

Capstone NEWSLETTER

Remote Supports For People With Disabilities

Posted 6/23/2020 via Capstone Newsletter By Michael Clausen | CQL Quality Enhancement Specialist

Living through a pandemic has forced us to become more reliant on technology to communicate, support, connect, and remain productive. We are all working to be physically distant while remaining socially and emotionally connected. As technology becomes more ubiquitous throughout our lives, the possibilities of what we can achieve through technology has become even greater. There is vast potential in using technology to support people with disabilities. Remote supports offer innovative technology-based solutions to people who are looking for something other than traditional 24/7 in-person staff support.



At a very basic level, remote supports are a tool for communication. This includes communicating when someone is in danger, needs support, or has veered from a typical routine. The hardware itself is a tool that requires human input and a human response. Sensors and communication devices produce an alert that can be responded to by a natural support such as a neighbor, or a staff member who is either nearby or in a remote call center. Devices are typically integrated through a central hub, and individualized plans developed ahead of time define the parameters.

Remote supports are usually delivered as part of a package of support that includes natural supports, paid supports, and enabling technology, such as smartphones, environmental controls, automated medication dispensers, and communication devices.

Technology is most effective when it is designed around the person and connected to goals and outcomes. As with more traditional supports, remote supports ideally will be continuously evaluated, modified, and/or faded over time.

Remote Supports: Types of Devices

The broadest category of remote support devices are sensors such as motion detectors, door and window sensors, bed and chair sensors, smoke and carbon monoxide detectors, and fall sensors. These devices use previously defined parameters to produce an alert when something happens that is atypical of a person's usual routine. If a sensor detects that a person has not gotten out of bed at their usual time, someone can be alerted to check on the person. Fall sensors or smoke detectors can notify emergency responders if it is needed.

Two-way audio devices allow someone to contact staff, or for staff to check in with the person. Personal safety equipment such as a personal alert device can also be worn by the person to help if there is an emergency. Video doorbells can be integrated into remote support systems to allow the person and others to see who is at the door.



Another category of devices involves video monitoring in the interior of a home, although they are ethically fraught (Hayward, 2017). While there may be some perceived benefit to watching a person remotely to monitor their activities or ensure their well-being, the use of video surveillance inside a home should be considered restrictive and intrusive.

The Ethical Implications of Remote Technologies By Carli Friedman | CQL Director of Research

Research suggests some remote technologies have benefits, such as increasing staff productivity, helping with staff shortages, or helping people stay in the community (Hayward, 2017); however, this technology also has a potential for serious ethical implications. For example, while research has found that many staff and managers feel remote technologies, such as telecare, allow people receiving services to be safe and secure, at the same time, research has also found that people receiving services felt stigmatized by the use of these forms of technologies (Brewer et al., 2010; Niemeijer et al., 2015).

Remote technologies are often implemented to increase safety, efficiency, and/or to promote autonomy (Hayward, 2017). Yet, remote technologies can also infringe on people's privacy, freedom, and confidentiality (Boström et al., 2013; Hayward, 2017; Niemeijer et al., 2015; Zwijsen et al., 2011). Some people receiving services have said that these technologies are stigmatizing and that they do not want to be watched (Hayward, 2017; Niemeijer et al., 2015). Remote technologies also can conflict with people's right to dignity (Hayward, 2017). In some cases, remote technologies can even serve as a form of restraint (Hayward, 2017). It is also important to note that in many countries, including the United States, surveillance technologies have always been racialized – utilized to surveil and police people of color unequally and unjustly (Hilton, 2017).

When utilizing remote technologies, there must be a balance between privacy, safety, and people's rights (Niemeijer et al., 2015; Zwijsen et al., 2011). Problematically, these types of technologies are often implemented without ethical guidelines and/or protocol (Niemeijer et al., 2013). Godwin (2012) suggests the following ethical checklist to determine if these technologies should be used:

- 1. "For whose benefit is the equipment being used? Consider who is the real beneficiary.
- 2. Whose definition of benefit is being applied? Would technology use primarily benefit the person [receiving services], the [staff] and/or the [provider]?
- 3. What are the potential effects of the technology on the wellbeing of the individual and his or her [staff]? Does it support the person's autonomy or simply reduce risk? How can a balance be struck, ensuring the wellbeing of both parties?
- 4. What are the actual or potential, active or passive detrimental effects of the technology? An individualized risk and wellbeing assessment is needed.
- 5. What are the costs and benefits (physical, emotional, psychological, ethical, financial) of using technology, and to whom do they apply?...
- 6. What is the real (not hypothetical) alternative to the use of this piece of [technology]? Consider the effect of [technology] use on the person's [future]." (p. 131)

An Individualized Approach To Remote Supports

By Michael Clausen | CQL Quality Enhancement Specialist

When focused on the person, remote supports can be an effective and cost-conscious tool. While there will always be potential challenges or hypothetical scenarios where remote supports may fail, this is also true for other types of support. It is always possible to imagine a "What if?" for any situation, and remote supports may not be the right type of support for every person. As with traditional supports, remote supports should be individualized, implemented with the person's input, and modified as needed. Organizations must have policies and procedures that protect people utilizing remote supports and maintain ethical guidelines that support privacy and security.

Organizational Perspective on Remote Supports

Remote supports provide a more customizable menu of services while offering greater independence due to less reliance on staff. Pressures in the direct support professional (DSP) workforce have created an impetus to alternative forms of support. With an average turnover rate of 44% for DSPs in the United States (National Core Indicators, 2018), there is clearly an incentive to look for alternative approaches to meeting people's needs.

Core Services of Northeast Tennessee has developed expertise in remote supports. The organization uses bed sensors to indicate when someone has gotten up for an extended period of time outside of a usual routine. They also use sensors that detect if a stove has been left on. Exterior cameras, such as Ring doorbells, are being used to provide protection or can indicate when someone has left unexpectedly. Two-way communication devices allow people to connect with a remote support person if needed. They also pair remote supports with other enabling technology such as automated medication dispensers, iPads, and smartphones.

"We can give people the support they need without being intrusive."

- Nick Filarelli, Core Services of Northeast Tennessee

Nick Filarelli, Program Director for Core Services of Northeast Tennessee, shared "People want independence. Technology is one more tool in the direct support toolbox that can be used to customize services to the needs/desires of the person receiving them. We can give people the support they need without being intrusive. Technology has benefitted every facet of life and every industry so naturally this should also apply to supporting people with intellectual and developmental disabilities."

The organization notes that in designing a program, it is important to acknowledge each person's unique needs. Starting with the person, the organization works outwards and focuses on desired outcomes. Mr. Filarelli notes that, "It is easy to get lost in the gadgets and lose sight of what the true focus should be. A provider agency must have a solid person-centered foundation at its core."

A Person Who Receives Services' Perspective on Remote Supports

There are a number of benefits involving remote supports. As with any type of support, the use of technology should be focused on enabling individual, organizational, and systems outcomes. For individuals, the benefits include less reliance on support staff and the opportunity for greater independence. For many people, using technology is a way to achieve their dream of living in a home or having greater independence.

"I want to remain independent for as long as possible and be safe as well."

- Pat O'Neil

Pat O'Neil is a person supported by Core Services of Northeast Tennessee who uses remote supports and enabling technologies. "I want to remain independent for as long as possible and be safe as well," shares Mr. O'Neil. He enjoys the independence and security that remote supports provide. Mr. O'Neil has a Ring doorbell, an emergency button if he needs help, and a medication dispenser that reminds him when to take his medications. An Amazon Echo also assists him with other reminders throughout the day. While he has made great progress, he notes that "It is not easy to learn technology in your seventies."

Systems Perspective on Remote Supports

There is also a strong motivation for governments and service systems to provide the framework and resources for remote supports. According to ANCOR, the number of people in the United States likely to need long term services and supports is projected to rise from 12 million in 2010 to 27 million by 2050 (ANCOR, 2014). Because remote supports cost significantly less than in-person staff supports (Wager, Tassé, Davies, & Stock, 2018), there is potential to serve more people with the same financial resources.

Some states have become "technology first" states, like Ohio, Missouri, and Tennessee. While the regulatory definition is different from state to state, this term generally implies that the state has an active plan to increase the use of technology throughout the service system. In Ohio, the definition is more literal. Technology, rather than in person staff supports, is the first option provided to those seeking services (Threnhauser, 2019). While the total amount invested in relation to overall waiver funding continues to be relatively small (Friedman & Rizzolo, 2016), some states have now included remote support funding as part of their waiver programs, or have provided other sources of funding to enable their use.

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