

# Leveraging Technology in Support of People with Intellectual and Developmental Disabilities

Amy S. Goldman 23 March 2017

## Summary:

This article defines and distinguishes assistive technology, mainstream technology, the “Internet of Things” and information and communication technologies. These technologies and trends have immense potential to improve the lives of people with intellectual and developmental disabilities. At the same time, they present new challenges in terms of data security, privacy, choice and informed consent, as well as the need to overcome policy barriers in funding.

It is certain that technology is transforming life in the modern world: from the Internet of Things (IoT) to 3D printers, from autonomous vehicles (AVs) to smart homes, there are wonderful things happening to help all people live more productive, safer, healthier, and satisfying lives. In their volume, *The Open Book of Social Innovating*, Robin Murray et al. defined social innovation as “new ideas (products, services and models) that simultaneously meet social needs and create new social relationships or

collaborations. These innovations are considered both good for society and capable of enacting greater societal involvement in the provision of social services.”<sup>1</sup>

Technology, defined as an activity that forms or changes culture, offers opportunities as well as challenges in the provision of supports and services to people with intellectual and developmental disabilities (I/DD). In amending the Assistive Technology Act of 1998 (the Assistive Technology Act of 2004, Public Law 108–364), Congress found “(3) Technology is one of the primary engines for economic activity, education, and innovation in the Nation, and throughout the world” and “(4) As technology has come to play an increasingly important role in the lives of all persons in the United States, in the conduct of business, in the functioning of government, in the fostering of communication, in the conduct of commerce, and in the provision of education, its impact upon the lives of individuals with disabilities in the United States has been comparable to its impact upon the remainder of the citizens of the United States.”

## **What is technology?**

British science fiction writer Arthur C. Clarke remarked, “any sufficiently advanced technology is indistinguishable from magic,” and those of us who are not “digital natives” marvel at our access to inventions that were once the stuff of Jules Verne or the Jetsons. What do we mean by technology? Merriam Webster defines technology as the

practical application of knowledge.<sup>2</sup> The President's Committee on People with Intellectual Disabilities (PCPID) expanded on this definition in the context of people with disabilities, and in its 2015 report to the President defined technology as "the use of advances in science to support people and society, to reduce barriers and to make the everyday world more accessible."<sup>3</sup> Technology can provide and improve access to education, community living, employment, and health. Technology can be key to communication, self-determination, increased independence, and improved satisfaction with and quality of life.

## **What is assistive technology?**

The Technology-Related Assistance for Individuals with Disabilities Act (the "Tech Act," 1988) provided a definition of technology used by people with disabilities, coining the term "assistive technology" (AT). As it is defined in the current AT Act, an AT device is "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." In that sense, it is a "relative" definition; an item is or is not AT depending upon who uses it (a person with a disability) and for what purpose (to increase, maintain, or improve functional capabilities). Thus, an "app" calendar and reminder system is AT for a person with a memory/cognitive impairment, but is not AT

for a person with a mobility disability (unless s/he also has a cognitive impairment). Wisely, the federal definition also includes AT services, recognizing that without supports in selecting, acquiring, or using an AT device, the item may be an expensive doorstop or paperweight.

## **What is “mainstream technology”?**

Assistive technology is sometimes used synonymously with the terms rehabilitation technology or adaptive devices. However, the latter imply a special purpose item, specifically designed for persons with disabilities, whereas “AT” can be literally any item, regardless of whether it is specialized, “generic” expensive, low-tech, high tech, do-it-yourself, mass-marketed, customized or uniquely designed and fabricated. The PCPID report contrasts “special” devices with mainstream technologies, e.g., “technology intended for general use rather than for use entirely or primarily by people with disabilities.”<sup>3</sup> In a prescient statement in the AT Act findings, Congress recognized that “Any development in mainstream technology will have profound implications for individuals with disabilities.”

The good news about mainstream technologies is the size of the market. This means the R&D costs are spread over millions of units sold, and the price goes down accordingly. The devices, and often the maintenance and repair services, are widely available, from Internet retailers to “bigbox” stores. YouTube is replete with videos on how

to install, program, and use the products. Consumer reviews are easy to find, through sites like engadget.com, techradar.com, and Amazon. The advent of smart phones and tablets and “apps” is a primary example of mainstream advances that created a paradigm shift in the world of assistive technology, from a dependence on devices built for use only by persons with disabilities to adaptations and applications of mainstream—and less expensive—alternatives.

## **The Internet of Things**

The Internet transformed technology. In 1985, Peter T. Lewis described the concept of a network of physical objects embedded with electronics, software, sensors, and network connectivity that enables these objects to collect and exchange data, and coined the term “the Internet of Things.” The Global Standards Initiative on the Internet of Things defined the IoT as “the infrastructure of the information society.”<sup>4</sup> This integration of the physical world with computer networks results in improved efficiency, accuracy, and reduced need for human intervention. IoT systems have the potential to track, exchange, and act on data. The mainstream marketplace includes smart home components and appliances (e.g., Nest Learning Thermostat, August Smart Lock, Phillips Hue light bulbs). They include networks of sensors that can do everything from (remotely) reporting the number of times a senior with dementia has used the bathroom,

measuring pressure and adjusting support in hospital beds without a nurse or other personnel, to conveying items needed to a shopping list “app” based on refrigerator contents.

For some people with disabilities, these connected technologies have the potential to replace specially designed AT, and at a lower cost. However, when it comes to acquiring mainstream devices that are going to be used as “assistive technology,” the funding picture becomes problematic. Most sources of payment for assistive technology come from health care insurers, both public and private, where the AT device is in a covered benefit category such as durable medical equipment (DME), prosthetics or orthotics. These require a connection to “medical necessity,” including a prescription by a physician and, in the case of DME, meeting the criteria of “medical in nature”—not otherwise useful in the absence of injury. Mainstream technology will fail to meet the last criterion.

Another challenge with IoT is the “I.” All too often, people with disabilities remain on the “have not” side of the “digital divide.” Lower income may make the monthly bill for Internet beyond their reach, although basic plans may be available through some providers to income-qualifying seniors or others (e.g., with low-income families with children). IoT devices for home automation may require speed and amounts of gigabytes beyond those plans. In addition, according to the National Telecommunications

and Information Agency, rural areas still face challenges in terms of availability of broadband.<sup>5</sup> Even where there is sufficient access, the greater the dependency on the Internet for basics such as heat (e.g., a functioning thermostat), lights, and access to the home (e.g., automated locks), the more urgent reliability becomes. Public programs that may pay for mainstream devices (especially when they are the least costly option compared to specialized AT), rarely pay for the recurring charges for the services to support the devices.

As recent headlines have revealed, control of Internet-enabled devices presents unique concerns related to security and privacy of personal data. Laptops with integrated cameras can record video even when they are off; televisions are transmitting, not just receiving. Amazon is learning about you from your purchases, and providing data to others. It is critical that, as per the recommendations of the Federal Trade Commission (2015), consumer protections in regulation include data security, data consent, and data minimization (the collection of only needed data and the retention of such data for only a limited period of time).<sup>6</sup>

One area of increasing interest to providers of services to people with I/DD is Personal Support Technology (PST). The PCPID defined PST as "an electronic monitoring device or system that supports individuals with I/DD to be independent in the community or their place of residence with limited assistance or supervision by paid staff." 3

Such technologies have been shown to save money as well as trips to the emergency room, for example, when psychiatric intervention can be effectively provided via telemedicine. Here again, security, privacy, and informed consent are important considerations.

## **What is ICT?**

ICT (information and communications technology; sometimes communication(s) and sometimes technolog(ies)) is an umbrella term that includes any communication device or application, and includes radio, television, cellular phones, computer and network hardware and software, and satellite systems, as well as the various services and applications associated with them, such as videoconferencing and distance learning. ICTs are often spoken of in a particular context, such as ICTs in education or in economic development. ICT has been transformative in advancing communication to create global "communities."

Access to communication is a basic human right, key to self-determination and participation in society. Beyond this general right, specific communication rights that should be ensured in all daily interactions and interventions involving persons who have severe disabilities are articulated in the Communication Bill of Rights developed by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities.<sup>7</sup> Actualizing these rights may in fact depend

on technology devices and services.

The Coleman Institute for Cognitive Disabilities broadened the concept of communication in its treatise, "The Rights of People with Cognitive Disabilities to Technology and Communication Access."<sup>8</sup> Similarly, in its 2016 report, the National Council on Disability called on Congress to establish a Technology Bill of Rights "that identifies principles to be used for any future technology legislation and clarifies that the current landscape of laws, regulations, and Executive Orders establishes a right to accessible and inclusive technology and ensures equal and fair access for Americans with disabilities to existing and emerging technology and related services."<sup>9</sup>

## **Universal Design and "Cognitive Design"**

Central to these rights is insuring access to ICT through universal design (UD) of all technology products and services, assuring comprehensible information and interoperability as well as security and privacy. Universal design means that products and services (in the physical as well as virtual/electronic environments) are constructed in a way that is usable by as many people as possible, regardless of their characteristics. UD principles include equitable use, flexibility in use, simple and intuitive use, perceptible information, and tolerance for error.<sup>10</sup> While great strides have been made in terms of the "built environment," there are still concerns about accessibility to mainstream technology products and services,

including the Internet. The PCPID suggests that a subset of UD considerations specifically focus on mainstream technologies for people with ID/D, and that “cognitive design” require participation of people with ID in the development of new technologies and systems.<sup>3</sup>

## **Conclusion**

Technological developments will continue to offer opportunities and challenges for people with disabilities, especially for the 28 million U.S. citizens with cognitive disabilities.<sup>8</sup> The potential of technology to enhance the lives of people with disabilities will need to include consideration of accessibility and usability in design and development, consumer protection and consumer choice, and resolution of policy barriers to funding.

## **References**

1. Robin Murray, Julie Caulier-Grice, and Geoff Mulgan, “The Open Book of Social Innovating,” The Young Foundation (March 2010), accessed March 20, 2017, <http://youngfoundation.org/wp-content/uploads/2012/10/The-Open-Book-of-Social-Innovationg.pdf>.
2. Definition of Technology, Merriam-Webster, accessed March 20, 2017, <https://www.merriam-webster.com/dictionary/technology>.

3. "Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities," President's Committee for People with Intellectual Disabilities, accessed March 7, 2017, <https://acl.gov/programs/aidd/Programs/PCPID/docs/PCPID-2015-Report-to-President.pdf>.

4. "Internet of Things Global Standards Initiative," ITU, accessed March 20, 2017, <http://www.itu.int/en/ITU-T/gsi/iot/Pages/default.aspx>.

5. National Telecommunications and Information Administration, accessed March 20, 2017, <https://www.ntia.doc.gov/>.

6. "FTC Report on Internet of Things Urges Companies to Adopt Best Practices to Address Consumer Privacy and Security Risks," Federal Trade Commission (January 27, 2015), accessed March 20, 2017, <https://www.ftc.gov/news-events/press-releases/2015/01/ftc-report-internet-things-urges-companies-adopt-best-practices>.

7. Nancy C. Brady, Susan Bruce, Amy Goldman, Karen Erickson, Beth Mineo, Billy T. Ogletree, Diane Paul, Mary Ann Ronski, Rose Sevcik, Ellin Siegel, Judith Schoonover, Martha Snell, Lorraine Sylvester and Krista Wilkinson, "Communication Services and Supports for Individuals with Severe Disabilities: Guidance for Assessment and Intervention, American Journal on Intellectual and

Developmental Disabilities 121 (2016): 121-138.

8. "The Rights of People with Cognitive Disabilities to Technology and Communication Access," Coleman Institute for Cognitive Disabilities, accessed March 20, 2017, [www.colemaninstitute.org/declaration](http://www.colemaninstitute.org/declaration).

9. Progress Reports, National Council on Disability, accessed March 20, 2017, [http://www.ncd.gov/progress\\_reports](http://www.ncd.gov/progress_reports).

10. Center for Universal Design, accessed March 20, 2017, <https://www.ncsu.edu/ncsu/design/cud/>.

## **About the Author**

**Amy S. Goldman, MS, CCC is technical assistance specialist for the Eastern US with the national Assistive Technology Act Technical Assistance and Training Center (AT3). She recently retired from her position as Co-Executive Director of the Institute on Disabilities at Temple University, PA's University Center of Excellence in Developmental Disabilities where she directed local, state, and federal projects related to assistive technology (AT). Amy has specialized in augmentative and alternative communication (AAC) services, pre- and in-service training about AT and AAC, and has been a vigorous advocate for people with complex communication needs throughout her long career as a speech-language pathologist. She is past chair of the steering**

**committee of the American Speech-Language-Hearing Association's (ASHA) Special Interest Group on AAC and represents ASHA on the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC).**