate time, expense, and/or labor.⁴

Window dressing, lip service, and evasion are common: ads for the FitBit, for example, prominently featured wheelchair users, yet the device itself could only calculate walked steps, not wheelchair pushes, more than a decade into its existence (Elman, 2018). Thus, access often functions as a vague expression of, at best, good intentions rather than as a specific social project; as Elizabeth Ellcessor (2016) has argued, “the very discursive flexibility of access has too often allowed it to pass unexamined, conferring cultural value even as it may constrain civic, cultural, and technological possibilities” (p. 7).

This is not to dismiss the importance of access policies and features, especially in relation to digital media economies. On a practical and political level, “access,” understood as accommodation through assistive technology, is crucial to inclusion and participation in the digital media era. A wide range of studies, such as Meryl Alper’s *Giving Voice* (2017), carefully details the possibilities and complexities of assistive digital technologies and their value to persons with disabilities. In a different vein, Brown and Anderson (2021) have produced a catalogue of accessibility features in video games that creators may use to enable players with a wider variation of bodyminds to play their games. From a policy standpoint, it is better to have an ADA or a United Nations Convention on the Rights of Persons with Disabilities than to have no legal framework within which to advocate for civil rights and social change.

Nonetheless, “access” as accommodation can only be one element, albeit a significant one, of a broader disability rights project. When understood as specific technological affordances or legal requirements, access can facilitate entry into the ableist habitus but may fail to alter it in meaningful ways. As Darcy et al. (2019) note:

[A]n emphasis on usability and accommodations for disability is limiting, even when it allows space for consideration of the context of the individual. Such an emphasis can marginalise other factors affecting the successful integration of assistive technology into the life of an individual with disability. These include skills and expertise, digital literacy, economic capacity, as well as social and cultural engagement. (p. 540)

In particular, we need to be extremely skeptical of the extent to which legal mandates can reshape the ableist habitus; as Aimi Hamraie (2018) observes, “liberal rights-based approaches to accessibility, pursued through antidiscrimination law, have failed to provide meaningful inclusion for disabled people” (p. 459; see also Bagenstos, 2006). Similarly, Goggin and Newell (2007) note, “Too often we leave un-reformed the exclusionary power relations and technologies that require inclusion in the first place” (p. 166). Thus, the rights-based version of access falls short as a political project, substituting compliance with narrow sets of legal requirements for broader activist and coalitional efforts to address ableism within complex systems of oppression. Continues Hamraie, “Compliance ... precludes politicized, cross-disability, and intersectional understandings of access, which address how diverse disabled people experience environmental exclusion based

on their gender, race, class, and lived experiences of disability” (p. 459). Mia Mingus (2011) may have summed it up best: “We don’t want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them” (n.p.).

A move away from a rights-based understanding of access thus presents the opportunity to reimagine digital media in terms that foster greater social justice, and scholars attending to access have proposed several ways to move beyond technological accommodations (see e.g. Ragnedda, 2017; van Dijk, 2005; Wilson, 2004). Of special interest to digital media economies, Elizabeth Ellcessor (2016) has suggested “cultural access” for thinking through the inter-relationships among technological affordances, economic access, and access to representation and media production. This necessitates a conceptual shift from designing for “access” to designing for “variation”: “[I]f content can be molded to fit the needs of different interfaces and forms of technology, it can simultaneously accommodate human variation and physical difference. Furthermore, the variability of new media allows accessibility to be implemented more completely (and cheaply) than was the case in older forms of mass media” (Ellcessor, 2010, p. 304). Similarly, Dokumaci (2018) has emphasized the importance of understanding technological affordances not as properties of media technologies themselves but as products of “the mutuality of body-environment relations” that are suffused with social power. Instead of technologies that are imagined and designed in relation to a standard, normative body and thus constrained by how that body is presumed to be and act, Dokumaci calls for a potential “heterogeneity of affordances that would support our bodily singularities, reciprocate our needs, and make us feel at home” (n.p.).

Designing for variation is closely related to the concept of “universal design,” which the United Nations (2006) defines as “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” And indeed, thinking in terms of universality in recent decades has enabled designers of technologies and environments to expand the range of usability to include more possible users. But one could argue that, conceptually, universal design still thinks of affordances as inhering in the technologies themselves, rather than in “body-environment relations” (Dokumaci, 2018). To name one potential problem here, Alan Roulstone (2016) points out that universal design technologies can work at cross-purposes, such as bumps on the sidewalk that help blind people but can be a hazard to people with mobility impairments.

In contrast to universal design, then, and given the sheer range of unforeseeable variables that might comprise the body-technology-environment relations in any given context, designing for variation is perhaps closer to the idea of “usability for one” (Friesen et al., 2015). The challenge is to maximally account for the diversity of disabled experiences, leading Ellis and Kent (2011) to observe, “Universal design, a process that seeks to include the broadest base of potential

users, paradoxically is most effectively applied at the level of the individual” (p. 4). One practical digital media approach to designing for variation is what Brown and Hollier (2018) call “interface-casting,” i.e. creating interoperable interfaces controlled by devices that are more likely to be designed and customized for a specific individual user. Drawing on ideas about the “Internet of Things,” they use the example of elevators controllable not solely by buttons on the wall but also by interfaces on smart devices.

But lest this discussion – rethinking technological affordances as relational, and designing for variation – lead us too far from the point, “access” cannot begin and end with technological or physical accessibility and usability; the larger issue from a critical disability perspective remains social justice. Design is crucial here, of course, but it must unfold within an intersectional framework of design justice that “rethinks design processes, centers people who are normally marginalized by design, and uses collaborative, creative practices to address the deepest challenges our communities face” (Costanza-Chock, 2020, p. 6). As Ellis and Kent (2011) remind us in their discussion of digital media, this must be a political project as well as a technological one: “The internet will not be fully accessible to all until disability is considered a cultural identity in the same way as class, gender, and sexuality” (p. 2; see also Goggin & Newell, 2002). Thus, Ellcessor’s (2016) notion of cultural accessibility includes, among other elements, access to representation, production, and the public sphere, all of which depend on a range of factors that have consistently marginalized persons with disabilities (as well as women, people of color, queer people, and more). For example, Ellcessor notes that “historically, access to production has meant the ability to enter the industry, gain experience, and attract funding” (2017, p. 37). Her case study on Kickstarter-funded media production shows the potential for the digital media economy to facilitate “coalitional, collaborative, and participatory forms of production, reception, and interaction” that may expand the range of possibilities for cultural access (Ellcessor, 2017, p. 34; see also Ellis, 2016a). Meryl Alper (2021), in her work on the ways that the value of “autism-friendly” media and cultural programming must be complicated by consideration of “the larger availability of social, cultural, political, and economic means, as well as the ease with which individuals can mobilize these resources within institutional and infrastructural constraints,” has proposed a “critical media access studies” that also integrates questions of intersectional interdependence (see below) and spatial justice (p. 853; see also Costanza-Chock, 2020).

As the above illustrates, new ways of thinking about and structuring digital media technologies and economies will be necessary if we are to achieve greater cultural access and dismantle the hegemonic ableist habitus. Instead of designing for the “normal” and subsequently coming up with “accommodations” for the “abnormal,” then, the goal must be to design for human variability in bodies, abilities, needs, and possibilities from the outset, while also attending to the economic, political, and cultural structures that perpetuate inequality and

stigmatization.⁵ “What emerges,” writes Ellcessor (2010), “is a possibly transformative focus on variation, a means by which the goals of universal internet access, closing digital divides, and a more accessible and socially just online public sphere may come closer to realization” (p. 305).

MEDIA INDUSTRIES OF THE DIGITAL ECONOMY

With the foregoing in mind, I will now turn to insights from critical disability studies relevant to specific areas of the digital media economy.

Representation

Media representations of disability remain a crucial area of concern in the digital age, and despite some encouraging developments in recent years, deeply problematic texts show no signs of fading away (Barnes, 1992; Barnes & Mercer, 2010; Cumberbatch & Negrine, 1992; Fox & Sandahl, 2018; Garland-Thomson, 2001; Longmore, 2003; Mogk, 2013; Norden, 1994). Key issues here include negative and positive stereotypes, from the resentful villain made evil by his disability to the super-crip overcoming all odds (a trope that has become known as “inspiration porn” (Young, 2014)); the question of non-disabled actors playing disabled characters; and the fundamental misunderstanding of different kinds of disability experiences and perspectives that informs much of what ends up on screen. The range of cultural and structural roots of these problems in representation are beginning to be addressed, including the now-familiar question of who is in the writers’ room and the producer’s office. But the cliché of “long way to go” doesn’t begin to cover it, reimpressing the importance of seeing media and media economies within a broader sociocultural context of ableism.

One revealing example of the complexities of representation in relation to the digital media economy is characters with autistic spectrum disorder (ASD). As Pinchevski and Peters (2016) have explored, autistic savants have become common characters on shows like *Big Bang Theory* and *The Good Doctor*, impressing and entertaining audiences with their computer-like cognitive abilities (and non-normative social interactions), but they have also become a way to imagine the digital media industry itself: “The high-tech industry is here portrayed as a hothouse for high-functioning autistics: socially forgiving yet technologically demanding” (p. 2516). On the one hand, as Tasha Oren (2017) notes in her work on Temple Grandin, popular representations of autists can help translate between the autism experience and neurotypical norms, thus becoming “crucial sites of two-way mediation across and among neurotypicals and people on the spectrum” (p. 224). On the other hand, however, these shows risk distorting public understanding by “neglecting the wide margins of the less glamorous, less functional” variants of autism (Pinchevski & Peters, 2016, p. 2516). Furthermore, even the

classification of high- and low-functioning autism represents a classist and ableist distinction that mostly serves capital: “The high-tech economy puts a premium on the high-functioning ... and has no use for the so-called low-functioning,” a state that “mirrors the vast inequalities in global resources today” (Pinchevski & Peters, 2016, pp. 2518–19).

Without losing sight of complexities like these, however, it is to be welcomed that a fuller range of disability representations has proliferated in the digital media age, many of which break out of standard disability stereotypes and tropes. This has been a cumulative effect of, most notably, disability activists pushing for better representations; shifts in models of funding, production, and distribution; and persons with disabilities gaining power within the industry. Infuriating characters like *Glee*'s Artie, in which an able-bodied actor plays the “sad cripple” stereotype and fails even to use his wheelchair persuasively, will doubtless continue to be put on screen. But it is becoming increasingly possible to point to characters whom most disability activists praise as well-rounded, complex, and reflective of their own experiences of disability, increasingly played by disabled actors (two examples, recent as of this writing, are Gaten Matarazzo's character with cleidocranial dysplasia on *Stranger Things* and Micah Fowler's character with cerebral palsy on *Speechless*).

Representations on screen are inseparable from the broader question of disability representation within the media industries at large. In this connection, Katie Ellis's important *Disability Media Work* (2016a) discusses many of the obvious and not-so-obvious technical, cultural, and economic factors that shape the industry, from the need to adapt cameras and other specialized equipment for media workers with non-normative bodies, to the claim that hiring disabled crewmembers makes it more difficult to secure production insurance (see also Pointon et al., 1997). Even the new possibilities represented by crowdfunding and online distribution come with risks, such as established industry figures drawing resources away from more marginalized creators; as Ellcessor (2017) points out, “As those with access to more traditional forms of financing come to crowdfunding – and set records when they do – there is a very real possibility that the opportunities for underrepresented groups will shrink” (p. 48). Thus, even as we celebrate disabled media-makers who are making inroads into the media industries and positively affecting representation on- and off-screen, we need to recognize the diverse range of social and material challenges that continue to reproduce ableism within the digital media economy.

Data Justice and the Digital Divide

While the issue of disability representations is as old as human storytelling, the digital era also brings much newer wrinkles to the relationship between disability and media. Prominent here is the issue of data justice: as Anna Lauren Hoffmann (2016) argues, “‘Big data’ and algorithmic decision-making, when applied to

particular sorts of problems, risk worsening already unjust distributions of important liberal goods like rights, opportunities, and wealth” (p. 900; see also Alper et al., 2015). While racial, class, and gender bias in data analytics and artificial intelligence have been widely covered (Barocas & Selbst, 2016; Benjamin, 2019; boyd & Crawford, 2012; Burrell & Fourcade, 2021; D’Ignazio & Klein, 2020; Madden et al., 2017; O’Neil, 2016), a disability lens reveals specific ways that these digital media technologies perpetuate pre-existing patterns of ableism, from the results of a simple Google search (Banner, 2018) to the construction of AI systems intended, ironically enough, to assist persons with disabilities (Park & Humphry, 2019). Big data and other digital tools can also be used specifically to exclude disabled persons from full rights and participation. For example, Sharona Hoffmann (2016) has analyzed the discrimination against current and future persons with disabilities made possible by advanced data collection and algorithms used by employers to gather health information, arguing that the ADA needs to be amended to keep up with technological trends (see also Elman, 2018; Oravec, 2020; Whittaker et al., 2019).

These issues are further complicated by the digital divide and other dimensions of what Goggin and Newell (2002) call “digital disability” and that Chaudhry and Shipp (2005) label “information inequity.” The digital divide has long occupied scholars of digital media, and evidence continues to pile up demonstrating that “existing social exclusion such as income, education, region, gender and age, is reinforced by digital exclusion” (Park & Humphry, 2019, p. 935). Disability is clearly among those categories. In that sense, as Darcy et al. (2019) point out, the digital divide is not just about access to digital technologies and spaces, but to full “digital citizenship”: “The digital divide caused by the lack of access to the technology effectively reduced [disabled persons’] digital capital, hence limiting social capital and their relative position within their communities. ... [I]n every sense digital citizenship is interrelated in almost every way with social participation and without access to the former then access to the latter is not possible” (p. 551; see also Dobransky & Hargittai, 2006).

The above issues notwithstanding, several disability scholars have expressed that their worst fears of digital exclusion have not been realized. Alan Roulstone (2016), for instance, noted that “While some people cannot access the Web, the dissemination of access to it has been greater than any of the first wave technology and disability analysts could have guessed” (p. 97). Projects intended to facilitate greater inclusion and participation often yield positive results, such as the work of an Australian nonprofit to collaborate with the private sector to close the digital divide (Darcy et al., 2019); researchers found that “for a number of participants, the mobile technologies and training provided greater independence and autonomy away from their service providers and significant others. ... In essence, the technology platform and the associated training and customization introduced them to the benefits of active citizenship that until that point had been denied” (p. 551). Importantly, however, even such indicators of improvement

reinforce the need for not just technology and training but also a range of socio-cultural supports that begin to chip away at the ableist habitus, including within specific local contexts. Once again, simple “access” is insufficient.

Biomediation

Media have long been used to make sense of the body and vice-versa (Marvin, 1988; Peña, 2003; Scott, 2018), and digital media are no exception. These include fears about physical ailments (e.g. electromagnetic hypersensitivity a.k.a. “wifi poisoning”), sociocultural concerns such as a reduction in our attention spans (Carr, 2011), and the danger to our mental health as we substitute mediated communication for supposedly “authentic” face-to-face communication (Turkle, 2011). At the same time, digital media are increasingly presented as extensions to and enhancements of the body’s capabilities. “Biomediation” refers to the convergence of medicine and life sciences with media discourses, technologies, and practices (Thacker, 2004), and this convergence is only strengthening in the digital age, from voice synthesizers to blue-tint “computer glasses” to Bluetooth-connected epidermal electronics.

A critical disability lens helps us think through relationships of media and the body in a range of sophisticated ways. For example, Mack Hagood (2019) has studied the use of phone apps and other digital and analog technologies to help regulate and repair the body, using the “phantom disability” of tinnitus to think through biomediation and its relationship to biopolitics. His work challenges our ideas about what counts as “media” – even house fans, when used as white noise machines, have become sound media – and also points to the ways that mediation produces a knowable body, with media “used to perform the reality of disease and disability” (Hagood, 2017, p. 324). Alternatively, in her aptly titled study *Made to Hear*, Laura Mauldin (2016) shows how parents of deaf/hard-of-hearing children are scripted into logics of medicalization and ableist ideologies that construct deafness as a disability, with biomediation (in this case cochlear implants) presented to families as the only viable “solution” to the “problem” of a non-hearing bodymind.

Importantly, biomediation also operates on people who do not identify as “impaired” or “disabled.” For instance, Julie Passanante Elman (2018) has demonstrated how wearable health trackers normalize and naturalize compulsory able-bodiedness, encouraging users toward self-responsibilization by stigmatizing disability and reinforcing desires to avoid an “unhealthy” body at all costs. Furthermore, these technologies make the body knowable in a range of ways that put persons with non-normative bodies at heightened risk, especially within a political context (particularly in the USA) that allows people with “pre-existing conditions” to be denied health-care coverage. Noting that FitBit partnered with major corporations like Target, Elman powerfully connects these issues of body surveillance and compulsory able-bodiedness within digital media economies back to the questions of social justice at the heart of the disability studies critique:

In the age of “patient-centered care” and the Internet of Things, wearables offer a cultural fantasy of individual agency as health entrepreneurialism through the continual self-optimization of a networked body. This perspective occludes how the meaning, access to, and development of wearables continue to be shaped by histories of surveillance that have disproportionately targeted non-White, poor, disabled, and immigrant subjects as “unhealthy” targets of intervention. Which populations have (and, historically, have had) the privilege to “choose” surveillance? Or to put it another way, why position Fitbit within the genealogy of the stethoscope rather than that of the ankle monitor? (p. 3773)

The technologies and social practices of biomediation will only be intensifying in the coming years, a fact of the digital media economy that highlights the urgency of a critical disability perspective to media scholars.

Social Media

A final key area in which a disability lens provides new insights into digital media is social media, especially as it figures into movement activism. As in all civil rights struggles, embodiment has played a central role in the disability rights movement, including the powerful imagery of the 1990 protests in advance of the passage of the ADA, during which activists crawled up the steps of the US Capitol. However, embodied forms of protest can also present a range of particular challenges and exclusions for people with disabilities, and thus many disability scholars and activists have explored the organizational opportunities represented by digital media. As Sara Ryan points out, “Disabled people’s exclusion from society is such that, too often, they’re even excluded from the traditional means to protest what is being done to them. Tweeting, Facebook, below-the-line comments, or blogging, has given many a new way” (quoted in Ryan & Julian, 2016, p. 37). Similarly, Benjamin Mann (2018) contrasts the history of embodied protest with new online activism “that challenges compulsory able-bodiedness inherent to defining embodiment as a necessary prerequisite to a social ‘movement’ ... by considering the ways in which kinetic embodiment may be inaccessible for particular body–minds” (pp. 606–7).

The power of critical disability studies for social media theory and practice is illustrated by a growing range of studies on how persons with disabilities use social media to bring about change in politics and culture, from #CripTheVote activists sharing information on accessible voting places to the ways that persons with aphasia use Pinterest as an alternate mode of communication and world-building (Alper & Haller, 2016; Mann, 2018). In terms of theory, Katie Ellis (2016b) draws on work by Löwgren and Reimer (2013), who rooted the significance of social media in participation, personalization, and collaboration; however, Ellis and other disability scholars have given each of those affordances a “crip” twist. For example, “participation” for disability activists moves beyond *produsage* and similar theorizations to take on meanings associated with physical and cultural access as discussed above, e.g. using Twitter to pressure Netflix into adding an audio description option to its programs (Ellis, 2016b). A disability

approach to “personalization” goes beyond the common themes of nichification, tailored news feeds, and recommendation algorithms to include design for bodily and sensory variation, accessibility software, the adaptation of sign language for the constraints of videoconferencing and vice-versa, and specialized hardware like the Lorm glove (which enables tactile communication for deaf-blind people; see Bieling et al., 2016).

Perhaps most interesting here is Löwgren and Reimer’s third point, “collaboration.” For disability activists, social media provide not just tools for working together on ideas and projects, but the ability to form a “collaborative media ethos” (Ellis, 2016b, p. 149) that stands in stark contradistinction to the neoliberal ideology and the romantic and utilitarian individualism that helped shape the origins of digital media (Streeter, 2010). For example, Lucy Burke and Liz Crow (2016) critique the ideology of “autonomy” that motivates much of the thinking and design work that goes into digital tools, writing, “[T]he assumption that social media platforms are inherently democratized and democratizing spaces of ‘autonomy’ ... also occludes and arguably reinforces an unacknowledged but constitutive ableism” (p. 61). And as mentioned above, Alper (2021) has called for more work on media that “shift[s] the goal of access from individual independence to the collective interdependence of bodies and the specific interdependencies of disabled people” (p. 854). In opposition to a conception of social media (and the online world more broadly) as a space of individual self-actualization and reinvention, then, critical disability theorists emphasize the ways that digital collaboration, connection, and community can reinforce an ethos of co-dependence and co-construction as a valuable alternative to the ableist ideology of self-reliance, individualism, autonomy, and independence as the *sine qua non* of full humanity and cultural citizenship.

GEOGRAPHIES OF THE DIGITAL MEDIA ECONOMY

The affordances of digital media that “liberate” individuals from some of the strictures of place can often be that much more significant to persons with disabilities, particularly persons who have restricted mobility. Indeed, one prominent trope in the history of digital media, as has already come up, has been the power of technology to enable greater access and participation by persons with disabilities. Nor is this promise necessarily false. In the post-industrial workplace, for instance, digital media have the potential to reshape spatial norms and possibilities; as Dimitris Michailakis (2001) noted relatively early in the internet era, “Since ICTs [information and communications technologies] bring work to persons, rather than transporting persons to work, by telework at home or other location, thus avoiding problems of access to buildings, transportation, etc., they create new possibilities to work for persons with physical impairments” (pp. 480–1). Similarly, Tom Boellstorff (2019) has examined the possibilities

that digital media present for new kinds of economic activity, exploring how entrepreneurialism in Second Life “challenges the ableist paradigms structuring digital socialities and regimes of labor” (p. 476).

As those authors would be the first to acknowledge, however, we need to approach such claims critically. For starters, the ability to telecommute or run an online store already presumes a range of cultural, economic, and material supports that are, as the discussion of the digital divide noted above, inequitably distributed. Elsewhere I have explored how analogous tropes in the early radio era were often used to keep disabled “shut-ins” literally shut into the private sphere by positing media technologies as an acceptable alternative to a more accessible public sphere (Kirkpatrick, 2017), and that danger has only grown in the digital era, especially in light of the social and technological rupture of the COVID pandemic (see e.g. Alper, 2021; Mondelli, 2020; Shew, 2020). Nonetheless, the advantages of digital media for many persons with disabilities are substantial, and disability activists and scholars have pointed to a range of ways that digital media can alter spatial (and thus social) relations. One exciting example is Aime Hamraie’s (2018) work on accessibility and participation mapping, using detailed site analysis informed by a disability lens to produce “politicized, cross-disability, and intersectional” representations of physical space that foreground the kind of cultural access discussed above. Pinchevski and Peters (2016) argue that digital media can prove valuable for people on the autism spectrum for whom face-to-face interactions are challenging, while Trevisan and Reilly (2014) have analyzed social media as alternative spaces for effective activism by persons with disabilities. Again, however, as Ellcessor (2016) reminds us, these and other possibilities require not just technological accommodation but also close attention to the range of economic, political, and other factors that tend to restrict cultural access to those with pre-existing privilege, as well as to “the social pressures that increasingly construct the functional life to be the technologically competent life” (p. 3).

The global geographies of disability and the digital media economy are no less fraught. The technologies that enable greater participation for persons with disabilities are unevenly distributed, a fact as true for digital tools as for analog ones. As Alan Roulstone (2016) noted, “While the design of wheelchairs, for example, becomes more user-centred, their availability, especially of power chairs, is increasingly problematic in the context of austerity, even in the historically better resourced northern hemisphere” (p. 4). Poorer countries in the global South are, unsurprisingly, less able to take advantage of digital media technologies, especially those that require the latest hardware and better connectivity; as Sarah Lewthwaite (2014) writes, speaking specifically of the web but in terms that are true of digital media more broadly, accessibility standards “implicitly reflect Western norms ... for example, with expectations of literacy, assistive technologies and un-interrupted broadband internet connections. Thus, when applied in non-Western settings of emerging economies and the global South, standards

may propagate forms of web practice that actually exacerbate the exclusion of groups of disabled people who exist outside the norms of Western accessibility practice” (p. 1378).

Furthermore, disability itself is unevenly distributed and inseparable from legacies of colonialism and exploitation that persist into the digital media era (see e.g. Grech, 2015; Meekosha & Soldatic, 2011; Nair, 2017). Toby Miller (2017) has linked the digital media economy directly to disability in poorer nations, particularly in his research on the e-waste ragpickers who dismantle and recycle computers and other devices. The literally sickening conditions of these “effluent citizens” (in Miller’s provocative coinage) disrupt the triumphalist narratives of “overcoming disability through technology” that inform the debate in the global North: access to the tools of digital media in the affluent world depends, under current political economic arrangements, on the *production* of disability in the effluent world. The exposure to dangerous materials “change[s] the bodies and life chances of very poor, very young people forever, altering their very DNA, hormones, fertility, breathing, and other functions” (p. 305). In that sense, economic geographies of digital media map onto disability geographies of digital media in often unseen or ignored ways, further reinforcing the insufficiency of “access” as a way to dismantle the ableist habitus.

LAW, GOVERNANCE, AND POLICY

As the foregoing suggests, the governance of digital media economies, from a critical disabilities perspective, is inseparable from trade law, environmental law, and anti-discrimination law, as well as media policy. Thus, the legal and political landscape is devilishly complicated, even before accounting for local, national, and global policies that affect questions of digital media and disability, promulgated by a bewildering array of agencies, regulatory bodies, standards committees, and legislative authorities. Even then we must account for the inadequacy, as discussed above, of rights-based approaches to inclusion and equality in the first place. For example, the United Nations Convention on the Rights of Persons with Disabilities (2006), a major achievement of the global disability rights movement, seeks to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” Yet as Roulstone (2016) points out, even this landmark convention is severely limited in not just its effectiveness but its scope: “Such measures, although important, do not have a great deal to say about technological interventions and the processes which surround them ... [The CRPD] does not mandate a right to inclusive education nor does it halt the growth in segregated schooling. Such legal approaches are concerned jurisprudentially with individual events and acts rather than the evaluation of disablism systems” (pp. 52–3).

A further complicating factor can be summarized in Lawrence Lessig's (2006) famous dictum, "Code is law." As Hassan and De Filippi (2017) argue, "As more and more of our interactions are governed by software, we increasingly rely on technology as a means to directly enforce rules. Indeed, as opposed to traditional legal rules, which merely stipulate what people shall or shall not do, technical rules determine what people can or cannot do in the first place" (p. 89). From the technical decisions that make certain kinds of affordances and interactions possible or impossible, to the design decisions that make those affordances more or less accessible, to the social and economic conditions (including market forces) that determine who can or cannot benefit from that accessibility, the relationships between policy, code, technologies, and users are thoroughly imbricated with the ableist habitus within which they emerge. As Gerard Goggin (2015) notes, "[P]olicy is not hermetically sealed as a stand-alone, specialized realm attached to the domain of law and regulation. Rather, it is strongly and creatively connected to social and cultural domains – and disability, often thought to be the realm of social policy, rehabilitation, special education, or other specialized policy inquiry and deliberation, is an excellent case in point" (p. 328).

The only viable response to this complexity is to recognize what policy can and cannot accomplish and then, as part of that process, to identify core principles that may guide further actions and activism. Foremost among these core principles must be that persons with disabilities should have full, direct participation in law and policy making, an imperative that seems to be increasingly recognized (if not yet sufficiently acted upon). A next level would seek broad frameworks that can organize and provide focus to policy thinking. For example, many scholars emphasize "communication rights" (a subtle shift from the narrower "right to communicate"), a concept that goes beyond freedom of speech to encompass "democratic media governance, participation in one's own culture, linguistic rights, rights to enjoy the fruits of human creativity, to education, privacy, peaceful assembly, and self-determination" (Ó Siochrú, 2005, p. 13). Within those broad frameworks may be ordered specific policy goals such as web accessibility standards or regulations that provide for media ownership and control by persons with disabilities. At all levels, a critical disability lens and the participation of disability activists are indispensable if law, governance, and policy are to serve as effective tools in dismantling digital media's role in sustaining ableism and other forms of injustice.

CONCLUSION

This chapter has only scratched the surface, but I hope to have demonstrated, across a range of key issues, the power and urgency of a critical disability lens to the study of digital media economies. In terms of future research, I would borrow from one of the most important scholars in this area, Gerard Goggin (2018), who

articulated a five-point research agenda for disability and technology. Adapting his framework to digital media, I close by encouraging scholarship and activism that, first, demonstrate a more expansive understanding of disability and media, incorporating theories and methods from critical-cultural media studies as well as critical disability studies; second, foreground social, political, cultural, and economic power relations in the production of media and disability; third, advocate for rights and legal frameworks that support cultural access for persons with disabilities as one part of a larger social-justice effort to disassemble ableist habituses; fourth, investigate participation by persons with disabilities not just as end-users of assistive technologies but across the breadth and life-cycle of media; and fifth, learn from international perspectives that challenge dominant understandings of disability, of media, and of the role of disability in digital media economies.

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Notes

- 1 As of May 2022, no resolution to Suris's suit has been reported, and the applicability of the ADA to websites and mobile apps remains unsettled in US case law; at issue is primarily whether and under what circumstances websites are "a place of public accommodation" (Gil, 2021). Meanwhile, the European Accessibility Act mandates that most websites offering "essential" goods and services must comply with EU accessibility standards, but this exempts a vast range of digital content, including (unsurprisingly) pornography sites.
- 2 Fiona Campbell (2001) offers a particularly good definition of ableism: "A network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. 'Disability' then, is a diminished state of being human" (p. 44, FN 5).
- 3 See also Alper (2017), who uses cultural capital and other concepts from Bourdieu to generate important insights about assistive technology.
- 4 Compare the idea of "crip time" that challenges normative temporality from a critical disability perspective (see e.g. Kafer, 2013; Samuels, 2017).
- 5 An example of ableist structures that perpetuate inequality but *could* be relatively quickly changed: for years, calls by disability activists to expand opportunities for workplace videoconferencing were largely ignored; only once the COVID-19 pandemic transformed the world for *normate* individuals did wide-scale videoconferencing become integrated throughout the economy.

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