Transcript of Dr. Kristin Sohl presenting “ECHO Autism: Bringing Best Practice Autism Care to Communities through Guided Practice and Technology.” at the 2019 Autism Summit on 11-02-2019.

Slide 1:
[Dr. Kristin Sohl] Thank you all, I'm really excited to be here with you. I am a pediatrician. I specialize in autism and spend most of my time both diagnosing autism and then also taking care of individuals with autism across their lifespan. So what I hope to do in the next 15 minutes or so - 12 to 15 minutes, is share with you what we created at the University of Missouri and we call it ECHO Autism.

Slide 2:
But first I want to walk you through a little bit and kind of bring together some things that I think will summarize and pull together some things that we've talked about all this morning.

So obviously we talked this morning about the rise in prevalence of autism. Sorry I'm just trying to get this to cooperate. So when we, oh boy there we go. Can you guys hear me okay? So when we think about the rise in prevalence we certainly then think about the fact that this prevalence leads to a rise in awareness as well.

So if we think about Autism Speaks and some of the other incredible advocacy organizations across the world, we know that that has led to a significant rise in awareness around autism, which is wonderful. However, that then also results in many, many more people having questions about their own child or loved one about having autism. So we hear things on the Today Show or Good Morning America or whatever the case may be, which then leads to rise in referrals to tertiary care centers or therapy or various entities that take care of individuals with autism. And then certainly that leads to individuals with autism needing more help.

Slide 3:
But as you can imagine, that also leads to significant issues related to supply and demand.

I want to bring your attention to though, a significant issue related to perspective. So you have perspectives from, here there's three, there are many other perspectives we can consider, but when we think about these particular perspectives.

So I work as you heard at a tertiary care center or specialty center. And at a specialty center, you've heard from several of us, the families that make it to those places have great access to cutting edge therapies, to cutting edge diagnostics, to fantastic resources. And yet they don't necessarily have access to those types of things in their own home communities.

So what happens if you live in a rural part of Idaho, or Missouri, or the Navajo Nation, or, or, or right? What happens to those individuals and what does it say about their outcomes if they can't make it to an academic institution, for example?

Then you think about primary care, and I know we heard from Dr. Epperly this morning, and others, I am a general pediatrician. I do practice developmental behavioral pediatrics, but I also practiced general peds for the first five years of my career as I was building my developmental behavior specialty practice. And so one thing that's important for you to realize is that a general pediatrician gets four weeks total of training in developmental anything during their residency. So that is not a lot of time. So when you think about then four weeks over the course of a 3-year training program. And then if you go out into general
pediatrics practice and your practice then contains, around 40% of your total practice, is going to be made up of about 40% of development and behavioral issues, it results in a feeling of very overwhelmed and very unsure of what to do. Now, you could argue that as a pediatrician, oh you know, you'll figure it out, and you're amazing, and everybody loves their pediatrician. And that's true, except that that's a very unnerving feeling to have as a doctor. And so certainly that perspective is often lost on people. They think, "Oh you're a pediatrician, you know all of these things." Well not really. And so four weeks of training is not enough, and that includes, by the way, everything in development, not just autism. So Down syndrome, spina bifida, cerebral palsy, ADHD, on and on and on, right? So that perspective is important to understand.

And then of course, you have the family who's asking and seeking answers. They hear, go to the pediatrician, ask your pediatrician questions, but your pediatrician is like, "Ahh, I'm not really sure what to do, go see the specialist." And the specialist is like, "Ahh, I've got a wait list from here to kingdom come with 12 months' worth of people backlogged trying to get into see me." Now what, right? So all of these perspectives come together. So as you're thinking about those, if we can synergistically figure out a way to work with those perspectives, that's how we could actually maximize our outcomes.

So I'm going to tell you a little bit about what we've been doing in Missouri, and then actually quite a bit beyond that, and how we've been using some technology strategies, but really it's education strategies, to try to improve how that looks.

Slide 4:
So again, it's really rooted in this supply and demand issue. So if you think about, obviously the healthcare system, we know it's fraught with major, major issues, but it really then leads to this overarching issue of health inequalities, and health inequalities are everywhere. It's not just autism. We could fill in the blank with any other disease, disorder, whatever you want to call it, and certainly those rising inequalities lead to declining health for the individuals who are experiencing those health inequalities.

Slide 5:
So a gentleman named Sanjeev Arora, is a hepatologist, or a liver doctor, who lives in New Mexico, and he designed something called ECHO, which stands for the Extension for Community Healthcare Outcomes, and I'm going to tell you a little more about that in a minute.

But in a simple thing, and if you hear nothing else from my talk today, the easiest way to remember what ECHO means, it's moving knowledge not patients. Sounds super simple but it's actually very revolutionary. And so when you think about what we're about to talk about in the next set of slides, keep reminding yourself about what this is. And so it's about moving knowledge, not patients.

And if you think about what we do in the U.S. healthcare system, it really is all about moving patients to knowledge, right? So how many times have you had maybe a cancer scare, or maybe an infectious disease scare, and they're like, "Oh you need to go see this specialist in X, Y, Z, fill in the blank big, big center." Well it doesn't matter if you live 200 miles from that big, big center, you have to go see that specialist. So we've designed a system around going to higher and higher levels of care because that's what you do. But this is a way to really redesign how we think about this.
Slide 6:
So I'm going to, in the interest of, I am going to show you a quick video because ECHO can sometimes be a little bit difficult to understand unless you see a decent visual of it, so I will show you this. Give me one second to pull it up. It's actually very simple, but it's just easier if you see it visually. So it's about 80 seconds.

[Video Narrator] Project ECHO delivers specialist medical knowledge to regions most in need. It's spreads new knowledge from teaching hospitals and academic centers to the front lines of general practice and primary care. Rather than medical expertise residing in a hospital, PCPs learn from specialists, they learn from each other, and specialists learn from PCPs as new best practices emerge. Under ECHO, primary care teams use video conference technology to participate in case-based learning with expert mentors. They acquire new skills that allow them to treat patients they would otherwise need to refer on. Patients with chronic complex conditions get high quality care closer to home from providers they know and trust. No waiting months to see a specialist, no long drives back and forth to large hospitals. ECHO exponentially increases access to best practice care by moving knowledge instead of moving patients. Time lost from work and school is reduced and more family centered care is delivered. Project ECHO. Improving the care of children and young people fast. Are you part of the ECHO?

[Dr. Sohl] So why I like to show you that before we go into kind of some of the nuts and bolts of what ECHO is, is because I think it gives you a decent overview of the project itself.

But again as a reminder, really it started with Hepatitis C. And so the notion there being that people with Hepatitis C in New Mexico were waiting for months and months to get into see a specialist in Albuquerque and they were having to drive 4 or 5 hours from the rural parts of New Mexico to get in for healthcare. And unlike autism, they were passing away before they could even get in to see a specialist and even once they got in, they couldn’t afford the trips back and forth to Albuquerque to get the treatments. And there were no providers in those rural communities to take on that treatment. So ECHO became this means by which the specialist at Albuquerque, in this particular case, Dr. Aurora, started to work with, through guided practice, the community practitioners in rural New Mexico.

Then as ECHO spread, as he started using this model, his wait went from 8 months to 2 weeks and people all across New Mexico were able to get access to Hepatitis C care. So, and I always like to make this clear, it wasn’t second rate care. This was top notch care but close to home. And actually was able to publish a very pivotal study in the New England Journal, that that care, those patients who got care in their own hometowns through the ECHO project actually did better, had better outcomes than those who were traveling to Albuquerque to get that same type of care.

And if you think about that it kind of makes sense, they were staying closer to home, and had their community care, that kind of thing.

Slide 7:
So the ECHO model in a nut shell is made up of As, Bs, Cs, and Ds. So we use technology to amplify and leverage scare resources. So some of you may, or may not know if you look at this field of developmental and behavioral pediatrics, of which I don’t mean to imply that that’s the only type of professional who can take care of kids with autism, but let's look at that as an example.
There are about 575 board certified developmental behavioral pediatricians in the country, and well over 50% are over the age of 55. So, that’s a problem, and when you think about that that represents a huge scarcity of workforce. And thinking then about well what are we going to do there. And again, that doesn't mean that there aren't other very well credentialed and equipped professionals that can take care of people with autism, but certainly that’s a scarce resource. So we use technology to amplify those resources.

Then we share best practices through case-based learning. Case-based learning is deidentified. So there’s never an opportunity where there's a doctor patient relationship set up, so there's often questions about medical legal responsibility because these cases are being presented, and I as a specialist, am sharing considerations that the primary care physician or practitioner may consider to do for their patient. But, because there's never any identified information being shared, so it's not Johnny Jones' birthday 2002, I'm telling them what to do. It's more case number 50101. This is the story, here are things that you might consider. There isn't a medical legal relationship. So that's an important piece to know too.

And then the D is monitoring outcomes. We have a really robust opportunity to essentially look at outcomes based on the practitioner's learning. So it's not necessarily patient level learning, but it's practitioner learning. We would like to eventually get to patient level learning, but that's challenging, which is a talk for a different day.

**Slide 8:**
So telemedicine and ECHO are very synergistic, but they are not the same. So this is an important slide for those of you who are interested in those kinds of things. Telemedicine, I do that in my clinic, but it doesn't leverage any kind of scarce resource. I see patients, and I see patients through telemedicine, but it doesn't do anything to increase capacity. It allows that family to not have to drive but it doesn't do anything to leverage what I'm doing.

And ECHO though, on the other hand, takes a team of experts and then teaches a bunch of other community practitioners, so physicians, and nurse practitioners, and physician assistants, how to provide best practice autism care who then go out and provide that care. So that's really that accelerator that we're talking about.

**Slide 9:**
The core of ECHO is really this HUB and spoke model. So you have a HUB of experts, it really can be anything, you'll see a bit of this in a bit. ECHO has now been used in the education space, it's actually been used in community policing, which I think is fascinating. So police departments in Ferguson, Missouri, again I'm from Missouri, Albuquerque, New Mexico, all of these places that have been struggling with conflict resolution and different types of issues, are doing ECHO together.

So they, the learners, or the spokes, are police departments, and the HUBs are experts in conflict resolution, de-escalation strategies, things like that, and they're moving knowledge, not police departments, right? So they’re not sending all their people to some center or whatever, but they’re using ECHO to really move that knowledge which is really cool and innovative I think.

But again, core is a HUB team of people who have content expertise and then spokes of learners who are trying to learn something complex and typically common.
Slide 10:
The platform that we use is Zoom. The reason we use Zoom, and it's not proprietary, no one is making money off of this, but the reason we use it, is because it's optimized for low bandwidth. So ECHO proper, meaning ECHO worldwide, is in many, many countries. India, Africa, all over South America, all over the place. And so we need something that's really optimized to low bandwidth, and Zoom is the best for that.

So anyway, you have your HUB and your spoke participants. You can get up to 200 spokes on at any time, although that's not really recommended. Ideal is probably around to 25 to 30 at any given time.

Slide 11:
Moving into more specifics related to ECHO autism. So my team at the University of Missouri heard about what was going on with the hepatitis C world, and HIV, and tuberculosis, and things like that. And I was sitting at this meeting and I thought, "Oh I think that could apply to autism." So essentially came up with this notion around ECHO autism, and how it applies, and how could we use this to move knowledge not patients.

So our team, as you'll see, is made up of physician content experts, that's me in this particular example. Clinical psychology, a child and adolescent psychiatrist, a registered dietician, a parent advocate, and a resource expert. We really believe in modeling parent professional partnerships, and so that's an important piece of what we do, so we do have an equal, a parent expert on our panel, and every replication that we've ever done, which I'll tell you about, also has a parent advocate as an equal on our expert team.

Our goal here is to increase local access to high quality healthcare for children with autism, and we think that's a really important piece.

Slide 12:
And so then we have been running continuously since March of 2015. I have updated numbers that I accidentally didn't graph into here. So we've had about 596 individuals participate since March of 2015. We've held 108 sessions. And had about 810 CME hours in Missouri alone. We have over 25 partners across the US who've taken our model and used it in their states. So that's just Missouri numbers. And so certainly we're having a lot of success in that area.

Slide 13:
In Missouri, our original model was really designed to help improve access to identification of symptoms with autism as well as management of common medical and psychiatric conditions, which you've heard about from many of the speakers this morning. And so when you think about those common conditions that you've heard about, so constipation, sleep, things like that. Those are things that primary care docs are really equipped to do but unfortunately, when they hear autism on top of it, they're like, "Ahh, I don't know, go to the specialist." And so the fortunate thing is when you guide them through that practice and kind of demystify the process of the autism piece, they then become very equipped and willing and able to take on the rest of it.

So that was our original model. Then we started to really work on diagnostics. Because while we had a lot of success in treating and helping them to manage the underlying conditions and recognizing symptoms of autism, we also knew we needed to help them with recognizing and diagnosing autism.
So we branched out and started doing what we call ECHO autism STAT, which is a little bit more of a robust program. And essentially these little yellow MU's represent about half of the people, we haven't updated our map yet, but we have now 30 primary care physicians and practitioners spread out strategically across the state who can diagnose children with autism with the most obvious symptoms between the ages of 14 and 48 months. And now all children within the state of Missouri are within 60 miles of an ECHO Autism provider. We actually have just trained a whole bunch of new primary care practitioners, so it's actually 40 miles. So every child within Missouri is now within 40 miles of an ECHO Autism provider.

**Slide 14:**
We've essentially created a multi-tier autism diagnostic process that allows kids to get diagnosed in a community when they fit that most obvious symptom criteria. If however their symptoms are more subtle or complex then they go on to their next level of care.

**Slide 15:**
That is the next piece, so we created ECHO Autism Psychology, actually is what we call it now, the first iteration was diagnostics. We trained community psychologists in diagnostics. Trained them on the ADOS, trained them on the best practice diagnoses, and created again, access points within the community to help them with autism diagnostics. So that families wouldn't have to travel to St. Louis, Kansas City, or Columbia, where I live, to get those access to diagnoses. This has significantly reduced the wait times all across the state and families are now getting access to what they need, when and where they need it.

**Slide 16:**
So this is essentially how it looks. So we call this the Right Care, the Right Time, and the Right Place model. So again it's moving that knowledge without moving the patients. So certainly, there are plenty of children who still need to come to tertiary care centers and receive that very intensive diagnostic evaluation because they're the most complex kids, but that isn't the case for everyone. So if we can instead streamline that approach and triage them more appropriately and get those families what they need, when they need it then that's how we've been doing this.

**Slide 17:**
We are spreading well beyond primary care and medical entities. So we now have ECHO Autism in multiple areas. So education, intervention, and then beyond. So this slide represents that, and I'm going to be going a little bit faster.

**Slide 18:**
And so we are developing what we call Autism Ready Communities. Which is where we hope to or we are using ECHO Autism to essentially support and equip communities of both physicians, so the medical community, educators, advocates, to really be able to support families and their individuals with autism, no matter what sector of the community that they are in, to really ramp up the ability to support those families.

**Slide 19:**
I'm not going to spend much time on this slide, but if you're interested I can talk to you more about it, but we're using ECHO for a lot of different places both in Missouri and then beyond.
Slide 20-21:
We are part of a large collaborative.

Slide 22:
This is just a small list of the people that are using the ECHO Autism model that we designed. To use that notion of moving knowledge not patients. So we have folks in Kenya, and India, and Uruguay, and Vietnam, and all over the place that are using the same curriculum that we developed and designed in order to be able to move knowledge and deliver best practices regardless of geographic location. And I think that's a really important piece, because there are phenomenal resources that have been developed to support people with autism and they can't access them unless they go to one of our top tier institutions.

Slide 23:
(no comments on this slide)

Slide 24:
So you may be asking, "Well how do you learn about this?" Well all you need in order to join is the internet and a forward facing camera, and a collaborative spirit, and a willingness to learn. So what's the catch? There really isn't a catch. It's no cost. It's free. You do earn CME or CE's if you're interested, and you can learn more by going to echoautism.org.

That we have been definitely engaging in conversations with the ECHO program here in Idaho to bring something like this, right here to you. And so your very own autism content experts, and figuring out ways to use your own autism content experts to deliver this kind of program to your own Idahoans. Am I saying that right? So we certainly think that that's great.

Slide 25:
So we like to say, "Are you part of the ECHO?" And a really, a really, really inspiring mission that's part of a worldwide effort to touch a billion lives by 2025. Not obviously just in autism, but all around healthcare in general, so we would welcome any and all of you to be a part of that as well. So thank you very much for your time and I'm going to hand it back over.

[audience clapping]