

## REALTIME FILE

Association of University Centers on Disabilities  
EARLY IDENTIFICATION OF AUTISM SPECTRUM DISORDERS  
FEBRUARY 25, 2019

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>> Ben Kauffman: Hi, everyone. Welcome to "Early Identification of Autism Spectrum Disorders." My name is Ben Kaufman. [Inaudible; off mic] I would like to thank all of you for joining us today. Before I begin, I would like to address a few logistical details. In a moment I'll be providing a brief introduction of our moderator, Dr. Alacia Stanbrook and following her introduction of the speakers and the speakers' presentations there will be time for questions.

Because of the number of participants, your audio lines will be muted through the presentation. However, we'll unmute your audio lines one at a time. You can submit questions during the presentation via the chat box. You may send a chat to the whole audience or to the presenters only. We'll compile your questions throughout the webinar and address them at the end. Please note that we may not be able to address every question and may combine some questions.

This webinar is being recorded and will be available on AUCD's webinar library. There will also be a short five-question evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar and also to provide suggestions for future topics. So please join me in welcoming today's moderator Dr. Alacia Stanbrook.

Alacia Stanbrook is the Director of Early Learning at the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders, VKC TRIAD. Dr. Stanbrook completed her work at Peabody College, Vanderbilt University, working with young children with Autism Spectrum and their families. As Director of Early Learning, Dr. Stanbrook oversees programs that provide early diagnostic and early intervention services for families of young children with identify and professional development opportunities for early childhood providers

across the state of Tennessee.

Welcome, Dr. Stanbrook.

>> Alacia Stanbrook: Thank you, so much. It is my pleasure today to introduce our three fantastic speakers. First this morning or afternoon, depending on your Time Zone, we'll hear from Dr. Wiggins, a behavioral scientist from the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. She is the lead clinician [Inaudible; off mic] and oversees all clinical activities related to autism includes those that explore how many children have autism and factors that put children at risk for autism. She also serves on the Board of Directors at the Atlanta Autism Consortium.

Dr. Wiggins has a Ph.D. in developmental Psychology, MA in Developmental Psychology, and MS in Applied Clinical Psychology. She has over 15 years of experience with psychological assessment in working with young children with autism and other developmental disabilities. Dr. Wiggins is an author of about 40 publications and has delivered over 100 presentations she researches and lectures on a variety of topics including the surveillance, epidemiology, and early detection of autism in young children.

Our second speaker, Dr. Kristin Sohl, an Associate Professor of Clinical Child Health at the University of Missouri's Thompson Center for Autism and Neurodevelopmental Disabilities and Vice Chair of the Child Health Department. She was a pediatrician with extensive experience in medical diagnosis, evaluation, and treatment of children with the concern of autism and other neurodevelopmental disorders.

Dr. Sohl is regarded as an expert in quality and process improvement for autism diagnostic and longitudinal services. She is a site principle investigator for the autism intervention research through the Physical Health/Autism Treatment Network and serves in leadership roles with each of these programs. She's a founder of ECHO Autism.

And our third speaker, Dr. Jeffrey Hine, specializes in pediatrics and primary care and treatment of ASD and other neurodevelopmental disabilities, and direct application of behavioral health services and parent/teacher training for children with a wide variety of behavioral-health and developmental needs. His current research and clinical interests includes integration of behavioral-health services into pediatric primary care practices, early identification and treatment of Autism Spectrum Disorders within primary care, and use of telemedicine to enhance care and support for children with developmental and behavioral health concerns and their families.

So with that, I will turn it over to Dr. Wiggins to talk to us about early identification of children with developmental delays from a public health perspective.

[Live Captioner Standing By]

[No Audio]

>> Alacia Stanbrook: Dr. Wiggins, can you hear me? This is Alacia Stanbrook. We're having trouble hearing you. We're not getting any audio.

>> Lisa Wiggins: Can you hear me know?

>> Alacia Stanbrook: Yes. We've got you.

>> Lisa Wiggins: Ok. Great. Sorry about that. When did I go out?

>> Alacia Stanbrook: We never heard you.

>> Lisa Wiggins: Oh, no! Ok. Well, I did show you the slide with our learning objectives and the four questions that I hope that you will be able to answer after the presentation today. I also noted that I will be referring to Autism Spectrum Disorder as autism throughout the presentation.

The developmental delays in disabilities are common conditions in children throughout

the United States. About one in four children aged 0 to 5 years are at moderate to high risk for developmental behavioral or social delay, which means they have not met a particular milestone in their development. About one in six children aged 3 to 17 years has a developmental disability which are more chronic conditions and can last through the a person's life. And about one in 59 children has autism. However, the diagnosis of autism is not until after four years as age. It is important to identify children with developmental delays and disabilities early because early identification can lead to early intervention. It is particularly important to identify children in the first few years of life, preferably by 36 months of age, in order to capitalize on neuroplasticity and opportunities to alter brain development.

Research has shown that early identification that leads to early education and intervention can improve skills and outcomes, increase school readiness, and reduce participant stress and empower families to help their child reach his or her full potential.

Two ways to identify children with developmental delays and disabilities as early as possible are developmental monitoring and developmental screening. Developmental monitoring, which is also known as developmental surveillance, is an informal process where one tracks the child's development. This can be done through milestone checklists, conducted at every well child visit, but can also be conducted a parents and early educators.

Developmental screening is a more formal process that is conducted with standardized tools and conducted at the [Inaudible] and 24 or 30-month well child visit. Both developmental surveillance and developmental screening referred to achievement of milestones to guide decision making.

Signs at the early campaign is CDC's efforts to improve early identification of developmental delays and disabilities by empowering parents and other care providers to learn the signs of typical development and act early on developmental concerns so that children and families can get the services and support that they need as early as possible. We accomplished this mission through three main program components. First is developing and disseminating high-quality, research-based parent-friendly materials to engage parents and providers in ongoing developmental monitoring through age 5 years and provide clear, concrete guidance on what to do when there is a developmental concern. Second is performing research and evaluation activities to ensure materials are acceptable and effective with target audiences. And third, supporting Act Early initiatives such as the Act Early Ambassador that work in states and territories to improve early identification of children with developmental delays and disabilities.

The materials developed by the Act Early campaign [Inaudible: Background noise overpowering voices] that most children reach by a certain age. If a child has not reached a milestone by that age, then parents are encouraged to talk to their doctor or healthcare provider about their child's development. Learn the Signs, Act Early also provides information about how to act early such as discussing concerns with parents and providers, providing positive parenting tips to help children reach milestones, and promoting developmental screening on how to ask for further evaluation and get connected to services.

Some of our materials and resources are pictured here. There are milestone check list that highlight skills most children should have accomplished by a certain age. All of these milestones are portrayed in a booklet that also includes tips for parents. You can also download the free milestone tracker app to help monitor development and get tips and activities on how to help your child succeed. Moreover, parents can learn about milestones while engaging their child in reading activities with a Where's Bear book for 2-year-olds and Amazing Me book for

3-year-olds.

Finally, Learn the Signs, Act Early, offers free training for early educators and healthcare providers on how to identify, diagnose, and manage children with autism as soon as possible. A developmental screen should be administered anytime a parent or provider expresses concern about a child's development. The American Academy of Pediatrics has published recommendations for when to administer general, developmental, and autism-specific screenings during well child visits. In essence, the AAP recommends using standardized tools to screen for general developmental delays at the 9, 18, and 24/30 month well child visit and for autism at the 18 and 24/30 month well child visit and thereafter as needed.

A standardized screening tool is different from a milestone checklist in that these tools have been developed and validated on a normative sample to help identify the strengths and needs of an individual child compared to others his same age. However, general developmental and autism-specific screening tools may perform differently in diverse samples of children. Two common screening tools for autism are the Social Responsiveness Scale, SRS, Social Communication Questionnaire, SCQ. [Inaudible: Background noise overpowering voices.] a community-based case control study of autism, the SRS and SCQ correctly classified most children with autism and other developmental delays when compared to study definitions. Yet more children with developmental delays were falsely classified as having autism when they had mothers with less than a high school education or family income less than 30,000 per year. More children with developmental delays were also thoughtfully classified as having autism if they had lower developmental functioning and increased behavioral challenges.

These findings do not mean that the SRS and SCQ are ineffective screeners when used in the general population. Rather, these highlight the challenges of successfully identifying young children at risk for autism from low socioeconomic backgrounds as well as those with other developmental or behavioral challenges.

The data also highlights the need to follow positive screen results with a comprehensive developmental evaluation. Future research can continue to explore factors that influence autism screening and how to improve the utility of autism screening tools.

Surveillance helps us understand the number and characteristics of 8-year-old children with autism in select areas throughout the United States and how this information changes over time.

The estimated prevalence of autism has increased substantially over the past decade. With about one in 125 children born in 1996, estimated to have autism, compared to one in 59 children born in 2006 estimated to have autism. This increase in the number of children with autism is similar to increases found in studies performed in Europe, Asia, and other areas in North America.

One unique aspect of CDC surveillance is that surveillance staff collects information on the first age of ASD diagnosis and first age of the initial developmental evaluation from health and education records. And these data indicate that more needs to be done to ensure that children are evaluated as soon as possible after developmental concerns are identified. For instance, although autism can be reliably diagnosed by 24 months of age, the average age of first ASD diagnosis is still not until 52 months. Also, concerns by 36 months were documented for 85% of children with autism, yet only 42% had a comprehensive evaluation by 36 months.

So, certainly more needs to be done so that autism can be diagnosed and treated in a timely manner. You can learn more about the Learn the Signs, Act Early campaign, and the study to explore early intervention and the autism and developmental disabilities monitoring

network by going to [www.cdc.gov/ADDM](http://www.cdc.gov/ADDM).

Thank you very much for your time and attention and for the invitation to speak with you today.

>> Alacia Stanbrook: Thank you very much, Dr. Wiggins.

Just a reminder that we're going to hold questions until the end of all of our presenters. If you have some questions for Dr. Wiggins, take note of those.

And now we'll turn it over to Dr. Sohl.

>> Kristin Sohl: Great. Can you hear me ok?

>> Yes.

>> Kristin Sohl: All right. Good. Thank you. Just thought I'd double check.

So thank you very much for having me today. I'm excited to share with you a little bit about our program, ECHO Autism. And what we're doing to partner with primary care providers as they are really the front line for caring for kids with developmental [Indiscernible] and all of our children at the well child visit.

We are very well aware we ever increasing gaps, both because of the rise in the prevalence that we just heard about and also are aware of. We now have children being diagnosed at a rate of one in 59 children with an Autism Spectrum Disorder. This link to rise in autism awareness as well as a rise in referrals to [Indiscernible] that do diagnosis. And that certainly results in parents seeking answers and more children needing help.

We also know that there are increasing gaps related to a few treatment options and less trained professionals than we need to keep up with capacity, resulting in long wait lists at specialty centers. When I think about this I think about it as an healthcare system I like to think about this as a way for us to conceptualize ways that we can move our field forward in a particular -- and particularly hopes to identify children with autism an/or developmental concerns.

So it's truly supply in demand issue that then leads to rising inequality and potentially declining health. So we know that many, many individuals that are affected by the inequalities across the board in our healthcare system, that certainly this also impacts our children and certainly those that have developmental issues as well as autism. I'm going -- what I'm going to tell you about today is a program called ECHO. Really the first and foremost thing that I like to think about is that it's about moving knowledge not patients. So when we look at our healthcare landscape, many families are moving themselves, not physically moving but they go to the doctor, you know, upwards of a couple of hours from their home. Or if they need to have access to a therapist or various other aspects of their healthcare, they may have to drive miles in order [Inaudible: Background noise overpowering voices.]

This is a short little video that walks us through what echo is. But for the interest of time, I'm just going to describe it to you and I have a few slides as well.

So ECHO, Extension for Community Healthcare Outcomes. Essentially it's built on a framework of technology. We typically use the technology called Zoom, although it's not mandatory, but we use that technology to leverage scarce resources so in our field of pediatrics when taking care of children we know [Indiscernible] scarcely resources so how can you use technology to really amplify those scarce resources.

[CAPTIONS PAUSED to notify host of audio quality]

I will pause for a second to make sure that my captions are able to keep up.

[CART NOTE: your audio is a little muffled sounding]

There we go. So it sounds like -- I wanted to highlight the fact that best practices are very

important in this process as well. So we share best practices so that all families regardless of where they live have access to the standard of care and the knowledge and information that they need. We also monitor outcomes through the program as well.

So what ECHO is not, it is not traditional telemedicine. As a practicing pediatrician, I do provide telemedicine to some of the patients I see in Missouri. That's where I am physically taking care of a patient through telemedicine. What ECHO is, is we're having a team of experts where we are able to then coach and mentor learners through cases, and then they take care of their patient population through that mentorship.

Our ECHO autism clinic framework essentially is made up of what you can see on the slides. But we're building a community. For example, we have 131 participants on the call with us right now. And if this were going through as an ECHO, we would be figuring out where you all were from in a very streamlined fashion, of course, but certainly have that. And then there's a case presentation by one of the participating pediatricians, family physicians, or nurse practitioners. There's a short didactic that summarizes the best practice in autism care or identification. And then time for a wrap-up.

Our team is comprised pediatrician, clinical psychologist, adolescent psychiatrist, registered dietician, parent advocate and research expert with the goal to increase local access to high-quality healthcare for children with autism.

In Missouri we've had over 400 individuals participate in this. We have held over 88 sessions and have delivered well over 750 hours of continuing medical education credits.

We also completed a small pilot study where we looked at 14 participants who participated in the ECHO autism model and were able to see that they had improved their self-advocacy and autism screening management, as well as adherence to screening guidelines.

As Dr. Wiggins mentioned, this is important that we have our pediatricians, family physicians and nurse practitioners who are equipped and ready to help our families when and if there is a question or even if the family doesn't have the question or concern just yet we still want that pediatrician and primary care provider to be equipped and able to help. What we know is they have difficulties or barriers in adhering to those guidelines but our pilot was able to see we had nice movement in that as well.

So then we replicated our work across 10 different APN centers or Autism Treatment Network centers. We essentially did the exact same thing we did in our pilot in Missouri. We did that in 10 different locations you can see a map of all of the different Autism Treatment Network sites that participated in the study. You can see many are on the East Coast but we had a few on the West Coast as well.

Methods we used, we had each of those 10 sites recruit 15 primary care providers, and their populations with the primary care providers served needed to be at least 50% underserved. We conducted the 12 session clinics over a six-month period and randomized those various sites into five cohorts.

And this is essentially what the study design looked like. This is called a [Indiscernible] wedge design. And results are being analyzed as we speak and we should have some results in the very near future.

We have many other clinical rep applications this is a sample of those other groups across the world at this point who are using ECHO watches to -- so we all know that there are children in all parts of our world that have developmental concerns. And echo is a convenient as well as effective way to be able to spread that knowledge even if the child [Indiscernible] in their

local areas.

So ECHO Autism STAT was an iteration of the program in Missouri. We started this in the fall of 2016. And it essentially is empowering primary care providers, which are physicians and nurse practitioners, to diagnose young children, ages 14 to 48 months, who are at the highest risk for autism. Their training is focused on screening and diagnosis using a multi-tiered risk-stratified approach as well as management strategies for those children as well. It consists of in-person training on standardized tools, 12-month virtual training through the ECHO program. It shows wait time for diagnosis, children receive diagnosis without travel, as well as expedited early intervention services.

This is a schematic of how this can look. We have universal screening, as Dr. Wiggins mentioned, in all of the components that the AAP recommends. That is standard. Then our primary care providers who are trained in the diagnostic assessment conduct their assessment and present their information to the ECHO autism team that I mentioned previously, the interdisciplinary team. And if symptoms are unambiguous, a diagnosis is made and support provided for the child and their family. If the symptoms are less -- more complex, then referrals for further evaluation is the next step.

ECHO Autism STAT in Missouri, you can see the map of the state of Missouri. We've been very strategic in recruiting and also engaging primary care providers throughout our state. As of November 2017, all children in Missouri are within 60 miles of an ECHO autism provider that means no matter where they live, they can get access to the answer that they're looking for. So their primary care physician, if they are not one of these, [Indiscernible], their own network of communication with each other and will refer out to other nearby ECHO autism providers that way families don't have the long wait list that they have in the past.

We have completed a pilot study of this as well. Again, just to recap, it says 12-month study or 12-month process. They include an in-person training on a standardized diagnostic tool and an additional 12-month virtual training through ECHO. We meet twice a month. And this happens for about 90 minutes twice a month. And these primary care providers become very, very good at what they do. And we are in the process of validating their diagnoses compared to [Inaudible; off mic] looking forward to those results.

In addition, we did a strong initiative as part of the ECHO Autism STAT movement. And adhering to the AAP standard guidelines. This is an example of where our participants were at the very beginning of their ECHO Autism STAT participation. It shows the rate of the first [Indiscernible] when certainly in the low 40s, even 30s for the general developmental screening. And then by the end of the 12-month cycle, they were reporting all appropriate screenings at the 18 and 24-month well child check for those general development and autism specifically.

So as part of our small pilot that we did, we were able to see increased primary care self-advocacy and screening and management. There were 47 cases during the pilot that I mentioned who were presented for diagnostic consideration and 16 referred for further evaluation and 31 diagnosed through this program, an average of 173 miles of travel were avoided. And their diagnostic wait time was eliminated because they did not have to go to [Inaudible; off mic]. We have a diagnostic evaluation study underway.

What I shared with you today is a little portion of what our team is building out into something that we call Autism Ready Communities. So when we think about this, we want and we are building this as well as other areas of our network. How can we start thinking about moving knowledge around therapy or early intervention or clenching behaviors? How can we start thinking about capitalizing on scarce bodies of knowledge but then capitalizing on the

technology that we now have at our fingertips to actually make Autism Ready Communities equipped and ready to take care of children and their families regardless of where they live?

So question for you. Are you part of the ECHO? We are always interested and excited to have new teammates and members in our attempt at revolutionizing how autism [Indiscernible]. We are very excited about the movement that we are making. This is all part of a not for profit effort to significantly change how this works. So we would love to have you check us out if you're interested.

This is a picture of our Missouri team. You certainly could join any ECHO Autism team anywhere. But if you're interested in joining and seeing what ours looks like, we meet on the first and third Wednesdays of every month, 11:45 to 1:15 central. All you need is a forward-facing camera and internet. There's no cost. You can sign up at one of those two websites, [showmeecho.com](http://showmeecho.com) or [echoautism.org](http://echoautism.org). We would love to have you join us.

With that I thank you for your time and appreciate you having me here to share with you about this program. And I certainly would love to answer questions when the time comes.

>> Alacia Stanbrook: Wonderful. Thank you so much, Dr. Sohl.

We have some questions coming up in the chat box and we will address those after we hear from Dr. Hine. So at this point, we'll go to our final speaker, Dr. Jeffrey Hine.

>> Jeffrey Hine: Good morning or good afternoon for those of you on the East Coast. Can everybody hear me ok?

>> Yes, we can.

>> Jeffrey Hine: Ok. Good. There's always that worrisome pause there.

Ok. So I'm Jeffrey Hine. And I am at the Vanderbilt University Medical Center and the Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders. We call it VKC TRIAD. Much of our recent work as a group has involved setting up services for children with autism that are embedded within their medical home or within pediatric primary care clinics. And personally through those clinics we have been able to streamline model for early identification of autism. So today I'll be discussing how we've adapted this model for use through telemedicine in our work with underserved and rural families within part of our state.

Before I do that, this project would not be possible without a close partnership with the Tennessee Department of Education as well as the Tennessee Early Intervention System, nor would it be possible without our leadership from our directors, Zach Warren, Pablo Juarez and Alacia Stanbrook, as well as our fantastic team.

I generally like to start out with some things that are generally well-known about autism or about the topics that we're talking about. And Dr. Wiggins and Sohl have actually covered this rarely well so far so I'll kind of just touch on some of those things.

So what do we know? We know accurate and stable diagnosis is possible during the second year of a child's life. We know that most children identified with autism have concerns that have been documented within their medical record before the age of 3, well before the age of 3. But unfortunately less than half of those children have received a developmental evaluation, especially an evaluation for autism, by age 3. So this, of course, contributes to an age of diagnosis that is still remaining above 4 years of age.

As you can imagine, this lack of general access to evaluation can contribute to a large amount of family stress. And it restricts delays of the early intervention service that we know are so important for kids at this age, especially if they have a diagnosis of autism.

Also, of course, we know that any barriers or challenges in this area are always amplified for groups from traditionally underserved communities, and that includes rural families.

Vanderbilt University Medical Center is located in Nashville, which we are also the primary diagnostic center for the Part C or birth the 3 services within our state. The catchment area spans most of the state for diagnostic evaluations for children with autism. Meanwhile, north to south you can drive across the state in maybe two to three hours, depending on traffic. We're actually 500 miles from east to west. So a lot of our families, in order to gain access to an evaluation, are driving four to five hours round trip.

Another thing about our state is that we're largely a rural state. And most of the counties within Tennessee are considered a mental health professional shortage area. So not only are families have costs that are associated with travel and having to travel long distances, including taking days off of work when they can't afford that, paying Nashville hotel prices can be pretty insurmountable at times. There are also oftentimes experiencing a significant wait times, from six to eight to nine months in order to gain access to an evaluation for autism. And that's a long time for parents or children that are that young to wait in that zone of uncertainty trying to figure out whether or not a child has autism or not.

So in order to address this need, we have taken advantage of our partnership with a regional health center in Jackson, Tennessee, which serves a 23-county area. It is one of our higher need areas of the state. We have two Vanderbilt early interventionists that actually live in Jackson so they are able to work directly with the families that come to the regional health center. They are able to work with them directly while in clinic but we also psychologists that Zoom in or over telehealth from our Nashville site.

I'll tell you a little bit about how families are able to become part of our telediagnostic or telehealth diagnostic evaluations families are typically already enrolled in their state's Part C or 0-3 services. And either the early interventionist or the EI coordinator will have suspicion of ASD while working with the family and will complete a triage flowchart which helps them determine whether or not a referral for an autism evaluation is appropriate. And at that point the family is offered a choice as to whether or not they would like to be a part of our telehealth services and able to talk or speak with a psychologist in Nashville while not having to leave their immediate area or they're still welcome to come into Nashville for that comprehensive assessment if needed.

This telediagnostic program was not designed to be a replacement for comprehensive assessment, especially for those children where we know substantially evaluation is needed over time. Instead it was designed to streamline care, an efficient manner for us to be able to rapidly identify autism or clearly rule it out, especially clear and pressing issue for a lot of families we work with.

This is what our streamlined telediagnostic evaluations typically look like. As Dr. Sohl kind of referenced, we also use a screening tool for autism in toddlers, which is a 20-minute interactive level II screening device designed for use in primary care. That is administered by our Vanderbilt early interventionist that is working with the family in Jackson at the rural health center. Then we have a psychologist in Nashville that is able to observe the evaluation as well as give a clinical review with the family, provide or ask for more observation it's needed. Then we're able to talk with the family to find out whether or not we think their child clearly meets behavioral material for Autism Spectrum Disorder or not. If so we talk about next steps. And since the Vanderbilt early interventionist is also there, that early interventionist is able to provide some in-person psycho education to the family. That Vanderbilt interventionist is also the same interventionist that follows up with that family in the home over telehealth for a follow-up services.

These are a little bit about what the follow-up services look like. Our Vanderbilt early interventionist that lives in Jackson works directly with the state's early interventionist. And they both provide caregiver trainings weekly for about six to eight weeks, going through a number of our modules or curriculum modules that have been created by our early intervention team. These include common concerns for families that have children with autism, including communication, social play, challenging behavior, sleep, toilet training. And after the six to eight weeks of caregiving, the Vanderbilt early interventionist is also able to provide local mentorship to that state early interventionist for up to six months or at least until the child ages out of the birth to 3 system.

Before we roll this out with our West Tennessee families, we did a validation or diagnostic accuracy study with 20 children who were already coming into Nashville or were already referred for evaluation in a primary diagnostic center. These 20 children were 20 to 34 months of age. And instead of us Zooming across the state, we were actually Zooming across the campus. So we were able to compare our telediagnostic evaluations and then we have families complete another blinded gold-standard assessment with a different psychiatrist. We found 100% of the children identified through telemedicine for Autism Spectrum Disorder were also confirmed by our gold-standard in-person assessment. And no children were inaccurately identified.

So those of you that want to take a closer look at the specifics of this model as well as the validation, I provided a reference here but I will pop this up at the end as well if you want to take note of it.

This pilot study gave us a confidence in order for us to be able to roll this out with our West Tennessee families and up until this point we've seen I think close or near 125 families through our telehealth diagnostic evaluations but this is for the first 45 children we saw from the program this data. These children were between 19 and 32 months 35 boys, 10 girls. They were referred over an 11-month period through our state EI system. The families that we served were an average 145 miles from Nashville. And this saved them about four hours estimated travel time and all the costs associated with that.

The results of this study, for our psychologists we were able to provide an ASD diagnosis for 64% of the children and rule out an ASD diagnosis in 22% of the families, which means that through our telehealth diagnostic evaluations we were able to achieve diagnostic clarity within 66 of those appointments while 13% were invited to Nashville for more comprehensive assessment.

Psychologists were also asked at the end of appointment their level of certainty in giving the diagnosis. And psychologists were able to say that they were certain or very certain in 87% of the cases through telehealth. This very closely matches the same percentage of diagnostic clarity that we were able to [Indiscernible].

We also were able to survey all of our families that went through this program, about a range of different questions in terms of their comfort level and the effectiveness of this appointment for their family. Our families were able to say that they were either satisfied or very satisfied for a range of questions including: The telemedicine provider was engaged; parent was able to communicate concern to the provider; the provider was able to collect important information about my child; the equipment was not distracting; the telemedicine made it more easier and convenient for my family; I received enough from the guidance next steps; this visit was just as private as an in-person visit; I'm going to recommend this to others; I'm also interested in participating in future telemedicine visits -- which also included many of their home follow-ups were also done over telehealth. And generally speaking, 100% of our families

answered that they were very satisfied or satisfied with their overall experience of telehealth.

This is a little information about the overall impact of this new service of this telehealth service. This graph shows the referrals, their total amount of referrals made through our VUMC Diagnostic Center in Nashville. As you can see, for the four years before initiation of telediagnostic services, we were getting about 30, 40 referrals from our target region in West Tennessee per year. Upon initiation of telediagnostic services, however, our referrals jumped nearly 90% from that region. And while one can think that this could possibly be due just to the availability of the telehealth service, we were able to pull numbers from comparison region that was near our target region. And their amount of referrals also jumped 115% and they did not have access to telehealth at that time.

So this tells us that in addition to the availability to telehealth causing an increase in referrals, there was just generally more need for these evaluations and especially for regions that don't have these services or don't have easy access to these services. The difference being between these two services that for our target rates that had telediagnostic services we had a 65% decrease in referrals to our Nashville site, meaning most of our families were satisfied and were able to be seen through telehealth in our target region. This also caused a 15% increase in our overall show rate to our family that had to come to Nashville, meaning for our families that had to come to Nashville, they were coming to Nashville.

So here are some of our recent studies regarding the use of this model, both in our primary care clinics as well as telehealth, for those listeners that would like to see a bit more of the specifics of the model and, again, some of the data behind that.

I think the overall story of this project and what this model has allowed us to do is to go from our families in West Tennessee having to experience really long waits and numerous barriers to accessing diagnostic and intervention services to families, going from that to be able to get a clear answer for the young child, within a month or so and immediate start supported and tailored interventions in their home, either in-person or over telehealth. We are really proud of this work. We are really excited about the future of these types of services.

I think I can pause there and maybe turn it back to Dr. Stanbrook to see if we have general questions for the group.

>> Alacia Stanbrook: Great. Thank you so much, Dr. Hine. Yes, we have about 12 minutes for questions. We did take note of several questions that came through during the presentations and we'll start with those.

If there are additional questions, feel free to add those to the chat box and we will try to get to as many of those as we can.

So, this first question is actually for all speakers. How do you see pediatric and nurse practitioners fitting into the specialty side of ASD diagnosis and treatment?

>> Lisa Wiggins: This is Lisa Wiggins. Can you hear me?

>> Alacia Stanbrook: Yes.

>> Lisa Wiggins: Great. So I will answer that first and just say that pediatric nurse practitioners play a very important role in the early identification of children with autism and other developmental delays and disabilities particularly because they are our first line resource for families and can help connect families to services and supports and also help families of young children learn about developmental milestones and the importance of tracking development. So the Learn the Signs, Act Early materials can certainly help nursing professionals educate families with simple yet effective materials and also provide guidance on how to talk with parents about general child development and specific concerns they may have regarding a suspicion

that a child has a developmental delay.

>> Alacia Stanbrook: Thank you, Dr. Wiggins.

Dr. Hine or Dr. Sohl, would you like to add anything?

>> Kristin Sohl: This is Dr. Sohl. I think that -- I think that it is very important for us to have as many team members as we can engaged in developmental screening and monitoring. So I definitely echo what Dr. Wiggins just said. And I think there is an excellent role in the community, particularly with ongoing professional support for the diagnostic process and/or [Indiscernible] treatment for individuals with autism. So I think having them as engaged as we can is excellent.

>> Alacia Stanbrook: Great. Thank you.

Dr. Sohl this next question is also for you. Are most of the PCPs who participate in ECHO training and private practice or work at an academic center? And if they are in private clinics, how do they have the time and money to participate?

>> Kristin Sohl: Excellent question. No, they actually aren't in private practice versus academic. It's about 50/50. We have some good data in our publish publications which tell us most of the practices are rural but not academic. So we have a mix of solo practitioners with a mix of kind of group practitioners. But I would say most of them are in either kind of a community [Indiscernible] or in their own -- like in a group practice.

So the way they do it, it takes about three hours a month for the actual ECHO process. And then the other pieces of the actual diagnostic evaluation, the ECHO STAT eval, those do take time so we've worked to help maximize billables by making sure they're coding properly.

But to be honest, most of the providers have grown incredibly passionate about this population and about doing what they can to provide answers for these families. So that has lent itself to significant growth of the program. And I think they also recognize that they now have a tool that they didn't have before where they can answer these questions rather than answering or kind of waiting long side the family while they waited to get into the center.

So I think from that standpoint it yields significant satisfaction for the participants, but the specific answer to your question is it's about three hours a month and it's usually over the lunch hour so they just donate that time, if you want to call it donate that time. But we also give them medical education, maintenance and certification credit, if they are interested in that. And they get this network of providers that providers that I think is why they stay because they enjoy getting to know each other.

>> Alacia Stanbrook: Thank you.

And [Indiscernible] Dr. Sohl. How could participants find out if their state is connected to this ECHO program or have an ECHO hub? I believe a link to the extent center was included in the chat box earlier. Are there other ways participants can look into this?

>> Kristin Sohl: Absolutely. The link to the website is probably the easiest way. But you're also welcome to e-mail me. I apologize for not putting my e-mail on my slide deck, but I'll send it to the participants here in a minute so you're welcome to e-mail me if you have questions.

>> Alacia Stanbrook: Great. Thank you.

This next question is for Dr. Hine. Could you talk a little bit about the equipment needed for the visit?

>> Jeffrey Hine: Sure. So the equipment can vary but we use the Zoom system, similar to Dr. Sohl. On the receiving end or at the Regional Health Center they have a stationary camera that we're -- not stationary -- a camera that we're able to control remotely, set up to the work station within the clinic room. And for us as psychologists, we're able just to use our laptops and the camera that's embedded within our laptop.

Dr. Stanbrook, you might be able to help a little bit with more of the specific camera itself, the name. I know it's a lot of letters and numbers I haven't memorized. But I know we typically use easily accessible technology. In fact, we're starting to be able to think about sending families what are called [Indiscernible] which would allow for them to use an iPad or phone and they kind of connect to a system. We're able to help move it around remotely. So we're trying to make it as accessible as possible both being able to roll this out with families and being able to disseminate a lot of this model in place that don't always have matching equipment. So we try our best to be able to use a lot of different types of technology on either end.

>> Alacia Stanbrook: Great.

We have one for you, Dr. Hine, and then a couple more pretty big questions for all the speakers. So we're going to try to get to those and that will probably be all we have time for today.

Dr. Hine, the person present during the telediagnostic evaluation for the family delivers the STAT, are they giving guidance from the clinician that's live in Nashville? And related, are the psychologists providing the diagnosis?

>> Jeffrey Hine: Yes. The second question, the psychologist is the one remotely being able to interview the family, observe the STAT, and provide that diagnosis. The early interventionist that is with the family in Jackson, they were trained on the STAT. So they're not getting any directions from the psychologist on what to do outside of if there's a technology issue we can talk to them that way.

Sometimes we're able to touch briefly over the phone if some things were unclear but otherwise the Vanderbilt early interventionist that is with the family is not receiving any directions from us. They've been trained on the STAT and they have a background in early intervention. So they're well equipped and families can provide a lot of that follow-up information.

I think I answered both questions. Right?

>> Alacia Stanbrook: Yes. Thank you.

Ok. For all speakers: How do you envision addressing the disparities not just in identification and implementation but also with implementation of appropriate services? As well as, what could be done on a federal level about improving transition services to Part B and implementing the medical home?

Let me repeat. How do you envision addressing disparities not just in identification but in implementation of services? What can be done on a federal level about improving transition services to Part B and implementing the medical home?

>> Jeffrey Hine: I can answer part of that question. I think the nice part about the project that we have is the Vanderbilt early interventionist working with the family at the Regional Health Center is able to build capacity within the state early interventionist to provide some of those services so the Vanderbilt early interventionist is able to be there at the appointment with the family receiving the diagnosis, provide some of those -- some of the education during that appointment. But then that same interventionist also follows that family home, either literally -- not in the same day but provides those services in the home or does telehealth follow-up. So they provide caregiver training through the early interventionist system as well as -- or building capacity within the state's early intervention system. So I think being able to bridge that gap from families, receiving a diagnosis, and immediately starting tailored and supported interventions is really important. I really like how this model has been able to kind of support that.

>> Lisa Wiggins: And I'll also echo the importance of building capacity within states with the Learn the Signs, Act Early campaign, and engaging the state Act Early Ambassadors to identify

particular disparities within their own communities and then how to address those disparities so that all children can get identified and supported in the way they need.

And I'll also say the transition to adulthood is a topic that is extremely important among the field of autism right now. There was actually a report to Congress submitted in 2017 about young adults and transitioning youth with Autism Spectrum Disorder. And this report essentially summarized existing federal investments focused on the transition period from childhood adulthood for individuals with autism and identifies gaps in federal research programs and services to support youth with autism during that critical time period. So anyone interested can access that report on the Interagency Autism Coordinating Committee website. It is available for free public download.

>> Alacia Stanbrook: Great. Thank you both for your answers. We'll have time for one more quick question, also for all the speakers from someone who says they are in Oklahoma and have been told a child cannot be diagnosed for autism until age 5. What do you think might explain the discrepancy in diagnostic services from state to state?

[No Audible Response]

Again this last question, if you can hear me ok. Do you all have thoughts on what might explain some of the discrepancy and diagnosis between state-to-state, thinking about the age that children are being identified?

>> Lisa Wiggins: This is Lisa Wiggins. I definitely think that with forced capacity influences how children are diagnosed so how many professionals are trained and the diagnostic skills that are needed to differentiate children with autism from other developmental disabilities and also the professional education opportunities that are available to communities.

So again, you know, the free autism case training that is available online can help build that workforce capacity and also educate professionals on the signs and symptoms that are specific to children with autism versus other developmental delays and disabilities.

>> Jeffrey Hine: And if I could briefly add to that. I think a lot of the first concerns for autism are brought up with providers that necessarily don't have the specialty in helping recognize or detect Autism Spectrum Disorder. So just to add on to what she said, I think being able to kind of build capacity in that first sign of folks that work with families or in the content which a lot of these primary concerns have.

>> Alacia Stanbrook: Wonderful. Thank you all, Dr. Hine, Dr. Higgins, Dr. Sohl today for your fabulous presentations.

I'm going to turn it back over to Anna and Ben. I'm not sure if there's anything we need to do to conclude today's webinar.

>> Anna Costalas: Yes, thank you so much, everyone, for attending. Thank you for the wonderful presentations.

This webinar is being recorded and will be available on AUCD's Webinar Library in about two to three days. And that's [aucd.org](http://aucd.org). If you go into the Resource section, that's where it will be located. If you would like a Certificate of Attendance, e-mail [aucdinfo](mailto:aucdinfo) and we will get you a Certificate of Attendance for this webinar.

Thank you again for attending. Please take a moment to fill out a short evaluation survey. Have a great rest of your week, everyone.