



People with Intellectual/Developmental Disabilities (I/DD): Telehealth Overview

Introduction

Approximately eight percent of individuals dually eligible for Medicare and Medicaid under the age of 65 have an intellectual disability or related condition.² People with intellectual and developmental disabilities (I/DD) face disproportionate barriers to receive whole-person centered healthcare;³ not only do access-related challenges exist, but it is often difficult to find an adequately trained provider who is knowledgeable in both medicine and intellectual or developmental disabilities.⁴ The COVID-19 public health emergency (PHE) further exposed these inadequacies and care gaps in the system, and many organizations have responded by seeking to improve care delivery via telehealth.⁵

Telehealth has been increasing in popularity and usage in the US healthcare system over the past 12 years.⁶ However, despite marked strides in increasing access for older adults and individuals in rural areas, it wasn't until the COVID-19 PHE that many organizations and policymakers realized the positive impact telehealth could have on individuals with I/DD.⁷

Health plans can utilize the information in this brief to further their understanding of how telehealth modalities can improve access to person-centered care for people with I/DD.

I/DD Impact

Research suggests that individuals with I/DD are more likely to experience poor health, have unmet healthcare needs, be a victim of abuse (such as sexual abuse) and not live as long as people without intellectual or developmental disabilities. Analyses of South Carolina's Medicaid data showed that from 2001-2011, Medicaid members with I/DD had more than 21,000 potentially avoidable visits to the emergency department.¹

¹ CDC (2019). *Addressing Gaps in Health Care for Individuals with Intellectual Disabilities*. Retrieved from <https://www.cdc.gov/grand-rounds/pp/2019/20191015-intellectual-disabilities-H.pdf>.

² Medicare Payment Advisory Commission and the Medicaid and CHIP Payment and Access Commission. (2018). *Data Book. Beneficiaries Dually Eligible for Medicare and Medicaid*. Retrieved from: http://medpac.gov/docs/default-source/data-book/jan18_medpac_macpac_dualsdatabook_sec.pdf?sfvrsn=0.

³ CDC (2019). *Addressing Gaps in Health Care for Individuals with Intellectual Disabilities*. Retrieved from <https://www.cdc.gov/grand-rounds/pp/2019/20191015-intellectual-disabilities-H.pdf>.

⁴ Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). *Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review*. <https://doi.org/10.3399/bjgpopen20X101030>.

⁵ Jercich, K. (2021). *Telehealth as a tool to keep people with disabilities out of the hospital*. Healthcare IT News. <https://www.healthcareitnews.com/news/telehealth-tool-keep-people-disabilities-out-hospital>.

⁶ American Hospital Association. (2019). *Fact Sheet: Telehealth*. Retrieved from <https://www.aha.org/factsheet/telehealth>.

⁷ Young, D., Edwards E. (2020). *Telehealth and Disability: Challenges and Opportunities for Care*. National Health Law Program. Retrieved from <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

Background

Telehealth, also referred to as “telemedicine,” encompasses a variety of technological modalities that aim to deliver care outside of traditional in-person, “brick and mortar” healthcare establishments. Telehealth currently includes four main types of technology:⁸

- **Live video (synchronous):** This modality utilizes devices such as computer monitors, tablets, and smartphones to facilitate live, two-way interaction between the patient and provider.
- **Store-and-forward (asynchronous):** This utilizes secure networks to enable providers to communicate with their patients about data (e.g., x-rays or prerecorded videos) through a secure portal that allows access to data after it has been collected.
- **Remote patient monitoring:** This technology strives to collect patient data through different sources (e.g., Holter monitors to track cardiac rhythms). The data is uploaded and transmitted to a provider in a different location who can then draw inferences and direct care based on this data.
- **Mobile health (mHealth):** mHealth is a broader form of patient engagement that offers public health programs via devices such as cell phones and tablets. Applications can focus on promoting health behavior or notifying groups of people about disease outbreaks in their areas.⁹

Research shows that organizations have increased their use of telehealth technologies to better serve individuals with I/DD. Some reported benefits of telemedicine for people with I/DD include lower cost of care, lower transportation costs, improved medication reconciliation communication, and less exposure to communicable diseases especially during the PHE.¹⁰ By assessing the impact of telehealth on individuals with I/DD, healthcare providers can continue to adapt and innovate ways to better serve people with I/DD through the use of various telehealth modalities.

Impact of Telehealth

The telehealth landscape for individuals with I/DD is still emerging, but many organizations and providers have secured funding to pilot innovative telehealth programs for individuals with I/DD.¹¹ Examples of the benefits that expansion in telehealth could offer for this population include:¹²

1) Reduced Emergency Department (ED) Utilization and Increased Cost Savings

⁸ Altarum Healthcare Value Hub. (2017). *Telemedicine: Decreasing Barriers and Increasing Access to Healthcare*. Retrieved from <https://www.healthcarevaluehub.org/advocate-resources/publications/telemedicine-decreasing-barriers-and-increasing-access-healthcare>.

⁹ Ibid.

¹⁰ Agha Z., Schapira R.M., Maker A.H. Do we want to talk about cost effectiveness as a benefit? Cost effectiveness of telemedicine for the delivery of outpatient pulmonary care to a rural population. *Telemed J e Health*. 2002;8(3):281–291.

¹¹ UNH Today. (2021). *Telehealth and Individuals with IDD: Challenges and Best-Practices*. Retrieved from <https://www.unh.edu/unhtoday/2021/12/telehealth-and-individuals-idd-challenges-and-best-practices>.

¹² Young D., Edwards E. (2020). *Telehealth and Disability: Challenges and Opportunities for Care*. National Health Law Program. Retrieved from <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

- In 2018, aggregate ED visit costs totaled \$76.3 billion across \$144.8 million ED visits in the United States.¹³ ED and hospital utilization among individuals with I/DD significantly contributes to rising healthcare costs. Some organizations have begun to successfully target this challenge with innovative telehealth solutions.
 - For example, in 2018, Partners Health Plan (PHP)¹⁴ partnered with StationMD¹⁵ to offer telehealth services to their members, ultimately resulting in fewer ED visits and reduced costs of care.¹⁶ Through the StationMD mobile App, PHP members can initiate a video conference call with a StationMD Board Certified Emergency Room physician 24 hours per day, 365 days per year (a landline option is also available for non-smartphone users). Most commonly, the StationMD physician will treat the member virtually, including prescribing the appropriate medications and following-up with the patient as needed. If medically appropriate, the physician will instruct the member to present physically to the ED. In this case, the provider at StationMD has access to the patient's chart and will collaborate with care managers at the hospital, overall creating a much more seamless and less stressful interaction with the healthcare system. According to PHP, approximately 1,100 PHP members had access to StationMD's telehealth service during the 12-month pilot program, and of the 679 telehealth calls placed to StationMD, StationMD was able to resolve 90 percent of medical problems in the virtual environment. PHP is also focused on cost savings: a 12-month pilot of PHP's telehealth program demonstrated \$2.2 million savings in ED and hospitalization costs, \$20,800 savings in transportation costs, and savings of up to \$1,900 per member in medical cost.¹⁷ Please see [this spotlight](#) for additional information about PHP.

2) Overcoming Transportation Barriers

- Public transportation varies greatly by location in terms of access, affordability, and schedule. If a person can safely commute and has the means to afford it, public transportation can be an effective way for people to access healthcare services. Members with I/DD are often disadvantaged financially and may have physical barriers to commuting, rendering standard public transit options quite difficult. Specifically:
 - Paratransit services (ridesharing, car or van pools, demand responsive buses, and other public transit services, which are characterized by their nonscheduled, non-fixed route nature¹⁸) typically need to be scheduled a day in advance, are not available everywhere, and are often expensive.

¹³ AHQR (2020). *Costs of Emergency Department Visits in the United States, 2017*. Retrieved from <https://www.hcup-us.ahrq.gov/reports/statbriefs/sb268-ED-Costs-2017.jsp#:~:text=In%202017%2C%20aggregate%20ED%20visit,cost%20per%20visit%20of%20%24530>.

¹⁴ PHP is a not-for-profit managed care organization focused solely on services and supports for individuals with I/DD and those who care for them.

¹⁵ StationMD is a physician service that provides care to individuals with I/DD via virtual telehealth consultations. All of StationMD's providers are Board Certified Emergency Room Physicians who have additional training in caring for individuals with I/DD.

¹⁶ StationMD (2021). *New Partnership Improves Care and Reduces Costs for People with Disabilities*. Retrieved from <https://stationmd.com/press-release-new-partnership-improves-care-and-reduces-costs-for-people-with-disabilities/>.

¹⁷ HomeCare Magazine. (2021, July 6). *New Partnership Improves Care & Reduces Costs for People with Disabilities*. Retrieved from <https://www.homecaremag.com/news/new-partnership-improves-care-reduces-costs-people-disabilities>.

¹⁸ Meriam Webster. Retrieved from <https://www.merriam-webster.com/dictionary/paratransit>.

- Rideshare options like Uber and Lyft are expensive and often not accessible for people with physical disabilities.
 - Many people with disabilities, including I/DD, routinely require a caregiver's assistance to leave home which can be problematic if a caregiver is unavailable, is sick, or has other work or obligations.
 - People with social anxiety, agoraphobia, or similar diagnoses may need to avoid busy spaces like those within public transportation or healthcare settings.¹⁹
- Telehealth eliminates these transportation barriers by providing members online or phone access to providers, increasing overall access to needed services and member satisfaction.

3) Improved Access to Specialists

- Members with I/DD often have mental and physical health needs that require the attention of various specialists. Coordination across multiple specialists in different locations with varying schedules creates barriers to care. Specialists are often located in urban areas, furthering the challenges for members who live in rural areas.²⁰ Telehealth is expanding into many subspecialties in addition to emergency medicine and primary care, including dental care, cardiology, endocrinology, genetic counseling, dermatology, psychiatry, oncology, ophthalmology, and obstetrics.²¹

4) Increased Patient Satisfaction

- A systematic review of the literature in 2017 concluded that higher patient satisfaction correlates directly with the availability of telehealth.²² The most cited factors contributing to patient satisfaction include improved outcomes (20 percent), preferred modality (10 percent), ease of use (9 percent), low cost (8 percent), improved communication (8 percent), and decreased travel time (7 percent).
- Premier HealthCare in New York launched a telehealth portal serving members with I/DD in 2019. A regional director stated:

"When we began using the telehealth portal at three of our residences in the Bronx, the differences were striking. Residents who previously had a lot of fear around going to appointments told me that completing their doctor's visit at home made them feel much more relaxed."²³

5) Improved Health Outcomes

¹⁹ Young D., Edwards E. (2020). *Telehealth and Disability: Challenges and Opportunities for Care*. National Health Law Program. Retrieved from <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

²⁰ Bhavaraju N., Nanni J., Carlson C., Sholk J., Peterson K., Smith L. (2022). *Breaking the Barriers to Specialty Care*. FSG. Retrieved from <https://www.fsg.org/resource/breaking-barriers-specialty-care/>.

²¹ Rural Health Information Hub. (n.d.) *Telehealth Models for Increasing Access to Specialty Care*. Retrieved from <https://www.ruralhealthinfo.org/toolkits/telehealth/2/care-delivery/specialty-care>.

²² Kruse, C. S., Krowski, N., Rodriguez, B., Tran, L., Vela, J., & Brooks, M. (2017). *Telehealth and patient satisfaction: a systematic review and narrative analysis*. *BMJ open*, 7(8), e016242. <https://doi.org/10.1136/bmjopen-2017-016242>.

²³ YAI. (2019). *Premier HealthCare Launches "Game-Changing" Telehealth Portal*. Retrieved from <https://www.yai.org/news-stories/press-releases/premier-healthcare-launches-game-changing-telehealth-portal>.

The influence of telehealth on individuals with I/DD is still an emerging field of research and the current body of evidence is limited regarding patient outcomes. However, telehealth on a larger population scale has proven to be an effective modality for providing patient care and improving health outcomes.

- The Agency for Healthcare Research and Quality (AHRQ) published a [white paper](#) based on a meta-analysis which concluded that, “there is a large volume of research reporting that clinical outcomes with telehealth are as good as or better than usual care and that telehealth improves intermediate outcomes and satisfaction.”²⁴
- Studies have shown that health outcomes have improved substantially with telehealth usage. “One study found that 6 percent of patients using telemedicine required a follow up for a similar condition, compared to 13 percent of those visiting a physician’s office and 20 percent of those visiting an emergency department.”²⁵
- The Ohio Department of Developmental Disabilities leads an initiative spearheaded by Dr. Julie Gentile that focuses on providing telepsychiatry services for youth and adults enrolled in Medicaid with a dual diagnosis of Mental Illness and Intellectual Disability. In Fiscal Year 2021, there were over 300 youth enrolled statewide. None of the youth enrolled had a visit to the emergency room for a psychiatric reason.²⁶

Opportunities for Improvement

While there are myriad examples of the ways in which telehealth benefits the dually eligible population with I/DD, there are also usage barriers to consider. Financial constraints can limit internet and device access. There are also patient privacy concerns when caregivers or support staff facilitate discussion between the individual and their provider.²⁷ These issues and others, including licensing, medical errors, and patient safety, are all being studied to hopefully overcome these barriers.²⁸

Next Steps

The impacts of telehealth on individuals with I/DD are still being investigated. The University of New Hampshire recently partnered with the Patient-Centered Outcome Research Institute (PCORI) to specifically evaluate telehealth services on mental health outcomes for people with I/DD.²⁹ Additionally, The Association of University Centers on Disabilities (AUCD) was awarded funding from

²⁴ AHRQ. (2020). *The Evidence Base for Telehealth: Reassurance in the Face of Rapid Expansion During the COVID-19 Pandemic*. Retrieved from <https://effectivehealthcare.ahrq.gov/products/telehealth-expansion/white-paper>.

²⁵ Altarum Healthcare Value Hub. (2017). *Telemedicine: Decreasing Barriers and Increasing Access to Healthcare*. Retrieved from <https://www.healthcarevaluehub.org/advocate-resources/publications/telemedicine-decreasing-barriers-and-increasing-access-healthcare>.

²⁶ Ohio Department of Development Disabilities. (2022). *Annual Report 2022*. Retrieved from https://dodd.ohio.gov/wps/wcm/connect/gov/7f29cc57-5495-47aa-bbac-21714b31e2d1-nJpioKd.21714b31e2d1/DODD+Annual+Report+2021.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGKIK0N0JO00QO9DDDDM3000-7f29cc57-5495-47aa-bbac-21714b31e2d1-nJpioKd.

²⁷ Jessica, H. (2021). *The Need for Disability-Inclusive Telehealth Services*. The National Center for Disability, Equity, and Intersectionality. Retrieved from <https://centerfordignity.com/the-need-for-disability-inclusive-telehealth-services/>.

²⁸ Altarum Healthcare Value Hub. (2017). *Telemedicine: Decreasing Barriers and Increasing Access to Healthcare*. Retrieved from <https://www.healthcarevaluehub.org/advocate-resources/publications/telemedicine-decreasing-barriers-and-increasing-access-healthcare>.

²⁹ PCORI. (2023). *Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities*. Retrieved from <https://www.pcori.org/research-results/2021/evaluation-telehealth-services-mental-health-outcomes-people-intellectual-and-developmental-disabilities>.

the Working for Inclusive and Transformative Healthcare (WITH) Foundation for a one-year initiative to investigate best practices for offering telehealth to people with I/DD.³⁰ There are many other promising initiatives in the pipeline and evidence is still evolving, however, the research thus far is promising, and federal organizations remain invested in this emerging healthcare modality and the impact it has on dually eligible people with I/DD.

The Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) seeks to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. This spotlight is intended to support health plans and providers in integrating and coordinating care for dually eligible beneficiaries. It does not convey current or anticipated health plan or provider requirements. For additional information, please go to <https://www.resourcesforintegratedcare.com/>. The list of resources in this guide is not exhaustive. Please submit feedback to RIC@lewin.com.

³⁰ Association of University Centers on Disabilities. (2021). *Telehealth and Individuals with IDD: Challenges and Best-Practices*. Retrieved from https://www.aucd.org/template/news.cfm?news_id=15753%20Professor%20Kimberly%20Phillips.