

## PART 1

## Opening

*Americans with disabilities are Americans first and foremost, and like all Americans are entitled to not only full participation in our society, but also full opportunity in our society.*

President Barack Obama, 2012[27]

The “information age” is transformative for people with disabilities. Never before in modern history have the civil and human rights of people with disabilities aligned so well with fast-moving developments in communications and information technology. Without doubt, the center of the knowledge revolution is the Internet’s World Wide Web (web) which has opened up unprecedented opportunities for meaningful and active participation in democratic society; indeed, it has changed the ways in which we interact with each other and with machines.

The Americans with Disabilities Act (ADA) of 1990 is helping to ensure that the physical and online worlds are inclusive of people with disabilities and their families.[28, § 12181–12189] Although there have been unparalleled developments in disability rights during the past twenty-five years, much work remains to ensure self-determination and equal opportunity in global society for people with disabilities.

This book aims to contribute to disability rights scholarship and advocacy. It builds on the ADA’s principles to articulate the right to web content equality, or the just distribution of digital knowledge, for people with cognitive disabilities defined broadly and functionally. Individuals with cognitive disabilities include those with: intellectual and developmental disabilities; acquired and traumatic brain injury, autism, learning and reading disabilities; and attention, perceptual, memory, and communication processing limitations. There are tremendous individual differences across and within these conditions that change with time and circumstance. These conditions often overlap and it is difficult to identify one distinct diagnosis and cause.

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978-1-107-05180-5 — eQuality: The Struggle for Web Accessibility by Persons with Cognitive Disabilities

Peter Blanck , Foreword by David Braddock

Excerpt

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Whereas cognitive conditions typically vary over the life course and with environmental context, they often present with other neurological, sensory and motor, and mental health impairments that may or may not be visible to others. Cognitive conditions impact individual functional capabilities, motivations, emotions and behavior. Each of the many cognitive conditions warrants discussion in their own right. The focus of this book is on the functionality (behavioral manifestations) of cognitive conditions, as compared to an understanding of cognition itself (although the two are related), in the context of interactions with online digital services and products.

## 1

## Introduction: The Struggle for Web Equality

*We, the undersigned, . . . hereby acknowledge the rights of people with cognitive disabilities to technology and information access and recommend implementation of these rights with deliberate speed*

The Rights of People with Cognitive Disabilities to Technology and Information Access, 2013<sup>1</sup>

## OVERVIEW

This first chapter sets out foundational questions that will be explored in this book. Who are people with cognitive disabilities for the purposes of the present discussion? What is web content equality, and web content itself? What is the ecosystem within which the web resides? How has disability rights law approached the right to the full and equal enjoyment of the web in the U.S. and elsewhere? And, in what ways are the lived personal struggles for disability access rights playing out? These and other subsidiary issues are raised, although many of the answers are far from straightforward.

## DISABILITY RIGHTS

Web content equality is grounded in disability antidiscrimination and accommodation law and policy. Online technology and computer code are the means by which web equality is achieved to prevent discrimination on account of disability. The means to achieve substantive web equality is to enable reasonable and individualized modifications and adaptations to web content, such as interoperability with screen reader software, captioning and subtitles. For these reasons, web technology has the unique capacity to diminish tensions in the disability rights arena as to the perceived conflict between the goals of equality (sameness of treatment) to eliminate disability discrimination and the goals of positive action (individual accommodation) necessary to achieve just participation in society.

Achievement of the central elements of the disability rights paradigm, antidiscrimination and accommodation, is emboldened by web technology. In later chapters, this synergy is explored and it is suggested it may be maximized by approaching universal design and “design for all” methods that support full and equal opportunities to access technology. Put differently, ubiquitous (across multiple contexts), yet personalized, web content enables the same experience, as well as individualized and comparable enjoyment. In theory, personalization allows that the meaning of web content may be communicated, regardless of individual characteristics and functional differences associated with disability, and other factors attendant to age, language, and environmental context and demands.

The goal of ubiquitous, yet personalized, web content is to recognize the influence of individual self-identity and culture. Thus, technology is not a “cure” for disability, just as it is not a magic bullet for improved cognition. Although the focus of this project is on cognitive disability, normative judgments are not suggested about a hierarchy of disability worthiness for web content equality.[30, p. 230] An approach to the contrary would resort to the medical prioritization of disability and, in the extreme, deny the importance of self-identity as an element of disability, which is part of the universal human experience.<sup>2</sup> In this view, web content equality is a crucial enabler of recognized fundamental liberties, such as the right to equal participation and autonomous speech in the information society. Moreover, web content equality may be viewed as a fundamental human right unto itself; certainly, as in the same way as the right to housing, education, health care, transportation, and so forth, are viewed as such.

Given historical and present attitudinal discrimination, the right to web equality is a means to ensure that disability is respected as an element of human diversity, when individuals and communities would otherwise exclude disabled individuals. The law accords people with disabilities individual and collective rights to web equality, regardless of obvious or hidden individual characteristics that may subject them to artifactual, invidious, and paternalistic forms of prejudice and discrimination. Later, the concepts of web accessibility and usability for persons with cognitive disabilities are portrayed as a central means to support web content equality; although, these concepts presently are not well defined by courts and policymakers in practice.

The progressing state of digital technology makes it difficult to articulate a sweeping vision of web content equality, for instance, in terms of presentational and semantic formats. Yet, it is the answers to these sorts of difficult questions that are needed to ground web content equality for persons with cognitive disabilities. Equally challenging is that, like the law itself, the web does not evolve in a social vacuum. It mirrors human and computer interaction across the life course, space, task, culture, and community. Web equality is likewise affected by views of the content development team, who are often spread among different product groups, as well as by individual user characteristics, skills, motivations and emotions, attitudes and expectations, and digital knowledge. It is similarly impacted by organizational, political, legal, and economic motivations and incentives. These forces collide to affect individuals and classes of individuals over their lives and time.<sup>3</sup>

*Agreements and Precedents*

Web equality as a disability rights imperative may further be conceived in regard to the attitudes and organizational cultures of public and private online service providers. Later chapters examine the circumstances where online service providers have entered into innovative agreements with persons with disabilities to approach web content equality. One example discussed involves Monster Worldwide, which operates the job search website Monster.com. Another innovative agreement was reached between the Bay State Council of the Blind (BSCB) and the Bank of America in regard to the accessibility of online desktop and mobile banking security features.<sup>[33, part 3]</sup>

Because I conceive of web equality as a civil right in the American tradition, the analysis inevitably must involve balancing with other coexisting liberties, such as that of free speech and privacy, and the economic rights accorded content owners established under intellectual property and copyright law. The U.S. Constitution provides the Congress with the power to grant a copyright to promote science and the arts. This economic right allows prescribed periods for content producers (authors) to control the dissemination and sale of their content.

We will see later, however, that one U.S. federal court has interpreted this authority as a time “limited monopoly for authors” that must be balanced against other non-economic liberty privileges, such as the freedom of speech under the First Amendment to the Constitution and those disability civil rights accorded under the ADA.<sup>4</sup> This rationale is consistent with the principle that there are proper and recognized exceptions and limitations to copyright privileges that enable individuals with disabilities and other marginalized groups to have full and equal access to these protected works, whether presented in traditional book print formats or as digital web content. This view is revisited later in the context of recent cross-national agreements for the exchange of e-books, of which the Berne Convention on copyright is the most prominent undergirding treaty, whereby an author who creates and publishes a creative work as a citizen of one member country is entitled to the same copyright protections in other member states.<sup>5</sup>

Other legal cases to be discussed examine the balancing of the economic rights of content ownership and secure dissemination of intellectual property (“digital rights management” or DRM protections) with the principles of full and equal web content access under disability rights laws. Some content owners have portrayed this as an issue of inherent conflict, as writer and president of the Authors Guild, Scott Turow, believes, viewing the “global electronic marketplace [as] rapidly depleting authors’ income streams.”<sup>[35]</sup> Given the discussion of web content adaptability, we will see that these are not insurmountable barriers. Indeed, to preview Part 3 of this book, I contend that not only will legal regimes such as copyright, DRM, and disability web equality rights coexist effectively, but also that they will emerge over the longer term with advantageous synergies for users with and without disabilities.

*Global Context*

Although the ADA has been in effect for twenty-five years and there has been a concordant growth in the political strength of the disability rights movement worldwide, the notion of web content equality for people with disabilities has generally received limited attention and, when examined, has faced resistance and pushback. For the principle of web content equality to evolve in law and practice, concordant clarity is necessary from multiple disciplines, and organizational and technological perspectives (domestic and transnational).<sup>6</sup>

When the ADA was signed into law, there were high hopes by the millions of Americans with disabilities and their family members to be included equally in society and at all stages of life. Over time, the ADA's integration mandate has transcended U.S. borders. There are more than one billion individuals with disabilities around the globe with similar expectations for self-determination and involvement in their communities.<sup>7</sup> These individuals are living longer, yet most still live in poverty.<sup>8</sup> The majority of people with disabilities live in developing nations. These individuals experience low levels of literacy, education and employment, and disparities in access to basic resources in social services, healthcare, rehabilitation, technology and AT.<sup>9</sup>

Even with longer life spans that normalize disability through increased age-related disabilities, young women and men with disabilities across the globe continue to experience dire conditions for economic and social advancement. Joseph Stiglitz finds that in the U.S., the gap is widening between individuals living in poverty and those with higher incomes.<sup>10</sup> This growing inequality has disproportionately affected the disabled and, as noted by Stiglitz, "leads to lower economic growth and less efficiency." This lack of future prospects presages that the country's "most valuable asset—its people—is not being fully used."<sup>11</sup>

In 2008, the human rights of disabled people were recognized in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and today more than one hundred nations have ratified the treaty.<sup>12</sup> The CRPD reflects a commitment by member states to value active participation by persons with disabilities in the global community. Article 1 of the CRPD states its purpose as: "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."<sup>13</sup> Persons with disabilities are those with long-term physical and cognitive impairments who face societal barriers that "hinder their *full and effective participation in society* on an equal basis with others" without such conditions.<sup>14</sup>

The CRPD's human rights lens is similar to, but different than, that of the ADA's civil rights approach. Its enumerated fundamental liberties are expressed as universal and interrelated conditions arising from the human experience. These liberties are not granted by governments or laws. Rather, they are fundamental to personal dignity and fulfillment, autonomy and capacity, and individual development, well-being, and flourishing regardless of disability.

Among its protections, the CRPD (Article 9, Accessibility) established that comparable access to communications technology and to the web are fundamental rights.<sup>15</sup> Johan Borg and colleagues believe that the CRPD declares the right to technology equality for people with disabilities “to ensure their *full and equal enjoyment* of all human rights and fundamental freedoms.”<sup>16</sup> In her general comments on Article 9 of the CRPD, Anna Lawson similarly notes that “accessibility is a precondition for independent living and for full and equal participation in society.” This view is supported in the CRPD<sup>17</sup> in which “accessibility is also given the status of a ‘general principle’ . . . which highlights its cross-cutting relevance to the entire Convention.”[53]

In November 2013, former Governor and U.S. Attorney General Dick Thornburgh testified before the U.S. Senate in favor of ratification of the CRPD. Thornburgh’s powerful testimony reminded that ratification is not just about U.S. citizens who already have protections under laws such as the ADA:

We must recognize that the Convention will not provide instant legal solutions that can effect immediate changes in attitudes and cultural perceptions; nor will it dispel the ignorance that leads to discrimination and human rights abuses of people with disabilities. What it will do is create a permanent place for disability within the human rights framework. It will put disability issues on the radar screen of governments and societies as a legitimate human rights concern to which they must pay heed. It will provide guidance and standards and create legal obligations for governments to respect the rights of this sizable population. It can serve as a powerful advocacy tool for the global disability movement to promote inclusion and equality of opportunity.[54]

Although as of yet the U.S. Senate has declined to ratify the treaty, the ADA, like the CRPD, directs that in a free society, people with disabilities have the right to use online materials to learn, work, play, communicate, shop, and participate fully in their communities.

### Ubiquitous Web

According to the website Internet World Stats, one third (32%) of the world’s almost seven billion individuals use the web, and almost half of all users (45%) live in Asia.[55, 56] While India has the largest number of English-speaking persons, China has the most web users.[57, p. xxviii] After Asia, Europe accounts for about one-fifth of all web usage (22%), with North and Latin America and the Caribbean contributing another one-fifth (22%).[55] From the years 2000 to 2011, use of the web increased more than five-fold globally.

Web usage is expected to accelerate for those who have previously faced barriers to it, including those with disabilities, those who are aging (or who acquire disabilities with age), those living in poverty, and others who face economic and political restrictions to web access. More people use mobile and tablet devices to

access the web than desktop personal computers, and, to a greater extent, these users have lower incomes.[58] In 2013 alone, there were greater than one billion smartphones and tablets bought worldwide, and this number is set to double by 2015.[59, 60] There are almost seven billion mobile subscriptions across the globe and fifty billion mobile applications were downloaded in 2013.[61] How many of these apps are accessible to and usable by persons with cognitive and other disabilities? At astounding rates, people are accessing web content on multiple devices and often simultaneously, expecting real-time responsiveness and ubiquitous usage across contexts and environments. Do persons with cognitive disabilities have such equivalent opportunities?

In addition to increased usage, the growth in the prevalence of websites is staggering. As of January 2014, there were over 864 million websites globally, containing billions of web pages and links.[62] In December 2007, there had been 155 million websites, reflecting more than a fivefold surge in six years.[63] The U.S. Census Bureau expanded its 2010 Current Population Survey (CPS) to include questions on web use in American households. The findings show that more than two-thirds (68%) of households used online services, an increase from 64% the prior year.[64]

Similarly, web content is proliferating at a staggering rate. The world's largest online collection of library books (e-books) is available to persons who are blind and with print disabilities, although that right has been contested in the courts. These are persons with disabilities who cannot read print because of visual, physical, perceptual, and cognitive conditions.<sup>18</sup> Yet, as fast as web content is multiplying and as persons with disabilities connect online, many remain excluded. By the end of 2011, broadband access was 29% lower for homes headed by a person with disability than for homes headed by someone who was not disabled.<sup>19</sup>

Even though almost eight out of ten Americans use the web,<sup>20</sup> there are high rates of non-use or non-effective usage by persons with disabilities due to the lack of available and usable technology.<sup>21</sup> If not addressed, and with web use accelerating, individuals with disabilities, and those who have low literacy and who are acquiring age-related disabilities, will become a web underclass. This development will widen the social, economic, and civic rift among those who have access to web content and those who do not.

Web content equality, therefore, is critical not only to people with disabilities (my focus here is on people with cognitive disabilities), but also to future democratic engagement and the expression of global self-identity. The web is *the* means for autonomous communication and community engagement in the creation and sharing of ideas. The right to the web as a fundamental freedom is recognized beyond the ADA and the UN CRPD, by the constitutional courts of some countries and some domestic laws.<sup>22</sup>



## THE LIVED STRUGGLE

Progress towards web content equality has been born out of the lived stories of individuals with disabilities seeking their right to participate fully in daily life. In *Rights of Inclusion: Law and Identity in the Life Stories of Americans with Disabilities*, David Engel and Frank Munger chronicle stories of those fighting for disability rights and the “opportunity to explore from the . . . outset what rights actually did and how they mattered.”<sup>23</sup>

The lived stories of disability advocates are fitting points to ground this introductory discussion of web content equality because, as Patrick Henry Wilson has commented generally, they are models for our world experience.<sup>24</sup> As never before, people with disabilities are pursuing their rights to join in their communities. Sometimes they are successful, often they are not. Some have sought to change the law and influence its interpretation and implementation. Others endorse a business-case rationale, pointing to commercial and non-commercial advantages to engaging consumers with disabilities.

Robert is blind and was one of the first individuals in the U.S. to raise his right to web equality under the ADA because an airline’s website was not equally usable by him. He was not successful in this early legal challenge.

Bruce, Melissa, and James are blind and, along with the National Federation of the Blind (NFB), brought one of the first successful class action lawsuits to ensure their right to equally enjoy the website of Target Stores; they wanted to shop online at Target.com, but it was not compatible with their screen reader software.

Jennifer and Edward are deaf, and along with the Greater Los Angeles Agency on Deafness (GLAD), challenged CNN to caption CNN.com so that they may have the opportunity to learn of the world’s news as millions of others did. CNN responded that if it was forced to caption CNN.com it would violate the company’s right to freedom of speech.

Lee, a deaf individual, along with others from the National Association of the Deaf (NAD), confronted Netflix to caption its online streaming media programming. Alan, another NAD member who is deaf, and his wife who is deaf, have two hearing teenage sons who had asked their parents to subscribe to Netflix; they refused because, without the possibility for conversion of sound to text, they were not able to not monitor their children’s shows and watch programming as a family.<sup>25</sup> Donald, who is deaf, challenged Netflix’s practices, saying that the company’s failure to caption imposed a “deaf tax” because its DVD-by-mail plans, which provided him access to the video programming, were sold at a premium as compared to Netflix’s online streaming subscription.<sup>26</sup>

Angela is blind and tried to use Redbox’s touch-screen kiosk at a California supermarket to rent a DVD, but it was not accessible to her because it needed to

be operated by sight.[83] Angela was not able to use the kiosk to rent movies independently and had to ask others for help.

Karen has bipolar disorder and lost her battle to maintain her cancer survivor's online social network on Facebook. The court sympathized with Karen's situation, her lackluster experience with Facebook's customer services, and losing connection to her online lifeline.[84, p. 1118–19]

Melissa, who is deaf, wanted to be a seller on eBay. She was not able to use the service because registering as a seller on eBay.com required that she verify her identity using an automated telephone process. Melissa asked that eBay use a readily available, simple, and inexpensive solution to fix this problem, but eBay had responded that she would have to use the service with its Live Help function.

Alexander claimed his cognitive and visual impairments were not effectively accommodated in Sony's online gaming systems and that this prevented him from enjoying them with others.[85] Sony contended that it was not required to make its products "easier" in order to be played by people with disabilities. Likewise, Todd alleged that Google, YouTube, and Myspace discriminated against him because of his reading disability by denying him the equal enjoyment of their online theaters.

Courtney could not take classes requiring library research and Blair could not read recommended texts to complete his physics classes.<sup>27</sup> This limitation was because they did not have equivalent access to the contents of their university libraries that they required as students who are blind. These students, along with the NFB and others, defended their right to have access to the digital information society in their education that was comparable to others without print disabilities.

Cari and Amber were annual pass holders to the Disneyland Resort in California and Teresa was a visitor of the Walt Disney World Resort in Florida. They each have visual impairments and wanted to enjoy Disney's parks. However, they could not make use of Disney.go.com and other Disney websites because they were not accessible to them.

Mika, along with members of the NFB of Massachusetts, wanted to be able to use the smartphone mobile applications LevelUp and Square Wallet, as others could without visual disabilities. They were not able to use these mobile apps to make payments and receive special offers from e-merchants. Both companies agreed that future versions would enable individuals with print and other disabilities services equivalent to those for its sighted users, with the same ease of use and quality of experience.

Ali worked at Marriott Hotels and is blind. He sought to keep his job and advance at the company. Ali had requested that the company's intranet system operate effectively with his screen reader software program JAWS to perform his job and participate in management training programs. Marriott claimed the requested modifications were not reasonable, and Ali brought suit for discrimination under ADA.