

## **BoggsCast Episode 19: Katie Arnold & Patrice Keiling**

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JAIME ZAHID: 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 Jaime Zahid, Training and Consultation Specialist at The Boggs Center on Developmental Disabilities. And I'm thrilled to be kicking off season three of BoggsCast. In this episode, we'll be discussing sibling experiences with Katie Arnold and her sister, Patrice Keiling.

Katie Arnold is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago, a family faculty member for UIC's Leadership Education in Neurodevelopmental Disabilities program, and founder of the Sibling Leadership Network.

Katie grew up in New Jersey as the second oldest of four, including her sister, Patrice, who is joining us for this episode. Having a sister with intellectual disabilities has shaped Katie's worldview in many ways, which she will share about today.

Katie and Patrice, let's get started. I'm hoping we can start just telling me a little bit about your sister and sibling relationship.

KATIE ARNOLD: First, thanks so much for having us. We're excited to be here, aren't we, Patrice?

PATRICE KEILING: Yeah.

KATIE ARNOLD: And yeah, we have a great sister relationship. There are five of us kids in the family. So we have an older brother. Who's our older brother, Patrice?

PATRICE KEILING: Keith.

KATIE ARNOLD: We also have a younger brother—

PATRICE KEILING: Bobby.

KATIE ARNOLD: And a younger sister.

PATRICE KEILING: And Maggie.

KATIE ARNOLD: And we're all about two years apart. And Patrice and I, I mean, we've been sisters since you were born, Patrice. And how old are you now?

PATRICE KEILING: 42.

KATIE ARNOLD: And I'm two years older than you. And we all grew up in New Jersey with our mom and dad.

JAIME ZAHID: Jersey girls. Love it.

KATIE ARNOLD: Yeah, Jersey girls. That's right.

PATRICE KEILING: Yeah.

KATIE ARNOLD: And with all five of us kids, there really was never a dull moment. And our sibling bond has lasted throughout our lives. And I know for me, in my sister relationship, I really learned to advocate at a young age as a sister, handling some questions from classmates, having people-- when people would stare or name call sometimes. And my experience growing up with Patrice really changed my worldview and influenced my career path in a big way.

JAIME ZAHID: Patrice, I'll start with you on this topic. What do you do to support your siblings? I know that you've got some that are close, and obviously we just talked about those that are far. How do you support your siblings?

I think that's something that's often overlooked. We always talk about how siblings without disabilities support the sibling with a disability, but as a sibling myself, I know that that's really a reciprocal relationship. It's a relationship where Patrice, I know you support your siblings. So how do you do that?

PATRICE KEILING: I call them, and go out to dinner, and play games with the grandkids.

JAIME ZAHID: So a lot of emotional support?

PATRICE KEILING: Yeah.

KATIE ARNOLD: I think you're a good listener, Patrice. Whenever I call you—

PATRICE KEILING: Yeah—

KATIE ARNOLD: --you're always helpful.

PATRICE KEILING: --I am a good listener.

JAIME ZAHID: Being a good listener is a huge thing because there's lots of people who love to talk. There's not a lot of people who like to listen, so that's good. And you said that you spend a lot of time with your nieces and nephews when you can play with them? I bet that's a huge help to the moms and dads.

PATRICE KEILING: Yeah.

JAIME ZAHID: When my sister comes over, I know I'm like, OK, great. I can vacuum the floors and wash the dishes. Because there's somebody playing with the kids. So Katie, how do you think that Patrice-- what do you think that she does to support you and your siblings?

KATIE ARNOLD: Yeah, I think Patrice does a lot to support all of us, probably more than we even realize. A few things. Patrice always knows what's going on in the family. She knows what mom's up to, what older brother Keith's up to. She's kind of like a hub of information for the family.

Also, Patrice always knows where everything is. If somebody loses something in the house, usually you ask Patrice and she knows where it is. If mom can't find her phone, or someone can't find their glasses, or where is that book? You just-- how do you know, Patrice? You always know.

PATRICE KEILING: Yeah, I know everything.

KATIE ARNOLD: You do. And then also, I think growing up, I mentioned this before, but Patrice really did shape my worldview and influence my career path in a big way. I think Patrice really helped me find my calling and I can anchor so much of my work in my experience as a sister to Patrice.

I talk to her about my work with other people with disabilities. I work with other people with disabilities. And so then I sometimes ask Patrice for advice, or her opinion on things. Also, Patrice, do you remember you've kind of helped me out sometimes when I'm doing research with people with disabilities where you'll test out some of the survey questions, and—

PATRICE KEILING: Oh, yeah. You do.

KATIE ARNOLD: I'll see if I'm asking questions in a way that's understandable and you'll give me feedback to kind of help me do my work better. And also I helped to found the Sibling Leadership Network, which is a national nonprofit for siblings of people with disabilities, really, because of my sibling relationship with Patrice.

JAIME ZAHID: Excellent. Katie, can you tell us a little bit more about the Sibling Leadership Network for our listeners? We've got people in-- hopefully lots of people in New Jersey listening, but also beyond Jersey.

KATIE ARNOLD: Yeah, sure. So the Sibling Leadership Network, or SLN for short, was created in 2007, really from seeing a need to bring together the work regarding siblings of people with disabilities that was happening across the country. And the mission is really to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

And so the Sibling Leadership Network welcomes siblings of people with any type of disability. We tend to draw the most members as siblings of people with intellectual and developmental disabilities, though we're open to siblings of people with any type. And we have members who are people with disabilities because after all, people with disabilities are siblings, too.

And we have sibling supporters that are part of our network as well and they're really important. Sibling supporters are like parents, professionals, really anyone who believes it's important to support siblings. And so there are sibling chapters of the SLN in 26 states and New Jersey has a chapter called SIBS New Jersey. And so people can find more information on the SLN website, which is [siblingleadership.org](http://siblingleadership.org).

JAIME ZAHID: A lot of good work coming out of the Sibling Leadership Network.

KATIE ARNOLD: It's a great community. It's really like a community of people where you get together and you're with people that get it in a way that's really refreshing and awesome.

JAIME ZAHID: In a safe space with like-minded people, always a good thing. So what can you both tell me-- and I think I'll start with Patrice on this. What would you tell other people with disabilities about how they can support their siblings?

PATRICE KEILING: Call them and talk, and keep talking.

KATIE ARNOLD: You're good at that, Patrice. You always call me and we get to talk. And we do FaceTime, because I know my son loves FaceTiming and seeing you and your picture sometimes. And so I can add some ideas that I have about that question.

I think you said it well earlier, Jaime, where there's a lot of ways that people with disabilities support their siblings, but often, that's not what people think about. Usually people think about ways family members are supporting the person with a disability. But there's so many important ways that families have these mutual and reciprocal relationships.

And so for my dissertation research, I actually had the opportunity to interview adults with intellectual and developmental disabilities and ask them not only about the support they get from their families, but also

the support that they give to their parents and their siblings. And some of the things that came out included the following. People with disabilities talked about how they provide a lot of companionship support to their siblings, just as friends throughout life. Siblings are each other's first friend, usually, and then are companions throughout life, and especially as aunts and uncles to their siblings' kids, like you talked about, Patrice.

Another thing is a lot of people with disabilities provide emotional support to their siblings when they're sad or grieving. You do that, Patrice, with me and the rest of our brothers and sisters. And I think a lot of people with disabilities do that just by listening, by being there and providing that emotional support. And then another thing is that people with disabilities who live with their aging parents often help support their aging parents with things around the house, even with things like reminders for the parents to take their medications. So sometimes some health support. And I think a lot of times, that can provide a sense of relief to the siblings knowing that their brother or sister with a disability is living there with their aging parents.

And I think sometimes it could even delay aging parents from needing outside physical support, such as nursing home support, because the person with disabilities can help with some of those things around the house. And I think that's really not acknowledged. And there's a lot of policy implications around that that are really important to think about those roles that people with disabilities are playing in supporting their whole family.

JAIME ZAHID: Thank you for all that great information, Katie, that came out of your research. And if anybody listening is interested, Katie actually did one of our DDLS, our Developmental Disability Lecture Series back in the spring of 2023. Anybody listening, you can check that out on our website.

Katie, I can't help but sort of hang on to that last note about siblings that live at home with parents being such a great support to parents, and ultimately delaying the need for parents to need support, or even to move out of their family home. And it almost gives me chills because that's huge. That's absolutely huge for parents, for siblings who don't live at home to know that there's that in-home support. So Patrice, your siblings who live outside the home, I'm going to say that they kind of owe you a lot, don't they?

PATRICE KEILING: Yes.

JAIME ZAHID: You get that Christmas list ready.

KATIE ARNOLD: Although, Patrice has moved out. You were living with our parents, but you have moved out. And so we can talk about that in a little bit when we talk about how we did future planning. And that was one of the things. You live close to mom and dad and you visit them, but yeah, now you've got your own place.

JAIME ZAHID: Oh, OK. But Patrice, going back to that, being a support to your parents, do you agree? What kind of things have you helped with around the house to support your parents?

PATRICE KEILING: I cooked a lot when I was living with them.

KATIE ARNOLD: You're a good cook, too.

PATRICE KEILING: Yeah.

JAIME ZAHID: What's your favorite thing to make?

PATRICE KEILING: Lasagna.

JAIME ZAHID: That's good. That's time consuming.

PATRICE KEILING: Yeah.

KATIE ARNOLD: You're also good at cleaning and you're great at doing the laundry.

PATRICE KEILING: Yeah.

JAIME ZAHID: Patrice, do you fold it and put it away?

PATRICE KEILING: Yes.

JAIME ZAHID: I can get it washed. Fold it and put it away? Oh, that's a whole 'nother thing.

KATIE ARNOLD: No, you're amazing, Patrice. You do it all. I can never get to the socks. I always take a pile of socks for weeks.

JAIME ZAHID: And we always lose socks in our house. I don't know where they go.

PATRICE KEILING: Yeah.

JAIME ZAHID: Awesome. So Patrice, do you mind, can I ask a little about your future planning? I know that was one of our topics we wanted to cover. What's going on with all that? Where do you live? Tell me about it.

PATRICE KEILING: I live in an apartment.

KATIE ARNOLD: Yeah, you moved out into this supported living place in the community that we all grew up in. So it's really only-- how far from mom and dad, would you say?

PATRICE KEILING: 15 minutes.

KATIE ARNOLD: Like 10 or 15 minutes away. And it's section eight affordable housing, so you pay monthly rent for it. Money that you make from your job.

JAIME ZAHID: That's awesome. I bet living in the community that you grew up in is super helpful for those relationships.

PATRICE KEILING: They are.

JAIME ZAHID: Awesome. So Patrice, how do you think that future planning has helped your life?

PATRICE KEILING: I am happy.

JAIME ZAHID: Patrice, do you feel like you're living like the life that you've chosen for yourself?

PATRICE KEILING: Yes.

JAIME ZAHID: That's such an awesome thing for anybody, disability or not, to be able to say, because there's a lot of people that are just stuck in situations that aren't exactly what they would have chosen for themselves in an ideal situation, you know?

PATRICE KEILING: Oh, yeah.

KATIE ARNOLD: And I remember, though, when we started doing future planning as a family, Patrice, it was actually kind of hard to find out what you wanted. That was something that was a challenge at first for our family because—

PATRICE KEILING: Oh, yeah.

KATIE ARNOLD: What's the most common response that you have when somebody asks you a question?

PATRICE KEILING: I don't know.

KATIE ARNOLD: Right. Usually when you're asked a question, you either say, yes, no, or most often you say, I don't know. And so it was kind of hard for us to-- I feel like we kind of had to be detectives and work with you to figure out what you really wanted. And so what was one of the things that we did that helped with that? What did we make?

PATRICE KEILING: A scrapbook.

KATIE ARNOLD: Yes, we did a scrapbook. What was in the scrapbook?

PATRICE KEILING: Pictures of family and friends.

KATIE ARNOLD: We talked about what things you like, and what things you don't like, and we wrote that all out. And then we asked you what your dreams are for the future. And we cut things from magazines, and put together collages, and really got to know more about what you wanted.

PATRICE KEILING: Yeah.

KATIE ARNOLD: Yeah. And I remember we talked about what you're good at. There were certain things you were really good at already and then there were certain things that you wanted to get better at. At that time long ago, you were not as good at cooking, and you wanted to learn more about cooking. And so you really focused on that. How are you at cooking now?

PATRICE KEILING: I'm good.

KATIE ARNOLD: You're more than good. I would say you're great.

PATRICE KEILING: Yeah.

JAIME ZAHID: You're making lasagna, I'm going to say you're more than good, because there's a lot of people who are good at cooking who can't make lasagna.

KATIE ARNOLD: Right. Totally. I can't make lasagna.

JAIME ZAHID: It's a lot of work. And patience. It requires patience. That actually tells me, Patrice, hearing you can cook lasagna, that tells me you're a patient person.

KATIE ARNOLD: Yeah.

PATRICE KEILING: Yeah.

KATIE ARNOLD: So I think it just gave us an opportunity as a family to really kind of focus on you, Patrice, and talk to you about what you were great at, what you wanted to get better at. Then as all of us other siblings, we were moving out, Patrice, you were the last one to stay living with mom and dad. Eventually, you started thinking about how maybe you would want to move out into your own place.

So you looked at different options for places to live, and then you found the right place. And you were super excited about it. Our whole family was super excited about. And what did we do when you moved out of mom and dad's house into your own place, your own apartment? What did we do?

PATRICE KEILING: Have a party.



KATIE ARNOLD: We had a huge party. We invited everyone under the sun. And it was almost like a big graduation for you. And it was such a celebration of you in that milestone, moving out into your own place. It was so exciting.

And I think that was because we had really talked about as a family. There were a lot of people who, when they get to that step, they're worried, and they're scared, and they're afraid. And there were other people, I think, moving into your place that were feeling that way. They were all anxious, and worried, and we were at this other place as a family because we'd done all this future planning where we were ready and celebrating.

JAIME ZAHID: That's an exciting-- that's a huge step for life for anybody, and super exciting. So I'm glad that you celebrated accordingly. I just want to touch back on the beginning of this conversation. Katie, you were reflecting on how in the beginning, Patrice didn't really know what she wanted. A lot of her responses to questions were I don't know.

And I couldn't help but think about how we talk about with people with disabilities, the three E's, the education, exposure, and experience. And so I feel like just hearing you talk, do you feel like that was what was going on there, was just the lack of exposure, of experience, and education of what her options were?

KATIE ARNOLD: Yes, I think that was a big part of it that we really-- it was a real process for our family that happened over many, many, many years. It didn't happen overnight. And one of the things we realized when we first started meeting as a family is that Patrice, you really didn't always have the opportunities to do things for yourself, or speak up for yourself.

We had kind of gotten into some habits as a family of speaking for you and doing for you because it would take you longer. Because I remember-- and this still happens today sometimes. When someone asks you a question, who did you usually look to and turn to when someone would ask you a question?

PATRICE KEILING: Mom.

KATIE ARNOLD: You would just-- you were used to mom answering for you. And we really had to realize, although we thought we had your best interest in mind and we thought we knew what you wanted, we weren't really giving you the opportunity and the practice to be able to tell us for yourself, even though it took a little longer. So mom came up with two phrases.

PATRICE KEILING: Put your hands in your pockets and zip your mouths.

KATIE ARNOLD: And zip your lips, yes.

PATRICE KEILING: Yeah.

KATIE ARNOLD: Put our hands in our pockets so we wouldn't do for you, and give you a chance to do for yourself. And zip our lips so that you would have a chance to open your mouth and share your voice with everyone. And so it was like hands in pockets and zipped lips. Those were the two phrases the family was kind of like a little mantra we would try to remind ourselves to help you practice more and get better at.

JAIME ZAHID: I think I might steal that idea when I talk to families.

KATIE ARNOLD: Yeah. And it took a long time. And even still sometimes we have to remember that, and sometimes we fall back into answering for you when it takes-- because sometimes it takes you a little longer to respond, or to think about things. But I think that the process has really helped us become more aware of it as a family, which has been really good.

JAIME ZAHID: Excellent. And I'm glad that you all have recognized that and addressed it. Because I mean, it's a hard topic to talk about. But ultimately, mom and dad are likely not going to be there forever. And so it's so important for everybody's sake, for your parents' mind, for your quality of life in the future and for your siblings' peace of mind to know that you're going to be set up in a situation where we've done-- you've done, excuse me, the best that you can to make sure that Patrice is going to be happy, and well cared for. And obviously, things in place for when things do go wrong, because ultimately, they will and that's just life.

KATIE ARNOLD: Yeah. Yeah. One thing we did as a family also that really helped is we realized, as we started talking as a family, that a lot of us, like our parents, they know all the details.

They live and breathe the day-to-day details related to Patrice's life. They know all of her doctors, and medications, and all of those things. And as a sister, and even my other brothers and sisters, we didn't know a lot of those things.

So if there was an emergency situation, we would be just trying to figure it out in the midst of a crisis. So we put together-- my mom actually put together a day in the life of Patrice, and it's got all that emergency contact information. It's got a lot of good information about her likes and dislikes, any allergies, any-- and also just her basic routine of what a typical day in your life is, Patrice, that we can know all of those details.

Because I know some of it. I mean, we talk a lot. But I don't know everything. And so now we kind of have that document that we've shared with each other, and we update once a year, and we can kind of go to if and when we ever need it.

JAIME ZAHID: Excellent. Excellent. I love that. Can you share a little bit about how your family got started with planning for the future? And what was that first meeting?

KATIE ARNOLD: The first meeting-- so we really started planning for the future out of a sense of fear. Because I had heard in my work with other families and siblings a lot of families that hadn't planned and had all of these negative ramifications, and it scared me. And so I went to my mom. I was like, we really need to start talking about this and planning. So originally, it was really from this place of fear, wasn't it, Patrice?

PATRICE KEILING: Yeah.

KATIE ARNOLD: Yeah, and our family meetings, they began many years ago. And it was difficult because we were talking about some tough issues.

I remember at our first meeting, we quickly discovered that we all had very different assumptions about what the future would hold and we'd never really shared it with each other. So we went around and discovered certain things. Like Patrice, do you remember what our youngest sister, Maggie, was thinking back then?

PATRICE KEILING: Living with Keith.

KATIE ARNOLD: She thought you would live with our oldest brother Keith if something happened to mom and dad. And that was a surprise. What did you think of that?

PATRICE KEILING: Uh-uh.

JAIME ZAHID: That was a no from you? You didn't want to live with Keith?

PATRICE KEILING: Uh-uh.

JAIME ZAHID: What did Keith have to say about that?

KATIE ARNOLD: Well, Keith was surprised, too. He was like, oh, I'll think about it. But let's not make any assumptions here. I mean, he had a busy life. He had his own family, and kids, and career. And so it was really interesting just to hear and learn what everybody else was thinking so that we could slowly get a little more on the same page about it.

And it was tough because we didn't really know how to do it in that first meeting. We really were kind of talking about Patrice with her there and it was uncomfortable. Patrice, do you remember how you felt?

PATRICE KEILING: Upset.

KATIE ARNOLD: Why did you feel upset? Can you talk a little more about that?

PATRICE KEILING: About mom and dad.

KATIE ARNOLD: Yeah. We were talking about what would happen when mom and dad aren't there anymore. And so it was really difficult and emotional. And then we learned some other things from our parents, like my oldest brother Keith and I learned that we would become co-guardians of Patrice when our parents passed. So Patrice, did they ask you about that?

PATRICE KEILING: Uh-uh.

KATIE ARNOLD: Nope. Did they ask me and Keith about that?

PATRICE KEILING: Nope.

KATIE ARNOLD: Nope.

JAIME ZAHID: Surprise.

KATIE ARNOLD: So-- surprise. So it was really good that we were meeting and finally talking about it. And in my parents' defense, they had made that decision when we were younger. They had written it into their will with the best of intentions. And then life got busy and they just kind of forgot and assumed that it would be fine. I think that really highlights that in a lot of families, information is not always passed down or shared.

There are sometimes assumptions that are made. And so it's really important for families to just sit down and really talk about things. And we've started talking about is that the right thing for Patrice? Does she need a guardian in the future?

Let's look at all the alternatives to guardianship, things that my parents didn't have information about when they made that decision. We've been learning more about supported decision making, and what that looks like, and how to support Patrice in those ways. Because I think initially, the idea was my parents are doing it this way, and then if they're not there, they'll pass it on to-- it was for us, the two oldest brother and sister, to kind of step into their shoes.

But that's a lot of pressure for siblings. And we're not going to do it exactly like our parents. And Patrice, I mean, do you want me to become like a mom to you in the future?

PATRICE KEILING: Uh-uh.

KATIE ARNOLD: Yeah, and I don't really want to become like your mom. I love you as a sister and I want to still be sisters. And so we're kind of learning what that could look like for us to maintain our sister and sibling relationships in the future, even if mom and dad aren't there. I think that's something important for a lot of families to really try to get all that information to learn about the alternatives to guardianship, supported decision making, and ways to really help learn about what the person with a disability wants for the future.

JAIME ZAHID: Absolutely. And I think that your experience is something that likely happens in so many families, where when we finally do talk about it, there's a lot of surprises and a lot of realizations that we haven't asked anybody those obvious questions, and those questions that the answers to could have a huge impact on how to move forward.

So Katie, as a professional, do you have any resources or tips that you can share with our listeners about how to prepare for the future?

KATIE ARNOLD: Starting the difficult dialogue about planning for the future is so hard, though once you start, it becomes easier. So I mean, our family we started and we did a lot of it wrong. It wasn't perfect. We made a lot of mistakes along the way. But just getting started. That's just the first step, as difficult as it is.

I just encourage families to try as best they can to get that conversation started, whether it's to come together all together as a family and talk, or have one-on-one conversations separately throughout time. Every family can do it in a different way that works best for them.

Try to include everyone in the family that the person with a disability wants to include and really be sure to give everyone not only a voice, but also a choice in the process. I mean, in some families, the parents are assuming that the siblings will have a certain role and sometimes the siblings, they choose not to have that role, or it's not really the right fit for them. And that can be hard for parents to hear, but it's better to learn sooner and then be able to rework the plan, or think about other possibilities. And so really giving everyone a voice in the choice and the process is important.

In my work at the Institute on Disability and Human Development at the University of Illinois at Chicago, we've created The Future is Now curriculum, and it helps families plan for the future. It's an evidence-based curriculum that helps get families talking about and planning for the future. And we've just created a brand new virtual version where we do it on Zoom with families. And we can reach even more people.

It's been really fun and exciting because a lot of families don't live in the same place. Sometimes they're spread across the country, or even across the world. And so doing it in this virtual format different, family members can Zoom in from different locations and be part of the process. And so if people are interested in our future planning curriculum, they can contact me. And my email is just [kkeiling@uic.edu](mailto:kkeiling@uic.edu). It's K-K-E-I-L-I-N-G at uic.edu.

JAIME ZAHID: Thank you. Awesome, Katie. Thank you for sharing that. I think that sounds like such a helpful resource for a lot of people in that it's sort of a third party to help be that moderator in the situation that can be really hard and emotional.

And I know I've seen myself in some of my former work where that conversation is hard because people have things they want to say but are scared to, and they have feelings that they haven't even quite

recognized before. So having that third party can be super helpful in allowing some of those things to come out.

KATIE ARNOLD: Yeah. And what's also been helpful about the way we do our Future is Now curriculum is that there's other families and you get to hear and learn from other families, and what's worked well, and what hasn't worked well. And then we also really try to center the voice and perspective of the people with disabilities in the process. There's some times where there's breakout groups where just the family members and just the people with disabilities get to talk with each other and then other times where everybody gets together and gets to hear from each other.

And I know for me, sometimes if my mom says something, I'll be like, eh. But if I hear another mom say the same exact thing, I might listen better and hear it in a different way that will be more effective. So there's something about that learning amongst family that's been really valuable.

JAIME ZAHID: Absolutely. I think that's probably most of us. I think I'm guilty of that, too.

Well, The Boggs Center is grateful to both of you for being so open. I know a lot of the conversation today is pretty personal stuff. And so we're very grateful for you for sharing with everybody.

And we hope that people listening were able to take some words of wisdom from our conversation and hopefully have some good conversations with their families about their future and make sure that they're honoring their siblings as whatever contributions that they have towards their families.

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