

Transcript of Ron Oberleitner presenting “Telehealth Technologies and More for Families and Professionals” at the 2019 Autism Summit on 11-02-2019.

Opening slides and Introduction:

Title Slide: Telehealth Technologies and More for Families and Professionals.

>> Ron Oberleitner: Ten or 20 years ago that was not a thing in autism. Technology was a piece of paper maybe or a questionnaire. The doctor would kind of make some analysis notes or so. In a fairly short time technology is becoming available and it's coming here because it's needed. You know technology comes when it can add service, add value, and change lives. And we're at the starting point I think with autism in that regard.

So we could talk about a lot of things but today we're going to focus on technology for healthcare. And then at the end we'll make some references to some technology initiatives around Idaho here that are exiting for other things. Like education, family support, and others.

Slide 1:

Let me start by saying a journey that many families that enter this world go through. And this happened to us 23 years, four months, and three days ago where our one-year old son, who was starting to talk, and starting to interact, started to lose his skills and his ability to interact with Sharon and I. And after two more years with 10 different doctor visits, at least, and 1,000 miles of travel we finally got the diagnosis of autism. It felt like a death. But it was the important start for us to know a direction to go in.

We were living in New Jersey at the time, and by luck, I told you guys that I had a factor of luck before. We lived in a town that had the Yale and Harvard of autism service schools. Princeton, New Jersey. Even so, there was no room in the inn for somebody new at that point. And we had to put our son on a bus, and he had to be driven out 30 miles to go to another school that you know, was okay, but you know, there was a lot of money spent just to get him to another place. And on and on we went on a journey of trying to get him services and support.

He would be what you consider low-functioning autism. Level 3 is kind of the current terminology on the right-hand side there. He can't speak for himself. I love the informal testing that Thomas the Tank Engine is a testing method, because it's true in our family. Robby there wearing his sweatshirt has all the Thomas characters on him. And he wore that sweatshirt until it fell off his body because he loved it so much. He's our, we love him, he inspires so many folks but he needs help to this day.

Slide 2:

During the time, I also worked in a high-tech industry, and I had the privilege of being able to use things like telemedicine, this was in the 90s, to help prisoners get access to psychotherapy and support. Also was involved with surgery missions where we would go into the jungles of Honduras, and be able to use telemedicine for post-operative visits for cleft palate patients to surgeons back in the states. And when we'd come home and look at our son, who still needed support. We would make a doctors appointment, wait 2 weeks, go drive 100 miles, and try to describe our issues. At that point we said, "You know prisoners and children in the jungles are getting better access to healthcare than the autism community."

Slide 3:

And we feel technology is a way that we can change that. Nothing will replace the expertise of the

clinicians, but technology can support those clinicians to get more information to make better informed decisions.

We started a non-profit in Princeton, and we had some funding to be able to do some pilots of n=1 or n=5 of what you could do with technology to access healthcare. Or could distance learning help people learn how to work with kids? This is back in 2001 or so, so distance learning wasn't really proven. Can somebody learn on the Internet? And we developed some successes, and we started going to med tech meetings and showing what might be possible with technology for autism.

And one of the receptive research areas was the three universities in Idaho. Already they were given some resources to say, "How can you help rural communities using technology?" And we got invited in 2003 to come out and talk about some technology solutions for autism. There was a telemedicine network which was seemingly, we'll hear about ECHO shortly, but it seemed like a precursor where a speaker could be in one location and be able to talk to multiple states.

So we got invited, Sharon and I, to talk about some technology solutions to support people with autism, both at the doctor's office and in the families. And within two weeks of alerting of our talk, 225 people in 10 different sites throughout the state showed up in the middle of summer to hear about autism. And it blew us away. That there was a receptive audience. There was a need even in the rural communities to say, "What can we do with autism?" And that incidence was about one in 250 or 500 at that time. We all know how prevalent it is now.

So we were so inspired by the call of the people and the can do spirit here, we moved our company and our family out to Idaho and we started collaborating with the universities here to study technology and autism. Our university partners did the first telemedicine presentation, ATA stands for telemedicine association. In 2005 we published technologies that lessened the distress of autism, book chapter in 2006, the world's first ever autism telemedicine summit was here in Boise 2007. And then on and on, we've had some other great experiences here.

The message back at that time, this message is 16 years old, but this video kind of shows a little bit of what we saw the vision of what you could do with technology in healthcare from somebody's home. It's old, but it will give you a perspective of sort of the day a family's might have an ability to collect and share with their doctors remotely. And I want you to give an impression because it's important to us when I look back at this video, you'll see my son, there's no better way that I can understand what his levels of skills were then going back to a video. It doesn't work well with paper records for him or whatever. So this is what in 2003 was very interesting to the Idaho audience, and hopefully this will play.

Full video link: <https://www.youtube.com/watch?v=EI9-t58S8no>

>> Narrator: The Autism Center now uses telemedicine to address these issues. When families visit the Center for evaluations, prescriptions, or even dental surgery, they can now go home with simple telemedicine tools such as video phones or digital cameras. These tools will help capture troubling episodes and indescribable side effects. Professionals get a first-hand view of what families mean by tantrums, seizures, or self-injury and can intervene more appropriately and quickly.

Telemedicine helps reduce stressful trips to rule out ailments that an autistic child cannot communicate. Special cameras in the home and school capture sore throats or inflamed ear canals. Instruments such as digital stethoscopes can capture other vital sign information. An experienced clinician can review this by video conference, or email or video clips, still photos, and vital sign information all stored in an

electronic patient record. Even diagnostic tests, which can take months to arrange, can now be performed in the home and reviewed more quickly.

>> Woman: The number 2 test and we're doing number 18. Point to picture and have child name it. "Robby, what is this?"

>> Narrator: With this new data collection process doctors now have more information about the patient at their fingertips, and can reference patient history including video files, diet, neuro-imaging, and medication. This database has huge implications for the Center's research projects. For more information on telemedicine to benefit the treatment of autism, please visit [www dot](http://www.dot)

>> Ron: So that's just one possibility of getting access to help. We believe very strongly that all the health information starts in the home or in a classroom. That if it's contained properly and shared to the right professional, clinicians can make better decisions and families can be better supported.

Slide 4:

My message to everybody here is that symptoms of autism, either medical or mental health, can be detected and supported via telehealth or digital health type technologies that Matthew has shared with us. I am a big believer that we could be the leaders in the world delivering services with support by telehealth when it makes sense. Conventional care the way we're going is not sustainable. Our professionals are in short supply. We need to leverage technology and access through technologies.

Many kids can't communicate their needs, you see the distance issue. I hate to verbalize this, but it's really true that if we don't understand our patients better, folks necessarily die younger without access. So I don't want to say more about that.

Slide 5:

We are pioneers in this state for delivering telemedicine. Boise State, in 2005, worked with autism organizations around the country to support Katrina families. It was the first published case of real time telemedicine diagnostic assessment that they coordinated, between diagnostic expert in New Jersey and a family displaced from New Orleans over to Atlanta to get the child into services in Atlanta in a fraction of the time. And many other things.

Slide 6:

Real time telehealth is being used. St. Luke's has pioneered a program to support access to families in McCall and has plans to go beyond that as of last year. There was an article in Thursday's paper about use of texts by the behavior health group at St. Luke's to support folks who need support. And on the right-hand side we could be using real time telemedicine like Dr. Desai was giving support to family medicine via real time telemedicine.

Slide 7:

But don't forget there is other kinds of telemedicine out there and this is the stuff that saves time, saves money, save access. Asynchronous telehealth behavior imaging, that's what we do. I'll let you visit our website and there's some use case videos. I'd love you to see the way that asynchronous telehealth works with video sharing between patients and doctors.

Remote screeners and questionnaires. Primary care docs can use already out of the box tools to be able to automatically send questionnaires to the families prior to the families showing up and giving the

doctor much more informed information by the time they're meeting. That can be used for screening and quicker access to diagnosis and assessments. And what Matthew was sharing very eloquently is the use of emerging amounts of patient support apps, sensors, and things like that.

Slide 8:

We have many assessment types that have already been proven in use of behavior imaging, which is asynchronous telehealth, from diagnosis assessment, behavioral, and reassessments, and some other applications.

Slide 9:

Families follow doctors' instructions on apps, which are on the left-hand side, for certain procedures, and send data in by text and by video captures of behaviors that doctors are given a suite of tools to be able to analyze the video on the right, to be able to diagnose earlier, or treat problem behavior earlier, and some other applications as well.

Slide 10:

Lot of clinical efficacy out there, publications both in diagnosis in treatment and supervision. Big interest from NIH, DOD, and the autism organizations.

Slide 11:

And I'm so proud of our autism research teams here in our state that for the NODA autism diagnosis application we worked with two other states to say, especially with rural families, "Can you use a smartphone app with a family?" And does it quicken access to diagnosis? And this structured study shows that in half the time you can get a diagnostic assessment using this kind of telehealth.

In the areas of problem behavior, shown in the map of Georgia structured study, that shows behavior assessments can be done in a fraction of the time, less costly. Excellent data for behavior consultants to be able to review remotely, saving clinical time with less data collection errors.

Slide 12:

All this can be organized into a telehealth platform that can be tracked per patient or per population to be able to see access between families and their respective caregivers. Many different applications that we've talked about.

Additional video: <https://www.youtube.com/watch?v=El9-t58S8no>

I'll show you one video to show the ultimate behavior specialist that wasn't on this panel today, working with families to collect data very important to the assessment of the child's behavior. And hopefully it will play and this will be how we end. This is the best behavior analyst that wasn't here today.

[Christmas music playing from video]

>> Man: Okay, okay

[Child crying]

[Child crying]

[Music from Carol of the Bells]

Slide 13:

>> Ron: With that my call to action for everybody is start your Christmas shopping early, but also regarding telehealth, if you're family, start challenging your providers to say you would like to have an interaction with them. If you're providers, look at telehealth as a compliment to what you're doing right now. Know you're saving families some trips, increasing access to healthcare.