

Reimagining the Good Life with Disability: Communication,
New Technology, and Humane Connections

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Many deeply cherished notions of “the good life” are based on limiting notions of humans, things, and their environment. In particular, “the good life” is often imagined as a realm beyond illness, impairment, and especially, disability. This view is informed by deficit models of disability, which individualize disability rather than explore the “socio-cultural conditions of disablism” (Goodley, 2011, p. 29). With contemporary communication and new media, disability is even more seen as an impediment, barrier, or tragedy, to be overcome with digital technology. Regrettably, the widely shared experience of disability and its complex relationships with communication are only rarely seen as a resource for how we achieve “the good life,” in our own lives and societies, now and in the future.

Indeed while the field of communication increasingly engages with questions concerning marginalized populations—including issues of race, ethnicity, gender, sexuality, and diasporic populations—the study of disability and its relationship with social, cultural, and political life is stagnant. New media are often hailed as a great “equalizer” for people with disabilities. Such arguments though tend to obscure the complex ways in which disability and technology intersect for better and for worse in the lives of people with various disabilities from diverse backgrounds. However, with the rise of new social movements, disciplinary formations, and theories—such as critical disability studies—communication studies is slowly engaging with the challenges and new conceptual possibilities disability offers.

Accordingly in this chapter, we take up pressing yet sorely neglected questions of disability and communication in order to illuminate how we might see “the good life” in much more enabling, humane, and democratic ways. To do so, firstly, we discuss the state of the art of communications and disability theory. Secondly, we focus on the ways in which contemporary information and communication technologies (ICTs) shape and are shaped by notions of disability and ability. Thirdly, we identify and debate the lessons from disability and communication studies that help us to rethink “the good life,” especially in the new media environment.

Theoretical Approaches: Communication as if Disability Mattered

Communication, as a discipline, has much to gain from taking on the theoretical and philosophical questions raised by the notion of leading a good life with disability. That is, rather than visions of “the good life” being premised on the assumption that impairment and disability need to be overcome, transcended, or cured, there can flow new ways of imagining, creating, and inhabiting lives—that embrace rather than reject or disavow disability.

Thus, disability studies scholarship calls into question the naturalness of “normal” as a category (Davis, 2002), and, as a corollary, the idea that there is a singular “good life” to be had by all. Societal determination of which individuals have marked disabilities and whose needs are “special” greatly varies across history, geography, and cultures (Garland-Thomson, 1997; Moser, 2000; Goodley, 2011). Critical approaches to disability draw attention to the ways in which notions of “the good life” provide a basis for government and society to discriminate against and segregate individuals with disabilities from their fellow citizens (Tremain, 2005). Disability is part of, and very much interacting with other discourses of “otherness”—such as race, gender, and sexuality—in the production of bodily differences often seen as a social stigma and ground for exclusion and discrimination (Anspach, 1979; Goffman, 1963; Kafer, 2013; Siebers, 2008).

The attainment of individual “well-being” is a socially constructed ideal, one that rarely acknowledges “being unwell” as a state of wholeness or completion (McRuer, 2006).

Communication and its scholarship have a profound role to play in such reimagining “the good life” via disability. After all, the basic constituents of communication—speaking, hearing, listening, and writing—all stand to be altered if disability is introduced. This encompasses formulations of language and signs, image and symbols, economies and production of communication. Take, for instance, the question of speaking—a long-standing topic in communication as much as culture generally. For a range of different groups, speaking—or articulation and expression more broadly conceived—occurs quite differently than norms of “speech communication” would suggest. For the most part, communication scholars are comfortable with the idea that communication is a very broad arena indeed—and that communication is multi-modal, that most communication involves forms of mediation, and, more recently, that new media do not simply concern screen-based media. When it comes to disability, however, there has been little reflection on what its complex entanglement of meanings, practices, and media has to say for our ideas of communication.

The magnitude of this enterprise can be indicated by reflecting on Peters’ (1999) resonant argument in relation to the idea of communication: “Communication as a person-to-person activity became thinkable only in the shadow of mediated communication” (p. 6). In relation to disability, this would at the least imply that we need to think about the history of mediated communication forms to understand disability and communication. More radically still, we could formulate the bold hypothesis that communication only became thinkable in the penumbra of *disability*-mediated communication. Or, rather, we need to think through the history of disability and communication to understand communication as a general concept. In the brief compass of this chapter, we can only offer this provocation—suggesting that a future priority for research and debate is the argument that our bedrock models of communication still are not centrally informed by the materialities and imaginaries of disability communication.

Consider, for instance, Deaf people “speaking” via sign language (Bauman, 2008). Or people with profound speech disabilities communicating via gestures, signs, keyboards, and now tablet computers. Then there is the question of listening, an emerging topic of research (Dobson, 2014; Lacey, 2013). Questions of voice, who speaks, from what position, and in what context and power relations have been central to communication and media studies (Couldry, 2010). Yet questions of listening—who listens to whom, why, for what purposes, and with what implications—have not often been systemically posed (O’Donnell, Lloyd, & Dreher, 2009). From a critical disability standpoint, listening suggests many important challenges to how we understand communication, its architectures, imperatives, and politics (Goggin, 2009). To attend adequately to people who communicate “differently”—that is, the non-dominant, non-normative ways that might be associated with autism culture, Blind culture, people with intellectual disability, or people who take longer than some others to articulate their thoughts, or who use different words, sounds, or signs—requires a shift in how we understand communication.

Despite the fertile promise of communication and disability, it truly has been a specialized, minority pursuit in communication and media studies. It has been the province of particular professions and researchers focusing on improving communication by and with people with disabilities (cf. Abudarham & Hurd, 2002; Parr, Duchan, & Pound, 2003). It certainly has not been seen as a *transformative* force in communication, as gender, sexuality, race, post-colonialism, and other intellectual and social movements are commonly regarded. Consider, for instance, the paucity of full-length studies of communication and disability, or the fact that there

is just *one* reference work on communication and disability, now 15 years old (viz. Braithwaite & Thompson, 2000). While there are various anthropologists who have contributed important research—such as Boellstorff (2008), Ginsburg (2012), and Rapp (Ginsburg & Rapp, 2013)—there are very few scholarly books dedicated to media and disability *per se* with a notable exception of Haller (2010). By contrast, disability has been much more visible in cinema and film studies, and literary studies (Garland-Thomson, 1997; Longmore, 1985; Norden, 1994). Happily, a wave of scholarship and publications is now emerging in disability and media (e.g., Ellis, 2015; Ellis & Goggin, 2015; Rodan, Ellis, & Lebeck, 2014).

So, our argument in this chapter is two-fold. First, to think about and discuss “the good life,” we need to consider the fundamental challenges disability poses—and indeed embrace the opportunities it offers for doing things otherwise, perhaps much better, fairer, sustainably, and, even more happily. Second, communication as a field needs to engage with disability, as a long overdue priority. To substantiate this argument, we provide a concrete set of examples revolving around technology. A great deal of the 2014 Seattle ICA conference, highlighted in its call for papers, plenaries, and many of its panels and presentations, interpreted the theme of “the good life” via the question of technology. So the three examples that follow in the second half of this chapter provide a common line of inquiry, analysis, and conceptualization concerning communication and technology—from a critical disability perspective. In doing so, we make common cause between disability studies and science and technology studies (STS).

The Interdependence of Dis/ability and ICTs

A dominant way of seeing disability in relation to communication and technology is embodied in the concept of “assistive technology.” That is, technology associated with disability is typically positioned as “assistive” and “specialized,” rather than mainstream. Placing communication scholarship in conversation with disability studies and with STS contributes to a larger public dialogue about the tools that give assistance to all human bodies, as opposed to conceiving of “assistive technologies” as outside the domain of communication studies (Goggin & Newell, 2003). Some cultural anthropologists have argued that all human communication is “assisted” in some manner by learned techniques, linguistic equipment, and other resources (Moser & Law, 2003; Reno, 2012). What makes an ICT “assistive” is largely shaped by the context of its use as opposed to the purely intrinsic qualities of the technology or the technology user (Mills, 2011).

STS offers ways to understand ICTs as having a politics in that they contribute to the production of particular social orders and the perpetuation of social ideals (Winner, 1986). One pervasive ideology in technology circles is the idea that “bits” or the digital will eventually replace “atoms” or the physical (Negroponte, 1996). McLuhan (1964) theorized media as the ultimate bodily extension while also warning of its potential to diminish human capacities, a tension evidenced throughout modern history (Foster, 2004). Critical STS scholars have voiced concern with this conception of prosthesis, as well as the romanticization of the “cyborg” figure (Haraway, 1991; Hayles, 1999) and its celebration of the merging of organic and mechanic parts. Kafer (2013), Mills (2011), Sobchack (2004) and others call for prosthesis to be understood as more than a metaphor but as a material reality.

Disability also figures heavily into the aesthetics of media, art, and architecture (Siebers, 2010). For example, “good” web design and “accessible” web design are often framed in opposition to one another (Ellcessor, 2014). Viewing disability in terms of “accommodation,” the term often used in anti-discrimination law (cf. Pothier & Devlin, 2011; Pullin, 2011), instead figures disability as resource and inspiration for creativity and innovation. Williamson (2012)

explores how today's "do-it-yourself" or "Maker" movement among (often white and middle-class) U.S. consumers is rooted in post-war society. During that time, more people were living with significant physical impairments than ever before (e.g., surviving polio or loss of limbs in WWII). Faced with built-in obstacles to living in their own homes and sharing public spaces, a privileged disabled population (also generally white and middle-class) re-designed their environments as a form of self-preservation at the margins of society. The design of assistive technologies is always historically situated within the consumer culture of a given era and how dreams of "the good life" are packaged and sold.

Against this background, the following examples highlight various ways in which disability is bound up with conceptions of technological and social progress. We focus here on three technologies—tablet computers, closed captioning, and video descriptions—often figured by state and corporate actors as inherently improving the lives of individuals with disabilities. Each case study illuminates the cultural, historical, political, and economic forces that for better and for worse shape the lived experience of disability and so too the communicative technoscape through which disability is lived in contemporary Western society.

Tablet Computing

Recent developments in mobile technology have had a dramatic impact on individuals with disabilities, particularly those who have significant difficulty speaking. People across the lifespan (most famously, physicist Stephen Hawking) use speech-generating or augmentative and alternative communication (AAC) devices because they desire additional means for expression. While computerized AAC devices have traditionally cost thousands of dollars, less expensive tablet computers equipped with specialized software applications (or "apps") for AAC are rapidly overtaking the market (McNaughton & Light, 2013). These devices also enable other forms of mediated communication, such as email and social networking sites.

How are tablets, used primarily though not exclusively as AAC devices, similar or different from any other tablet computer a person might obtain? It is a complex question, but one entry point is through analyzing how well leading social scientific theories predicting ICT adoption explain the purchase and use of tablets for AAC and other purposes. Any model of technology adoption that counts people with disabilities as rightful technology users must take into account the variation of lived experiences with disability.

Two leading theories—Diffusion of Innovations (DOI) theory (Rogers, 2003) and the Model of Adoption of Technology in Households (MATH) (Brown & Venkatesh, 2005; Venkatesh & Brown, 2001)—are particularly relevant starting points. Researchers studying technology use by people with disabilities often employ the DOI framework (e.g. Hurst & Tobias, 2011). MATH attempts to explain the process by which households make purchase decisions about consumer electronics. Family members play a significant role in the adoption of tablet-based AAC devices. Recent surveys have found that 68% to 73% of individuals using an iPad for AAC obtained it through a family purchase (e.g. McBride, 2011).

DOI and MATH have particular advantages and drawbacks. Strengths of the theories encompass three key areas: discontinuance, confirmation, and contingency. First, these theories account for when a person adopts a technology and then ceases to use the device. It is estimated that 8% to 75% of all assistive technologies are adopted but their use is eventually discontinued, depending on the device (Scherer, 2005). First, a person might stop using an AAC device because they do not know what to do or whom to contact when a device needs repair or replacement. Second, confirmation, or social reinforcement for an adoption decision, is especially important in the digital age. Hurst and Tobias (2011) note that for users with

disabilities, having access to online communities of fellow assistive technology users shapes adoption. Third, these theories also account for contingency, or when people reference earlier purchase decisions when making new technology adoption decisions. The tablet-based AAC devices that people with disabilities use may impact their adoption and use of other ICTs, and vice versa.

There are also weaknesses to these models. They do not account for the bureaucracy in assistive technology delivery, which varies by country. While some AAC users can afford to buy tablet devices out-of-pocket, others must go through a time and labor intensive process of obtaining outside funding. In the U.S., Medicare, Medicaid, and private health insurance plans generally do not fund tablets fearing the fragility of technologies like the iPad and the potential for fraud. Also, Rogers (2003) proposes that the observability of a technology (i.e. the visibility of its use) increases adoption rates. This does not necessarily hold true for assistive technologies and can in fact have the opposite effect. Some devices are discarded because they draw unwanted attention to users (Shinohara & Wobbrock, 2011). Observability, as a predictor of technology adoption, is complicated by the identity politics surrounding disability, design, and assistive technologies.

In sum, existing models of ICT adoption are not a perfect match for explaining the processes by which people with complex communication needs adopt tablet-based computers for AAC. Certain concepts are useful and relevant, but there are complications in directly applying these theories to commercially available tablet devices and AAC apps. They are problematic in light of the political economy of production and delivery systems for tablet-based AAC devices, as well as the values and meanings associated with technology used by individuals with disabilities in specific sociocultural and historical contexts.

Goggin and Newell (2007), in their writing on the “business of digital disability,” argue that to bring about truly accessible ICTs for all requires revisiting “what it is we mean by inclusion and how too often we leave un-reformed the exclusionary power relations and technologies that require inclusion in the first place” (p. 166). More critical thought is needed regarding how it is that people with communication disabilities—many whose participation in the social and public arena and attainment of “the good life” is intimately tied to mobile devices—are so understudied among communication scholars in the first place.

Closed Captioning

A second provocation regarding the accessibility of “the good life” comes from the shifts that digitization has brought to closed captioning for digital television and online video. First, the “closed” component of captioning indicates that it is an opt-in service, hidden by default, which reinforces the invisibility of disability in much of mainstream culture and in utopian visions of a technological future (Elcessor, 2012; Kafer, 2013). Moreover, the rise of mobile and streaming forms of media viewing and concurrent legislation in the U.S. context has created a context in which this invisibility is perpetuated and extended. Ideologies of “disability as deficit” are reinforced through the deskilling of labor and denial of the cultural work of captioning, which may produce low-quality captions that poorly serve d/Deaf and hearing-impaired audiences.

The technical and cultural forms of skilled labor that are part of creating captions are, like captions themselves, often invisible. Downey’s (2008) history of closed captioning for television demonstrates the invisibility of the geographically dispersed stenographers who create captions, and ties them to processes of digitization and related professions such as courtroom reporting or real-time captioning for d/Deaf and hard of hearing individuals. These workers often work in

non-urban settings, or even from home, and are predominantly female. Their work is not understood to be creative, or transformative of content. However, captioners are engaged in “accessibility labor.” Downey (2008) understands accessibility labor as a form of translation that allows information to be accessed and circulated, and notes that, “Real-time stenographers on television must adapt scripts and speedy verbal delivery to the very limited time and space of the television screen, taking care to judiciously drop words, phrases, and even sentences when the flow becomes too fast and when the commercial break looms” (p. 158).

The processes described here indicate that there is a cultural awareness inherent to the production of high-quality captions, as captioners must have the literacy and dexterity to make moment by moment decisions and produce a final product that is different from, but equivalent to the original. The choices made by captioners effectively alter content to make it accessible, resulting in the “dilemma of accuracy”; difficulty in finding a balance between fidelity to the spoken components and its stylistic or larger function within a context of restricted space and limited time in which viewers could read content synced with the video (De Linde & Kay, 1999).

Although this labor has always been invisible, and undervalued, digitization has entrenched an ideological inferiority of accessible media and its users by allowing this work to be further deskilled or made unnecessary. Downey (2014) suggests that information labor such as captioning might be “entirely extracted from human minds and hands existing as automated algorithmic labor” (p. 145). In one sense, if a literal transcoding from audiovisual to textual content is possible, it would seem to be a boon to access. However, the drive to automate captioning labor coincides with the rise of industries such as search engines and social networking sites that need vast quantities of textual data upon which to build their systems (Ellcessor, 2012), and the increase in U.S. legal requirements for captioning. Thus, automated systems like Google’s auto-captions are rarely highly accurate.

Such automation is a logical outcome of what Striplhas (2014) refers to as algorithmic culture, in which “computers, running complex mathematical formulae, engage in what’s often considered to be the traditional work of culture: the sorting, classifying, and hierarchizing of people, places, objects, and ideas” (para. 11). In this environment, textual data has a heightened market value as it can be used to create and improve algorithms; its value as an assistive technology and its cultural value as a translation for viewers with disabilities are correspondingly deprioritized in accordance with a deficit model of disability in which disabled audiences are less deserving of access to mediated communication than are mainstream audiences, advertisers, or even web crawlers.

Digitization, automation, and the proliferation of available forms of mediated communication are often invoked as a signal of “the good life,” or an impending utopian future in which information is increasingly accessible, transformable, personalized, optimized, and circulated. Looking to the ways in which these same processes eviscerate the cultural values and possible political equity conveyed through assistive forms of media communication, however, indicates that this futurism is a fantasy of dominant classes. In imagining such a future, it is often suggested that problems of disability, inequality, and prejudice might have technological solutions; these solutions inevitably take the form of cure, meritocracy, and tolerance, failing to interrogate larger social structures and ideological investments (Kafer, 2013; Nakamura, 2002). Automation of captioning labor and the market value of textual data may appear as a rationalizing force for increasing available information, but they simultaneously may lower the quality of captions as an assistive technology and further marginalize audiences with disabilities by providing them only a second-class form of access to media content.

Video Description

Our third example for understanding disability communication and access to “the good life” is video description. It is an audio feature that describes important visual elements of a television show, movie, or performance between lines of dialogue and allows people with vision impairment access to a predominantly visual medium. It outlines relevant facial expressions, visual jokes, costuming and anything else essential to the story that a person with vision impairment could miss out on.

In particular, the availability of video description on television is increasingly recognized as vital to the social inclusion of people with vision impairments (American Foundation for the Blind, 1997; Cronin, 1998; Ellis, 2014). As an American viewer expressed in the 1980s,

.... [It was] was very emotional. I found myself pacing the floor in tearful disbelief. It was like somebody had opened a door into a new world, in which I was able to see with my ears what most people see with their eyes. (Cronin, 1998, para. 25)

More recently, a 12-week technical trial conducted on the Australian public broadcaster ABC found viewers celebrating a renewed experience of social inclusion (Madson, 2013; Mikul, 2013) with video description enabling them to “watch” television independently in their own homes:

To be able to come home at the end of the day, sit on my lounge chair, turn on the TV and ... be able to relax watching that. Not having to squint or try to figure out what’s going on or pester other people to say, “Hey, what’s just happened there?” It was a wonderful thing. (K. Ellis, personal communication, May 13, 2014)

People with vision impairment frequently connect the availability of video description to notions of “the good life” because it offers access to information and recreation, independence, and feeling of social inclusion. As Lauren Henley, National Policy Officer at Blind Citizens Australia explains,

You might think that missing out on television is no great loss, but it’s about more than watching the latest episode of *Days of our Lives*. Like the rest of my friends and family, I want to have choice about what I watch and have the ability to be informed about what is going on in the world. I lost many things when I lost my sight, but one of the things that I lost was social inclusion. (Henley, 2012)

Video description has progressed with the digitization of television (Australian Communications Consumer Action Network, 2012; Ellis, 2014; Utray, de Castro, Moreno, & Ruiz-Mezcua, 2012). Despite the potential to create “new worlds” and new forms of communication for people with disabilities, digital technologies are not inherently accessible (Ellis & Kent, 2011). Different countries have taken different approaches to its implementation. In the U.S., Federal Communications Commission (FCC) directed “the four big TV networks and the five biggest cable networks to show 50 hours of audio described programmes per quarter by April 2002” (Mikul, 2010, p. 5). Motion Picture Association challenged this and the Supreme Court eventually ruled in their favor. However, in the meantime, the networks had already begun to comply with the FCC’s mandate. In 2010, the Twenty-First Century Communications and Video Accessibility Act restored the rules earlier set up by the FCC to mandate four hours of audio described content per week (Media Access Australia, 2012).

While the Australian government acknowledged the potential of video description for digital and online television in a 2010 policy discussion paper, there is still no specific legislation in place, and as a result, no Australian broadcasters offer this feature (Ellis, 2014). When funding was not continued for the ABC service, a coalition of viewers with vision impairment

initiated legal action against the Australian government and ABC under Australia's Disability Discrimination Act. The case is currently undergoing mediation (Ellis, 2014).

A recent report by the European Union found that accessibility is more widely available on digital and online television in countries where legislation is in place (Kubitschke, Cullen, Dolphi, Laurin, & Cederbom, 2013). In 2012, OfCom, the independent regulator and competition authority for the U.K. communication industries, created *The Code on Television Access* to help encourage accessibility for the blind and vision impaired. Section 8 of this code stipulates video description targets up to a total of 10% of content after 5 years of broadcasting while still allowing for some exemptions if audience share is less than 0.05%, or where there are technical or financial difficulties (OfCom, 2012). Following the introduction of this code, broadcasters began exceeding their minimum requirements, with some achieving 100% (OfCom, 2013).

Taken together, three approaches can be distilled to video description accessibility as potential contribution to, "the good life" for audiences with vision impairment: (1) industry innovation emphasised by governments and legislators, (2) the importance of legal interventions through disability discrimination acts by activists, and (3) industry regulators such as OfCom playing a vital role in not only ensuring the availability of video description, but also in suggesting opportunities for mainstream benefits.

Conclusion: Disability and the "Good Life" in the Digital Age

In this chapter, we presented three examples to illustrate the dynamics, tensions, and texture of communication in the lives of people with disabilities. The case of AAC devices and assistive technologies highlights a neglected area in theories of technology adoption and use, as well as media policy and political economy. It shows that the AAC area is no longer, if it ever was, a specialized realm where disability and technology professionals rule. Rather, especially in the smartphone and tablet phase of mobile, online, and social media, the social shaping of AAC is very much bound up with mainstream questions of design, production, and consumption of digital technology.

Closed captioning is another area rendered marginal, indeed invisible, in mainstream media and culture. Yet in many ways, as our analysis suggests, the political and cultural economies associated with the shaping of closed captioning raise in a vivid and pressing form key questions to do with digital media technology generally. These are questions of labor as well as cultural citizenship, and matters of participation, equality, and enjoyment of common societal resources—and whether these will be open to all, regardless of class, wealth, or ascribed, subjected difference such as disability.

Video description also is an area of considerable significance and impact in terms of the cultural access, participation, and resources afforded to people with disabilities. Although it is often denigrated as a "low" or "anti-social" cultural form, television has gained acceptance as a vitally important, internationally ubiquitous medium. If one experiences exclusion from television, as various scholars have argued, in subtle ways one also is marginalized and excluded from participation in the public and private sphere. Especially in the emerging television ecologies associated with post-broadcast, digital networked infrastructures, technologies, and participatory cultures, technologies such as video description are strategically important for ensuring contemporary diversity of audiences is acknowledged—and that all audience members are embraced.

It is no accident that these examples each have to do with technology. In its various guises, technology has moved to the center stage in contemporary societies. Technology

provides crucial tools, infrastructures, support, and networks, as well as feeding into forms of social and cultural capital, that structure patterns of domination, participation, exclusion, and belonging. A longstanding insight from STS has been that technology amounts to “society made durable” (Latour, 1991, p. 103). In the cases of disability and communication technology we have explored here, this is clearly the case. However, there are more complex dimensions to communication technology that disability helps us to appreciate, which has also been the focus of developments in STS theory, as much as it has been in communication, cultural, media, and social theory. Returning to the argument we made earlier in this chapter, it is our view that a critical examination of disability has much to teach us about communication. Hopefully, the analysis provided here has indicated the fruitfulness—if not, urgent necessity—of a disability turn in communication studies. Nowhere more does this stand to be useful than in confronting the question of technology, a cardinal matter in communication today—but especially in the politics of the future, that we predicate when we imagine and debate “the good life.”

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