

Autism: Achieving Success with Special Needs Kids

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Introduction

Andrew Schorr:

Good morning. We are live on KVI. I'm Andrew Schorr. In just a minute we are going to be talking about a very important topic on this beautiful day, and that is this: If you have a child or grandchild who may be slow to develop language or have difficulty with it, if they have difficulty with social interaction, and if they have unusual behaviors or restricted interactions, it could be something that we might describe as in the autism spectrum, something that's often not talked about, but we will talk about it for your benefit, understanding and maybe for someone in your family next on Patient Power on KVI Talk Radio, 570.

Andrew Schorr:

Good morning across sunny Western Washington or wherever you may be with us, on the Internet or out in your boat there somewhere, and I hope you are if it's not too cold. I am Andrew Schorr. We are live on KVI with a show that we have done for more than a year each week now, Patient Power, and this is the program, the only one of its kind in the country where each week we talk about serious health concerns. Now, it may be something that you are dealing with, something that is affecting someone you know, or it will be in your future.

Today we are going to talk about something that maybe as we describe it you do know somebody who has been living with some of these symptoms but it was just never recognized, and the shame of it is of course if that person couldn't live as full a life as possible because it wasn't recognized. What we are going to be talking about is autism, and that was a condition where if a child was severely autistic, had these language and social interaction and behavioral problems years ago, they would just lock them away. And if you look back in literature you can come across stories of that. And what a shame because what we are going to tell you is here in Western Washington now we have at least one school, some professionals who can help you that are really guiding lights for the country. And we are going to meet a woman in a minute who brought her child about 2,000 miles from Illinois to get the benefit of what we have here. So we are going to hear that story.

First I want to tell you we have great weather here, and so I hope you enjoy it. I was out in Hood Canal. I wanted to say hi to the folks in Quilcene and Brinnon, and

also if you go out there along Highway 101, make a turn at Brinnon, there is a beautiful waterfall out there, and today's the day to go. Stop at the local store, say how do I get to that waterfall Andrew was talking about, because it is not on the map. And it is not a state park. And be careful. If it was a state park we would put \$500,000 into making it safer than it is, but it's certainly beautiful. So I don't want any liability, but it's gorgeous. Take a picture. Okay.

Let's get to what we are talking about today, and if you hear it and you know there is somebody who should be hearing it, either wake them up or tell them to replay it. It will be on patientpower.info by Monday afternoon. Okay? And you are welcome to call.

All right. So here we go. Kathy Breene.

Kathy:

Good morning.

Andrew Schorr:

Good morning, Kathy. I met you at a Starbucks here in Seattle or just outside of Seattle one day, and we got to chatting. Where are you from? You said Sterling, Illinois. I said what are you doing here? You said I've come here to have my child be part of a special school. My child is autistic, Victor, 13, sixth grade. Okay. And you are a nurse.

Kathy:

I am a nurse.

Andrew Schorr:

You are married to an ophthalmologist?

Kathy:

Correct.

Andrew Schorr:

You have a very nice life back in Sterling, Illinois. Why did you come here? What was it about Victor where you said we have to go to wherever we need to get the best help?

Kathy:

Well, what happened was Victor is in the high functioning, and the doctor will talk about this later, in the high functioning end of the spectrum, and the services that he required were not available out where we were in this great city of Chicago in the state of Illinois. Everything was not in one place. We became a broken family. The school devastated us. We were told horrible things about our child and his behavior at school. He had no friends, never invited to birthday parties. I was

made to wear a beeper and have a cell phone on me and could never be more than ten minutes away from the school because they didn't know how to deal with his issues. And we were a family in complete distress.

And my husband got on the website and started looking, and we were learning and educating ourselves, and he found several different schools. We looked into all of them, and we found this fantastic school on Mercer Island, spoke to the director, found out about it. They told us everything that we wanted to hear and had been promised by many other schools. We flew out here, visited it, put him in the summer program, and for the first time they carried through with everything that they promised they would do. So we relocated out here, my son and I.

Andrew Schorr:

How long ago was that, Kathy?

Kathy:

There was four, almost four years ago.

Andrew Schorr:

Four years ago. So you have been coming every school year now to have your son, Victor, get the benefit of special programs for autistic kids.

Kathy:

Right, right.

Andrew Schorr:

And you felt that it was a benefit to the family with your teenage daughter and your husband and yourself, if you had all been together, the turmoil that might have been created there, just the stress for all of you.

Kathy:

Oh, the stress was unbelievable. It was already there.

Andrew Schorr:

So for families affected by autism then, by getting the right care you have a happier marriage, better home life.

Kathy:

Absolutely. Absolutely. You need so much support, so much education. You need to have a group behind you, a support system that gets it.

Andrew Schorr:

Okay.

Kathy:

We were not willing to reinvent the wheel by the time he hit third grade. All the information says you have got to get early intervention, early intervention. And we were not willing to reinvent the wheel or go on a waiting list for a school. We found what we needed. We got very proactive.

Andrew Schorr:

You got on a plane.

Kathy:

We got on a plane and got out here.

Andrew Schorr:

Okay. Just help me understand, as a parent what were you observing in Victor that gave you concern and where you felt he needed special help. What were his symptoms?

Kathy:

Okay. With Victor, born, Apgars perfect, developed normally up until the age of two, and then we had regression. We lost speech. He was speaking normally. He stopped walking, started crawling again. Was loving and affectionate but became very, very what we called in our household hyper focused on certain things, and we couldn't break him from it to eat or do other things. He would get on a computer, start doing mazes, incredible advanced things. And to break, if I tried to break him from doing his maze book, he would have what we call in our household a meltdown. And we started working with doctors, but those were the first signs.

Andrew Schorr:

But that was not going to work in school?

Kathy:

Absolutely not. And the story from many of the parents, the support group that I have through the school we came out here for, is that most of us will tell the story that our children were dismissed from two or three preschools. That's about the age where you first start finding out that your child is, you know at home, but you start hearing from others.

Andrew Schorr:

Thank you for sharing is your story of coming from Illinois for the benefit of your son, an incredible four-year journey now that I think he will always thank you for. I should mention to our audience that Victor is in the control room. Hi, Victor. And there he is enjoying, very focused on our radio broadcast today and loving it.

There is a lot to talk about, and I want to after the break. We want to take your calls. We are going to meet a neurologist who specializes in autism, and we are going to meet Trina Westerlund who is the director of this incredible school that Kathy came out for, which I should tell you what the punch line is, Children's

Institute for Learning Differences, or CHILD, that Trina established 29 years ago. And it is tucked away on the north end of Mercer Island. A lot of people don't know about it, don't know anything about autism, or Asperger's that we will also describe, but yet there are people like Kathy who fly across the country to get the benefit of it. How come? And how can these kids be successful?

And I will tell you, meeting Victor, he is successful. This is a kid with some language now, wonderful, personable kid. Certainly there are issues that need to be dealt with in life, and we all have them. Some might call it quirky, some might call it focused on one thing. And I have even heard, by the way, and we will talk more about this, some people sometimes--and this is no disrespect--sometimes describe it as kind of geeky, and just can sit at their computer for hours but are really not very sociable. Could be something in what we call the autism spectrum. So it may be somebody you know in our high tech world in Western Washington.

Let's take that break. We will be right back with more Patient Power and our discussion today about autism and the autistic spectrum, which includes a lot, and may be somebody you know. We will be right back.

Andrew Schorr:

Welcome back live on this beautiful, beautiful spring day in Western Washington. I am Andrew Schorr on Patient Power on KVI Talk Radio 570, and I will emphasize talk radio. Give us a call.

Now, we may be talking about something that you are not familiar with so I want to put it in perspective. About one--they say now about one out of every 166 people, and we see it in kids and increasingly are getting better at diagnosing it, have something that we would describe as autism or in the autism spectrum. Another term you may hear sometimes is Asperger's syndrome. And so let's understand what that is. What sort of behaviors it is. It may be in some adults you know as well.

But the point is years ago with the people who were the most severely autistic, they were institutionalized and the thought was there was no way they could be successful in life. And now we are finding that they can be with the proper help. Proper understanding at school, devoted parents, and it takes a lot of devotion from parents and grandparents. And I know we have a lot of grandparents who listen to this show. So it may be someone in your family, or if you are--somebody younger in your family calls up and says, you know, your little grandchild is just not developing, what's going on? It could be, one out of every 166 times, could be this. But we can take heart that there is help, and there is help here in the Seattle area.

Let's meet Gary Stobbe. Gary is a neurologist in Seattle. He practices at Minor and James Medical, right where all the hospitals are, a lot of them are at the top of Pill Hill, I guess we call it there. He is a neurologist, as I said, and he specializes in

autism. He is the medical director for the Autism Spectrum Treatment and Research Center, or ASTAR. Gary Stobbe, welcome to Patient Power.

Dr. Stobbe:

Thanks, Andrew.

Andrew Schorr:

And help me understand what this is. What is autism or the autism spectrum? Help people understand it when they say, gee, maybe I have heard of that, maybe I have heard of it.

Dr. Stobbe:

Sure. Well, as you mentioned before and as Kathy has pointed out, autism is a neurodevelopmental disorder. It's something that we see in early childhood, and Kathy described her son, Victor, with what's called the regressive form of autism where we see an actual loss of skills typically in the 18- to 24-month range. That occurs in about a third of the kids on the spectrum. The majority doesn't have that regressive pattern. What you see instead is just a lack of normal rate of development in specific areas. And as you mentioned earlier the three critical areas are the areas of language and communication, being one, the second area being social interaction and social connectedness to other people, and then the third area being these unusual repetitive behaviors, restricted interests, as Kathy described in Victor this hyper focused tendency.

And this is truly a spectrum disorder, so you will have degrees of severity. There's three major subcategories in autism disorder. The formal subcategory, which is a kid that typically is more severe when they present, often have unusual motor behaviors such as hand flapping, what we call stimming behaviors. There is a condition that's on the continuum of the more formal form, and it's a clunky term called pervasive development disorder not otherwise specified, also known as PDDNOS. And then a third subcategory which has become more popularized lately is a condition called Asperger's disorder that before the early 1990s was not even recognized in the United States as a formal disorder, and these individuals have normal rates of language development, but then later on you recognize that their social communication is significantly affected.

Andrew Schorr:

Okay. Now, let me ask about how examples might come up for dealing with something like that. Could this be the virtuoso musician who just doesn't talk very much to people but can sit down at a piano or play a violin and is like out of sight?

Dr. Stobbe:

Yes. We have several of those kids and adults in our practice down at ASTAR Center. Some amazing what we call splinter skills that can be present in some of these individuals. Some of these skills are on a functional level that allows them to get by and survive on that specific skill. Unfortunately that's not the majority of cases, and often what you see in the stories and newspapers and magazines are

some really beautiful stories, and those are great. Unfortunately the majority of our kids lack those real high-end specific splinter skills and really struggle as they go through their early years and into adulthood.

Andrew Schorr:

Okay. That gives me an opening for Trina Westerlund to get to the microphone here. You can throw her that. It sounds like a horror movie. That's fine. Trina, maybe you can lean forward to the microphone there.

Trina Westerlund, 29 years ago with a background in special ed and I know with some own issues that you had to research for your son, you decided to start a school. It's on Mercer Island, Children's Institute for Learning Differences, the very school that Kathy Breene and some others around the country decided that they were going to move to the Seattle area to be part of. Okay. And you wanted to supplement or fill the gaps in what was available in some school systems, and let's be frank. It's very variable. Some are great for special needs kids, including even severely autistic, and some are not or don't have the resources to do it. So no disrespect to the school system, but parents want to do what's right for their kid, and so you established this school.

And so do you feel that children with some of these disabilities as Gary described or as Trina described or these kids who get frustrated and may melt down otherwise regularly in school as was a problem for Victor, that there is a place where they can be taught so they can be successful?

Trina:

Absolutely. These kids are amazing, and they teach us educators new things every day. We are not particularly good at dealing with them yet. It's a brand new specialty within the field of education, and it's causing us all to become much more sensitized to the needs of kids in ways we never thought we would before. When Children's Institute began the intention was to have a safe place for children who were struggling with the business of getting into school in the first place, and I think we specialized in the preschool and day care dropouts in the beginning. These were all kids who deserved a different kind of start, a more protected environment, a highly individualized situation for them in which the extra help they needed was always available.

When we look at these kids now in classrooms, we find that many of them fall through the cracks simply because they have been properly identified perhaps, and the school districts are doing their very best to program for them, but the talents isn't on the front line yet. We aren't good implementers. And every district that has hustled around and tried new programs and created them during the last five years deserves a gold medal. There are some districts here locally in the Puget Sound area that are doing a fabulous job, and others don't have that critical mass of kids to create a whole program for children in the autism spectrum, so they are struggling more. The smaller districts have a much harder time.

Andrew Schorr:

And you have contracts, your institute has contracts with many of these public school systems, and there are other, some other exemplary schools around the country, they do too, where parents can have their kids brought there, and the school system will pay for it. I know you have other cases where parents are paying privately. But there are laws, am I right? So if I am in a certain school district, and my child is identified with the expertise of people like Gary Stobbe and psychologists, etc., to have these conditions where they need the special help, the law requires that the school system make an effort to help; right?

Trina:

Absolutely. And I think that school systems do make an effort to help, and it's a phenomenal effort. The hard part is having the expertise available that matches the needs of the individual child, which is what Kathy's frustration was. Even in an area as big as huge, old Chicago, she could not find that match. And one of the things that we have learned to do is individualize our programs for kids one at a time as opposed to saying we do X program and everybody gets the same thing. We are not putting the square pegs in round holes.

Andrew Schorr:

Lots of responsibility, though, and for parents and grandparents. And I heard as I visited your school the other day that the parents are often overwhelmed. Kathy kind of picked up the pieces and put it together, and I know parents eventually do. The grandparents who may be our listeners, some of them on KVI, are the ones who often can have a clear head and go to bat for that kid, and I know how critical that is.

Trina:

We have seen more and more grandparents become the advocate to support the parent who is overwhelmed, and it's that family system that is really critical.

Andrew Schorr:

Okay. We are going to talk about what are your rights should you have a child like this, what are treatment options today, and also what about people who have Asperger's or are autistic as adults? We have to think about that too. But the emphasis is on people, if you address these special needs, can be successful. They can have a job. They can be productive in an area, play to their strengths, and we are going to talk about that.

We will be right back with much more of Patient Power on KVI Talk Radio 570. Give us a call.

Andrew Schorr:

Thanks for spending part of your Sunday with us on KVI. Now, what's this? I hope I don't see any clouds out there. It looks beautiful. I am going for a bike ride later. I hope you have a wonderful Sunday. Go out along the Hood Canal if you can get over there if you are in Western Washington. It's so beautiful. I was out there at

the third oldest Boy Scout camp in the country, the oldest west of the Mississippi, Camp Parsons. Some of my friends are still out there. We took little Eitan out there, and we had a great time, but boy, did we luck out on the weather. And this is, I always begin to think of these weekends in spring as the beginning of summer. And that way if you take the beautiful weekends in spring and make it summer, we have a really long summer here. And I'm all for that.

Okay. We're talking about autism and the term that Gary Stobbe, Dr. Gary Stobbe mentioned also that in the last ten years or so we have been talking about as well, Asperger's syndrome. We want you to give a call because this may show up in your family. You may know somebody. And it really is an encouraging message I think of helping play to the strengths of special needs children and adults and help them. And these are kids with often high or certainly normal IQ. They are not developmentally disabled as far as their ability to absorb things. They just have special needs.

Dr. Stobbe, neurologist, specialist in autism, what do we do for kids who are autistic? Now, Trina will talk about what happens in school. Are there medications? And what's going on in the brain? If we did an MRI of the brain, what would we see that would be different?

Dr. Stobbe:

Well, one of the difficulties that we have had is that we don't have what we call a true biological marker for the disorder. It is diagnosed based on our observations and symptoms, but we are making progress, and the researchers are developing new imaging tools that we hope that we are going to get there, but currently we don't. So you really have to get your child in with a provider that is experienced in diagnosing children with--on the autism spectrum.

I was very interested when I first started this journey back the early 1990s in my training at UCLA. I presented a grand rounds on autism at UCLA, one of the centers that has done research over the years, and as I was preparing for the presentation in my pivotal textbook of neurology, the section on treatment was about one paragraph long.

Andrew Schorr:

Oh, my.

Dr. Stobbe:

And I was left with the impression that there was no treatment for autism. And it wasn't until I got out into my practice, and I have to give credit to the parents for this, that I realized autism is actually very treatable. The core of the treatment however, as Trina pointed out, is the educational process. And this is probably one of the reasons why autism has suffered because it lives in this middle ground between psychiatry, neurology, pediatrics, and education. And I kept hearing the same story over and over again like you heard from Kathy of we need help, we need support. Here in the Northwest at the time in the early nineties and

mid-nineties there was a 12-month wait list just to get a child in for diagnosis. Diagnostic services were so overwhelmed that you left basically with a two-page paper with phone numbers, here is who you need to call, we will see you back 12 months later. And, now, some kids are lucky enough to be born into a family that has access to resources and can manipulate the system, but as you can imagine there are a huge number of families that don't have those resources, and that really led to us opening up ASTAR Center to try to partner with families along this wonderful journey.

Andrew Schorr:

One thing you told me on the phone the other day was when someone has something in this autistic spectrum there are just some systems in the brain that aren't functioning right, but there are other systems that are working great.

Dr. Stobbe:

That's right, yes. But when you look at the brain, it's really a network of multiple systems, each system having some unique jobs, and those systems then interacting with each other. In autism the system that is primarily affected is the system of language and social communication. So when you typically see a child 18 to 24 months, and if the child was playing and you walked into the room, your face becomes the most interesting thing in the room, and that child looks to your face. If mom is in the room and you are a stranger, the child will reference mom to see if you are friendly or not.

An autistic child is literally in their own, so-called autism world. They are disconnected from the social world. And as Kathy pointed out, she had difficulty getting Victor to pull away from that world. And what we believe happens if we don't engage these children socially, and it is a 24/7 job, we can't convert their platform network away from the autistic circuitry over to this social circuitry, and that's the goal of early intervention as well as the jobs through elementary and middle and high school.

Andrew Schorr:

One thing that is fascinating, I went to Trina's institute the other day, and I will tell you the name again, Trina Westerlund, founder and executive director, Children's Institute for learning Differences or CHILD. Trina, at your school you were telling me about a child who is very interested in the history of the Vikings and Norsemen and all that, and so the way you have been getting to him is to communicate in his language.

Trina:

Absolutely. The business of entering a child's world is really the core of our educational approach. If we don't join the kid where he is when he first comes, we don't have a very good access to what makes a difference to him. These children have very often very fine, narrow interests, and they go into them in depth. They know everything about it, whether it's trains, the Norse history, or it's superheroes. Another child I am reminded of presented to us as nonverbal and all he did was

play superhero games with light sabers, and all he wanted to do was have battles. And the school district that referred him to us said don't do that because he will get lost in it, and you will never get him out. Well, we went the opposite direction. We played superhero with him, and before we knew it we had a common vocabulary. We had something we could jointly reference. He would smile at us. He would look forward to us showing up. And it was only by entering where he truly was finding satisfaction that we could get access to him.

Andrew Schorr:

You built a bridge. Okay. Let's take a call as people are calling in Brett, you are calling from Covington. Welcome to Patient Power.

Caller:

How are you doing this morning?

Andrew Schorr:

Okay. What's your question or comment?

Caller:

I need some help from you guys. I am a grandparent. I have a grandchild coming from Colorado, will be here next week. They are moving out here, will be living out in the Burien area. My grandchild is six years old, but yet he has a lot of the learning disabilities you guys talked about. He is reading at a very, very high level already at this age, he does multiplication, but yet he is missing in social development and a lot of the other things. I want to be able to, when they get here, possibly give my son some guidance. He has had problems in school, simply I call it he gets bored because he does well in so many things, but yet he does not like to do other things and will only focus on those, a lot of the description that you guys--I don't know much about it. Where do I turn him to or guide him when they get here to be able to keep this child on track and have success with him?

Andrew Schorr:

Well, I want to start with Trina for a second. So the first thing is, though, Trina, isn't it, an assessment, because we could be talking about something on this autism spectrum, and it rings a little bit that way, but maybe not.

Trina:

Yes. Anything this child's parents have that is an assessment from a professional would be very useful.

Caller:

Okay.

Trina:

That initial paperwork. It gives you a baseline. Whether it's correct or not it at least gives you a sense of what professionals have seen and paid attention to up to date.

Caller:

Okay.

Trina:

The next thing you want to do is you do want to contact your local school district and let them know this child is coming. The minute he arrives you want to arrange as much contact with that district as possible so that they have half a chance to do their very best in assessing his needs from their point of view.

Caller:

Okay.

Trina:

You will also want to connect with a really good pediatric service and possibly someone with the expertise of Dr. Stobbe, and you will want to have a sense that you are working on it together so that nobody feels isolated and alone. Your school district will do everything they can to make sure that this child qualifies for services based on the evaluation that is concluded, and they will then offer you their very best programs that they have. At that point either you and/or the parents will have to go in and take a look at what's in that classroom, how are services being rendered, what is the emotional feel of it, and trust your gut. You are going to know if it's the right place for this little child or not, and don't ever hesitate to say it doesn't fit.

Caller:

Okay.

Andrew Schorr:

Because that's when some of these special schools like Trina's kick in with often the school district, even though they aren't thrilled about it, but writing a check to somebody else to fill in for the services they don't have so that that child, your grandchild gets what they need and deserve and is required by law.

Caller:

Okay. Now, here in, obviously we are listening to the radio, is this a program that is offered in Washington state if we had to go that route?

Andrew Schorr:

Yeah, yeah.

Caller:

It will kick in up here?

Andrew Schorr:

Yes. These are federal laws, right, Trina?

Trina:

Right. Correct. Yes. Every child has the right to a free, appropriate public education, and that is determined by every single school district across the country. They all know what the federal mandate is. They know what the state mandate is. And we are all aligned around children getting what they have coming. The hard part is the actual fine-tuned match to the individual child.

Andrew Schorr:

Fred, we are going to let you go. Listen off the air, but we are going to give some resources to parents and grandparents, websites. We will do all that, so get a pen if you can.

Caller:

You bet. I have got a pen here, and I thank you, you guys, for your help. It's sounds like be involved and stay on top of it and don't be afraid to yell.

Andrew Schorr:

There you go. And to you as the grandparent too, Brett, all the best. Thank you for calling in.

Caller:

You bet. Good-bye.

Andrew Schorr:

Well, I had a feeling there were grandparents out there, and there are. Let's mention some resources. So first if all, Gary, I am sure you have a busy practice, but if people want to consult with you as a neurologist who specializes in autism and gave that talk at UCLA when there wasn't much written, how do they get in touch with you?

Dr. Stobbe:

Well, they can go to our website at astarcenter.org. And they can also call our phone number at 206-332-1646.

Andrew Schorr:

Say it again.

Dr. Stobbe:

206-332-1646.

Andrew Schorr:

And what's the website?

Dr. Stobbe:

Astarcenter.org.



Andrew Schorr:

Okay.

Dr. Stobbe:

But there is also a great resource in the community called FEAT or Families for Effective Autism Treatment, and they have a great website, and they have a wonderful resource guidebook that you can get.

Andrew Schorr:

And what is the website for FEAT?

Dr. Stobbe:

And their website is--I'm not sure.

Andrew Schorr:

Okay. We are going to check. Trina though, your school is Children's Institute for Learning Differences, or CHILD, on Mercer Island in Washington. What's the phone number there?

Trina:

The phone number is 206-232-8680. And our website is www.childrensinstitute.com.

Andrew Schorr:

Childrensinstitute.com. Okay.

We are going to take a break. When we come back I want to hear from Kathy on how you go to bat as a parent, or Brad as we were saying as a grandparent, to get what's right for your kid when they have special needs, not be daunted but move ahead and fight for what your kid needs. We'll be right back with more of Patient Power.

Andrew Schorr:

Welcome back live to Patient Power. Andrew Schorr here as we are talking about autism and the spectrum of behavioral learning disorders that relate to the autism spectrum, which is about one out of every 166 people they say now, and we are learning better about that.

Just a word of thanks to our sponsors: The University of Washington Medical Center, Harborview Medical Center, Virginia Mason Medical Center. If you get treatment or get care through one of those places, this week or whenever you see your provider, I want you to give them a hug. Give them a hug and say thank you for your organization supporting Patient Power because this is the only program of its kind in the country and maybe in the world, and we do this week after week, talk about these serious conditions that affect you or your family or somebody you know, but not where it's medical breakthrough today, but where people are living with this every day.

Unfortunately there are other medical centers and insurance companies and maybe even employers that we have talked about supporting Patient Power and so far it hasn't been a priority. So you can be my little army, and say to them, you know what? This would be really helpful to me. This could help a lot of people. Why don't you put a few bucks into that? And help them do that, okay? And so I really appreciate it. I want to thank the folks at Boeing who are considering supporting us now and some of the other major employers because if you are one of the 100-, 150,000 people associated with a company like that or some of the others, you have these concerns. Okay.

Kathy Breene, mom who came from Sterling, Illinois out here because of Victor who had special needs to get the care that he needed and deserved and the education that can help him move on with his life. And Gary Stobbe had explained to me the other day, our neurologist here, that kids with autism or on the autistic spectrum don't have the spikes of development, language, certain behaviors that other kids might have, but it doesn't mean that they don't continue to develop maybe on more of a line going up, but it may take a much longer time, so you have a feeling as a parent that you want to keep them on that line rather than get their frustration deflecting them or get them not getting the help that they want.

So, Kathy, what's your word to parents or grandparents so that when this presents itself early on, whether it's through their pediatrician and/or at school, that they don't get deflected, and that they fight it, they have to, for the needs being met for their child.

Kathy:

Yeah. We came out here after being exhausted from fighting. It takes a whole team of people to raise an autistic child as well as other children with special needs. All you need is one or two people who aren't on board with you to totally derail that child if you are trying to educate them. And so you need to have a group in the school that is all on board with your child. One or two teachers, one or two family members, one or two neighbors or friends who mean well but aren't on board can derail that child and your family. And that's what brought us out here, because Trina's school offered everything under one roof. It's one thing, you know, to go to physical therapy privately and then go to school and say I need this implemented so that he can learn to write because that's his delay, and then not have it being used. Everything is under Trina's roof. We have our physical therapy, our occupational therapy, our speech therapy, and all the teachers and staff were on board as well as all the families were on board. We were all on the same page. It made my life very easy. I was blessed that I was able to have this opportunity.

For those of you who do not, it is possible out there to do it. I just happen to have the resources and the background to make this work for us. You can get everybody on board. You have to remember you as the grandparent or the parent are your child's best advocate. You have got to go with that gut. You are going to know when something is off, when something isn't working. If your child isn't very

verbal, you will know it through their actions. And you need to be that detective and find out what's going on. It may not be language-wise, but you can figure it out if you keep looking. Talk to specialists, find parents, get on websites, type in autism, start looking, see if your kid matches any of these, and start looking into it. And find other people. Talk to the person sitting next to you at Starbucks.

Andrew Schorr:

There you go. That's how you get on the radio. Kathy, now the point is, though, sometimes if either you are being derailed or you are not, your gut tells you that despite all your advocacy you are not making headway and the needs of your child are not being met, sometimes you need a lawyer who helps people with certain disabilities, right?

Kathy:

Absolutely. And there are special lawyers out there who deal with education. Trina, what are,

Andrew Schorr:

I don't mean to be confrontational but, Trina, I mean, let's face it. There are school systems invest what they can and are required by law to help kids with special needs, and they want to use those resources that they and their community have invested in, but when that parent or grandparent has the gut that little Johnny, little Susie, it's just they are frustrated or they are being sent home all the time, or they are being put in a padded room basically because the kid is acting out and frustrated or the pager is going off. Like Kathy, you have to take this kid home, we can't deal with it, he is acting out, when maybe they have the special need where they can be successful. What do you do?

Trina:

The first thing you do is you decide for yourself you are going to bat and that it's your job to do it. Many parents and grandparents will say, well, the schools know. They will take care of it. Don't worry. And then they wait another year or another quarter or another month.

Andrew Schorr:

Time lost.

Trina:

Time is lost, and the hardest part is to know that it's okay to go into action. The hard part however for parents is to know what the rules are about working with the community of folks who are good at this, and they are specialists in handicapped law. So you don't want to call any attorney. You want to talk to someone who has a specialty in this arena and who is used to doing mediation and negotiation with school districts, who knows the language, who knows the law and can represent you quickly and well.

There are several people in this community. I can think of about three just off the top of my head, Bill Dussault is an excellent resource. Jeanette Cohen, Karen Mitterer, these are all people who are very, very well informed, and they know how to play by the rules.

Andrew Schorr:

Okay. Here's the point, and that is for a parent or grandparent who finds themselves dealing with something that sounds like this, many, many people have paved the road ahead of you. Trina, you have been with your school for 29 years. Kathy, you have, and with all the parents you have networked with. Gary Stobbe is a neurologist working in this area. So you want to get to these resources.

So again Trina's school on Mercer Island, we will make your phone ring off the hook, okay, Trina?

Trina:

Yes. I am thinking of Monday morning.

Andrew Schorr:

Yeah. There you go. Children's Institute for Learning Differences, CHILD, and the phone number again on Mercer Island?

Trina:

206-232-8680.

Andrew Schorr:

And Trina Westerlund, and then you can call and speak with Trina or somebody on her staff, get networked with other parents.

Rick, we have one more break to take, right? So let's take a quick break, and then we will be back with some final comments. And I want to give Victor, Kathy's kid, a chance to say hi. An autistic kid who is a really wonderful kid, can do a lot, and I know will be successful maybe on the radio someday. We will be right back, Victor.

Andrew Schorr:

Welcome back. Andrew. We have done a show on autism and the autistic spectrum. We mentioned during the break sometimes this gets combined with things. I mean, a kid could have Down's syndrome or epilepsy or other conditions. This could all be mashed together, if you will. You can imagine it's like peeling an onion to try to figure out what's going on and give them the best. Okay.

Thirteen-year-old Victor from Sterling, Illinois has come here to get the best in what we have to offer for your education. Victor, has it been a good thing coming all the way from Illinois to be here?

Victor:

Yeah. I mean, well, we did a lot. And, well, sure, I left part of my family, but it was for the good of education.

Andrew Schorr:

Yes, sir. Victor, thank you for being with us, and I think you are a shining example of kids who are autistic who can do well. And you are going to be a radio star someday. Okay, Victor?

Victor:

I know.

Andrew Schorr:

All right. Thank you for being with us. Kathy, what a great kid. Thank you.

Kathy:

Thank you.

Andrew Schorr:

And I know parents everywhere want to applaud you for your dedication to do what you need to do for Victor. We hear he is charming.

Trina, I want to thank you with your Children's Institute for Learning Differences on Mercer Island, 29 years of dedication to kids. You are a jewel here in our Puget Sound area. Thank you.

Trina:

Thank you, Andrew.

Andrew Schorr:

And Gary Stobbe, neurologist who specializes in this at Minor and James, and with your ASTAR Center, just briefly we just have a minute or so left. So when kids like Victor grow up, though, they can be successful if we just play to people's strengths, right?

Dr. Stobbe:

Oh, absolutely, and we have seen it time and time again. One of the big problems we are having, though, is letting the community and business leaders and employers understand the needs of these kids and the future adults. They have great skills, but if we don't let the employers understand their needs, that's been the major hurdle to get over, and we have a big job ahead of us because all these numbers and these kids are getting older, and we strongly believe that they can be taxpayers instead of tax burdens.

Andrew Schorr:

Okay. And people who have much less severe issues but may be only focused on the computer, may be the great programmer or the great engineer, we can help them to have a broader life as well.

Dr. Stobbe:

Oh, absolutely. And it's really a wonderful thing to be able to watch them continue to grow.

Andrew Schorr:

Okay. And that's what it is, it continues to grow. Thank you so much for being with us. Each week we talk about important issues, and then you say, gee, I wish somebody else had heard this. So remember, go to patientpower.info probably by tomorrow afternoon, and the replay will be there for you, the kids, other grandparents, and for people across the country it will be on the internet.

Next week we are going to talk about something that unfortunately is sort of an epidemic in the country, a viral condition, hepatitis C. And somebody may be walking around with it because they had a blood transfusion years ago, maybe even got a tattoo, and so we are going to discuss that with a leading expert from the University of Washington. I want to thank the UW for being our sponsor, Virginia Mason. Have a great week because knowledge is the best medicine of all.

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