Creating Connections:

Addressing the Needs of Children with Autism and Other Developmental Disabilities Using Telehealth



2017 Capacity Assessment

Executive Summary

WASHINGTON STATE DEPARTMENT OF HEALTH

Introduction

Telehealth remains an untapped resource for providing services to children and their families across the state. Our assessment, conducted in 2017, shows that there are inadequate numbers of providers and applied behavior analysis (ABA) providers specifically to meet the needs of children with autism spectrum disorders and other developmental disabilities. This is especially true in rural and urban regions of Washington, resulting in long waiting times for diagnostic and treatment services. In order to use telehealth to address this issue, we will need to build capacity across the state to use this technology.

To better understand the current telehealth landscape and potential barriers providers and caregivers may face, the Autism Spectrum Disorders and Other Developmental Disabilities (AS3D) Initiative at Washington State Department of Health reviewed Medicaid coverage, state laws and rules, and conducted a provider capacity assessment, a family and caregiver survey, and key informant interviews with a variety of providers (e.g., psychologists, physicians, and behavioral technicians). This report shares recommendations for expanding the existing telehealth infrastructure which will be incorporated into a strategic plan to be released in 2018.

Provider Capacity Assessment

The goals of the provider capacity assessment were to understand the current capacity of health care providers to offer telehealth services, to understand challenges that limit capacity, and to determine if providers needed technical support around telehealth for children with autism spectrum disorders and other developmental disabilities (ASD/DD). The survey focused on the capacity for telehealth in neurodevelopmental centers (NDCs), Medicaid-designated centers of excellence for autism diagnosis (COEs), and applied behavior analysis (ABA) providers.

Results

According to the results, an average of 60 percent of the providers' patients were covered by Medicaid. Many providers reported concerns about their ability to bill and be reimbursed by Apple Health (Washington State's Medicaid program) for telehealth services for children with autism spectrum disorders and other developmental disabilities, for physical, speech, and occupational therapies and ABA services. Lack of equipment and funding were also top barriers to the implementation and use of telehealth. Among providers that are not yet offering telehealth services, "provider training" and "lack of technical knowledge" were common barriers. Providers were also concerned with privacy, HIPAA compliance, and malpractice liability related to virtual appointments. Among survey participants, the demand among patients for telehealth services would need to increase in order to justify the additional investments necessary to provide those services. Southwest and Eastern Washington have the lowest percentage of providers offering any telehealth services (22 percent each), which represents an opportunity for outreach in those areas to expand telehealth capacity.

> "Driving to and from appointments can add up financially. Any money I can save there, I can apply towards other care that we currently can't afford." **Response from the Caregiver Telehealth Survey, "Can You Hear Me Now?"**

AS3D Key Informant Interviews

Key informant interviews were conducted to supplement the information given by providers in the provider capacity assessment. The goal of the key informant interviews was to learn from a variety of providers (e.g., psychologists, physicians, and behavioral technicians) about their experiences with telehealth for children with autism spectrum disorder and other developmental disabilities. The interviewees were selected based on experience and expertise using telehealth and were identified through AS3D partnership activities.

RESULTS

While there is a fair amount of support among providers for the use of telehealth, there are barriers that need to be addressed. Providers wanted more information on how to bill and get reimbursed for telehealth services and want clarity (training and clearly written insurance policies) on exactly what is currently billable according to insurance, including Medicaid. Additionally, providers want training on setting up a telehealth program to include how to train staff. Providers also wanted information on standards of care for services delivered via telehealth as well as information on how to access language interpreters.

Family and Caregiver Survey

The purpose of the family and caregiver survey was to assess how caregivers of children and youth with special health care needs (CYSHCN) perceive telehealth services and what telehealth services might mitigate or eliminate. This survey included families and caregivers of children with special health care needs, including autism spectrum disorders and other developmental disabilities.

"My son gets distracted in new environments. He is fearful of many things so it's hard to gauge when something may trigger his anxiety. I also have a three year old at home, and very few sitter options, so being able to utilize telehealth service would relieve a lot of stress." **Response from the Caregiver Telehealth Survey, "Can You Hear Me Now?"**

RESULTS

The most common barrier (reported by caregivers) to accessing health care services was waitlists. The second greatest challenge was transportation. The third most common challenge was having access to providers in their communities. Caregivers reported experiencing delays with speech, occupational, autism-related therapies including ABA therapy, and other behavioral or social therapy. Caregivers also noted insurance coverage as a barrier to services access. They are most receptive to trying telehealth for consultation or coaching and to access pre-recorded videos. Half of participants would consider using telehealth to learn how to do ABA therapy with their child, and 37 percent were open to using it for diagnostic services.

Caregivers also reported that they would want to have a clearer understanding about the "qualifications of the provider," in the case where the telehealth provider is different from the provider they have been seeing in person. When asked about potential benefits of using telehealth, caregivers noted the following advantages: reduced stress related to leaving the home environment and long commutes to a doctor's office, greater scheduling flexibility and shorter wait times for appointments, saving time and money on transportation to appointments, and having access to specialists in other areas.

"Pues que sería algo muy bueno, especialmente para los padres solteros como yo. Nos ahorraría mucho tiempo... Las ventajas serían que podría hacer las citas médicas más rápidamente. Además de que no tendría que preocuparme por transporte."

[Telehealth] would be a very good thing for single parents like me. It would save us a lot of time... I would be able to make the appointments a lot faster. Moreover, I would not have to worry about transportation. Parent Interview

Conclusions/Recommendations

Overall, the capacity assessments show that caregivers are very interested in using telehealth to receive services and that providers see it as a viable option for their practices. Both caregivers and providers see telehealth as a way to support consultation, screening, diagnosis, functional analysis, applied behavioral analysis supervision, and parent coaching or training. Washington Medicaid covers many services that are allowed to be delivered via telehealth.

However, there are barriers to successful implementation. These include lack of knowledge on how to use telehealth technology, a need for infrastructure (for example, internet bandwidth large enough to support telehealth), start-up costs, equipment and maintenance, billing and reimbursement questions, a need for appropriate equipment for active children, insurance policies that do not include telehealth, and questions about Health Insurance Portability and Accountability Act of 1996 (HIPAA)-compliant telehealth. Further supports are needed around how to access interpreter services for children and families receiving ABA services. Technical assistance related to billing and reimbursement for telehealth services should be considered a priority.

Overall, the information gained from the literature, key informant interviews, and the surveys support the need for parent/caregiver and provider training. Additionally, having a person who is the single-point of contact for telehealth in the state would help advance telehealth throughout the state. This contact could be a resource for information and technical assistance for providers and families as well as drive the development and testing of telehealth services for children with autism spectrum disorders and other developmental disabilities would greatly assist the advancement of telehealth.

"Sí. Las ventajas van a ser eso... que van a estar allí las 24 horas... a todo momento. Que va a ser al momento. O sea, cuando sea algo ligero no vas a tener que sacar al niño de casa. Esas van a ser las ventajas, creo yo."

The advantage [to telehealth] would be that they are going to be available all 24 hours, at any time of day. That is going to be instantly. Meaning that when you need to consult about something easy, you do not have to take your child outside the house. That is going to be an advantage, I think. **Parent Interview**



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