

REALTIME FILE

Center for Connected Health Policy  
NCTRC November Webinar - Toddler Tracks  
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>> Hello everyone, my name is Aria Javadin.  
Welcome to the latest presentation Toddler Tracks Online Autism Resources. These are designed to provide timely demonstrations and provide support to your telehealth programs.  
These webinars are presented on the third Thursday of every month. Before we get started today, we wanted to acknowledge National Rural Health Day. The national organization of state offices of rural health sets aside the third Thursday in every November to celebrate National Rural Health Day. This celebrates the power of rural by honoring the self-preserving rural minded spirit in rural America.  
It showcases rural providers, state offices of rural health, and other rural stakeholders to express the unique challenges rural health care faces today and into the future. We're proud to celebrate the 11th year of National Rural Health Day. To learn more please visit [powerofrural.com](http://powerofrural.com).  
We are located throughout the country. There are 12 regional TLCs and three national. Each serve as focal points for advancing the use of telehealth. And supporting access to telehealth services in rural and underserved communities. A few tips before we get started today, your audio has been muted. Please use the Q&A portion of the Zoom platform to ask questions. Please note that closed captioning is available and is located at the bottom of your screen.  
Today's webinar is being recorded and you will be able to access today's and past webinars on our YouTube channel.  
Today's speaker is Boyd Mark. Boyd is a program manager for the Southeastern Telehealth Resource Center. He founded the National Autism Telehealth program on the campus of the Florida Institute of Technology, a tier one STEM university. Boyd has extensive experience in management, operations in finance, with fortune 500 companies including Microsoft, Intuit and Apple. He holds a B.A. from the University of Texas at Austin and with that I'll pass it over to Boyd.  
>> Thank you, Aria.  
Thank you everyone.  
It's great to be here.  
I'm very excited to tell you about Toddler Tracks, a program that was developed at the Southeastern Telehealth Resource Center. Something that I think offers opportunities for everyone that is here today to work with groups in your area to give them tools and I'd like to tell you about what we're doing and encourage you to please follow up with me if this is something that you would be more interested in.  
And with that I'm going to jump over to the presentation and go into presentation. Wait a minute.  
There we go.  
Share sound and optimize for video.  
And can everybody see that okay?  
>> Looks good.  
>> Great.  
Thank you.  
The Toddler Tracks program was developed with CARES Act funding and it is a program that when I was with the Florida Institute of Technology, we had envisioned this program for some time and I'm really excited to be part of the Southeastern Telehealth Resource Center and to be able to do this.  
Also Happy Rural Health Day to everyone.  
This is definitely a rural health initiative and can have a very positive and disproportionately positive impact in areas where people are in a rural health situation. So the need, at one in 54 children, autism has reached epidemic proportions. At any time that's a million kids between the ages of about 2 and 15 in the United States.  
Boys are four times more likely than girls to have autism. Symptoms typically appear between 24 months and are often 75% of the time accompanied by other cooccurring medical conditions and other intellectual disabilities. Critical intervention between the age of 24 months and five years can dramatically reduce symptoms.  
However, if kids are not reached during that window of opportunity due to neuroplasticity, they will have the symptoms for the rest of their lives. There's an opportunity to go in and really dramatically reduce these difficulties around communication and socialization, challenges with behavior, or those symptoms last for the rest of their life and there has to be management of the environment around them. And that obviously has a dramatic impact on the potential for these children, for their families, for the school systems, and for the health systems.  
85% of parents and caregivers have concerns about the development of a child with autism by three years of age.  
This is something that we know how to recognize, that we can do a lot about, yet it's not happening.  
So fewer than half of children with autism receive a developmental screen by the age of three years.  
Between 3 and 4 years.  
Only another 19% are screened and by the age of four, only 39% of kids have been screened.  
That is in direct contradiction to the American Academy of Pediatrics guidance for well over a decade that 100% of children should be screened for ASD.  
And by definition it's all children, not just children who may be displaying children or about whom there are concerns.  
All children should be screened.  
We know that less than half of them are being screened.  
And then of those children who are screened and diagnosed, less than 50% actually receive access to care according to the American Academy of Pediatrics.  
So when we look to add the Toddler Tracks program, we saw that there were already many great programs out there about what to do to get your child to a provider, how to find providers, a focus on screening.  
But what we saw especially for folks in rural areas, many times even when children have been identified as at risk or have a diagnosis, there are simply no services available for them.  
Again less than 50% have access to care.  
There's a huge impact to families, parents of children with autism experienced increased stress, mental and physical health problems.  
Some of you might be familiar with the caregiver strain index.  
The CSI index for parents of children with disabilities and especially kids with autism is really off the chart.  
According to the NIH mothers earn 56% less than mothers of children with no health limitations.  
So we're already talking about people who are in challenging situations with regard to social determinants of health.  
And now you start laying on top these factors.  
Nearly 60% of parents with a child with autism took a leave of absence from work within the past year.  
Again big factor, big socioeconomic, social determinants factor.  
Siblings cope with feelings of embarrassment and difficulty because they can't do the things with their sibling that other kids can.  
These families have a lot of difficulty going out, just going out to dinner is a big challenge, much less taking a vacation and going some place where the change in environment can be really, really difficult for a kid with autism or who's showing symptoms of autism.  
Big part of the challenge is the shortage of providers which we're all aware of.  
The current capacity of applied behavior analytic therapists meets less than 50% of demand.

According to the AMA 60% of all U.S. counties and 80% of rural counties do not have a single psychiatrist.

61% of rural counties lack a psychologist and 91% lack even a psychiatric nurse-practitioner.

So major shortages, these shortages are really exacerbated in rural areas and in rural areas of color even more so.

The AAMC estimates that there will be a shortage of between 50 and 100,000 physicians by 2034.

So again we have this situation where we have millions of kids.

We know that they are going to present symptoms.

We know how to identify those symptoms and we even know what to do except it's just not happening.

The issue though is that there are things that parents and caregivers can do in the meantime and that is the focus of Toddler Tracks.

Absolutely free resources that parents and caregivers can use to help these kids while they are getting access to services.

And we know that telehealth, tele-mentoring can be efficient.

Tele-medicine based treatments and what we refer to as caregiver intermediated intervention can have equivalent outcomes.

Outcomes can be provided at significantly reduced costs and the triple aim is achieved.

So again the focus of Toddler Tracks is to provide tools to parents, caregivers, and health care workers for these families when they don't have access to services or when they're awaiting access to services.

I'd like to play you this short promo video.

>>> Once upon a time, not long ago when children showed red flags for autism, their parents were told wait and see.

Now we know, that's just plain wrong.

Early intervention can dramatically reduce the severity of autism and in some cases even eliminate symptoms entirely.

It is critical that parents urgently begin evidence-based intervention.

They can't wait and see.

But knowing what to do can be overwhelming.

Who do they turn to for help?

The global partnership for telehealth with CARES Act funding is launching a suite of telehealth programs including parent training, resources for health care professionals, and online treatment services.

Visit us at [GPTH.org/autism](http://GPTH.org/autism) to learn more and join the effort to make access to autism care for everyone the new normal in 2021.

>> Can everybody hear that okay?

>> Yes.

>> Yeah, okay, terrific.

So Toddler Tracks was launched in April/May.

And the program includes materials for parents.

And when I say parents, it could be parents, it could be grandparents, aunts, uncles, but for caregivers.

It's online training for parents of children who have been identified as at risk or may have a diagnosis but are not able to get services.

There is data that shows intervention is important so we wanted to give these families access to services.

All of the tools are empirically evidence based.

As I mentioned earlier, the American Academy of Pediatrics is clear but these kids are not being seen.

In particular on the ABCs of behavior intervention, paced on applied behavior analytics, the antecedent behavior and consequence.

Using these techniques to help these parents with their children.

Enrichment exercises and daily living skills, and parent interviews as well as other tools and resources.

I'd like to play you a short clip from the website and then we'll jump over and take a look at it.

And this is a video from Patrece who is really the host of the program and through all of the videos that have been developed for people, developed for parents who don't have a lot of time, who at any particular literacy level that they can understand this.

And Patrece is someone that appears throughout the program.

>>> Hello and welcome to the Toddler Tracks program.

The pathway to tackling autism.

My name is Patrece, and I will be here to take you through this program.

This online education and training program on early childhood autism intervention is made possible by the nonprofit southeast telehealth resource center and the nonprofit charitable global partnership for telehealth through CARES Act funding.

We've designed this program for the parents and caregivers of infants and toddlers.

That includes children between the ages of 12 months and four years.

However even if your child is older and is late in reaching their developmental milestones, these videos can be very helpful.

You'll learn how to identify and track the important progress points or milestones in your child's growth and development.

How to identify concerns, information about autism and its symptoms, what to do if you have concerns, and how to find help, including online or telehealth services.

You will also learn some overall healthy parenting practices that will make your efforts at parenting less stressful and more successful.

The toddler tracks program is divided into three sections.

Each section has several short videos that can be watched in order or you can skip around and choose which video you want to view.

Keep in mind however that you will learn things in earlier videos that will come up in the later videos.

Any time you can go back and rewatch some videos to be sure you are following along.

The first section is focused on developmental milestones.

This section looks at how children develop progressively, more advanced abilities or skills as they grow through their infant and toddler years.

From listening and pointing to learning new words and constructing complete sentences, your child has many opportunities to learn.

Our goal is to increase your child's ability to learn through practice as they grow and build these new skills.

Acting early can make a lifetime of difference for your child.

Thank you for joining us and let's get started.

>> We're going to take a quick jump over here to the Toddler Tracks website.

And then come back to the presentation in just a moment.

So can you see the website?

>> Yes.

>> Okay.

So here is the Toddler Tracks website.

[Toddlertracks.org](http://Toddlertracks.org).

There are videos here to kind of get started on issues about how to get treatment, what are symptoms, don't wait.

The introductory video from Patrece.

And here are all of the different areas, teach your child about autism, family stories, parents often feel very, very isolated when they're dealing with these issues and we've found that hearing from other parents and caregivers is very powerful.

There is a section for clinicians and health care workers.

Also focusing on directing people to the CDC milestone tracker app which is really a fantastic little tool that is available and parents and caregivers can use it.

Teachers can use it.

We get a lot of interest from teachers as a matter of fact.

They can personalize it, they can track milestones.

There's additional material.

And the focus of toddler tracks are the pathways to tackling autism.

Parent resources, professional training, and connecting people to telehealth resources.

If we move over to the teach your child section just very quickly.

I'm going to do this.

There's a focus on a brief introduction about how to teach and what it means and then the building blocks of learning and these were developed with some of the advisors that we had.

We had Dr. Michael Kelly who is a licensed psychologist, ABA, PhD.

Dr. Lane who is a developmental psychologist in Georgia, works closely with the Southeastern Telehealth Resource Center.

Her practice is solely a telemedicine practice.

Focus here on the building blocks of learning, preparing to learn, positive reinforcement, positive association, comparing the environment, focus on success.

And then we chose four of the basic skills for daily living.

Positive reinforcement, improving communication, trying new foods and dealing with problem behavior.

There are examples from therapists and then there are experts talking about things that a parent should know.

Communication skills are very important because so many of the difficult behavior examples with children in autism is their frustration in not being able to communicate.

There are picture communication systems and other things that we talk about.

Often restricted diet, that means nutritional challenges so trying new foods is also one of the big challenges.

Again there are examples of how parents and caregivers can introduce that and then we have experts discussing it.

And then we have a whole section here on healthy parenting skills.

And among those resources, then we have a whole section on about autism, parent stories, and a section for clinicians.

So please feel free to stop by the website.

And I'm going to jump back over to the presentation.

So Toddler Tracks for clinicians, we have heard a lot of feedback from the folks that we talk to at we're in pretty close contact as I'm sure many of you are in the birth to 36 month programs, whatever they may be called in Florida.

It's the early steps, in Georgia it's baby can't wait.

It's the CHIP program.

We work closely with AHEX and health worker education programs.

And in a lot of the clinics, the critical access hospitals, the FQHCs, there are real challenges and even among pediatricians sometimes.

When children with autism come in and they're being screened, there are challenges with assessment and diagnostics.

For example is a child presenting delays in language as a result of sort of typical physiological speech therapy related programs, or is it a developmental delay that's causing that?

It's pretty tough to tell a lot of times.

And that can really delay treatment during this critical, critical window of time.

Telehealth diagnostic and treatment options.

As I mentioned Dr. Lane is a purely telemedicine based practitioner and she does diagnostics via telemedicine.

And there is an ample amount of peer reviewed literature demonstrating that for 80% plus these children an effective diagnosis can be made online.

Behavioral health integration, BHI is really a significant thing as I'm sure many of you are aware.

And we have a great program from Rainy Children's Hospital in San Diego on Toddler Tracks where they talk about their award winning BHI program.

How to advise and counsel parents is very important.

Pediatricians and doctors will say look I know this child has a developmental delay, it's quite possibly autism and I know there's a critical window here, but I have no place to send these kids, I have no one to refer them to.

So how do you talk to a parent in that situation?

And imagine if you're a parent and you're told you can't wait a minute, you can't wait a day, you've got to get your kid in for treatment right away.

But then you find out that you have to wait 12 months, nine months for a diagnosis which is not uncommon.

And then if you're able to get a diagnosis and therefore are eligible for services under Medicaid or commercial payers, you find out that there are no providers in your area.

So there's a lot of things that we can do to help health workers talk to parents.

Then there's information on the parent training program and of course the parent interviews.

Along with Dr. Lane we had Dr. Kelly help us with this program and I want to play you a short video from him.

Wait a second.

There we go.

I'm still optimized for audio and video.

So we should be good.

>>> My name is Michael Kelley.

I specialize in diagnosis and treatment of autism in young children.

I'm an educator, a trainer, a clinician, and a researcher and I am pleased to be here to talk to you about this program.

We are so excited to be a part of bringing this free medical education program on early autism intervention to you.

This program has been made possible through the CARES Act funding and the global partnership for telehealth.

We've consulted with pediatric specialists to develop this program for medical professionals all to assist you with early, timely assessment and intervention among infants and toddlers.

You'll hear from Dr. Lane, a board certified adult and child forensic psychologist.

She'll address challenges like identifying presentations of ASD, solutions to cooccurring medical presentations and treatments, and the coordination of all of these

multidisciplinary care specialists that are a part of the team.

Dr. Lane has been successful in utilizing telemedicine to minimize geographical aspect barriers to care.

We're also very pleased to have a presentation from Rainy Children's Hospital in San Diego.

You'll learn all about Rainy's award winning kid start program, a very successful approach to care, coordination, and behavioral health integration for young children on the autism spectrum.

The kid start approach brings together multidisciplinary specialists to create a treatment plan for children with multiple needs.

Intensive family support services are also provided which will help families understand the unique needs of each child as well as to access immediately all of these needed services and then of course to plan for future services that might be needed as a child grows older and matures.

Behavior health integration models are so well suited for a telemedicine based approach because you can deliberately organize custom care activities and information sharing among the entire care team.

The caregiver training modules will include exercises and information for working with children to address symptoms of autism.

And this is especially important while these parents and children are waiting for access to services.

Once upon a time not so long ago when children showed red flags for autism, parents were often told just wait and see.

Of course now we know better.

Whether these developmental delays are caused by autism or some other factor, children who are diagnosed with developmental disabilities are unlikely to simply just grow out of their problems.

We know that waiting is the absolute worst thing we can do.

We risk losing valuable time at an age when children have the best chance of improvement.

We hope you find this information valuable, and remember don't just wait and see. Please act early.

Thank you.

>> Okay, information from my good thing Mike Kelley there.

And I want to jump over quickly and take a look again at the Toddler Tracks website here to show you the clinician page.

This is Dr. Lane's information on diagnosis and assessment.

It's about a 25 minute presentation and it's fantastic.

It's for health workers and it talks about all of the different aspects of working with families and kids.

Here is the program's about a 12 minute section on care, coordination, and behavioral health integration from Rainy Children's Hospital.

And this is from Dr. Lane discussing telehealth, telemedicine options for autism.

Okay, I'm going to jump back over here.

And we're back on the presentation, right?

>> Yes.

>> So some of you may have heard the term if you build it they will come.

It's from a Kevin Costner movie, field of dreams.

The trouble is if you build it, they will come is not actually a strategy.

And while we've created this content and we've created a nice repository for it, we're going to need to be more proactive and we are being more proactive about getting this material into the hands of people who can use it.

And in particular a force multiplier effect where through working with the rural telehealth mentoring program, working with our local, we can put these tools into the hands of people who are already out there working with these families.

Working with them in the prenatal programs to get the information to these families.

We have three major things that we're doing.

One is the Toddler Tracks ambassador program where we reach out to organizations and professionals in their community and we're going directly to them.

The other thing that we're doing is working with the rural tele-mentoring training center.

That's Dr. Allison and her team at University of Texas San Antonio UT Med Center.

They are focused on peer to peer support based health care workers that meet regularly to speak about specific health care issues.

I really want everyone, please, to take note.

If you are interested, I'm working with Dr. Allison and her team to do training at some point early in Q1 of next year so that we can go out and start working and contacting children's welfare organizations, and we can do this nationally, inform what they refer to as a community health club.

And it can be done online.

Traditionally it's done in person.

But we're moving it forward where say once a month, something like that, you would have social workers who are working in federally qualified health care centers.

They're working with the early start programs where they would meet online and they would learn about these tools that are available that they can provide to families for children who are awaiting access to services.

And believe me, we've heard from children's health care organizations, the state, children's health care organizations, they are really desperate for tools because they

come into contact with these families on a regular basis and they have nothing to offer them.

So by working with the rural tele-mentoring training center, we're going to put together as part of what we're doing in Q1, we're going to put together a framework and a system where we can then go out and reach out to health workers in our communities, in our areas, bring them together online for this community health care program.

We're happy to partner with the RTTC to do it.

It's a way we can have a force multiplier effect.

Again if you build it, they will come, that's not the best strategy.

The idea that there are families out there and they realize they need services and then among all of the other things they are dealing with, they go to this website and they find the information, that will happen in some cases.

It will be much better though if the health workers who are already out there interacting with these families have these resources in their toolkits.

That's really the way we are looking at getting these resources out to families.

And this is tailor made for telehealth.

If you would like to get involved and learn about how you can bring this to health care workers in your areas, please reach out.

I would be so excited to talk to you.

I want to wrap it up with some comments from Rena Brewer who I'm sure a lot of you know and this program was in large extent her vision.

I want to leave you with some closing words from her.

>> This free program is made possible through CARES Act program to the Southeastern--

>> I'll start that again.

>> This free program is made possible through CARES Act funding to the Southeastern Telehealth Resource Center, and the nonprofit global partnership for telehealth. This program is designed to provide needed training and increase awareness of using telehealth as a means to reach hard to find, specialty care.

My name is Rena Brewer, and I lead the nonprofit global partnership for telehealth. I'm also a registered nurse, a mother, and a grandmother.

In the past it has been very common that when parents reported to their doctors that their child was showing red flags for autism or were behind in their development, they were told to wait and see if these issues will go away or improve.

But now we know better.

Waiting is the worst thing you can do.

You risk losing valuable time at an age when your child has the best chance for improvement.

And whether the delay is caused by autism or some other factor, kids are unlikely to simply grow out of their problems.

The symptoms of autism can often be seen between 12 and 18 months.

If action is taken between 18 and 48 months, intensive treatment may help to rewire the brain and reverse the symptoms.

Research proves that acting early can have major positive effects that last a lifetime.

You must act early.

It can make a lifetime of difference, but it can be overwhelming.

How do you know if your child is at risk?

Where do you turn for help?

If you suspect delays or autism, it is critical that you contact your child's doctor or nurse immediately.

These services can be covered by most health insurances and Medicaid plans.

While you are waiting for an evaluation or therapy services, you can still act early.

This program will help you.

It will help your child get started on the right path.

>>> So that wraps up the presentation.

Thank you everyone, really appreciate your time today.

There is my email address [Boyd.mark@GPTH.org](mailto:Boyd.mark@GPTH.org).

If you would be interested in having you or someone from your team join us as we work with the RTTC to develop this program in Q1, create the framework and the approach for going out and working with health care workers in your areas to get this information out to the families who need it, it would be great.

Would really, really love to talk to you.

There's absolutely no reason that especially using telehealth and online methods that we can't take this out to health care workers nationally and using the program through the rural telemedicine or rural tele-mentoring center, it's going to be really well structured and well organized and it's great to be working in partnership with the organization.

So I'm very excited.

These tools can just make a huge difference for families who are awaiting access to services and by getting it into the hands of health care workers, we can have a big force multiplier effect.

As Rena mentioned, it lasts a lifetime.

Time is brain time.

If these kids don't receive intervention between 12 and 48 months and four years, their set up for the rest of their life.

But in this window their trajectory can be changed, in many cases dramatically changed.

While half of these families or more are waiting for services, there can be things that are done in the meantime, we can train these families to help themselves and help their children.

I hope that you will help us do that and please get in touch with me and thank you again for your time today.

>>> Thank you, Boyd, for your detailed presentation.

We have a couple of questions in the Q&A and the chat.

The first question I see is have you done outreach through the autism society of America?

They have a large parent support group, patronage, and can be told about this resource directly?

>> That is a great question and the answer is no, we have not.

We have been in touch with Autism Speaks and some other groups.

The Autism Society of America is yeah, that's a great suggestion.

If whoever posted that has any contacts or additional information on that, please let me know.

I think that goes to the value of everybody coming together on this because we've created tools and we're going to continue to build them out.

But it's really going to be a matter of getting the tools into the hands of people who are already working with these families.

And none of us are as smart as all of us.

So I appreciate that input.

>> The second question I have in the Q&A is from Michelle Hollander.

It says I work for our county infants and toddler program and children in our program are receiving early intervention.

As a licensed psychologist, I'm able to diagnose autism.

Is there a benefit for using toddler tracks for the families in our program?

>> I would say yes, I certainly hope so.

The idea would be that if the child has screened at risk on the modified checklist for autism in toddlers and/or any concerns have been identified and in particular if the child's received a positive diagnosis and yet they're awaiting access to services as is so often the case as I'm sure you know better than I do, what do you do?

What do you tell them?

And one of the things that they can do, you can direct them to some of these resources so they can learn to use the basics of behavior analytic intervention around positive reinforcement.

It's certainly and we try to be super, super clear about this, this is absolutely in no form or fashion any kind of substitute for professional intervention, however so many families do not have access to professional intervention and what do we do for them?

And that's where these resources could hopefully be useful.

And I would appreciate any input you have about how we could put these together in a way that's more useful for families.

People have said you need to have DVDs in the library and all kinds of other ideas.

So this is all about continuous improvement and figuring out how we can get these to these families.

If you have some additional thoughts, please let me know.

>> All right, thank you.

I don't see any more questions in the Q&A or chat.

There are a lot of comments, thank you for your presentation.

I'm sure a lot of folks will be reaching out to you.

We will post Boyd's slides along with the full webinar recording later today, if you have any questions after this presentation, submit your question on our contact us page on [telehealthresourcecenter.org](http://telehealthresourcecenter.org) and I will make sure it gets answered.

I will bring up our closing slides.

So a reminder that this is our last webinar of 2021.

We do not hold a webinar in the month of December due to the holidays.

The next webinar is scheduled for January 20th and will be presented by the Center for Connected Health Policy.

Registration and further information will be sent out soon.

We value your opinion and ask that you take a few minutes to complete the online survey that will pop up at the conclusion of this webinar.

Thank you again to Boyd Mark for presenting today and for the Southeastern telehealth resource center for hosting this webinar.

Have a great day, everyone.

>> Thank you.