

BRENDA

Good morning, all. I am absolutely thrilled to be able to be here today and to go through a conversation with you all about how we can continue to provide advocacy skills in our school communities.

HENNE:

And one of the things that I want to draw some attention to is I purposefully use the term community versus environment. Environment to me is a location. It's buildings. And the community involves the people that are around there. And for our patients who are active in our school communities, it's really the people that we are going to affect change and have interventional support with. So just think through that as we're going through our slides today.

OK, that's me. So one of the things that we do in education is we tell you what we're going to tell you. And then we tell you. And then we end by telling you what we told you.

So this is my what we're going to talk about a little bit today. These are your takeaways. So when we're finished with our conversation today, I really want you to have this burned into your brain a little bit.

The medical community is unbelievably complex. Our school community is unbelievably complex. The roles of an educational specialist, or otherwise it's known as a school interventionist, they're really varied. They have a lot of different things that they have expertise in and have a lot of different things that they promote supports for our patients and our students.

Early intervention for our patients is critical. And school intervention for our patients when they become school age is critical as well. We want to create awareness. And we want the information that gets to the people who are providing those interventions.

So how do we do that? What do we know? So we navigate those complexities in the school, because it becomes advantageous for our patients. We know that heart disease receives a lot of intensities of medical treatment. We know that the more intense the treatment is, the greater the likelihood that our kids will experience some impacts on their learning.

We also know that our patients are living longer. They're living stronger. They're living healthier. And they're returning to their typical childhood communities, which school is a component of.

And we know that our kids are entitled to an appropriate school community where they can do three things which are really important. They can access their education. They can participate in their education. And they can make progress in their education. Each one of those are different. All three of them are required.

So how do we do that in terms of an educational specialist? We've got the medical community. We have the school community. And we have a bridge between them.

That bridge between them is the educational specialist role. It's really the medical team. You're well-versed in the intricacies of care of our patients.

And due to advancements and exceptional care, our patients are living longer. And there's a whole group of people who help our patients navigate their medical world. I think we saw some slides talking about all of the components that are important along the way.

There's also a whole group of people in a school community that are helping patients to navigate the school world. So it's really a benefit for our patients to be able to have someone bridge what's happening medically, to translating it to what can happen in that school setting.

The other part-- I don't how that became [INAUDIBLE] blue. Sorry. So that educational specialist role is really five main pieces. This is who we are. This is what we do. We're a translator. We're a synthesizer. We're a publisher. We're a coordinator. And we're an educator.

This translator component's really important, because what it does is it translates that medical information, that complex medical information, that complex neuropsych assessment information into what I call school speak. Those languages are not the same. And it's really important for us to be able to take that information from the medical team, from our neuropsych development team, and get it into school so that school understands how that looks in their community.

This just describes it a little bit more in detail. That synthesizer goes through, and it organizes that information into some meaningful products. And that publisher gives information in multiple forms. What we know is that people need to have information in varying formats and over lengthy periods of time.

This is where not only the educational specialists can be helpful, but also the educational specialist is a part of the team for the long haul. It is taking that information and being able to provide that continuum of follow-up that's really critically important for our patients to be successful.

The other part is being a coordinator and making those connections between the medical community and the school communities. And then an educator, providing good and relevant education for parents, for families, for our patients, for our school communities, and for all the others that impact our children.

So a little bit of our targets for an educational specialist, or a little bit of our aims-- you can tell I'm a teacher. I keep looking up to see what my kids are seeing, as opposed to looking here. They always say never, ever put anything up that you've not already seen. So anyways, I keep peeking at it.

We provide access to really solid educational services. And we provide support for the involvement in communities. And that's really important.

A child's community in the school is not-- you may think, first of all, when you think school, I'm not sure where your vision goes. Maybe it's that third grade classroom you sat in, could be on the basketball court. There's lots of different components to that school community. So we want to make sure that we provide the supports and information so that good things can happen in all of those school locations.

We also want to change and help be a catalyst for looking at what the possibilities are and not what a patient's limitations are. So what we really want to be careful about is saying we know what we need to look at. It's how does that translate into the school, and how can our kids be benefits of really solid instruction. And then to maximize, obviously, their future educational potential.

So we, again, we want to look at our patients in terms of how do they access their school community. How do they participate in their school community. And how do they, most importantly, make progress in their school community, thinking that school community is all academic, is all cognitive, is all social emotional, is all physical, is all the realm of being just an awesome child.

So schools are complex. Medical care is complex. So at the very top component of that, we have a little bit of a slide showing a cyclical round of medical treatment. And that continues to go around, and around, and around. And that trajectory of school, that continues on the trajectory. It's time limited. It is going to happen in that direction.

So we take a look at the complexities of both of these. And that's really where the role of the school intervention specialist or the school educational specialist has their work cut out for them. We know that early intervention is the best intervention. And we know that early intervention also provides the most success in promoting our positive outcomes.

So this is just a little bit of a slide to show that, well, we're in third grade in elementary. And we've got elementary school figured out. We have meetings with the teachers. We have meetings with the staff. We have meetings with the ISD folks. We're good to go.

And now we're hitting the middle school. And it's like, OK, middle school, that's a whole new complex system. Middle school parents, middle school children, it's an odd time.

So we had a little bit of conversation about this a few days ago when we first met. And we talked about what do we hear as a provider. And we asked this question, gosh, how's school going? And our patients will or our families will say, oh, it's going fine. And so our heads think, well, what does that look like? What does that mean to our providers? So you wear the own experiences that you've had.

So if a patient says to you, that's fine, you're thinking, they must really like their teacher. Or it's fine. School lunch must be awesome there. Or it's fine. You must have scored three baskets at the basketball game last night. So you wear your own hat with that.

The hat that a educational specialist wears is very different. And one of the reasons is is because we've had so much opportunity to navigate those complexities within our schools. So when we ask our patients, how's school going, and they reply it's fine, these are the environments that we look at.

So at first glance, the conversation doesn't appear to have a very complex answer. We take it for its simple answer, because we draw from the experiences that we visualize our own school experience to have been. But when a child says that school is not going well, what do you picture?

So here's a typical book bag of a patient that may have some learning challenges, part of that 50% of our kids with CHD. Not all of our patients have all of these. But most of our patients have some of these.

So their book bag's full. And it's full of pencils. It's full of crayons. It's full of scientific calculators. It's got some other stuff, an iPhone, some ear buds, some trashed sandwiches, a granola bar, whatever. But it also has these things that children bring to school with them every day.

The part that we want to look at as well is the area of recommendations versus instructional strategies. So we can make recommendations for challenges that our patients have. But one of the things that the school specialist can do, or one of the things that the educational specialist can be a part of, is really making the conversation with the classroom level. And look at the change agents for instructing children in the way that children learn, as opposed to accommodating a challenge that a child has.

So school intervention, it's really an essential part of exceptional care. Schools need this information. They need it as early as they can possibly obtain it. They need it in multiple formats over periods of time. They need it in a way that they can use it. And they also need it so that the child benefits from their education.

When we look at a classroom in America today, a average classroom teacher in elementary has approximately 30 children in their classroom. Middle school, probably about 90 children on their teacher load. High school, about 130 children on their class lists. That's a lot of kids.

And one of the things that we also know is statistically, approximately 20% to 25% of a classroom has some type of complex medical condition that needs to be attended to. So when we have an opportunity to advocate for our patients, and we have an opportunity to be the voice that connects the medical component to the school component, that voice becomes a little louder and becomes a little more pointed. And we would like to have that opportunity to work with our families, and our patients, and also our school communities in that manner.

So we talk about some purposeful questions, this slide about, hey, how's school going? Oh, it's going fine. A couple of things that providers can do is to ask just a couple of more pointed questions, like, how do you go through and explain the medical information to your school? Or the other one could be, if available, who did you get the neuropsych assessment to? So you're having families report back a little bit.

And then the last one is you can ask a family to walk through or ask a patient to walk through a part of a child's day. So an example of that might be, walk me from the time you leave the cafeteria for lunch to your next class, or from the time you leave the cafeteria to your class. What does that look like? Walk me through it. If I'm following you, what do I see?

And a lot of times, that's where really good information comes out for us. It's like, I've got to walk down the hallway. And then I got to put my book bag away. And then I got to go to the school nurse. And then I got to climb three flights of stairs. And I'm always late to class. And I've got a lot of fatigue.

And so you really start getting richer information when you have them walk through a section of their day. That might be a little opportunity to do that.

So we're going to conclude a little bit about really exceptional care in the medical community. You provide such exceptional care. We've heard patients, we've heard your colleagues, talk about the care that they receive.

We really want to be able to provide that exceptional care in the school community, because when we can put those two things together, we really have best practice. And we have continuity of care. And if we look at continuity of care, we're concerned with quality over time.

And that's what's really important for our patients, because if we reflect back on the slide that had the steps, every single educational transition becomes a more complex event. And the more we can have that navigated well, the better opportunity our patients have for extraordinary, stellar outcomes. And that's what we all are wanting to see happen.

I thank you.