Heike Johns:
Welcome to this month’s edition of From the Director's Desk with Val Huhn, Director of the Division of Developmental Disabilities.

I’m Heike Johns, Learning and Development Coordinator for the Division, and your host for this podcast.

In addition to having Val on today's podcast, we have a special guest with us, Dr. Kristin Sohl with ECHO Autism, to talk with us about some exciting resources designed to help local providers improve their ability to serve individuals with autism in their communities.

Val Huhn:
Hello Dr. Sohl, and thank you so much for joining us to discuss ECHO Autism. We're really excited to hear about the plans we have to expand ECHO Autism in Missouri, and we wanted you to really come in and shed some light on what ECHO Autism is, what we've been doing, how it works, and where we're going next. So, can you start out by just explaining to everybody what ECHO Autism is? You've got to take it all the way back, even to what ECHO is.

Kristin Sohl:
Absolutely. First of all, thanks so much for having me. Really delighted to be here.

You're right, ECHO stands for Extension for Community Healthcare Outcomes, and it was originally designed by a liver doctor, a specialist in hepatitis C at the University of New Mexico. He was working with patients, and their families, who had hepatitis C and couldn't really get meaningful access to treatment for that without driving five, six, seven hours to get to the main academic center in Albuquerque. So he created ECHO in order to be able to improve the capacity to take care of hepatitis C patients, but it's since expanded.

Let me explain a little bit more about what ECHO actually is because, right now, you think it's an acronym but actually what it is is a very interesting and creative way to disseminate knowledge. We use multipoint videoconferencing, which is a lot like The Brady Bunch. If you think about seeing 20, 30 people all at the same time on their own little, individual video conferencing square. Then, we use evidence-based practices and we teach or mentor other providers through their own cases. Then, we use evidence-based practices and we teach or mentor other providers through their own cases.

I like to think about it as trying to teach someone to drive. If you tried to teach a child to drive, you wouldn't give them textbooks and a whole bunch of pieces of paper to read, and then say, "Here are the keys". You would say, "Let me guide your practice. I'm going to coach you, I'm going to mentor you, and then, over time as you learn, you'll be ready to take the keys". So it's very much like what ECHO uses in that teaching another doctor how to take care of a common-but-complex condition can often be pretty scary. Like driving a car, it's complex. It's common, but certainly not just something you generally do by reading a textbook and going on. So that's how ECHO uses this virtual space, is by mentoring and guiding practice, and it really works super well.
We, then, at the University of Missouri, adapted the ECHO model to autism in 2015, and have been having a tremendously wonderful time being able to spread that knowledge throughout the state of Missouri and then to other places as well.

**Val Huhn:**
So, if you are a provider that is using ECHO Autism, who are you? What kind of providers are you serving today, and what kind of cases are you helping those providers understand, get better at managing?

**Kristin Sohl:**
Our original ECHO Autism model was specifically to primary care providers. That's pediatricians, family physicians, nurse practitioners, physician's assistants. That's been going on for four years. The cases that they bring are things like, "Johnny is a ten-year-old boy in my practice who has autism, and he's not sleeping at night. What can I do?" Or, "Sally is a two-year-old who just raised flags on her screeners and I'm concerned she has autism. What are my next steps?" Or this extra model that we added about two years that's called ECHO Autism STAT where we actually have been mentoring primary care physicians and practitioners to make autism diagnoses so that those kids don't have to wait on long wait lists and they can get into services immediately.

Those are the main kinds of ECHO Autism cases that we've done, up until about a year ago when we started adding in addition kinds of providers. It's not all together. We have an ECHO Autism for primary care, then we have an ECHO Autism for community psychologists, and an ECHO Autism for crisis care providers. I'll explain that one a little bit more because it's a little bit more complicated than the other two. Essentially, if you're a community psychologist, there's an ECHO for you. If you are a mental health professional or an inpatient psychiatry provider, or a staff member, there's an ECHO for you. If you're a pediatrician, then the ECHO Autism primary care is for you.

We're really trying to work on building a network of coordinated providers across the state of Missouri so that people with autism can experience best-practice care, no matter where they live. So it doesn't dictate, if they happen to live in very rural south Missouri, or southwest or southeast Missouri, they don't have to drive to St Louis, Kansas City, Columbia to get that best-practice care. We're trying to really empower local communities to take that really great care of families.

**Val Huhn:**
I like that; empowering and keeping it local. That's really important, because we all know how difficult it is for families to travel. Most families have multiple children, and that can be really challenging. I think it's interesting how you talked about we're pushing diagnosis out. Can you explain more how that works, because I know the answer already and it's really cool.

**Kristin Sohl:**
Sure. Thanks. I really love what we're doing with the early diagnosis. The thing is, when you have a child, we all know, as parents, that your pediatrician's kind of you go-to person for your questions and often your answers. But what people don't really often realize is that a general pediatrician gets four weeks of development in their entire training. That's not a lot, so when parents come to them for questions about autism, they often don't know the answers, and they certainly don't have the expertise to make a diagnosis.
So, as we started with ECHO Autism primary care, originally, back in 2015, we started to think about, "Well, gosh. We're hearing about cases from these primary care physicians and practitioners that are clearly autism", but we didn't really have the direct behavioral observation, as an expert team, to feel confident in making that diagnosis. So my team and I started thinking, "Well, what would it take to feel confident that our primary care colleagues in rural and underserved Missouri were making a solid diagnosis?" That's where we started with this notion of ECHO Autism STAT.

One of the things I think is really important to clarify is that it's not a shortcut to diagnosis. It's not a half-done or a half-baked diagnosis, it's truly a high-quality diagnosis, and we've set up this process to help us deliver that. Essentially, what we decided was that our ECHO Autism primary care providers were gaining clinical expertise, for sure. They were learning how to do a very high quality diagnostic interview, but we still didn't have a structured behavioral observation that could essentially provide that objective evidence that we felt like we needed in order to validate an autism diagnosis.

We landed on a tool called the STAT, which stands for the Screening Tool for Autism in Toddlers, and we tested it out. Thanks to our partnership with the Department of Mental Health, as well as some others across the state, we explored this idea of bringing in primary care providers, pediatricians, family physicians, and nurse practitioners, for a one-and-a-half-day training on, basically, the basics of autism and learning this measure called the STAT.

Then, we taught them even more about diagnostic interviewing, DSM-5, and really helping them to build those clinical skills so it wasn't just, "Let me ask this laundry list of questions, and then not know what else to do". We taught them how to really dig deeper into those questions. Then, they participated in ECHO Autism for six months. At that point they were eligible then to present a case for a diagnosis.

So, all of that mumbo-jumbo goes in to mean that we now have built the first-of-its-kind, very high quality, early-access points throughout the state of Missouri. We have 19 primary care physicians and practitioners who are able to make these diagnoses through the ECHO Autism program. We did a recent study looking at this, and we actually were able to show, at minimum, 173 miles of savings to families. In other words, they're not having to drive, on average, 173 miles to get their answers. We also were able to show at least a two-to-six-month increased access to early intervention, compared to what they would have had through the traditional methods. So we're really proud of that.

Val Huhn:
Well, we're really proud of that, too, because early intervention is huge if we're going to make any changes in a young person's life. You touched on the other stat I wanted, which was how close we are now. If you're a family member who wants to access one of these providers out in the community, how do you get that information?

Kristin Sohl:
It's a little tricky, still. We are a very grassroots organization at this point. One of the things that we're planning to do is really build that up so that families can have their own easy access to figuring out where can they go. Right now, most of the time, families hear about word of mouth, so it's very much through other providers. Most other primary care providers know about ECHO Autism, and they know how to get their patients to an ECHO Autism provider. But what we'd like to see is that it be very much a any-point-driven process where, if a family has a concern, they can go and figure out where's their closest access point. If another pediatrician, not involved in ECHO Autism, has a concern, they can go and quickly figure out their access point. That's what we're wanting to build up, is trying to figure out a
way to make sure... It's not hard, it's just a matter of figuring out how do we make that accessible to families, and make sure that they know how to get the points of access that they need.

Val Huhn:
Another area, for me, that is really important is getting access to care for our young adults, teenagers and young adults, who may be experiencing some sort of crisis. We all know that we do not have an adequate network for that. I know you guys have started working on a Crisis Autism ECHO. I probably didn’t use the words in the right order, but I'll let you fix that for me.

Kristin Sohl:
Sure.

Val Huhn:
But can you explain more how that is working right now in the state of Missouri?

Kristin Sohl:
Yeah, absolutely. You're very right. Our crisis pipeline or continuum, I like to think of it as a kind of a behavior crisis continuum, is really not very continuous. Many families get stuck in this systematic communication problem, so we decided to think about addressing this through ECHO Autism. We created ECHO Autism Crisis Care. It launched in February 2019, so very new. We spent about six months really studying the system, building relationships with both community mental health, emergency department personnel, and then also inpatient child psychiatry units, or psychiatry units, to think about what is it that they need in order to improve that communication across that continuum.

What we really have focused on, and it's gone very well, is thinking about how do we improve that communication. So if a family who's receiving their care in a community mental health clinic, let's say, starts having a behavioral crisis, currently what often happens is that that patient calls the clinic, the clinic says, "Oh, well, are you a harm to self or others? Go to the nearest emergency room". But, unfortunately, what that looks like on the family's side is that they show up to the emergency room and the emergency room's ill-prepared. Not really to their own fault, but they don't really know what to do. They know what to do with other psychiatric issues, but autism is its own entity, and so they're often feeling ill-equipped and ill-prepared to take care of these kiddos.

Then, they're trying to find a bed in an inpatient unit for these children, adolescents, and unfortunately there are not a lot of beds to be had in Missouri. So that obviously creates some major issues for families. Here you have a young person with autism who may have significant behaviors, they're in a behavioral crisis after all, but they often are out of their element, they're upset, they're in bright lights at the emergency room, all these things. So Crisis Care is trying to create awareness among the three points of access for behavioral crisis, the outpatient world, the emergency room or emergency department, and the inpatient unit, to help think about how can we better support these families.

Now, of course, we're also talking about things like psychopharmacology and various things like that, but really the crux of that ECHO is about communication; how can we help families and their providers prepare their patients and their children to have the best experience that they can have? So, that might be through a communication tool, something like what we call This Is Me; it's kind of like a patient resume. Identifying little things like, "These are triggers for my child", or if the person's able to do it themselves, "Loud voices and bright lights trigger my aggression". Things like that.
Then, also being able to figure out ways to support each of these different points along the continuum with cutting edge behavioral strategies. There are great resources out there for de-escalation, and distraction, and on and on and on, but unfortunately that often is a missing link for so many of our systems. So that's another huge focus, is really thinking about how do we support these families when they are there.

Lastly, I also am really proud of this part: safety. One of the big things I think results in negative experiences for patients, and their families, with autism is this piece of safety. Keeping the child safe, but then also the staff at the ER or the staff at the inpatient psych units. So a heavy focus of our ECHO Autism Crisis Care is also how do we protect our staff, which is incredibly important if we're going to build a system that takes care of these kids in an effective way.

Val Huhn:
That is really great. So we got those two Autism ECHOs up and running, and we got some new funding this year to continue to expand the providers we're reaching with Autism ECHO. That's even to go to not the doctor level, but even below that level, the therapy level, that kind of level. Can you give us more information on how you see the state using this money to get more providers out there educated and able to support individuals with autism?

Kristin Sohl:
Yeah, absolutely. First of all, very appreciative to Governor Parson, as well as the Department of Mental Health, for the leadership in order to help really think about ways that we can build a different system. The way I like to think about it is this notion of autism-ready communities, where no matter where a child with autism lives, they're in a community that knows how to support them. That doesn't necessarily mean an individual rural town, but a collective of towns, for example, where you may have a pediatrician in one space and then, maybe 15 miles away, you might have an emergency department that equipped to take care of them. Whatever the case may be, but really thinking about this notion of "autism-ready", where we have providers of all levels, whoever may interface with these families, who have the requisite knowledge and skillset to take care of families.

With that, obviously we know early intervention is incredibly important. We have phenomenal providers through First Steps and also many hospital-based clinics and outpatient-based clinics, but just like with pediatricians who only get four weeks of training on development, most therapists also don't have tons of knowledge about autism. They may have some, but that's probably not their area of focus. So one of the things that we had thought about is could we use ECHO Autism to really expand and push the boundaries of supporting those rural and underserved therapy providers, as well. For example, could we partner with...? I like to think of experts being relative, but experts in speech therapy, occupational therapy, applied behavioral analysis. Can we connect those folks who have an expertise in that type of therapy related to autism with our rural and underserved therapy providers? The answer, I think, is "yes". We know, by talking to many of them out in the field, that they are very eager to learn more about how they can support kids with autism in a more evidence-based, cutting-edge type of way.

This ECHO Autism for early intervention, it's honestly the one I am most excited about because I think it's going to transform the access families have to what they need. Getting a diagnosis, obviously, is your starting point, but it's so much more than that. Of course early access to diagnosis is pivotal but then, if you still have to wait a year or maybe never get into really good quality therapy, what does that say?
One of the things that drives my passion related to building rural communities, and supports for families with autism, is that in my own clinic I take care of lots of families who drive many, many, many hours to come and see me. Yesterday, I was in clinic and the furthest that someone drove was five hours, because they were from way, way south in the corner of Missouri. When I think about what that means, and I think about what that would feel like to have to drive that far to get access to what your kid needed, it really hurts, frankly. Then, I also see that most of our small towns are struggling to provide evidence-based resources for their families, and that directly impacts outcome.

So I have very high hopes for ECHO Autism Early Intervention to really support our First Steps providers, our Headstart providers, our community therapists that are working in the schools and all around, that I think we will be able to bring really nice change and support to those individuals.

Val Huhn:
I do, too. I know, anecdotally, when you talk to them, they want help. They want to be able to support those families and those kids in their communities, and hopefully this opens those doors.

So, we've got these great opportunities for people to learn, treat, and support individuals and families locally. How do providers find out? How do they get involved? How to they unroll? What do providers have to do?

Kristin Sohl:
Really, all it takes, and we do a lot of outreach, so many times we are really out talking to different types of providers, groups of providers. Typically speaking, that’s how we do it. They hear word-of-mouth, again. But one of the pieces that we’re planning to strengthen is this path to getting connected. So if you are a provider of whichever variety, and you want to learn more about autism or you want support for the patients you’re already seeing, then we are working on building out a much more proactive approach, if you will, for you to be able to get connected. Currently, all of the success and all of the participants that we have are really from this grassroots, word-of-mouth effort. Which is great, but we want to make that a little bit easier for people. So, that’s one way.

The other thing I will say is that many patients and their families know about ECHO Autism, and so they’ve been driving a lot of the traffic to getting their doctors, their psychologist, their whomever, to participate. We love that, and that’s a huge piece of what we want to do as well, is to really empower parents to say, "Hey. We need you, speech therapist" or, "We need you, special educator", whatever the case might be. So we’re super excited about the opportunity to do that, as well.

Val Huhn:
Well, I think, as a provider, if you hear it from your families, you’re going to be more inclined to be, "I can do it. They have faith in me, they want me to this job, let me go learn how to do it". We know our providers want to learn new things.

Kristin Sohl:
Yes, exactly.

Val Huhn:
So, very exciting. Anything else that you want to share, that I have not included about the ECHO Autism evolution here in Missouri, and really across the world, right?
Kristin Sohl:
Yeah. It has been just a joy, honestly. Sometimes people think about going to work as being a chore or whatnot, but this has truly just been a remarkable journey. To be able to take this kind of knowledge-sharing, I always like to tease people that it's like what we learned in kindergarten, just to share freely. It's so freeing to be able to say, "Yeah, I just want to share with you. I'm not really gaining anything out of it other than all of us working together". I think that that's certainly something that is remarkable to be a part of.

I will say, too, that we are very much interested in trying to make Missouri, and we're well on our way, this place of truly networked autism providers. Again, that "provider" being used in a very, very broad sense around education, diagnosis and treatment. We think that Missouri can really set the bar high for how autism services are delivered in a cost-effective and family-centered way. So we're very, very proud of the partnerships that we have, and are very much looking forward to this expansion.

Val Huhn:
Well, your data's great. I know the families and the providers love it, and I cannot wait to see how it continues to evolve.

Kristin Sohl:
Me too.

Val Huhn:
Thank you so much, Dr. Sohl, for your time today.

Kristin Sohl:
Yes. Thank you.