Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Remote Technology and Supports
A System of Assistance and Empowerment
Preamble
January 26, 2022

Some of the early advocacy work on behalf of individuals with intellectual and developmental disabilities was initiated by allies or those with a strong connection to someone with IDD. Parents, siblings, and friends were among those at the forefront fighting for equal access to public school education and against the exclusion and segregation of their children in the community. These knowledgeable and fierce advocates raised consciousness and helped catapult intellectual and developmental disabilities from the category of social welfare to that of civil and human rights, from assistance to empowerment.

For two years, ABCD opposed a bill publicly promoting camera surveillance because it would have enshrined into law an ineffective prevention policy which could negatively impact the rights of the individual. During that span of time, we learned that too many parents do not trust agencies to adequately care for their adult children. In response, we challenged ourselves to a set of goals, three of which were to consider current approaches to electronic monitors while ensuring institutionalization does not reassert itself and individuals are not shoved to the margins of their lives.

ABCD members vary in their use of cameras, but many will consider cameras and/or monitors for specific purposes in limited areas with the approval of their Human Rights Committee which analyze and weigh the risks of potential rights restrictions. Recently we analyzed the use of remote supports and technology to help connect individuals to their communities and increase safety and independence, while respecting privacy concerns in our policy paper, Increasing Independence for Individuals with Intellectual and Developmental Disabilities through Remote Technology and Supports.

Though people who need assistance may be exposed to more risks to their health and safety while living in the community, we believe this is no reason to narrow the aspirations and values of the individuals, families, and providers who came before us. Unfortunately, rights are never forever won and must be constantly and vigilantly defended. The field has evolved thanks to new discoveries and methodologies so there is no reason that we cannot build a better and safer system that continues to stand up for human rights honoring the privacy, identity, dignity, and choice of the individual -- a system of assistance and empowerment.

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Increasing Independence for Individuals with Intellectual and Developmental Disabilities through Remote Technology and Supports

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For people without disabilities, technology makes things easier. For people with disabilities, technology makes things possible.

Summary

As technology capabilities continue to advance in the 21st century, opportunities are expanding to positively impact individuals with intellectual or developmental disabilities (I/DD) in a variety of ways. From broadening the capabilities for mobility, communication, and employment opportunities, individuals with I/DD have seen increased fulfillment in their lives through increased independence provided by the adoption of enabling technology. Remote supports are a form of technology that seeks to increase the independence and life satisfaction of individuals with I/DD, while maintaining privacy and dignity. In fact, remote supports technology does not have to equate to camera monitoring or a live video feed; rather, through the implementation of motion sensors, 2-way audio devices, and smart home devices such as stove sensors, individuals with I/DD can live more independently and privately than ever. Remote support services have the power to transform lives from ones of continual 24/7 staff presence to ones filled with increased autonomy, self-determination, privacy, and safety.

Based on a leading Home and Community Based Services (HCBS) provider agency's scan of current remote supports vendors in 2021, remote technology supports more than 3,000 individuals customized to suit their specific needs. Remote supports can provide significant benefits for individuals, provider agencies, states, and disability agencies. Individuals receiving remote supports indicate an increase in privacy, feel safer being alone, and can do more things on their own. For provider agencies, the ability to staff based on the level of need is a clear strength considering the current industry-wide Direct Support Professional (DSP) shortage. States and funding agencies see a decrease in HCBS expenditures since the cost for technology is lower as compared to in-person staff. With these benefits, the time is now for more states to join the movement to push for the expansion of remote supports so that individuals with I/DD can realize their full potential.

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Technology First

As of 2020, more than 17 states have formed a Technology First consortium to develop strategies for incorporating technology as a critical element of Medicaid Home and Community-Based Services (HCBS) to improve outcomes and maximize independence of individuals with I/DD and other disabilities.[1] Technology First is a movement to promote a framework for systems change where technology is considered first in the discussion of support options to individuals, with a person-centered approach to promote participation, inclusion, and self-determination.[2] The Technology First approach aims to help people learn more about how to use technology to improve their quality of life and how they can experience more independence and personal freedom, and is supported through a medley of systems infrastructure, outcomes-based care, assessments and service planning, education and advocacy, and funding. States adopting the technology first approach have created an environment of promoting individuals' independence by considering technology and remote supports as a first option in plans of care, with a key focus on individual choice. Individuals and their integrated care team consider the applicability of remote supports technology as part of the service planning process and the opportunity it provides in terms of independence and increased functioning.

In 2018, Ohio's Governor signed an Executive Order to establish the Technology First initiative to become the first Technology First state, with the aim of expanding the use of supportive technology for individuals with disabilities.[3] The Ohio Department of Developmental Disabilities (DODD) has implemented a series of benchmarks, ranging from increasing the adoption of supportive technology (including remote supports), expanding capacity of certified technology vendors across the state, developing a national model for using the National Core Indicators (NCI) survey process to gather data on the impact of technology, and expanding community integration opportunities as supported by assistive technology. As of March 2020, Ohio has increased the number of individuals using remote supports from 170 to 685, and assistive technology to 1,100 individuals.[4]

Other states participating in the Technology First consortium include NY, DE, PA, MO, IN, TN, WI, and AK. NY has implemented a program aimed to provide education and promote the adoption of technology assistance for individuals with disabilities, while MO has implemented their own Technology First initiative focused on improving quality of life, increasing independence and privacy, providing tools to increase safety and health, reducing costs, and addressing the DSP staffing shortage. DE has implemented the Delaware Assistive Technology Initiative (DATI), focused on increased advocacy for improved access to assistive technology and funding for services, technical assistance regarding technology selection and operations, and has implemented Assistive Technology Resource Centers (ATRCs) in each of the state's counties. DE's ATRCs are an example of systems infrastructure that provide localized advocacy and resources to help provider agencies and individuals understand the availability of services and how they can benefit individuals' functioning and independence.

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[1] Barth, S. et al. (2020). Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences. *Report to the Medicaid and CHIP Payment and Access Commission.*
[2] Lollar, R. (2021). Beyond the Pandemic: How Technology Influences and Ensures an Integrated Life in the Community Part 2.
[3] OH Exec. Order No. 2018-06K, *reprinted as amended in O.S.C. Section 5123.026 (2021).*
[4] Lollar, R.

Funding of services is a critical component of the accessibility of remote supports, which are typically provided through Medicaid HCBS waiver dollars. Remote supports may decrease an individual's annual budget utilization, allowing for increased access to other services that promote community integration. States utilize the levers available to them through Medicaid waivers (most often 1915(c) waivers), which can include remote supports as a discrete service for waiver recipients, resulting in potential benefits in terms of budget neutrality and overall Medicaid state cost savings. Remote support services are often reimbursed at the same rate as personal care services to promote diversion of DSPs to other services, whereas others offer the service at a lower rate for additional cost savings. Remote supports technology can also provide the opportunity for additional waiver slots due to decreased spending related to DSP-provided services.

Technology to Increase Independence and Safety

Remote supports, sometimes referred to as remote monitoring or enabling technology, can augment or reduce in-person support services using technology with off-site personnel on call for necessary back-up supports. Remote supports can be included in the array of services provided through assistive technology but serve a different purpose and are distinct from remote patient monitoring services. This technology challenges the idea that many individuals with I/DD require around-the-clock staff monitoring for health and safety, and instead allows individuals to lead self-determined lives with personal agency by managing their own activities in a safe and secure environment.

Examples of remote supports technology include motion-based sensors to identify if a door has been opened or to monitor general movement throughout the home, stove monitors to allow for safer cooking, temperature-regulated faucets, and bi-directional audio or video devices such as a tablet to allow an individual to contact a live support professional if they have questions or need help. The technology included in remote support services is always tailored to an individual's specific needs, goals, and circumstances, with health and safety being the top priority. Through person-centered care planning, individuals are actively engaged in selecting which remote supports interventions may best suit them through freedom of choice and personal agency.

Remote supports technology is a less intrusive form of monitoring for safety and quality of services than live streaming devices. The implementation of bi-directional communication devices, back-up support staff or natural supports, and thorough back-up planning creates an environment of security that greatly diminishes the need for camera monitoring, unless necessary for that individual's circumstances and needs. These technologies adhere to applicable laws and regulations, including privacy laws, to adequately protect and serve individuals at home and in the community. Motion sensors and other technologies provide the means for an individual to maintain their privacy and dignity, as opposed to ongoing camera surveillance that has been shown to have no positive effects in terms of promoting independence and increased functioning.[5]

[5] Hayward, B.A. (2017). The Arguments Against Camera and Closed-Circuit Television Surveillance in the Homes of People with Disabilities to Protect from Abuse and Neglect. *Research and Practice in Intellectual and Developmental Disabilities. 4 (2).*

Individuals not only benefit from increased privacy and dignity through the adoption of remote supports, but also through the promotion of increased independence, community integration, and self-determination. In a survey of 64 individuals receiving remote supports through a leading national HCBS provider, 89% indicated they were happy with the technology. Respondents communicated that they were able to do more things on their own than before remote supports (28%), they felt safer being alone (41%), and that they had more privacy at night (44%). Individuals were able to make their own breakfast (14%), take care of their home by washing dishes, emptying their trash, and tidying their home (19%), get up on their own in the morning (30%), and decide when to go to bed at night (34%). 89% of individuals understood who to contact if they had concerns or needed help. More than 80% of respondents would recommend the service to others based on their positive experiences with the service.[6] In a separate survey of individuals with I/DD receiving remote supports in OH, 64% of respondents endorsed safety as the number one benefit of the technology, indicating they felt safer and less worried about break-ins in their home and that they felt comfortable that they had access to someone in the case of an emergency.[7]

For Today and the Future: Addressing Staffing Shortages through Remote Supports

HCBS providers have historically struggled with labor shortages and high turnover rates—oftentimes as high as 50%, an issue only further compounded by the effects of the COVID-19 pandemic.[8] As a result, agencies are having to turn away new referrals, close sites, and delay the launch of new programs.[9] In addition, with pending additional federal funding via the Build Back Better bill coupled with lengthy waiver waiting lists of over 450,000 individuals across the nation and an aging population, the need for DSPs will continue to increase in the coming years.[10] The Bureau of Labor Statistics projects there will be a 26% increase in the demand for DSPs by 2024, while the number of people in the U.S. who are likely to need HCBS is projected to rise from 12 million in 2010 to 27 million by 2050.[11]

In 2017, a report titled *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy* was delivered to the President of the United States highlighting the critical role technology can play in creating more opportunities and supports for individuals with I/DD, including increasing their success in performing daily tasks while simultaneously reducing the reliance on DSPs.[12] There are various staffing reduction scenarios supported by remote technology, allowing provider agencies to focus staffing where there is an actual need for on-site presence. Staff displaced at one site can be transitioned to

[6] Satisfaction surveys were distributed in August 2021 to 64 individuals who have had remote supports implemented since January 2021 in IA, MN, and WI.
[7] Tassé, M. et al. (2020). Using technology and remote support services to promote independent living of adults with intellectual disability and related developmental disabilities. *Journal of Applied Research in Intellectual Disabilities. 33.*
[8] United Cerebral Palsy & ANCOR Foundation (2021). *The Case for Inclusion 2021: A Special Report on the Sustainability of Community Disability Services in America.*
[9] Merrill, B. (2021). Association of Developmental Disabilities Providers 2021 Workforce Policy Summit Kick-Off Message.
[10] Wu Tan, S. (2021). Caretaker organizations facing 'epic shortage' of direct service providers. *The Washington Times.*
[11] Tassé, M. et al.
[12] The President's Committee for People with Intellectual Disabilities. (2018). Report to the President 2017 – America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities, and the U.S. Economy.

other sites where direct, on-site care is needed, thereby increasing the number of individuals that can be served in total.

Remote supports can alleviate this barrier to access by allowing providers to reallocate scarce staffing resources to individuals with higher acuity needs while still providing customized support and safety to those who want and are able to live more independently. The technology provides the potential for removal of staff from overnight shifts, as individuals can go to bed and sleep in security with the adoption of motion sensors and other monitoring devices. Remote supports can also serve individuals with seizure disorders, detecting vibrations and movement from seizure patterns throughout the night and automatically calling 911 or back-up support staff, reducing the need for multiple overnight staff in a home. During the daytime, an individual may have downtime between employment or community activities and remote supports can grant the opportunity for alone time and privacy until their next assisted activity. Certain individuals may require no direct support staff after the implementation of remote supports, with assistance from off-site staff only being a phone call away through a tablet or audio device.

Remote supports can also provide additional support to complement on-site staff, including monitoring the movement in certain locations of a residence or to helping provide additional monitoring for elopement risks during the evening hours. By augmenting on-site staff, remote supports can increase individual privacy and well-being (e.g., reduced need for on-site staff to interrupt sleeping during room checks) as well as overall safety (e.g., by providing an extra layer of support for any elopement risks). In addition to the benefits for individuals, provider agencies can limit the need for additional staff at certain sites solely for low-likelihood scenarios and can instead deploy staff to sites that need in-person care.