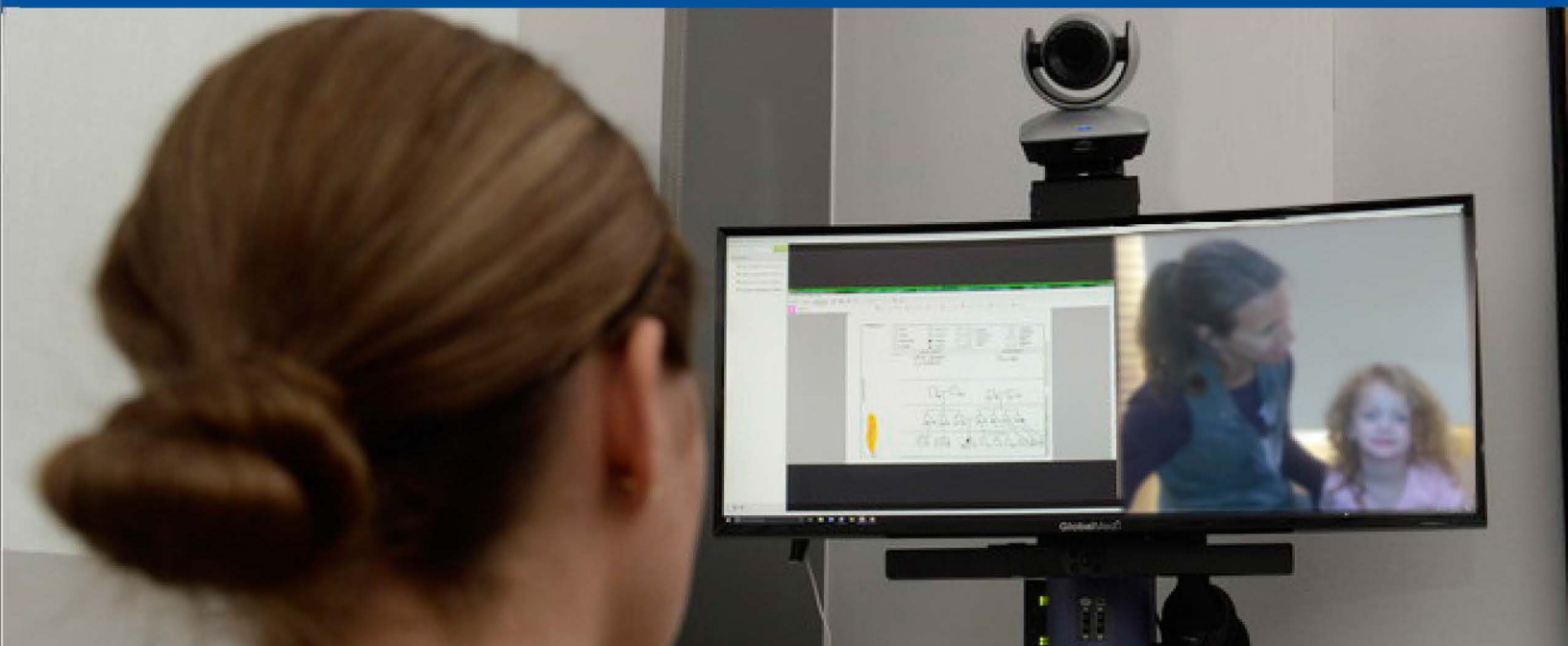




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ISSUE BRIEF 2019

Improving Access to Autism Assessment and Intervention Through Telehealth



The Wisconsin Care Integration Initiative (WiCII) project aims to increase family-centered, integrated systems of care for children with autism spectrum disorders and other developmental disabilities (ASD/DD), with a particular focus on medically underserved people in rural and urban settings. The project period was funded to the Waisman Center University Center for Excellence in Developmental Disabilities (UCEDD) at the University of Wisconsin – Madison from September 2016 thru August 2019.

One of the strategies being promoted through the Wisconsin Care Integration Initiative is the use of telehealth, with this brief as one result of the work. For more information on the content of this brief, please contact:

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Overview of Issue

- The prevalence of autism spectrum disorder continues to increase in the United States.
- Access to early diagnostic assessment and intervention has not increased at a level required to meet the demand for these services.
- Diagnostic assessments and intervention services may not occur until well after concerns arise and/or after critical developmental periods have passed.
- Telehealth technology provides a way of bringing state-of-the-art assessment and intervention services to families facing geographic or scheduling barriers to obtaining care.
- A growing body of research demonstrates effectiveness and acceptability of telehealth practices for autism as well as the potential to reduce disparities in access to services.

Background

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by challenges with social communication and interaction and restricted and repetitive behaviors/interests.¹ The newest research indicates that approximately **1 in 59 children have ASD**.² Due to this increasing prevalence, there is a growing need for both ASD diagnostic assessments as well as evidence-based treatment for ASD.

The importance of early detection and intervention for ASD has long been documented.³ Unfortunately, while many children and families are in need of these services, there are often barriers to accessing them. People in rural communities report increased difficulties and delays in accessing appropriate and timely care,⁴ including longer delays in obtaining an ASD diagnosis than families in urban areas.⁵ Mello and colleagues⁶ identified that behavioral

Background, continued

services were reported by both rural and non-rural families to be the service their child with ASD needed most; however, rural families were less likely to implement behavioral supports in home, reporting that this was not an available service where they lived.

Currently, in Wisconsin, ASD assessment and intervention services are largely provided via face-to-face meetings with providers in a clinic setting. There are some treatment providers who serve families in other settings (e.g., home, daycare); however, this is limited, and there are areas of the state in which receiving in-home treatment is not an option for families. This presents particular challenges for families who do not live near centers that specialize in ASD, as they must travel far distances to access ASD services. Traveling to clinics for care can also pose barriers to families living in more urban areas for whom transportation challenges and/or psychosocial difficulties (e.g., work schedules, childcare for other siblings) can make navigating to outpatient healthcare appointments time-consuming and burdensome. These challenges occur in addition to barriers families across the state are facing with regard to limited capacity and long wait times for many assessment and intervention services.

There is a clear gap in needs for children with ASD that is not being met with the current model of service delivery.

Telehealth

Telehealth is a method of service delivery that can help alleviate the barrier of distance for families to obtain high quality care. Telehealth technology allows for providers with expert knowledge to connect from their center to other locations, such as rural clinics, homes, and schools to expand families' access to state-of-the-art services. Research has identified promising results for delivering services across several specialty areas via telehealth, such as emergency medicine and psychotherapy.

Telehealth has been utilized for multiple facets of service delivery, including:

- Direct provider care with a patient and/or family, including assessment and intervention, which are services directly reimbursable by insurance
- Specialty care providers training and consulting with community-based professionals (e.g., school teams, primary care physicians) to expand local capacity; these services are currently non-reimbursable by insurance but critical to service expansion

Telehealth Defined

Telehealth is used in this brief as a broad term referring to the use of electronic communication and information technologies to provide clinical services (also called telemedicine) as well as the broader application of these technologies to distance education, consumer outreach, and provider consultation to support healthcare services when the provider and recipient of the services/education are at different geographic locations.

Advantages of Telehealth

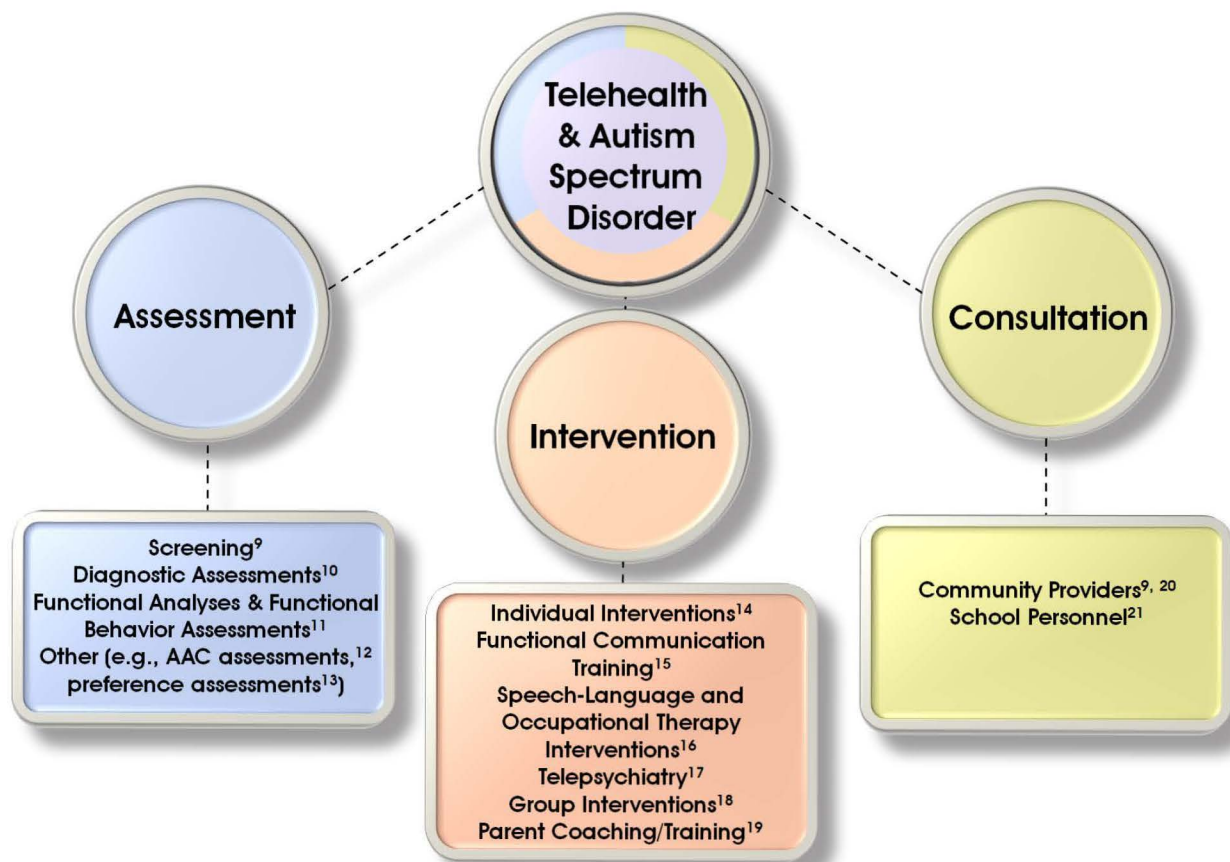
Advantages of using telehealth include allowing providers to use their clinical time in the most impactful way possible and by providing direct care during clinical hours rather than spending a large portion of their day traveling to remote sites (informally called “windshield time”). Additionally, research has found telehealth to be a cost-effective method for patients to obtain high-quality healthcare, with cost savings for both healthcare systems as well as individual families.^{7,8} In some areas of medicine, studies have found the use of telehealth to improve patient outcomes over standard of care practice.⁷

INCREASING ACCESS TO TIMELY AUTISM ASSESSMENT

Project ECHO is a learning and guided practice model in which expert teams provide training and consultation to community providers on a specialty care service through videoconferencing. Project ECHO has been used in a variety of specialty care areas (e.g., cardiology, infectious disease, substance use disorders) in countries around the world. Researchers have investigated the use of this model in ASD and found promising results.²⁰ Areas investigated include: compliance with ASD screening guidelines, use of ASD-specific resources, and diagnostic assessments for ASD.

The News Bureau of the University of Missouri recently shared a story (link below) regarding how Project ECHO directly impacted a Missouri family. The article shares how the family had to travel nearly *100 miles and wait 18 months* after initially having concerns about possible ASD to receive a diagnosis for their son. When the family had similar concerns regarding their younger child, they were able to obtain a diagnostic assessment in less than one month because of Project ECHO at the University of Missouri (called ECHO Autism).

<https://munews.missouri.edu/news-releases/2018/0815-mizzou-program-significantly-reduces-delay-in-autism-diagnosis/>



Findings: What does the evidence say?

Researchers have been exploring the **use of telehealth** to deliver a wide range of evidence-based ASD services **across various settings** (e.g., homes, schools, community clinics) and **across populations** (e.g. various ages of individuals with ASD, range of individuals providing services to people with ASD such as school-based personnel, parents, etc.) **with promising results**. Both reimbursable (assessment and intervention) and non-reimbursable services (consultation) have been investigated. A recent review of research regarding use of telemedicine in ASD found that studies have generally supported the potential **effectiveness and feasibility** of utilizing telemedicine in multiple areas of autism assessment, intervention, and consultation.²² See *Telehealth and Autism Spectrum Disorder* figure for specific examples of ASD services that have been explored by researchers.

Across many studies, **users have consistently reported high levels of acceptability** with ASD services delivered via telehealth.²² These studies have also shown promising results in terms of potential **effectiveness** of ASD services provided via telehealth. Study findings suggest that telehealth services can be as effective as similar services provided face-to-face.²³ In some studies, certain variables such as parent fidelity to intervention protocol were higher in the telehealth group as opposed to comparison group of community treatment-as-usual²⁴ or a self-directed intervention group.²⁵ Additionally, the technology to provide services through telehealth exists to make this possible in real-world settings.

INCREASING ACCESS TO AUTISM INTERVENTION SERVICES

A study completed by Lindgren and colleagues⁸ sought to teach evidence-based intervention strategies to parents via telehealth with the aim of decreasing challenging behavior in young children with autism and other developmental disabilities, as well as explore the cost effectiveness of this approach. Parents were taught to implement methods of applied behavior analysis-specifically, through conducting functional analyses (behavioral assessment to inform intervention) and functional communication training (intervention) via one of three delivery models: in-home therapy, clinic-based telehealth, or home-based telehealth. Results from the study indicated a >90% decrease in challenging behavior for child participants across all three delivery models. Parents successfully implemented behavioral treatment strategies regardless of whether the coaching was in-person or via remote video coaching. The home-based telehealth model was the least expensive model after calculating staff costs, facility costs, and family costs. Both home-and clinic-based telehealth treatment models were significantly less expensive than the in-home treatment model.



Telehealth and ASD in Wisconsin

Although research conducted to date has been largely supportive of accessing a range of evidence-based ASD services through telehealth, a critical barrier that remains in Wisconsin is the lack of insurance coverage for these services to be provided via telehealth. While several states have begun approving telehealth for ASD services, Wisconsin has not yet done so. Specifically, neither psychological/developmental testing nor adaptive behavior treatment (autism treatment) are currently covered via telehealth, despite these both being reimbursable services when provided in face-to-face meetings with clinicians. Although psychotherapy could be a covered service when provided via telehealth, only certain providers are able to bill for this treatment code. Additionally, Wisconsin has no legislation ensuring parity; that is, there is no rule stating that providers will receive equal reimbursement for the same service provided via telehealth versus face-to-face.

A promising step occurred in Wisconsin in June 2018 when the Treatment Intervention Advisory Committee (TIAC) of Wisconsin determined that telehealth for behavioral intervention for ASD is a Level 2 treatment on an efficacy scale of Level 1 (Well Established) to Level 5 (Untested/Experimental Treatment and/or Potentially Harmful). TIAC shares treatment efficacy information with the Wisconsin Department of Health Services to ensure that quality services are available to Wisconsin citizens. While this is an initial step to recognizing the benefits of telehealth for providing ASD services, it remains that autism assessment and treatment are not currently covered services in Wisconsin when provided via telehealth.

Next Steps

- Continue to explore the use of telehealth for consultation to build capacity with community providers in rural areas of Wisconsin.
- Educate all stakeholders about the need for insurance coverage of ASD services through telehealth and obtaining parity for telehealth services. Without insurance coverage for telehealth services, Wisconsin families will continue to face barriers of being unable to access needed ASD services, either at all, or without traveling great distances to clinic-based sites. This will lead to the continued disparity that families, particularly those in rural areas, face in accessing healthcare.
- Many of the studies in ASD and telehealth reviewed by Knutsen and colleagues²² were pilot studies. There is a need for more research to continue to establish the effectiveness of telehealth for ASD, particularly for diagnostic assessments.
- Finally, the use of telehealth alone will not reduce other barriers for families in accessing evaluation and treatment services (e.g., long wait lists). Additional efforts will need to be undertaken to address these barriers (e.g., increasing the workforce). The Autism and Developmental Disabilities clinic staff, educators, and researchers at the Waisman Center UCEDD are exploring how to implement a model such as ECHO to increase the capacity of community providers to provide quality ASD assessment and intervention services.

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