



ADA Live! Episode 100: Show Them How Smart You Are: Self-Advocacy, Parenting, and Autism

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Speakers: Clarise Shelby-Coleman and Chase Coleman founders of the non-profit 'Show Them How Smart You Are'

Clarise Shelby-Coleman: Hi, I'm Clarise Shelby-Coleman and you?

Chase Coleman: Chase Coleman.

Clarise Shelby-Coleman: And you're listening to ADA Live.

(singing)

Pamela Williamson:

Hello everyone. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, welcome to ADA Live. I am Pam Williamson, Assistant Director of the Southeast ADA Center. Listening audience, if you have any questions about the Americans with Disabilities Act, you can use the online form anytime at ADALive.org.

Today's episode is very special because we are celebrating our 100th episode and we get to do this with Clarise and Chase. What better way to celebrate than to talk about the importance of self advocacy. Of all the skills we can learn, the ability to advocate for

ourselves could very well be the most important. Knowing who we are, what we need, and how to share that information with others is important for all of us. However, it is critical for people with disabilities who are often denied choices in their lives or opportunities to make personal decisions.

People with disabilities must have the opportunity to learn self advocacy skills and become aware of how to ask for an accommodation in the workplace, the college or university classroom, or to make decisions about our lifestyles, living arrangements, and even everyday choices. Our guests today are Clarise Coleman and her son Chase Coleman. They have championed the importance of self advocacy through a nonprofit they started called Show Them How Smart You Are. Clarise and Chase, welcome to the show.

Clarise Shelby-Coleman: Thank you.

Chase Coleman: You're welcome.

Pamela Williamson:

Thank you, Chase. So how did you begin this self advocacy journey? Tell us how you got started.

Clarise Shelby-Coleman:

Well, Chase was diagnosed when he was about three and a half and because he was classified nonverbal at the time around first grade, he was getting ready to lose his one-to-one teacher's aide. And I realized he didn't have the voice to say, "Hey, I need to keep Miss Chestnut. She helps me get through my day-to-day." And I realized I had to be his voice, that he needed me to make his decisions to protect him and keep him safe across all environments, because he couldn't do it himself. When Chase was going through all those testing and diagnosis, I got this exhaustive list of, he will never, never, never, never. He will not. He will not. He will not. And Chase has turned all of those people into liars. They told me he would never talk. He wouldn't read. He wouldn't be able to socialize.

He's a actual member, he's been a member of a cross country team from 7th grade to 12th grade. And it was the first, 8th grade was the first time he made the honor roll. And every year in high school he made the merit roll. So you get all those, "He's not going to do this. He's not going to do that." And then you have a person like you, who comes along.

Chase Coleman: Yay.

Clarise Shelby-Coleman: You agree right, Chase?

Chase Coleman: Okay. Okay.

Clarise Shelby-Coleman:

And says, 'No, I think I could work with this kid. I think he can do this,' and that's all you need. And that's who I try to be all the time with my parents, especially when they come and they say, "Oh, Johnny can't do, he doesn't do it." I say, "Oh, don't say that. Yes, he can. Let's see. He may not be able to do it that way, but he can do it his way." Chase learned to read before he actually started using words because he just-

Pamela Williamson:

So did my young man that I worked with.

Clarise Shelby-Coleman:

He would watch television with the closed caption and he would listen to Elmo and he would run his fingers across the words. My Husband and I, we would just watch him. And then eventually he would try to use the word. So he was learning not only how to say the word, when to use the word, what was appropriate. Elmo taught Chase how to recycle. I couldn't teach him how to recycle, the concept, but watching Elmo recycle the hundred thousand times that he did with the closed caption, he went to school and he was on a recycling team in 3rd grade. Totally blew my mind.

Pamela Williamson:

And Clarise, that's so very important when our children are young. So I'm glad you learned to start being an advocate for Chase and set him on the journey to become his own self-advocate. Now in 2016, I believe Chase was 15 years old. There was this unfortunate incident that occurred. Can you share with us about that incident and the role it played in your development as self-advocates and also how you work with teachers?

Chase is a cross country runner and he's on the team. We're at an event in Rochester, New York. I usually run with him through the courses, but I was injured at the time. And we had did a walkthrough and it was a part that was kind of tricky. And he's on one side of this reservoir and I'm on the other side calling his name, trying to encourage him to keep going. And he must have stopped trying to decide which way am I supposed to go? He's used to people helping him. If you've ever been to a cross country race, there's all types of people just lined up around in the woods or along the road. And a stranger approached him. Chase calmly went towards that person, thinking that they were trying to help him. And this person tried to cause him harm.

He pushed him down to the ground and he attempted to do even further damage, but a biker and another runner came upon it before it was a worse situation. And this incident showed me that the world truly misunderstood Autism, that they missed a whole portion, about a half to two thirds of the population, the ones who are nonverbal, because everyone always tries to understand the ones who are verbal, who can communicate for themselves, but Chase can't communicate the way we communicate.

And I think he misunderstood what that guy was trying to do. And the man misunderstood what Chase was saying to him because he has what they call echolalia. So if you say, "Hi Chase," he says, "Hi Chase." So whatever this man was saying to him, Chase was repeating it right back to him. And it turned into a horrible mess. But the scariest part about this whole thing was that I also realized that first responders didn't understand people like Chase and it just became the catalyst that there's something that needs to be done. And I began not just advocating in the school environment. I started advocating for people on the Autism spectrum, verbal, non-verbal, out in the community.

Pamela Williamson:

Clarise, this story is just, I'll be honest. I mean, it's a bit overwhelming to listen to you tell it because I cannot imagine the frightening situation that was for you and Chase. But I want to focus on a couple of things here. One, the fact that Chase is a cross country runner. We are all about inclusion and this just shows me that there are ways for people to be involved at every level. And it's so exciting to hear you talk about that and kudos to you for being able to run along with Chase, because I'm going to tell you right now that wouldn't happen for me. I'd be on the gurney behind him. But then too, the fact that this really did spur that the advocacy that you're talking about and really helped you to understand better and how to move forward with self advocacy. So with this, so how did the idea that your nonprofit Show Them How Smart You Are come about?

From the day that Chase got his diagnosis, that very next morning I had to take him to daycare and I bent down and I cupped his face. And I said to him, "You go in there and you show them how smart you are and mommy loves you. And I'm proud of you." Every time we part ways, he's 20 years old now, that's what I say. Before I went to work last night, I tell him that. Before he gets on the bus to go up to SU, before he goes somewhere with his grandma out in the community. I just wanted him to have some self-confidence within himself. And that's where Show Them How Smart You Are came from. And the organization came about because I was looking for emotional support as I was raising him. And I was seeking other organizations for a support group, but I couldn't find what I needed.

And I just had an idea that after that experience that I would start my own support group because I wanted to bring families together and instructors and professionals and for us to come together and not just talk about, "Okay, these are the needs that I need," but to really get to know what I deal with day-to-day, what happened before I got to your office to have this meeting. I wanted professionals to start to see me as a person. And I wanted other caregivers like me to come together in a emotionally safe environment to be able to talk things through and share ideas.

Pamela Williamson:

Well, Clarise, I love the concept and I love the positive affirmation of Show Them How Smart You Are. I really do like that. You're bringing multiple groups together that do need to talk and to learn from each other, the parents, the professionals, the individuals. So if you had to identify one success story and I'm sure you have many that has come out of your group, what would it be?

Clarise Shelby-Coleman:

It's growth and the parents... One success story... Chase, you're a success story. Finding this college program for Chase and finding the others that are at different universities in Texas and Maryland. And knowing that our kids have a few [crosstalk 00:12:58], just like a neurotypical child does post high school. And Chase is going to college now with two friends that he started out in kindergarten with. And when we all three as parents, when we got our diagnosis, it was devastating for a moment, but I always tried to stick to the positive side, okay. This is this, but what else can he do? Well, he can't do it this way, but let's try doing it that way.

Pamela Williamson:

Clarise, this is so exciting because in our world of the Americans with Disabilities Act, we call these accommodations or modifications, but I love the fact that for you and Chase, this is just an everyday part of your life. And it really makes a difference. And not only in Chase's life, but you've talked about others in your groups making a difference. So I want to thank you and Chase for that because it's really important. And also too, I want to open this up to our ADA Live listening audience. If you have questions about this topic or any other ADA Live topics, you can submit your questions online at ADALive.org, or you can call the Southeast ADA center at 404-541-9001. And now we're going to have a word from our episode sponsor.

Commercial:

Show Them How Smart You Are is a grassroots Autism organization inspired by personal experiences. Show Them How Smart You Are, STHSYA, supports caregivers. For example, parents, grandparents, guardians, support service professionals of individuals

with Autism through activities, resource sharing, referrals, educational advocacy, and informal support meetings. While focusing primarily on the city of Syracuse, STHSYA also partners with surrounding suburban and rural residents of the Central New York area. For more information about Show Them How Smart You Are, please contact Ms. Clarise Shelby-Coleman at SmartWithAutism37@gmail.com.

Pamela Williamson:

Welcome back, everyone. We are talking with our guests, Clarise Shelby-Coleman and Chase Coleman. The Syracuse University campus news and community news recently interviewed you. And there was a quote in that article and it says, "People call us helicopter moms. Well, I'm an F-16."

Clarise Shelby-Coleman:

Yes, ma'am.

Pamela Williamson:

Now see, I have to tell you how much I love that because I live in the flight path of Dobbins Air Force Base in Georgia. And I hear those F-16s coming across. So I can only imagine what this quote means to you, but you've got to tell us about that.

Clarise Shelby-Coleman:

That means I love fighter planes. And when I think of a helicopter, they just kind of hover along. You hear them coming. You have time to get yourself prepared. Well, no I'm coming in fast and precise. If I find out that Chase's modifications or his accommodations weren't being properly appropriated, I'm right there. Before the building opens, I'm emailing everybody from the President of the United States until the custodian. That's what that means. And I've already done my research. So when you get in the meeting with me, you better have done your research.

Pamela Williamson:

Clarise, you are the kind of parent and self-advocate that we love to talk to because these things are so very important for folks to know. Chase, I'm going to ask you a question. I understand you recently graduated from the Media Studies program at the Institute of Technology at Syracuse Central High School. Now, first of all, congratulations, because that's a huge, huge accomplishment, but what are your plans now? And so I understand you're in the inclusive higher ed program at Syracuse.

Chase Coleman:

Yes. I want to go to Inclusive U college Syracuse University for a media certificate from Newhouse. I will be the camera operator for Show Them How Smart You Are. And the mayor of Syracuse one day.

Pamela Williamson:

Chase. I commend you on these goals.

Chase Coleman:

I want to coach and train in Autism learners like me.

Pamela Williamson:

I applaud your goals. I am really excited for you. And I look forward to the day you have that certificate and hopefully we can work together sometime. That would just be awesome.

Chase Coleman:

Yes. Yes I, yes.

Clarise Shelby-Coleman:

Good job.

Pamela Williamson:

Thank you, Chase. I really appreciate that. So Clarise, you've talked about the fact that you've worked with other parents and professionals but what advice do you have for parents of young Autistic adults who maybe haven't learned the same self-advocacy skills that you've learned or may not have had the same support? What advice do you have for them?

Clarise Shelby-Coleman:

I would tell those parents and those individuals to find their interests and encourage them to try everything. I've found that because Chase couldn't tell me what he wanted, I decided, I was like, "Okay, we're going to try everything." And then some of his actions and his few words and his temperament, let me know, no, we're not going to do that again. That's not what he likes, but to try everything because you want them to have a fulfilling life and you want them to have things to do other than the things they must do. And the more that I bring him out in the community and we work on election campaigns or we volunteer at food pantries, we go to church services. The more he gets used to those environments. And then he's able to let me know, "I like this. I don't really like that," and then I have to respect that. I have to respect it because that's what I want.

Pamela Williamson:

So basically if I'm understanding correctly, you really would encourage parents to try everything and to find what works. And then also too, to respect the young adults' decisions of when they really don't like something, let's not do this.

Clarise Shelby-Coleman:

Yes. Because it's important for them to make their own decisions. No matter how big or small they are. Chase loves socks and he loves hats. And when we go shopping, if he picks a hat that he really wants and we don't have it already, he gets it.

Pamela Williamson:

Chase, you are after my heart. I love socks and hats too. I have way too many socks I've been told, but I don't think there's such a thing.

Clarise Shelby-Coleman:

Not at all.

Pamela Williamson:

So Chase, as a young Autistic adult, what do you want to share with other young men and women like yourself?

Chase Coleman:

Use your words. It helps people help you.

Pamela Williamson:

"Use your words. It helps people help you." That is probably one of the strongest things I've ever heard said. Now Clarise, we know that you were recently recognized as an exceptional woman of Central New York for community service for your work with Show Them How Smart You Are. This is such an honor and so can you tell us about the sponsors of the award and the criteria for recognition?

Clarise Shelby-Coleman:

The award is sponsored by New York State Assemblywoman, Pamela Hunter. And two of my caregivers from the support group that I run, they wrote a letter to nominate me. They each wrote a letter to nominate me. And when I got the call, her secretary told me she had never had anyone nominated by two different people. And you must reside within the 128th district of New York State. And you must be contributing to your community in some way.

And I had two parents, I had no idea that they appreciated and were getting something from our support group. I bring caregivers together and we do things like brunch and we do fairs for the individuals on the spectrum. We do family and group activities. I help them with IEP meetings, which are individualized plan meetings for their education. I talk to parents about advocating for themselves, for their youth, for their young adult. And I help

them revise those IEPs to improve them. And I share every resource and partnership that I encounter, and I was doing that because it's always felt right. And then I got surprised with this award.

Pamela Williamson:

Well, congratulations, because it's definitely well deserved. It is definitely well deserved. And it's interesting to me because so much of what you're talking about has this long name called supported decision-making. And it's an area that we all look at at the Burton Blatt Institute. And you and Chase are bringing this to life, not only for your own family, but for others and helping others to be able to make their own decision. So I'm really excited about that. Well, Chase, let's talk a little bit about your inclusive running club on campus. What is the name of your club?

Chase Coleman:

Run, Walk, and Roll with Chase.

Pamela Williamson:

So what does your club do?

Chase Coleman:

Yes. We go for run, walk, or roll with mentors, peer-to-peer teachers, and friends, different people each time, whole campus is welcome.

Pamela Williamson:

So how many people join you for the walk, run, or stroll?

Chase Coleman:

25.

Pamela Williamson:

25 people. Wow. That's a lot. That sounds like fun. It sounds like it's a great way to get exercise and meet new people. So if I ever get to Syracuse, I may have to join you out there.

Chase Coleman:

Yes.

Pamela Williamson:

So Chase and Clarise, tell me a little bit more about, everyone is welcome, that's fantastic. But sometimes we know we have to adapt things for people with various disabilities. So how does that happen? How do you make the changes or adaptations?

Clarise Shelby-Coleman:

You want to tell her? So what do we have? We have-

Chase Coleman:

Three different courses named for me and my friends. It's not a race. Take your time with a group of friends. Chase course is one or two laps around Thornden Park. Take one way from Huntington Hall to Manley Field House. All flat ground. Reedy Trail from Huntington Hall to the Quad house has ramps. Everybody comes back to Huntington Hall.

Clarise Shelby-Coleman:

Good job. And I go out and I'm part of the walk group. And I usually walk with anyone who has a wheelchair or crutches, and we do the Reedy Trail. And then one of the mentors who just may want to walk or slowly run, or even if the person who's in a chair wants to roll their chair, they usually do the [inaudible 00:29:33] way because it's not a very long distance. And when they get to Manley Field House, they all get on the bus or the trolley, which is adapted for everyone. And they all go back to Huntington and Chase is usually the last one back because he's with the group that's doing one or two laps around Thornden Park, which is about anywhere between two and almost four miles.

Pamela Williamson:

Well, I love the whole concept of being able to get together with friends, to be able to get together with mentors, to the fact you've got multiple levels. It sounds exciting. This is the first time I've ever listened to the walking-type club that I might actually enjoy too. I'm just overwhelmed with so I think it's time for us to do one down here. All right. So well, as we get ready to wrap up today, let's talk about the Americans with Disabilities Act, Chase at 20 years old is what I call my ADA babies. And I mean this in the best of ways, because thankfully our children that are 30 years and younger came along after the ADA was passed. And so what has meant to you and how has it affected each of your lives since it was passed in 1990?

Clarise Shelby-Coleman:

It has been my soapbox. I've used it to fight for what he needs in school. I've used it to fight for things in the community. I've used it with politicians as soon as he got old enough to vote, to explain to them, "Well, he's your constituent, he's voting for you. What are you going to do for him? How are you going to make jobs available for them? How are you going to adjust things for those who depend on the ADA?"

And it has been what I go back to whenever I'm talking to my parents, especially the young ones. And then you run into the older ones. I have a parent in group who has a 37 year-old and she's like, "I never knew this was available." And so I just, I go out there and I advocate, advocate, advocate and I let everyone know and read it. You need to read it. I've read it a lot. And it helps. It gives people that strength, because I think as a caregiver, sometimes you get beat down. But that's my power charge. When I get to read that and say, "Oh no, you have to do this. This has to be changed. This has to accommodate."

Pamela Williamson:

Clarise, I think you have described the ADA in one of the best ways I've ever heard the fact that it gives you strength and a power charge. And we're talking about people's civil rights. And so that to me is so very important and the fact that you've taken time to read it, to learn it, to understand it. That just makes me excited as someone who's done nothing

but eat, breathe, and sleep the law for over 25 years. So as we head into our last question here, we've talked about so many things and so many exciting things, but there's more exciting things to come in the future. What are your hopes for the future in our society? What do you want to see happen? And this is a question for both you and Chase.

Clarise Shelby-Coleman:

Our motto for Show Them How Smart You Are on all our t-shirts and all our towels and all our knick-knacks we sell says, "Inclusion completes the puzzle." When you include people who fall under the ADA classifications, you're completing the full picture of our society. You're getting their ideas mixed with your ideas and it makes this machine run smoothly. So I stick to inclusion completes the puzzle. You can't help Chase help himself if you don't include him.

Pamela Williamson:

Inclusion makes things whole.

Clarise Shelby-Coleman:

Yes.

Pamela Williamson:

Inclusion makes things whole and everything and everybody has the opportunity and the right to be at the table.

Clarise Shelby-Coleman:

Yes. I'm going to have to steal that part now.

Pamela Williamson:

Please do. Please do. Well, Clarise and Chase, it has been such an honor and privilege to talk with you today. And to hear you talk about self-advocacy, about your experiences,

and really just to talk about, as we wrap up here, inclusion and one of the things I think we need to remember is inclusion must be intentional and those are the things you've talked about today and the way that we really need to think through this. Now, as we get ready to wrap up, so we will be sharing the resources that you've shared with us. They'll be posted with this episode on the ADA Live website and for our ADA Live listeners, we thank you for joining us today. You may access all ADA Live episodes with the archived audio, accessible transcripts, and resources on our website at ADALive.org.

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4 Wheel City: (rapping)

[End of Transcript]

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