Disability and the Internet:
Confronting a Digital Divide

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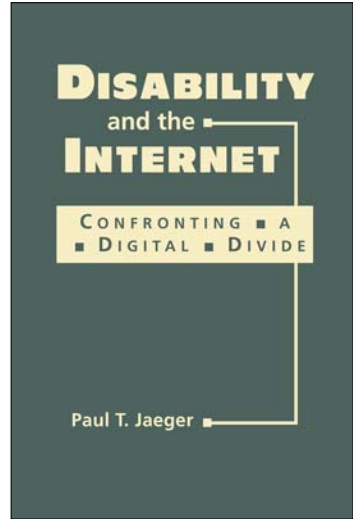
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Disability in
the Internet Age

It is nearly impossible to live a life exclusively offline in today's world. In most cases, registering a student for school, filing taxes, applying for social benefits, banking, and performing numerous other tasks require use of the Internet. In many cases, these types of services are offered exclusively online. Additionally, many entertainment options and shopping resources only exist online. When there are physical and virtual equivalents, the online versions often offer lower prices, greater selection, home delivery, and other conveniences.

The devices powered by the Internet have created new means of interaction and information resources that were unthinkable even ten years ago. A portable device that simultaneously surfs the Web, stores digital media, works as a computer, stores and plays audio and video, takes digital pictures, works as a phone, provides navigation, and performs many other functions is still incredible, even though such devices have become extremely commonplace.

Since the development of the World Wide Web in the mid-1990s, the Internet has dramatically changed the ways we live. Yet, the opportunities the Web offers are not equally available to all. Information technology (IT) has been both a liberating tool that provides increased access to information as well as "a creator of new or additional barriers to accessing information and the benefits of an information society" (Stienstra, Watzke, and Birch, 2007, p. 151). Issues of socioeconomic status, education, geography, literacy, and other factors shape the availability of the Internet and the extent of the role it plays in an individual's life. "While the digital

divide has definitely narrowed over the last decade or so, it's still wider than many would like it to be" (Rainey, 2011, p. 9). For most disadvantaged groups, however, gaps in Internet access can be overcome with the provision of computers, connections, and education. Many groups that were formerly severely disadvantaged in their access to the Internet are much less so now because public libraries across the country provide free public Internet access and training to their patrons, and Web-enabled mobile devices have become more affordable.

For persons with disabilities, the gaps in access and usage are much more complex. People with disabilities use the Internet and related technologies at levels approximately half of the rest of the population. The main reason for this is not a lack of interest or education or inclination, but the fact that the Internet is inherently unfriendly to many different kinds of disabilities. These barriers to access and usage vary by type and extent of disability.

Persons with visual impairments can face challenges in the lack of compatibility of content with screen readers, the failure to put text tags on graphics, the use of color schemes that negatively impact users with color blindness, and numerous other programming decisions that can shut out users with limited vision and no vision. For persons with mobility impairments, the barriers are created by incompatibility with alternate input devices, cluttered layout, buttons and links that are too small, and other important navigability considerations that can render entire sites and functions unusable. For persons with hearing impairments, the lack of textual equivalents of audio content can cut off large portions of the content of a site, and interactive webchats and other conferencing features may be impossible. People with speech and communication impairments can also be excluded from interactive webchats and other conferencing features. For persons with cognitive impairments, issues of design, layout, descriptive text, use of visual guides, alignment, and navigability are the difference between being able to use a site and not being able to use it. Persons with specific learning disabilities, depending on the nature of the disability, may face the same barriers as people with visual impairments or people with cognitive impairments. For people with seizure disorders, rates of flickering and flash can literally jeopardize their health.

Experiences with the Internet also frequently vary by type of disability. The same website often offers opportunities for one group and excludes another. Consider Web-based distance education. For a stu-

dent who is a wheelchair user, being able to take courses online may make education much easier; if the course website is not designed to be accessible for students with impairments that limit mobility in the hands, however, participation in the course may be limited or impossible. Similarly, the Web-enabled mobile device with a touch screen may seem like a miracle to a user with a hearing impairment and a nightmare to a user with a visual impairment. As such, the Internet and related technologies present a complex set of problems for persons with disabilities, both as a larger population and as separate populations by type of disability.

Although the range of potential barriers to persons with disabilities in the online environment is great, there are ways to develop and implement technologies so that persons with disabilities are included. There are known and achievable means to address the problems previously mentioned. However, these solutions are frequently not considered in the process of design and implementation of websites and Web-enabled technologies.

Many developers of websites and related new technologies simply do not consider persons with disabilities when they create or update products. The reasons include lack of awareness of disability issues, active belief that persons with disabilities have little value as users of the website or technology, bigotry against persons with disabilities, and simple neglect of persons with disabilities as users. In many cases, the websites and technologies that result from this disregard of accessibility run afoul of federal civil rights laws for persons with disabilities. Yet, these laws are not even enough to spur an accessible Internet. For a decade, the websites of the US federal government and those receiving federal government funding have been required by law to be accessible to persons with disabilities. Unfortunately, studies of government website accessibility regularly find government agencies with extremely low levels of compliance.

In fact, many of the issues of inclusion and exclusion online for persons with disabilities have been considered in law and policy, but the conceptions of disability under the law, exemptions from compliance, limited enforcement, and the inability of law to keep pace with technological development all hinder the impact that the laws have had thus far. An organized disability rights movement focused on the Internet also has the potential to force changes in the level of access by working to have greater say in the development and enforcement of online accessibility. Although issues of online accessibility affect most persons with disabilities, there has not yet been large-scale coordina-

tion between populations with different disabilities—and between persons with disabilities and other underserved populations—to create a movement that campaigns for equal access online.

The neglectful and negative attitudes of developers would be shocking even if persons with disabilities represented a very small portion of the overall population. These attitudes are even more shocking in light of the fact that persons with disabilities are a large and growing population. Currently constituting about one-sixth of the US population, persons with disabilities will continue to increase as a portion of the population as the baby boom generation ages. There is a very sizable market for accessible websites and related technologies, but the demand far outstrips the supply.

Such a disjunction is not new to the Internet, however. It is part of a much larger trend. "The introduction of new technologies sees people with disabilities overlooked, omitted, neglected, and not considered" (Goggin and Newell, 2007, p. 160). The distance between writing and writing systems for persons with visual impairments can be measured in millennia. The gap between typeset printed books and Braille and talking books was nearly half a millennium. More recent developments, like TTD/TTY services and closed captioning to include people with hearing impairments, came decades after the mass production of the telephone and television. While it is not a new problem, unequal access to the Internet is a broader problem than these previous gaps in access due to the scope of the Internet in social, education, government, entertainment, communication, information seeking, and other functions.

Many new Web products are developed and launched seemingly with the intent to be openly discriminatory against persons with disabilities. For example, although portable e-book readers can easily be built with the capability to verbalize the text of the e-books, they often are not. Amazon's Kindle reader has the capability, but, when it was launched, the speech function was blocked in most of the titles available for the reader, and the navigation options were limited for users with visual and mobility impairments. Later versions of the reader were improved so that the Kindle 3 enabled the speech functions on the device and had improved enlargement features so that users with visual impairments had far more access to Kindle texts. However, when the Kindle 3 was launched, it was still the only e-book reader that had such accessibility features.

Perhaps more distressing, the lack of consideration for disability in the design of information technologies often is replicated in the

adoption of information technologies. When the Kindle was intro-
duced, a number of major universities planned to start using it for text-
books, and that number continues to grow (Sadon, 2010), but without
consideration of the implications for students and faculty with visual
and mobility impairments. Threats of lawsuits from nine disability
rights groups were required to change the attitudes of Amazon and the
universities, though persons with disabilities were widely mocked on
technology blogs and websites—and on Amazon's site—for fighting
for equal access to the Kindle. Educational institutions were even
more enthusiastic to adopt the Blackboard online course software,
which was primarily inaccessible when it was launched and only
became disability-friendly ten years later. Nevertheless, Blackboard
software was used at most universities in the country.

In spite of all of these barriers, the Internet has been justifiably
viewed as having enormous potential for promoting social inclusion
for persons with disabilities. In 2000, people with disabilities who
were able to access and use the Internet were already reporting
notably larger benefits from the Internet in some areas than the gener-
al population. Adults with disabilities in 2000 were already more
likely to believe the Internet improved the quality of their lives (48
percent of people with disabilities vs. 27 percent of the general popu-
lation), made them better informed about the world (52 vs. 39 per-
cent), helped them meet people with similar interests and experiences
(42 vs. 30 percent), and gave them more connections to the world (44
vs. 38 percent) than the general population (Taylor, 2000).

More than a decade later, the potential benefits of the Internet
have increased exponentially, but the equality of access has not
improved meaningfully. In 2011, 54 percent of adults with disabilities
used the Internet, whereas 81 percent of other adults did (Fox, 2011a,
2011b). People with disabilities who regularly use the Internet also
lag behind in quality of access, with 41 percent of adults with disabil-
ities having broadband access at home, in contrast to 69 percent of
the rest of the population. A 2010 study similarly found that broad-
band adoption by persons with disabilities was two-thirds that of the
national average and that people with disabilities who have broad-
band engage in a much smaller range of online activities as a result of
accessibility issues (Horrigan, 2010).

Given the importance of the Internet in education and employ-
ment, such differences in access have serious ramifications for the
opportunities available to people with disabilities. The 2011 study
found 46 percent of adults with disabilities living in a household with

$30,000 or less in annual income, compared with only 26 percent of the rest of the population (Fox, 2011a). Similarly, 61 percent of adults with a disability had a high school education or less, while only 40 percent of other adults did.

Currently, some Internet technologies are a significant benefit to people with specific types of disabilities, while other Internet technologies offer potential opportunities to all persons with disabilities. Smartphones, although they exclude many other persons with disabilities, have been a boon for persons with hearing, speech, or other types of communication impairments, who can now use the phones to communicate face-to-face much more efficiently than they previously could. Similarly, with video chat, these same individuals can now carry on conversations over the phone in new ways. People with certain cognitive impairments that inhibit the formation of speech or short-term memories—such as Down syndrome and amnesia—also benefit enormously from the capacity of the portable technologies to provide instant communication through text. For the broader populations of people with disabilities, the Internet has a great deal of potential to create new means of communication and interaction through online communities devoted to particular types of disabilities. People who might never encounter someone with a similar disability in their physical environment can now interact directly with people with similar conditions worldwide. For people whose disabilities limit their ability to leave their homes, the Internet has the potential to provide a far greater world of interaction. People with disabilities even have the option to choose to live their online lives as people without disabilities.

Beyond the clear potential socialization and communication benefits, the Internet offers an enormous array of new ways to pursue education and employment. For people who might find it very difficult or even impossible to travel to a building for work or school, the Internet provides the ability to work or take classes from home. These potential benefits might be the greatest benefits in the long term for promoting social inclusion of persons with disabilities, as the current levels of employment and education for persons with disabilities are catastrophically low in comparison with the rest of the population. In this book I examine this tremendous ball of complexities that surrounds the intersections between disability and the Internet.

Exploring issues of society, technology, law and policy, communication, information, interaction, education, employment, and social participation, I analyze the complex and often contradictory relationships between persons with disabilities and the Internet. Though a

respectable amount of scholarship has been created about issues of disability and the Internet, such work is spread across many disciplines and is rarely considered as a whole. This diffuse approach also often results in a fragmented current picture of disability in society. For example, this text uses the most recent statistics related to disability available, but the limited attention to these issues often results in measures that are not frequently updated. Drawing upon this research from a wide range of disciplines, I identify the social issues of disability and the Internet, analyzes relevant research from across related disciplines, synthesize the implications of these issues and research, and consider future approaches that could promote online opportunities for persons with disabilities and address online inequalities they face.

For persons with disabilities, the Internet has enormous potential to increase social inclusion, but thus far it has offered only limited opportunities for equal participation as a result of issues of technological design and development, policy, and even overt discrimination. Despite laws intended to promote equal access online for persons with disabilities, access remains limited due to inaccessible design and implementation of websites and other technologies, incompatibility with assistive technologies, and widely used exemptions to the laws. Yet, the Internet also has provided significant benefits to some individuals with disabilities, ranging from allowing people with rare conditions to meet others with similar conditions online, to enabling speakers of sign language to converse over great distances. New online communities foster social interactions between different groups invested in disability issues, and not only do they allow persons with disabilities to discuss emotional and physical experiences of disability, but they also enable their parents, spouses, and friends to find information and support. Simultaneously, the Internet is helping to shape new social perceptions of disability—both good and bad—through the content about disability and persons with disabilities that is appearing online.

As Internet access becomes increasingly central to education, employment, government, communication, and social interaction, it is vital to understand the role of the Internet as an aspect of disability in society. By examining these issues across the research from diverse academic disciplines and from cross-national perspectives, this book is intended to provide a full portrait of disability and the Internet, and through this portrayal, illuminate means by which the Internet can ultimately serve to make society more inclusive of persons with disabilities.

Drawing upon scholarship related to disability and the Internet from a number of different disciplines, the book embraces related insights from information studies, sociology, education, computer science, law, public policy, communication, media studies, history, anthropology, and disability studies. With the intent of trying to thoroughly examine the social, cultural, and political dimensions of access to the Internet for persons with disabilities, I have written the book to be of interest to teachers, scholars, and students from any discipline. It is scholarly in nature but written at a level intended to make it useful and accessible to all of these readers. The discussions are not technical in nature; this is to ensure that they are understandable to readers of all levels of technological literacy. Additionally, discussions of specific websites are minimized to ensure that the book remains relevant, as the shelf life of most aspects of the Internet tends to be fairly limited, and many websites disappear or devolve due to "digital decay" (Dougherty, 2010, p. 445).

Structure of the Book

In terms of technology, it is important to consider the ramifications of technological change. The past twenty years of change have been so enormous and all-encompassing for information technology that things may have changed more in the past two decades than in the past five centuries. Even the most creative minds of science fiction in 1990 could not have imagined the world of interconnectedness, personalization, omnipresence, and miniaturization that technology now provides. Far too many people accept such changes unthinkingly, as if a rapid pace of technological change that threatens to leave many groups behind is a natural and acceptable byproduct of progress and a fair exchange for all of the applications in the newest Web-enabled mobile device.

Technological change has meaning to and ramifications for users and nonusers alike. Children who avoid television, the Internet, and video games still are affected by the decisions of the majority of their age group to focus on those same technologies as primary sources of entertainment. The rare teenager who is not constantly sending text messages is isolated from many peers by the decision to try to communicate face-to-face.

Accepting technological change without analyzing it allows technology to assert prominence over the users of the technology. "We

shall never experience our relationship to the essence of technology so long as we merely conceive and usher forward the technological, put up with it, or evade it" (Heidegger, 1977, p. 287). While most people accept the Internet as a revolutionary good for society and for their own lives, it is essential to ponder those disenfranchised by the Internet and the impact of such disenfranchisement from the central technology of the early twenty-first century.

Building on the large-scale issues and contexts discussed in this chapter, Chapter 2 examines the historical and legal issues raised by the intersection of disability and information technology, exploring the relationships between technology development and civil rights laws for persons with disability. Chapter 3 focuses on issues raised by online interactions for persons with disabilities in a range of important professional, personal, and public contexts. Chapter 4 discusses the roles of accessibility evaluation and policy reform in promoting a more inclusive Internet. Issues of online identity, representation, and advocacy for persons with disabilities are explored in Chapter 5. Finally, Chapter 6 synthesizes the themes from the book and offers a discussion of the ways in which individuals with disabilities, disability rights organizations, policymakers, technology developers, educators, and researchers can contribute to improving the accessibility of the Internet to promote the social inclusion of persons with disabilities.

The remainder of this chapter lays the groundwork for the subsequent chapters of the book. First, it discusses the different conceptual approaches to disability and the perspective used in the book. It then explores the different perspectives related to disability in societal contexts, the language of disability, and issues of access for persons with disabilities, three areas that inform much of the discussion that follows. The chapter next introduces the theoretical frame employed in the book—the theory of information worlds. The chapter concludes with a reflection on the implications of disability and the Internet both in terms of societal context and from the vantage point of an individual with a disability.

Conceptual Approaches to Disability

The conceptual foundations of this book exist within the larger contexts of disability studies research that shape approaches to disability, society, language, and technology. Building upon the discipline and perspectives of information policy, this text frames its discussion of

disability and the Internet in terms of the theory of information worlds. This approach also informs the language choices of the text related to disability, information, and technology. The goal of these discussions is to establish the parameters of and reasons for the conceptual, theoretical, and language choices in the text and discuss their relationships to other approaches to the study of disability.

Any academic discussion of disability in contemporary society is at least partially framed by the work of advocates and scholars of disability to move away from what is known as the "medical model" toward a "social model" of disability and beyond. In this context, the term *model* indicates the general frame that society employs in relation to disability. The primary difference between these models is the perception of disability as being located inside the person or socially imposed upon the person. Or, more finely, the medical model focuses on fixing individuals, and the social model focuses on fixing the environment (Hahn, 2001).

The medical model was long the approach taken to disability, and the definitions used derived from health and medicine and focused on "the causes, symptoms, and interventions that will help that individual or others who have a similar disability" (Stroman, 2003, p. 15). The medical model assumes that persons with disabilities have deficiencies that they must compensate for, that they must adapt to the social, educational, professional, and political conceptualizations that serve to marginalize them. The medical model is also strongly associated with the decisions affecting the lives of people with disabilities being made by others, particularly medical professionals, and with the forced reliance on external supports by persons with disabilities.

The medical model emphasizes disability as a purely functional issue, and persons with disabilities often associate it with oppression. Sadly, the medical model reflects the way that disability is still most commonly viewed among general populations of many nations (Prince, 2009). In contrast, the social model focuses on the ways in which social, educational, professional, and political conceptualizations marginalize people with disabilities and the ways in which these conceptualizations can be altered to become inclusive of people with disabilities (Stroman, 2003). Under the social model, "disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (Thomas, 1999, p. 3).

The argument that disability is socially produced has much historical evidence in its corner. For example, the approach of the social model is supported by the fact that in the eighteenth century, Martha's Vineyard was renowned for openness toward and inclusion of people who were deaf, with one in twenty-five residents actually being deaf. In this community, everyone knew how to sign, and there were no differences in employment or educational attainment between the deaf and the hearing residents (Shapiro, 1993).

As an advance over the medical model, the social model "has the great advantage for advocacy of diverting attention from what *happened* to disabled people as individuals (what caused their impairments) to what *happens* to them collectively as the result of unnecessary social and cultural restraints" (Couser, 2009, p. 27). The social model is clearly a major step forward as a societal frame for disability.

The social model has proven instrumental as a tool for advocacy in promoting the sizable gains in civil rights for persons with disabilities in many nations over the past several decades. Prior to the assertion of civil rights perspective inherent in the social model, the bigotry toward persons with disabilities was socially accepted as "self-evident truth" (Johnson, 2006, p. 54). Building on the social model, the terminology of the disability rights movement has emphasized concepts of independence and self-reliance, concepts that are resonant with the general populace in many places (Bagenstos, 2009). For all of its value as a tool for changing perceptions about disability, however, the social model is also problematic.

While the social model is now the most common approach among disability scholars and activists, neither the medical model nor the social model in isolation presents an accurate picture of disability, as it is simultaneously an issue of individual difference and of social construction (Corker and Shakespeare, 2002; Stroman, 2003). "Both the medical model and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people's lives and their knowledge" (Corker and Shakespeare, 2002, p. 15). Or, from a more individualized perspective, "the social model of disability proposes an untenable separation between body and culture, impairment and disability" (Hughes and Paterson, 1997, p. 326).

The social model also suffers from the fact that, if disability is indeed a social creation and not about the individual, then it makes little sense to provide legal rights specifically to people with disabilities as a population (Bagenstos, 2009). It is very hard to define poli-

cies to address social constructions, especially if the characteristic that defines the population is not actually a characteristic of the members of the population.

To address these types of issues, a postmodern model of disability has been proposed. The postmodernist approach to disability argues that there are no social structures that shape the individual lives of people with disabilities; instead, life is a series of opportunities for individuals to reinvent themselves (Corker and Shakespeare, 2002; Shakespeare, 1994). However, the postmodern model fails to adequately address the realities of disability as a personal, lived experience. "In most postmodern cultural theorizing about the body, there is no recognition of—and, as far as I can see, no room for recognizing—the hard physical realities that are faced by people with disabilities" (Wendell, 1996, p. 45).

As a result, there are currently multiple different ways in which scholars of disability may conceive of disability. There are also geographic differences in the conception of and approach to disability. In the United States, a good deal of the focus—both under the law and among disability scholars and advocates—has been on viewing disability as a minority group, with its own knowledge and experiences that others do not share (Siebers, 2006). The language of disability rights laws in the United States is all premised on disability as a minority group in society. From this sociopolitical standpoint, disability is "not a physical or mental defect but a cultural and minority identity" (Siebers, 2008, p. 4). As such, people with disabilities "are disadvantaged by the way society is organized," and the solution is a policy that "addresses various attitudinal and environmental barriers that prevent disabled people from participating" (Turmusani, 2003, p. xiii).

The problem with this approach, however, is that disability is not a binary experience but a range of very diverse experiences (Sherry, 2008). People with disabilities are all members of other populations as well, so individual experiences of people with disabilities are also shaped by race, gender, ethnicity, age, education, socioeconomic status, and other factors (Sherry, 2008). There are also limits to what can be accomplished by providing civil rights to persons with disabilities as a minority group. "We need to recognize that social justice and cultural change can eliminate a great deal of disability while recognizing that there may be much suffering and limitation that they cannot fix" (Wendell, 1996, p. 45).

These differences in perspective are exacerbated by goals for differing social outcomes among persons with disabilities, ranging from

the desire to cast off any social support as a form of oppression to the desire for a considerable expansion of the social supports and welfare provided to persons with disabilities (Bagenstos, 2009). Yet, for all of the differing approaches and disagreements about perspectives on disability that can be found in contemporary scholarship on disability, these perspectives are all united by the genuine desire to establish a perspective—or multiple perspectives—that help to realistically portray the societal standing of persons with disabilities and the ways in which that standing can be improved and made equal with other members of society.

From an applied standpoint, a useful way to reconcile these differences is to view disability as simultaneously a natural part of human diversity and an environmental outcome shaped by social attitudes toward such diversity (Enns and Neufeldt, 2003). A similar approach to understanding disability is to conceive of it as being the manifestation of two interrelated elements: (1) the ongoing presence of a physical or cognitive condition that society deems unusual; and (2) the social and institutionalized discrimination or exclusion resulting from this physical or cognitive condition that society deems unusual (Jaeger and Bowman, 2002, 2005). In the context of the discussions in this book, *physical* impairments include the range of sensory and mobility impairments that affect use of the Internet and related information and technologies, while *cognitive* impairments include the range of intellectual, developmental, and learning impairments that affect use of the Internet and related information and technologies.

In this book, the perspective toward disability in society is definitely on the applied side, driven by the disciplinary perspective of information policy that frames the text. Information policy is a discipline that encompasses elements of law, public policy, information studies, computer science, and communication to analyze issues of access to and use of information and related technologies (McClure and Jaeger, 2008; Relyea, 2008; Schmetzke, 2007a). A key part of this research is a focus on populations in society that face gaps in such access and use, which are often socially imposed differences created by technology design and implementation or articulation of law and policy (Jaeger et al., 2011; McClure and Jaeger, 2008). Information policy research is strongly oriented toward identifying such gaps, isolating their causes, and changing policy to mitigate them.

Such gaps have come to be collectively known as "the digital divide," though common understandings of the term do not capture

the complexities of the issues. In fact, these gaps result in populations being variously disadvantaged, underrepresented, and underserved in terms of information and technology (Jaeger et al., 2011). This status derives from a combination of social attitudes, educational and employment opportunities, technology development and implementation, and legal and policy decisions that negatively impact or discount the needs of persons with disabilities in relation to information and related technologies. Persons with disabilities are not alone in facing such disadvantages, because socioeconomic status, educational attainment, gender, language, literacy, age, and geography, among others, can influence access to and use of information and related technologies (Baker, 2001; Jaeger et al., 2011; Kinney, 2010).

These gaps have been especially pronounced for persons with disabilities, however. Such a lack of access can be seen as a civil rights violation that requires rethinking of technology design and social policy (DePoy and Gilson, 2006, 2008). As I detail throughout the book, persons with disabilities historically have been strongly disadvantaged—and continue to be in contemporary society—in access to and use of information and technology, deriving from a range of interrelated social, educational, technological, and political biases.

A key part of the approach of information policy is the analysis of the established legal context. As such, for an analysis rooted in the laws of the United States, the approach is inherently tied to the sociopolitical approach of persons with disabilities as a minority population. But that does not mean that assumptions under the law are not deconstructed as part of this analysis. Several of the major causes of the information gaps faced by persons with disabilities are a direct result of the constructions within the law itself.

Disability rights laws in the United States have been built on an antisubordination approach, meaning that rights are only available if one is a member of the legally defined class of people protected; in contrast, all other types of civil rights laws in the United States are based on an antidifferentiation approach, meaning that anyone has protections under the law if they are being discriminated against (Colker, 2005). This difference means that disability rights laws are much harder to enforce, as people with disabilities must first prove that they have standing under the law, something no other population must do under civil rights laws. The law also has many exceptions, loopholes, and inherent contradictions in terms of information and technology that serve to increase and even encourage discrimination against persons with disabilities.

The approach I take here, however, does not mean that a post-modernist approach to the interrelations between disability and the Internet would not prove insightful and useful. In fact, any additional detailed engagement with the topic of disability and the Internet in disability studies would be extremely valuable. Despite the enormity of the Internet in the social, political, educational, and economic lives of every member of society, the Internet is fairly neglected in the field of disability studies. One could read a great many disability studies books and articles from the past fifteen years and find few references to Internet-related issues. Most existing research and discourse on the issue of disability and the Internet has been generated by the fields of information studies, education, computer science, law, communication, universal design, and media studies. This curious neglect of the nexus of disability and the Internet needs to change, as the Internet will continue to increase in importance in individual lives and society into the foreseeable future.

Disability in Society

Paralleling the complexities of the approaches to and perspectives on disability within the scholarly discourse, disability is a difficult issue within society, though the approaches in society rarely fit neatly into one category or model. Part of the difficulty is tied to the fact that disability is not static. Most people with disabilities have variations in their condition that means they have different levels of impairment on a day-to-day level. The variable nature of an individual's disability may make it harder for someone without a disability to understand; for example, one might be confused about why a person some days uses a cane and on other days uses a wheelchair. However, a larger variable of disability is the fact that the population of persons with disabilities is not static.

Disability is the only minority group that can be joined during the course of one's life. Most people with disabilities acquire them during the course of their life, typically without the intent to acquire them. So, not only is disability the only minority group that people can join, but it is also one that people do not want to join but lack a choice in the matter. People do join the group, nonetheless. "In nearly no other sphere of existence, however, do people risk waking up one morning having become the person whom they hated the day before" (Siebers, 2008, p. 26). Though disability can happen to anyone, some

populations are more likely to experience disability as a result of unequal distribution of factors that cause disability, such as war, violence, disease, and famine (Sherry, 2008). In the United States, people with disabilities are actually the largest minority group, with more members than either Latinos or African Americans. Another indicator of the size of the population of people with disabilities is that, after English and Spanish, American Sign Language (ASL) is the third most widely used language in the United States.

There are many ways that societies view disability. As noted previously, the medical model approach of focusing on physical, sensory, or cognitive difference is still widely held across many cultures. In other circumstances, the focus follows the social model, emphasizing the issues of social, economic, religious, cultural, educational, and employment discrimination that result from societal reactions to differences. However, clear distinctions that specifically follow medical, social, or postmodern approaches rarely exist in daily life.

Consider the basic issue of difference. Not all differences carry the negative social connotations of disability. People with naturally occurring red hair carry a gene that results in an obvious physical difference that is very rare in the overall population. However, their ability to function in society is rarely questioned and they are not often looked down upon. It seems absurd to imagine children with red hair being put in special classes in school or their parents having support groups. While natural red hair may have no particular social or economic advantages for the individual, it likewise does not result in the individual experiencing discrimination.

Some differences even are celebrated. Students who perform very well on certain standardized tests are given their own advanced classes and labeled "gifted." Being tracked this way benefits the gifted students as they progress through elementary and secondary school and heightens their chances of attending a prestigious college that will ultimately improve their career opportunities. Certain physical differences are considered large advantages in life as well. Professional athletes are very well compensated and highly regarded for their physical differences, a group that some persons with disabilities call the "severely able-bodied."

Not all physical, sensory, or cognitive differences, therefore, are viewed as disabilities in society. However, disability is tied to specific individual differences that result in exclusion and social distancing. This situation clearly reinforces the notion that "to a large extent, disability is a social construct" (Schmetzke, 2002, p. 135). Society has

made the decision that red hair is irrelevant, a high IQ is to be cele-
brated, basketball is a high-paying career option, and deafness is a
deviation. Such social decisions are as old as human society. The con-
cept of disability, in fact, has been part of human culture through
known history (Scheer and Groce, 1998).

Disability clearly is "part of the natural physical, social, and cul-
tural variability of the human species" (Scotch and Shriner, 1997, p.
154). A more humane approach to disability than is generally taken
would be to acknowledge that disabilities are simply part of the spec-
trum of human variation, present in every culture and geographic out-
post of human life (Higgins, 1992; Scheer and Groce, 1998; Zola,
1993). The predominant social reaction to disability has not been
acceptance as natural variations, though, as most reactions through
time have emphasized disability as otherness and deviation (Barnes
and Mercer, 2003; Barnes, Mercer, and Shakespeare, 1999; Jaeger
and Bowman, 2005). "From the moment a child is born, he/she
emerges into a world where he/she receives messages that to be dis-
abled is to be less than, a world where disability may be tolerated but
in the final instance, is inherently negative" (Campbell, 2009, p. 17).

Though disabilities vary widely, people with disabilities share
common social experiences through their treatment by others
(Ziporyn, 1992). Throughout recorded history, the noted presence of
disability is paralleled by judgments about the meaning of disability
(Albrecht, 1992). As societies have articulated standards of normalcy,
disability has been the juxtaposition of normalcy (Campbell, 2009;
Davis, 1997, 2000). Through time, disability has been associated with
prophecy of pending negative events, wrath of supernatural powers,
demonic possession, burdens on society, fodder for public sport, and
entertainment; but all of the associations have been linked by percep-
tions of little social value or outside of the conception of society
(Baynton, 2001; Bessis, 1995; Braddock and Parish, 2001; Bragg,
1997; Bryan, 1996; French, 1932; Hibbert, 1975; Rosen, 1968; Stone,
1999; Warkany, 1959).

Disability, as a social factor, has been so powerful across time
and societies that some scholars believe that it has functioned as a
"master status" in society, the element that defines a person regard-
less of any other personal characteristics (Albrecht and Verbugge,
2000, p. 301). The presence of disability "floods all statuses and
identities" of an individual in society, such that "a woman who uses a
wheelchair because of multiple sclerosis becomes a disabled mother,
handicapped driver, disabled worker, and wheelchair dancer"

(Charmaz, 2000, p. 284). According to this line of thinking, a Latina who owns a successful business, has two children, and happens to be visually impaired would be most prominently perceived as blind by society. Supporting this assertion is the fact that discrimination against women, people of color, and immigrants has historically been justified by representing these groups as having disabilities (Baynton, 2001). This apparent situation has led to conclusions by many people with disabilities that "my disability is how people respond to my disability" (Frank, 1998, p. 111).

The discriminatory reactions to disability are strange given the number of persons with disabilities. Disability is not uncommon and it will become more common in the near future. In the United States, 54.4 million people have a disability (18.7 percent of the overall population in 2005), and the number of persons with disabilities worldwide is approaching 1 billion in 2010 (Albrecht and Verbugge, 2000; Metts, 2000; US Census Bureau, 2008). Disability does increase with age—13 percent of people age 21 to 64 have a disability, but 53 percent of persons over 75 have a disability. The number of people in the United States age 55 or older is increasing rapidly as a percentage of the total population; as a result, the number of persons with disabilities will grow significantly in the next few years as the baby boom generation ages (Rehabilitation Research and Training Center on Disability Demographics and Statistics, 2007). In fact, only 15 percent of persons with disabilities are born with them.

Disability, then, becomes more common with age but is much less common among the population in schools and in the workforce, which emphasizes the perceptions of otherness. A further aspect of disability that contributes to this sense of otherness is the fact that it is not a unifying, static, or immutable state. Numerous variables shape the ways in which a disability affects a specific person. The same type of disability can vary by severity, visibility, stability, age of onset, type of onset, levels of accompanying pain, and extent of impacts (Vash and Crewe, 2004). Most people with disabilities acquire them during the course of their life, so disability is very different from a characteristic like gender, which is constant through the lives of the vast majority of people. Disability also does not have a unifying cause; it can result from genetics, age, accident, or other external circumstances.

Nor are people with disabilities unified by a defining common characteristic—they cannot be recognized by a factor like skin color or language. Disability really is "the all-inclusive minority" (Riley, 2005, p. xiv). It touches people of all different cultures, ages, back-

grounds, religions, pigmentations, and sexual orientations. Some people with conditions that society classifies as a disability do not consider themselves to have a disability, such as the many people with hearing impairments who view the use of ASL simply as speaking another language (Branson and Miller, 2002). Perhaps most significantly, there is a wide range of physical and cognitive conditions that are considered disabilities, ranging from sensory impairments to learning disabilities to mobility impairments to limitations on cognitive development. The range of different disabilities leads to varying views of disability as, for example, a process, an interaction, a binary condition, or a continuum of abilities (Baldwin, 1997; Brandt and Pope, 1997; Cunningham and Coombs, 1997).

All of these differences make disability more unpredictable than other variations among humans. People can comfortably anticipate that their gender and skin color will remain fairly constant through their lives. The possibility of acquiring a disability, however, looms over the life of every person. The unpredictability of disability may make it harder for people without disabilities to accept people with disabilities, as people with disabilities may seem an unwelcome reminder of the randomness of life. In spite of the major gains in terms of civil rights and social inclusion for persons with disabilities over the past several decades, much of the overall population still does not regard persons with disabilities as an integral part of society, but instead views them with a mix of stereotyping, sentimentality, oppression, feigned concern, indifference, and even hostility (Barnes and Mercer, 2003; Barnes, Mercer, and Shakespeare, 1999; Campbell, 2009; Jaeger and Bowman, 2005; Siebers, 2008; Stiker, 1999; Switzer, 2003; Thomas, 1982).

The underlying social aspects of disability become clear by thinking about the basic design of buildings. Consider a society in which wheelchair users were the majority of the population and people who walked were the minority. Such a society would naturally be designed around the needs of the majority of the population—the wheelchair users. People who did not use wheelchairs would face the social stigma of disability and would find barriers at every turn. Stairs would be uncommon, doorways would be too short, places to sit would be very hard to find, and tables and other flat surfaces would be at very low levels. Navigation would be very difficult for the minority of walkers, and the users of wheelchairs would rarely think about these problems. Chairs and stairs, in fact, would be only grudgingly provided as accommodations in this society.

Even in the reality that we have, the example of wheelchairs points out the level of subjectivity of disability. Many wheelchair users ironically view chairs as an accommodation for the people who don't think ahead to bring their own place to sit. To the minority of wheelchair users, chairs are an accommodation for the majority. For the majority, ramps and curb cuts are the accommodations for wheelchair users.

Disability can be particularly hard to relate to if one neither has a disability nor is close to someone who does. Media presentations of disability tend to emphasize people with disabilities either as objects of pity, ridicule, charity, sickness, and menace or as paragons of heroism, innocence, nobility, and sweetness (Black, 2004; Condeluci, 1991; Mitchell, 2008; Norden, 1994; Riley, 2005; Thompson, 1997). Outside of entertainment portrayals, popular exposure of disability tends to be limited to telethons and other charitable functions (Charlton, 1998). The distancing of persons with disabilities from mainstream activities is reflected in the common occurrence of descriptions of disabilities being turned into slurs and social metaphors for negative things (LaCheen, 2000).

This social distancing of persons with disabilities directly translates into exclusion from many key parts of society. Persons with disabilities already face unemployment at more than three times higher levels than the rest of the population (54.4 percent versus 16.5 percent) and suffer similar gaps in educational attainment (US Census Bureau, 2008). For some types of disability, the gaps in employment are even higher—for people considered to have a severe disability by the Census Bureau, 69.3 percent are unemployed and 27.1 percent live in poverty, three times the national average (US Census Bureau, 2008). Yet, 75 percent of people with disabilities who are not employed want to work (Dispenza, 2002). Only 30 percent of high school graduates with disabilities enroll in college, compared with 40 percent of the general population; one year after graduation, only 10 percent of students with disabilities are still enrolled in two-year colleges, while only 5 percent are still enrolled in four-year colleges (Stodden, 2005; Wagner et al., 2005). These educational challenges are tied to the large number of postsecondary faculty who feel unprepared or disinterested in working with students with disabilities (Banard et al., 2008; Bourke, Strehorn, and Silver, 2000; Dona and Edmister, 2001; Hindes and Mather, 2007; Izzo, Murray, and Novak, 2008; Weimar, 1990; Zeff, 2007).

These exclusions also directly affect the usage of services and of technologies like computers and the Internet. When seeking health

services, for example, 74 percent of persons with disabilities report facing difficulties in getting the health care they need (Shigaki, Hagglund, Clark, and Conforti, 2002). Among persons with disabilities, 30.2 percent use a computer at home, 33 percent live in a household with Internet access, 26.0 percent use the Internet at home, and 30.8 percent use the Internet at any location (Dobransky and Hargittai, 2006). All of these percentages are less than half of the percentages for the rest of the population (Dobransky and Hargittai, 2006). People with disabilities who live in nonmetropolitan areas have the lowest Internet usage of any population in the United States (Simpson, 2009). These exclusions are not unique to the United States; in Canada, persons with disabilities are three times more likely to live in poverty and are less than half as likely to have Internet access as the overall population (D'Aubin, 2007; Jongbloed, 2003).

The Language of Disability

As with the differences in the approaches to the study of disability and the complicated roles of disability in society, the language of disability is also an area of disagreement. "People with disabilities? Disabled people? There are ongoing and unresolved debates about ways to talk about disability" (Church et al., 2007, p. 1). In part, this derives from the desire to find terminology that does not carry any of the stigmatizing or bigoted connotations of previous terms that have been applied to people with disabilities throughout history. Many terms that have been created as medical terms have quickly morphed into derogatory terms for people with disabilities.

Additionally, in Western culture, disability historically has served as a dividing line between "worthy poor" and "undeserving poor," creating other linguistic connotations that raise concerns of economic subjugation (Oliver and Barnes, 1998). For centuries the language used to describe persons with disabilities promoted dehumanization, dependence, and exclusion. The term *handicapped* used for so long was derived from cap in hand, based on the fact that persons with disabilities in England were long permitted to support themselves exclusively through begging. Other venerable terms like *crippled, retarded,* and *feebleminded* have equally disturbing connotations for persons with disabilities. As attempts are made to advance the language beyond historical biases, terminology that has been accepted at one time is often cast off as being outdated or offensive not many

years later. This trend is reflected in the abrupt change in the mid-1980s from the use of the term *handicap* to the use of the term *disability* in the legislative language of the United States (Stroman, 2003).

The biggest challenge with disability, however, may lie in the fact that persons with disabilities are primarily associated together by social exclusion. "Disability acts as a loose rubric and as an amalgam of dissimilar physical and cognitive traits that often have little in common other than the social stigma of limitation, deviance, and inability" (Mitchell and Snyder, 1997, pp. 7). Disabilities can be sensory, affecting sight, speech, or hearing. They can be mobility impairments, affecting control of the limbs due to injury, loss, palsy, paralysis, arthritis, and other conditions that restrict movement and muscle control. They can be impairments that impact the functioning of internal organs, such as difficulty breathing. Disabilities can also be cognitive, affecting the processing of information generally or in a specific area. Cognitive disabilities include impairments that range from severely limiting general cognitive functions to affecting specific cognitive functions. The array of cognitive disabilities includes more commonly known conditions such as autism, amnesia, aphasia, dementia, Down syndrome, and Asperger's syndrome, as well as much less common conditions such as Cri du Chat syndrome. Additionally, learning disabilities are cognitive impairments that impact the processing of specific types of information with extremely specific impacts, such as the ability to process numbers for computation.

Disabilities can also be described in terms of impact—the term *print disabilities* is sometimes used to describe any visual, learning, or mobility impairment that limits the ability to access physical or electronic print in standard means. Across these types of disabilities, there are often few linkages between persons with various physical, cognitive, and sensory disabilities beyond the social, economic, political, religious, cultural, educational, and employment discriminations that result from societal reactions to these differences. As a result, when it comes to disability, "there is virtually no vocabulary which has universal support" (Pollack, 2009, p. 5).

Currently, many scholars and advocates draw a distinction between disability and impairment. The social model asserts that *impairment* should be used to refer to the physical or cognitive condition, and *disability* should refer to the social construction of exclusion and oppression resulting from the impairment. However, this

distinction is logically flawed due to the fact that *impairment* is also a social construction of what is considered a normal body and what is considered not normal (Hughes and Paterson, 1997; Lupton and Seymour, 2000).

As noted earlier, in North America the language and thinking of disability rights has been much more focused on disability as a minority group than in Europe (Barnes, Mercer, and Shakespeare, 1999). The minority group approach is reflected in the language used to define disability in legislation—a physical, sensory, or cognitive difference that results in impairment of a major life function, the diagnostic record of such impairment, or the social stigmatization associated with such impairment. The advantage of this legal language of disability used in the United States is that it encompasses "the social, historical, political, and mythological coordinates" of disability (Mitchell and Snyder, 1997, pp. 2–3).

In terms of disability, the language throughout this book employs what is known as person-first terminology, reflecting both the common language of the United States and its disability rights laws. This literally means that the person receives greater emphasis than the impairment: a "person with a disability" rather than a "disabled person." The former is the terminology generally employed in North America, while the latter is the terminology generally employed in Europe.

The goal of person-first language is to avoid terminology that equates the person to the disability and language that disempowers or devalues the person, such as the difference between describing a person as a "wheelchair user" rather than "wheelchair bound." The former emphasizes that the person uses the wheelchair as a tool, while the latter allows the wheelchair to define the identity of the person. The European perspective on language, in contrast, sees placing the *disabled* term first as emphasizing the socially imposed discrimination against the individuals. Cross-culturally, person-first terminology is the language more commonly used by people with disabilities themselves (Lupton and Seymour, 2000).

In truth, there is no definitive answer to these language issues, despite claims to the contrary that can readily be found on both sides of this linguistic divide. These linguistic differences, however, do serve as a reminder of the complicated nature of the larger social challenges faced by persons with disabilities. The terminological awkwardness of disability is a potent symbol of the distancing and exclusion of disability in society.

The Language and Goals of Access

Following the language of disability, the terminology of access for persons with disabilities has its own differences. Unlike the terminology of disability, however, these differences are often more tied to different terms across disciplines for similar goals than rooted in inherent differences in goals. As will be shown, *access* as a general term has multiple meanings, but *access for persons with disabilities* has been variously described in terms of accessibility, universal design, universal access, and universal usability.

The oldest of these terms—at least in its use to indicate access for persons with disabilities—is *universal design*. Universal design has its roots in making commercial products and architecture more inclusive, taking focus away from the traditional design approach of creating things for an imagined average user. Instead, universal design focuses on making "products and environments welcoming and useful to groups that are diverse in many dimensions, including gender, race and ethnicity, age, socio-economic status, ability, disability, and learning style" (Burgstahler, 2008a, p. 3). Universal design is one approach to making products that are more inclusive of persons with disabilities, without focusing specifically on accessibility (Ostroff, Limont, and Hunter, 2002; Burgstahler, 2008b).

Traditional standards in design enable and create order for those with standardized bodies but disable and exclude those who do not fit the standards; in this way, the lack of compliance with standardization can be seen as a key means by which people are disabled by society (Moser, 2006). Universal design originated with the realization in architecture that born-accessible structures were both more inclusive of people with disabilities and of people belonging to other populations. For example, curb cuts on sidewalks not only support wheelchair access but also help parents with baby strollers, people with shopping carts and rolling luggage, bicyclists, skateboarders, rollerbladers, and many others (Zeff, 2007).

Following on the principles of universal design, the concept of universal access—or universal service—has been articulated in telecommunication and computer science contexts as the goal of making technology equally available to all (Shneiderman, 2000). The language of universal access can be found in government policy documents, business plans of communication companies, and computer science researchers, among others. While a worthy goal, universal access overlooks the very significant issue of usage. After

access is available to all, people still need to be able to use what they have achieved access to. Universal access does not overcome barriers to access such as language, literacy, technological literacy, and disability.

The concept of universal usability overcomes these problems if it achieves its goal of creating technologies that can be accessed and used by most, if not all, people. Established information technologies—postal services, telephones, television—successfully provide universal usability; that is, the vast majority of the population has access to, can use, and regularly does use the technology (Shneiderman, 2000). Thus, the belief is that information technologies should be designed to provide the same kind of widely usable products from the outset (Shneiderman, 2000). Universal design, universal access, and universal usability focus on a broad range of populations that the design is intended to reach, including age, gender, race, ethnicity, and other factors, as well as disability.

In this book, I use the language of universal usability to discuss broad goals of access across populations. However, the discussion focuses on information and technology for persons with disabilities in terms of accessibility. There are several reasons for this choice. First, *accessibility* is the term most commonly used within information policy to discuss access for persons with disabilities in particular. Second, it is a more finely grained term than *universal design*, *universal access*, and *universal usability*, as accessibility refers narrowly to the population of persons with disabilities, the topic of this book. Third, achieving accessibility in design is central to achieving universal usability—an accessible design will generally be more inclusive of many types of users disadvantaged by factors such as age, literacy, experience, and education. Finally, people with disabilities have a different kind of relationship to technology than other groups, as it plays specific supportive roles in the lives of many people with disabilities.

Because of these unique relationships, people with disabilities conceptualize technologies in two main ways: "as tools assisting bodily function and as contributing to the body/self as it is experienced and presented to others" (Lupton and Seymour, 2000, p. 1861). They associate technology with potentially facilitating communication, mobility, safety, autonomy, control, independence, competence, confidence, and participation in the workforce and social relationships. However, many people with disabilities are also uncomfortable with their reliance on technologies.

People with disabilities often want to be early adopters of new technologies, which may serve to increase independence and facilitate life outside the home, but people with disabilities often find the costs of new mainstream and specialized technologies prohibitive, and the design typically fails to account for the needs of people with disabilities (Harris, 2010). People with disabilities report a feeling of being continually left behind by new information technologies, due to the lack of accessible versions or training (Lupton and Seymour, 2000). Generally, people with disabilities find that information technologies can provide the means to more easily engage in social relationships, so long as the technologies have a "normalizing" rather than "stigmatizing" function (Lupton and Seymour, 2000). For example, people with visual impairments find that they are more accepted when using a guide dog rather than a cane, because the cane is a symbol of difference, but dogs, beloved as they generally are in society, are a symbol of commonality.

Given these unique relationships with technology in general and information technology in particular, to analyze the issues most effectively, it is necessary to isolate the needs of persons with disabilities in terms of accessibility. The focus on accessibility for persons with disabilities in particular also fits with the theoretical frame used in this book.

The Theoretical Approach of Information Worlds

Building on the information policy–based approach to disability and the Internet discussed in a previous section, the conceptual framework I use here is a theory constructed within the study of information policy. The theory of information worlds, which I codeveloped, is a conceptual framework for understanding the information behavior of specific populations within the broader social and policy context. This conceptual framework helps reveal the relationships between persons with disabilities and the Internet in two key ways. First, it illuminates the different levels of access to information and technology that are necessary for inclusion. Second, it demonstrates the ways in which access to the Internet—or lack thereof—shapes the information behavior of persons with disabilities at both the individual and broader social levels.

The theory of information worlds is designed to provide a framework through which the multiple interactions across information,

information behavior, and the many different social contexts within which it exists—from the individual to the social group to the society—can be understood and studied (Jaeger and Burnett, 2010). The theory posits that information behavior is shaped simultaneously by both immediate influences, such as friends, family, coworkers, and trusted information sources of the small worlds in which the individual lives, as well as larger social influences, including public sphere institutions, media, technology, and politics. These levels, though separate, do not function in isolation, and to ignore any level in examining information behavior results in an incomplete picture of the social contexts of the information. Explorations of information behavior need to account for the different levels if the social drivers of information behavior and the uses of information in society are to be fully understood. The theory of information worlds attempts to account for all of these social and structural elements at work in the shaping of information behavior within a society.

Levels of Access

A pillar of the theory of information worlds is that there are three levels of access to information and information technology: physical access, intellectual access, and social access (Burnett, Jaeger, and Thompson, 2008). Physical access is the most basic and familiar aspect in disability rights law—the ability to reach something, which in this case is information. Physical access to information is generally viewed as access to the document or other form embodying information, be it conveyed through print, electronic, verbal, or another means of communication—literally the process of getting to the information that is being sought (Svenonius, 2000). Most discourse on information access tends to focus on physical issues, such as the physical structures that contain information, the electronic structures that contain information, and the paths that are traveled to get to information (Jaeger and Bowman, 2005). While it is a necessary prerequisite, mere physical access is not sufficient for full access. "It is a common, but mistaken, assumption that access to technology equals access to information" (McCreadie and Rice, 1999, p. 51). The ability of a user to get to information and the ability of that user to employ information to accomplish particular goals are very different (Culnan, 1983, 1984, 1985).

The next level of access is intellectual access—the ability to understand the information. Intellectual access can be understood as

the accessing of the information itself after physical access has been obtained (Svenonius, 2000). Intellectual access to information "entails equal opportunity to understand intellectual content and pathways to that content" (Jaeger and Bowman, 2005, p. 68). Issues of intellectual access involve understanding how the information is presented to people seeking information, as well as the impact of such presentation on the process of information seeking; intellectual access to information includes the means through which the information is categorized, organized, displayed, and represented.

Social access is the most advanced level of access—the ability to communicate and use the information in social contexts (Burnett, Jaeger, and Thompson, 2008). Such social contexts can range from personal communication for entertainment purposes to educational and work settings to democratic participation. Gaining and understanding information without the ability to communicate that information prevents social engagement through the information. People also have a stronger sense of community and belonging in situations in which they can exchange information in social contexts (Johnson, 2010; Williamson and Roberts, 2010). Social access is now heavily dependent on information technologies for communication in many contexts. The social access depends both on an individual user's attitudes toward information technologies and on the ability of the user to employ information technologies to engage in social interactions.

Thus far, the focus on accessibility online in the United States and elsewhere has been almost exclusively on concerns of physical access. This focus on physical access carries through to both information and information technologies. As a result, even training materials to help developers create accessible information technologies reflect this strong bias toward physical access (Law, Jaeger, and McKay, 2010). For social equality to be achieved in access to information technologies, accessibility needs to place greater emphasis on achieving intellectual and social access to information and information technologies—Internet-enabled and beyond. This emphasis depends on a better understanding of information behavior in the online environment.

Information Behavior in Information Worlds

The theory of information worlds argues for the examination of information behavior in terms of the immediate social groups of everyday life, the mediating social institutions of the public sphere, and the context of an entire society (Burnett and Jaeger, 2008). Building on

previous developments of information theory, the social groups are known as small worlds, and the entire society is known as the life-world. These social structures constantly interact with and reshape one another, forming the ways in which individuals and groups interact with information and information technology. In examining these interrelated parts, the theory of information worlds focuses on five social elements:

- *Social norms:* a world's shared sense of the appropriateness of social appearances and observable behaviors.
- *Social types:* the roles that define actors and how they are perceived within a world.
- *Information value:* a world's shared sense of a scale of the importance of information.
- *Information behavior:* the full range of behaviors and activities related to information available to members of a world.
- *Boundaries:* the places at which small worlds come into contact with each other and across which communication and information exchange can—but may or may not—take place.

As with the social structures within small worlds, the elements are interrelated and constantly interact with and influence one another (Jaeger and Burnett, 2010).

As localized worlds of information, each small world has its own social norms, social types, information behavior, and understanding of information value. The members of each small world have established ways in which information is accessed, understood, and exchanged within their world and the degree to which it is shared with others outside the small world. Few individuals, however, exist in only one small world; it may not even be possible except in extreme circumstances of social isolation. In contrast, there is no real limit to the number of small worlds to which an individual can belong. A typical person is a part of many small worlds—for example, friends, family, coworkers, fellow students, people with shared hobbies, and people with similar disabilities.

Any one of these small worlds may offer many places where its members are able to interact with members of other small worlds. Information moves through the boundaries between worlds via people who are members of two worlds or through interaction between members of two small worlds in a place where members of different small worlds are exposed to other perspectives. Further, the contact

between small worlds and other inputs from the lifeworld can lead to the creation of new worlds as information passing over the boundaries between worlds either blurs those boundaries or otherwise transforms or changes information behaviors and perceptions of information value. Encountering other small worlds can occur through public sphere institutions, such as in a public library, or through new technological avenues of communication and exchange, such as social networks on the Internet. As information moves through boundaries between small worlds, the information is treated, understood, and used differently in each small world in line with the social norms of that world. As a result, the same information may have a different role within each small world.

Together, these small worlds constitute the lifeworld of information. The way that the small worlds as a group in the lifeworld treat information will shape how the information is treated within the lifeworld as a whole. As the information moves between small worlds, more and more small worlds will decide how to treat this information, generating an overall perception of the information across the lifeworld. The more small worlds that are exposed to information, the more exchange between small worlds there will be, and the better chances there will be for a democratic perception of and approach to the information.

However, beyond the small worlds, there are also influences at play in the lifeworld that shape the way that small worlds perceive information. Some of these influences increase contact between small worlds and promote democratic engagement in the lifeworld. Libraries, schools, and other public sphere organizations exist specifically to ensure that information continues to move between the small worlds and that members of each small world are exposed to other small worlds. In sharp contrast, other influences serve to constrain the movement of information between small worlds or constrict the socially acceptable perceptions of information. The most influential small worlds of information—such as those that possess political power or those that control the media—can use their power to push back against the collective small worlds to enforce a minority perception on the majority, asserting control over the information in the lifeworld.

Some influences on small worlds and the lifeworld are inherently neutral but can be used for the objectives of either increasing or decreasing information access. Information technologies act as a way for small worlds to connect in new ways and to reach other small worlds that would not otherwise touch their boundaries. The Internet and online social networks represent particularly powerful examples

of this phenomenon. But information technologies—like the Internet and more traditional media—can also work to homogenize perspectives or enforce hegemonic perspectives of small but powerful small worlds on the lifeworld. In total, the small worlds are shaped by all of these larger influences but also have the power collectively to define the parameters of the external influences.

For persons with disabilities, there are a multitude of small worlds at multiple levels of social organization. People with different types of disabilities, and different levels of severity of each disability, will likely have different information access needs, different information behavior, and different accessibility challenges. Each of these different groups, then, would be a small world, unified by the information and access issues. As such, people with no vision would be one small world, and a somewhat larger small world would be people with visual impairments. However, persons with disabilities as a whole are also an even larger small world, joined by broader information and access goals and challenges, heavily influenced by social perceptions of disability within the lifeworld of information.

In the subsequent examinations of online accessibility and the social impacts of the Internet on persons with disabilities, the information worlds framework will be of use in several ways. The three levels of access will help assess the emphases given to accessibility in the contexts of law, education, employment, commerce, communication, entertainment, and government on the Internet, as well as assess the ways in which accessibility could be improved. The framework for information behavior in information worlds will shape the discussion of the online social activities—education, employment, government, communication, entertainment, and commerce—of persons with disabilities and help to place them within the greater context of online activities. The levels of access will also inform analyses of policy related to the Internet and persons with disabilities. The framework for information behavior will additionally play a role in the considerations of identity, advocacy, and policy. The issues raised by the theory of information worlds will ultimately be considered in the discussions of accessibility policy and the future of accessibility.

Considering Disability and the Internet

Since the development of movable type, the evolution of the means by which information can be made available and accessed has moved

with increasing rapidity from books to newspapers to telegraph to telephone to radio to movies to television to the Internet. Yet, the dizzying technological changes of the twentieth century seem quaint in a new century that has already produced wireless computing, mobile Web-enabled devices, GPS-based navigation devices, social media and networking, e-book readers, and websites with hundreds of millions of users. By 2008, billions of people with Web access could visit tens of billions of Web pages, over 100 million of which were blogs (Golbeck, 2008). Google has made most of the Web searchable, while retail giants like Amazon sell virtually everything purchasable. Recent innovations in social media services such as Facebook, YouTube, and Twitter have created new levels of social interaction online. In 2010, Facebook had over 500 million users and Twitter had 200 million users posting 650 million messages a day, truly astounding numbers in a world of 6 billion people.

The promise of the Internet and its related technologies has been predicted in every corner of life, and many of these promises have already come to fruition to some extent. In an age where a message can crisscross the globe in a matter of seconds and all news is instant, it almost defies belief that the ability of the telegraph to share news across continents over a period of days was an undisputed wonder of its time (Hanson, 2008).

As with any new technology, the strongest proponents of the Internet have oversold its impact. It is unlikely that the Internet will ever lead to the elimination of poverty, 100 percent voter turnout, or a public fluent in the intricacies of all of the pressing issues of the day. But even the staunchest resisters of the influence of the Internet cannot escape the fact that education, employment, government, entertainment, communication, and socialization rely more and more on the Internet. Even many people who do not own home computers can still use the Internet constantly through their mobile devices.

Like most information technologies in human history, however, the Internet and its opportunities are not equally available to everyone. Factors of geography, socioeconomic status, literacy, and language can all affect how available the Internet really is. All of these factors are external to the Internet and its technologies. If the network is built, free access is universally provided, technology training is available, and content is produced in local languages, these barriers to access to the Internet can be made to disappear.

The barriers to Internet access related to disability, however, run much deeper. Inaccessible technologies and content—and accompa-

nying incompatibility with assistive technologies—are built directly into the Internet, creating enormous barriers to the Internet for many people with disabilities. Making the Internet accessible to persons with disabilities requires many significant adjustments to design, development, and implementation of Internet-related technologies and content. These barriers replicate the long-running barriers to all other aspects of society that people with disabilities have struggled against through time. "Perhaps the word that best describes the historical treatment of persons with disabilities is separation" (Switzer, 2003, p. 31). This description unfortunately remains true in the age of the Internet.

Equal access to the Internet—with its central role in communication, socialization, education, employment, government, and entertainment—is vital for equal participation in society. Advocates, researchers, and policymakers can try to promote equality of access through changes in civil rights laws that encourage or mandate the development of accessible technologies and content and that foster changes in social attitudes about people with disabilities. However, equal access to the primary technological means of disseminating, accessing, using, and exchanging information rises to the scale of a human rights issue when one group of people is at the center of the greatest exclusions.

Such exclusions are all the more pointed in light of the fact that the Internet has the potential to be the greatest mechanism for inclusion of people with disabilities ever invented. The ability to communicate and participate in activities in real time anywhere in the world without leaving home opens up enormous new avenues of participation for people with the entire range of physical, sensory, and cognitive disabilities. Physical barriers, transportation challenges, communication difficulties, and other major barriers to participation can be overcome through an accessible Internet and create wide new vistas for civic engagement, education, employment, and social interaction. These revolutions in the lives of people with disabilities, however, rely entirely on an accessible Internet. An inaccessible Internet is as threatening to persons with disabilities as an accessible Internet is exhilarating.

Throughout history, people with disabilities have usually had to wait for the accessible versions of technology to become available to catch up to the information access and other opportunities available to the rest of the population. Since the advent of the World Wide Web in the mid-1990s, this race to establish equal access to information and

communication technologies has grown increasingly untenable for persons with disabilities, as the introduction and evolution of technologies has accelerated to the point that most new technologies introduced are obsolete before they become accessible. If the Internet is to fulfill its promise of providing new levels of inclusion for people with disabilities, the barriers to equal access need to be eradicated. Otherwise, the opportunities for social inclusion that people with disabilities have fought so hard to win over the past half century will recede as participation in education, employment, government, and society as a whole become less possible due to technological barriers. The failure to address issues of accessibility for persons with physical, sensory, and cognitive disabilities ultimately threatens to segregate people with disabilities as the permanent second-class citizens of the information age.

An Individual Perspective

This book is of great personal importance to me not only as someone who has been a scholar of disability and information for a decade, but as an individual with a disability. My own personal experiences with the Internet are woven into the fabric of this text, given that I have had a significant visual impairment my entire life and my lifespan has neatly paralleled both the development of personal computers and the implementation of civil rights laws for persons with disabilities. I was born in the 1970s, the decade that saw the passage of the first substantial disability rights laws in the United States. Had I been born a decade earlier, I might not have been allowed to attend public school, as it was then common for schools to refuse to admit students with disabilities.

When I began school in the early 1980s, schools were still struggling with the implementation of the notion of equal—or at least vaguely equivalent—education for students with disabilities under the Individuals with Disabilities Education Act (IDEA). My experiences at different schools varied from being the only student with a disability in a class to being sent off on my own to learn at my own pace. My time in elementary school coincided with the period when personal computers began to widely appear in schools as educational tools. The first one I ever encountered was unusable for people like me, so it was hard to understand what everyone was so excited about. It was a while before these computers were accessible to most students with disabilities.

By the time I got to college, the Americans with Disabilities Act (ADA) was only several years old, so institutions of higher education were still fumbling toward the inclusion of students with disabilities. I found myself part of the struggle by students with disabilities to have these new civil rights enforced in terms of access to classrooms, course materials, activities, and dorms, as well as technology. Computers, at least, had become much more accessible, and the Internet—at that point, a text-based medium using simple and easy-to-memorize keyboard commands that could be made relatively accessible using optical character recognition (OCR) software and some other basic programs—was quite usable for me. Though, for people with other types of impairments, the early Internet was not as accessible; many people with mobility impairments, for example, were significantly disadvantaged due to the reliance on keyboard commands. The turning of the tide came soon after, with the explosion of the World Wide Web as the graphics-based environment that would soon utterly dominate the Internet. As the Internet became far more widely accessible, most people found it inviting and easy to use. Each new development, however, challenged my ability to use it. For years, I have wondered at the ways in which the Internet makes my life as a researcher and educator more powerful, but simultaneously have despised always feeling like a second-class citizen online.

These experiences spurred me to learn as much about disability and technology in different contexts and disciplines as I could, and I wound up with graduate degrees in law, information, education, and library science. Over the past ten years, I have written literally scores of books, articles, and book chapters about disability and technology. I now oversee a master's degree program devoted to making information and technology available to all. Yet, I still approach new versions of programs and software updates with trepidation, because that tiny, new update to some minor software program may negatively affect the functioning of the various accessibility programs and features on which I rely. And an update of a program or service means that the screen reader program I use may once again be trying to play catch-up to the changes. As a result, I feel pretty much shut out of new Web-enabled technologies when they are launched. Even the Web-enabled phone system on the campus where I work—which was installed while I was writing this book—is utterly inaccessible, being a touch screen product with a gray-scale screen the size of a credit card and completely lacking accessibility features.

I mention this personal perspective not only so that the reader knows where I am coming from as author, as such context is important, but also to emphasize the extent to which accessibility of the Internet is really a human issue. It involves technology, but it truly is a matter of civil rights, social inclusion, equality, and human dignity. Jonathan Young, chairman of the National Council on Disability, recently stated that people with disabilities "should participate fully in all aspects of our communities and have opportunities to take risks, to succeed, and—yes—to fail" (Young, 2010, p. 6). However, when it comes to new technologies, people with disabilities are usually relegated to fail as a result of inaccessible design. To build a system that potentially could benefit everyone but that constantly ignores the basic needs of persons with disabilities has tremendous ramifications for each person with a disability. As you read this book and consider the issues discussed herein, always keep in mind that these issues have very large and very real impacts on many, many people who could one day include some of your friends, members of your family, or even yourself. These issues are not just the concern of people who design and study technology. Issues of disability and the Internet matter to everyone.