

## Report to the President

Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities

Concern for man himself and his fate must always constitute the chief objective of all technological endeavors...in order that the creations of our minds shall be a blessing and not a curse to mankind.

Albert Einstein
"Science and Happiness"
The California Institute of Technology
February 16, 1931

#### **DISCLAIMER**

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Although some of the information and data contained in this Report were contributed by authorities in the fields of emerging technology, disability research, education, public policy and other related fields, the personal opinions that such contributors may hold or choose to express outside of this Report to the President do not necessarily reflect the views of the President's Committee for People with Intellectual Disabilities (PCPID), HHS, or other federal agencies.

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### **COMMITTEE PROFILE**

Americans with intellectual disabilities (ID) experience significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.<sup>1</sup>

Intellectual disability and developmental disability (DD) are not the same thing. DD is an umbrella term that includes ID but also includes other disabilities that are apparent during childhood, like physical, motor, neurological, psychological, or sensory disabilities. High quality, inclusive services and supports (including natural, unpaid supports) in education, health, employment, family support and other areas often assist people with ID and DD to live full lives in their communities.

A portion of research studies in the United States (U.S.) has focused on the prevalence of intellectual disability and the numbers of people affected. However, the findings of these research studies are not consistent. Estimates range from one to three percent, or from three million to nine million people (B. Bryant, Seok, Ok, & D. Bryant, 2012).

In 1961, President John F. Kennedy called the nation's attention to deplorable living conditions in institutions and limited opportunities for people with ID in communities across the U.S. To ensure the right of a "decent, dignified place in society" for people with ID, President Lyndon B. Johnson established the President's Committee on Mental Retardation in 1966. To underscore the importance of respect and facilitate the removal of negative labeling, the Committee was renamed on April 25, 2003, as the President's Committee for People with Intellectual Disabilities (PCPID).

PCPID serves in an advisory capacity to the President of the United States of America and the Secretary of Health and Human Services on matters relating to individuals with ID. The Committee upholds the right of all people with ID to enjoy a quality of life that

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<sup>&</sup>lt;sup>1</sup> As defined by American Association on Intellectual and Developmental Disabilities (AAIDD), http://aaidd.org/intellectual-disability/definition#

promotes independence, self-determination, and full participation as productive members of society. Executive Order 12994, as amended by Executive Order 13446, stipulates that the Committee shall provide advice to the President concerning the following: expansion of educational opportunities; promotion of homeownership; assurance of workplace integration; improvement of transportation options; expansion of full access to community living; and—the focus of this Report—increased access to technology.

The Committee currently consists of 18 citizen members appointed by the President, including a Chair who is responsible for planning the PCPID strategic direction, and 13 *ex officio* (federal government) members designated by the President. The 13 *ex officio* members are the Secretary of Health and Human Services, Secretary of Education, Secretary of Labor, Secretary of Housing and Urban Development, Secretary of Commerce, Secretary of Transportation, Secretary of the Interior, Secretary of Homeland Security, the Attorney General of the United States, the CEO of the Corporation for National and Community Service, Chair of the Equal Employment Opportunity Commission, Chair of the National Council on Disability, and Commissioner of the Social Security Administration.

PCPID is led by the Commissioner of the Administration on Disabilities (AoD), who also serves as the Committee's Designated Federal Officer, and supported by federal employees. Within the AoD, the Administration on Intellectual and Developmental Disabilities (AIDD) is the federal agency responsible for implementation and administration of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Organizationally, AoD is located within the Administration for Community Living at the U.S. Department of Health and Human Services.

#### **EXECUTIVE SUMMARY**

The President's Committee for People with Intellectual Disabilities is honored to advise the President and the Secretary of Health and Human Services about the role of technology in improving the quality of life for people with ID and ensuring their full citizenship rights. A new generation of technologies continues to redefine, at an accelerated pace, how we all live, grow, and excel. The same should be true for people with ID. Access to technology is critical for people with ID to fully engage in the everyday life of our society.

Interacting with technology should no longer be considered optional. Participating in education, communicating with friends and family, having access to various forms of transportation, working in competitive employment, and performing activities of daily living, such as cooking or washing clothes, all typically require the use of keypads, touch screens, and other forms of interface with displays and controls. The U.S. Department of Commerce (2011) reports that 96% of working Americans use new information and communications technologies as part of their daily life, while 62% of working Americans use the Internet as an integral part of their jobs.

People with ID are entitled to inclusion in their communities under current federal laws, including the Americans with Disabilities Act (ADA) of 1990, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000, the Individuals with Disabilities Education Act (IDEA) of 2004, Section 504 of the Rehabilitation Act of 1973, as amended, and under state and local laws. Access to technology is essential for people with ID to promote self-determination and to engage meaningfully in their communities in all major aspects of life such as education, employment, health care and healthy living, recreation, and civic participation.

New technologies have created opportunities and higher expectations for people with disabilities, including people with intellectual and developmental disabilities (I/DD).

However, mainstream technologies<sup>2</sup> are not often enough designed with the needs of individuals with ID in mind. Thus, they can create – rather than remove – significant obstacles to independent participation in life activities and communities. Many of these obstacles can be overcome when cognitive accessibility (as defined in the <u>Cognitive</u> <u>Support Technologies</u>) is considered during the design and implementation of new technologies.

The goal of the PCPID 2015 Report to the President is two-fold:

- To increase the cognitive accessibility of technology that is part of the fabric of everyday lives and strengthen federal policies to ensure that people with ID have equal access to everyday technology, and
- 2. To increase the availability, quality, and affordability of cognitive support technologies through policies, practices, development, and research.

This Report was developed by PCPID members, who have substantial expertise in the field of I/DD, for the consideration of the President. In addition to <u>several overarching recommendations</u>, it identifies specific <u>federal policy recommendations</u> that the Committee believes will help improve access to, and the design of, technology used by people with ID in four focus areas:

- 1. Elementary, Secondary, and Post-Secondary Education
- 2. Community Living
- 3. Employment and Economic Well-Being
- 4. Health and Wellness

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<sup>&</sup>lt;sup>2</sup> The term mainstream technology has no statutory definition or precise technical meaning. As the term is used here, it refers to any technology that is intended for general use rather than for use entirely or primarily by people with disabilities.

### INTRODUCTION AND KEY RECOMMENDATIONS

The U.S. Constitution starts with the words "We the people," and attached to it is a Bill of Rights, which sets out individual liberties and states that Americans have equal treatment under the law. The Rehabilitation Act of 1973, as amended, reminds us that disability is a natural part of human experience and in no way diminishes the rights of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in American society. It also states that the goals of the nation properly include the goal of providing individuals with disabilities the tools they need to do each of these.

Now more than ever, technology is a crucial tool that supports people with ID to experience the benefits of full citizenship and have greater control over their own lives. Appropriate and accessible technologies can enhance communication, daily activities and independence, education, and competitive employment opportunities. Technology can also make it possible for people with ID to participate in and contribute more fully to activities in their homes, schools, work environments, and communities. It can assist them in having more transportation options to accomplish all these things, and, in doing so, it can improve how individuals with ID interact with the greater community.

Historically, the emphasis on technology for people with disabilities, including people with ID, has been specialized, stand-alone assistive technology (AT) devices. These devices were often paid for by federal programs and designed specifically for one person. This is changing. Today people with ID are using and benefiting from mainstream technologies, including mobile technology such as smartphones and tablet devices as well as universally designed technologies, that may have specific applications ("apps") for use by people with ID. In addition, software systems are becoming more adaptable and personalized. Further, mobile and easy-to-use technologies are more affordable than specialized AT devices, so they have significant potential for assisting individuals with ID.

Individuals with ID should have an equal right to "fair access" to information and communication technologies. Fair access means that people with ID should have access to smartphones, tablet devices, and web access and use these technologies to make choices and live the kinds of lives they want to lead (O'Hara, 2015). It also means that the cost of technology will not be a barrier to getting access to technology and using it.

#### **DEFINITION OF TECHNOLOGY**

In the course of preparing this Report, PCPID members realized there was no precise definition of technology relevant to people with ID. They thus developed the following definition of technology, which is relevant to people with ID and was agreed upon by the members, self-advocates, advocates, and other contributors to this Report.

The use of advances in science<sup>3</sup> to support people and society, to reduce barriers, and to make the everyday world more accessible

<sup>&</sup>lt;sup>3</sup> Science is the study of why and how things happen. It includes everything people do to learn about the world, especially about nature.

## **Definition Of Technology Wordle (Word Cloud)**

The following *Wordle* is a conceptual reflection of how technology is defined in this Report and conveys the proportional meaning given by those who contributed.



The top 12 words in the *Wordle are*: 1) science/scientific, 2) advances, 3) application, 4) support, 5) people, 6) reduce, 7) barriers, 8) accessible, 9) society, 10) make/use, 11) everyday, and 12) world.

## **Key Recommendations**

As the most effective way to communicate the Committee's concerns related to design, access, and implementation of new technologies and illuminate possible solutions, PCPID members identified overarching technology challenges and recommendations in four focus areas: 1) Elementary, Secondary, and Post-Secondary Education; 2) Community Living; 3) Employment and Economic Well-Being; and 4) Health and Wellness.

## Focus Area 1: Elementary, Secondary, and Post-Secondary Education

How can technology be used more effectively to make educational materials, and the general education classroom, accessible to students with ID? How can accessibility tools developed in K-12 environments be used in post-secondary environments?

# Key Recommendations for Federal Agencies: Elementary, Secondary, and Post-Secondary Education

- Offices responsible for the Elementary and Secondary Education Act (ESEA),
   Individuals with Disabilities Education Act (IDEA), Higher Education Opportunity
   Act (HEOA), and other federal programs are urged to require accessibility in all
   educational technology they support.
- The offices that administer ESEA, IDEA, HEOA, and other federal laws should include accessibility requirements in any online learning tools or systems whose development they support, and encourage others to do so wherever permissible by law.
- The U.S. Department of Education (ED) should issue guidance recommending that all educational curricula purchased by schools (kindergarten through higher

education) meet current industry standards for accessibility including cognitive accessibility.

- Federal offices should support improvements in copyright law and practice
  wherever possible so that people with ID can access free electronic books for
  individuals with a print disability.
- The U.S. should ratify the <u>Marrakesh Treaty</u> to Facilitate Access to Published Works for Persons Who are Blind, Visually Impaired or Otherwise Print Disabled. The treaty will allow sharing of accessible materials, for use by members of the beneficiary groups, across international borders, thus increasing the number and supplies of materials accessible to persons with disabilities. ED should offer data and other support toward achieving the goal of ratification wherever possible.

<u>Full List of PCPID Recommendations on Elementary, Secondary, and Post-</u> Secondary Education

## Focus Area 2: Community Living

How can the requisite research and funding be acquired to achieve advances in accessible technology that will result in greater independent living options and full citizenship benefits for people with ID?

## **Key Recommendations for Federal Agencies: Community Living**

 The Centers for Medicare & Medicaid Services (CMS) should consider whether States are utilizing technology to improve and expand access to integrated community living as one aspect of the settings compliance analysis under the new Home and Community-Based Services (HCBS) regulation.

- Federal agencies should research, fund, and create more technology apps which expand the independence and participation of people with ID in everyday living situations.<sup>4</sup>
- Federal agencies should incentivize product developers to design software that is highly visual and customizable with verbal and non-verbal cues, and that contains real-time pictures and videos to orient and engage users with ID.

Full List of PCPID Recommendations on Community Living

## Focus Area 3: Employment and Economic Well-Being:

How can people with ID obtain and more effectively use technology in employment and to ensure their economic well-being? How can federal agencies incentivize the technology industry and employers to develop, promote and use accessible technologies that increase employment opportunities and on-the-job success for people with ID?

## Key Recommendations for Federal Agencies: Employment and Economic Well-Being

 ED and HHS should provide guidance on the inclusion of mainstream, accessible information and communications technologies (ICT) in the definition of "assistive technology" in federal education and vocational rehabilitation policy.

<sup>&</sup>lt;sup>4</sup> For example, U.S. Department of Housing and Urban Development (HUD) created a new housing counseling mobile app that allows smartphone and tablet users to locate housing counselors in their own area. HUD also unveiled the first housing discrimination mobile application for iPhone and iPad in 2013, and made it available on Android smart devices in 2015. Additionally, see information regarding the HUD Resource Locator on page 47.

- ED and HHS's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) should provide additional information and resources to the state vocational rehabilitation programs on the use of technology and related technology services, as part of Individualized Plans for Employment (IPEs).
- HHS-NIDILRR and the U.S. Department of Labor (DOL) should continue funding research that specifically focuses on the use of technology to increase competitive, integrated employment outcomes for youth and adults with ID.
- DOL should issue technical guidance to American Job Centers on the use of accessible technology in serving One-Stop customers (designed to provide a full range of assistance to job seekers under one roof) with ID. This guidance should advise contractors about best technology practices and resources to increase the hiring and employment of individuals with ID.

Full List of PCPID Recommendations on Employment and Economic Well-Being

#### Focus Area 4: Health and Wellness

How can product developers, researchers, funders and others use widely available technology as a resource to increase the involvement of people with ID in their own health care and health care decision-making?

## **Key Recommendations for Federal Agencies: Health and Wellness**

As a part of the review and approval process for Medicaid State Plan
 Amendments and Waivers, HHS-CMS should allow states to fund personal and
 mainstream technologies (including mobile devices) that can optimize
 participation of people with ID in their own health care and wellness.

- Technology should be used for ongoing training of health care professionals to increase their skills, knowledge and understanding of people with ID.
- Electronic records should be promoted and shared between health care systems and programs furnishing long-term services and supports to improve care for individuals with ID, and to provide longitudinal data for systems and planning.

Full List of PCPID Recommendations on Health and Wellness

## Overarching Technology Recommendations across the Four Focus Areas

Common themes emerged from the four specific focus areas that became relevant across them all. The following overarching technology recommendations illuminate themes of accessibility, affordability, independence, the enforcement role of federal agencies and creating incentives for product development and research. PCPID advises the President to:

- Recognize and affirm the equal rights of people with cognitive disabilities<sup>5</sup> to technology and information access by embracing the <u>Declaration of the Rights of</u> <u>People with Cognitive Disabilities to Technology and Information Access</u>, among other things.
- 2. Adopt and incorporate into federal statute, policy and recommended practice definitions for the following:
  - "Cognitively Accessible Technologies" Usability of technology by people with I/DD.
  - "Cognitive Design" Ensure that mainstream technologies are designed for people with I/DD from the beginning and that the design includes their input. Cognitive Design must not only include design, but also access functions.
- 3. Ensure that technology is accessible, affordable, and widely available to people with I/DD, who can benefit from it at home, in their communities, and at work.

<sup>&</sup>lt;sup>5</sup> Definitions of cognitive disability vary but are generally broad and include difficulties with mental tasks and/or processing. Students with cognitive disabilities often are unable to read or to gain meaning from standard print materials. They may struggle with reading due to difficulties with functional abilities such as problem-solving, memory, attention, and comprehension. They often need and can benefit from the use of accessible instructional materials to present the same information found in traditional instructional materials in a different format (National Center on Accessible Instructional Materials, 2015). ID is far more specific.

- 4. Direct the U.S. Department of Education Office of Civil Rights to revisit the definitions of the terms "otherwise qualified" relative to eligibility for accommodations under Section 504<sup>6</sup> of the Rehabilitation Act and the Americans with Disabilities Act. The emerging benefits of supportive, assistive and also prosthetic<sup>7</sup> technologies offer a significant extension of individual capabilities that were unavailable when these statutes were drafted.
- 5. Amend the functions of the U.S. Access Board (Section 502 of the Rehabilitation Act) to include the development of data standards to facilitate promotion of cognitive design and guidelines, incorporating solutions that include use of cognitively accessible technologies in businesses, communities, and the federal government.
- 6. Ensure that federal agencies interpret Section 508 of the Rehabilitation Act in a manner that creates cognitively accessible pathways to information, policies, and programs that are useful and available to people with ID.
- 7. Direct the U.S. Department of Justice to enforce the Americans with Disabilities Act so that public and private entities' services and programs that are available through electronic technology are readily accessible to people with ID.
- 8. Promote continued Research and Development funding and longitudinal testing of new cognitively accessible technologies, including speech-to-text technologies that increase the independence of people with ID. Request creation of a research agenda through the demonstration projects of the NIDILRR and the CMS.

<sup>&</sup>lt;sup>6</sup> Section 504 is a civil rights law that prohibits discrimination against individuals with disabilities. Section 504 ensures that the child with a disability has equal access to an education. The child may receive accommodations and modifications.

<sup>&</sup>lt;sup>7</sup> In medicine, "prosthesis" is an artificial device that replaces a missing body part, which may be lost through trauma, disease or other conditions.

- 9. Direct the U.S. Department of Education and U.S. Department of Health and Human Services to provide funding opportunities for the creation and support of an open access site (i.e., a repository of resources including codes), containing resources for developing accessible information and materials for people with cognitive disabilities.
- 10. Create federal incentives (e.g., tax credits) for the private sector to develop cognitively accessible technologies.

### Conclusion

Technology can enhance participation of people with ID in elementary and secondary education, higher education, competitive employment, home ownership, community living and all other aspects of society. Public-private partnership can be effective in making available technologies and technological innovations accessible and affordable. Universally designed technology can benefit all users, including those with ID, and can provide a market advantage to developers. Clearly, all civil rights protections apply to technology. The President's Committee believes that technology must be cognitively accessible, affordable, and widely available to individuals with ID.

Federal agencies can encourage, work with, and incentivize both the public and private sectors to develop and promote technologies that:

- 1. Incorporate universal design principles,
- 2. Are flexible and adaptable, and
- Can be personalized and used to match the unique needs and preferences of individuals with ID.

### RELEVANT TECHNOLOGIES, TERMINOLOGY AND DEFINITIONS

Technologies, terminology and definitions relevant to this Report are cited below:

## Personal Support Technologies – Mainstream Technology

Personal Support Technology (PST) is defined as an electronic monitoring device or system that supports individuals with I/DD to be independent in the community or in their place of residence with limited assistance or supervision by paid staff. The term mainstream technology has no statuary definition or precise technical meaning. As the term is used here, it refers to any technology that is intended for general use rather than for use entirely or primarily by people with disabilities.

 Universally Designed Technology – Universally design technology ensures that technology products provide an interface that is suitable for all potential users, including individuals with disabilities, without the need for adaptation or specialized design.

For information to be accessible to individuals with ID, it must:

- a. Decrease the dependence on rote memory as a tool for recalling information.
- Use as many complementary formats as possible (visual, audio, multi-graphic),
- c. Reduce the need for the recipient to utilize complex organizational skills for comprehension, and

d. Be presented in a vocabulary or at a reading level that is accessible to a full range of abilities.

More intuitive, user-centered computing interfaces are necessary to increase accessibility and empower persons with cognitive disabilities to use common technologies such as the Internet and personal computers.

- Cloud Technologies Computing that utilizes a hosted service rather
  than a product, with shared resources, software, and information being
  provided to computers and other devices over a network (typically the
  Internet). Some examples of cloud technology are: email, social
  networking apps, "smart" homes, and online banking services.
- Mobile Technologies Small, portable devices such as smart phones and tablets.

## Personal Support Technologies – Specialized Assistive Devices

- Assistive Technology (AT) Any item, equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (Assistive Technology Act of 2004, P.L. 108-364).
- Assistive Technology for Cognition (ATC) Devices that use computer technology and are specifically designed to help people compensate for cognitive impairments. ATC refers to a range of tools that includes lowtech and mainstream devices, as well as specialized technology (Sohlberg, 2011).

Assistive Technology Service (ATS) – Any service that helps individuals
with disabilities select, acquire, or use AT devices, including evaluating
technology needs, helping to purchase technology, designing or adapting
AT devices, training in using technology, and "expanding the availability of
access to technology, including electronic and information technology"
(Assistive Technology Act of 2004, P.L. 108-364).

## **Environmental Support Technologies**

- Smart Homes Technologies that can help individuals with functional limitations control their environment (e.g., operate heating and cooling systems, electrical appliances, and TVs and stereos, or safety features such as locking and unlocking doors).
- Innovative Transportation Technology New technologies that expand
  mobility and navigation options. Many mobile devices already include
  Global Positioning System (GPS) and other apps that help with
  transportation. In addition, more advanced technologies are being
  developed to increase access to more transportation options specifically
  for all individuals with cognitive disabilities.
- Robotics Personal robots, also called "technological assistants," are being studied as a way to supplement the role of educators, direct support professionals, and job coaches.
- Specific Workplace Technologies Workplace-based technologies that are used by companies to employ higher numbers of people with ID in integrated, competitive workplaces (e.g., The Walgreen Company or Walgreens).

## Virtual Technologies

Virtual Technology – Immersive multimedia or computer simulations that replicate an environment simulating places in the real (or imagined) world. Researchers are utilizing virtual technologies to provide instruction in daily activities such as shopping, work tasks, and social interactions, and are finding that skills learned in virtual environments successfully transfer to real world situations.

## **Cognitive Support Technologies**

Cognitive support technologies are technologies that include cognitive accessibility features and are as follows:

## **General Disability Technology – Cognitively Accessible (Everyday) Technologies:**

Cognitive support technologies enable individuals with ID to fully access and engage in the public/private infrastructure. Examples include:

- Smartphones with speech to text, symbol based applications, and/or customizable accessibility features
- Alternative keyboards with picture options
- Touch screens
- Sip-and-Puff systems
- Wands and Sticks
- Joysticks

- Speech or voice recognition devices
- Screen readers

## **ID Specific Technology – Cognitively Specialized Technologies:**

Specialized technologies are uniquely designed to address specific needs of individuals with ID to maximize independence and self-direction, support interdependence, and enable full participation in society. Some examples of such uses include:

- Cognitive orthotics, such as memory aids
- Job coaching video app
- Visual modeling and task prompting
- Online career interest assessments
- Public transportation navigation tools

#### TECHNOLOGY DISTINCTIONS

The four technology-related terms are often transposed and then used interchangeably, in a manner that muddles their meaning. There are both useful similarities and important distinctions among them. Having the right technology with the right design not only enhances usability for people with ID, but often is the difference in whether or not technology is truly accessible. The table on page 17 of this Report includes those distinctions.

Table 1
Four Technology-Related Terms

Universal Design	Cognitive Design*	Assistive Technology	Cognitive Accessible Technology*
<ul> <li>Ensures design of products and environments that are usable by all people, to the greatest extent possible, without adaptation or specialized design</li> <li>Empowers userfriendly approaches to designing living environments where people of any culture, age, size, weight, race, gender, and ability can experience an environment that promotes their health, safety, and welfare today and in the future</li> </ul>	<ul> <li>Ensures that mainstream technologies are designed for people with ID from the beginning</li> <li>Includes not only design, but also access functions</li> <li>Requires participation of people with ID in the development of new technologies and systems</li> <li>Is a component or subset of Universal Design features</li> </ul>	<ul> <li>Increases functional capabilities. There is nothing in the general definition of AT to exclude surgically implanted devices</li> <li>Uses hardware or software, or can stand alone</li> <li>Acquired commercially or customized</li> <li>Referred to as existing along a continuum and may be classed as low-tech, medium-tech, or high-tech depending on the level of sophistication</li> </ul>	<ul> <li>Increases usability of technology by people with ID</li> <li>Empowers people with ID to have equal access to information and communication technologies</li> </ul>

<sup>\*</sup>Definition suggested by the PCPID Members

### **RECOMMENDATIONS**

## PCPID 2015 ORGANIZATION OF RECOMMENDATIONS: CHALLENGES, BARRIERS, AND RESOURCES

Recommendations in the 2015 PCPID Report to the President are organized to highlight the following four focus areas:

- 1. Elementary, Secondary, and Post-Secondary Education
- 2. Community Living
- 3. Employment and Economic Well-Being
- 4. Health and Wellness

The PCPID working groups of self-advocates, experts, leaders, and advocates worked diligently to contribute to federal policy recommendations that will advance access, design, availability, and innovation to technologies that support full participation of people with ID in their respective communities. Text related to each focus area identifies an overarching challenge and specific barriers and concludes with recommendations and additional resources.

## Focus Area 1: ELEMENTARY, SECONDARY, AND POST-SECONDARY EDUCATION

**Back to Key Recommendations** 

#### Overview:

Only 17% of K-12 students with ID in the U.S. are fully included in general education classrooms (U.S. Department of Education, 2014), despite extensive research showing that students with disabilities who are included in general education have better success academically and in post-secondary education, social and employment outcomes. For example:

- Time spent engaged in the general education curriculum is strongly and positively correlated with math and reading achievement for students with disabilities. (Cosier, Causton-Theoharis, & Theoharis, 2013)
- Students with ID who were fully included in general education classrooms made more progress in literacy skills compared to students served in special schools. (Dessemontet, Bless, & Morin, 2012)

Cognitively accessible instructional materials and assessments are pathways to general education classrooms and curricula for people with ID – whether in preschool, K-12, online learning or higher education. The first nine recommendations in this section relate to increasing the accessibility of educational and assessment materials.

This section will also include specific recommendations intended to:

- Improve access for students with ID to online learning
- Improve access for students with ID to higher education
- Accelerate research and development of accessible educational tools and resources for learners with ID

- Increase family and student engagement though technology
- Support effective school-to-college/career transition using technology; and increase policy research in the use of accommodations in testing by learners with ID

## **Barriers to Availability of Educational and Assessment Materials**

Most educational instructional and assessment materials are not being designed and produced, from the outset, to incorporate accessibility for all students-creating barriers to inclusion and grade-level learning, particularly for students with ID. A number of factors contribute to this challenge, including:

- Lack of production of educational and assessment materials that are designed from the start to be accessible. Accessibility that is grafted on at the end (i.e., retrofitting) does not typically result in a positive user experience.
- Lack of financial incentives for commercial producers of educational material to design educational and assessment materials that go far enough to be accessible for all students, particularly for students with cognitive and intellectual disabilities.
- Lack of awareness (at various levels: school, family, policy maker, college, etc.)
   about available accommodations to improve the accessibility of educational
   materials for people with cognitive and intellectual disabilities.
- Under §121 U.S. Copyright Law, individuals with ID do not qualify under the definition of individuals with a "print disability."

<sup>&</sup>lt;sup>8</sup> See 17 U.S. Code § 121 (d) (2)—Limitations on exclusive rights: Reproduction for blind or other people with disabilities.

• Bookshare<sup>9</sup> provides free electronic books to hundreds of thousands of individuals that qualify with a print disability through a project funded by the ED. However, even though a significant percentage of individuals with ID potentially could benefit educationally by having access to these same electronic books due to not being able to read well, they may be excluded from receiving elementary and secondary textbooks sourced from the National Instructional Materials Accessibility Center (NIMAC) and many post-secondary resources since they are not included as qualifying recipients in the copyright exemption referenced above.

#### **Recommendations: Educational and Assessment Materials**

**Recommendation #1:** Offices responsible for the Elementary and Secondary Education Act, Individuals with Disabilities Education Act, Higher Education Opportunity Act, and other federal programs are urged to require accessibility in all educational technology they support.

**Recommendation #2:** Technology-related materials, equipment, and accommodations required for students with disabilities to access the general education curriculum in the instructional environment should be made available in the assessment environment.

**Recommendation #3:** Increase access to Science, Technology, Engineering and Math (STEM) instruction for students with ID. Engaging students with ID in STEM curriculum throughout K-12 will increase meaningful educational opportunities in STEM learning, and improve career related outcomes.

**Recommendation #4:** Build teacher capacity to use accessible curricula and technologies in instruction and assessment.

<sup>&</sup>lt;sup>9</sup> Bookshare is an accessible online library for people with print disabilities.

**Recommendation #5:** The ED should issue guidance to recommend that all educational curriculum being purchased or otherwise acquired by schools (K-higher education) meet current industry standards for cognitive accessibility such as EPub3 and EduPub3.<sup>10</sup>

**Recommendation #6:** Schools receiving federal funding (Title I, IDEA, HEOA, etc.) that are investing in technology and related resources should be required to make acquisitions that are accessible to students with ID.

**Recommendation #7:** Federal offices should support improvements in copyright law and practice wherever possible so that people with ID can access free electronic books for individuals with a print disability.

**Recommendation #8:** Expand the funding available for technology that creates access in schools for students with ID and create more flexibility within existing funding streams. For example, enable textbook-only funds to be used for other purposes, such as purchasing accessible instructional materials that originate in digital (as opposed to printed) formats.

**Recommendation #9:** The U.S. should ratify the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled. The treaty will allow sharing of accessible materials, for use by members of the beneficiary groups, across international borders, thus increasing the number and supplies of materials accessible to individuals with disabilities. ED should offer data and other support toward achieving the goal of ratification wherever possible.

<sup>&</sup>lt;sup>10</sup> EPUB (electronic publication) is a free and open e-book standard by the International Digital Publishing Forum.

**Barriers to Online Learning** 

Primary, secondary, and post-secondary schools increasingly use online courses and

distance learning as part of core academic instruction. It is imperative that online

learning is accessible to students with ID, but major barriers to cognitive accessibility

exist, including:

Lack of cognitive (and other) accessibility design for online and blended courses

Lack of awareness about the need for cognitive accessibility in online learning

Lack of an infrastructure to support cognitive accessibility in online learning

**Recommendation: Online Learning** 

Recommendation #10: The offices that administer ESEA, IDEA and HEOA,

other federal laws should include accessibility requirements in any online

learning tools or systems whose development they support, and encourage

others to do so wherever permissible by law. Intermediate steps might include

the funding of research on cognitive design principles, personalization and digital

learning; the funding of prototypes of flexible and responsive online learning systems designed to support usability; descriptive research of promising

practices in online learning for students with ID.

**Barriers to Higher Education Access** 

Federally funded initiatives such as Think College and the National Secondary

<u>Transition Technical Assistance Center</u> have contributed to increased access to higher education and other post-secondary and post-certificate options for students with ID.

But central barriers remain, such as:

 Lack of universal design principles and practices (including cognitive accessible design) in higher education curricula, for both online and brickand-mortar courses

 Attitudinal barriers and lack of awareness about the need for cognitive accessibility in higher education

Lack of infrastructure to support cognitive accessibility in higher education

 Uncertainty about the technological (and other) supports that students with ID are legally entitled to (under, for example, ADA, 508, & 504) within higher education.

**Recommendations: Higher Education Access** 

Recommendation #11: The Office of Special Education and Rehabilitative Services, the Office of Civil Rights, and the Office of Post-Secondary Education at ED should issue a clarification on the rights of individuals with ID to post-secondary settings under the civil rights legislation for higher education (such as Section 504 of the Rehab Act, the ADA, section 508 of the Rehab Act). This would include guidance on the question: to what extent can an accommodation (including, but not limited to, technological supports) be allowed if an individual wants to engage in a course of study for which they are otherwise qualified?

**Recommendation #12:** Maintain and strengthen Part D of HEOA<sup>11</sup>—Programs to Provide Students with Disabilities with a Quality Higher Education and its four subsections -- in the upcoming reauthorization of HEOA.

<sup>11</sup> Part D- Programs to Provide Students with Disabilities with a Quality Higher Education (p. 290 of HEOA)

## **Barriers to Research and Development**

There is a lack of research and development around the design and success of cognitively accessible educational and assessment materials and, if digital, the systems that deliver and/or render them. Additionally:

- Longitudinal research funding is not available to scale up, disseminate or support the benefits of cognitive support technologies for accessing educational and assessment materials.
- Research data are needed to empirically demonstrate the quality of life benefits and reduced costs to the service delivery system resulting from investments in cognitively accessible educational materials.

## **Recommendations: Research and Development**

**Recommendation #13:** Support new federal funding for a Center with the specific mission to maintain a repository that would include: a) open-source tools used to produce accessible materials and media; b) information on how to access tools that are for purchase; and c) track current industry and government standards for producing accessible materials and media. The Center will be responsible for maintaining existing materials and acquiring new ones, as they become available.

Recommendation #14: Support new federal funding for research, development, and implementation projects that increase the availability, variety, and quality of materials and technologies for people with ID. Examples may include field-initiated research grants, research and development projects, model demonstration projects that focus on research-based curricula, interventions and training modules, outreach projects to test the portability and validity of training or interventions, and evaluation research to determine the efficiency and

effectiveness of the development and implementation of interventions and products.

**Recommendation #15:** Award a cooperative agreement that would fund a technical assistance Center to support collaboration across all funded projects and programs (above), support communication across all projects, and develop and implement a standard evaluation that includes like measures and outcomes across all federally funded projects. The Center will develop more efficient and effective methods of producing and delivering accessible technologies and materials to people with ID.

## **Barriers to Family and Student Engagement**

Many individuals with ID and their families, educators, and employers are unfamiliar with the wide range of devices, software, and apps that are currently available and do not have the knowledge or expertise to effectively use them. Consequently, families and learners are unable to easily access technology that supports their engagement in a learner's educational experience.

## **Recommendations: Family and Student Engagement**

**Recommendation #16:** Develop parent engagement guidelines for IDEA/Part C/Education, best practices and definitions that include innovative uses of technology for families of children with ID to incorporate person-centered planning and to support better understanding of the general education curriculum.

**Recommendation #17:** Support the coordination of new projects with existing projects and programs that assist families and students to access technology. For example, coordination should be supported and promoted between the

Parent Information and Resource Centers (at Office of Special Education Programs and at Rehabilitation Services Administration); Health and Career Centers (at HHS); Independent Living State Grants; Centers for Independent Living; Assistive Technology State Grant Program; and Protection and Advocacy for Assistive Technology.

## **Barriers to Transition-Age Youth regarding Least Restrictive Work Placement**

Federal law (ADA and the Rehab Act) requires the full integration of people with ID into the U.S. job market, and calls for supported employment. However, transition-age youth will require appropriate, accessible technology in order to take advantage of the least restrictive work placement available to them.

- The June 22, 2012, Office of Special Education Programs (OSEP) letter that
  provided an opinion on the application of least restrictive environment (LRE) to
  transition-age youth has been a helpful resource to states and educators.
  However, additional OSEP clarification is needed to help answer questions about
  the types of supplementary technological aids and services that an IEP team
  may consider when determining a least restrictive work placement.
- Supplementary technological aids and services available to students with disabilities are defined generally in the law as "aids, services, and other supports". These aids and services are intended to help a student meet goals, make progress, and participate with peers without disabilities. The National Secondary and Transition Technical Assistance Center (NSTTAC) analyzed evidence-based practices to teach job skills. The NSTTAC's list of reviewed practices includes such things as job coaching to teach employment skills, video modeling, picture cues, and other AT. These supports could be provided through a variety of funding mechanisms, including vocational rehabilitation.

**Recommendations: Transition-Age Youth** 

**Recommendation #18:** ED should issue additional guidance and clarification related to the least restrictive environment in work placements for transition-age youth that includes access to new technology support.

**Recommendation #19:** Guidance should address and provide examples of appropriate supplementary aids and services in the least restrictive environment, including access to technologies that can qualify as appropriate supplementary aids and services in work placements prior to determining that a more restrictive setting is more appropriate. (Discussion of a more restrictive work placement would be allowed by law only after use of supplementary aids is discussed and considered by an IEP team.)

### Focus Area 2: COMMUNITY LIVING

Back to Key Recommendations

#### Overview:

Individuals with ID have the right to full inclusion in the social, economic and political life of their communities (affirmed by the Olmstead Decision). They have the right to a quality education, world-class health care, and fulfilling employment. Like other U.S. citizens, they have the right to worship where and when they please, to be mobile, engaged in the arts and interact with other cultural aspects of life. They have the right to contribute to their communities and be engaged in community discourse and decision-making. Individuals with ID also have the right to live in peace and safety, free from neglect, exclusion and discrimination, and free from financial, legal, physical and human rights abuses.

Each successive decade affords more individuals with ID greater opportunities to exercise these rights. Still, too many individuals with ID and their families remain underserved by services available to other U.S. citizens, or lack of access to life changing technology that could minimize their exposure to health, economic, social or personal risks.

Technology can exponentially leverage the capacity of individuals with ID to experience a full life of independence in their communities, immersed in the mainstream. It can improve communication and relationship-building with others, while enhancing personal safety. Technology can assist with connectivity to jobs, health services, housing, education, places of worship, travel, entertainment, and other facets of daily life. For example, technology now exists that can ensure all appliances are turned off after leaving home. Home thermostats can now be monitored from an application, and notices from landlords, medical providers and others can be delivered and received electronically. Technology has expanded the modalities by which business and personal communication with others can occur.

Technology that enhances the design of accessible transportation is a priority. The Accessible Transportation Technologies Research Initiative (ATTRI) is a multi-agency

initiative, led by the U.S. Department of Transportation (DOT), that researches, develops, and implements transformative technology solutions for travelers with disabilities to effectively plan and executive their travel. ATTRI research focuses on the needs of three stakeholder groups: 1) people with disabilities, 2) veterans with disabilities, and 3) older adults. It proposes areas of technology development on: Information and Technology Services and AT; automation and robotics; data integration; wayfinding and navigation; and enhanced human service transportation. Cloud-based navigational systems, wearable devices and interactive pedestrian crossing supports are also proposed for future development.

Innovations in transportation technology will greatly advance connectivity for individuals with ID in so many other functional areas of their daily lives. However, availability and accessibility are not enough. Training in the use of the technology is essential. Whether technological innovations are created to increase accessibility to transportation, education, job searches, health access, community engagement or other aspects of life, a strong training component must be a companion to any new technology design.

### Barriers to Technology Funding, Research and Design

New technological applications frequently enter the marketplace, offering wonderful life-enhancing options for millions of U.S. citizens. Making these options available to people with ID, however, requires research and funding to ensure the designs are accessible. Yet, limited research and funding impede the production of technological apps designed to dramatically improve independence and the overall quality of life for people with ID. It is a significant challenge to acquire the requisite research and funding that can optimize the independent living of people with ID.

### **Recommendations: Technology Funding and Research**

**Recommendation #1:** CMS should consider whether States are utilizing technology to improve and expand access to integrated community living as one

aspect of the settings compliance analysis under the new HCBS regulation.

**Recommendation #2:** CMS should recognize cognitively accessible equipment/supports as fundable under Medicaid to increase the quality of life, which will decrease costs for long-term services and supports. These investments require capacity-building and ongoing maintenance in order to ensure their efficiency.

**Recommendation #3:** CMS should issue new guidance on the coverage of mainstream technologies that provide the same functional assistance as covered assistive technology devices.

**Recommendation #4:** Pilot projects, funded by CMS, should investigate the cost-effectiveness of cognitively accessible technologies for people with ID in improving HCBS and other health-related services, supports and equipment.

### **Barrier to Accessible Design**

The inability to keep pace with the technological advances of everyday living continues to distance people with ID from the rest of the U.S. population. Research and accessible product design can help close that gap.

Recommendations: Accessible Design

**Recommendation #5:** Expand federal funding for interfaces that are easy to use by all ages and that are accessible on mobile devices, such as tablets and smartphones.

**Recommendation #6:** Expand federal funding for the design of a universal payment mechanism for all transit systems that would automatically pay for transportation, whether the individual uses a bus, train, plane, cab or real-time

ridesharing vehicles. The ability to have a support professional or the individual preload, ideally on a device that could be used across all agencies and organizations is encouraged.

Ben Kim (Student) uses a travel training app around the Washington metropolitan area:



www.youtube.com/embed/nMVL4MuvN3Q

### Focus Area 3: EMPLOYMENT AND ECONOMIC WELL-BEING

Back to Key Recommendations

#### Overview:

For most Americans employment is an important part of economic well-being and for people with ID in particular, working also has many benefits that go beyond the money they earn. It contributes to self-confidence and independence, and connects them to their communities by fostering inclusion and social connections.

Technology has become increasingly important in all workplaces and in all aspects of employment. For example, job applications are usually done online now – which means navigating the Internet has become more important for everyone. Everything from performing successfully on the job to filling out a timesheet can require use of information and communications technology. Thus, equal access to web content and technologies that are universally designed and usable by people with ID are key to competitive employment and vital for independence and full participation in the economy.

Assistive and universally designed mainstream technologies have significant potential for increasing the numbers of people with ID that are employed in competitive, integrated jobs. These technologies are contributing greatly to on-the-job productivity and success by helping work performance, enhancing communication with colleagues, and improving other job-related skills such as time management, planning and scheduling, and arranging transportation to and from work.

Today, use of technology is becoming an essential part of job skill development and job supports for people with ID. For example, the 2014 Workforce Innovation and Opportunity Act (WIOA) is designed to help all job seekers receive access to employment, education, and the support services they need to succeed at work. The law emphasizes that American Job Centers (also called One-Stop Centers) must be physically and programmatically accessible to individuals with disabilities, and says that

both assistive and accessible technologies are part of ensuring that these employment programs and systems are available to people with disabilities that choose to work.

### **Barriers to Employment and Economic Well-Being**

Technology can be a tremendous asset for making competitive employment and successful performance possible for people with ID. In particular, it can allow for the adaptation of workplace environments, processes, functions, tools, equipment and supports, that make it possible for people with ID to be productive and thrive in the workplace. However, financial and attitudinal barriers still exist to promoting technologies that can assist individuals with ID in obtaining and maintaining meaningful employment. These are some of the issues that need to be addressed to make sure that technology helps people with ID get hired and are able to succeed in competitive work opportunities:

- Accessible Design Technology programs and tools need to be designed so that they are more accessible to and usable by people with ID.
- Affordable and Available Technologies States need to enforce federal policies
  that support acquiring assistive technology devices and accessible mainstream
  technologies (such as mobile phones) by individuals with ID for job and economic
  success.
- Knowledgeable Employers and Human Resources Staff Employers need to
  encourage and welcome the use of accessible technologies and technology
  supports that increase the hiring, employment, and successful job performance
  of people with ID.
- More Education on How to Use Technology "Digital Literacy" resources need to be expanded greatly to people with ID and their support systems so that they can become more skilled at navigating the Internet and job-related online tools.

### **Recommendations: Employment and Economic Well-Being**

**Recommendation #1:** The U.S. Department of Labor (DOL) should issue technical guidance on accessible technology to state Workforce Development Boards and the American Job Centers, with information that specifically relates to serving customers with ID.

**Recommendation #2:** DOL should issue guidance to federal contractors on best practices and resources related to accessible technologies in order to expand employment opportunities for people with ID.

**Recommendation #3:** The Social Security Administration (SSA) should issue guidance clarifying that its work incentive provisions (such as Plans for Achieving Self Support and Impairment-Related Work Expenses) allow inclusion/coverage of both mainstream and assistive technologies that people with disabilities, including people with ID, use for employment-related purposes.

**Recommendation #4:** The U.S. Departments of Health and Human Services (HHS) and Education (ED) should clarify that the term "assistive technology" (as used in all relevant vocational rehabilitation contexts and funding guidelines) includes mainstream information and communications technology, such as technologies that are universally designed and mobile technologies that can utilize apps to facilitate the employment of people with ID.

**Recommendation #5:** HHS should issue new guidance providing for Medicaid and Medicare coverage of universally designed mobile and mainstream technologies that provide the same functional assistance as currently-covered assistive technology devices.

**Recommendation #6:** HHS's National Institute on Disability, Independent Living, and Rehabilitation Research should continue funding research that specifically

focuses on the use of technology to increase competitive, integrated employment outcomes for youth and adults with ID.

**Recommendation #7:** DOL and ED should provide additional guidance, information, and resources to state vocational rehabilitation programs on the use of technology and related services in Individualized Plans for Employment (IPEs).

Recommendation #8: DOL's Office of Disability Employment Policy (ODEP) should strengthen its efforts to increase the employment of individuals with ID through development, promotion, and use of accessible technologies. This effort should include the review and addition of technology resources offered through ODEP's Partnership on Employment and Accessible Technology (PEAT), Job Accommodation Network, Disability.gov, the National Center on Leadership for the Employment and Economic Advancement of People with Disabilities (LEAD Center), and the National Employer Policy, Research and Technical Assistance Center for Employers on the Employment of People with Disabilities (Employer TA Center).

**Recommendation #9:** All federal agencies with Small Business Innovation Research (SBIR) programs should incentivize, through the SBIR and entrepreneurial initiatives, everyday technologies that are cognitively accessible, widely available, and supportive of employment for people with ID, including instore job application kiosks with cognitively accessible interfaces.

**Recommendation #10:** Federal agencies with SBIR programs should create an award for the development of new technologies that promote, contribute to, and increase the employment of individuals with ID.

**Recommendation #11:** The Federal Communications Commission (FCC) should continue to expand and publicize its Lifeline Broadband Pilot Program, so

that low-income Americans with ID and their families can access affordable broadband services that support job-seeking and employment.

### Focus Area 4: HEALTH AND WELLNESS

Back to Key Recommendations

#### Overview:

To ensure that people with ID receive the full range of health care benefits available to all U.S. citizens through the Affordable Care Act (ACA), increased access to technology and new technologies are needed. The ACA, the public policy foundation for health care, administered by HHS ensures that individuals with pre-existing conditions can no longer be excluded from coverage by health insurers, lifetime limits in health coverage are prohibited, and coverage can no longer be retroactively cancelled. Rehabilitative and habilitative services are mandated in the ACA, as well as parity for behavioral health services.

Under the ACA, many people with ID will now have improved access to medical diagnosis equipment and medically relevant data collection. Advances in technology are needed to enable health care systems to provide coordinated, interoperable 12, community-based health care and long-term care services, as described in the ACA.

Access to technology and the development of new technologies are also needed to support and expand possibilities for people with ID to participate in their own health care, health maintenance, and wellness. Technology can facilitate many elements of coordination between people with ID, their long-term support providers and health care professionals, as well as product developers. As an example, possibilities now exist for accessing telemedicine, which is making health care more affordable and available.

Technology which is accelerating the availability of digital health literacy for the population at large, contributing to expanded health care knowledge and empowering individuals about their health and their healthcare information has not been as available

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<sup>&</sup>lt;sup>12</sup> Interoperability describes the extent to which systems and devices can exchange data, and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user.

or accessible to people with ID. People with ID need increased digital literacy and digital literacy resources to access their electronic health information and be able to comment on their own health information. Emerging technologies should be available for individuals with ID to send and receive health information in order to self-manage, enhance wellness and health care needs, and if they chose, involve their direct support professionals or families in their health care and health decisions. Providers and industry should increasingly offer digital literacy resources to people with ID to help shift the paradigm in how health care is often delivered, which will allow more coordination between providers, other health professionals, individuals with ID, their support teams and product developers: this will require a paradigm shift.

It is essential that health professionals, technology product developers, researchers and others are properly incentivized and engaged with people with ID, so that opportunities presented by advances in technology can be realized for people with ID and embedded in public health policy.

### **Barriers to Health and Wellness**

Accessible technology is essential to support people with ID to make informed health care decisions, and receive the care they need. How can wide-scale availability of technology designed to meet their needs become crucial to product developers, researchers, funders and other individuals and organizations that are resourced to impact change? Some barriers that affect access to health and wellness include:

• Health data and related privacy laws (i.e., Health Insurance Portability and Accountability Act, and Family Educational Rights and Privacy Act) protect health and other confidential information for the public at large. People with ID need their health information protected, but may also have unique needs for health information to be shared to achieve effective coordination of care. Privacy laws, as currently written or interpreted may inhibit coordination between multiple providers, other health professionals, and support people important to the person, such as family or health advocates.

- Medical specialists may not be located across all geographic locations, a barrier increasingly being addressed through telemedicine.
- Appropriate and accessible technology that can result in more independence is needed. Technology can expand opportunities for individuals with ID to interact and communicate directly and expeditiously with health care professionals and be more engaged in their own decision-making. Technology can also offer advances in managing one's own daily health and wellness, which can dramatically ease the required efforts and time commitments of support team and family members.
- A nationwide analysis of HCBS Waiver services and spending (2014-2015) reported that Waiver spending across states totaled only one percent for assistive and medical technologies (Braddock et al., 2015, p. 38).
- CMS' Final Decision Memorandum on Speech Generating Devices (July 29, 2015), while speech generating devices (SGDs) are considered durable medical equipment (DME) under Medicare, there was a 2001 National Coverage Decision (NCD) that restricted Medicare coverage to those dedicated devices that were used solely for speech generation and excluded from coverage more mainstream and normalized technologies, such as computers and tablets with speech generating applications that included other functions as they "are not primarily medical in nature" and therefore do not meet the definition of DME. CMS recently updated this definition of SGD in the 2001 NCD under a new NCD issued on July 29, 2015 that expanded the definition of SGDs to allow for coverage of devices that perform other functions as long as they are used solely by the patient with severe speech impairment and are used for the generation of speech. In addition, the capacity of the device to generate other forms of speech such as phone, e-mail, and text messages would be covered under Medicare DME benefit.

**Recommendations: Health and Wellness** 

**Recommendation #1:** Ensure that the benefits of the ACA are available to people with ID, including access to technology that can improve overall health care and decision-making, health maintenance and independence.

**Recommendation #2:** Make health-related technology accessible to all people with ID to enhance health outcomes, ensure access to preventive care, improve health literacy, and assist them to participate in their own health care, as provided under the ACA. Accessible, available, and affordable technology can advance the tools and equipment needed to improve the health care and preventive needs of people with ID. Such equipment includes, but is not necessarily limited to, accessible mammography, and exam tables.

**Recommendation #3:** HHS should support available technologies that can improve access to primary care for individuals with ID, which may include advances in telemedicine when geographic distance is challenging. The supported technologies should also improve access to crucial treatment information for primary care providers of people with ID. The agency should explore uses of telemedicine to provide access to and expand the pool of specialty care for individuals with ID when specialists are not geographically available.

**Recommendation #4:** Promote the recognition and awareness that technology which promotes health behaviors and independence (e.g., access to pictures of medications; smartphones to remind individuals about their medical appointments and medication times; support for healthy eating habits) is an important support for people with ID.

**Recommendation #5:** In funding demonstration and other projects, HHS should

encourage that Electronic Health Records (EHRs) and other data systems address compatibility across delivery systems.

**Recommendation #6:** Create a communication link between EHRs and other service systems to provide long-term services and supports (also see the <u>PCPID</u> 2012 Report to the <u>President</u>) that improve care and supports for people with ID. This would include longitudinal data for systems and planning.

Example: Use EHRs to help individuals with ID navigate the sharing of health information with providers, while protecting privacy and confidentiality.

Recommendation #7: Encourage the University Centers for Excellence in Developmental Disabilities (UCEDDs) Education, Research and Services; and Leadership Education in Neurodevelopmental Disabilities (LEND) programs to train health professionals about the importance of technology supports for people with ID to increase health literacy, participation in health care and wellness. Ensure the availability of technology supports for ongoing training of health care professionals to increase their skills, knowledge and understanding of people with ID.

**Recommendation #8:** CMS should ensure the availability of appropriate cognitive accessible technology in the web-based processes for beneficiaries with ID related to the application for, and benefits and coverage information within, health insurance marketplace, Medicaid and Medicare programs.

**Recommendation #9:** Promote stakeholder input to CMS nationally, and within each state on the Medicaid State Plan and Waivers, to raise the awareness of personal and mainstream technologies (including mobile devices) that are less costly and more socially integrative than traditional forms of durable medical equipment to optimize participation of people with ID in their own health care and wellness.

**Recommendation #10:** Encourage and incentivize providers to seek technology that can unleash and advance the capacity to practice interoperable coordination of care for the person with ID, their support team, other health care professionals and technology product developers.

**Recommendation #11:** HHS should use technology to enhance the participation and quality of individuals with ID in patient satisfaction surveys, such as voice activated surveys.

### **Creating Better Futures: Health Care Visit Satisfaction Survey**



https://www.youtube.com/watch?v=USIcXJUs32U&index=15&list=ULiNYfFpzjqyU

The list below includes current public and private sector initiatives, projects, and resources that share the goals of the PCPID 2015 Report to the President:

- 1. AbleLink Technologies: Focuses on research and development of innovative cognitive support technologies that enable people with cognitive limitations to live more independent and self-determined lives. (<a href="http://www.ablelinktech.com">http://www.ablelinktech.com</a>)
  Products include the Accessible Testing Learning and Assessment System (ATLAS), a research-based, cognitively accessible survey system that enables individuals with cognitive disabilities to complete tests and surveys, and independently share their responses using an iPad or Android tablet. (<a href="http://www.ablelinktech.com/index.php?id=141">http://www.ablelinktech.com/index.php?id=141</a>)
- Accessible Transportation Technologies Research Initiative (ATTRI): Leads
  research, development, and implementation of transformative solutions and
  applications so that all Americans, including those with disabilities, can effectively
  plan their travel. (<a href="http://www.its.dot.gov/attri/">http://www.its.dot.gov/attri/</a>)
- 3. Assistive Technology to Support Individuals with Intellectual Disabilities in Employment: Workshop presentation by Scott Renner and Michael Papp covering assistive devices and apps that can be used by people with cognitive disabilities in the workplace; presented at Assistive Technology, The Great Equalizer: 2014 Alabama Assistive Technology Expo and Conference, October 2014.

(http://www.auburn.edu/outreach/opce/alatec/documents/2014presentationkeynotes/AT%20to%20Support%20IID%20in%20Employment Scott%20Renner %20&%20Michael%20Papp.pdf)

4. **Association on Higher Education and Disability® (AHEAD):** Focuses on full participation of people with disabilities in postsecondary education, facilitating

collaboration and connections for those working on accessible technology through its Special Interest Group (SIG) on Technology and its 2015 Accessible Instructional Materials and Technology Summit. (<a href="http://ahead.org">http://ahead.org</a>)

- Bookshare: An accessible online library for people with print disabilities. (<a href="https://www.bookshare.org/cms">https://www.bookshare.org/cms</a>)
- 6. **Center on Online Learning and Students with Disabilities (COLSD):** Focuses on making online learning more accessible, engaging, and effective for learners with disabilities. (http://centerononlinelearning.org/)
- Center on Technology and Disability (CTD): Works to increase the capacity of families and providers to advocate for, acquire, and implement assistive and instructional technology supporting learners with disabilities. (<a href="http://www.ctdinstitute.org/">http://www.ctdinstitute.org/</a>)
- 8. Cognitive and Learning Disabilities Accessibility Task Force of the Worldwide Web Consortium (W3C): Focuses on improving web accessibility for people with cognitive and learning disabilities.

  (<a href="http://www.w3.org/WAI/PF/cognitive-a11y-tf/">http://www.w3.org/WAI/PF/cognitive-a11y-tf/</a>)
- Cognitive Disability and Technology-Universal Design Considerations:
   Workshop presentation by Clayton Lewis with tips for developers to make
   technology easier to use for people with cognitive disabilities; presented at the
   Association of University Centers on Disability (AUCD) Training Symposium,
   November 2008. (http://www.aucd.org/docs/ClaytonLewis.pdf)
- 10. Coleman Institute for Cognitive Disabilities-Declaration on the Rights of People with Cognitive Disabilities to Technology and Information Access: A statement of principles on the rights of all people to inclusion and choice in relation to technology and information access, building on the recognition of the

rights of people with intellectual and developmental disabilities to be integrated into the community. (<a href="http://www.colemaninstitute.org/declaration">http://www.colemaninstitute.org/declaration</a>)

- 11. Collaborative Innovation Center on Accessibility: Partnership between IBM and the University of Massachusetts' Institute for Community Inclusion, working to advance accessible technology solutions for people with disabilities, the elderly, people with low literacy, and novice technology users.
  (http://www.umb.edu/editor\_uploads/images/ocp/14.355\_OCP\_Newsletter\_Fall\_2014(spreads).pdf\_and\_http://m.ibm.com/http/www.research.ibm.com/university/cic/index.shtml)
- 12. Diagram Center Digital Image and Graphic Resources for Accessible

  Materials: Works to change the way image and graphic content for accessible electronic media is produced and accessed, so that students with print disabilities have equal access to educational materials. (http://diagramcenter.org/)
- 13. Digital Literacy Portal: Provides resources for individuals and organizations who deliver literacy training and services in their communities.
  (http://www.digitalliteracy.gov)
- 14. Employment and Training Administration Disabilities Programs: Provides information on policy and program initiatives addressing employment challenges of people with disabilities and resources for the public workforce system on how to better serve customers with disabilities (<a href="http://www.doleta.gov/disability/">http://www.doleta.gov/disability/</a>), and Includes links to employment resources/tools and help for finding the nearest American Job Center. (<a href="https://www.servicelocator.org">www.servicelocator.org</a>)
- 15. EPUB3 Accessibility Guidelines on Specification for Multimedia Publishing:
  Guidance from the International Digital Publishing Forum on producing
  accessible ebooks. (http://www.idpf.org/accessibility/guidelines/)

- 16. Flexible Learning for Open Education (FLOE) Project: Provides resources to personalize how individuals learn and to address barriers to learning. (<a href="http://www.floeproject.org/">http://www.floeproject.org/</a>)
- 17. Help Make Online Job Tools More Accessible to People with Intellectual Disabilities: U.S. Department of Labor Blog, "Promoting and Protecting Opportunity." (December 16, 2013) (http://blog.dol.gov/2013/12/16/help-make-online-job-tools-more-accessible-to-people-with-intellectual-disabilities/)
- 18. HUD Resource Locator: The Locator is a mobile and web application developed by the U.S. Department of Housing and Urban Development (HUD) with the functionality to connect HUD's many customers to affordable housing resources in their community. The tool utilizes plain language and a simple, clean interface allowing users to access relevant housing contact information utilizing geolocation to visualize nearby resources. The HUD Resource Locator is available on HUD's website as well as iPhone and Android mobile devices, making this tool highly visible and accessible to people with ID and the professionals who help them. (<a href="http://resources.hud.gov/#&ui-state=dialog">http://resources.hud.gov/#&ui-state=dialog</a>)
- 19. Improvements in Closed Captioning: Over the past few years, the FCC has adopted rules governing closed captioning to ensure that viewers who are deaf or hard of hearing have full access to video programming. First, in February 2014, the FCC adopted quality standards for the accuracy, timing, completeness, and on-screen placement of TV closed captioning, along with best practices for video programmers and captioning vendors. (http://hraunfoss.fcc.gov/edocs\_public/attachmatch/FCC-14-12A1.pdf)
- 20. Implementation of the Communications and Video Accessibility Act
  (CVAA): On October 8, 2010, President Barack Obama signed the Twenty-First
  Century CVAA into law to ensure that individuals with disabilities are able to fully
  utilize advanced communications services and equipment and better access

- video programming. (<a href="https://www.fcc.gov/encyclopedia/twenty-first-century-communications-and-video-accessibility-act-0">https://www.fcc.gov/encyclopedia/twenty-first-century-communications-and-video-accessibility-act-0</a>)
- 21. Inclusive Design Research Centre: Community of open source developers, designers, researchers, and advocates working together to ensure that emerging information technology and practices are designed inclusively. (<a href="http://idrc.ocad.ca/">http://idrc.ocad.ca/</a>)
- 22. **Journal of Special Education Technology (JSET)**: Presents information and opinions about issues, research, policy, and practice related to the use of technology in special education. (<a href="http://www.tamcec.org/jset/">http://www.tamcec.org/jset/</a>)
- 23. Learning Is for Everyone Higher Education Programs for Students with Intellectual Disabilities: Article appearing in *The Mentor, An Academic Advising Journal* (May 31, 2011) providing information about the types of post-secondary education programs currently available for students with intellectual disabilities. (<a href="https://dus.psu.edu/mentor/2011/05/intellectual-disability-programs/">https://dus.psu.edu/mentor/2011/05/intellectual-disability-programs/</a>)
- 24. National Center on Accessible Educational Materials: Supports the use of accessible educational materials in early learning, higher education, and workplace settings. (<a href="http://aem.cast.org/">http://aem.cast.org/</a>)
- 25. National Center on Universal Design for Learning: Works to implement universal design in learning by connecting interested stakeholders and providing resources and information on universal design. (<a href="http://www.udlcenter.org/">http://www.udlcenter.org/</a>)
- 26. National Institute on Disability, Independent Living, and Rehabilitation
  Research: Sponsors grantees focused on generating new disability knowledge, including the Wireless Rehabilitation Engineering Research Center (<a href="www.wirelessrerc.org">www.wirelessrerc.org</a>), a leader on issues and solutions related to the accessibility and usability of mobile wireless products and services by people

- with disabilities, and the Rehabilitation Engineering Research Center for the Advancement of Cognitive Technologies (<a href="www.rerc-act.org">www.rerc-act.org</a>), the nation's first center to conduct research and development on assistive technologies for people with cognitive disabilities. (<a href="http://www.acl.gov/programs/NIDILRR/">http://www.acl.gov/programs/NIDILRR/</a>)
- 27. Office of Educational Technology (OET) Initiatives: Provides leadership for transforming education through the power of technology and promoting equal access to the Internet by all learners. (<a href="http://tech.ed.gov/">http://tech.ed.gov/</a>)
- 28. Open Professionals Education Network (OPEN): Provides support and technical assistance to Department of Labor grantees under the Trade Adjustment Assistance Community College and Career Training (TAACCCT) grant program on accessibility and universal design for learning. (<a href="https://open4us.org/">https://open4us.org/</a>)
- 29. Partnership on Employment and Accessible Technology: Tools and resources for promoting the employment, retention, and career advancement of people with disabilities through the development, adoption, and promotion of accessible technology (<a href="www.peatworks.org">www.peatworks.org</a>), including 2014 webinar "Expanding What It Means to Be Accessible: Addressing the Workplace Technology Needs of Users with Cognitive Disabilities."

  (<a href="http://peatworks.org/webinars/2014/12/expanding-what-it-means-cognitive">http://peatworks.org/webinars/2014/12/expanding-what-it-means-cognitive</a>)
- 30. **Promise Project:** Works to ensure that children with learning disabilities get the technology supports they need to learn. (<a href="http://www.promise-project.org/">http://www.promise-project.org/</a>)
- 31. Quality Indicators for Assistive Technology (QIAT) Community: Works to identify, disseminate, and implement a set of widely-applicable quality indicators for assistive technology services in school settings. (Website: <a href="www.qiat.org">www.qiat.org</a>; Listserv: <a href="http://lsv.uky.edu/scripts/wa.exe?SUBED1=qiat&A=1">http://lsv.uky.edu/scripts/wa.exe?SUBED1=qiat&A=1</a>)

- 32. **Raising the Floor (RtF):** Works to make the web and mobile technologies accessible to everyone with disability, literacy, and aging-related barriers, regardless of their economic status. (<a href="http://raisingthefloor.org/">http://raisingthefloor.org/</a>)
- 33. Rehabilitation Engineering and Assistive Technology Society of North

  America (RESNA): Works to promote the health and well-being of people with
  disabilities through increasing access to technology solutions.

  (<a href="http://www.resna.org/">http://www.resna.org/</a>)
- 34. School-Wide Integrated Framework for Transformation (SWIFT): A national initiative that includes processes, tools, and resources for creating "powerful, unified teaching and learning environments for ALL students and educators." (<a href="www.swiftschools.org/">www.swiftschools.org/</a>)
- 35. Lifeline Program: Provides discounts on phone service for qualifying low-income consumers, and conducted broadband pilot program, to ensure that all Americans have the opportunities and security that phone service brings, including being able to connect to jobs, family and emergency services.

  (www.fcc.gov/lifeline)
- 36. The Power of Digital Inclusion Technology's Impact on Employment and Opportunities for People with Disabilities: National Council on Disability report examining how six key digital technologies enhance social engagement, increase workplace participation, improve employment prospects and create employment opportunities for people with disabilities.

  (<a href="http://www.ncd.gov/publications/2011/Oct042011">http://www.ncd.gov/publications/2011/Oct042011</a>)
- 37. The Struggle for Web eQuality by Persons with Cognitive Disabilities:

  Article based on the book eQuality: The Struggle for Web Accessibility by

  Persons with Cognitive Disabilities (2014) by Peter Blanck stating that the rights of individuals with cognitive disabilities to equal access to web content are

protected under the law and can be supported by current technologies.

(<a href="http://bbi.syr.edu/news\_events/news/2014/02/BlanckWebAccessibility2014BSL">http://bbi.syr.edu/news\_events/news/2014/02/BlanckWebAccessibility2014BSL</a>
Online.pdf)

- 38. **Think College:** National organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disabilities. (<a href="https://www.thinkcollege.net/">www.thinkcollege.net/</a>)
- 39. **Tech Toolbox:** The Arc's Tech Toolbox is a place to find, share, rate, and review technology for people with intellectual or developmental disabilities.

  (<a href="https://toolbox.thearc.org">https://toolbox.thearc.org</a>)
- 40. **UNDERSTOOD** *For Learning & Attention Issues*: Collaboration between 15 nonprofits working to support parents on issues related to learning; includes Universal Design for Learning (UDL) videos and resources.

  (<a href="http://www.understood.org">http://www.understood.org</a>)
- 41. United States Access Board: An independent federal agency promoting equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards, including standards for information and communications technologies.
  (<a href="http://www.access-board.gov/guidelines-and-standards/communications-and-it">http://www.access-board.gov/guidelines-and-standards/communications-and-it</a>)
- 42. **Universal Design for Learning (UDL) on Campus:** A collection of resources on UDL in higher education (including teaching approaches and tips for selecting media and technology) geared to postsecondary institutions, including faculty, administrators, and policymakers. (http://udloncampus.cast.org)
- 43. **WebAIM** (**Web Accessibility in Mind**): Works to expand the potential of the web for people with disabilities by providing the knowledge, technical skills, tools, organizational leadership strategies, and vision that empower organizations to

make their own content accessible to people with disabilities.

(http://webaim.org/articles/evaluatingcognitive/)

### FREQUENTLY-USED ACRONYMS

Abbreviation Acronym

**ACL** Administration for Community Living

ADA Americans with Disabilities Act

AIDD Administration on Intellectual and Developmental Disabilities

AT Assistive Technology

ATTRI Accessible Transportation Technologies Research Initiative

**CMS** Centers for Medicare & Medicaid Services

**DOL** U.S. Department of Labor

**DOT** U.S. Department of Transportation

**ED** U.S. Department of Education

**ESEA** Elementary and Secondary Education Act

**HCBS** Home and Community-Based Services

**HHS** U.S. Department of Health and Human Services

**HEOA** Higher Education Opportunity Act

**HUD** U.S. Department of Housing and Urban Development

IDEA Individuals with Disabilities Education Act

**ID** Intellectual Disabilities

I/DD Intellectual and/or Developmental Disabilities

IPE Individualized Education Program
IPE Individualized Plan for Employment

NIDILRR National Institute on Disability, Independent Living, and

Rehabilitation Research

ODEP Office of Disability Employment Policy (a DOL agency)
OSEP Office of Special Education Programs (an ED agency)

**PCPID** President's Committee for People with Intellectual Disabilities

SSA U.S. Social Security Administration

SBIR Small Business Innovation Research

WIOA Workforce Innovation and Opportunity Act of 2014

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