## ACCESSIBLE PODCAST: March 7, 2024

George Gotto: Welcome to Accessible, the podcast that opens the door to disability leaders and their ideas. I'm George Gotto,

Amelia Reighard: and I'm Amelia Reighard.

**George:** We're glad you joined us. Accessible features interviews and insights from leaders in the disability field. By listening, you can gain knowledge for your own life, career, and professional development; in turn, share these ideas to help others learn from you.

Accessible is a partnership between the Missouri Leadership Education in Neurodevelopmental Disabilities, or LEND, and the Missouri University Center for Excellence in Developmental Disabilities. LEND's purpose is to prepare graduate students for future work in the field of developmental disabilities.

We hope you enjoy the conversation...

**Katherine Toler:** In today's episode, George and Amelia chat with Colette Canchola Cox, director of Missouri Family to Family, housed here at UMKC Institute for Human Development. In this conversation, we learn about the social consequences of a developmental disability diagnosis and the positive impacts of a strong peer support network.

As a mother of a son with autism, Colette shares her personal experience navigating the developmental disability system. Now, as a professional in the field, she is leveraging that knowledge to advocate for families in our state.

Okay, enough intro. Roll it...

George: Well, today we're meeting with Colette Canchola Cox. Colette, welcome to Accessible.

Collette: Thank you.

**George:** We are so excited to have you here. So, we'll just state up front. We know you because we work together, but we know that you are the director of the Missouri Family to family program. But before we really start with that, let's just talk a little bit about how did you get into the developmental disability field?

Colette: I kind of entered the field, I guess, because of a personal connection. When my son, Gunner, was about 15 months old, he started receiving a different diagnosis for developmental disability. His first diagnosis was autism, and I really didn't know a lot about it. So, I started learning about what autism was and what family support organizations were and kind of what was out there. And one thing led to another, and now I'm here.

**George:** Okay. What did you learn about autism or what was a shock to you? Like, what was that like to discover that?

**Colette:** Yeah, it was a shock to us. You know, my husband and I, neither one of us had ever met a person with autism. And he was one of the children that had a sharp regression. So, in some

ways that was good because we noticed really quickly that things had changed for him and we weren't sure what they were.

But his diagnosis process was kind of traumatic for us, I think, because we were having a wait list, and I was having to call back because I was getting all these tips from these more seasoned parents like "you got to call back and be really nice" and "just tell them you can come tomorrow if anyone cancels." And so luckily with their guidance, I had gotten him in. At that time, I think the waitlist was nine months long for a diagnosis; and we had managed to, in a two-and-a-half-month period, get first steps in place, early intervention in place, and then get a diagnosis.

Now, we were a little shocked by the diagnosis. We were thinking we were going to go and they were going to say... By then, we had already pretty much figured out on our own that he had an autism diagnosis, because he was experiencing autism. But we kind of expected they would say like, "yeah, he's got a little autism. He'll grow out of this."

[Everyone laughs]

Colette: In our minds, that's what we were thinking. Just give us a couple of appointments and be on our way and he'll be back on track. So, I think for us, the physicians, the team... we were really kind of shocked because they were saying-they were very serious and stern-and they said he had the most profound autism they'd ever diagnosed. And we were like, "oh, not what we thought we were going to hear today."

And so they were, like, explaining to us that he didn't have the capacity to learn, even with picture exchange systems, 40 hours of ABA... Just really, no matter what we did, he was not going to progress. And so, they just wanted us to know upfront to save our money on that and start thinking about adult placement for him and kind of preparing us that as he got older, he would become aggressive.

George: Wow.

**Colette:** And you have to think Gunner is 12 now. So, that wasn't that long ago. I mean, we're not talking like he got a diagnosis in, like, 1982. So, we pursued additional second opinions because we were like, "these people don't know what they're talking about."

Amelia: Right?

George: Was it that or were they just do you think-I mean, I can hardly believe that happened.

**Colette:** I think that they really believed that. I think they were really trying to prepare us. I think some ways, they knew that maybe our ideas around autism were not maybe accurate or something, and they were trying to kind of prepare us for it. Like, he's not going to grow out of autism.

George: Right.

Colette: Like, he's always going to experience autism. I do think that he did have... knowing what I know now, he was experiencing a lot of challenges to his day to day. And I think that they

did believe what they were saying. We were just, at that time, were like, "oh, they don't know what they're talking about."

Amelia: Well, it's amazing that you had the foresight to say, "I don't think they're exactly correct about this. Let's pursue a second opinion or go on our own and find something" instead of just accepting at face value what they were saying.

Colette: Yeah. It was a little tough, I think, too, at that time because, socially, some people did know what we were told and they just, you know, [told us] you need to tone it down.

Amelia: So, you guys needed to tone it down?

**Colette:** Yeah, with the supports and the expectations and providing him opportunities. Like, I think that some of that kind of resonated with people and they were like, you know, "your expectations for him, for his involvement in the community, for his experience is like-all that is a little much, don't you think?" And we were like, "No." Actually, we disagree.

And, you know, part of that is we kind of thought about the process. Like, what made that diagnosis so hard? And really what it was, was on that day in that moment, we were hearing that Gunner would always be the kid down the room in the basement classroom. Like, we knew that society was counting him out at that moment. And so, when we kind of processed that and were like, "okay, what are we going to do for our community, for him, for other kids, other parents?" Because that's really what's traumatic about the diagnosis.

You know, you hear a lot of parents say that that part is kind of traumatic. Well, if they're there, they probably know their kid's experiencing some sort of developmental disability. So, it's not that that makes it traumatic. It's the kind of reality of what that means for their child in society. I think, at least for us.

**Amelia:** This self-reflection you did on the diagnosis experience. Was that right after? How many years was it down the line from the diagnosis to kind of think through why that was traumatic? What will we do about it?

Colette: I think it took me a while to really process through that. I think at that time, what was really beneficial to us was connecting with the seasoned parents. You know, we connected with the Missouri Family to Family Resource Center. We got a peer mentor. We connected with some people locally, and those were the people that were like, "No, you're right. He should get to go to school." And so those were the people that really picked us up and really were our support system when nobody else really understood what that was going to mean for him. And strangely, enough, the people also didn't understand his rights.

So, I could call my mom and I could call some of these people I went to school with. Great people, but they didn't really understand disability rights. They didn't understand why I'm so fired up about whatever this IEP meeting was. And so, I really needed to have that other support system that really understood some of the things we were experiencing in our life as a family with a three-year-old, four-year-old and what that meant like.

Amelia: Yeah.

Colette: I remember his kindergarten transition. When he was in kindergarten, when we went to enroll, they were like, "Oh, he can't go here because kids with autism all go to this other program. He should go to his neighborhood school." We were like, "Well, he's here."

And I remember it was the other parents that we had met up to that point-so, from 2 to 6-that were really were supportive of us during that time because a lot of other people were like, "Well, maybe he would be better at the specialized program." Like "maybe he should ride the bus 35 minutes to the others school to the other side of town," because I think that they just didn't know enough about the topic at the time.

George and Amelia: Yeah.

**Colette:** And they didn't really understand those concepts of inclusion. They didn't really understand the research around why we were pursuing some of those opportunities for him, I guess.

**Amelia:** Right. And you were learning them from other families.

Colette: Right.

**George:** Wow. So, did you feel like once you sort of pushed the school to say "No, he you know, he does belong here. He legally has a right to be here." Did you still get pushback from the school or parents? What was that experience like?

Colette: Yeah. We got a lot of pushback, I think, from the district. We even got pushback from other parents. I mean, the reality of it is we had made friends with some folks, some other families back in preschool. And so, when we decided that wasn't the right path for our child, that also caused a little... I don't want to say "division," but some strange dynamics with some of those other families because they're like, "Well, that program is good enough for our kid." So, it kind of created a lot of different things. That year was rough for us, for Gunner.

I mean, because we were really doing something that wasn't being done in our community at the time. Kids with autism went to the autism program; and at one time, that was really great. And even local families fought lawsuits to have those programs in place. But we really didn't feel it was the best path for him. And so, it was an interesting time in his life.

I think my main thing, too, is... I don't know why I've always had this strong desire that Gunner would never feel like he wasn't allowed at any table and that he wouldn't always be welcome and that we would always push that for him. It's just like not okay for people to not include you in a decision or not invite you somewhere because you have autism. And so, we really started modeling that; and sometimes that was really hard and really uncomfortable. I'm actually not a very confrontational person.

So, some of those conversations, early conversations were really, really tough because I was almost retraining my brain, too, because that wasn't something that my husband and I had ever really experienced. And really just kind of helping people to take a look at learning about what able-ism is and then also examining their behavior as well. Like, I remember when he was in

kindergarten, they didn't want him to go to lunch with other kids because he moved his feet under the table and it was like a distraction and they're kindergarteners.

Amelia: What kindergartner is not shoveling their feet or any body part at lunch?

Colette: Yes. So, we would have to go and, like, point this out. Yes, he's verbally stimming in the lunchroom, but other kids are talking and so like... why is he the only kid who has to sit silently in the lunchroom?

Amelia: Right.

**George:** I mean, you would see, like, light bulbs go off for people. Sometimes they'd be like, "Oh, I don't know. Now that you mention it."

**Amelia:** Right. The expectation was different, but they couldn't even see or verbalize why.

Colette: Right.

**Amelia:** And I imagine those conversations didn't just happen at the school level. But maybe like with other relationships in your life like family or where you had to sort of advocate. Like, "No Gunner will be assumed capable like every other child in our family." Would that be true?

**Colette:** Yeah, I think so. I think one thing that we've been pretty fortunate about is I have a lot of siblings. My husband has a lot of cousins and they're all really close. And Gunner was kind of fortunate in one sense, that he's kind of like the in-between kid. So, it's like he kind of had these maybe five years where it was like Gunner time all the time for everybody.

George: Yeah.

**Colette:** And so, I think some of that made it a little easier for everyone to adjust and to learn about how to best support him, I think.

**George:** Wow. So, you're helping Gunner get through school. You're kind of breaking into that whole system. At some point, you became a professional within the DD service field. How did that come about or what prompted you to do that?

**Colette:** So, pretty quick. I guess it was a couple of years in, but my mentor that I was connected with had a nonprofit in my area. And so, I got really involved with that nonprofit and started doing a lot of the community relations stuff, hosting support groups and things like that. And it's kind of interesting. My family in general is very community organizer focused. So, it kind of came a little naturally.

So then, the director of a county board starts showing up to our support group meetings and I was like, "What is she doing here?"

**Amelia:** And by, "county board," you mean a developmental disabilities county board?

**Colette:** Yes. She started showing up and observing. Part of the support groups had kind of moved into an advocacy coaching type thing. And so, when a professional started showing up,

I'm like, I need you to leave because we're in top secret discussions you and you were not invited."

But what happened was she called... Well, she didn't personally call. She started having other people call and said, "Hey, we've got this job opening up for a family navigator to help families learn how to navigate systems, support them." I was also very outspoken at the time that navigating systems and the entire process could not be any more confusing, any less family friendly. Two people who are getting kind of just plunked in the system.

George: Yeah.

**Colette:** And so, I made no secret about things that I thought could be better. And so, I kind of feel like at the time, it was like "Challenge accepted. Make it better then."

[Everyone laughs]

**Colette:** "Figure it out if you know so much. If you think this could be done so much better, then you should come in and do it." I don't think I realized that at the time, but I always have these things that I process later. I'm like, "Yeah, she was probably like..."

**George:** The director?

**Colette:** Yeah. She was like, "You think it can be done so much better? Well, come in. Come and do it then." So, I started doing the Family Navigation program when Gunner was four and a half. It was his last year preschool and that worked out really well because it was still pretty flexible around his schedule.

So, that's how I kind of started from there. I worked that position for about seven years and then I applied to be the director of the Missouri Family to Family program. So, I was kind of taking some of those same concepts and moving to a more state level.

**George:** Yeah. So, can you talk about what the Missouri Family to Family is?

**Colette:** So, Missouri Family to Family is the statewide resource center. So, there are several different service offerings within that. So, information and referral can help families kind of figure out where to start. And there's systems navigation that's a little bit more of that coach-seeing and problem-solving. And then, there are things like the peer mentor program.

We also have Good Life groups, which are more of like an action-based support group that are... We call them peer learning collaboratives. So, we have an opportunity to talk about a specific topic. So maybe it's IEP planning, maybe it's transportation. So, we kind of take those hot topics that people call and need information over and host a group around those and help people think through their next steps.

**George:** When you think about sort of what's happening in our state, what are some of the hot topics, the things that, either parents are asking to know about or that you think they need to know about, that are going on?

Colette: I would say the hot topic... Our number one call-in item is childcare. Childcare, poverty, poverty type things. Families in particular of younger children don't have access to childcare because of their child's disabilities, because the childcare center is ill-equipped. And then, that's either turning a two-income home into a one-income home or it's turning a one-income home into no-income. And there's really nothing that these... I mean, there are resources and we help, you know, identify Head Start in some programs. But it really seems to be an issue that rising over the last, I would say, two years or so.

And it's really a pain point for families, I think for adults that are calling because we support people all the way through the life span. Like, a lot of adults are calling about their rights, about guardianship issues, about decision-making. I think those are probably the two biggest topics. I think if I have to recommend that families learn something, it would be to learn how to get connected, to learn where there are either support groups or Good Life groups or People First chapters, whatever it is that makes them feel. Like, they have a support system, whether it's calling us and getting a mentor. I think that is instrumental to people feeling... having the strength to do some of the things they need to do and having someone that you can ask questions to about whatever it is they have going on.

I think, oftentimes, people have navigated the situation before or the system before and they can really help give some of those tips because it really is individualized and complex oftentimes. Where you live, what insurance you have, how old the person is, what their diagnosis is. I mean, there's so many specific things that can make it hard to really figure out where to go for information.

**George:** So, what does a family do that has to go from two-to-one income household or one-to-zero income? I mean, how do they make it?

**Colette:** We made it out. It was very tough, you know? And that was another thing I didn't talk about. And our personal story was, you know, we experienced poverty for the first time, both of us, my husband and I, because I wasn't able to work. And I think that happens to a lot of families.

And I think it really causes so much stress because you've got added expenses, added medical expense, and a loss of income. And then, you know, especially for some families, I think that's where some of the frustration kind of comes in at times when they're trying to access systems. Even on one income, you make too much for state insurance for Medicaid. But you don't have the money to pay for these services.

And so, everyone's kind of saying, "you should sign up for speech therapy." Like, you keep hearing a lot of what you should do's, but you can't afford to do it. And so, I think that kind of causes some challenging or stress-I would say probably stress-for the family that's trying to figure out what really do they need to do to help their child because they think sometimes they feel a little powerless and trapped in this really bad situation and they can't figure out..."Where do I go first?"

**Amelia:** Who in our state is collecting these stories of families that are identifying these huge gaps, like gaps in early childhood care for children with disabilities? So that way, those that are

able to make policy decisions or legislative decisions are aware of where people are falling through the cracks.

**Colette:** So, in Missouri, I'm collecting as much of that information as I can. We have a process now where if we get so many calls around a certain thing, we start tracking and we kind of keep track of that. We have that process as a team. And then, we have a plan to deliver these sort of things to George, to Sheli, to different people. If the DD Council wants access, if the division wants access, whoever wants access to information so that they can plan.

I think where I'm starting to see a lot of gaps is in the community. There are gaps that are kind of outside of this DD system, where they're like, "Oh, the Division of Developmental Disabilities should do it." And really, they shouldn't because it's a community based program. So, I'm collecting it and I'm hoping that we can figure out a way to bring some of the community programs along. I used to find, at least in my smaller community, people just didn't know where to start and they thought it had to be perfect. I have to have a a registered nurse to support this child because they have autism or they have to have a one-to-one aid. Sometimes that's the case, but maybe not always. And so, I think it's kind of helping people have the courage to start somewhere.

Amelia: Sure, like educating the community organizations and community leaders about ways that they could support or step in. The childcare one is a great example. So many early childhood centers are privately owned. And so, for those that are making those decisions to just have some basic knowledge about disabilities and how they could support students with disabilities, maybe more would be open to like, "Oh, well, we could do that. We could support these kids to be in our center and not be so exclusionary" because they're not aware of their own capacity.

Colette: Yes. Something we did in my other community was we had identified that this was a problem. And I thought at that time, it was isolated to the smaller community; and so we were able to partner with the United Way Success by 6 and also Missouri Western at the time and created a micro-credential. So, any childcare worker for early childhood could had their education paid for for this micro-credential so that they could feel prepared to support the kids that have a developmental disability.

Also, it was kind of working them towards another program track. But for us, it really gave us a way to get some buy-in from some of the childcare providers because if you're a teacher, if you are in early childhood, you can get this for free.

Amelia: Yeah.

**George:** Does that still exist?

Amelia: Yes.

**George:** Oh, that's awesome. Is it only for Buchanan County?

Colette: No.

George: So, anyone can do it?

Colette: Anyone can take the program. I don't know the limitations on the United Way fund, but I would assume that's something that you could figure out other ways. We just had a great mom who was at Missouri Western who decided to put it in place; and then just a great neighbor... She wasn't really anyone's neighbor, but she was just a really good community member in United Way that was like, "What's happening with these families." And since their focus is to really think about poverty, it was really just having that larger conversation of we're creating poverty in our community. We have a lot of jobs that need [to be] filled, a lot of parents that are at home unable to work. But we could really help a lot of different things if we would provide this to the childcare workers.

**Amelia:** Wow, what a great model. That sounds like it could be used widely throughout the state and in other states, too.

George: Yeah.

Amelia: Yeah. I'm looking at George, like, a project? We just need to find some funding for it.

**George:** We quite literally work in every county with early childhood education in another one of our programs. Why aren't we connecting?

Colette: I don't know. We should.

**George:** Light bulb, right? We're going to do it. So, then you mentioned adults. So, you know, we do needs assessments every couple of years for either in partnership with the DD Council or the Division of Developmental Disabilities or whatever partner. And we have a few things that always show up as the greatest needs; and I'm just wondering if you heard about these things and what are some of the solutions you're encountering around the state.

But one you already mentioned is guardianship and supported decision-making? I mean, I was shocked to learn that Missouri, or maybe not, but Missouri is one of the leading states in the nation in terms of... and this isn't a good thing. We want to lead. But in terms of having people with disabilities, having a guardian other than themselves. But the other big one is transportation. And I'm just always baffled. Like, how is it that we live in this country with so many vehicles and we are having such a huge transportation issue?

Colette: Yes, on guardianship. That's one of the main ones. We connect with parents a lot. There's a lot of misinformation, I think that happens before 18. And so, I think connecting people and giving them a little more education around that seems to help for people that I think are over 30. Those are oftentimes the people that are calling, trying to figure out now how to get their rights restored. But we're trying to provide parents with more options, more ideas and more ways that they can be a participant and switch that advocating with not for role at 18; and that seems to really help.

Transportation does come up quite a bit. I keep asking questions around and I can't get any answers on it. So, one question I've been asking about is, "What if someone wants an accessible vehicle?" Because, you know, there's always like the "you have to have a job first before you find a vehicle." Like there's all these caveats all the time. But okay, what if someone wants to be

accessible transportation? Like, what if they want to be a taxi driver? Can they get someone to help out with that? And then, they can give other people rides.

Amelia: Yeah.

**Colette:** I think that transportation hasn't caught up yet with HCBS. You know, it used to be, "We're going to have OATS, we're going to have these companies and they're going to bus people. Everyone's going to go to the same school, everyone's going to go to the same job. Everyone's going to go the same church."

But as HCBS has really pushed for people to live in their communities and do what they want to do during the day, not have this kind of schedule. Like, people want to go listen to live music. They can go on a Friday night. And so, I think that our transportation infrastructure hasn't caught up with the idea that it's not going to be this school bus of adults.

George: Right.

Colette: Going to these programs. And there needs to be more options, whether that's public transportation, whether it's the way that vehicles are funded, whether that's more driving programs that are specialized. You think of, like, a mom who let her daughter start with a golf cart when she was like 12. She wrecked that golf cart like, I'm not joking, 43 times, but the mom kept getting it fixed and she made friends with some people that really could help her prepare because she knew, like, my daughter's going to have to drive, right? She's going to have to be comfortable driving. I need to really figure out what's happening with her driving. Is she getting distracted? Like, I need to kind of watch and figure out how to support her.

They figured it out. She does drive now, but I mean, it takes a lot of courage or I don't know. It took courage for the girl to keep trying to drive after she'd wrecked it that many times. She never got hurt. But then also for the mom to keep encouraging her to do it. It's not like, "Yeah, you wrecked this three times. We're done." And I always like to think about how many times... I'll just say this in case my dad listens, but like, how many times I wrecked cars and, like, backed up into stuff. Like, I remember when I was 16-ish, I backed up into the big red pole at the gas station. Like, how do I even do it? I don't know.

Amelia: Yeah, I mean, I've had some stories like that.

**Colette:** My dad was so annoyed. He was so mad; and he had the power to revoke my license. But then going back to that ableism piece and thinking though [things] like, do we sometimes hold people with a disability to a way higher standard?

**Amelia:** Right. You can never have an accident. You never run into the pole pulling out of Sonic if you were getting tater tots.

**George:** I have a 16-year-old daughter, and just the other day, we were backing out of our driveway. She backed out, put it into drive for the car to drive, and then just drove straight into a light pole. How do you do that? Why didn't you turn?

**Colette:** Did she have any response? Did you revoke her license?

**Amelia:** Did you say no more?

George: No.

Colette: He wanted to.

George: I was frustrated. So I totally can relate. Pretty impressive that she was able to go

through 43.

Colette: Yeah. It might not be that exact number but it was a lot.

Amelia: I can imagine though too for that mother that part of the motivation of sticking with it is like this is also my independence. Right? If you can learn to drive and transport yourself to places, you can have a life and I can have a life because I'm not being your chauffeur or having to organize your transportation. So, the motivation is also how does the needs of this individual impact the family system?

**George**: Yeah. I think that's exactly-like, even with my daughter, I want her to drive so that she can drive herself to school and I can get to work on time. So, anyway, I totally see this as one of the big things that I feel like we could actually solve if we can be creative, I guess.

**Colette:** I don't know if you guys saw about a couple of years ago. I was very excited for it. They were proposing-and I know what happened. I'll have to Google it. They were proposing some kind of like-I'm not gonna say the name right-but like some kind of massive train. Do you know what I'm talking about, George?

George: Yeah.

Colette: Do you know the actual name of it?

George: I just thought of it as like the super train from Saint Louis to Kansas City.

Colette: Yeah.

**George:** Do it, like, a half hour.

**Amelia:** Oh, one of those, like, high speed ones?

George: Yeah.

Amelia: A half hour?

**George:** Can you imagine?

Amelia: Would you get sick?

**Colette:** I don't know, but I'm willing to try it. And I think a lot of other people would be willing to try it to be able to get around the state.

**Amelia:** I mean, 30 minutes. You could work in St. Louis and come back to Kansas City or wherever.

**Colette:** Yeah, and especially for some-I know some families are starting to utilize the train and some adults with disabilities are starting to utilize the train in Missouri as a public transportation to get from city to **city**. And I think these are things that some people just don't think about.

Amelia: Right.

Colette: Like, I don't live in this city, but it's a better work opportunity for me. So, I drive here and you really think about when people are-like, they can't leave their community or [go] a five-mile radius or somewhere that their mom can drop them off, or a friend or neighbor. It really limits where they can work or if it's a good fit for them or where they want to work. And I always think about sometimes, like when you have to go through all your questionnaires as a family, it's like, why can't the neighbor drive them to school? Well, the neighbor has a job, too. But you could always give a ride.

**George:** I mean, yeah. You live outside of Kansas City and come into town. Like, what supports do you need and do other parents need in order to be able to do that? Like what natural supports or otherwise make that possible?

**Colette:** I think for employers, some of the things that I hear often are really looking at some of those remote and hybrid options that kind of eases some of the childcare, some of the different stressors or one more thing to manage. I think that's always a big one.

I'm trying to think natural supports. I've used a lot of natural supports over the years. Like, every Thursday, Gunner was two, I take him to like his equestrian stuff. So, it's like one hour a week from spring through summer that I know that I can get a hair appointment, like I can schedule something. It's like [when] my husband and I go out to eat the Thursday after work because we have that hour timespan to do that.

So, I really think for supporting people, really thinking about... And then also, if you're a member of a club, some sort of community-based club and you notice that people, whether it be families or you notice that people with disabilities are included, kind of taking up a whole inventory of like, is this accessible? Would people want to come, could they use an invite to come?

**George:** How do you see the Supporting Families-like, how do you see that going? Is there anything on the horizon that is important that people need to be aware of?

**Colette:** I think on the horizon for Supporting Families, there are a lot of opportunities for peer support training. It's not just peer support but really professionalizing these skill sets that so many of the parents and the people with lived experience have. Really taking that a step further and being like, you already know how to do this. We're just going to give you a little bit more training so that you can really make a difference in people's lives.

And that's what I see is on the rise or more of a trend nationwide, is that more organizations are beginning to hire people with lived experience to fill some of those information referral system navigation type roles.

**Amelia:** And Missouri Family to Family just recently put out a job posting for that very thing. Is that correct?

Colette: Yes.

**Amelia:** And what's the sort of vision for this individual in this role?

**Colette:** So, we're looking for a LifeCourse fellow. So, we are trying to identify a person with lived experience that can help... They'll learn about Charting the LifeCourse and they can really help us develop a leadership and advocacy training, really enhance what we have and help us to deliver that to other people that live in Jackson County, Missouri.

So, we're really wanting to find a person that lives in Jackson County that's 18 years or older. Do I do my job posting here?

Amelia: Yeah. Do it. This is your time.

**Colette:** So, 18 years or older to help us train... I guess "train" is not the right word. Provide some kind of community education to help people learn about self-determination. That's kind of the first starting point, is what is self-determination?

What type of choices should you be able to make in your own life? How do you do that? For some generations it comes a little easier. For others, not so much.

We're really just hoping to find someone with lived experience to help us enhance the training and also so we can learn from them, too. I mean, that's one thing I've learned over all my years in the field is I just learned so much from every family and every individual I connect with, and really hearing their successes and their barriers and just what their experience was. I think [it] really helps me. I sat at tables with others who might be making decisions to consider.

You know, I had my own experience. Gunner has his own experience, but there are thousands and thousands of people across the state that all have their own. And so, I always try to keep that in mind as we plan projects. So, I don't live in Jackson County. I [would] really love to find someone that lives in Jackson County that really knows the ins and outs and all those pro tips.

**George:** Yeah, I mean that seems to be the theme of what you're saying. Just connecting, like not letting yourself be or letting your family be isolated, making sure that you connect with your community in a whole variety of ways.

Amelia: Yeah.

**George:** Alright, Colette. If anyone wants to learn more about you or your program, how could they do that?

**Colette:** They can find us on Facebook. It's the best way, I think, if people are on social media. Missouri Family to Family, we have a website, mofamilytofamily.com, I think. And they can also

call our 1-800 number that'll be in the show notes as well. Also, it will make it easy to click the hyperlinks. But they can connect with us if they have questions about resources, questions about leadership, just give us a call and see what we're about and we will see if we can get you connected anywhere.

George: Awesome. Alright. Thank you, Colette.

Amelia: Yeah, thank you so much...

**Katherine:** Thank you for listening to this episode of Accessible. Accessible is hosted and produced George Gotto, Amelia Reighard, and Katherine Toler from the University of Missouri-Kansas City Institute for Human Development, which is the home of the Missouri UCEDD. Accessible is a joint project between the Missouri UCEDD and the Missouri LEND program, which is funded by the Health Resources and Services Administration of the U.S. Department of Health and Human Services through grant number T73MC00022. Episodes of Accessible are released every 2 weeks and can be found wherever you subscribe to your podcasts. Join us next time to hear more insights and ideas from leaders in the disability world.