



## **ADA Live! Episode 128: Helping Youth and Adults with Autism Build Independent Lives**

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**Guest:** Stacey Hoaglund - President of the Board of Directors, Autism Society of Florida

**Moderator & Host:** Barry Whaley, Project Director at the Southeast ADA Center

**Recording:** [adalive.org/episodes/episode-128](https://adalive.org/episodes/episode-128)

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### **Stacey Hoagland:**

I'm Stacy Hoagland and you're listening to ADA live.

Music

### **Barry Whaley:**

Hi everybody on behalf of the South East ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, I want to welcome you to ADA live. I'm Barry Whaley. I'm the director of the South East ADA Center. listening audience. If you have questions about the Americans with Disabilities Act, you can use our online forum anytime at [ata live.org](https://adalive.org), or call the South East ADA Center at 404-541-9001. And remember, those calls are free, and they're confidential. Well, it's April and in recognition of autism acceptance month, we will talk about the rights autistic people have under the Americans with Disabilities Act. Many people who are autistic or are neurodivergent have difficulty in social situations and personal interactions. We'll also offer strategies for

copied with workplace and community barriers. We're pleased to have as our guest today, Stacey Hoagland, Stacey is the President of the Board of Directors of the Autism Society of Florida. So Stacey, hi, I want to welcome you to the program.

**Stacey Hoagland:**

I'm so honored to be here. Thank you for having me.

**Barry Whaley:**

Stacey, April, as I mentioned, is autism acceptance month, what is autism? And can you tell us maybe about your personal experiences with autism?

**Stacey Hoagland:**

Sure. So autism is a neuro diverse way of looking at the world and responding to the world around them. Many times in a person with autism, you'll find some social differences. So not necessarily deficits, but just a way of interacting, that may be a little bit different than what we're used to seeing in most people. Some people don't verbally communicate, they use other forms of communication when they are given an appropriate education. Also sensory challenges. So maybe the lighting or the noises, the different sounds in their environment could be the clothes that they wear, so different, just a different way of sort of experiencing the world around them. And I suppose that medical establishment couldn't come up with a better way to kind of explain somebody and their differences. So they gave them you know, many years ago, a diagnosis which at the time, had all sorts of colorful ways of describing it. But we do still tend to hear it is a developmental disability. But with the Autism Society, we really look at it more as a neurodevelopmental difference.

**Barry Whaley:**

In your personal experience with autism, I want to talk a little about that.

**Stacey Hoagland:**

I have a 29 year old son who has autism, when he was very young, and I thought, okay, something is up. He's just, he's a little bit different than a lot of the other kids. And I had had another child just 19 months before him. So I was kind of still in the thick of raising very young children. And so I was like, something's up here, and went to my pediatrician. Oh, look, he's right where he supposed to be on the growth chart. Don't worry about it. Don't compare him to his brother, oh, he's a boy. He develops later. You know, all those things that I heard 20 some odd years ago, sadly, parents are still hearing today. So I would love to see the day when we're significantly better. There are some doctors definitely that have gotten better. But we're still the very common story for parents to say that they were kind of put aside. So when he was diagnosed, he was about two and a half, because I advocated that was really my first experience with advocacy was I had to advocate for somebody to look at him and to really understand autism, and how to consider the way that he was sort of processing and communicating which he was not, he had no effective means of communication whatsoever at that point. And so that was my first start of advocacy. And then, you know, made sure that he had all the supports and strategies and services and everything then I could get him into kind of got him into it. And, and I'm very proud to say he is today a college graduate. That did not come easy for him at all. We hear a lot of times, you know, autistic individuals with these high IQs and you know, you kind of hear those stories, and that is not, that is not his path. His path was one that was filled with a lot of challenges with coming up against a system that frankly didn't really know how to educate him, didn't know how to help him with Employment, actually post secondary education college was actually better than then the lower when it came to accommodations and people who really thought outside the box. So that's kind of kind of my story with him. And you know, we still dealing with vocational rehabilitation and jobs and the whole industries, and how industries are or are not open to people who have autism.

**Barry Whaley:**

Well, congratulations to him for graduating. That's wonderful. Stacey, as I mentioned, you're the president of the Autism Society of Florida, can you tell us a little bit about the work that you do with that organization,

**Stacey Hoagland:**

I'm very proud of all the work that we do, we are a working board, which means that we don't get paid. And we all work really hard. So a bunch of volunteers just from across our state, and we've got a pretty big state, we want to make sure that we represent our communities, we have autistic individuals on our board that really are our guiding, if you will, our Northstar, because they keep us on the track that we need to stay on if we're going to do the work that we hope to accomplish. Every year, we have something called training in transition, which is a pretty large training program that I can talk a little bit more in a few minutes as we go on. When it comes to employment, employment opportunities. For adults, we train a phenomenal number of police officers and other first responders, we will always make sure that we have adults with autism who are part of the trainings, otherwise, it's just a bunch of talking heads. And then of course, we have, you know, parent support groups, and we have an adult, it's called the peers program out of UCLA to social program for autistic adults, we offer all kinds of different types of programs, from music classes, to art classes, to a gaming class, I mean, all kinds of stuff, and all that stuff is free of charge. And you can access all those things through our website, we will have a special page on there that is just for adults, one of my autistic board members right now is working on, you know, further developing that page, because we want to be a resource to the adults in our state, there are so many deficits in our systems, in making sure that these individuals have what it is that they need. And so organizations like ours is just clamoring and trying to keep up with the need, it's really hard, because there are many more of them than there are of us. And when we're dealing with systems that are inadequate at best. Just it takes a tremendous amount of advocacy, to help connect them with the resources that are there, knowing that there's so many resources that are missing.

**Barry Whaley:**

So I'm really interested in the work you do with adults who are autistic, because really the emphasis was on diagnosis of children with autism, and and really not a lot of attention paid to adults. That's, that's very important, right?

**Stacey Hoagland:**

10 plus years ago, most of our emails and phone calls were about the babies, they were, oh, where do I go for diagnosis? And who do I talk to do you have a support group, and all that kind of stuff. And you know, that's still something that we provide. But now the number of autistic adults that contact us far far outnumber the parents of the young children. And it could be a 40 year old who's asking like where we go for diagnosis, and I think of on the spectrum, and and from so from that individual all the way over to an individual that may have been diagnosed many years ago who may really struggle to communicate, but yet, maybe they were tapped into resources. When they were in school. They had an IEP, so the individualized education plan, but then they become an adult, and it's like, I have nothing. What am I supposed to do now. And so it's not just one type, if you will, of a person who has autism that we're getting calls from it is across the board. One of the core things that we do is advocacy at the state level, every year, we have an Autism Awareness Day in our state capitol. And we always have an agenda of the things that we're going to focus on. Self determination was a big one this year, we had in the past, we had Bill on self determination that we were really passionate about making sure that adults with all disabilities that they have a voice and not just other people telling them what they should do or what they can't do. But rather that you know, their their voice be taken seriously in planning for their own lives. When we're parents. We want to take care of them. We want to make their lives better. We don't want them to have to struggle the way that we did. But that is how you develop rigor and grit, and the ability to be able to deal with a world that is not very friendly to what you need. But when we don't give our kids the opportunity to learn those lessons, and they become adults, it's a huge challenge. And I definitely think that, you know, as we have discussion about employment, I think that's a major player in that realm, as well. And some of the barriers

that we face is, is that I think we need to do a little bit better job both in our education system and in our parenting styles, to make sure that our kids are really ready, you got to be intentional, you got to think about it, how am I setting this person up for success, and not failure. And it's tricky, but it can be done.

**Barry Whaley:**

I did want to touch on something you had mentioned earlier about your training with law enforcement, because I would imagine that that is a critical area, especially for autistic people who may have some communication difficulties, we want to keep people safe, right. And that becomes difficult. If law enforcement is not well trained.

**Stacey Hoagland:**

There's this statistic that says that adults with autism have a 22% greater chance to have a police interaction than the general non autistic public, it's hard to read them, sometimes their facial expression, their body movements are just a little bit different. That's all. And so when a police officer doesn't know, then they could think this person is on drugs, or you know, they look a little guilty, because they're not giving me eye contact, and what are they're trying to evade me, why are they doing that. And then we also have to talk about de escalation, you got your flashing lights on, you got your siren on. I mean, if nothing else, those two things can send a person who's sensitive to lights and sound right over the deep end. So make sure that the officer knows he there's space, talk slower, move slower, just the whole thing of kind of how to size up the situation. And if they are escalated? How do I bring them down, because in almost every instance, when an officer doesn't know how to de escalate a heightened situation, it's it's gonna go bad. So we want to keep our people safe. But we also want to keep officers safe. We don't want anybody to get into a dark and ugly situation there. One of the projects that we do is called tour de force. And it's where we kind of set it up with different police departments where we have adults with autism go on a tour of the police departments. And that has been really amazing. Because we we want them to look to the officers as a resource for them. And when we're there for the tour, there's no stress, it's all fun. And it's funny, so they tour around, they go on, you know, they talk to police officers, and the police officers

love it. Because sometimes they'll say, I had no idea that autism was so diverse, it's an all around good experience. And, again, we do those because we want both parties to know that they can count on each other that they know how to communicate with each other, they understand a little bit better of each other, that we really we count on them to protect, protect them. But it really can't do that if they've never been to training, they haven't interacted with the person with autism. And so we do what we can do about in that area.

**Barry Whaley:**

Stacy, I'd mentioned that you were the president of the Autism Society of Florida, that you're also involved with the National Autism Society as well. And if you could maybe take a couple of minutes and tell us how the state and national organizations work together to improve lives of autistic people. The

**Stacey Hoagland:**

Autism Society of America has been around for decades. I mean, the reason that I got involved with it many years ago was because it's grassroots. It's people with autism, it's family members, loved ones. And we really just want to improve the quality of life for people with autism. And one way that we do that is through public policy. There's a public policy committee for the national organization, we come together every month, and we kind of review where are we at federally like what's going on in Washington. There's something called the Autism Cares Act that is getting ready to kind of sunset here if we don't get things going. So we've been talking to senators and Congress members to get more support for that. It's really just making sure that those people in a position of power are aware. And so many of the things that our national organization does kind of trickles down to the States. Well, actually, sometimes it pushes up as well, Florida, we actually developed a drowning prevention program. We were the first ones because we're in Florida, we just have more drowning than any other state. So we created it and now national also has been like Like, Oh, well, you know what, this is a national thing. This isn't just the Florida thing. And so we've kind of worked reverse in that. But with our grassroots advocacy that certainly began with the national organization. And then there's affiliates. Some affiliates are statewide like mind is Autism Society of Florida, and some

are not, some are regions. But we all are dedicated to our communities, of course, you'll see a difference in like mine, we cover the whole state. So we don't do a lot of on the ground. We have a podcast, we do online trainings, online meetings, just because we're a big state. And we cover the whole state. So there are some affiliates that are very localized, and they're just focusing on a township. So what they do is going to look a little bit different. So the beauty of the national organization is they're there to support us. But yet they also give us autonomy, to look at our own area that we're covering to figure out what do we need to do to help our look whether it's our local community, or or our statewide community.

**Barry Whaley:**

Thanks, Stacey for this great information at a live listening audience. If you have questions about this topic or any other ADA live topic, you can submit your questions online at [Ada live.org](http://Ada.live.org). Or you can call the SE ADA Center at 404-541-9001. And we'll pause now for a word from this episode sponsor the Autism Society of Florida.

**Stacey Hoagland:**

You're scrolling and scanning and digging around, but what is it you're really looking for? Is it resources because we've got those on a user friendly website at [autism.org](http://autism.org), I felt that parent support, check out across the spectrum in online groups that tip and focus on what concerns families most today, how about training by some of the most seasoned authors and innovative artists and thinkers, you'll find those on the live streaming REACH program. Every post out there seems to be telling us what we can't do or what's wrong with our world. When it comes to making a difference the Autism Society of Florida is doing, whether it's training first responders about how to protect those on the spectrum advocating at our state capitol for laws that lead towards a higher quality of life providing hurricane kits to families in need for teaching water safety instructors about how to teach kids how to stay alive in the water. If you're looking to make a difference join us for the journey and help impact the lives of those with autism across the state of Florida.



**Barry Whaley:**

Hi, everybody, and welcome back. I'm very widely from the southeast ADA Center and our guest today is Stacey Hoagland, President of the Board of Directors of the Autism Society of Florida. Stacy is also a parent of a young man who's autistic. So Stacey, knowing about your rights under the Americans with Disabilities Act and other disability rights laws, we know can help somebody who is autistic in many areas of their life, especially in the workplace. As you've already mentioned, lawyers must give people with disabilities equal chance to benefit from job related opportunities. And this includes areas like recruitment and hiring and promotion, training pay. So what are some of the ways the Autism Society encourages young people who are autistic to exercise their rights,

**Stacey Hoagland:**

We run here's program and really focuses on social development, the person who coordinates that, you know, she kind of really goes with what the group wants to talk about. And a lot of times that is, you know, self advocacy, and being able to recognize what are my needs? What kind of accommodations do I need? How do I speak up for those accommodations, and making sure that that's in place? I'm gonna say it's probably 15 years now. We started something called training in transition. I was part of a group at the time, and I had this guy who was my mentor, that was one of the most brilliant people when it came to transition. And his name was Dr. Herman Fishbein, we were working together on another project. And he said, you know, we're spending a lot of time advocating with our schools, but we really need to start looking at the people who support individuals after they get out of school, job coaches, and vocational rehabilitation counselors and the such, and working with them. And so we've done that for the last like I said, I think it's 15 years it started out it was just in one county, and then it kind of branched off into multiple counties. Now we do it online so anybody can attend. But that the focus on that is really to educate those individuals who help people find the employment. We're working with these people who help people get jobs, but it's industries. We need to make a difference in industries because we can get people as ready as college graduates. I heard a recent statistic that said, for college graduates who

have autism, unemployment rate or underemployment rate is actually at 9%. Really our discussions right now we're really looking at industries, how to work with our state government, encouraging industries, to get outside the box that they seem to be living inside of, and help recognize the strengths of the autistic individuals that we have. So that we can build a better workforce or one and make them taxpaying citizens because that's the goal for everybody, but also to help plug people with autism into jobs where they want to be.

**Barry Whaley:**

Know, I'm just stymied by the statistic, you threw out that for those college graduates 89% are not working. And that shows a real breakdown, I think, not only in programs to prepare people to go to work and colleges and universities, as well as employer as well. So I'm sitting here thinking, Stacey, that one of the unintended consequences of pandemic has been that labor force participation across the board for people with disabilities has improved. I mean, we're seeing the highest numbers of labor force participation we've ever seen for people with disabilities. And yet, you know, we talk about 85% of people who are autistic, not going to work 89% of college graduates. So the challenge is there. What can we do about it?

**Stacey Hoagland:**

So we're still missing out on making sure that our job coaches, VR counselors and other people that make money, frankly, to help people find jobs, they really need to learn more about working with industries and major companies to make sure that they understand autism. I mean, you know, it's capitalistic, right? So it's, they want to make money. Well, we want you to be able to capitalize on employing people on spectrum. And, you know, helping them kind of figure out, alright, so what do I need to do? How do I do that, but before we can even get to that, we have to get them to be more open to it as an educational advocate for almost 25 years. I really see it being similar to what we face when we talk about inclusion in schools. And the number one deterrent to a teacher or school when we want to talk about inclusion is fear. Yeah, they don't understand, they are not going to know what to do with this kid. And I think it's the same thing when we talk

about employment. And I think that different companies are afraid. They're afraid of what this person might do. They're afraid of dropping their bottom line, if nobody takes the time to learn a little bit about autism and do some things like there's, you know, there's job sharing, there's peer support programs, there's celebrating the neuro diversity of your employees mean, there's lots of different activities that you can do to make your organization more diverse. And when we do that, we're able to again, capitalize on your strengths, instead of looking at weaknesses. Just look at inclusive education wasn't till 1975, where kids actually could go to school wasn't that long ago, it took just so long to get that in. So we are on a major cultural curve, again, when it comes to employment. And you know, we don't want sheltered workshops. We don't want segregated employment programs, that things just start more easily happen in segregated communities. That's why we don't do segregation in school. It's not safe. We don't want segregation in our employment, because it's not good. It's not safe. It doesn't give the person a sense of belonging. But in the end, if we don't have industries, willing to understand more about the people that we're talking about, and welcome them, we're going to remain in that 85% spot where we've been for quite a while now.

**Barry Whaley:**

There's a culture to every business. Often autistic people have a very difficult time eating that culture. But what are some strategies that you can think about to help somebody in that situation?

**Stacey Hoagland:**

The biggest problem that I see is when it's the job coach, or the person from vocational rehabilitation, who's making the decision about where that person should work. And I've seen those go south really quick. Sometimes it's social, because, yes, the social dynamics, the people might be really talkative. They may be catty, they might do a lot of gossiping, and a person on the spectrum may think that is just wrong and mess up, and I'm going to let you know what I think about that. That's going to really put the kibosh on how they're viewed by their peers. And so making sure that you're plugging the person in right into what they choose. I think that's, that's number one. Sometimes that happens. So

sometimes maybe the person wants to be a chef, if they got a job working in the kitchen, and there aren't, they're prepared, because they've been through training. So they know the pace of a kitchen, right? Kitchens are fast, you can't be a lollygag around the kitchen. So you got to be able to keep up with the pace, they're good at their job, but maybe the server's you know, they have more of a social dynamic. And the person with autism may be like, Oh, I just don't get that. So, you know, if the person disclosed their disability, and so the supervisor knows, there are certainly things that a supervisor should kind of recognize, okay, wait, something's up here. And social dynamic is a little bit of a challenge, because maybe the autistic individual doesn't pick up on that doesn't really pick up the social differences in the environment. So we would hope that the supervisor knows enough because they've gone through some autism training that the individual has been really forthcoming. Hopefully, you've been educated on this so that you can say, these things move too fast. I kind of get lost in all the words or when the environment seems overstimulating, I gotta go put the headphones on, because it really helps me be able to get through the moment, or I can't wear that uniform, because it's too scratchy. So maybe can I get this other uniform? So understanding not just that you have a diagnosis, but how does that diagnosis affect you? Because, you know, Stephen Shore, who's an autistic individual, you know, is pretty famous, or maybe infamous for saying, if you've seen one person with autism, you've seen one person with autism. So that is definitely a message that we work really hard at getting out there and making sure that the person understands the benefits to disclosure.

**Barry Whaley:**

So you see that was an excellent closing to this episode, I want to thank you for being our guest today to share your experiences your expertise and resources regarding young adults and adults with autism. And listeners, I want to thank you for joining us for this episode celebrating autism acceptance month and the rights of autistic workers under the ADA. You can access all ADA Live episodes and archived audio accessible transcripts and resources at our website, [Adalive.org](http://Adalive.org). And we invite you to listen to ADA live on the SoundCloud channel, you can search [soundcloud.com](https://soundcloud.com) forward slash ADA live. You can also download ADA live to your mobile device, go to your podcast app and search for

ADA live. If you have questions regarding the Americans with Disabilities Act, you can use our online form anytime at [ata.live.org](http://ata.live.org) or you can contact your Regional ADA Center at 1-800-949-4232. Adalive is a program that was Southeast ADA Center the Burton Blatt Institute at Syracuse University, and a collaboration with the disability inclusive employment policy rehabilitation research and training center. show is produced by Celestia Ohrazda was Cheri Hoffman, Mary Morder, Marsha Schwanke, Chase Coleman and me. I'm Barry Whaley, and our music is from four wheel city the movement for improvement. So we'll see you next episode

### **Music4 Wheel City**

They watching. They don't want us be part of the city, man. They put all these steps, man. All these curbs we can't get over. All these inaccessible stores. 4 Wheel City. They don't want us here. We'll survive and we're going to make our own place. Our own world. The 4 Wheel City-

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