

Transcript of Dr. Ted Epperly presenting “Integral Role of Primary Care Providers to Meet the Healthcare Needs of Patients with Autism Spectrum Disorder” at the 2019 Autism Summit on 11-02-2019.

Slide 1:

Title Slide: Integral Role of Primary Care Providers to Meet the Healthcare Needs of Patients with Autism Spectrum Disorder

Slide 2:

>> Dr. Ted Epperly: An early diagnosis can actually save two-thirds of the total cost of funding of roughly what costs about \$250 billion a year in collective healthcare costs. So why wouldn't we want a system to be responsive in a way that really starts to identify early, starts appropriate management and integration early, gets everybody aligned, and accelerated in the progress being made?

It's really true especially in rural areas, frontier areas, and socioeconomically deprived areas. We know kids that are from minorities or in rural or frontier areas are diagnosed later. So why wouldn't we want broad trained work force of primary care physicians, pediatricians, family physicians, PAs, nurse practitioners, that are going to be a part of that system?

As you all know we have a few developmental peds resources in the Treasure Valley. We've got some good ones, but you know it's one of those things that can be a challenge for anybody that's needed timely access. So again if we build out the front end of the system we can help maximize then how the system responds as a whole.

And of course this last bullet point goes without saying really, autism isn't just a neurocognitive issue, this affects the whole body.

Slide 3:

And speaking of that, what are some of the issues then the primary care physician can be integrally involved with? Well sleep problems, happening with over 50% of kids with autism.

Attention deficit disorder, anxiety disorders, depression, as you see here, GI disorders - 8 times more common, 8 times more common than other neurotypically normal children of the same age.

Overweight problems, obesity almost two-fold increased.

Healthcare conditions extend across the lifespan. It just doesn't stop in childhood. This goes on into adolescence and adulthood and beyond.

Slide 4:

So why not have in one person, the type of person that can have a relationship with the family, build trust, and then be able to handle the issues over a long period of time. That's where you start to see progress made, versus just reactive fixes one at a time. I think it really kind of comes down to this ongoing relationship of trust. Any of us that have practiced as primary care physicians, I know we've got some pediatricians in the room, and Paul can really I think, relate to this, it's all about the relationship with people. It really is. The magic sauce of primary care medicine is knowing someone, and knowing them over time and developing that trust. Not only with the person, but with their family. And there's synergy in that. The data is really replete, internationally on this, that the usual source of care with one provider that gets to know the family and the patient, that team that he or she represents with that

interface with the patient and the family, absolutely both increases satisfaction with the quality of care, increases quality outcomes, and decreases costs. Outcomes improve, cost goes down. And when you take a look at the definition of value, quality divided by cost, value increases. So that integral relationship is important.

It also provides a timely access system. A front door that understands and is open. That can be in the clinic, but it can be leveraged through technology in many different ways as well, from phone and emails, to Skype and to Zoom, to home visits if that makes more sense.

The neat thing about being a primary care doc, because knowledge is broad, is you can kind of take that 30,000 ft view, and you can see what's going on with the dynamics internal to the family. You can still start to help solve not only the puzzle, but the mystery of the issue, as opposed to just reacting to an organ system, or some behavioral focused issue. You can see it in context. You can see it in its full approach. The integration and coordination of care is a valuable function that we in primary care do.

I look at myself as the quarterback of the team. Maybe a conductor of an orchestra or a chef. I know exactly what sorts of ingredients need to be put in to the music or into the food. I know when a consultation with an appropriate person is necessary. I can help access and facilitate that. My friend Ron Oberleitner called it being a Sherpa. That's another nice way of looking at this, but it's that function, it's that integration function.

So please all of you, when you think of kids out there with autism and Autism Spectrum Disorder, think about that relationship with a primary care physician, and how that can be absolutely critical to the outcomes of this child. It also provides an anchor and home base. This whole concept of the patient centered medical home, many of you might not know this, actually started with pediatrics in 1967. And it was around kids just like this. It was developmentally disabled kids, and how do we start to get the system to respond better. How do we get integration and coordination of care to happen? So, perfect for what we're talking about.

Slide 5:

Some of the other things, I think being an advocate. With the school systems, with individual educational programs, with disability. Working with Medicaid, the SSI system, Idaho Department of Health and Welfare, or others, that's all important.

Home visits, I think is really important too. Certain kids very much respond to home visitation, others don't. So it's not one size fits all, as we said earlier, but if home visits is a really nice way to do it because the child feels more comfortable, the family feels more comfortable, it's really insightful for the physician because you get to go into the home and see the context, of how many of the things are working. And with your physician lens on, can help make suggestions, and connect the dots with consultations that might be of further assistance.

And I think that's really an unrecognized power of this. Understanding social determinants and how this is playing out. A lot of transportation potential issues for caregivers, having the ability as a primary caregiver to not only understand the child, but their parents. Anxiety and depression doesn't just stop with the child, and as you know, the caregiver burden can be huge. So understanding mom and dad, understanding the dynamic with brother or sister, understanding how this plays out with healthcare

problems in the family. How the stress of this can increase headaches, which can increase job performance issues, and how you can intervene with that becomes really important.

Integration across clinics and hospitals. Many of us work in all those places, so if the child needs to be hospitalized, it's great to have a friendly face, a comfortable face.

And of course we want these kids to grow into adulthood right? So that transition from childhood into adolescence, adolescence into adulthood becomes important. And you know in adolescence there's a huge deal around sexuality. So how can we not pay attention then to the issues that emerge through this time period as well? So to have a complete doc that understand this and can integrate this becomes important.

I couldn't help but put this quote in here from Zoey Roberts who is in British Columbia, diagnosed with autism at age 34. And she says, "I want the world to know that autism is not a tragedy, but a journey of learning and growing." And I think that's true for healthcare professionals. I think it's true for the healthcare system.

Slide 6:

So in summary, primary care physicians are vital to this. I hope that I've helped you understand why, and how that can happen.

Early diagnosis, treatment, and intervention is paramount to this. It's almost like anything in medicine. The earlier we can pick up on this the more exact we can be with what we do about it. It'll help outcomes downstream, it'll help costs downstream, it'll help satisfaction downstream.

The better the integration of whole person and body with the whole family is important. Part of the training of a family physician, and part of the training of a psychiatrist, and part of the training of a pediatrician is to see the whole person. That's really important. I don't mean to denigrate my sub-specialty colleagues. Not at all, they're very good at what they do. But sometimes the scope's too narrow. You must be able to see the bigger picture. And there's strength in seeing that bigger picture.

And of course knowing the patient over time. There is no replacement for someone who knows the patient over time. So with that I thank you.

I think that I've kept us pretty close to the time. I don't know Julie, if you want to have a couple questions now, or if you would rather that happen at another time. Okay. [inaudible]

Thank you everyone.

[audience clapping]