

## **BoggsCast Episode 23: Jill Harris & Pat O'Hanlon**

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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 in Neurodevelopmental Disabilities program.

I'm Carrie Coffield, Assistant Professor of Pediatrics at Robert Wood Johnson Medical School and Director of Pre-service Training at The Boggs Center. In this episode, we're going to be discussing the transition from pediatric to adult health care. And we're so fortunate to have with us today Dr. Jill Harris, who is a psychologist and Autism Advancement Ambassador at Children's Specialized Hospital. And Dr. Harris is also the mom of an adult son with autism.

And we're also joined by Pat O'Hanlon, who is family faculty at Children's Specialized Hospital and mom of an adult son with special health care needs. So we're joined by two wonderful partners who are professionals and parents and I think we're just going to dive right into our conversation about this topic.

So Jill and Pat, I think the place to start is really to talk about why transition to adult health care is important to talk about and often such a challenge.

JILL HARRIS: Well, one thing is that kids grow up. And as they grow up, not only do their bodies change physically and their minds change and their emotions change, but just the focus on who is a patient here also kind of changes. So what you often find in pediatric practices is that at least when kids are really young, the communication goes through the parent.

It may be less so to the patient himself or herself. But that really is not the focus in adult health care. So it's really important that as youth with special needs become adults that they have a source for health care that really focuses on their being an adult and their role as an adult.

CARRIE COFFIELD: Yeah. I can appreciate that. They grow up. And as adults, we are susceptible to adult onset health conditions which pediatricians are not trained to manage or help us manage or monitor or provide medical advice about. So that's definitely important.

But Jill, you also mentioned this cultural shift between the pediatric delivery of health care and that in the adult world. And there is this shift in focus of who the patient is, who the sharer of information is, who

reports history, who brings the chief complaint. And all of that really moves to the patient him or herself in this world of adult medicine.

JILL HARRIS: Right. I mean, and I think that a lot of pediatricians really kind of tend to have more of a family centered approach and kind of a holistic philosophy that is not necessarily seen by adult health care practitioners. I mean, sometimes yes, but more typically not. So that's kind of, as you mentioned Carrie, there's a shift in the scope of practice in terms of medical expertise but also I think kind of a shift in terms of the philosophy of care and communication patterns, as you mentioned.

PAT O'HANLON: Yeah. I mean, I was just thinking as you were both speaking, I remember 25 years ago when I had to find a pediatrician that understood special health care needs. I started out thinking if a doctor, an MD at the end of their name, everybody was the same. I just had to find somebody close by, easy access, get an appointment. And I came to learn it's not really like that. You have to find someone with the right approach, the right philosophy, great expertise.

And then 25 years go by and in my case, I stayed with the same person till my son was 22 years old and I didn't want to leave. And you know what? You have to find the right partner again. And whether you're older and tired and worn out from all the journey, you have to regroup and find that energy again, because there are good people out there. You just have to find that partner.

JILL HARRIS: With pediatricians for our kids, there's really a need for a lot of care coordination and being aware of the resources in the community and oftentimes help in linking to those resources. And that can be time consuming, and P.S. it's not often billable. So that's a challenge. And then when you go to adult health care, who's really doing that? It doesn't mean that the need goes away for that care coordination and the linking to resources, but it can be a whole lot tougher getting that through your health care provider, I think.

CARRIE COFFIELD: I think all of this is going on at the same time that there's a lot of other change and shift happening in one's life. And so I think there's a number of things that that raises. One, it's really hard but critical to focus on the whole person and to really consider that health is critical and underpins well-being and positive outcomes in so many areas. But it is often just kind of one area of transition that's happening at this time.

And then I think also pediatricians, Jill, when you talked about care coordination, there's care coordination kind of within the health system. And so coordinating with other subspecialists or therapies and other disciplines. But then there's coordination with more of those community resources. And again, that's an area where I think pediatrics has much more experience coordinating and navigating some of those connections with schools or other community-based programs.

And I'm not sure that most adult providers are comfortable coordinating or making referrals to the adult services, because things do become a lot more complex in a lot of areas as youth make this transition from school to the adult world.

JILL HARRIS: Yeah, exactly. And I think that for better or for worse, sometimes we get, I don't know what's the phrase, I don't know if codependent is the right term. But we talked about how the family and the youth with disabilities might become very comfortable, hopefully, and have a good relationship with their pediatrician. And likewise, their pediatrician or their pediatric specialist hopefully has a good relationship with them.

And so sometimes it's all three of this triad kind of not wanting to make the change. So we certainly see people into their 20s and well beyond still seeing the pediatrician or their pediatric specialist because it's comfortable and it's challenging to find the right source for an adult provider.

PAT O'HANLON: Yeah, definitely. I mean, I can remember, and I've shared this with you, I'm a car crier. I used to cry about this while I was driving. I remember my first appointment in the adult world, their concentration was on blood pressure and weight and it didn't run anything like the pediatric visit.

And I'm crying calling my pediatrician, who we know, he's at Children's Specialized, and I'm crying to him thinking he's going to say to me, don't worry, you can come back. I don't want you to go through this. And he just said to me, it's going to take time. [LAUGHS] And that just set me off more.

So you're the psychologist, but it's almost like a grieving process. You're leaving people you cared a lot about and they cared about you. And you have to face that. But it's the next step. It's a new beginning. And it might not work out day one. You might have this whole plan and it might fall apart and it's OK. You've got your whole adult life ahead of you. There's going to be ups and downs just like with anyone else. But it's that mindset of getting ready to embrace it. And I do celebrate it. It is wonderful.

CARRIE COFFIELD: So change is hard, but this change comes upon us. And so what advice or suggestions do you have for how to get ready? How do we start preparing knowing that this transition is coming at 18 or 21? What can we do?

JILL HARRIS: I think part of the conversation is having conversations with your son or daughter about what it is that they want and what it is that they value. Because I mean, transition to adulthood, the health care is one piece of it. It's only one piece of it. Obviously there's lots of other things. Education, employment, housing, and so forth. But with health care, what is it that they want? And to the extent possible, to build their ability to identify their own strengths, their own knowledge about their health care condition, the ability to communicate about it.

I mean, it doesn't have to be like snip, snip that you're jumping off a cliff and it's all or nothing. I mean, even when the person has a pediatrician, you could start talking about who's going to call to make the appointments? Who's going to go to the pharmacy or going along with you to the pharmacy to ask questions about medication? Things like that. Because it's all part of, well, that part is really trying to build health advocacy, self awareness kinds of skills, which I think is important.

CARRIE COFFIELD: Yeah. I think it's critical. And the pediatric visit should be evolving. So that there is time for the patient and the physician or clinician or provider to be alone. And so encouraging that to happen I think is a good way to practice in a supported environment where it still is family centered and the communication lines are often open in that setting.

JILL HARRIS: And I think most pediatricians would do that starting at a certain age. Kind of say, look, we're going to have some time alone and mom or dad, you wait out here. But if they don't, I mean, I think mom or dad could say, I'm going to wait out here.

And I know, Pat, we ran into this sometimes at Children's Specialized that sometimes the providers, especially if the patient was non-speaking, was directing a lot of the communication to the parent caregiver and not necessarily recognizing that they could still find a method of communicating with that patient. So I think that as a parent caregiver, some of it could be to educate the provider about how to communicate if your child has some communication challenges.

And we talk about developing health passports or about me. Here are the things that I like here or the things that might trigger me. Here's ways that I express pain. So I think that that's something they could partner with the pediatrician to develop, because that's a tool that I think builds self awareness, it helps the provider, and it's something that could be used with the adult provider as well to educate them about how the person best communicates.

PAT O'HANLON: I think that's a really good point. I know for my son, during his time where he had an IEP when he was in the school, we added a section where he would learn about his disability, what it was. He learned about his medications. He could look at them and identify them. And if you're not verbal, maybe it's through pictures. You could do something like this. But he can answer those questions when he talks with his provider. But he started doing that in the pediatric world, so he was ready to continue it. I think it's important.

I think sometimes we take for granted and think our children understand their disability and they may not. They may just know what the name is and that's it. It's who they are. That's it. And it's really important for them to understand. It is a part of who they are. And there's ways you can do that. Embrace your whole team if it's through an IEP through school or if it's through your pediatrician.

But it may be the parent that needs to ask for this, unfortunately. Someday I'm praying it will be that the provider will just automatically say this. But right now, I think it's important. It's a way to help your child begin to advocate for themselves in the health care environment.

JILL HARRIS: That's a great idea, Pat. Because like you were talking about in school a lot of our kids are going to have IEPs, Individualized Educational Plans. And starting at 14, they have to start considering transition. But we could also make sure that this includes the transition to health care and not just transition from the educational setting to some other kind of setting.

CARRIE COFFIELD: And what a great way to think about the whole person and building skills, self advocacy skills and self awareness skills. This is really about empowerment. And I think that's what's so wonderful about these approaches is that we're giving people a voice in their own health care and in their own health care encounters and then preparing them for those expectations as they move into the adult world where that is the expectation.

Similarly, what about families who are a little more hesitant? And Pat, your own story kind of speaks to this a little bit. But how can we support families who may need a little bit more encouragement through this transition?

PAT O'HANLON: I'm giving it thought, because part of my job, I talk to families about this. And it's very challenging. Families are so aware of the aspects of their child's disability, and they will tell you they can't leave the pediatric world. And they'll give you this list of reasons why. And so, you try to have this conversation. But you know what? At a certain point, everybody becomes an adult, if they make it, and that's a good thing. But to get them over that hump, it can be very challenging. And I think it's just step by step conversations.

And there's a lot of great-- I encourage families to attend any webinars or any of these talks. It just helps. You keep going. You hear other parents' stories. You hear from great experts. I mean, I remember going to many through The Boggs Center and they were all very helpful about process. But also, it just gets your mind-- you get to a different mindset little by little, and then you're ready to do it. And it will happen. It's going to happen, whether you want to participate or not. It's going to happen.

JILL HARRIS: Right. And in addition to Pat, like you mentioned, webinars and lots of great resources. But I think it's also helpful word of mouth sometimes. Hopefully word of positive mouth, if that's even a term. But connecting with others who've been through this journey maybe a few years-- maybe their kid is a few years older than your kid.

And having a partner help or a friend to talk to, whether that's somebody that you already know in your circle or by going to a support group, virtual or in person, or some of the social media or some of the disability advocacy groups, things like that, to meet with people who can kind of help you on your journey by holding your hand.

CARRIE COFFIELD: I think that's great. So Pat, how did this transition go for you and your family?

PAT O'HANLON: Well, [LAUGHS] after I did a lot of car crying, as I shared, I got there. I mean, it was a process. I tried, specific to health care, I had tried one practice. And when I went with Kenny, I realized they only had maybe 15, 20 minutes to give each patient. They had to see a certain amount of patients every day. The adult physician was not engaging with Kenny at all. And it was hard. And I gave it another try, another try. And then I realized this is just not going to work.

So then I had this notion I would talk to the physicians. I would call different practices. I had my insurance book out looking to see who would be covered. For Kenny, he has Medicaid, but I also am able to have him on my insurance because of his disability for his lifetime. So that opened up a lot more for him. Because having Medicaid is another thing you need to consider.

But I couldn't get past the women and the men that ran the front desks. You're not a patient? No, you can't speak to someone. They thought I was crazy. And then I finally did find a practice not so close to me, but I was able to talk to the physician. I asked him, did you ever treat someone with the diagnosis that my son has? And he said, no, I haven't done that. But I care about my patients. I'm invested in them. And I'll learn. I can learn.

So that's what sold me. And I've been with this same practitioner with my son, now my husband goes to him as well, for 10 years. So he knows him inside and out. But it was that little bit of what I heard him say. And he's a wonderful partner in Kenny's health care. So it may not work the first time. I always want to say that.

We have this mindset at 21 you have to figure it all out on that day for the rest of their life. And that's not the case. And you try things and you see how it works out. And even programs or other things that you decide with your adult child, it might be good, but it might not be. And then you look again.

And that's the beauty about being an adult. There's lots, like we talked about before, options. That's my story. And thankfully for my son, things are working out well. But I believe it can happen for everyone, but it's not going to come to you. You do have to participate and you do have to see what's available to you.

JILL HARRIS: Pat, on that topic, we talk about disability friendly practices. And you mentioned having a longer appointment, not being in such a rush. So mentioning that when you were looking for an adult provider, there were lots of things to consider. Did you ask about that as far as the length of the appointment or if they could have an appointment first part of the day or the end of the day or a quieter part of the waiting room or any of that kind of stuff?

PAT O'HANLON: Yeah, I didn't ask, but it became apparent to the provider we were going to need more time. And so we started to be more or less the last one of the day. It just worked for everybody's schedule. And then there was no more rushing. But I didn't ask, but that would be a great question to ask, because it does take longer. If you want this kind of interaction, it takes longer.

JILL HARRIS: Yeah. I think that sometimes-- one of the things that I was thinking of in terms of with the pandemic, something positive that came from it is really trying to reduce the time people spend in waiting rooms. So be in the car and you'll be texted or whatever when the provider is ready for you and then come in. So it minimizes that kind of downtime in the waiting room, which could be really very stressful for a lot of people. So I think that's one good thing.

But speaking of offices, just to be concrete, if we have an adult child who has physical accessibility needs, I mean, sometimes you think, OK, when you're calling these different offices, is there a ramp? Are there steps? But I mean, other things I think you probably experienced, Pat, is what about the examining table? What about how they weigh and measure? Do they have adaptive equipment? Can they problem solve about how to do that when there are accessibility issues?

PAT O'HANLON: That is definitely our situation. Kenny is an ambulatory, so he's in a wheelchair. Probably the funniest moment was with our adult ophthalmologist when we went for an appointment. So they like to do the glaucoma screening. You need to put your, at least at this office, you had to get yourself lined up with this machine. Well, I knew that and I knew they didn't have anything, because I go to the same eye doctor. So I brought his Hoyer lift with me.

I had him-- you should have seen us walking through the waiting room. [LAUGHS] He's driving, I've got the Hoyer lift with me. Mine's portable. It's not easy to fold up, but it folds up. And in we go and I had him in the sling and I was able to wedge him in so that he could get the eye exam. But this whole visual, if you could picture this, I don't know if everyone knows what a Hoyer lift is and all. But if you could just see us, you better believe they figured out a way to do the glaucoma test next time. [LAUGHS]

But yeah, you run into that. And you have to figure out how to make it work and have the conversations. Even a scale, as simple as a scale. There's certain scales for wheelchairs. Kenny can't get weighed on a regular scale. Weight's important in the adult world, and for him it's real important. So it's things like that. But those are all conversations that you have to be courageous enough to have. You can't just wait for it to happen.

And I know families can make these changes. Look at the schools, I mean, over the last 20 years in inclusion and all of that. So the new frontier is the health care world and the adult world. We can do it. It's really relationships and sharing your story. And people are open if you give them that opportunity. Some. Many.

CARRIE COFFIELD: And Jill, was your son's experience similar?

JILL HARRIS: Well, for us, he transitioned from a pediatrician to a family practice doctor. So we all see the same family practice doctor. So we didn't have that same challenge in terms of the medical. But where we had more of a challenge was more for behavioral health.

So he was seeing a psychiatrist and she only worked with up until age 18. So that was hard. So we went through some different people who were not good matches. Found somebody who was very good, but didn't accept insurance. That became very expensive.

So then our family practice doctor said she would write the prescriptions. But after a while you think, well, maybe he should see somebody else. And so I wanted him to be independent but I said, OK, why don't we sit down together and we'll look to see on the internet or whatever who's in network and who might be



a good match. And that's not always so easy. You'll find the sites don't-- when you call up, they're not accepting new patients or at all, whatever.

But I have a little bit of a story to tell about communication I think that illustrates some things. My son was seeing somebody new for medication. And like I was saying, what kind of practitioner is this person? Is it a psychiatrist, a nurse practitioner? I don't know. I don't know. Well, you need to ask.

One time he was having a session with her virtually at our house. And I overheard his end of the conversation. I was down the hall. I want to say I wasn't in the same room. And I could hear him trying to talk and she was cutting him off and he wasn't able to get his point across. And I thought, oh God, oh God, I don't really want to go in and intervene. I shouldn't intervene. He's an adult. But this is not going well.

And then finally I said, look, I'm his mother. I just walked into this room. And we had a conversation. And P.S. she didn't have to talk to me, because he is an adult. And then when I left the room, she says, oh, I see your mom really cares. I'm thinking, yeah, but does she also think, I can see your mom is really way intrusive?

[LAUGHTER]

My point being, even if you know you've made a transition to an adult provider, sometimes the communication can still be challenging. And the underlying disability that could cause all sorts of anxiety or what have you, it's a factor. And how do you address that? So whether that's practicing, role playing. I'm not sure. But when we have this conversation about transition to adult health care in addition to the medical, it's also the behavioral health and any other specialties.

CARRIE COFFIELD: Absolutely. Absolutely. And we at The Boggs Center are really trying to support all parties involved through this transition process. And so thinking about resources and developing materials and different kinds of opportunities to bring speakers, content experts in for families for individuals with disabilities, but also really thinking about supporting the training of health care practitioners themselves, because that communication is really two ways.

And we find that focusing on those interactive interpersonal skills and really kind of supporting some of those opportunities to engage in ways that aren't threatening but provide this practice really helps as the providers move through their training and into their careers. And so I think some of it's just lack of having been able to have opportunities to interact and not understanding differences in communication. So it's really interesting and sometimes shocking how little content about that is in training for professionals from a lot of different disciplines.

So I think we shouldn't make any assumptions that that's covered in someone's training. And our experience definitely with the students that we work with is that they all go into their professions because



they really want to help and they really want to be the best providers that they can be. And so we're here to try to support that.

PAT O'HANLON: That's really wonderful. And I'm very hopeful for the future of medicine. Through our work at Children's, we get to meet with second year medical students. They spend a day at our hospital. But they also practice interviewing families that have children with disabilities. And just to get that sense of what it's like, what the day to day is like. And it opens their eyes to seeing the kids as their entire person. And it's really amazing how open they are and how they do want to practice that way.

And just listening to you, Carrie, and with Kenny's adult provider, I think sometimes we were different to him. We kind of initiated building a relationship with him and asked him questions about how would you like to communicate with us? He's about an hour away from us. So if there's any emergency or anything, he's not right in our neighborhood. So he needs to be aware of it.

And we came up with this whole system. It's an email if it's not a real emergency. And if you're OK, text me. I want to know so I can participate if he has to go to the ER or something. And he said, as long as you're not going to sue me, HIPAA and all that, if you're OK with that, I'm OK with that. So we developed this method of communication. But it fostered a relationship.

But I also shared with him things Kenny may have done in the community. He sometimes speaks on behalf of our hospital at dance marathons and stuff. And I'll send him a picture and say it went really well. Look at what Kenny did. So whether he wanted to or not, he got to know our family and he got to know Kenny in ways that Kenny might not be able to communicate to him. So that if he does get really sick or if there's a behavior that's not common to Kenny that he needs to address, he now knows him. It's not just that 15-minute visit.

And that's what was so important to me, so Kenny could get the best care. Because with someone with a disability, they could change so quickly. A behavior can happen to them that you don't know where it's coming from. They may need meds. They may need interventions. But if you don't know their baseline, you might just say, oh, that's what happens when you have that disability. It'll be all right.

So I think it was so important. But it was on us to do that. So I have a lot of hope for the future of medicine. But right now I think families are very powerful. They underestimate the amount of power they have in these relationships and they can help foster positive relationships that are going to help their adult children.

CARRIE COFFIELD: I think that's awesome. And we hear that from families who work with us in our training of medical students that they really want a provider who's willing to get to know them, to be supportive, and to say I don't know, but I'll find out. And I think sometimes that's another way of creating a barrier is to go out thinking that you need a provider who kind of knows everything about every condition rather than the person who's really going to be willing to get to know you, to get to know your child, and to work with you in very supportive ways.

And Pat, you're a champion and I think an inspiration. And the subtle way that you shaped up your relationship with Kenny's provider is really magical, I think, because how successful. And I think that's a great note to wrap things up for this conversation. But just to say that there are a lot of resources and there's been both a lot of local attention and national attention on this issue.

And so at the national level, things like [gottransition.org](http://gottransition.org) as well as [movingtoadulthealthcare.org](http://movingtoadulthealthcare.org) are both really great websites that have a lot of supportive materials to help young adults get ready, to help families get ready, and to help providers get ready, both the pediatricians to let go and the adult providers to receive and to welcome young adults with disabilities.

But there's also work being done locally. And at both of our organizations, we've developed supportive resources for young adults and families. So at The Boggs Center's website on our resources page, we have a [timeline](#) that really tries to help families understand this complicated process and all of the kinds of things that they should be talking about starting at 14 but even earlier. And it addresses health as a piece of all of the considerations. And then we've developed some other resources as well. But I know that you all at Children's have also developed some helpful information. So do you want to talk about that a little bit?

JILL HARRIS: Sure. So we'll be sure to have that website linked. But as similar to Boggs at Children's Specialized Hospital's [patient and family resources](#), part of our website has a really extensive transition to adulthood resources, whether it's covering not just the health care but also education, housing. And we have a lot of those resources in Spanish as well as in English, which I think is important as well.

One other resource is the The Arc has a Center for Future Planning. And they have a really nice [templated letter](#) that can be shared with health providers that covers a lot of the stuff that we've been talking about.

CARRIE COFFIELD: Yeah. And we wanted to acknowledge also the [Center for Transition to Adult Health Care for Youth with Disabilities](#), which is a virtual center that provides training and resources to youth and young adults and their families and the professionals that serve them. So clearly there's been a lot of effort made to really develop resources and products that are supportive through this process.

I don't think that means it's any less daunting or any easier necessarily, but hopefully we're moving that way. And I think parents and families like Pat, yours, and Jill, yours, are certainly leading the charge in helping to revolutionize this process a little bit and make it more accessible for more people.

JILL HARRIS: One thing I just wanted to add. We were talking about resources for parents and supports for parents but also the resources for the youth or young adult themselves. I think it would be great if there's other people that they know of that they could hook up with and get support from. Because it's not just, we're so used to focusing on the caregivers and support for the caregivers. But this would be really great.

And I know that one thing, hats off to The Boggs Center, which is the site for New Jersey LEND. And you were talking about a lot of the training that's done for people who are early in their careers. But that LEND program also has a role for the self advocates. And I think that that's invaluable in terms of hearing directly from people with disabilities about wants, needs, and strengths that should always be part of the conversation.

CARRIE COFFIELD: Thank you, Jill. Thanks for mentioning that. And thank you both so much for being here. 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](http://theboggscenter.podbean.com).

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