

BoggsCast Episode 4: Julie Lounds Taylor

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CARRIE COFFIELD: Welcome to the 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 University's Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental Disabilities program.

I'm Carrie Coffield, Assistant Professor of Pediatrics and Training Director for our student programs at The Boggs Center. And today I'm joined by Tara Palamarik, a New Jersey LEND family fellow.

TARA PALAMARIK: Hi, I'm Tara. And I'm the parent of a 22-year-old son on the autism spectrum, as well as a typically developing daughter a little bit older than that.

CARRIE COFFIELD: And in this episode of BoggsCast, we'll be discussing the transition to adult life with Dr. Julie Lounds Taylor. Dr. Lounds Taylor is an Associate Professor of Pediatrics at Vanderbilt University Medical Center and an investigator at the Vanderbilt Kennedy Center. She received her PhD in developmental psychology from the University of Notre Dame and completed a postdoctoral fellowship in lifespan family research at the Waisman Center, University of Wisconsin-Madison.

Her research focuses on understanding the factors that promote positive outcomes for adults on the autism spectrum and their families, particularly during the transition to adulthood. Dr. Taylor's work has been funded by the National Institutes of Mental Health, Autism Speaks, and others. And she was the 2014 recipient of the American Association on Intellectual and Developmental Disabilities Early Career Award. And so thank you for being with us, Julie.

JULIE LOUNDS TAYLOR: And it's great to be with you, Carrie and Tara.

CARRIE COFFIELD: OK. And so we were so lucky to host you in New Jersey in April, and to hear about your work at The Boggs Center's Developmental Disabilities Lecture Series. As a way of kicking off our conversation, can you tell us a little bit about the ASSIST program?

JULIE LOUNDS TAYLOR: Sure. So this is a program that we have been working on and developing for a little while now that works to teach families, and parents in particular, about their local adult service system. This grew out of some of our more descriptive research where families were coming into our lab.

And their sons and daughters were in their last year of high school and we were having conversations about what's going to happen next, and what services and supports do you think are going to be helpful. And it became really clear that families just weren't getting a whole lot of information and were feeling pretty lost trying to switch from one service system to the next and trying to navigate and plan for what might happen next.

So we worked with collaborators at Vanderbilt, and University of Illinois now, and University of Wisconsin to try to put together a program that can help demystify the adult service system for families. So it really covers the different pieces of services and supports.

The different aspects, the different agencies, but with a real focus on helping families try to identify which of the services and supports might be the most appropriate or the most beneficial for their son or daughter. And then what are the most effective ways to go about pursuing and hopefully ultimately getting those services and supports.

So it's a 12-week program. Each week is two hours. It's a pretty good investment of families' time, but we've realized that even 12 weeks, two hours each week is only enough time to scratch the surface, in terms of adult services and supports.

I think the other thing that's important to note about ASSIST is we really, throughout the whole entire development and when we implement the program, we do it in full partnership with our local disability community. And so for each session, we rely on local experts to come in and talk about the specifics of that session at hand.

So if we're talking about SSI, for example, we're going to have someone come in from the community who works with families on a regular basis in terms of getting SSI that can really speak to the local context, that can speak to-- here's the person you need to talk to, here's how this works in our local office here. And someone who has a lot of experience kind of shepherding families through that process. And we do that for each of the different types of services and supports too.

So we really rely on our local community members who do a beautiful job really working with families and helping them trying to understand what aspects of the services might be helpful, and how do you go about getting them.

CARRIE COFFIELD: That sounds like such a meaningful, important, useful program. Are families finding it to be really helpful?

JULIE LOUNDS TAYLOR: Yeah, that's exactly what we're testing right now. And so the families are telling us that it is helpful. And now what we're going to test is does it actually-- participating in this program-- actually lead to improvements in service access in post school outcomes. Because we, I think, all know all of us on this call and probably many people who are listening to that not getting information about adult services in a digestible way is only one barrier. There are lots of other barriers to getting services and support. So what we want to test is whether removing at least to some extent this informational barrier is enough to budge the needle at least a little bit in terms of outcomes.

So we're testing that in this intervention. So what we have learned so far or what we're learning is that families do seem to be learning about the adult service system. These are brand new analysis that we're doing with the project. And they do seem to feel more comfortable advocating for services and supports after they take the program. What we'll be testing next and what we're collecting data on right now is whether that actually translates into better service access and to a greater likelihood of community participation.

So the jury is out on that. We're hopeful. We have some pilot work to suggest that's hopefully going to be the case. But that's exactly what we're testing right here in the program. But families are telling us that they are really grateful to be getting this information and that they're looking forward to using it. So we'll see what happens.

CARRIE COFFIELD: Yeah. One of the things we hear repeatedly about the transition process is how overwhelming it really is. And oftentimes, families are challenged by the abundance of information and how to cut through it and find the right information that they need at the right time. And I know, Tara, does that resonate with your experience?

TARA PALAMARIK: Absolutely. I was actually planning to ask Julie, is this 12 week program geared to a particular student's age, parents of particular age? Or would it possibly be helpful to stagger some of the lessons to say parents of a 14-year-old, parents of a 17-year-old, parents of a 20-year-old.

I know that from attending many, many lectures, and no matter how useful the advice is sometimes all those acronyms all those SSS's and PPP's go right over your head. And it takes a few times and it turns into-- it only gets absorbed when it's most needed.

So a lot of times somebody will go into a beautiful explanation of SSI and Medicaid and the most that I can absorb at a certain age is that's something I'm going to look at in more detail in two years. But at least I know it's something I need to look at.

And for some parents, you're bombarded with all of that information with confusion between what comes from the state, what comes from the federal government. And if you get it all at once it's really hard to distill what do I need to do today?

I've heard many parents ask me questions about this. And my most useful advice that I've received and given to my parents is get to be the best friend of somebody who's child is about two years older than yours, and I think that becomes your best resource. And then you pay it forward to someone whose child is a little bit younger to know the tips and tricks.

JULIE LOUNDS TAYLOR: I love that advice. This issue of when information like this is the most helpful I think is a really, really important question. And I don't think the answer to that is easy. We're actually going to test that to some extent in the research project, in the ASSIST research project right now. So in our pilot work, the grant that funded that pilot work that allowed us to first develop the program was very specifically aimed at youth on the autism spectrum who were exiting high school in the next two years.

And they were very specific about the age range there to prepare them to leave high school. So that was who we recruited for that study. And I think sort of conventional wisdom would be that getting people information early is better. The earlier you can get people information, they can plan and they can-- And I think there's some truth to that. But I also feel what you're saying here, Tara. And we've seen this in our work where you can give families a lot of information early, but it's hard to know what to attend to, especially when there's a lot.

It's hard to know what services and supports your son or daughter is going to need after they leave high school or what's going to be the most beneficial. And also service systems change. And so you can give families information five years out and the Medicaid waiver may completely change between then and when-- that actually happened in our pilot work. We ran the intervention twice. We had our intervention group who took it right away, then we had a group that got to take it after a year. And in between those two sessions, our Medicaid waiver completely changed. And so we had to redo that whole entire session.

And so we also had some families in our pilot work whose sons and daughters were in high school, they were leaving and going to college, and they of told us at the time I don't think a lot of these services and supports are going to be relevant in our situation, but we're going to be good citizens and research participants. And we're going to help you out with your program and your intervention even though I don't know that we're going to really use this.

We had more than one case where once they left high school, the son-- in one case, the son and one case had a daughter, encountered some pretty significant challenges. Both times in post-secondary education. A couple of circumstances where people actually dropped out of college pretty quickly, and the services and supports start to take on a different meaning than they had before their son or daughter had these experiences.

So there may be something to be said for having some experience in the adult world and seeing where the challenges are and what to attend to and what might be the most helpful. So we're actually, for this—

it's not answering all the questions that you talked about here, because I do think sort of ultimately staggering some of this information may end up being the most effective.

But we will be testing. We have some people who are still in high school, they can be as young as 16 up through 26. And we're going to at least run some statistical analyses to see if getting this information at a certain age, before high school, after high school, right after high school, a little ways after high school seems to be more beneficial to families.

I think it's a tricky question. And I think it's really important because you want to get this information to families at a time when they can really maximally use it, right?

TARA PALAMARIK: That's right.

CARRIE COFFIELD: So I think along similar lines, a lot of the work that we've done at The Boggs Center around transition and in gathering together stakeholders has really raised the issue that one of the major frustrations with transition is that there is nowhere that considers the whole person, that you're working across silos and often focusing narrowly on one aspect of a person's life.

And it's almost like you work so hard to get a person settled in a job, and then you're finally ready to think about a living situation. And maybe now's the time where we're ready to have our family member move out of a house.

Or at least in my personal experience, have my sister now that she's sort of settled in her job and she, I guess prior to COVID, had her certain things that she did, certain days of the week. And now my parents are ready to think about moving her into her own home. And we're hearing options like, well there's this house available four towns over.

And it's kind of like, well, that's not going to work for her because that's going to disrupt everything else that we've already put in place that is working for her, and that's making her happy. So I'm not sure quite where my question is, but there's really a need for all of this to think more broadly about the whole person and how we really attend to a full meaningful life.

JULIE LOUNDS TAYLOR: It's such an important point, Carrie. And I've had the opportunity to be in some conversations at a federal level in terms of what are the challenges with the adult service system. And other than being underfunded, this is the other thing that comes up all the time is it's the services are so siloed.

And there's really not like a-- in a lot of places at least, sort of a central point that somebody can go to have somebody managing the services and supports to really help them live a full life and think about it in a holistic way.

What tends to happen in these meetings is people say, Yeah, you're right. This is a real problem, but boy, that would be a really big change to adult services and supports. And that's just that's such a huge overhaul. I think what you've hit on, Carrie, in terms of not thinking about the holistic person within the service system is one of the grand challenges of the service system. And I think it's incumbent upon all of us who care about people on the autism spectrum and people with disabilities, or who advocate for people on the autism.

I think this is a real area where we need to think about advocating, not just for more services and supports, but really for a structure of the service system that works in terms of really thinking about the person as a whole person. And really improving quality of life, not just in employment, and not just in working, and not just in income, but really thinking about the person and their hopes and dreams and goals, and what is the suite of services and supports that we need to put together to make that happen.

We're trying to help families do this a little bit better in terms of our intervention, but I think it's a stopgap. I think the real change needs to happen at the systems level for this to really be effective.

CARRIE COFFIELD: Yeah, and in our experience in New Jersey it was the family stakeholders who were the ones saying you can't think about health care without also thinking about how that interacts with school, and with work, and with home life. So I really appreciate that.

TARA PALAMARIK: If I could jump over to thinking about employment as, again, one of those siloed areas. There are many assessments out there for students with and without developmental disabilities to help them assess what direction they should go, what fields, what careers they should consider. What might match their personalities and talents.

But for some of our children, some individuals like my son, who are much less verbal or more cognitively challenged. What are some ways that parents can begin to do that assessment online? Or how can we do it within our home life?

When these workshops come up and the first question is what are your child's hopes and dreams. It can be very upsetting, because there's no way for me to know what his hopes and dreams are. It's a very abstract concept. And it's hard for us to even get to that when we're trying to deal with much more concrete questions.

Can you point to any more structured assessments or exercises that parents can do to look for a future jobs, future employment, or future paths for their children who are less likely to go the route of secondary education?

JULIE LOUNDS TAYLOR: Having somebody try out a handful of different opportunities and seeing what seems like it's a reasonable fit. And I also think it's important to think about a job that's a good fit is not

necessarily just about the job itself and the work. I have had jobs that I loved that were not my long term-- like I waited tables when I was in college. And I loved waiting tables, because I loved the people that I worked with there. And it was fun and I really enjoyed it, even though that wasn't necessarily the work that was fulfilling.

I think there are actually like lots of things that go into a job feeling like a good experience or fulfilling other than just sort of the specific work. I think coworkers can be a big piece of that, or a boss that is really understanding, and a good boss, or even the location where it is. If it's a convenient one.

But I'm not sure if I know at this point of any better substitutes, particularly in a situation like what you're talking about, other than trying things out and see what feels like it's a good fit. And what kind of information can you get to suggest that this is something that the youth is enjoying or seems to not be enjoying at all.

We clearly need to do a better job of thinking about this in a more systematic way for people that would have a more difficult time answering assessments and different things like that. But I think continuing to try to figure out, what does it feel like they're good at and what seems to hold their interest, and then trying some things out to see how it fits.

That's about as systematic as I can think about it. I don't know if you have learned anything else or had any other tips from clearly the hard work that you've been doing to try to figure this out.

TARA PALAMARIK: I wish I could. Well one of the lessons, I know we're skipping ahead a little bit, because my son happens to be in a program that naturally leads into an adult services program, we'd always assumed that I don't need to do much of this because I know where he's going right after school. And bam, he graduates in the middle of a pandemic. And he was home for 404 days. No day program.

But because of some of the lessons and exercises that I've done with The Boggs Center, for example, the life trajectory course, it forced me to think about what other resources do we have, what else is available in the community? Do you have relatives who can give you some-- not even paying jobs, but opportunities to have meaningful days?

So we happen to belong to a church that-- and because of the pandemic, could not have services indoors and so they started an outdoor mass. And for social distancing, they had to put cones out in the parking lot and every other space. I know somebody who can take cones and put them. And there are two natural job coaches.

So my husband and I-- that was the only thing structured that he did for most of the pandemic. Every Saturday night, we would go out in the cold or in the hot and lay out those cones. He learned how to figure out patterns.

But that's a connection that I'm hoping that in the future we can continue within our community, whether as a paid job or not. Whether it leads to a full-time maintenance position or occasional help. That's a ready-made community that I'm hoping that we can take advantage of and continue.

JULIE LOUNDS TAYLOR: That's a great point. And we do talk to families about exactly this in terms of really thinking through your personal networks and where that could potentially be helpful. And so like a faith community is a great place for that. Or if as a family, you happen to know somebody, a friend who has a business that could be interested in potentially an internship-type experience.

Or if there's a certain store that your family goes to on a regular basis that knows the youth and could be interested. That is kind of in the-- because formal services don't always cut it, we do talk with families a lot about exactly this. Thinking through your networks and where that could potentially be helpful in terms of widening out the opportunities that a person might have.

CARRIE COFFIELD: So I guess I want to steer the conversation towards just thinking about how can we think about a better system. How can we think about supporting people, parents, and young adults better through this transition period so that it doesn't feel like falling off a cliff, or the other ways that it's been described. How can we do a better job?

JULIE LOUNDS TAYLOR: So it's a great question. I think if there are-- I think having people who can sort of walk with families through this process. So families don't feel like they're figuring it out by themselves is one way that could be super helpful. That doesn't involve huge system changes. Whether you consider that maybe a case manager type person.

That's actually the next direction, the next step we feel like in this curriculum for our program. Is the best most efficient solution in terms of thinking about ways to demystify the adult service system to try to teach every single parent to become a mini expert in adult services and supports?

Maybe not. Maybe that's not sort of the ultimate best use of this. Although, I do think it's-- let me just-- I think it's a nice use of this curriculum. We're really excited to see if it's helpful. But I think ultimately, perhaps, the best use of a program like this, bringing it back to the work that we're doing. But just in general, would be to train advocates or people who can walk alongside multiple families and adults themselves in some cases.

And really hear and think through what goals are, either with what the adult goals are, what parents' goals are, in cases where the adult may have a harder time sort of contributing to that conversation. And then help steer parents towards the services and supports and understanding how to apply those.

So this program that we've adapted and worked on was built and developed originally from a program that was developed by Meghan Burke who was a doc student at Vanderbilt at the time. Now she's at the

University of Illinois, but she developed this program that trains advocates to work with families who are in school around their rights as parents under special education law.

So that's really the origins of the type of program that we're delivering, and that's where, ultimately, I think it's going to be the most effective and impactful, would be to train navigators or advocates or people that can work with multiple families.

That, of course, doesn't have to happen through only through a program like ASSIST. Advocates or navigators could be trained through all kinds of different curriculum. But at least from my experience, that feels like ultimately what could be super helpful and impactful for families is just someone to walk

alongside them and help them figure this out. A knowledgeable person. This goes back to what you were saying Tara, with finding somebody who's a few years older than your son or daughter that can help. It's it comes back to that same idea of just having sort of a knowledgeable person that can really walk alongside and help you work your way through it and figure it out.

So that's where we see this program going ultimately. But again, I think there are lots of ways that you could sort of train people to be that navigator or that advocate. And I think that I really think that could help a lot.

CARRIE COFFIELD: I think that's so interesting and I wonder if that advocate would also end up becoming somewhat an emotional support as well. And so maybe just suggesting maybe some additional training in how to help support families emotionally.

But it could definitely help cut through a lot of the information and get right to the heart, or the meat, or the most relevant at the right moment, which I think is where we started talking about some of the complexity of all of this. And the other-- Oh, go ahead, Julie.

JULIE LOUNDS TAYLOR: I'm sorry. I was just going to say I have a colleague at Vanderbilt, Erik Carter, who has sort of a new program where they're actually going to test this more directly, really around employment. But this intervention is going to pair parents of adults with intellectual developmental disabilities whose sons or daughters have been employed or currently employed with parents of sons and daughters who have never been employed.

And he and his team, and I've had a chance to contribute to this a little bit, which has been really lovely, have developed a curriculum around having sort of the mentors walking through the different steps, but it includes pursuing formal supports and services, but also these informal networks and things that we've been talking about to really help them walk alongside parents in terms of potentially casting the vision for employment. And then helping them take the steps to support their son or daughter in that.

So that's actually going to be a direct test. We're going to be testing that out in a trial where we're going to see if parents have this mentor advocate to walk through employment with them. Does that lead to

greater likelihood of employment for their sons and daughters than families who-- I think all families will get a chance to do this eventually, but some families will just have to wait a little bit for that.

So it's getting at exactly these issues that we're training our pilot group of parent mentors right now in this intervention. And it's going to be-- we're just going to collect a lot of data about how this works and what this looks like. But you could envision a program like that becomes a little wider. To thinking about life beyond employment and the whole person, like you were talking about before.

CARRIE COFFIELD: Yeah, and I think my family's experience too has been that there are a lot of folks who are helpful in giving you information, but it's like, OK, you need information about housing, and you need information about employment. Here are 15 phone numbers and go ahead and start calling. And so some support with the actual connection as well, I think would be useful.

TARA PALAMARIK: That's so true. Even if it's call this number first, and make sure you have this in front of you when you call that phone number. Things like that, which aren't going to show up on formal lists of things to do would be very helpful.

CARRIE COFFIELD: I think our time is coming to an end. And Julie, there's one last question we like to pose. And that's what do you wish we had asked you?

JULIE LOUNDS TAYLOR: It's a great question. The only-- I don't know how I wish you would have asked me this, but I just think we have to always be keeping in mind when we're talking about the transition to adulthood specifically, that there's not really an endpoint here.

We don't usually say, somebody has transitioned and now things are done. I think sometimes we actually sort of our services think about it in that way. And maybe sometimes unintentionally we kind of think about that way even in the educational system in terms of when people have transitioned. But that's not how things work in reality.

I'm trained as a developmental psychologist, and so we think about lifelong learning and lifelong growth and change over the whole entire life course. And that is certainly the case for people with disabilities and people on the autism spectrum. And so really thinking about transition as a process that continues throughout the lifespan. And maybe services don't look like how we want them to now, but there's always the opportunity to advocate and grow and change. And maybe there are, maybe daily living skills don't look like where we want them to be. But we can always continue to work on that and grow and change.

And for employment, helping people get a job is great. But we should be thinking about how to help them be successful and sustain that employment, and maybe even be upwardly mobile. But I think always

having in mind that adult development is lifelong, and transition is a process that doesn't end when somebody is 26. And really I think encouraging families and professionals to continue to think along those lines, I think is super important.

And so I don't know if I wish you would have asked me that per se, but I think it's something that is important for all of us to keep in mind, especially when we think about the transition to adulthood. A lot of our research stops at age 26 and someone gets kicked off of their parents' insurance when they're 26. And there's sort of is this idea that transition has ended and adulthood has started, and that's not the real world. So thinking about it as a process I think is really important.

CARRIE COFFIELD: Yeah, thank you. Thank you so much for being with us this afternoon. Thank you, Tara, For

TARA PALAMARIK: Thank you.

CARRIE COFFIELD: Co-hosting with me. And thank 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. Be sure to subscribe to this podcast on your favorite streaming service to stay up-to-date with the newest episodes.

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