



Expanding the Use of Remote Supports for People with Intellectual and Developmental Disabilities: **An Interdisciplinary Working Group Report**

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Abstract

Recognizing the value of technology in enhancing the connectivity, inclusion, and personal freedom of people with intellectual disability and/or developmental disabilities, why isn't it utilized more often in service delivery? What are the barriers to the usage of technology? What technology solutions hold the most promise? And what are actionable steps that could be adopted by states, service providers, case managers, and other support staff and families to accelerate the adoption of technology, specifically remote supports? Recognizing the importance of accelerating the widespread adoption of this new service model, an expert working group consisting of academic researchers, the president of a large disability rights advocacy organization, and a senior executive of an organization that advocates for service providers, was invited to evaluate the role of remote supports in serving those with intellectual disability and/or developmental disabilities (ID/DD) and their families.

The stated goal of this group was to develop a series of recommendations which a number of stakeholders, including state directors of developmental disability services and their staffs, could use to more readily integrate remote supports into their existing care plans. These recommendations include building partnerships with technology companies, tracking the growth of remote supports in states, creating a national peer-to-peer video library and prioritizing data collection methods.

Keywords: Intellectual disability, Remote supports, Technology, Workforce, Inclusion, Independence

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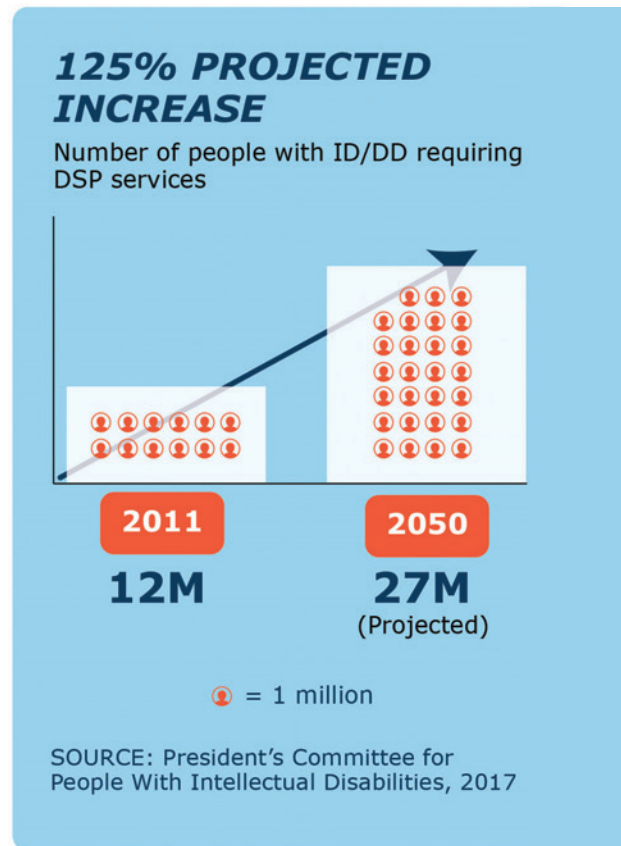
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Expanding the Use of Remote Supports for People with Intellectual and Developmental Disabilities

The value of technology in enhancing the connectivity, inclusion, and personal freedom of people with intellectual disability and/or developmental disability (ID/DD) has long been recognized (Brent & Tanis, 2020; Clauson, 2020; Tassé et al., 2020). Technology solutions that advance these goals are many. They range from supportive or assistive technologies that improve the functional capacities of individuals with disabilities, such as off-the-shelf, relatively inexpensive items, like smartphones, access to a computer, or an email account, to specialized technologies designed to promote greater autonomy, increased personal safety, and enhanced privacy. The best technology solutions, however configured, provide those who use them with increased opportunities across environments.

This document focuses principally on the latter, more specialized category –remote support services (also referred to as remote supports). These aid individuals from a distance using a variety of technologies such as monitors, sensors, cameras, and computers, who wish to live independently. As their value has become recognized, remote supports have increasingly been included in a new service model in which they supplement and reinforce the essential role played by direct support professionals (DSP). This model transforms the role of support staff in new and innovative ways, leveraging their commitment to advancing autonomy and social well-being while enhancing the efficiency and efficacy of everyday tasks through automation and technology supports. The model is thus a resource multiplier, allowing DSPs to be deployed in circumstances where their valued skills can be most effectively applied (Tanis, 2021).

The potential benefits of technology in supporting people with ID/DD becomes even more apparent in light of the continuing DSP workforce crisis — the projection that as many as 27 million people with ID/DD will require DSP services by 2050 — up from 12 million in 2011. This crisis has profoundly impacted those with disabilities and their families (President’s Committee for People with Intellectual Disabilities, 2017).



Fortunately, there is a new service model, a combination of remote supports and DSPs, that holds the promise of not only reducing dependence on a rapidly shrinking DSP workforce, but also of creating a context in which those with ID/DD can learn new skills for greater autonomy.

Recognizing the importance of accelerating the widespread adoption of this new service model, an expert working group consisting of academic researchers, the president of a large disability rights advocacy organization, and a senior executive of an organization that advocates for service providers, was invited to evaluate the role of remote supports in serving those with ID/DD and their families. The stated goal of this group was to develop a series of recommendations which a number of stakeholders, including state directors of developmental disability services and their staffs, could use to more readily integrate remote supports into their existing care plans. The effort embraces the goals of “Technology First,” which began first as a movement but has since transformed to a framework of systems change where technology is considered first in the discussion of support options available to families through person-centered approaches that promote meaningful participation, social inclusion, self-determination, and quality of life. The Technology First concept has become a legislative and regulatory priority in some states. (Brent & Tanis, 2020.)

Remote Support Services Defined

Remote supports have often been incorrectly viewed as a surveillance tool (meaning predominantly video-based), rather than a sophisticated interactive communications pathway directed by the user. Remote supports do not consist only of a single product or device or technology; rather, they are better described as a diversity of services tailored to the individual’s support needs and desires. While these needs and desires may evolve over time, the supports recommended are strictly aligned with those outlined in the person-centered service plan and are operational during the times when the service is in use and when responding to specific alerts. Again, they can range from relatively inexpensive “off-the-shelf” items such as personal assistants like Alexa, digital door locks, and video doorbells, to more complex sensor-based tools deployed to detect risks to safety, such as fall risk mitigation and appliances unintentionally being left on, or doors and windows left open, or to alert remote supports staff to potential health-related concerns, such as excessive time spent in bed or missed medications. The elements of these services are monitored during pre-established hours,



Personal assistant devices



Digital door locks



Video doorbells



Sensor-based devices

Examples of Assistive Technology Devices Used with Remote Supports Services

specific to each individual, by a remotely located trained staff familiar with the support needs of the person being served.

Though sensors are only monitored through preset times, often the remote support service system enables remote support staff to respond on-demand at all times of the day and night for advice, emergency help, or even casual social interaction, while not intruding on the physical space of the user. The interactions between the user and the staff involved are documented objectively, thus importantly not dependent on subjective observation and circulated weekly to the care circle. Vendors of remote support services are required to ensure that the system is carefully maintained, updated, and functioning properly while protecting the users' privacy and security. Those providing such services should be carefully vetted as to their ability to execute all of these requirements in a HIPPA-compliant environment.

Because remote supports consist of ever-evolving technologies that are tailored to the users' changing needs, in the future they will likely include some we cannot even envision now. The service is therefore best understood as taking advantage of a variety of cutting-edge options in a rapidly advancing technology landscape, continually creating new ways to address the needs of those using them as they age or their support needs change, and always based on the goals that individuals with ID/DD envision for their lives.

Factors Slowing Adoption of Remote Supports

Despite the opportunities remote supports may provide, their adoption has not yet been widely embraced. While this may be in line with the general adoption rate of new technology (Straub, 2009), there are some specific issues that may be contributing to this resistance. Technology solutions for individuals with ID/DD belong in the category of conceptual advances, which can only be incorporated into everyday practice when those responsible for proposing them can demonstrate their value and persist in incorporating them into processes that will ensure their acceptance. Below we identify some issues that have slowed adoption and describe some actionable solutions that may be of help to those who advocate for their inclusion as a standard approach to designing a personal care plan for people with ID/DD.

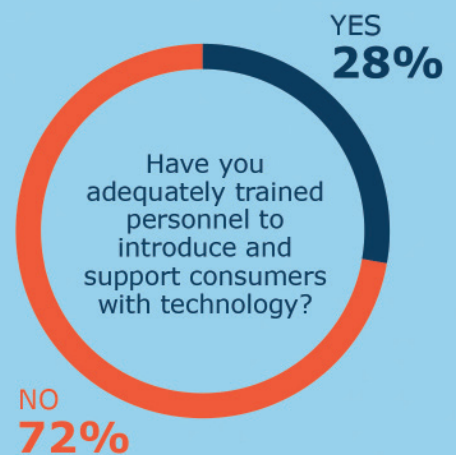
Technology Literacy for Service Professionals

An essential element in the adoption of technology solutions is digital literacy, not only for the workforce that is asked to implement them but also for their users and supporters. In one parameter of the recent survey co-authored by the American Network of Community Options and Resources (ANCOR) & Tanis (2020) for the State of the States in Intellectual and Developmental Disabilities, an assessment was made of whether organizations felt they had adequately trained personnel to introduce and support consumers with technology, only 28% believed that they had.

Case managers, department/county staff members, and DSPs all play important roles in guiding families, guardians, and the individuals who receive person-centered services and supports, so exposing all of the participants to technology solutions and education to plans that include remote supports regulations in their states is an investment in their successful implementation. Without this component, the plans can fail, with subsequent technology abandonment and withdrawal of resources.

Thus, assuring the availability of appropriate training, together with continuing education as new regulations and new technology solutions become available, are essential components in integrating remote supports into a person-centered planning process. Building a team of technology advocates, or at the least encouraging a dedicated staff member within a state department of disability who interacts with case managers and others involved in that process, can foster a positive attitude towards technology across the spectrum of available services. Including these advocates in family conversations can also benefit the member in need of services, regardless of the intensity of the individual's needs.

ORGANIZATIONS' TRAINING READINESS



SOURCE: American Network of Community Options and Resources (ANCOR) and Tanis, 2020

CONFUSION SURROUNDING MULTIPLE FUNDING MECHANISMS



State developmental disability agencies that list HCBS waiver as primary means of purchasing technology (2019)



People who receive remote supports using public funding



People with ID/DD who are known to the state delivery system

SOURCES: "Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences" | "In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017"

Confusion Surrounding Multiple Funding Mechanisms

Medicaid-Funded Waiver Programs

Medicaid is the most dominant source of public funding of long-term services and supports for the ID/DD community. In 2019, 93% of state developmental disability agencies listed the Medicaid Home and Community-Based Services (HCBS) waiver as the primary means by which they purchased technology (Barth et al., 2020), although it is well worth noting that only 20% of those receiving remote supports use public funding (see Private Funding section below) and only 40% of people with ID/DD are known to the state delivery system. (Larson et al., 2020).

A recent scoping review conducted to assess what is known about the impact of HCBS policy on the lives of people with ID/DD determined that Medicaid HCBS waivers "provide economic benefit at the state and federal levels, reduce unmet healthcare needs, increase the likelihood that parents will be able to continue working, and reduce racial disparities in access to care." (McLean et al., 2020; p. 684). However, HCBS waiver have been created in such a way that, although intending to increase access to technology, have often inhibited its adoption. An example of such a rule is limiting remote support providers to companies operating from within the state or requiring annual cost caps that are too low for service adoption.

In addition, although they have broad support among policy makers, waivers differ from state to state as to who is eligible for services and what level of funding will be allocated, resulting in long lists of those awaiting services. There is an important exception, however, in dealing effectively with this problem. In Ohio, a Technology First state that has an active plan not only to increase the use of technology as a standard part of its waiver programs but also to require its consideration before in-person services are contemplated, the tax system that funds such services is modeled after the state's school system.

STATES USING LOCAL FUNDING



Share of ID/DD
spending from local
funds (2019)



Local taxes are allocated to local boards of developmental disabilities, which can then leverage federal matching dollars. Ohio is singular in the level of local funding used for ID/DD services, with approximately 27% of their total ID/DD spending coming from local funds in 2019. (As a point of comparison, Missouri ranks second in local contributions, with 7% of their total ID/DD spending coming from local dollars.)

Adoption of a generous funding formula has uniquely allowed Ohio to provide services to many more people awaiting waiver services. However, Ohio has recently finalized a rule that mandates that support teams make a determination about whether technology solutions, including remote supports, are appropriate for each individual who receives support from a DD waiver in that state. This is the first regulation that Ohio has instituted that is more specific about how support teams are supposed to implement the rule (Ohio Department of Developmental Disabilities, 2022).

A funding formula that expands availability of remote support services would not only be a cost-effective strategy that would allow capacity to grow, it would also remove some of the barriers that disparate rules create.

Private Financing

As mentioned, there is evidence that 60% of people with ID/DD are outside the public funding system. Lacking such funding means those in need of services can only access them with private funds. Families who want services for their loved ones must turn to personal resources, private donations, grants, and fundraising to pay for technology that they consider essential, such as smartphones, tablets, or the internet access that makes their use possible.

One idea, admittedly available only to those who can afford to fund them, are ABLE accounts. These are the equivalent of the 529 plans used to fund education. As of January 2026, they will be available to all who have a disability that was diagnosed before age 46 (the previous Act set the threshold at age 26). The accounts let people with disabilities save and invest for future needs such as housing, education, and transportation while they remain eligible for Medicaid and Supplemental Security Income. Although disappointing that it will take so long for the benefits to be expanded, the new Act will allow millions more people to apply. Forty-six states and Washington DC currently offer ABLE accounts. Many programs accept out-of-state participants.

The funds, which can be contributed by family, employers, and friends, may be used for a wide variety of expenses, including assistive technologies. Individuals who receive benefits through Supplemental Security Income (SSI) or Social Security Disability Insurance Programs (SSDI) are all automatically eligible to establish an ABLE account.

Thus, a combination of both public and ABLE account funding represents a viable model for acquiring remote support services. This public/private funding combination is an example of a creative approach to achieving a desired result, as is the use of braided and blended funding (i.e., using separate funding streams to purchase needed products or services). This latter strategy has been employed successfully and is another example of creative thinking around this topic.

Policy Complexities

The processes involved in applying for support and qualifying for waivers can be extremely confusing. As an example, in 2019, the State of the States in Intellectual and Developmental Disabilities Project in collaboration with the National Association of State Directors of Developmental Disability Services (NASDDDS) indicated that there was an average of twelve different funding authorities per state that can be used to purchase technology (Brent & Tanis, 2020).

These complexities can frustrate families trying to secure remote supports for their ID/DD family members, a problem that could be ameliorated by a more standardized approach that public agencies at all levels of government could agree upon. Doing so would have the extra benefit of allowing states to compare certain parameters of their plans, as well costs and outcomes, and would go a long way toward providing a roadmap for families seeking supports.

Lack of Systemized and Diversified User Training

Although people can benefit from remote supports even if they do not have computer skills or are not familiar with how to manage the services (remote support technologies are automated and do not require any prior technical knowledge from the individual who uses remote supports), often overlooked is the importance of increasing capacity to discern differences among various technology-enabled supports and their relative advantages.

Involving users in decisions as to which supports would facilitate their personal goals can best be achieved through training programs that would also enhance their ability to successfully use the tools once they are provided. Because technology changes rapidly, commitment to training should be seen as a permanent requirement. A training program designed to enhance digital knowledge and skills and familiarize the potential user with managing the services that are available would maximize their utility. Even in the absence of a formalized commitment to ensure such programs are made permanent, regular promotion of them via easy-to-navigate web sites or at conferences and other events would be reinforcing.

CMS/Internet Access

The Centers for Medicaid and Medicare Services (CMS) is the administrative authority for the Home and Community Based Services (HCBS) waivers, the most prolific public program supporting people with ID/DD to live meaningful lives in the community. However, as the adoption of technology solutions has grown, so has the demand for funding the broadband that is necessary to utilize connected and technology devices and systems.

To support states and agencies in their adoption of technology solutions, CMS has leveraged alternative federal resources such as the Federal Communications Commission's (FCC) Emergency Broad Band Benefit program and the Broadband Infrastructure Program. Each of these programs outside of CMS requires users and states to navigate information, eligibility criteria, data supports, and programmatic needs. The complexities in navigating unfamiliar federal programs often leave consumers and states confused and frustrated by the lack of accessible information and enrollment protocols. It would be valuable for federal agencies to work in partnership to provide access to broadband through a one-stop system that could be embedded in the CMS HCBS waiver program.

Reluctance to embrace the “Dignity of Risk.”

Behind every innovation seeking mainstream acceptance is hesitancy at embracing new ideas. In the case of those living with mental or physical challenges, there is an understandable fear on the part of those caring for them that they may not have the ability to weigh the potential risks inherent in a choice to live their lives more independently outside of the system on which they have always relied. There is little question that technology is empowering individuals with ID/DD to achieve more independence and autonomy. In pursuing those goals, these individuals may be presented with situations which formerly they have not previously been allowed to manage. Embracing the dignity of risk means accepting that they can benefit from having to deal with such challenges. The result is an improvement in self- confidence and self- esteem, goals that are desirable for everyone to achieve at every level of capacity.

Accelerating the Adoption of Remote Supports

There are a number of key decision makers in the complex process for determining who should receive funding via Medicaid waivers for remote support services, and how those waivers should be distributed to ensure that benefits are equitably distributed. Responsibility for identifying potential improvements that will ensure that every facet of the process can be equally fragmented. The contribution that each of these stakeholders makes to such outcomes, especially with the challenge of staying ahead of developing opportunities, cannot be overstated. The key players in this process are these:

State Directors of Developmental Disability Services

Almost half of state directors have not yet mandated regulations for “Technology First” status. As of this writing, Washington, Colorado, Alaska, Hawaii, Minnesota, Missouri, Oklahoma, Tennessee, North Carolina, Indiana, Ohio, Pennsylvania, New York, Delaware, Maryland, North Carolina, Washington DC, and Connecticut, have been leading the way and have all initiated “Technology First” principles (Ohio and Missouri were the first to do so).

States moving along in the process of designating their states as “Technology First” states are Maine, New Hampshire, Massachusetts, Iowa, and Illinois. Missouri, New York, Ohio, Pennsylvania, Tennessee, Washington, and Wisconsin are designated as “Technology First” states (Tanis & Collins, 2021). Arkansas and Louisiana have written Technology First into their American Rescue Plan Act; Maine has a new Technology Initiative in process, Illinois has proposed a Technology First bill, and a committee in New Hampshire has proposed to the Governor that the state should support the adoption of assistive technology inclusive of remote support (NH Governor’s Commission on Disabilities, 2020). Singling out “Technology First” as a policy initiative shifts the focus to an improved service plan that holds the promise of greater autonomy and privacy.

Agencies

Agencies that devise the rules by which individuals qualify for HCBS waivers that cover remote support services. Some states maintain separate waitlists for each waiver, some allow people to be on multiple waitlists, and some use different methods of prioritizing people on their waitlists. The result is that the need for supports outweighs provider capacity. The patchwork system leads to thousands of people on waitlists. States, through their national association, NASDDDS, share information regarding rules governing waivers, amendments, and promising practices, but even with excellent communication, the ability to standardize eligibility criteria is more complex due to the variability of state policies.

Solving this problem may require new state legislation. The goal should be to reduce the burden on families. The 2020 Joint Position Statement adopted by the Boards of Directors of both the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc of the United States recognized that “relying on families for lifelong care cannot be a substitute for creating a national solution to provide appropriate long-term supports and services.” With greater commitment on the part of policy makers, this goal could be achieved.

Families

Inter-family communication, as advocacy groups importantly recognize, is sometimes overlooked. Families often don’t know how their family members with IDD/DD would benefit from remote supports. For example, as mentioned previously, there has been considerable misunderstanding of what remote supports consist of and how they operate.

Sharing positive experiences, especially case histories and personal experiences, can be highly influential in decisions surrounding their adoption. Advocacy organizations can be particularly effective in this arena, forming and advising local chapters that serve as champions of high-performing strategies that aid their members. Ensuring that families have the latest information on new developments in technology – even inviting them into discussions on technology development that might better serve their family members with ID/DD – can be an effective way to persuade state agencies to incorporate such technologies in their programs.

Service Providers

Administrative challenges can be significant in managing technology support services. Recruiting and training staff at all levels can be a significant burden. Such issues affect every disability services agency. Giving priority attention and resources to these challenges could significantly expand the use of remote supports and increase the number of people who could benefit from them.

Case Managers, Direct Support Professionals and Other Members of the Support Team

As has been discussed earlier in this document, digital and technology education is a critical element for adoption and retention of remote support services. If team members are not enthusiastic about the role of technology solutions in helping the people they serve to achieve their personal goals, or if they are presented as simply neutral, it is possible, even likely, that they will not be a central element in an individual service plan. When positive towards technology, support team members can serve as trusted guides who will help their clients achieve more than they might have expected. Through digital literacy education, the role of DSPs can be further professionalized. Once trained they can actually become technology ambassadors within their organizations and communities.

Advocacy Organizations

There are dozens of advocacy organizations that work to support the disability community, not only to help families and caregivers, but also to influence state and federal public policy. These organizations have a great deal of influence in the local communities with which they routinely work. There are talented and accomplished people working in these organizations who have succeeded in making changes to laws that positively impact the communities they serve, but few have made concerted efforts to provide technology education to their audiences. Including such organizations in technology literacy education programs for people with ID/DD would expand their vision around technology in general and remote supports specifically. Alliances with advocacy organizations can advance the interests of states that want to incorporate technology solutions in their person-centered planning by educating those who are not yet considering such solutions as to their value.

Recommendations

There is much literature on the importance of technology in contemporary life, and a broad consensus that technology can greatly enhance self-determination for people with ID/DD. There is also considerable evidence that singles out the value of remote supports (Brent & Tanis, 2020; Clauson, 2020; Tassé et al., 2020).

The impact of technology on the quality of life of those using it is under study, but early indications suggest that the data are positive, in which case there is some urgency in ensuring that those most in need of it can secure it without having to wait months or years.

The following compilation is an amalgam of ideas that are already in circulation, plus some that are original to this study group. All should be considered as a means to support a population of individuals who wish for more autonomy, more privacy, improved self-direction, better access to health care services, and increased personal safety in pursuit of their own ideas of the life they desire.

Champion the concept of self-direction, enact streamlined policies that support it, and make them standard among states.

Many studies have demonstrated positive outcomes for people who choose remote supports in order to achieve personal goals of satisfying human interactions, meaningful work, and community involvement (American Association on Intellectual and Developmental Disabilities, 2020; DeCarlo et al., 2019). Although its administration might be regarded as more complex, the answer is not to increase the number of rules and regulations that govern a self-directed model. Rather, it behooves both state and federal administrators to reduce regulations that prevent the model from working. The benefits of self-directed programs aided by remote supports and other technology solutions are too great to remain a hindrance to adoption.

Build partnerships with technology companies that are developing remote support services on a continuing basis.

Corporations and academic researchers involved in the evolution of such services are natural constituencies for those on the frontline of serving ID/DD individuals. Much has been learned at the annual Consumer Electronics Showcase and many other such events that bring researchers and industry together to form public/private partnerships that can result in collaborative research grants. All of these activities point to the direction that technology may be taking that could be beneficial for this community. There are already programs that provide Continuing Education credits for those who take courses in areas that advance ID/DD support services; these programs can be expanded.

Convene an annual technology conference for state and federal agencies, or include such a conference in the programs of national organizations.

This will help bring the attendees up to speed on technology innovations that are applicable to individuals with ID/DD, inviting speakers with the most innovative or promising practices in the field.

Fund research that investigates the impact of remote support services.

There are some indications that remote supports are beneficial, but the evidence is still nascent and limited in quantity. Evaluations should be prioritized, especially as adoption of these services expand. The potential for remote supports to promote independence, safety, and self-direction, and curb the DSP crisis referenced previously, are all reasons to ensure that these services are introduced in a way that maximizes these benefits.

Address directly concerns that some states report as barriers to adoption.

In a recent study of states that offer some form of remote support services, four reported having no problems with implementation, while eleven had some difficulties (Wagner et al., 2022). The issues involved a variety of concerns that should be studied and addressed even while expectations are that these services will offer the benefits that have subjectively been noted.

- Promulgate the accurate definition of remote supports among those who may have misconceptions about what they are and how they work.**

Provide evidence in the form of videos, interviews with users and families of users, or articles in advocacy organization newsletters that expand the awareness of these important innovations.
- Track the growth of remote supports in states, identify changes to improve their services, and contact users of remote supports to survey them about their experience.**
- Create a national peer-to-peer video library that informs families about the benefits of remote supports in a self-directed service model via real-life case histories.**

Some states already have such programs in place, and their availability could be publicized.
- Form strong links with advocacy organizations that focus both on families of people with ID/DD or other disabilities and organizations of self-advocates to build strong community support and education for families.**
- Create a national resource and technical assistance center endorsed by the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR) or the Administration for Community Living (ACL) through which those wishing to promulgate Technology First principles can advance policy, practice, and research.**

This group could serve as consultants, or technology ambassadors, to state policy directors. Although there are many experts in this area who are likely providing such advice, conferring an “endorsed” status could accelerate the process by which Technology First outcomes are achieved.
- Form a new technical assistance center as part of the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act.**
- Design a communications program aimed at the general public.**

Public support for expanded local funding of ID/DD technology initiatives and education on the capabilities of those with ID/DD to join mainstream education or work programs would further confirm the value of remote supports.
- Prioritize data collection methods that allow states to track the growth of remote supports in their states, identify changes to improve the service, and contact users of remote supports to survey them about their experience.**

There are other steps that can be implemented to further the goal of accelerating the adoption of remote supports, and more research that should be conducted on their efficacy for users and their families about their economic benefits. If even a few of the above recommendations were implemented, however, the benefits would be enormous. That is the outcome we, from our different perspectives and disciplines, desire above all.

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