ADVANCING TECHNOLOGY ACCESS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPEMNTAL DISABILITIES

Perspectives from Intellectual and Developmental Disability Service Providers Across the Nation

SHEA TANIS, PH.D.
UNIVERSITY OF COLORADO
ANSCHUTZ MEDICAL CAMPUS
AND
THE AMERICAN NETWORK OF
COMMUNITY OPTIONS AND
RESOURCES (ANCOR)

JULY 2021







THE TECHNOLOGY DISRUPTION AND THE CRISIS OF THOSE LEFT BEHIND

The technological disruption of the 21st century has transformed the natural routines and rhythms of American culture and even challenged what it means to be human. Inequitable access to information and communication technologies (ICT) and technology solutions has created new barriers to community inclusion and left people with intellectual and developmental disabilities (ID/DD) in crisis, isolated behind digital walls.



Conference of State Parties to the Convention on the Rights of Persons with Disabilities Twelfth Session

"The Convention on the Rights of Persons with Disabilities recognizes the critical role that information and communication technologies (ICT) and assistive technology play in **enabling** and **empowering** persons with disabilities and in ensuring that they fully enjoy **human rights** and **fundamental freedoms**." (p.2).

EVALUATION OF TECHNOLOGY BARRIERS AND USE ACROSS THE NATION

In 2017, The University of Colorado State of the States in Intellectual and Developmental Disabilities Longitudinal Data Project of National Significance initiated an investigation into the use of technology by people with intellectual and developmental disabilities and barriers to use. This project investigated technology solutions through the triangulation of data between state agencies for developmental disabilities, service providers, and advocates and family members. The following report reflects what we have learned from service providers across the nation.

TECHNOLOGY SOLUTIONS SUPPORTING PEOPLE WITH ID/DD AND THEIR FAMILIES: PROVIDER SURVEY

National Survey

The Technology Solutions Supporting People with ID/DD and Their Families: Provider Survey was a collaboration between the University of Colorado and the American Network of Community Options and Resources (ANCOR). The purpose of the survey was three-fold: 1) to investigate the understanding and utilization of financial and programmatic resources to support the acquisition and sustainability of technology solutions for people with ID/DD and their families; 2) to examine current and future investments in technology solutions; and 3) to examine the impact of the COVID-19 pandemic on technology utilization and barriers to access and future investments.

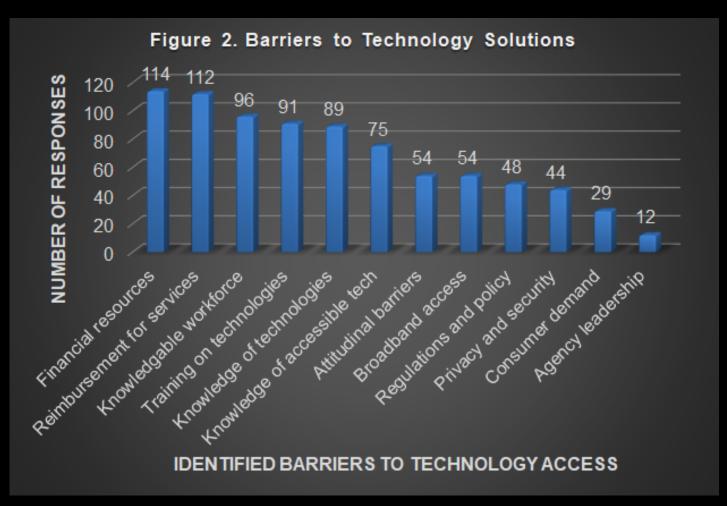
Throughout the survey and this report, we use the term *technology solutions* to describe a broad array of technology options. Using the term technology solution instead of *assistive technology, enabling technology*, or *supportive technology* provides several benefits in theory and practice.

- The term technology solutions allows for the inclusion of multi-functional and diverse technologies such as smartphones where a single feature may mediate an impairment, but in addition, the technology can be used to achieve other goals such as personal communication, education, and civic engagement.
- The term implies a person-directed and goal-oriented approach to the identification, acquisition, and ongoing training of technologies.
- The term is an umbrella term that includes technologies identified for a single domain or function.
- The term is familiar to engineers and technology developers and supports the development of solutions that eliminate the mismatch between the person and environment (functional perspective of disability).
- The term allows for the inclusion of emerging and future technologies not yet identified to be supported through policy and practice.



BARRIERS TO TECHNOLOGY SOLUTIONS

Providers were asked, "What are the barriers within your agency/organization that prevent advancement or acquisition of technology solutions for members with ID/DD?" In alignment with previous reports, financial resources and technical expertise with accessible technology solutions were identified as the primary barriers by service providers (Figure 2.).



SURVEY RESULTS

2021 Technology Solutions
Supporting People with ID/DD and
Their Families: Provider Survey



States Represented in Survey

The online survey launched in January 2021, and closed in April 2021. It was disseminated through the ANCOR listserv and recipients included ANCOR members and non-ANCOR members. One hundred and eighty providers (N=180) from 38 states responded to the survey (Figure 1.). Responding providers varied in size from small, medium, to statewide organizations. Iowa had the largest representation, with 40 providers responding to the survey.

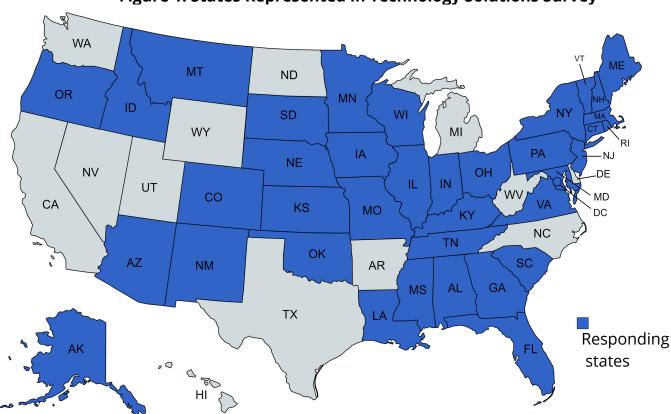


Figure 1. States Represented in Technology Solutions Survey

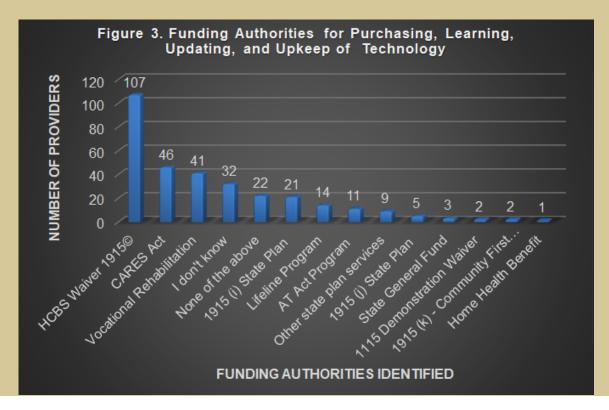
PURCHASING TECHNOLOGY SOLUTIONS

Primary Funding Authorities and Knowledge Gaps in Resources Available



In 2018 and 2019, the State of the States project collected data on technology access through the lens of the state developmental disability agencies in collaboration with the National Association of State Directors of Developmental Disabilities Services (NASDDDS). The results indicated an average of twelve different funding authorities per state used to purchase technology services, applications, devices, or other solutions for people with ID/DD (Brent & Tanis, 2020).

In 2019, 93% of state developmental disability agencies listed the Medicaid Home and Community-Based Services Waiver(s) 1915(c) as the primary authority used to purchase technologies. Fifty percent of states listed vocational rehabilitation as the authority to purchase technology. However, state agencies identified other funding authorities such as state plan services and general funds as other dominant funding streams while a limited number of providers used these resources (Figure 3.).



WHICH TECHNOLOGY SOLUTIONS ARE SERVICE PROVIDERS ADMINISTERING FOR PEOPLE WITH ID/DD?

Providers reported the technology solutions they administered to people with ID/DD through their programs. The predominant technology solutions were explicitly covered under the following Medicaid waiver definitions.

59%

Durable Medical Equipment is defined as equipment furnished by a supplier or a home health agency that meets the following conditions: can withstand repeated use; effective with respect to items classified as DME; has an expected life of at least three years; is primarily and customarily used to serve a medical purpose; generally is not useful to an individual in the absence of an illness or injury and is appropriate for use in the home. Examples include wheelchairs, inhalators hospital beds, medical regulators, etc.



50%

Assistive Technology is defined as any item, piece of equipment, or product system used to increase, maintain, or improve the functional capability of a person with a disability.

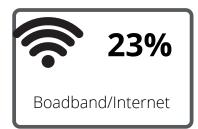
50%

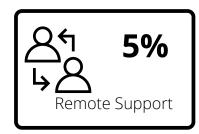
Adaptive Aids or Equipment/ Environmental Accessibility Adaptations (EAA)/ Environmental Controls/ Home Modifications are defined as architectural and environmental modifications and adaptations to the home, required by the person's individual support plan of care, which are necessary to ensure the health, welfare and safety of the person or which enable the person to live with greater independence in the home. Such modifications or adaptations include the installation of ramps, grab-bars, widening of doorways, modification of a bathroom or kitchen facilities, specialized safety adaptations such as scald protection devices, stove guards, and modifications required for the installation of specialized equipment which are necessary to ensure the health, welfare, and safety of the person or that enable the person to live with greater independence in the home.

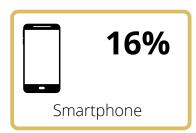
DEMONSTRATED COMMITMENT TO TECHNOLOGY ACCESS THROUGH INDEPENDENT RESOURCE ALLOCATION

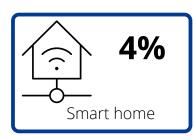


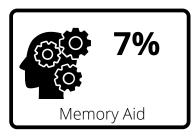


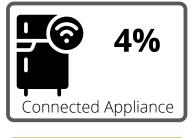


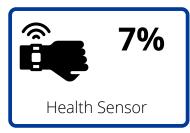


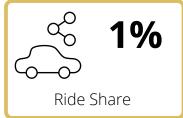










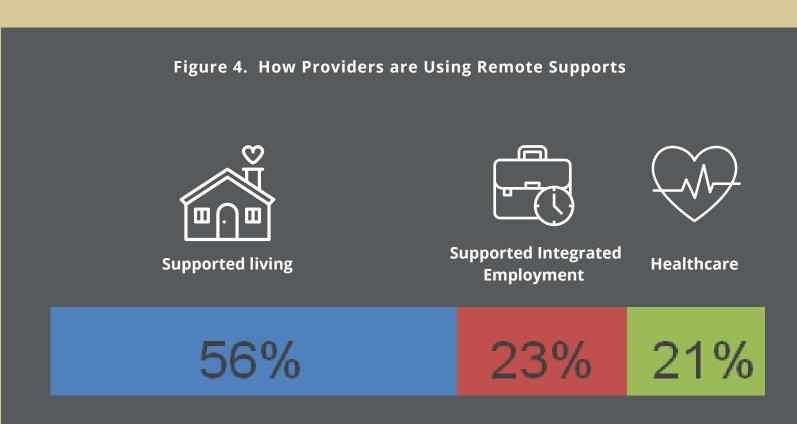


Technology Solutions Purchased with Provider Resources

Many providers use private donations, grants, and fundraising dollars to purchase technology solutions not covered under public funding authorities. These technology solutions tend to include multifunctional, mainstream, and emerging technology solutions like smartphones, computers, wearables, and accessible appliances. There is a clear relationship between the technology solutions available to people with ID/DD and the funding mechanisms. While 85% of Americans report owning a smartphone, people with ID/DD are still restricted to access by outdated policies, limited opportunities, funding restrictions, and universal design (Pew Research Center, 2021).

REMOTE SUPPORTS: A GATEWAY TECHNOLOGY

Remote supports "allow an off-site direct service provider to monitor and respond to a person's health, safety, and other needs using live communication while offering the person more independence in their home" (DODD OH, 2018). Provider identified several functions for the use of remote supports (Figure 4.).



Increased Investment in Remote Supports

Remote supports have gained popularity as a technology solution due to the preexisting remote monitoring service definitions, apparent cost efficiencies, and demonstrations of personal growth through interdependence. In this sense, for many technology policies, remote supports have become a "gateway" technology paving the way for creative rate structures, broadband access, training opportunities, equipment rental terms, and long-term technology maintenance contracts. Remote supports are often misrepresented as simply live video feeds. However, remote supports may include motion sensing systems, radio frequency identification, live audio feeds, webbased monitoring systems, or the application of devices that facilitate two-way communication. Myth-busting and clear communication is essential when introducing remote supports to caregivers and users.

DISCOVERY OF DIVERSE PAYMENT OPTIONS FOR TECHNOLOGY SOLUTIONS

Payment Options

States, providers, families, and advocates have discovered creative solutions to purchase and maintain high-demand mainstream technologies with built-in accessibility features. Braided and blended funding approaches have been used to purchase component elements of technology solutions, sometimes using one funding steam to purchase hardware and another to provide the related service. Table 1. describes the dominant payment options used for high-demand technology attainment.

Payymistoit Optikamis	Table 1. Number of Providers Utilizing Payment Options				
Technology	Direct Payment as a Service	Indirect Payment Through Inclusion in Residential or Other Rates	Goods and Services	Other Payment Mechanism	No Payment Options Available
Internet and/or Broadband	34	54	17	20	29
Smartphones	28	25	15	2 5	39*
Computers or Tablets	36	38	16	41	23
Shared Transportation	14	16	4	11	69*
Smart Home Solutions	15	9	5	12	72*
Wayfinding or GPS Technology	13	11	0	10	81*
Executive Functioning Memory Aids	11	8	0	14	76*
Digital Health Sensors	15	9	0	15	74*
Accessible Appliances	12	8	0	12	81*

Blue shading indicates the payment option most frequently utilized

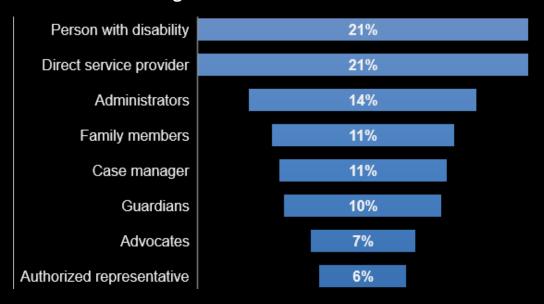
^{*}Indicates that providers indicated no payment option available for the identified technology solution most fequently.



DIGITAL LITERACY, AGILITY, AND RESILIENCE

Acquiring technology hardware and software provides the initial step to access. However, without digital literacy, agility, and resilience acquired through training and supports, users are at risk for technology abandonment. There is a critical need to advance digital and technology training. Thus we asked providers, "What State and federal authorities are utilized to provide ongoing technology training to learn, upkeep, and update purchased hardware, software, or technology solutions for people with ID/DD?" We also asked, "Who may receive ongoing training for technology solutions?" as the lack of availability to technical support may also contribute to technology abandonment. Twenty-seven percent of providers responded that they used the Home and Community-Based Services (HCBS) Waiver to fund training, 10% used CARES Act funds, 9% used Vocational Rehabilitation funds, and 4% used the statewide Technology Act Program. Figure 5. demonstrates who can be trained on technology solutions.

Figure 5. Who Can Be Trained?



ENHANCING THE ROLES OF DIRECT CARE PROFESSIONALS AND STAFF

The role of direct support professionals (DSP) and caregivers can be challenging, which is why with high demands and low wages, our most valuable employees need support to do their jobs effectively. Technology solutions can provide DSPs greater flexibility and time to apply their skills and facilitate opportunities for their clients to experience greater autonomy. Technology solutions should not be considered a replacement for the unique roles that direct professionals or caregivers play in the lives of people with disabilities but instead a tool to enhance their care. Direct support professionals' technical skills and ingenuity are often an untapped resources to advance the adoption and use of technology solutions. On the other hand, they can also serve as barriers if they do not possess the confidence or skills to provide mentorship and guidance.

86%

86% of providers believe greater applications of technology can help address the national direct support professional workforce crisis



Gatekeepers

Caregivers and DSPs play a critical role in the adoption and advancement of technology solutions. In the survey, we asked providers to rate the attitude of their staff or co-workers toward the application of technology solutions for people with ID/DD. Figure 6. shows the results. Only 28% of respondents believed they had adequately trained personnel to introduce and support consumers with technology.

Figure 6. Staff and DSP Attitudes Toward Technology Solutions



TECHNOLOGY FIRST

"Technology First gives me and my friends technology like everyone else."

- Advocate



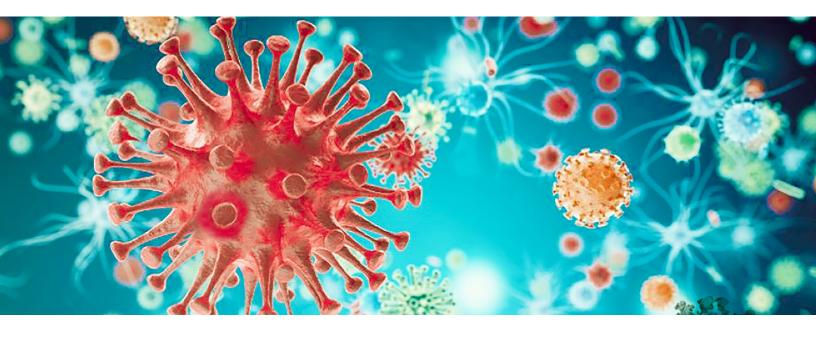
Advancing Technology First

Technology First began as a movement but has transformed into a "framework for systems change where technology is considered first in the discussion of support options available to individuals and families through person-directed approaches to promote meaningful participation, social inclusion, self-determination, and quality of life" (Tanis, 2019). Eighteen states are engaged in Technology First activities (Figure 7.).

WA МТ ND OR MN ID SD WY ΙA NE NV UT СО CA KS МО OK ΑZ AR NM AL MS TX

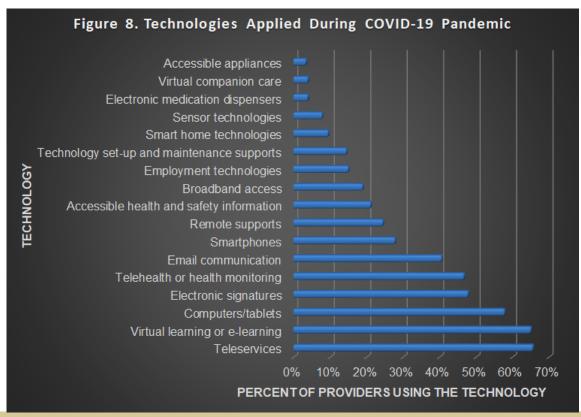
Figure 7. States with Technology First Initiatives

78% of providers indicated they would be interested in obtaining assistance in conceptualizing, drafting, or advancing technology related policies or initiatives.



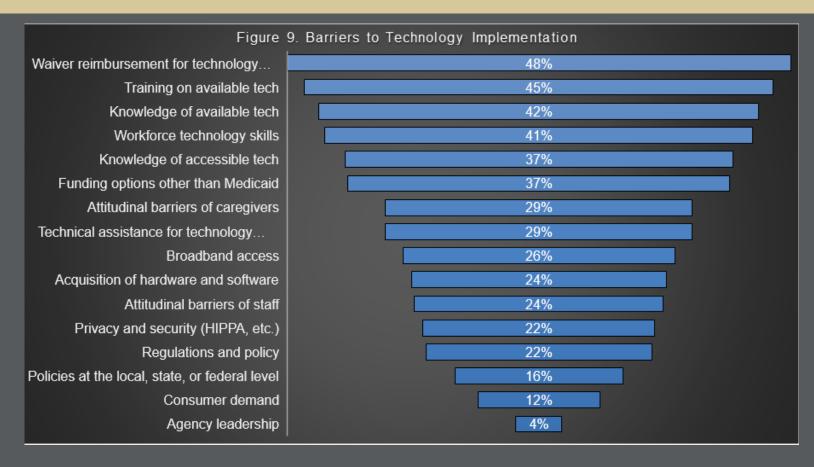
THE IMPACT OF COVID-19 PANDEMIC ON TECHNOLOGY ACCESS

The COVID-19 pandemic has accelerated the adoption of disruptive technologies and driven innovations to solve immediate challenges. Providers were asked about the use of and barriers to technology solutions during the pandemic and what innovations they hope to continue. Figure 8. demonstrates technologies applied during the pandemic.



Barriers to Technology Access During the COVID-19 Pandemic

As many providers transitioned to virtual services, invested in organizational technologies, and identified solutions for personal technologies to communicate and provide care to people with disabilities and their families, new barriers to technology use surfaced. Prior to the pandemic with policies and training methods already established, providers who had invested in technology solutions found it easier to respond and provide care. Others found new areas for structural growth to address the demand and need for technology use. Figure 9. highlights the barriers that providers experienced when transforming services to include technology solutions.



What to Maintain Post Pandemic

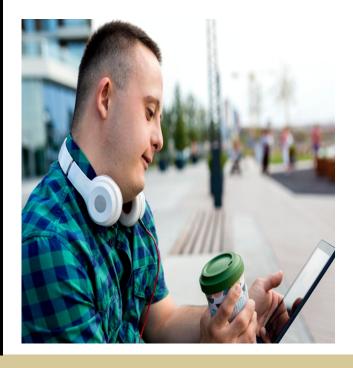
The technology solutions applied during the pandemic have transformed the delivery and access to long-term supports and services forever. However, we have yet to see what technology solutions will be permanent. Providers were asked which emergency technology solutions they hoped would be maintained post-COVID-19. All technologies were deemed valuable; however most valuable were telehealth technologies (10%), electronic signatures (9%), HIPPA flexibilities (9%), telepresence (9%), broadband access (8%), and remote supports (8%).

ACCESS TO TECHNOLOGY FOR COMMUNITY LIVING



Advancing Technology Access in the Future

The ubiquity of technology has made it clear that technology can no longer be seen as a luxury but rather a necessary utility to engage in meaningful community living. Applying technology solutions is not only valuable for promoting autonomy, but it is also good business, with 53% of respondents indicating that they could demonstrate cost efficiencies as a result of technology utilization. However, the pandemic has shown that barriers to technology access remain, and creative strategies are needed to address the digital divide through the modernization of policies, practice, and investment.



"Technology lets me and my friends do things just like everyone else." - Self-Advocate

REFERENCES

Brent, B. & Tanis, E.S. (2020). *Technology for People with Intellectual/Developmental Disabilities and their Families NASDDDS' National Policy Workgroup Subcommittee.* National Association of State Directors of Developmental Disabilities Services. Alexandria, VA.

Ohio Department of Developmental Disabilities. (n.d.). *Ohio Technology First: Technology First. https://dodd.ohio.gov/wps/portal/gov/dodd/about-us/resources/tech-first/Technology-First/*

Pew Research Center. (2021). *Mobile fact sheet. [Fact Sheet]. https://www.pewresearch.org/internet/fact-sheet/mobile/*

Tanis, E.S. (2019). Advancing Technology Solutions for People with IDD in Colorado. Alliance, Denver, CO.

United Nations. (2019, June 11-13.). *Technology, digitalization and information and communication technology for the empowerment and inclusion of persons with disabilities.* [Note by the Secretariat]. Convention on the Rights of People with Disabilities Twelfth Session, New York, NY. https://undocs.org/pdf?symbol=en/CRPD/CSP/2019/2

CONTACT INFORMATION

Shea Tanis, Ph.D., FAAIDD
Assistant Professor, Department of Psychiatry
University of Colorado Anschutz Medical Campus
Institute Co-Director for Policy and Advocacy
Coleman Institute for Cognitive Disabilities
University of Colorado
1800 Grant St. 7th Floor, #754
Denver, CO 80203
shea.tanis@cu.edu