

The Rights of People With Cognitive Disabilities to Technology and Information Access

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Abstract

Information and communication technologies are ubiquitous and valuable tools for billions of people worldwide today. Yet people with cognitive disabilities, particularly individuals with intellectual and developmental disabilities, have quite limited access to such technologies. This article presents the case for mounting significant efforts to advance the rights of millions of people with cognitive disabilities to technology and information access. A formal statement of these rights is presented, formulated by professionals and consumers representing a variety of disciplines and perspectives. The statement is currently endorsed by numerous national, state and local organizations in the developmental disabilities field in the United States. Your comments and participation are invited and appreciated.

The Rights of People With Cognitive Disabilities to Technology and Information Access

Cognitive disabilities include intellectual and developmental disabilities; autism spectrum disorders; severe, persistent mental illness; brain injury; stroke; Alzheimer's disease; and other dementias. An estimated 28.5 million Americans, more than nine percent of the U.S. population, had a cognitive disability in 2012. People with cognitive disabilities worldwide are believed to exceed 630 million individuals, according to recent World Health Organization estimates (2011).

The prevalence of people with cognitive disabilities living in developing nations substantially exceeds their presence in developed nations. This is primarily because the vast majority of the world's population resides in poor countries with limited access to medical care and educational opportunities. However, there is considerable cause for optimism.

Advances in technology and information science have positively impacted the potential for learning and information access for all people, including people with cognitive disabilities. As Eric Schmidt and Jared Cohen (2013) observed in their book, *The New Digital Age*:

Soon everyone on earth will be connected. With five billion more people set to join the virtual world, the boom in digital connectivity will bring gains in productivity, health, education, quality of life and myriad other avenues in the physical world—and this will be true for everyone, from the most elite users to those at the base of the economic pyramid (p.13).

People with cognitive disabilities comprise a very significant component of “the base of the economic pyramid” in all countries, not just in the developing world. Reducing barriers for people with cognitive disabilities who cannot readily access or utilize information and communication technologies without significant support therefore becomes an extremely important objective in the context of Schmidt and Cohen's prediction.

The pace of the digital age is expected to accelerate rapidly through new innovations in cloud computing, which lends itself exceedingly well to the development of customized, personal platforms to fit varied interests and competencies (Coleman, 2013). Highly individualized cloud computing platforms are expected to become formidable tools analogous to “utilities” fostering inclusion and promoting quality of life of people with cognitive disabilities. Areas of potential positive impact of cloud-based initiatives include not only improved personal communications, but

also health promotion, disease prevention, enhanced social interaction, and individualized supported employment opportunities such as remote job coaching.

A particularly provocative question must also be addressed about the future of over one billion people with disabilities worldwide, including those 630 million individuals with cognitive disabilities. How effectively, and how soon, can human-centered computational support technologies be adapted or uniquely developed and properly disseminated to match the unique needs and preferences of individuals with cognitive disabilities? People with cognitive disabilities, in fact, comprise over 60% of the world's total estimated population of people with disabilities. They also often present quite unique challenges for technologists developing personalized human-computer interfaces.

People with sensory disabilities and their advocates have promoted the benefits and adoption of technology and information access for their constituencies much more intensely and effectively than cognitive disability advocates and consumers. The diffusion of captioning online video content and screen readers are two recent examples of effective advocacy by sensory disability constituencies and subsequent responsiveness by industry. People with cognitive disabilities and their parents, friends, and professional support personnel, have not been nearly as effective as sensory disability constituencies in promoting access to personalized technologies and information to meet their unique access needs.

Writing in the inaugural issue of the journal, *Inclusion*, Gomez (2013), immediate past president of the American Association on Intellectual and Developmental Disabilities (AAIDD), drew attention to this point in stating that “focusing on friendship networks for people with (intellectual) disabilities represents a paradigm shift from skills development to social inclusion” (p.1). Thus, the key related question becomes how can greater attention to cognitive disability and technology be generated to promote diffusion of innovation in inclusion to enhance friendship networks, general social participation, employment, education, health and general communications?

One obvious objective is to stimulate greater attention nationally and worldwide to the possibilities now at hand for people with cognitive disabilities through technology while simultaneously championing their rights as citizens to

access such technologies in home, school and workplace. On October 21, 2010 at the University of Colorado's Coleman Institute for Cognitive Disabilities Tenth Annual National Conference on Cognitive Disability and Technology, the following question was posed by the lead author of this article and conference chair to one of the most respected civil rights attorneys in the history of our field, Thomas Gilhool. As Gilhool was introduced to a national audience from over 40 states, he was asked: “Forty years after *Pennsylvania Association of Retarded Children [PARC] v. Commonwealth of Pennsylvania*, is there an emerging right to technology and information access for people with cognitive disabilities, including intellectual and developmental disabilities?”

Gilhool, formerly chief counsel of the Public Interest Law Center of Philadelphia, Secretary of Education of the Commonwealth of Pennsylvania, and University of Southern California law professor, argued the seminal case in a Philadelphia Federal Court in 1971 that led to establishing the right to a public education for children with disabilities (*Pennsylvania Association for Retarded Children V. Commonwealth of Pennsylvania*, 1971), and ultimately led to the enactment by the federal government of the Education for All Handicapped Children's Act in 1975 and its successor legislation, The Individuals With Disabilities Education Act (IDEA) in 2004.

In a poignant response to the question about access to technology, Gilhool stated that he believed a right to technology access by people with cognitive disabilities was ascendant in the United States today—potentially enabling a future with far better access to appropriate education, community living and employment opportunities. He encouraged the 500 participants at our conference in Colorado that day to advance this issue with further thought and action.

The Coleman Institute subsequently engaged Gilhool and Syracuse University law professor Peter Blanck, head of the Burton Blatt Institute. We asked them both to explore the implications of existing legal precedents to the rights to education, habilitation and community living as those established rights might inform, and possibly encompass, evolving law and policy pertaining to inclusive technology and web access rights for individuals with cognitive disabilities. This research was commissioned by the Coleman Institute and will be published in book form by Cambridge University Press in 2014. British law

instructor Eliza Varney recently authored an important, complimentary international treatise published by Cambridge University Press as well. *Disability and Information Technology: A Comparative Study in Media Regulation* (2013) comparatively and meticulously examined information and communications technology (ICT) regulation across four international domains: Canada, European Union, United Kingdom, and the United States). In addressing the rationale for access to information and technology by people with disabilities, she stated that:

The regulatory approach for the ICT (Information and Technology) sector should perceive persons with disabilities not only as consumers but also as citizens with democratic expectations of effective access to information. Furthermore, the regulatory framework should be based on a clearly defined framework of principles such as equality of citizenship and the protection of human dignity (p.38).

We concur, and Ms. Varney will deliver a keynote address at the Coleman Institute Conference on Cognitive Disability and Technology on October 2, 2013 in Colorado.

To build on the groundwork already done towards documenting the rights of people with cognitive disabilities to technology and information access, in the fall of 2012, the Coleman Institute convened a group of leaders in the United States representing numerous national disability associations and disciplines in cognitive disability, computer science, technology, engineering, special education, disability studies, rehabilitation, psychology, philosophy, philanthropy, and law and public policy. Together we crafted and collectively endorsed *The Rights of People with Cognitive Disabilities to Technology and Information Access*, which appears at the end of this article along with a list of its authors and the initial organizational endorsers of that document*. This document is being officially released internationally through the new AAIDD journal, *Inclusion*, and at the Coleman Institute's October 2, 2013 conference in Colorado where approximately 500 attendees from over 40 states and abroad will have the opportunity to endorse it. Additional supporters may endorse the document online at the Coleman Institute's website (<http://www.colemaninstitute.org>)

The Rights of People with Cognitive Disabilities to Technology and Information Access is a statement of principles. It builds on the history of community

integration rights for people with intellectual and developmental disabilities established in law, policy and practice through decades of advocacy by parents, people with disabilities themselves, and conscientious professionals in the field (Syracuse University, 1979). Centuries of abuse, social isolation, prejudice and incomprehensible discrimination toward people with cognitive disabilities and their families are being addressed in our nation today, albeit at a painstakingly slow pace and unevenly across individual states, cities, communities and neighborhoods. In fact, advocacy by people with cognitive disabilities themselves and their siblings and parents, through organizations like *Self Advocates Becoming Empowered* and the *Sibling Leadership Network*, are playing larger roles in advancing the rights of people with cognitive disabilities today. And *The Arc of the United States*, sixty-one years after its initial formation, retains significant vitality and nationwide influence across virtually all states and in many local communities.

To date, these three advocacy organizations are among those who have officially endorsed our Statement. Other boards of directors of national organizations endorsing *The Rights of People with Cognitive Disabilities to Technology and Information Access* include those from the American Association on Intellectual and Developmental Disabilities (AAIDD), The American Network of Community Options and Resources, The Arc (United States), Beach Center on Disability at the University of Kansas, the Burton Blatt Institute at Syracuse University, the Coleman Colorado Foundation and Coleman Institute for Cognitive Disabilities at the University of Colorado, the Institute on Disability and Human Development at the University of Illinois at Chicago, the Kansas University Center on Developmental Disabilities, Self Advocates Becoming Empowered, and the Westchester Institute for Human Development, New York. AAIDD, it is noted, had the foresight to establish a Technology Special Interest Group (SIG) 15 years ago and continues today to define and lead key aspects of the field by creating and disseminating new knowledge about services and supports.

As signatories of the document presented herein, we are honored and grateful that leading organizations in the intellectual and developmental disabilities field are charter signatories of *The Rights of People with Cognitive Disabilities to Technology and Information Access*. Their collective

endorsements signal substantial momentum to advance the right to technology and information access and to act forthwith to implement those rights.

Inclusion and *choice* are indeed cornerstones of the disabilities field today. Their implementation in the United States, incomplete it may be, spans several decades of commitments to deinstitutionalization and community integration, implementation of the right to education nationally, promulgation and implementation of the Syracuse University Community Imperative (1979), and enactment and implementation of the Americans with Disabilities Act of 1990 and the Developmental Disabilities and Bill Of Rights Act of 1975. Inclusion and choice have also driven the self-

determination movement by people with developmental disabilities to new heights of independence and productivity (Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007).

Advancing the rights of people with cognitive disabilities to technology and information access is an extremely important next step in the worldwide implementation of inclusion and choice. Modern and developing societies are capable of moving more rapidly toward an inclusive future through the diffusion and application of information and communication technology supports. In this spirit, we present our statement of *The Rights of People with Cognitive Disabilities to Technology and Information Access*.

Figure 1

The Rights of People With Cognitive Disabilities to Technology and Information Access

WHEREAS:

Twenty-eight million United States citizens have cognitive disabilities such as intellectual disability; severe, persistent mental illness; brain injury; stroke; and neurodegenerative disorders such as Alzheimer's disease;

People with cognitive disabilities are entitled to inclusion in our democratic society under federal laws such as the Americans with Disabilities Act (ADA), the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and under state and local laws;

The disruptive convergence of computing and communication technologies has substantially altered how people acquire, utilize, and disseminate knowledge and information;

Access to comprehensible information and usable communication technologies is necessary for all people in our society, particularly for people with cognitive disabilities, to promote self-determination and to engage meaningfully in major aspects of life such as education, health promotion, employment, recreation, and civic participation;

The vast majority of people with cognitive disabilities have limited or no access to comprehensible information and usable communication technologies; People with cognitive disabilities must have access to commercially available devices and software that incorporate principles of universal design such as flexibility and ease of use for all;

Technology and information access by people with cognitive disabilities must be guided by standards and best-practices, such as personalization and compatibility across devices and platforms, and through the application of innovations including automated and predictive technologies; Security and privacy must be assured and managed to protect civil rights and personal dignity of people with cognitive disabilities;

Enhanced public and private funding is urgently required to allow people with cognitive disabilities to utilize technology and access information as a natural consequence of their rights to inclusion in our society;

Ensuring access to technology and information for the 28.5 million people with cognitive disabilities in the United States will create new markets and employment opportunities; decrease dependency on public services; reduce healthcare costs; and improve the independence, productivity, and quality of life of people with cognitive disabilities.

THEREFORE, BE IT RESOLVED THAT:

We the undersigned hereby affirm our commitment to equal rights of people with cognitive disabilities to technology and information access and we call for implementation of these rights with deliberate speed.

INITIAL ENDORSING ORGANIZATIONS

AbleLink Technologies

AbleLink Technologies was founded in 1997 specifically to address the significant need for research-based cognitive support technologies for individuals with cognitive disabilities and those experiencing cognitive decline. The team has been built purposefully with individuals representing relevant fields of expertise including human services, human factors, rehabilitation technology, software engineering, occupational therapy, and clinical and experimental psychology.

American Association on Intellectual and Developmental Disabilities

Since 1876, the American Association on Intellectual and Developmental Disabilities (AAIDD) has been providing worldwide leadership in the field of intellectual and developmental disabilities. AAIDD is the oldest and largest interdisciplinary organization of professionals and citizens concerned about intellectual and developmental disabilities in the world.

American Network of Community Options and Resources

The American Network of Community Options and Resources (ANCOR) is a national, nonprofit trade association representing more than 800 private community providers of services to people with disabilities. Combined, they serve over 400,000 individuals with disabilities and work to shape policy, share solutions, and strengthen community.

The Arc

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. They encompass all ages and all spectrums from autism, Down syndrome, Fragile X and various other developmental disabilities. With more than 140,000 members and more than 700 state and local chapters nationwide, they are on the front lines to ensure that people with intellectual and developmental disabilities and their families have the support they need to be members of the community. Founded in 1950, The Arc was comprised of a small group of concerned and passionate parents and community members who would be a catalyst for changing the public perception of children with disabilities. For the past 60 years, The Arc has continued to grow and evolve along with the changing needs and issues people with disabilities and their families face.

ASSET Consulting

ASSET Consulting (Applying Systems, Software, and Engineering Technology) helps organizations adopt, market, or develop emerging technologies. For over 20 years, ASSET Consulting has specialized in applications for long-term care and people with cognitive disabilities. Clientele include service providers, technology vendors, academic institutions, trade associations, and government agencies. The mission of ASSET Consulting is to advance the effective use of emerging technology in service of social needs.

Assistive Technology Partners, University of Colorado

Assistive Technology Partners was established in 1989 and is part of the Department of Physical Medicine and Rehabilitation, School of Medicine, University of Colorado. It encompasses programs in four major areas: clinical services, outreach and information services, research and engineering, education and professional development. Assistive Technology Partners provides a unique integration of capabilities and services for persons with disabilities and associated professional affiliations.

Beach Center on Disability, University of Kansas

The Beach Center on Disability is a multi-disciplinary research and training center committed to making a significant and sustainable positive difference in the quality of life of individuals and families affected by disability and the professionals who support them. Its staff of approximately 40 professors, researchers, educators, doctoral students, and support personnel carry out research, technical assistance, and undergraduate, masters, and doctoral training. Its staff focuses on families, family quality of life, and family support; public policy in special education and disability services; school reform, with emphasis on inclusion of students with and without disabilities in general education; conceptualizing self-determination and its application to people with disabilities; conceptualizing and defining intellectual disability; defining

and measuring supports and support needs; technology use by people with cognitive disability; and positive behavioral supports and services.

Burton Blatt Institute, Syracuse University

The Burton Blatt Institute (BBI) at Syracuse University reaches around the globe in its efforts to advance the civic, economic, and social participation of people with disabilities. BBI builds on the legacy of Burton Blatt, former dean of Syracuse University's School of Education and a pioneering disability rights scholar, to better the lives of people with disabilities. BBI has offices in Syracuse, Washington, D.C., and Atlanta. Given the strong ties between one's ability to earn income and fully participate in their communities, BBI's work focuses on two interconnected Innovation Areas: Economic Participation and Community Participation. Through program development, research, and public policy guidance in these Innovation Areas, BBI advances the full inclusion of people with disabilities.

Coleman Colorado Foundation

The Coleman Colorado Foundation (CCF) supports the Coleman Institute for Cognitive Disabilities' activities through a private endowment and sustained annual contributions by the founding donors, William T. and Claudia L. Coleman. The CCF is a 501 (c) (3) public charity classified as a 509 (a) (3) supporting organization to the University of Colorado.

Coleman Institute for Cognitive Disabilities, University of Colorado

The Coleman Institute for Cognitive Disabilities' mission is to catalyze and integrate advances in science, engineering, and technology to promote the quality of life and independent living of people with cognitive disabilities. The Coleman Institute for Cognitive Disabilities was established in 2001 by the Regents of the University of Colorado. A private endowment and sustained annual contributions by their founding donors, William T. and Claudia L. Coleman, support the Institute's activities through the Coleman Colorado Foundation (CCF).

Imagine!

Imagine! was established in 1963 as a private, not-for-profit organization and as the first community-centered board (CCB) in Colorado. In addition to serving as a state CCB, Imagine! provides services designed to incorporate people with developmental, cognitive and physical challenges into the fabric of their communities. Services include educational and therapeutic services, job training and placement, recreation and leisure activities, opportunities for community living, behavioral health services, technology solutions and support for families.

Institute for Matching Person and Technology

The Institute for Matching Person and Technology was formed to better match users of technologies with the most appropriate devices for their use. The Institute works to enhance the situation of technology users through research, assessment, training and consultation. The Matching Person and Technology (MPT) assessment process is one means for providing a more personal approach to matching person and technology.

Institute on Disability and Human Development, University of Illinois at Chicago

The Institute on Disability and Human Development (IDHD), a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) is dedicated to promoting the independence, productivity and inclusion of people with disabilities into all aspects of society. The mission is addressed by conducting research and disseminating information about disability to academicians, policymakers, businesses, government agencies, service providers and the general public. The IDHD also provides an extensive array of clinical and community service activities and, through the Department of Disability and Human Development and other academic departments, offers interdisciplinary pre-service training. The values of cultural diversity, consumer choice and self-determination are emphasized across the life span in all training, public service, and research activities of the IDHD.

Kansas University Center on Developmental Disabilities

The Kansas University Center on Developmental Disabilities (KUCDD), established in 1969, is a component of the Life Span Institute at the University of Kansas. The KUCDD maintains facilities on the University's main campus in Lawrence, at the KU Medical Center in Kansas City, and in Parsons. In addition to these primary sites, the KUCDD supports affiliated projects in many Kansas communities and provides training and other types of support to all regions of the state. As a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities, the

core functions of the KUCDD are: pre-service training, research, information dissemination, and community services.

The National Center on Disability and Access to Education

The National Center on Disability and Access to Education (NCDAE) exists to address issues of technology and disability in education policies and practices to enhance the lives of people with disabilities and their families. NCDAE works on policy, research, training and technical assistance, and dissemination of information. NCDAE accomplishes its purpose through an affiliate network of over 500 national and international partners in education, business and industry, and government.

Self Advocates Becoming Empowered

Self Advocates Becoming Empowered (SABE) is the self-advocacy organization for people with developmental disabilities in the United States. It consists of local, state, and national components. Founded in 1990, the organization promotes the full inclusion of people with developmental disabilities in the community throughout the 50 states. Their non-profit advocacy organization is run by a board of self-advocates representing 9 regions of the country.

Sibling Leadership Network

The Sibling Leadership Network's (SLN) mission is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. The Network promotes a broad network of siblings nationally who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the lifespan. This enables them to be effective advocates with their brothers and sisters, and to serve as change agents for themselves and their families.

Westchester Institute for Human Development

Westchester Institute for Human Development is a leader in addressing major social and health issues affecting people with disabilities and vulnerable children. WIHD addresses major social and health issues by developing and delivering medical, clinical and support services to individuals, their families and caregivers. As one of only 67 University Centers for Excellence in Developmental Disabilities, WIHD creates better futures for these individuals through the creation and dissemination of innovative research, professional leadership education and best practices trainings.

***Acknowledgement of co-authors of the Statement on The Rights of People With Cognitive Disabilities to Technology and Information Access:**

Twenty-four people participated in the Coleman Institute Preconference Workshop on Cognitive Disability and Technology. The event was held in Broomfield, Colorado on November 16, 2012. Discussion at that event centered on the merit, content and dissemination strategy of a formal statement to advance the development, access and utilization of technology by people with cognitive disabilities in the United States. A formal statement was collectively drafted and revised over the course of the following year. That Statement appears as Figure 1 of this article as *The Rights of People With Cognitive Disabilities to Technology and Information Access*.

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