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Persons with Cognitive Disabilities

Peter Blanck

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eQUALITY

Never before have the civil rights of people with disabilities aligned so well with developments in information and communications technology. The center of the technology revolution is the Internet's World Wide Web, which fosters unprecedented opportunities for engagement in democratic society. The Americans with Disabilities Act likewise is helping to ensure equal participation in society by people with disabilities. Globally, the Convention on the Rights of Persons with Disabilities further affirms that persons with disabilities are entitled to the full and equal enjoyment of fundamental personal freedoms. This book is about the lived struggle for disability rights, with a focus on web equality for people with cognitive disabilities, such as those with intellectual disabilities, autism, and print-related disabilities. The principles derived from the right to the web – freedom of speech and individual dignity – are bound to lead toward full and meaningful involvement in society for persons with cognitive and other disabilities.

Peter Blanck is University Professor at Syracuse University and Chairman of the Burton Blatt Institute (BBI). Blanck received a Juris Doctorate from Stanford University, where he was President of the *Stanford Law Review*, and a Ph.D. in social psychology from Harvard University. He is Chairman of the Global Universal Design Commission (GUDC) and President of Raising the Floor (RtF) USA. His books include *Genetic Discrimination – Transatlantic Perspectives on the Case for a European Level Legal Response* (with Quinn & de Paor, 2015); *Disability Civil Rights Law and Policy* (with Myhill, Siegal, & Waterstone, 2014); *People with Disabilities: Sidelined or Mainstreamed?* (with Schur & Kruse, 2013); *Legal Rights of Persons with Disabilities: An Analysis of Federal Law* (with Goldstein & Myhill, 2013); and *Race, Ethnicity, and Disability: Veterans and Benefits in Post-Civil War America* (with Logue, 2010).

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Advance Praise for *eQuality*

“We must do our best to invite people with cognitive disabilities to become an integral part of our digital world. It’s their right. It’s society’s gain. It’s the right thing to do. So, hooray for *eQuality*! And hooray for Peter Blanck’s high achievement in the publication of this path-breaking book.”

–David Braddock, Professor & Director of Coleman Institute for
Cognitive Disabilities, University of Colorado

“The 25th anniversary of the ADA is a fitting time for Professor Blanck to break wide open new territory in the civil rights struggle of persons with cognitive disabilities. *eQuality* is a must-read that will prove essential to scholars and practitioners concerned about web content equality for all people.”

–Michael Waterstone, Associate Dean & Professor of Law, Loyola Law School

“Ground-breaking achievement! In *eQuality*, Peter Blanck sets the stage for future advocacy of equal access to the information society.”

–Jutta Treviranus, Professor of Design, Director of Inclusive
Design Research Centre, OCAD University

“Jefferson wrote that freedom has to be secured from one generation to the next. The web allows this and future generations of persons with disabilities opportunities to open up worlds that were previously locked away. *eQuality* unlocks this potential and secures freedom into the 21st century – a virtual civic republic.”

–Gerard Quinn, Professor of Law, Director of the Centre for
Disability Law and Policy, NUI Galway Ireland

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Edited by Peter Blanck and Robin Paul Malloy

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eQuality

THE STRUGGLE FOR WEB ACCESSIBILITY BY
PERSONS WITH COGNITIVE DISABILITIES

PETER BLANCK, PH.D., J.D.

University Professor and Chairman
Burton Blatt Institute, Syracuse University

WITH A FOREWORD BY
DAVID BRADDOCK, PH.D.
University of Colorado



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*To my children – Jason, Daniel, Albert, and Caroline –
who show me all the possibilities for a better future.*

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Foreword

The Coleman Institute for Cognitive Disabilities at the University of Colorado is honored to have commissioned this important book project. Our support emanated from a dialogue between Professor Peter Blanck and me at the Institute's tenth annual national technology conference on October 20–22, 2010, in Boulder, Colorado. Thomas Gilhool, former Chief Counsel of the Public Interest Law Center of Philadelphia and Secretary of Education of Pennsylvania, was our distinguished keynote speaker that year. Tom is the legal champion who argued the seminal case in 1971 in federal court for the Pennsylvania Association for Retarded Children. More than any other, this case helped establish the rights of children and youth with disabilities to a public education in the United States. It furthered the momentum underpinning the federal government's groundbreaking legislation, Public Law 94–142, the Education for All Handicapped Children Act, subsequently termed the Individuals with Disabilities Education Act (IDEA).

I asked Tom to speak at our 2010 Coleman Institute Conference on the following topic: “Forty years after the 1971 *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* lawsuit articulated the right to education for children and youth with cognitive disabilities, is there an emerging right to online technology access for people with cognitive disabilities?” We all recognize that the World Wide Web is a ubiquitous, mainstream technology. Being able to access it is necessary for everyone to have equal opportunity to an appropriate education and to participate more fully in our society. But is the basic need for web technology access evolving as a legal right for people with significant cognitive disabilities such as intellectual disability and autism?

Using Tom Gilhool's thoughtful response as a starting point to address this profoundly important question, the Coleman Institute for Cognitive Disabilities subsequently engaged Professor Blanck and the Burton Blatt Institute at Syracuse University to continue the conversation. Specifically, we asked Dr. Blanck to address the following question from a legal perspective: “Do people with cognitive disabilities have a legal right to equal access to appropriate online content and services?”

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We intended Peter's inquiry to be predicated on the idea that the World Wide Web is an unprecedented global information resource for everyone. And we meant "everyone" in the most inclusive sense of the term – including people with the most significant cognitive disabilities.

Thus, we aspire for the World Wide Web to become a formidable social networking medium not only for the general population, as that's comparatively easy to achieve technically, but also for all members of society. Furthermore, our most important, more inclusive, and more challenging objective is to use the World Wide Web to promote health and wellness, and employment participation, for all persons in society – including in particular, those people with, I would argue, the most significant cognitive and physical disabilities. The moon shot by comparison was less transformational and less consequential for humankind.

With Coleman Institute financial support, Professor Blanck has taken some bold new steps for humankind. This book – *eQuality* – is the product of Peter's groundbreaking efforts. It is an extraordinary contribution. As explained by Professor Blanck in *eQuality*, the Coleman Institute convened a working group of leaders in the United States representing national associations and disciplines in cognitive disability, technology, policy, and web accessibility. Our group then crafted and endorsed a declaration of *The Rights of People with Cognitive Disabilities to Technology and Information Access*. The declaration, discussed in the last chapter of *eQuality*, was released at the 2013 Coleman Institute National Conference in Colorado and subsequently published that year by the American Association on Intellectual and Developmental Disabilities in their new electronic journal *Inclusion*.^[1]

The legal, research, and policy implications presented in *eQuality* border on revolutionary thinking. The book should be read not only by stakeholders in the cognitive disability field such as persons with cognitive disabilities and their families and advocates, but also by research and development leaders in universities and industry, web content developers, general policy makers, lawyers, legislators, and judges who purport to advance greater equity and inclusion for everyone in our society.

eQuality is indeed a book for all seasons. It's written for all of us (with its *eQuality* Pocket Usability end chapter) and it is relevant for all disciplines, ages, and levels of ability. This book helps us to understand and appreciate emerging opportunities through technology as we fragile humans inevitably encounter age-related decline ourselves – or watch our loved ones experience the same inglorious fate. What can we do about the inevitable? We can appreciate that the rights of people with cognitive disabilities to web technology and information access is relevant to all of us. There are no exceptions. In fact, as developed nations age across the world and their members live longer, we are witnessing an inexorable increase in the presence of people with cognitive disabilities, ranging from intellectual disability to autism and the dementias. The rights of such individuals have become increasingly visible

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David Braddock, Ph.D., is the Coleman-Turner Chair and Professor in Psychiatry, University of Colorado School of Medicine; Senior Associate Vice President of the University of Colorado; and Executive Director of the Coleman Institute for Cognitive Disabilities.

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Preface

ASSIGNMENT FROM DR. BRADDOCK

To prepare for the tenth annual Coleman Institute conference in 2010, at which I first presented the ideas in this book, I was given what seemed like a manageable assignment from Dr. David Braddock, Executive Director of the Institute. I should have known better. In his usual insightful and low-key manner, David asked if I would consider examining “the right under the Americans with Disabilities Act (ADA) to web access for people with cognitive disabilities.”

I am not sure if even now I fully grasp the challenge of David’s charge. I did not recognize when I started how many people were, and are now, spending countless hours parsing and studying each of the terms in this Act with the same questions in mind: if there is an equal “right” to online information, what is it and how may it be applied? How may it be used by people with cognitive and other disabilities? Against what standards is such a right to be measured, if at all? Who are people with cognitive disabilities for purposes of disability civil and human rights law and policy? Why, even at the 25th anniversary of the ADA, does this group remain among the most stigmatized in society?

If web equality may be realized, or for my purposes “web content equality,” how may it further economic, civic, and social participation by people with cognitive disabilities? Is it feasible to implement and enforce such a right involving online service content providers and their web developers and designers? Service is provided over the web through public and private enterprises that use hardware and software products and systems to provide functionality to web content; for instance, to offer governmental amenities, commercial services and goods, as well as social media, educational, entertainment, and gaming platforms. Providers use multimedia inputs (text, video, sound, images) across an array of computer desktop browsers and the portable computing power in mobile and tablet devices and their software applications.¹

These technologies, operating systems, and web applications vary in their degree of accessibility and usability for persons with different disabilities. They are part of the

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global information and communications technology (ICT) ecosystem, which is evolving and has many necessary layers that include hardware and software, operating and network systems, applications and assistive technologies (AT), application programming interfaces (APIs), and web browsers. These parts must work together to seamlessly support web equality in digital information to users with disabilities.² Even considering the complex and dynamic nature of ICT, the concept of the right to web equality from the perspective of users is further framed by developing legal, economic, and policy considerations and by advocacy domestically and transnationally.

I do not assume or conclude that litigation is the only, or even the preferred, way to advance web equality. In significant part, this book is not about litigation strategies or myriad ways to conform to technical and performance web standards, which are often aspirational rather than directive; instead, its more modest aim is to contribute to the belief that today the web is the principal way to spur individual and collective action in democracy and to foster those participatory rights of people with cognitive and other disabilities.

In the last forty years or so, there have been dramatic changes in the perceptions of disability, from primarily viewing it as a medical state to be cured and pitied toward acceptance of disability as an element of the human experience and self-identity. The modern understanding of disability is as much shaped by diversity in our biology, local culture, and self-identity over the life course as it is by the barriers to inclusion we build and maintain in society. This view reflects the paradigm shift from the prior and dominating medical model to a social and environmental approach to disability civil and human rights.

The groundbreaking legal cases involving the right to the web and discussed in this book – *Target*, *CNN*, *Netflix*, *Authors Guild*, among others – illustrate this changing perspective. Yet, as important as these efforts were, they are about to be followed by a challenging and complex wave of rights-based advocacy involving people with cognitive disabilities, again based on the modern social model of disability.^[5] This book examines the leading edge of that coming change: the fundamental right to online digital information. The focus is directed toward web content that is originally digital as well as information that is transformed (typically by digital scanning) from legacy print products, and then offered on the web.

The web, and its interactive and responsive design, is evolving at a fast pace, and is spawning an increasingly intricate system of compromises and trade-offs among technological advancement, privacy, and security. Although I examine web equality for people with cognitive disabilities, much needs to be said elsewhere about the technological and dynamic underpinnings and architecture of the web (Internet network design and development, software and hardware infrastructures, and product applications and life cycles) in interaction with human development, individual preferences, and learning across circumstances and time.

At the forefront of this analysis are disciplines in the fields of Human-Computer Interaction (HCI) and Artificial Intelligence (AI); the brain sciences of perception,

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cognition, emotion, and motivation; web infrastructure design, development, and distribution; and computer coding and markup languages. Multidisciplinary study is underway across cognitive, neurological, and rehabilitative sciences in the design of web interfaces and AT used by people with cognitive and other disabilities. These activities involve the study of web accessibility and usability by people with disabilities.

I cannot, and do not, address the countless contributions from these important areas; they each require careful study in their own right as well as their interrelations. However, repeatedly, the work in these fields is showing that web equality for individuals with cognitive disabilities is entirely possible and that digital and Internet technologies have reached a point where technical methods to provide web content equality are readily implemented. This book provides a framework to examine the right to web content equality, building on the growing understanding in these related fields and the increasing body of case law that interprets anti-discrimination laws such as the Americans with Disabilities Act. This multidisciplinary approach provides both a practical and principled understanding of how to approach web equality for people with cognitive disabilities.

While I was working on this book, Walter Isaacson's biography on the late Steve Jobs (former CEO of Apple, Inc.) was published. Although Apple products, as any other, have strengths and limitations, the company's mantra was always at the forefront – its products must be intuitively simple and easy to use. Jobs understood that the right combination of technology, usable web content, aesthetics, and function could result in an unprecedented appeal for entertainment and communications products, which Apple developed in its mobile devices. To reach everyone, Jobs believed that Apple products had to be capable of universal use.

Tim Berners-Lee understood the idea of intuitive and universal use when he invented the web in 1990. His dream from the start was that the web be trustworthy and transparent and that all may use it intuitively.[6, p. 159] Intuitive use, to Berners-Lee, was access to online knowledge to allow a diverse group of individuals to “‘come to a common understanding’ by achieving a sufficient set of consistent associations between words.”[6, p. 184] This common understanding approaching semantic universalism is increasingly derived from human and machine-supported communication using the Internet to interact with digital content.

Web content is a creation and derivation of computer code to convey text, sound, images, and human and virtual forms, across languages that are written, spoken, and gestural, including sign languages.³ Clayton Lewis has posited that electronic web content offers the opportunity to level the web's playing field for people with disabilities precisely because such computational representations may be transformed to meet individual needs.[10] Yet, Lewis acknowledges that even with technological advancement, society has been slow in moving concepts of universal use and web equality from theory to practice.

This book examines the assumptions underlying full and equal access by people with cognitive disabilities toward the common understanding of web content. It

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explores how web content equality is grounded in law and policy that may help people with cognitive disabilities to fully partake and flourish in the information age. This examination necessarily leads to queries such as what is the nature of web content in all its forms and adaptations and who owns, controls, and distributes it? These questions have arisen in the U.S. and other countries' domestic laws, as well as transnationally through international laws, agreements, and treaties. Such issues occupy a good portion of this book because an understanding of web content in context is needed to begin to articulate coherent law and policy concerning the full and equal enjoyment of the web by persons with cognitive and other disabilities.

To be able to fully and freely use web content within reasonable bounds is to be empowered to participate in society. This opportunity should not be denied by societal and technological barriers because of disability. Full participation may require the prospect for appropriate adjustments to web content to promote its accessibility and usability, for example, in terms of its reasonable ease of use and comprehensibility. Web content equality is the fighting chance for comparable enjoyment of all that digital information has to offer, for full and equal enjoyment of online services offered to the public. This ideal is separate from, but related to, concerns about those barriers created by the format and language in which that electronic information is conveyed.

Indeed, the vast potential of online digital content, as compared to non-digital print legacy materials, lies in that information need not be bound to a presentational format. This content flexibility, as we will see, turns pre-digital conceptions of content ownership (intellectual property in copyright law) on its head, which, as Laurence Helfer and Graeme Austin say, was to "protect the form in which ideas are presented, not the ideas themselves."⁴ The present challenge is to find an effective and fair balance between the rights of web content owners and distributors and the rights of disabled users to access and use web content fully and equally as compared to others. In later chapters, I contend that this perceived tension is dissipating with developing synergies in technology, the growing market for digital materials, evolving domestic and international law and policy in disability civil and human rights, and exceptions and limitations in copyright law as recently endorsed by the World Intellectual Property Organization's (WIPO) Marrakesh Treaty.

Unfortunately, some of the personal stories and legal cases examined in this book illustrate that online service providers and distributors often spend as much or more time, energy, and money defensively to keep people with disabilities limited in their access to web content, than they would by promoting proactive, inclusive web equality in ways that create value for their endeavors. Rather than enhancing their services and products, these defensive efforts too often lead to market inefficiencies from lost opportunities to reach diverse users, students, consumers, gamers, employees, and citizens.

These lost opportunities are costly, principally when shared web infrastructure and architecture are in place and there is a low rate of reaching additional underserved individuals. Nevertheless, the book provides examples where organizations

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have effectively maximized their market opportunities by proactive efforts to shift their attitudes and culture toward acceptance of the inclusive design of web goods and services resulting in diverse, engaged, and loyal consumers and users of their content.⁵ These organizations realize that access to their online information and services is increasingly valued by online users when they are able to personalize the format for delivery and presentation of that information.

Conceived in this manner, the principles of web content equality are as applicable to blind individuals who use screen readers to translate visual information as they are for deaf individuals who use caption text to convert audio information. For individuals with cognitive disabilities – intellectual and developmental disabilities, dyslexia, autism, TBI, and the print disabled – it is similarly essential to have access to easily used and comprehended digital information. Moreover, there are cross-disability synergies in web content equality to be considered and explored. Indeed, this overlap in who requires accessible web content is the untapped benefit to be derived from flexible, inclusive, and universally designed web technologies and applications that are available to persons with disabilities and to others who experience low literacy and limited digital literacy.

Like all individuals, people with cognitive disabilities seek the opportunity to use digital content on web-enabled devices; to purchase movies, games, and music; and to connect to their social and business networks. The denial of this opportunity because of an individual's disability is discrimination. Such inequality in accessing and using the web prevents people with cognitive and other disabilities from participating fully in the daily life experiences they seek to enjoy.⁶

This book is about the pursuit of web *eQuality* in our globally networked digital information society. At its best, the right to web content equality fosters self-determination, human fulfillment, meaningful inclusion in society, being heard, a sense of belonging, and empowerment to participate in one's community.

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Acknowledgments

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The Coleman Institute is leading a national dialogue about cognitive disability, web access and use, and the implications of cloud computing, which has been advanced at the Institute's events over the past several years. Visionaries such as William T. (Bill) Coleman III, an expert in cloud technology development and founder of the Coleman Institute, and computer science and accessibility leaders, Judy Brewer (Director of the Web Accessibility Initiative at the World Wide Web Consortium (W3C)), Clayton Lewis (University of Colorado), Gregg Vanderheiden (University of Wisconsin), and Jutta Treviranus (OCAD University, Toronto), have provided me with insightful and generous comments and support during the course of this project. Enid Ablowitz, Associate Director of the Coleman Institute, provided ongoing encouragement. They, like others, are examining web equality; that is, the opportunity for reasonably equivalent online access and use, and nondiscrimination in access and use of the web. Our collective goal has been to ensure that people with cognitive disabilities are considered in hardware and applications design, distribution, and support over the product life-cycle, governmental regulation of web design and distribution, and development of online content.

This project builds on the important prior work of many others from multiple disciplines and perspectives. My work benefited tremendously from my being at a university committed to "Scholarship in Action." Former Syracuse University Chancellor Nancy Cantor (now Chancellor of Rutgers University–Newark), Vice Chancellor Eric Spina, and former Vice Chancellor Debbie Freund (now President of Claremont Graduate University), led a vision for the university to pursue interdisciplinary study and exchange and collaboration with the local and broader

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other colleagues in Israel Dr. Chaia Aminadav, former Division Director for Services for Persons with Intellectual and Developmental Disabilities.

Over the years, I have had the pleasure of partnering with leading NGOs in Europe on projects on eAccessibility and Persons with Disabilities (including focus on persons with cognitive disabilities), in activities funded by the European Commission: I thank Technosite (Fundosa Technosite, Spain), Empirica (Germany), Tech4iz (United Kingdom), AbilityNet (United Kingdom), NOVA (Norway), and the Centre for Disability Law and Policy at the National University of Ireland School of Law. These activities included examination of eAccessibility in European Union (EU) Member States and other countries and best practices in legislation, accessibility standards, policies, and practices.

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The ideas in this book project were enriched by comments from colleagues at symposia and presentations I have made, including: "When God made a cripple he made him lonely": The Web, Disability, and an Inclusive World," Symposium on Including Disability: How Legal Discourse Can Shape Life's Transitions, at the University of California, Los Angeles (UCLA); "The Right to the Web for People with Cognitive Disabilities and Ownership of Web Content," Cherry Blossom Symposium on Intellectual Property and Federal Policy: Universal Access in the Digital Environment, American University Washington College of Law, Washington, D.C.; "The Right to Web Equality for People with Cognitive Disabilities," NIDRR Presents Series, National Institute for Disability Rehabilitation Research, Washington, D.C.; "Web Quality for People with Cognitive Disabilities," Irish National Disability

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This book is intended to be of interest to these many partners, including disability advocates, legal practitioners, academics, law students, policy makers, standards organizations, web-based service providers that are involved with commercial and public activities, and those in disciplines ranging from HCI and engineering to cognitive and brain sciences and organization behavior. It may be used as a text or casebook in upper-level law graduate and post-graduate classes.

All that said and done, this book project builds on the contributions of those thanked above and many others. I am certain that I have inadvertently omitted partners and friends, and for that I again apologize. The gaffs and opinions are my own, for others to clarify and correct.

This project developed over several years during which dynamic changes have occurred in technology, law, and policy, and I am sure that there is much to add and differentiate. Typically for me, in a project of this sort, after years of trying to be coherent, the book is completed, sent to the publisher, and thereafter are roughly five minutes of mixed satisfaction until the press of the next project deadline. Then, my 93-year-old mother buys the twelve copies sold.

My more serious hope is that this book will contribute in a modest way to dialogue about web equality for those with cognitive disabilities and many others.

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