In September 2016, the Washington State Department of Health’s Children with Special Health Care Needs Program was awarded the Autism Spectrum Disorder and Developmental Disabilities (AS3D) federal grant. The goal of the grant work is to ensure early diagnosis and entry into services for children with autism spectrum disorder and other developmental disabilities, with a focus on medically underserved and rural populations. One mechanism for increasing diagnosis and access is telehealth. Telehealth encompasses a broad variety of technologies and tactics to deliver virtual medical, health, and education services; telehealth is not a specific service, but a collection of means to enhance care and education delivery. Program staff are working to maximize existing telehealth laws and other infrastructure to increase access to services and to facilitate communication and capacity building among providers. In order to better understand the current landscape for telehealth among families of children and youth with special health care needs, a survey was conducted in summer 2017 to determine caregiver access to technology, interest in telehealth, and barriers that limit telehealth utilization.

Who Took the Survey
There were 118 caregiver respondents included in the final analysis of the survey results. Out of the 118, 106 took the survey in English and 12 in Spanish, 43.5 percent reported having a college degree or higher, 94.4 percent of the respondents were mothers, 71 percent identified as White, 42 percent had Medicaid insurance, the median age of the child receiving services was 8 years old, and 39 percent of respondents had a current prescription for applied behavioral analysis (ABA) services. While the geographic range was wide, this survey should not be considered representative of Washington parents of children and youth with special health care needs as a whole.

DEFINITIONS

mHealth
A form of telemedicine using wireless devices and cell phone technologies.

Telementoring
The practice of developing mentorship relationships between learners and those with more experience in a particular subject or area of expertise; experts are geographically removed from learners and use web and phone-based methods to interact.

Telehealth
A variety of technologies and tactics to deliver virtual medical, health, and education services. For the purposes of this survey, the term “telehealth” will encompass the concepts of telemedicine, telehealth, mHealth, and tele-mentoring.

Acronyms
ABA  Applied Behavioral Analysis
COE  Centers of Excellence for Autism Diagnosis
NDC  Neurodevelopmental Center
CYSHCN  Children and Youth with Special Health Care Needs
TA  Technical Assistance
AS3D  Autism Spectrum Disorder and Developmental Disabilities (federal grant)

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For additional information, email cshcn.support@doh.wa.gov, or call (360) 236-3507.

Top Access Barriers and Concerns
Telehealth could be a vital resource for families/caregivers that experience barriers to health care. Leading issues in accessing care included backlog and transportation problems; a majority of the people that reported these barriers lived in the NW region of the state. Additionally, 22 respondents indicated no delays or difficulties. Caregivers reported the most delays when accessing speech therapy (23), occupational therapy (16), and autism-related or ABA therapy (16).
Interest in Telehealth by Appointment Type
Caregivers reported varying levels of interest in telehealth depending on the types of service provided. Consultation and pre-recorded videos were favored over diagnostic services.

Percentage of Caregivers Interested in Telehealth for Different Services

FAMILIES TELL US HOW TELEHEALTH CAN BENEFIT CHILDREN AND FAMILIES
- It reduces stress for caregivers and children with special health care needs. For example, the child may “not like to leave the house,” “going places sometimes gives [them] anxiety,” or they may have “a hard time in waiting rooms and with doctors in general.”
- It allows for the child to “be in the safety of his own home and it would not disrupt his daily schedule.” This was consistent among both respondents with and without ABA prescriptions.
- Having opportunities to become familiar with a provider from home via telehealth could help reduce anxiety when an in-person visit is needed.
- It cuts down on general wait time and provides greater scheduling flexibility.
- It saves time and money by eliminating commutes to appointments that might otherwise require hours of travel time, especially for families who live outside of cities.
- It increases access to specialists not currently available to the caregiver.

WHAT CAREGIVERS WANT TO KNOW ABOUT TELEHEALTH
- Online providers’ qualifications and credentials.
- The linkage between telehealth appointments and potential in-person follow-up care (e.g., “What types of appointments are best for using telehealth, and which require an in-person visit?”).
- Providers’ familiarity with the child and his/her medical history (caregivers would prefer to use the same doctor as they see for in-person visits, if possible).
- Evidence that telehealth is beneficial/ effective.
- How to minimize technical difficulties and ensure a reliable/secure/confidential online connection.
- Security, privacy, and confidentiality of the live telehealth appointment as well as any video or audio recordings of the appointment that are included in the medical record.
- How the child might engage/respond differently to interaction with a provider through a screen compared to in person and how this could affect quality of care.
- What types of telehealth services are covered by insurance and what out-of-pocket costs (if any) to expect.

To access the Telehealth Capacity Assessment full report and the executive summary, please go to: https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/HealthandSafety/ChildrenwithSpecialHealthCareNeeds/Publications