

BoggsCast Episode 21: Carol Schall

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CARRIE COFFIELD: Welcome to BoggsCast, where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts. Part of Rutgers Robert Wood Johnson Medical School, The Boggs Center is New Jersey's University Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities Program.

I'm Carrie Coffield, Assistant Professor of Pediatrics at Robert Wood Johnson Medical School, and Training Director for the New Jersey LEND program. I'm joined today by my co-host, Steve Gruzlovic, who is the Advocacy Discipline Coordinator for the New Jersey LEND program.

In this episode, we'll be discussing employment for autistic emerging adults with Dr. Carol Schall. Dr. Schall is the Co-director of the Virginia Commonwealth University Autism Center for Excellence, the Director of the Virginia Autism Resource Center, and the Principal Investigator in the development of the community-based functional skills assessment for transition-aged youth with autism spectrum disorders, a grant funded by Autism Speaks.

She has over 30 years experience supporting adolescents and adults with autism as a teacher, administrator, researcher, and consultant. So we're thrilled to be able to bring you this conversation with Dr. Schall, as we hear a little bit about her journey and her work. So thank you for being with us today, Dr. Schall.

CAROL SCHALL: Thank you so much, Carrie and Steve. I really look forward to our conversation.

CARRIE COFFIELD: I'll go ahead and start with the first question and just ask you if you could talk a little bit about your leadership journey and what drew you to the work that you're doing.

CAROL SCHALL: This is a really great conversation to have because it involves my family experience. I happen to be the sibling of a person who is deaf. And she went deaf when I was about five or six years old. And so as a kid, I experienced what it was like to be the sibling of a person with a disability that really significantly impacted her and her participation in school.

In fact, I don't want anybody to do the math here. But my sister was identified with her deafness before the Individuals with Disabilities Education Act was passed. And so she's one of the first kids to receive any mandated special education services.

From there, I always had an awareness of the impact of disabilities in the lives of individuals as they develop and that impact from a very different view, as a sibling, as a family member, as my sister. And moving forward, I became really interested in-- as even a high schooler-- what happens to people with disabilities? How do we include them more in society? What are the best ways to support them?

As I became a professional, that translated to a specific interest in both practice and clinical research, but clinical research from the perspective of interventions that would really help people today. There is lots and lots of clinical research that goes on that's asking questions about, how do we address things for tomorrow? But my research interest is really about, how do we make life better today?

And as I grew as both a clinician, a person who supports individuals with autism, and as a researcher, my interests really shifted from this whole question of what is this to let's forget about what is different about people and look at how we can provide people with the opportunities to enrich all of our lives. And so my interest in the transition to work came out of that.

One of the first most identifying ways that we as adults talk about ourselves is in terms of our work. When people say to you, when you meet a new person and they say, what do you do, they don't mean, what do you do at home? They mean, what do you do at work? And if you don't have a good answer to that question, it becomes kind of complex to identify who you are in the world.

So my interest in the transition to employment came out of that, that this is a pretty essential activity of life. It's defining. Many of us get a sense of importance and joy out of the work that we do. And so we really should consider, how do we help autistic adults, especially emerging adults, make that transition into work more smoothly?

STEVE GRUZLOVIC: When it comes to transition, especially from education to the workforce, what advice do you have for parents and individuals with disabilities?

CAROL SCHALL: So my biggest advice is get a job. It sounds simple enough. But one of the major ways that we learn how to work is by working. Our relationships that we develop through jobs are unique. When you're in school, your teacher can't fire you. Your parents can't fire you. There is only one place in the world where you can be dismissed and that's a forever dismissal. And that is at work.

And so even what I refer to as crash and burn jobs early on, we need those. Jobs that we maybe hated. But we learned a lot about ourselves, about what we do well, about what we never want to do. And so it's really important for autistic adults to have those same opportunities.

At the same time, there is a reason why autistic adults, and particularly their family members, may worry about them at work. Autistic adults are both very, very skilled, but also somewhat vulnerable in the world of work. And that vulnerability may give pause to a parent or to an individual who wants to work but doesn't know how to go about that. And so it makes sense why we would be cautious. And so part of my research has been around, how do we help people really get work experience, real work experience, not

pretend work experience, not the work experience, where you're going to high school and you get to run the popcorn stand at lunch, or you get to sell cookies at the pep rallies, or something like that, real work in the real world?

And so that is the strongest predictor. And it sounds weird to say it. But the strongest predictor that you'll get at a job as an adult is if you had a job as a teen. So... work. And early on before you're actually quote, "allowed to work", lots of folks without disabilities do odd jobs for their neighborhood. They rake leaves for their neighbors. They deliver newspapers. They babysit children. They help neighbors clean out their attics.

Those kinds of experiences really teach you some very important lessons. First, that you have something to offer. We refer to that as self-efficacy, the idea that you can be successful at helping someone, at contributing to your neighborhood, to your community.

Second, you learn that you've got to do things the way the boss wants you to do it, not the way you think it should be done, that there are very specific ways that we share information with our supervisors to help them understand what is the next step. How do I go about this? How do I come up with a better idea? I have a better idea for how to rake your leaves. Is it OK if I do this? You have to ask those questions as an employee. You don't just get to do things the way you want to do them.

And then thirdly, you learn important lessons about your own future, like I don't want to rake leaves for the rest of my life. So now I have motivation to work a little harder in school, to learn some different things, and to identify what I really want to do as an adult. That is the number one advice that I have.

STEVE GRUZLOVIC: And I think also before people attempt to obtain employment, some career planning and life trajectory planning would also be important. It's not as widely done as it should be—

CAROL SCHALL: Right.

STEVE GRUZLOVIC: --a lot of times. But I think what's really important is to find out what the job seeker really wants to do. If you leave it up to a government entity, a lot of times, it's the three F's they like to place people in, which are flowers, food, and filth. So we really need to be able to customize those plans. And I think that's important.

What do you what do you say to parents who are afraid of potentially losing Social Security or benefits that they could be obtained by working?

CAROL SCHALL: I say to those families-- and I understand the concern-- it's really important to contact your local Social Security disability services office and find out about benefits counseling. There are some programs that exist that will allow persons who are receiving disability benefits to earn money. And inevitably, whatever you earn is going to actually increase your financial status than decrease it.

So for example, there are ways to save money using what they call ABLE accounts that will help families who are worried about their child with a disability having too much money and impacting their eligibility for Social Security disability payments.

There are other ways that you can get-- for example, ticket to work programs or different programs that will assist individuals who want to work to continue to receive benefits while they're also working. Working and receiving Social Security disability benefits are not mutually exclusive. It's not one or the other. There are ways to combine the both of them.

And I know it's scary to families because very often for a person with disability, in addition to the monthly check, they also get access to a number of other services such as Medicaid and health insurance. And they don't want to give those benefits up that come with the Social Security disability benefits. But you don't have to by work.

Ultimately though, you will make more money. What Social Security has done is to try to incentivize work in a much more mindful manner. And so it's important to reach out to benefits counselors and to find out what the impact will be on the individual who is working based on the number of hours that they can work, based on the amount of money that they can earn, and based on how that money can be used to that person's benefit.

I'll add to this conversation though, because what you get from work as an individual, particularly an individual with autism, we have research showing that what you get from work as an individual is much, much better than what you might get if you weren't working.

So we did a randomized controlled trial, where we looked at the Support Intensity Scale, which measures the amount of support individuals require in order to live an adult life that they choose. And what we found is that for the individuals who were employed, even part time, even up to 20 hours, those individuals grew in every area of living.

And I didn't expect this. I expected that the individuals that we were supporting, the folks that we were working with, might not advance their academic learning. But in fact, work resulted in higher gains in academic learning when compared to their peers who remained in high school.

So what happens when you're working is you learn to read better. You learn to do math better. You learn to get around better. You learn to take buses. You learn to interact with people better. You learn to take care of yourself better because you've got to have clean clothes and a clean uniform every morning to go to work. You've got to make a lunch or you've got to make lunch plans.

And so what happens as a result of work has much, much more benefit for individuals, even individuals who are significantly impacted by their autism and require a lot of supports. So what you're going to get from work in addition to the financial benefit of earning money is far more than what you would get if you remain in high school or stay at home.

STEVE GRUZLOVIC: So for the job seekers that are out there looking for employment at many different places, what advice would you have for employers that are hesitant about hiring individuals with disabilities for a multitude of reasons? But how can we ease those fears?

CAROL SCHALL: So the first thing I would say is need people with autism on your workforce. To answer your question, Steve, I'm going to give you a story of an individual that is working.

He is a central sterilization assistant technician. And what he does in his job is he takes instruments that have been sterilized in a hospital facility. He peel packs, vacuum seals and peel packs these instruments in plastic to be used in surgery. There are very specific requirements there because surgeons have to be able to open these peel packs very quickly. So there is just-right amount of peel packing. That vacuum seal has to go at the exact right place. It can't be too short. It can't be too long. It's kind of a Goldilocks rule. It has to be just right.

In addition, he then takes the peel packed instruments-- by the way, they all have to be barcoded and logged, which helps decrease the likelihood that a surgeon will leave an instrument in a person. If they're all logged into surgery, they all have to be logged out using the barcode. So he does that, number one.

Number two, he then takes those instruments and wraps them into surgical trays. Those surgical trays are very specifically organized based on the type of surgery that they will be used for. So someone who is getting an ortho surgeon is going to have a very different surgical tray than someone who is getting a general surgery. And so the surgical trays vary greatly.

Here's the story. This young man has significant support needs. In fact, he had, as a young man in high school a one-to-one aide because he had very difficult behaviors in high school. Some of those behaviors show up at work.

He's a young man who doesn't use a lot of words. He rocks. He flaps. He jumps up and down. And he presses on himself. But among his work crew, which includes other individuals who also do this same job, every single person-- and he's been employed there, by the way, for 10 years. Every single person in his department has made a mistake in the surgical tray, in the peel packing process. Every single person that is, except for him. He is so precise and so detailed that in the 10 years that he's been employed he has never made a mistake in peel packing a sterilized surgical instrument or in wrapping a surgical tray.

And I'm going to be honest with you. If I ever go into surgery, I want my tray to be packed by him because I know that when my surgeon needs a particular instrument, it's going to be on that tray exactly where it's supposed to be.

So to those employers who are worried about what might happen, we go in and we support this young man regularly. We help him out.

So for example, this young man would show up at work. And in his head he would set a number of instruments he wanted to peel pack. So let's say he wanted to accomplish peel packing 100 instruments in a day. And let's say that as he's working, it's 15 minutes before the end of his shift. And he realizes he's only 75 instruments in. And he's not going to make that 100th instrument. He will get frustrated. And he will begin to display some behaviors that are confusing to those around him.

So we went in. And we developed a plan to build a 15-minute buffer at the end of his day. And that buffer was-- people in his department regularly have to go through new training. Like every year they have to be retrained in sterile procedures. Every year they have to complete a number of computer modules. And so we just said, let's take 15 minutes out of his day. And they also, by the way, have to re-sterilize their stations very regularly. They have to sterilize the vacuum sealing machines, et cetera.

So let's take 15 minutes at the end of his day that is generally for those tasks, sterilizing his station, completing some computer training modules, et cetera. If he's getting to the point where he's realizing he's not going to make it, that 15-minute buffer allows us to say, take another 10 minutes to reach your goal, your personal goal that you set for yourself. Take another 15 minutes to reach your goal. And that gave us the buffer to assist him in managing his behavior at work.

He loves this job. And so he has never shown behavior challenges being asked to do something that he didn't want to do because he loves doing what he's doing. That is the story that I want to tell employers. If you want an excellent worker, you should hire people with autism, people with disabilities in general. And you should rely on the community around you to help you solve whatever challenges you face in terms of accessibility.

STEVE GRUZLOVIC: And for those that are hesitant about the financial implications of an accommodation, the average accommodation is around \$25, except for exceptional circumstances. But most accommodations could be done for not too much of a financial difference.

CAROL SCHALL: Yeah, yeah.

STEVE GRUZLOVIC: So I think that's really important.

CAROL SCHALL: Carrie.

CARRIE COFFIELD: Yeah, I think this conversation about thinking about moving into work seems like it just should be what happens for all of us. And yet when people have a disability or other need for support, it often creates a barrier.

And in thinking about it, it really does kind of stem from our experience and the ways that we are all exposed to disability and the ways that disability accommodations are provided throughout life, and the way that in school maybe students with disabilities are educated in separate classrooms or maybe separate schools.

And so we grow up thinking that it has to be in a different place. And I think that creates some of the challenges that are related to employment.

CAROL SCHALL: I think you're right. This idea that you have to be somehow special to provide support to someone with disabilities, the idea that we call it special education, like it's not regular education, it's very specialized, and the idea that if you're a teacher or if you're a person who works in the disability field-- at some point in your life, you've been asked the same question we were talking about, what do you do? And you've said, I work with people with disabilities. And inevitably somebody somewhere in your life has said to you, you must be so special. You must be so patient.

And that is exactly where the bias lives, in this notion that, oh, I can't imagine a person with autism working here in our central sterilization unit when in fact, that's exactly what you want. You want people with a diverse way of looking at the world to help you think about new ways to do this.

What we've found as well is that-- and we've done a lot of research around what happens to co-workers and supervisors of individuals with autism in their workplace. And what we found is they say everybody's morale increases. Everybody on the job begins to think differently about their work because all at once they have someone who's working very differently, but very competently. And so all at once, they are realizing that wow, this person has made our work experience better.

And we've also found that when we do those accommodations that we're talking about, the accommodations where we create a visual schedule for how to do something for someone, they help everyone. Everyone in the workplace now has a better way to put things away, has a better way to sterilize these instruments, has a better way to identify when they're on a scale of 1 to 5 getting to a 5 where I'm really frustrated and I need a break or I need help. These accommodations help everyone. We are not going in and dramatically changing the way people work. We're bringing in things that help everyone.

And so to the employers out there who are worried, what I want to tell you is we encountered, as we started our research around Project SEARCH for individuals with autism, we encountered people, departments in the hospital who had first said no, we can't imagine a person with autism working here. Our jobs are far too complex.

But as they saw our autistic young adults working, they began to say things like, wow, these folks work better than the people that I'm hiring from the street. These folks come to work every day. They will walk to work when it's snowing. They value this job. They bring an enthusiasm and joy to our environment that we've never seen before. Not only do we want that person. We want a lot more people who have autism and are going to work here and change our workplace.

So to the employers who are worried, start with one person and see how it works. It is transformational.

STEVE GRUZLOVIC: And I think with more people opening up about neurodiversity-- you mentioned something about hospitals saying, oh, we're not going to hire an autistic person-- a lot of times now, people don't know that they're neurodiverse.

CAROL SCHALL: Right.

STEVE GRUZLOVIC: And they find out later in life. So I think that has a significant impact on employment.

CAROL SCHALL: In fact, that has also happened. As autistic adults have worked, what we found out is that other people within the environment have come forward and said either I think this is me or this is me. I just never told you. Or I think my child might have this. And those connections are really important.

We are all temporarily abled. And at some point in our lives, all of us will experience the need for accommodations, all of us, regardless of our presentation in the world. Think about the things that happen to us just going through life. You step off a curb wrong. And you've sprained an ankle. Or you get COVID. And all at once your brain is very foggy for a period of time after having COVID.

We are all temporarily abled. And rather than looking at disability as something different-- this also gets to stigma and bias-- we tend to describe people with disability in the ways that they are different from us rather than saying, we are all temporarily abled.

Being abled is not the norm. Having a disability is the norm. When we have everything kind of working for us, that's a joyful moment. And it happens rarely. It's not the norm. And disability is not different. It's the way we all live.

CARRIE COFFIELD: I think going back to the point you made too about accommodations often helping, or assisting, or clarifying for more than just the autistic employee or the employee with the disability, I think that's so true. And so many of us probably benefit or would benefit from accommodations that we don't even know or couldn't even articulate or describe. But once it's there, it's like, oh, that really does make this job or this task so much easier or more efficient.

CAROL SCHALL: Almost every worker at some point or another has to log something in a computer program. Maybe it's your hours. Maybe you have to make a request for time off. Maybe you have to input travel.

And you think about how often those systems change. And you have to make a big transition. Oh, last week we used river track. Now we're using road track. And everything's in a different place. And I have to learn it again.

And if you had a task analysis that we use to help a person with a disability learn a new skill, boy, would that make your life better. Instead we have these long, detailed written manuals. And we want to know step one, where do I put this? Step two, where do I put that? Step three, how do I submit?

These very simple things that when we provide those supports to autistic adults, autistic emerging adults, everybody in the environment comes to us and says, oh, thank you. That's really helpful.

I mean, the reality is that our ability to cope with our environment varies day to day, hour to hour, minute to minute. And the kind of accommodations that we provide are accommodations that help all of us. So it really is, to your point, Steve, earlier, it really is a matter of thinking about, how do I make a confusing environment make sense from the perspective of the person that I'm supporting?

So maybe the story here is accommodations for everybody.

STEVE GRUZLOVIC: I think the accommodations for everybody mantra has really been helped by everything that we went through with COVID as well. Could you talk a little bit about some of the-- I don't want to say benefits-- but some of the positives that came from the pandemic and what we can learn?

CAROL SCHALL: So it's almost like all of us were tossed into a basket and thrown up in the air. And we are all landing at different rates, just like throwing up a bunch of paper or marbles. Some went higher and hung up there a little longer.

And we're landing in different places than where we started. We've seen a huge turnover, particularly in those essential jobs. And what we're finding is that individuals with disabilities were a part of that, that tossed up in the air, I don't know where I'm going to land.

A number of individuals' jobs have changed after the pandemic. Getting back into work after COVID has been difficult. Those individuals who worked in the service end of the entertainment industry, workers who provide services to the public directly at food establishments, those jobs have not come back as quickly as other sectors.

And so Steve, you referenced earlier the four F's. You said the three F's. We usually talk about four. Then the fourth is filing. So filing—

STEVE GRUZLOVIC: I forgot about filing.

CAROL SCHALL: Food, flowers, and filth. Filth is stable. Flowers, that whole landscaping has decreased some through the pandemic. Food has significantly changed and decreased through the pandemic. And then filing has also changed dramatically through the pandemic as work has become much, much more virtual.

So there have been changes in those. So it's even more to the point that we need to look to open up more and more industries.

We've opened up the healthcare industry. I can tell you tons and tons of jobs that people are working in. And the reason that that's important is because people with disabilities just from an economic perspective use healthcare far more often than people who are not classified as having disabilities. In fact, hospitals can track almost a third of their budgets to services to people with disabilities. So they owe people with disabilities the opportunity to work in their environment, literally.

And we're working on a military base. We thought going in that some of the unusual and somewhat quirky behaviors that we saw in individuals with autism might be problematic on a military base. But what we found out is that our autistic youth love the structure of military bases. Military bases love how rule-based autistic emerging adults are. And so this turned out to be a match made in heaven. And so working on a military base, we've opened up industries like working in military.

We need to continue to work from that business perspective. What are the industries where you look around and you think, no one with a disability is working here, why?

One of the industries that I'm kind of thinking about is big law. Why aren't there more people with disabilities working in big law? And when you think about how big law has to really track computer files and how that's a niche skill that autistic emerging adults could do really, really well at. That's a place where I'm kind of thinking we need to open up the types of jobs that would work well for the skill sets of autistic adults in big law.

What about manufacturing? How do we get manufacturing locations more open to people with disabilities in general and emerging adults with autism specifically? These are the production lines that make stuff. How do we do that?

What do we do about people who live in rural areas, where you don't have a big hospital or a big banking center? How do we open those industries up? And so for the advocates out there, we really need to think from that perspective. What can we bring to those industries that have not opened up to people with disabilities that makes economic sense to them?

CARRIE COFFIELD: Yes. I mean, everything that you said I think Steve and I both—

STEVE GRUZLOVIC: Yeah, I know there's no visual. It's just an audio recording. But we were both nodding our head yes the entire time.

CARRIE COFFIELD: Thank you. Thank you. Thank you for this conversation.

STEVE GRUZLOVIC: This conversation was wonderful.

CAROL SCHALL: Well, thank you so much for having me. It has been really a joy to speak with both of you, Steve and Carrie. And I really, really appreciate to kind of do a deeper dive and think about the really deep questions that you asked and the really thoughtful time that you put into this interview. So thank you.

CARRIE COFFIELD: Thank you. And thank all of you for listening to this episode of BoggsCast, a podcast by The Boggs Center on Developmental Disabilities. A full transcript of this episode can be found at theboggscenter.podbean.com.

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