

ACCESSIBLE PODCAST: March 22, 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 Karen and Candace Cunningham, amazing mother-daughter duo. The conversation covers Karen's role as Candace's mother, but also her first advocate. We learn about their journey through diagnosis into transitioning through adulthood and how Karen taught Candace to advocate for herself and get out of her comfort zone. We love these two and know you will, too. Ok, enough intro. Roll it...

George: Well, today, we're talking with Karen Cunningham and Candice Cunningham, mother and daughter. And this is a part of our Supporting Families series. So, Karen and Candice, welcome to Accessible.

Karen Cunningham: Thanks for having us.

Candace Cunningham: Thank you.

George: We're excited that you're here. So, you know, we usually start with one person. We start by kind of following your career or what brought you into the field. So maybe we will start with you, Karen. And so, how did you end up getting into the developmental disability arena?

Karen: Well, basically, it was actually giving birth to Candace. And so, I was pretty young when I had her, and we had some emergency situations that occurred at birth, which we didn't know exactly what would be in store for her. But because of that, the trauma at birth is what led up to the disability diagnosis that she received probably when she was closer to about a year and a half or two years old. Just not developing with the typical milestones and so forth.

And she was diagnosed with cerebral palsy. And so that's pretty much what brought me into this arena. I was 18 when I had her, so not really sure what was in store. Actually, I remember getting the diagnosis, then I went to a friend's house, and we actually pulled out the encyclopedia. So

that tells you anything-we're talking over 30 years ago- to learn more about it. And so, from there, I just wanted to learn more [about] how I could help her and make sure that she had the best life that she could possibly have. And that just kind of came naturally.

George: Yeah. So, as a young woman, what were you thinking and where did you turn when you first started figuring out that Candace might have a disability?

Karen: I'm probably like, why? Why us? Why me or why her? And as far as that goes, I had a couple of close friends that... I think I was in denial as she was progressing, you know, like, "oh, there's nothing wrong with her," you know, as far as sitting up and things like that. But then continuing to go to doctor's appointments and then getting referred to Children's Mercy.

Then, the Kansas City Regional Center is where they did a series of diagnostic testing and came up with the diagnoses that Candace has. So, what was I thinking? Just how I could help her, you know, be the best person she could be.

George: Yeah. So, what did the doctors or other professionals say to you about Candace's trajectory, life trajectory? Because we all know how awesome that has turned out. But what were they initially saying?

Karen: Well, after I had given birth to her, she was not supposed to make it through the night. They transported her from a Baptist Medical Center at the time to Children's Mercy. And I think they always give the worst-case scenario. And so, they did not think that she would survive; and if she did survive, she would not have a fulfilling life.

Not sure if she would walk or talk or just... they weren't sure. And I mean, obviously, just to see her now, you know, she talks so much.

[Laughter]

George: I never noticed.

Karen: Right? Exactly. So, they thought she wasn't going to survive, basically. And so, she's definitely proved everyone and everything wrong, obviously. Just to see her today and thriving, you know, more than most people I know, really.

Amelia: Likewise to you, Candace, because you're our coworker here at the institute. So, what led you into the field of disabilities professionally and how [did] you end up deciding to make a career out of this?

Candace: When I was a freshman in high school-I love telling this story-I did the Kansas City Summer Transportation Institute, which was here at IHD. And I could tell you that the week before it started, my mom was in Starbucks. You probably don't remember this. And she met this man, okay?

It was Derek Willis. And it was a week before school, and she was like, "I don't know what I'm going to do with her." Didn't want to go to summer school. So, I don't know how they... So, she

came out one day. “You’re going to do the Summer Transportation Institute thing.” I was like, “I don’t want to do this.” I was tired and shocked and shy. You probably can’t tell now. I probably cried a couple times and was like, “I don’t want to do it” and then at the end of the first day, I didn't want to leave. I love this.

George: Well, two things I want to say. One is what listeners should take is always listen to your mother.

Candace: Yes.

George: And then I just want to acknowledge that Derek Willis was at IHD for a number of years, but he's now the director of the UCEDD, University Center for Excellence in Disability in Iowa. So...

Candace: He's moved up!

Amelia: So, you’ve met Derek and Carol and some people from the institute and the rest is history. You stayed in touch.

Candace: Yeah.

George: And engaged through high school and then through college?

Candace: It's funny because we did the Community Health Vocal Training program, and we volunteered with Family to Family and you guys were at the old office on the fourth floor, and I was like, “I want to work here one day.” And they still keep-I mean you guys still keep me working.

George: Yeah.

Candace: But yeah. I’m very blessed. I feel like I'm giving back what I got when I was younger.

George: Yeah. Karen, obviously, we've known Candace and you for all these years. But why did you push her into these opportunities? Like, what was your thinking behind that?

Candace: I know why. To get me out of her hair.

[Laughter]

Karen: There you go. No, I just think it's so important to try different things. And I didn't really exactly know what it was at the time, but just hearing about it and I just think, like Candace said, she didn't want to do it. But I would always tell her, like, you at least have to go, see what it's about. You have to give it a chance because Candace is a little bit older now. She's in her thirties.

And back then, there weren't a lot of different programs for individuals with disabilities. So just to come across, like, the Transportation Institute, we're going to try this program. I'm like, “great, this sounds great.” I felt good about it. It wasn't too far from home. And so, you just don't know, and I didn't know where that would lead. But there was, then, the Youth Leadership Academy.

George: Yeah, that was my project.

Karen: So, I'm like, "Yep, you're going to this, too." And you know, if she had said, "Oh, I hate it," and whatever the reason might have been, then maybe we would have changed. But once she tried it, she really enjoyed it. And I'm like, that's so important just to continue to network and having those different opportunities and just, I mean, from there, you did, like, My Life as well. Missouri Youth Leadership, you know, it's just one program leads to another one. And talking to other parents like I'm always trying to spread that information to share because it's just so important to share those types of programs with others, I think. But yeah.

George: So, we all know that Candace made it through elementary school, high school. But then you did something that a lot of kids don't do who have a disability, which is you went to college. And so, I guess from both of you, what was that whole decision and thought process?

Candace: I will say she didn't want me to be a couch potato, you know.

[Laughter]

Amelia: Graduate to the couch. Yes.

Candace: But I knew that my parents went to college. My cousins went to college. That's the next step. Yes, it took me forever. But she always told me, "Once you get that degree, nobody can take it." So, yeah.

Amelia: Yeah, and didn't you just recently complete another degree?

Candace: Yeah. I got a master's degree in Clinical Vocational Rehab Counseling.

Amelia: Congratulations.

Candace: Thank you. What am I doing with it?

Amelia: That was going to be my next question.

Candace: Well, you're going to find out, George.

George: Well, so I guess going back, then, and you could start wherever you would like, Karen, but when we think about just family supports or supporting families, what were maybe some of the supports that you needed and your family needed or that maybe were the most helpful? However you want to frame that. Like, when Candice was young and growing?

Karen: Yeah. Thinking back when Candice was younger, I do remember meeting some other families who also had children with disabilities; and back then, they had started a family support group, and it was called EFFECT. So, we're talking 20+ years ago. So, that was my first interaction of other families who had loved ones with disabilities.

And those are some of the families I'm still in contact with. But we would just meet most the time at, like, a barbecue restaurant and just have a chance to talk and connect. And so, that's kind of where we would learn about other programs. And I remember hearing about Camp Barnabas. I was taking lots of notes.

And so, I think that's initially where a lot of the support came from, was just from other families and just listening to what worked for them, even though our kids probably had totally different diagnoses, different needs and so forth. But just hearing from someone that's been through it is what's so important. I remember coming in contact basically with Family to Family, and that was really another support program that was helpful for me where it didn't typically have to be a crisis. But just to talk to someone else who might have a daughter also with cerebral palsy, you know, that was real helpful for me as well.

I feel like nowadays, there's so many more opportunities and programs because back when Candice was in high school, yes, we talked about college, but I didn't really know what that was going to look like.

And the high schools didn't really support that, at least at that time, you know, to try to help figure out what the next steps were.

Candace: Voc rehab training.

Karen: Yeah, voc rehab was a tremendous support for me. And I know everyone has different experiences and opinions, but that was really helpful. I'm glad I read whatever piece of paper came home with Candice one day and she was going to meet with voc rehab at her high school and I was like, "I'm coming to that meeting, you know?"

So, going to that because I honestly had no idea what that meant or what that was about. I'm like, "Voc rehab?" She hasn't even got a job yet, let alone to get rehab back to-you know, whatever. So, I didn't really know what that was, but I'm a fan of voc rehab and I do try to share that with other families.

And sometimes it is about who the case manager is that you get, how hopeful someone might be. But I just tell people, keep pushing, you know, because they are there to help you. The end result is to get someone to work. But what does that look like for you versus someone else? And so, they were real supportive for Candice and myself because anything that helps her is helping me at least mentally, knowing that she's okay.

So yeah, hopefully that answers your question.

Candace: And they helped my sister, too.

Karen: Yes, and they helped her sister as well with schooling and getting to where she wanted to be.

Amelia: What advice would you give to other families just about your own journey, maybe from a parent perspective, but also from an individual perspective? Like, what does it mean to have the support of your family and to walk through some of the decisions you made, Candice, for your own life with the support of your mother and that dynamic?

Candace: The advice I give... Well, one [piece of] advice is, like my mom said, we might have the same disability, but we all have different lifestyles. But finding that support [is important]. I was lucky enough to have a mom. But not everyone is lucky enough to have a good mom. So,

finding that person that will kick you out of bed, not literally. But making you do things because they want you out of the house, but they see a brighter future for you if you do good. Does that make sense?

Amelia: Yeah, totally.

Karen: I think, you know, as far as when Candace was younger, yes. Giving her that gentle nudge to get out of bed and try different things because you don't know until you try. But letting her also make that decision for herself, that's something she wants to continue with because there were days where she didn't want to finish school or whatever the case may be.

But like talking through that with her, I think is more so than me saying, "Oh, you're going to do this type of thing." But allowing her to make those types of decisions and then just being there to be supportive for your family member or your loved one. So, yeah. But ultimately, I can't be the one to tell her what she's going to do because she needs to be able to live her life the way that she wants to.

But I think the fact that we do have a good relationship, that does help because I do think she trusts some of my opinions but allowing her to make the decisions really for herself because I'm not going to do the homework for her or anything like that. And that's what helps motivate individuals if it's the decisions that we all want for ourselves.

George: Yesterday, Candice and I were at this meeting.

Candace: Yeah.

George: It was a conference for the Missouri chapter of the Association of Intellectual Development.

Candace: Yes, that one.

George: And anyway, both of the keynote speakers talked about this idea of the dignity of risk. And one of the things that I've always been impressed with you, Karen, is you let Candace take risks. I know that you're always there helping her, but you do let her take risks.

Karen: With lots of prayer.

George: I was going to say that takes courage as a parent, I know how much courage that takes to let your daughter or son, but in this case, your daughter, do things that you're like, "Oh my God, I hope she'll be okay."

Candace: She let me drive to Columbia. And then the weekend before, we went to Jeff City, and I have narcolepsy and sleep apnea. So, I'm always tired, so I'm probably yawning but not because I'm bored, but because I'm tired. But I was tired. But she let me drive because she doesn't want to.

Karen: That's not true.

[Laughter]

Candace: And she always tells me, “I want you to do things without me because this is for you and your life.” She doesn’t always need to be doing it.

Karen: That is definitely true. But I do pray like a lot now, just like I do for her sister. But it is different, you know? But yeah, as far as driving, some people are like, “I can't believe you let her.” And I'm like, “What am I going to do?” Like, that's what she wants to do. Like, it took a little bit.

Candace: I drove her crazy more than I thought.

Karen: Well, I don't know.

[Laughter]

Karen: But there were definitely some times years ago that I was like, “Phew.” But I think we got through those times and she learned from some of those situations and, hopefully, she'll be able to share that with others to keep them out of harm's way. But I think she's learned just with growing up and just bumping your head against the wall a couple of times.

Candace: Well, the wall always went into me.

Karen: Yes, but I think it is important that she's able to get out there and make those life decisions. And she knows right from wrong.

Candace: But I don’t know right from left.

Karen: And she does stand-up comedy in her spare time if you’re interested.

Amelia: It sounds like what was really important for you, Candace, to be where you are now and do what you're doing was your own expectation, that you would follow the trajectory that everybody else would and your family's expectation that you also would follow that.

Candace: Yeah. I always tell people that I know I have a disability. But if I say, “Oh, I can’t do it because I have a disability,” they're not like, “Okay.” They’re like, “No, you got to do it. You got a master's degree? Go do it.” Like, dang it.

George: I think about our... One of our main audience groups are students who are just getting ready to enter the field, and they are, in fact, from multiple different disciplines, whether it's the different therapies like physical therapy, occupational therapy, psychology, social work, social work, special education, etc..

Well, you guys are both Linde grad students.

Candace: Yeah.

George: Okay. So, with the Missouri LEND, I mean, what kind of advice would you give Linde graduates, Karen, when you think about-okay, they're getting ready to go into the field and

they're going to obviously be engaging and encountering mothers primarily, but probably fathers as well. How would you say they should engage with you or what's the most helpful [way]?

Karen: As far as engaging, I think if we're speaking of parents and also with their children that are older, obviously, talk to [Candace], you know, talk to the children, see where they are and [what] needs they have as well. But just be open, like, don't treat us all the same. Meet us where we're at, you know, this type of thing. Just be supportive to those families and just know they're probably going through rough times, you know, different challenges and so forth.

I think programs like LEND are tremendously helpful because it does give the social workers and the doctors and therapists a little bit more training that they did not receive once upon a time. And from my understanding, [it was] very eye opening to walk alongside of families who are in the trenches, I guess I would say. And just to be supportive to them and, you know, hear them out, see where they're at and so forth.

George: So, when each of you think about... Well, we can look at it in a number of ways, but one way is maybe start with when you look at what's going on either in our state or in the field of disabilities. And if you put on your future seeing glasses, what do you think... Where do you think our field is going or what do you think our field needs?

Candace: Well, I'm thinking of one part of the Star.

George: From Charting the LifeCourse?

Candace: Yeah. And when I did my internship last semester, I got to work with individuals one-on-one on helping them get a job or stay [with a] job. And I will always hear, "I'm afraid to get a job because I'm going to lose my benefits."

George: Yeah.

Candace: I hate that. Finding what that person can do and finding... Like, do you need someone to do mailing or whatever? Maybe we can get this person to do that instead of just putting them into a workshop, where they make less than minimum wage. I have a big thing against it and I can't... But I know it's for some people but it's not for all people.

Amelia: I think we need to have Candace back for an employment series.

Candace: I would love that.

Karen: Well, and speaking of employment and benefits and things like that, that is a big thing. And she knows it because it's kind of hard to explain it to others. But I'm always fighting to get her medicine; and this week, it was, well, what was it from last week to this week? For one medication, it was \$1,000.

And so, because she does have Medicare also from when she was receiving disability, we still pay into that for her. But they changed her insurance from, I don't know, one company to another. And we fought at the end of last year trying to get it changed back because they had already pre-approved the medication that she needs in order to function on a daily basis.

And so anyways, they wouldn't approve the medication that she needed. And so, I'm going back and forth with the doctor's office.

Candace: Is that what was going on?

Karen: That was when we were making those calls at the end of last year before the 1231. That was the last day. And they're like, "No, we can't change it." It was just a lot of calls back and forth. But so, she had a lapse without any particular coverage there for a little bit.

But anyways, this week, we've been fighting to get her medication and it's \$1,000 to get the particular medication that she needs; and she was going out of town driving and I'm like, "Oh, my God. This is just going to be so bad." So, I'm like house payment or her medication? And that's literally where I was at and I was like, "Oh, my goodness."

So, I called the pharmaceutical that makes the medicine. And I was like, this is what is happening. And so they sent me this coupon code or whatever the case is, and there was a delay with the doctor's office as well. So I mean, it was just a multitude of several different things occurring. So, in the future, coming together like that would just be better because I don't even know how to leave these directions for someone else. If I were to, heaven forbid, pass away and somebody needs to help Candace get this medication.

But anyway, they gave me the coupon code and I ran back down to the CVS here because we go to the CVS here, even though we live in independence now, but they help us. So I would rather drive 40 minutes or whatever it is to get medication for her.

And finally, the code, it worked. I was like, "It did? It worked?" I was like, "Oh my gosh." So, I got her medicine and everything was fine. And then the next day, the doctor's office calls and the nurse is like, "I'm working on the medication," and I'm like, "Okay, thank you so much." Like, even though I wanted to be real nasty with her.

But I did put in the message and it goes to her and the doctor who was over the whole department... Here's this coupon in case someone else has the same issue as we did and so forth so that this will benefit them. But I guess kind of on a tangent here, but just bringing-like she wants to work. She can't work if she doesn't have this medicine.

George: Yeah.

Karen: And to get this medicine it shouldn't be this hard.

Amelia: I mean it sounds like a full time job almost tackling it all that. Yeah. And that impacts not just Candace's employment, but your own. And you're spending days trying to just getting a prescription refill. So, these are good issues to bring up.

George: Yeah. I just think of all the people... which I know, you know this, Candace, how fortunate you are to have your mother. But look at how many people are sitting at home because they don't have an advocate, whether it's a parent or some other advocate to call all those times and follow up. I mean, it's just... because you want to work.

Candace: Oh, yeah. Yeah, because I love bugging Katie and you, George.

[Laughter]

Candace: But employment is good for everybody because you get to be social, you get to make good money. Like, me working at IHD, I get to make a system change and local change and everything and take it step by step. Whereas, if I was at home, I'd be watching CNN and doing nothing. And yeah.

Amelia: Speaking of some of your work, Candace, like what are some of the things you do here at IHD that people could look into or get connected with, like Candace's Corner?

Candace: Yeah. I'm starting back Candace's Corner. It is informational interviews with local self-advocates and people that work in the field to spotlight local advocates. So, I'm going to start that back this May and I will interview Cathy Webb on some of her projects.

George: Well and you're like our primary outreach person for IHD. You might want to talk about that.

Candace: Yeah. So, my mom and I went to Kirksville. She drove because she didn't like me driving.

Karen: Don't take it personal.

Candace: We attended the...

Karen: The resource fair.

Candace: Yeah. The resource fair. I'm going to one in a couple weekends. So, I just take all the stuff that Kathy gives me and [help spread] IHD and all the wonderful things we're doing. We have a lot of problems, if you don't know.

Karen: Great programs.

George: We do. And so, I really appreciate that. I mean, you go all over the state, promoting our programs. So, that's wonderful. And you keep mentioning Kathy. I just want to give a shoutout to you, the producer for Accessible.

Candace: She's George's assistant, but mine, too.

George: She takes care of all of us. Okay. Well, so you've talked a little bit about some of the things you're doing, Candace, but if people want to learn more about either one of you or your work...

Amelia: We have a few links to Candace's Corner on the website or on social media.

Candace (to Karen): Where can they find you?

Karen: I'm probably driving Candace around somewhere. No, I'm just kidding. I'm on Facebook and Instagram and so forth. Karen Cunningham. I do a lot of resources for other families in the area and so forth.

George: Awesome. Well, thank you both so much for joining us.

Amelia: Yeah, it was a pleasure.

Karen: Thank you so much.

Candace: Thank you.

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.