

Episode Summary

Rural Health Voice # 32 – Autism Services, To Go!

Aired 03/20/2020

Q: your mission is to improve the quality of life for individuals with autism and their families, through education, intervention and research directed towards effective treatment or prevention. How does that mission play out on a day-to-day basis?

A: Through the Autism Clinic, we train graduate students in our clinical science doctoral program to provide services to the community. The way we do that is through our classes, our research, and the experience through the clinic, they can provide supervised experiences, interventions, consultations and diagnostic assessments to people in the local community.

Q: What was the motivation behind creating the Center for Autism Research?

A: The Autism Clinic was founded in 2005, a couple of years after my own son was diagnosed. He was diagnosed right after his second birthday with autism. And at that time, I realized there were limited resources in my local community for him, and also for others who were being diagnosed. It turned out, at that time, that autism was a rapidly increasing diagnosis, and there were few evidence-based services in our area that could help the local community. So my son was actually the inspiration for starting the clinic.

Q: What changes have you seen in how autism is diagnosed and treated in the last few years?

A: The biggest change is the Diagnostic and Statistical Manual, updated in 2013. Before that, the diagnosis fell under an umbrella term called pervasive development disorders. After that the individual diagnoses, like Autism and Asperger's disorders, fell under a term called Autism Spectrum Disorder. Autism wasn't just one thing, but many things, and we didn't understand what all the etiologies, so it was time to put all the diagnoses back together. So we realized autism was a spectrum; that was one big change, that it varies widely from person to person, in its presentation and its severity. And we also realized that autism may or may not have language impairments, intellectual impairments.

Another thing was being able to recognize autism in adults. Although it starts early, it may not surface until environmental demands bring it to the forefront as an adult. So understanding autism is throughout a lifetime and is a spectrum were some huge changes.

Q: You mentioned adults with autism, but in the news, I hear almost exclusively about children with autism, about parents dealing with schools, but it doesn't go away when the child turns 18.

A: It follows into adulthood in some way, shape or form. What may start as difficulties in the classroom (with children) may turn into challenges with independent living skills in adulthood, interviewing skills for a job. This affects how we can support adults on the autism spectrum, best by getting the supports in place earlier on, improving the trajectory.

Q: What age ranges are you seeing at the Center?

A: All ages. We've assessed children as young as 16 months of age, and adults up to 86 years of age. We do tend to see most school-aged children, though, both for assessment and treatment.

Q: Looking at rural communities, what do you see as the greatest barrier in the autism community?

A: Spread out resources in rural areas are the biggest problem, and a lack of autism providers specifically trained in rural communities is a problem. We see a lot of families come in that have not been able to get access to that knowledge or expertise before, in schools, doctors' offices, etcetera. An extension to that is just the geographic isolation. Parents have to take off an entire work day to travel for an assessment. In addition, affordability and cost of assessments and treatment services can be higher. Also, a difference in family supports. In rural communities, extended family involvement is common. This can actually be good, when more family members understand the disorder.

Q: Who are the strongest collaborators for your work?

A: Biggest partners are Mount Rogers Community Services, and CA Human Services based in Richmond.

Q: Who else would you like to invite to the table (as collaborators)?

A: Mostly with the community services board that involves counselors and mental health providers. Educators, early intervention specialists, pediatricians and family practitioners would be good additional collaborators. They help bring all services together, helping with early identification and diagnosis of autism, and then moving into early intervention. Also, policy makers could be involved to work with us to find ways to reach the people in affordable, accessible ways.

Q: In 2018, you put the show on the road. How and why did that happen?

A: Reports from Appalachian Regional Commission and Robert Wood Johnson Foundation back in 2017, indicated that Appalachian region continues to struggle with mental and physical. Barriers are because there are not a lot of specialty providers, including mental health. There also continues to be economic struggles, poverty and lower income. We wanted to help with this. Being a land grant institution, we wanted to serve the community. We applied for and received some grant funds, and this allowed us to provide services out in the rural areas. We purchased a 29-foot RV and renovated it to provide therapy space inside the vehicle. If people couldn't come to us, we could come to them.

Q: How did you get the RV?

A: A rural outreach coordinator was hired, and she did a lot of the work in finding the right kind, size of RV, and we found a used one in our budget, purchasing it from a rural community vendor.

Q: Do you have a feel for how many you have helped with the mobile unit (to date)?

A: Since June of 2018, we have served about 25 families with 109 appointments, including individual therapy sessions, biweekly, with children and their parents. In July 2019, this expanded to include assessment and education, parent education. About 17 individuals have had individual autism assessments since then, and follow-up with up to two more psycho-education sessions with parents to teach autism spectrum, related services, navigating services, insurance.

One of the exciting things about the mobile autism clinic is that we're now able to overcome some of those barriers that we faced, accessibility and availability, and also discounted rates for research, even free. We've been able to benefit from different grants.

Q: Can you give an example of someone who has used the mobile autism clinic that may not have otherwise been able to benefit from your services?

A: Of course, as I'm a clinician who travels on the mobile autism clinic each week. Rather than speaking about a specific family, I think we're seeing a trend with the type of family that shows up on the mobile autism clinic unit. While we're assessing children from toddlerhood up to just shy of adulthood, we've seen a really high concentration of older school aged, up to middle school aged kids going into high school. For a lot of these children, this is the first time they're getting a diagnosis. We know we can make these diagnoses in the first few years of life, so for these individuals, the diagnosis is coming quite late compared to when we could first detect autism. So these children have not had access to an Individualized Education Plan (IEP) that could have helped them with their schooling. This helped parents get IEP's, that give them more accommodations to help the children through their school day.

Q: I would guess having a mobile autism clinic has its challenges as well.

A: It's definitely different to have a clinic that you drive, on wheels. Many families meet us in their hometowns, but also from further out, families are driving in, so we're meeting them halfway. But there is a cost to clinicians in time spent on the road going out, making for a really long day. Also weather can be a factor, as a mobile clinic cannot operate in 60-70 mph winds, so we've at times needed to reschedule up to a week for assessments. Cell reception and internet access are additional barriers. Some parents have a monthly phone plan and run out of minutes, so they're hard to reach, or likewise, do not have access to email. But we've been able to overcome many barriers of technology, and even do parental video conferencing once we understand their situations.

Q: I understand the mobile autism clinic, in addition, serves as a mobile training site for clinicians. Tell me about that.

A: Because we're part of the clinical science program in psychology, part of our mission is to train our student clinicians, service providers and researchers. We combine research training and service training. We have students from all over, who may not always have the experience of needs and challenges of our families. This gives them a view to their barriers and challenges thrown in the families' ways.

Q: Jennifer, for you as a student clinician, what are the benefits you've seen from the mobile autism clinic?

A: We get autism treatment experience outside of the Blacksburg setting. We get autism assessment training experience and we get to see the barriers and stressors that the rural area families face every day. We see people who can't take a day off work for an assessment. Personally meaningful, is building relationships with these families we might not otherwise engage with. Being able to see the variation and what knowledge is out there about mental health services, broadly, but particularly about autism. Angela mentioned before, how long we've come in the past 10-15 years about our understanding of autism. Outside of the university, that trajectory is slower in terms of gaining knowledge, and so we're seeing where that knowledge is still lacking, affecting services and understanding of the difficulties children and their families may be facing. We spread that knowledge to them, or explain the diagnosis to them for the first time. They take that knowledge into their school district. The void is filled of the knowledge gap, which benefits other families.

The autism clinic opened in 2005, but in 2012, we established the Center for Autism Research. We currently function together, where the clinic is able to provide the clinical services to the community, but the Center is designed to bring faculty and students from all over the university. The university applies their knowledge and work to better understanding autism, so we're really working to merge the science with the service, and take the knowledge we're learning, train the students and work with the faculty to make the most impact in these communities.

Q: If you could reach out to a family with a recent diagnosis that doesn't know where to start, what would you want those families to know?

A: I would say that if they are concerned that they may have symptoms of an autism spectrum disorder, they might contact their pediatrician, their early intervention office, their local school, for screening. The earlier autism is identified, the earlier treatment can be recommended. The earlier supports and treatment for behavioral or language difficulties, the better the outcome. Autism can follow a person throughout their life, but there is hope now, because evidence-based practices do really help. We know more than before about how to treat and support families and individuals. Starting earlier would be best. But rural communities often get the diagnoses later than the average age. The sooner the better, though. But a diagnosis at all is helpful. So, whether in an early intervention age, in school age, or even adulthood, if there are social and communication difficulties getting in the way, as soon as possible, to reach out and contact someone to point them in the right direction, including a clinic or university such as ours, gets them on the right path.

Q: How can families and providers work together to help rural patients?

A: I think it's important to realize that autism affects a vulnerable population. It's often under-recognized and under-diagnosed, and also people with autism are at increased risk for other mental health problems besides the autism itself. Depression, anxiety, behavioral challenges, traumas experienced... these can lead to difficulties with relationships, with school, later with employment, and being able to live on their own. Families and providers must recognize this populations' vulnerabilities, and needs for support, such as evidence-based practices that Jennifer mentioned. Interventions, diagnostic tools that have been verified by science to show that they are effective, and that they should be used to treat and provide diagnoses. If families and providers work together to find evidence-based practices most useful, that maximizes the outcomes for families. There's a disconnect between developmental and mental health problems. The intersection of those is important to find. It's important to train mental health providers in autism, and autism providers to understand mental health. This will give best, most effective treatments for this population.

Q: If you could do anything to improve health and healthcare in rural America, what would you do?

A: Complex problems require complex solutions. One thing we have found in our work is that the two biggest hurdles to getting the services to the people in Rural America, are the availability and affordability. It is complex. People need to put their heads together to make these services available and accessible, and affordable, in these areas. One exciting thing is to be able to have universities partner with the community, such as we've been able to do. This overcomes some of the barriers. But there are still problems with finding the resources. Training, more people providing the services, to reach the community will be good.

In addition to training, the biggest hurdle with the biggest impact, is just education and knowledge. The more providers with training for assessments and interventions, the better. There are other members of the communities with whom families interact who could identify autism, and behavioral supports in school or daycare. More schools, extended family members, and others in the community who understand these behaviors, this takes a village. Suspecting behaviors that are concerning, to finding the diagnosis, and where to go from there, financially, time-wise, and feeling like everyone else in the community doesn't get it, would be a really big barrier to families that would otherwise benefit from the wider network of the community. Community awareness and support will help.

I'm going to put in a final science plug. Awareness is the huge first step. Science is second step. We still have a lot to learn about what's best for autism, for mental health, and how to get those to the people that lead them. Policy is the third most important thing, finding ways to disseminate the reach, and get the services to the people.