

ACCESSIBLE PODCAST

Season 3 Episode 1: *The Family Factor: Impact on Disability Outcomes with Dr. Sheli Reynolds, UMKC-Institute for Human Development*

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: Hello, Accessible listeners. We're back. I'm Katherine Toler, producer of this pod. You'll be hearing dulcet tones to introduce our amazing guests. Another season is cooking; and we're excited to start off with a mini-series on family supports. In today's episode, George and Amelia catch up with Sheli Reynolds, associate director here at UMKC Institute for Human Development and director of LifeCourse Nexus.

Growing up as a sibling of someone with a disability, Sheli brings a personal perspective to her work in advocacy, systems change, and her development of the LifeCourse Tools framework.

This was a fascinating conversation about the landscape of supporting families of individuals with disabilities and how the context of the family is vital in providing care in all areas.

Ok, enough intro. Roll it...

George: Well, we're really excited to have Dr. Sheli Reynolds here with us today on the Accessible podcast. Sheli, welcome.

Sheli Reynolds: Thank you. I'm excited to be here and share information with you.

George: Great. So today, we're really excited to learn about Supporting Families and I guess I would just like to start with how you got into this field and how this became an area where you do a lot of your work?

Sheli: So, I bring both personal and professional experience to the field, to this job. I have a brother, who is 42 with a developmental disability, who was a foster child and came to us as a family [member] when he was about 18 months old and required a lot of additional supports. And as a family, we made the decision that we wanted him to be a part of our family. And so,

with that decision came a lot of doctors, a lot of therapists, a lot of special education, a lot of figuring out how to navigate the system; and I was pretty young.

I was probably in 5th or 6th grade when he came to our family. And so, [I] had the role of having this new member of our family as a young child. But [I] also was old enough to start kind of understanding a little bit of what was going on. As he got older, supports and services got harder; and so, as a family, by the time I was in high school, I knew I wanted to do something in the disability field. And so, finding an art program, a soccer program and a disability program were all of my 3 passions in high school; and so, I started to look at sign language interpreting, occupational therapy, and [in] my last month of high school, we were required to do a volunteer program; and at that time, my little brother was going on Monday-to-Fridays and staying at a place called St. Mary's Special School out of St. Louis. And it was horrific on our family because they would drop him off on a Monday morning and pick him up on a Friday. And so, that's where I did my volunteer [hours].

And I started working in the preschool and learned a lot about supporting people of all ages, learned a lot about the occupational therapy field and ended up, actually, at Rockhurst here getting an occupational therapy degree. While I was there, [I] stumbled upon UMKC Institute for Human Development, and never left. I've been here for 26 years. I was here as a student and had no idea that I was going to stay here, but I think the experiences of really being able to work on policy and systems change is really what has continued to evolve me in this career.

George: Yeah. And I guess we should just let everyone know that we work for you at the Institute for Human Development.

Amelia: That's true. Yes. It's fun to talk to a coworker today.

George: But before we get into that, I'd like to go back to like when you were in 5th or 6th grade and [talk about] your brother. And I don't know if he had any diagnoses at that time or, you know, what was that like for you as a sibling at a young age and maybe for your family to discover that he had disabilities?

Sheli: So, he came to us at 18 months old, and couldn't hold his head up and had no control over his body. Essentially, the doctors said that he wasn't going to live, take him home and just love him. He was malnourished and there were clearly some other indicators of something going on in his development.

And so, we just played with him like a newborn, even though he was not a newborn. And then, as he got older, it became evident that his speech was going to be delayed, he had muscle tone issues, and I think what was really, probably the hardest growing up is that he, I always say, utilizes behaviors as a form of his communication.

And so, that causes the most challenges, I think, with families when they have an individual in their family who you can't take to grandma's house without worrying about something happen. So, as a sibling, there are a few times I remember it was more about worrying about what other

people thought about you. There're some very distinct, potentially traumatic experiences that we've had, you know? I remember one time, vividly, taking him to the grocery store by myself. I thought I was a cool 16 or 17-year-old or whatever, and some trigger went off in that grocery store man. I was by myself and I had to block the aisles off. Everyone's staring at you, they want to help, they want to stare. And [I was] just thinking, "Well, this is hard;" and it's really hard not to self-isolate as a family, right?

George: Yeah.

Sheli: And then, I remember other times. I was pretty young. I remember we were at a Burger King, we were out on the slide, we were playing and Eric was just playing along and there were other little kids; and all of a sudden, they started, like, talking about him and pointing at him and saying things about him. And, like, we didn't understand that. We were like, "What are they doing?" It hurt, right? And luckily, Eric had no idea. He didn't share.

So, I think some of those things as a family member, it really is the attitude of the community.

Amelia: It's interesting, the medical diagnosis or the medical perspective that they had of your brother when they first placed him with your family. [How] do you think your family's approach or expectation on your brother's life and development impacted his trajectory? Because he obviously didn't pass at 18 months.

Sheli: Right. You know, it's kind of funny. So, fast-forward to Charting the LifeCourse or Supporting Families, which is what a lot of the body of my work is, we weren't a diagnosis-driven family; and you really are just trying to survive or create a quality of life. So, you're like, "Oh, friends. Let's go do something. We might go on vacation. We want to do things."

So, we weren't thinking about the diagnosis and we kind of laughed because we had many foster children growing up and you just brought them in and you loved them. You didn't know how they were going to go, how long they were going to be with you. So, we like to tease ourselves and say that some of Eric's adult nuances are because we just loved him and maybe didn't give him all the natural consequences he should have had as a child because we probably just let him do whatever he wanted to do. Because it was like...

And as you know, I have a twin brother and an older brother. So, we were older; and so, he was the center of our world.

George: Right.

Sheli: And so, you don't really think about it. And I don't know. I obviously didn't experience being confronted when a child is born with a diagnosis. So, I mean we knew there were going to be additional supports needed, but I don't think you think about it. You just think that he came into our lives and he was supposed to be in our lives and we had no idea [of] the hurdles we were going to face as a family, which is probably good that you don't know.

George: Yeah.

Amelia: Right, yeah. Well, it seemed like you sort of approached it from, as you said, “We’re going to go on vacation. We’re not going to not go on vacation. We’re not going to not do these things. We’re bringing Eric along for the ride.” Right? And that impacts his quality of life.

Sheli: Yeah, and this is probably what every single family will tell you across the entire life span is that those little day-to-day activities that you do as a family seem really natural, but we had to put a lot of thought into it. We were like, “Did we give him enough time to prepare? Are we going to create some sort of incident?” Or “did we tell him too soon because he’s going to ask about it for 2 hours?” Or “what’s your exit plan if you go somewhere and something happens?” So, you are constantly planning for the “what if” as a family. And so, that becomes your new reality.

George: Right. So, does that carry into all adults, including Eric? Like, does that carry into your planning now?

Sheli: Absolutely. It doesn’t go away, right? Because Eric still requires 24-hour oversight so to speak. And so, he does need supports with people understanding his communication style. He is very fidgety; he loves to get himself into very innovative situations. His favorite thing to do is to tie things up and use chains and keys and connect things; and so, all of a sudden, things will be very connected together. Your cars will be connected together, and you can’t get them apart.

So, you have to be aware of the environment, to be aware of something that he’s going to find creative in the environment; and you also have to be very cautious of, or be very mindful of his characteristics because you can see when something is going to switch and you just got to be really prepared to get up and leave or figure out how you’re going to distract him.

George: Right.

Sheli: I think for my parents, who are now aging, it’s harder and harder because they don’t want to leave that to someone else all the time. So, it’s finding both staff and siblings and others that... Mom and dad can only relax if they trust the person that he is with, because they can never fully relax even when he’s not around because they’re worried that those little things that someone might not be ready for might happen.

George: Yeah. So, you became an occupational therapist, which you are not practicing now. But how did growing up with Eric impact the career decisions you made and where you are?

Sheli: [I] honestly thought I was going to be a graphic designer. I mean I honestly thought that that was what I was going to do.

Amelia: That actually makes a lot of sense. I didn’t know of this art background that you have, but so much is coming together for me. Like, “That’s why she’s really good at visuals.” I may or may not have a logo design in my bag that I was like, “I’m seeing Sheli and George later. Maybe I should have them weigh in on this.” So, yeah. This makes a lot of sense.

Sheli: Yeah, I think that... I don't really know... You know, [when] I started going to Rockhurst, you don't know what you want to do when you're a Freshmen in college. So, I did what everybody does that doesn't know what they want to do and I went into psychology, right?

And then it was like, "Wow." Rockhurst had a physical therapy and occupational therapy degree program that you could do in your 5th year, and that was pretty cool; and I didn't really understand what occupational therapy is. I don't think most people understand what occupational therapy is. But it really is this title, right? It's really about-I always tell people-it's your everyday activities of daily living. Even your instrumental ones, your executive functioning and your bills and activities and that kind of stuff.

[I] just kind of went through it; and it's funny because I got out, and my dad is like, "So, you finished school and you're never going to use that degree." And ironically, I would say almost everything that I've done at the institute has actually leveraged that degree without really thinking about it. I think it serves as an amazing foundational degree. I actually think it should be a pathway for more professionals in the disability field because you might not want to provide direct therapeutic occupational therapy.

But I think the fact that if you think about the framework that has evolved, it's all about thinking about what the person wants and driving that; and that's Person Centered Practices. And occupational therapy has always said, "You might need all of these things done, but that is not going to be your treatment plan. Your treatment plan is what you want to work on." So, it's the underpinnings of everything we're moving the disability field to.

George: Yeah.

Sheli: Yeah, [I] started doing that and a lot of occupational therapists from Rockhurst would come over here and do internships at the UCEDD here. And so, I came along and started doing that under Dr. Chris Rink and learned about aging in disability and the rest is history.

George: Yeah. Thank you, Dr. Chris Rink (15:23) for bringing Sheli in.

Sheli: I always tell people that are talking about going into the disability field, or even if that's not the field you want to go into... When you're in college or even high school, you just think of the big careers, you know? "I want to go into business, I want to go into this or that." I mean if someone said, "Oh, you're going to go work on systems change and policy change, and you're going to do it through the lens of research," I'd be like, "I don't understand anything you just said to me." Like how do you get on that trajectory? You have no idea, right?

And so, I think the thing that is awesome about working here is that every single day is different, right? One day, I could be working one-on-one with families, impacting their plans and thinking about how to help them support their loved ones. And then the next day, we're working on national policy change.

I think the background in occupational therapy allows for both that sort of person level all the way up to that social and psychological level of policy change.

George: So, I know that when, you know, given all of our history here, I know that when you started, you were in an individual advocacy program, [then] moved into our Family-to-Family Network. So, let's start talking about that. How did you get into that and what was that [like]?

Sheli: I think being a sibling has brought a really unique perspective and advantage to where I think our field was as I grew up in this field. So, the Family Support Movement has been evolving for many years, right? The disability field wouldn't be here if it weren't for families. We're really pushing in the 30s, 40s and 50s for some sort of programing. And then, you really look to the '90s and you really look at the Turnbull family and some of the other greats around family support and that was really looking at how are we supporting families; and at the time, it was really about how are we supporting families so that they don't move their children to institutions.

So, there were a lot of programs and policies that started in the '90s; and if you think about the early '90s, well late 80s, that's when our Home and Community Based service waivers, which was a form of family support without calling it family support because it really allowed people to keep their loved ones in the community, in their home. So, between the Home and Community Based waivers and ADA passing, because they also say the other form of family support was when your kid could go to school. And so, I just remember going to this big national meeting that was hosted at KU, the Beach Center over there, and they were bringing together-

George: I think I was at that same thing.

Sheli: You were.

George: But we didn't know each other then.

Amelia: That's wild.

Sheli: And they brought together national leaders around Family Support, and then they brought together national leaders from the Self-Advocacy movement. And there was a big, huge fight between the two movements. And it was amazing to look back and be a part of that historical movement because... I always talk about the fact that... think about the movements as if that was a teenager, right? You got to express your own independence and launch your own personhood from your parents in order to figure out who you are. But that doesn't mean you aren't part of the family.

And so, I think it was the Self-Advocates really expressing that family voices are very important. Their needs are very important but you can't do it without the context of the person.

And so, for me, I was in a very interesting position because I was supporting People First of Missouri and I was a sibling. And so, it was kind of [like] parents against children, right? Adult Self-Advocates. And so, as a sibling, you were in this sort of neutral position because you could

experience it from both sides, right? You could both be the advocate for the person and you could also see where the parents [were] coming from as a family member. And so, that was really good.

Fast-forward to 2011, when I was asked to be a part of the leadership team to bring together and create another one of those summits, we very intentionally recognized that we needed to address that elephant in the room. And that's where the phrase "supporting families" came from, and that's where the phrase "supporting the person withing the context of their family" came from.

And I really think it's... For probably 7 years, I supported the People First movement here in Missouri and nationally; and I always said that probably was some of the greatest training and experience that I ever had. And I always said, to be able to rub the elbows and be in the life trenches of people with disabilities, in cars for hours, driving all over the state, all over the country. And I always [like] listening to the underground stories, you know? Not the stories about the Person Centered Planning meeting, but how they're sneaking out and have boyfriends and girlfriends and they want tattoos. [Those] real life stories served as an underpinning to, I think, being able to start thinking about supporting the entire family because it's every single family member; and I think that's where the National Agenda for Supporting Families is.

And you asked earlier, why did I tell you to switch from Family Support to Supporting Families. It was very intentional in 2011 that we did that. Family Support became known that our country is a program.

George: Right.

Sheli: It was also very identified with that sort of child welfare system. And so, it didn't have a lot of meaning anymore in the disability community. Or it became a program meaning only this group of people can get this family support service.

Amelia: Like very specific to eligibility criteria.

Sheli: Yeah. And so, when we met in Wisconsin for the National Agenda of Supporting Families, and we brought together 35 national leaders from around the country, we said, "We don't have a better phrase to call it, but we don't want to call it 'family support.' We want to create a national agenda on supporting families," because the idea was that it's not about a program. It's about creating and providing anticipatory guidance to families and not just being reactive and getting certain families or caregivers into these programs.

And so, that's really when we flipped the language, and you can see it now across the country.

Amelia: So, practically speaking, especially knowing how many students may be listening to these episodes, and you're a clinician, or you're a case manager and you're working with an individual. Why support the family and what does that look like when my job deliverable is to

work with this individual to make a case management plan, but they're embedded in the context of their families?

And they might say, "Well, we don't have a program for families here. I don't have anything I can offer you." But what actually could they offer?

Sheli: And I think that's the big messaging that we are doing around the country. So, the first thing I always tell somebody is, "There is no way to remove the genetics of my family. So, you can't know me and know what I need if you don't know my family and my genetics." Right? And maybe I don't even know who my family is. But my genetics, the color of my eyes, the way that I look, the way my health is is really [from my] family.

You also have to think about the context of the family of the environment that I'm coming from. So, if I either live or don't live with my family, did I grow up on a farm? But the other point that I make specifically about people with developmental disabilities is that probably 85% of people with disabilities live at home with their family throughout their entire life span. And so, to ignore the family unit and that family environment, you can't support that person.

So, you could create the greatest treatment plan, or the greatest person-centered plan, they're going back home to their family. And so, if that's not in there in the cards or they don't know understand it and... You know, I use 2 examples when I'm homing in on this.

The first example is, OK, what if I'm treating a 13-year-old with autism and I ignore the fact that maybe mom is working two jobs or has a newborn at home or is taking care of her mother, who is sick and living in the home? So, you think as a clinician that your plan is the most important plan to that family's life. That is one of many plans. Or mom is too depressed and can't get out of bed. So, she's going to be your implementor of your plan.

The other [example] is I work a lot over the years with vocational rehab counselors. And I would say, 5 or 6 years ago, they were like, "the family is not our primary beneficiary, and quite frankly, we don't need to interact with families after all." And we said, "well, how do you think you're going to get this individual to want to have a job, to have expectations to have a job, to get to a job?"

So, it was interesting [to see] the federal push, looking at the Workforce Investment Act, and transition planning, to really think about that transition age. I had a team of adult employment providers and voc rehab councilors sitting around and they said, "We got this totally figured out for this person. We figured out how he's going to get there. We figured out what job he is going to be. We found the employer." Everyone was excited... We forgot to tell the family, and the family is like, "Nope, they're not working there."

Amelia: Oh, wow.

Sheli: And so, you can't ignore the impact the person has on the family or that the family has on that individual. You have to also recognize that they're trying to balance that. And then sometimes, it's overbalanced towards the family more than the individual.

So, you have to figure out how to facilitate that.

Amelia: Right. That's speaks a little bit to the conflict between the two movements. I'm curious. Are there still summits where family members and self-advocates come together like that? In the past 10 years, have you seen those tensions relieved as the language has changed? Maybe here in Missouri or nationally? Do you think it's still a hurdle that is being overcome?

Sheli: So, I still think it's a big hurdle that needs to be overcome. We had a "10 years later" summit in 2022 up in D.C. And so, we invited a number of the same self-advocates from the 2011 summit as well as a number of those self-advocates were actually at the Beach Center summit and then some other self-advocates. I think that it's always going to be the "nothing about us without us." And I think as a whole system, we have to get better at that.

I think that people default and think it's easier to have members there and say that the lived experience is represented. And I think that... You know, Julie Petty (27:44) is a really good friend of mine and she's really pushing, "how do we intentionally teach parents how to be allies?" And I think that needs to be taught in the sense that... You know, your child is 18. Even if they require supports, how are you helping them have their own personhood? How are you helping them have their own voice?

And I typically angle it, especially when I'm working with older families, as, "your voice is going to be there." So, either you need to help them have a voice or help those around them help them know that voice, because in the end, it's going to harm them.

George: I just want to go back and say that Julie Petty (28:28) is at the Arkansas UCEDD and is a great partner of Sheli's and of ours.

Sheli: Yeah, and then the other thing I want to say is... So, in the '90s, they funded a lot of family support programs. It's in a lot of state legislations. And then, in the early 2000s, everybody wanted to fund self-advocacy. Now, you fast-forward to 2020, and nobody wants to fund either of them. But they keep saying how important both of them are.

So, I think that's important; and I think that the other thing that is really important to keep in mind that I appreciate, fast-forwarding to 2022, is the diversity, both the cultural diversity, the language diversity, the diversity of disabilities. But most importantly, those self-advocates are families themselves. So, they're parents, they're married, they're spouses; and I think that part of the equation is often missing when you are talking about supporting families.

George: So, Sheli, one of the things that people around the country know you most for is your work in developing Charting the LifeCourse framework. How does that work influence your commitment to supporting families?

Sheli: So, after we had Wingspread in 2011, we received a federal grant in partnership with the National Association for State Directors on Developmental Disability Services to create what's called a Community of Practice, where we started in 6 states, and we said, "We're going to bring stakeholders together and we're going to figure out what state policies need to be written, what practices need to be developed to truly support families across the lifespan. Because what we found was there's early childhood programs, there's aging programs but there's really nothing for families of 18 to 62-year-olds; and that's the longest lifespan. So, you have families talking about how their children have graduated to the couch. So, that's when families need the most support.

So, that Community of Practice is still going strong. It's now state-funded, it's not federally funded at all anymore, and it's in 22 states. And when that Community of Practice started, we went through and did an environmental scan of all the family-centered principles that existed along with the values and principles of the DD Act. We pulled out all the Family Support stuff, and we started to use those principles for our Community of Practice. And so, we adopted those principles as the National Agenda for Supporting Families principles.

And full circle back to graphic design, I was asked to go around the country and present on those principles. Well, I saw those principles as colors and images and icons. And so, [I] made PowerPoint slides, and the states that we were working in were like, "Oh, those are really cool. Make that into a worksheet." So, I would make it into a worksheet.

And more importantly than the tools themselves are the principles. And then, the other thing that happened nationally is you've got Center for Medicaid Services that really started to create policy around Person Centered Practices. So, that was kind of happening around the same time. And so, again, we kept pushing that supporting families was about larger systems change and not just a program, and that it was about changing what we would say is the DNA of the entire service system.

So, I'm not just training Family Support workers. I'm training every case manager to think differently about a family. I'm looking at every policy to impact both the person and the family. And so, those principles evolved into what I considered person-centered and family-centered principles.

That was the other thing that was happening, was there was this kind of power struggle between people that were pushing for person-centered practices and those that were pushing family-centered practices, saying "neither could exist together." And Charting the LifeCourse actually integrates those together and really says, "you can support the person in the context of their family that doesn't override that person's self-determination and their independence." It actually fosters it.

And so, the Charting the LifeCourse framework has now evolved to almost being complimentary or really even pushing person-centered thinking. It's what we call a more human-centric framework or a more citizen-centered framework.

Amelia: Not only that, but the tools are so great and helpful, I think, for vision planning that we use them for advisory groups, strategic meetings; and we're thinking about projects and I've seen them and used them in my projects. So, they're neat tools that get people on the same page to think through things together. How can people who are not familiar with Charting the LifeCourse tap into that and learn about how people are applying the tools?

Sheli: So, lifecoursetools.org is a website that all the tools are on. There's videos on there and there's opportunities to get involved on there. I think that when we designed the tools, and going back to what you just said, they were always intended and developed by individuals with disabilities and their families. They aren't disability-specific but it was always written in a way that recognizes the person. Like, I go back to our core belief that it's about all people have the right to live, love work and play in their community, because I felt like sometimes in the disability field, we created a different core belief for people with disabilities and then that just created the segregation again. It created a whole specialized route of programs for people with disabilities.

So, the tools, I think, are really cool in that they're designed to help the person think about their own life. But I can use that exact same tool to do transformational change for legislation or for program development or needs assessments. So, for us, it's about creating a language that every person in the system can be a part of because that's, I think, the other thing for individuals with disabilities and their families. We have System Speak, or we have Professional Speak or we have Research Speak; and they can't participate. And the LifeCourse framework can create plain language that all of the different players can communicate with.

Amelia: And that National Community of Practice you just mentioned that started with 6 states is now 22?

Sheli: Yes.

Amelia: 22 states. Wow.

Sheli: So, it's in 22 states and those states continue to do 2 things. They all use the Charting the LifeCourse framework for that larger systemic change. But then we are also constantly pushing them to say, "What are the specific program elements for families?" Right? Respite, information, navigation, you know? Really thinking about older family caregivers. What are things families actually need as the primary beneficiary in addition to how are we using the LifeCourse to change the person-centered practices? And to think differently about things, I think you need both.

So, the Community of Practice is really creating these networks all over the country that are now crossing the systems. So, a number of those systems have crossed into aging, early childhood. A lot of those systems are now taking the Charting the LifeCourse into the school settings and thinking about it for transition planning.

I can't tell you how many people have said to me, "Wow, they're going to use the exact same tools and language in early childhood so that when my kid goes through IEP, we're going to use the same one. And then, we're going to get to 14 to 26 and use the same for transition planning." And, like, in St. Louis, they also use it for their adult person-centered plan. Or they're also using it for post-secondary transition to college. And so, I don't think you feel like you have all these different segments of systems that you're interacting with.

George: Yeah, exactly. I'd like to go back to where we started, which is with your family and your brother and talk a little bit about aging. So, you're aging, he's aging, your parents are aging.

Sheli: Well, I'm not aging.

[All laugh]

Amelia: You're mistaken, George.

George: I guess I don't know what the question is other than what advice [do you have] or how is that impacting you all or what advice to you have for other families who are all maturing?

Sheli: Yeah. You know, it's really... We are, as a country, have an aging caregiver issue regardless of disability, right? And then you add the layer of having a member in the family with a disability. And there is a lot of thinking that has to go into that and oftentimes, when you're working with families, they don't want to think about what going to happen when they're gone no matter what age they are. And so, how can we help families and professionals interacting with families approach that conversation in a respectful way? We're kind of nudging them in that direction.

I think my parents, and I don't know if this is because Eric was adopted, but my parents always recognized no one's family members should dictate and dominate the family unit; and that we all in any given time might be the center of the needs. It might be because my dad has health issues or something is going on with me or my family. And so, we always talk about, like, Eric can't always be the center. The universe can't just revolve around him.

George: Wow, that is so true.

Sheli: Right? And so, are there things that dominate the family? Absolutely. But then you also have to balance the other siblings' needs, my parents' needs to have their own life. And so, I remember at a very young age, I was always like, "Oh, I'll just get married and Eric will move in with me." And my parents were like, "Yeah, no. That's not going to happen."

And I think that there's a couple of things that happen in families. There's the family's desire, as siblings or other members of the family, to do that, not recognizing some of the sacrifices they might have to make for good or bad, right? Then, there are also families that just assume that's going to happen. And I remember my parents saying, "I don't want you to be forced into that choice. If that's a choice that you and your husband [make] and you're in a life stage where you want that to happen, [then] we want to have everything set up for that."

And so, they started at a pretty young age with Eric, making sure he had a special needs trust, really thinking about his services and supports just like they did for each of us. And now, they've moved Eric out to his own home in his early 20s and it was really hard on my parents. But they knew he had to do it eventually. And so, if they could start doing it while they were still around and while they could still support him, to understand that's his home, his life, you know? I was just with them this weekend and they're like, there's nothing greater for our family than [when] Eric comes home every other weekend, when on Sunday, they went to his room and all of his stuff is packed up and they're like, "What are you doing?" He's like, "I'm ready to go home," and he stopped calling his home "home." And it sounds small, but as a family who is aging, who's kind of concerned about their own health... Because if one thing happens to them, that whole infrastructure falls apart.

And as a sibling, if something happened to my parents, I'm not only either supporting or grieving [for] my parents. I'm having to figure out how to plan for Eric. What we know statistically and what we know happens in the states is that when that prep isn't there, that person typically gets removed from wherever they [are now] and get thrown into an environment that isn't really the best fit for them. But no one knows what to do in that crisis situation.

So, you have to figure out how to keep getting those families to think about those little pieces.

Amelia: I think that's hard for anyone to think through the steps to help my children become independent, [to] think about our family unit as they get older.

Sheli: Well, I'll tell you. I think one of our most powerful Charting the LifeCourse tools comes from this conversation. And I went and met with about 5 or 6 families in St. Louis. They said, "Will you come plan with us? I think it's time we start thinking about the future." And the average age of these 5 people was probably 95. They were very old.

And I said, "Oh, okay. What are we going to plan about?" And so, we now have this principle called-it's where you think about caring for you or caring about you. And so, when I first met with these families, they were like, "Okay, we got this all figured out, Shel. We've got their special needs trust. We've got their housing figured out. We know what provider they're going to use." And I said, "So, who knows how they like to celebrate their birthday?" Like, who's their best friend? Who knows their childhood memories? Who's going to show up at the doctor's office and advocate for them?

And it was dead silent in the room. They were like, "Hold on, that's not what we need a future's plan for." And I said, "It absolutely is" because all those other things, that provider could go out of business, the rules on HCBS waivers could change. There's all these things that could happen to all those things that you think are planned. Because not any one of our lives stays the same, right? You don't stay in the same home, you don't stay in the same job. So, those things aren't static.

I said, "You have to figure out the people in that person's life." And they couldn't. So, we had this tool where we say, "Think about who loves that person. Think about who can advocate for that person." Who's a person who knows their childhood memories? Or who just loves them unconditionally?

And that is a really difficult exercise for families. But what I tell people is to start now. So, I could be having that conversation with the parents of 3-year-olds or the parents of 60-year-olds. Start writing those dang names down because, 1) you probably have people in your life, but they don't know you think of them in those roles and you don't know that you might need to engage them or tell them you're thinking of them in those roles.

But getting someone else to care for your child, especially if they are quirky or have behaviors like my brother, maybe they have some physical things that you're worried other people don't want to... you know. So, you have to try a little harder on identifying the people on the aging side of the equation.

Amelia: Right. That's something that... I'm thinking of a Charting the LifeCourse tool. I'm thinking of the Star. I think it has helped me out a lot. I'm watching my own parents kind of go through some of these caregiver challenges. My aunt has a developmental disability and she's deaf and her parents have passed and she's moved in with my parents; and they're just now thinking, "We didn't really think through what we will all do in our 60s."

So, I'm watching them grapple with this and think through it, and I'm thinking of the Star and like, "Let's think of all the community supports," because they're looking at "what is she eligible for?" And I'm like, "We have to think about all the things" like "could you get a house cleaner now so you don't have to worry about cleaning your own house;" and just starting to think about all the things that support them in what they're doing as a caregiver outside of what paid services could I get. So, it's just a neat tool and it's been so enlightening to take that knowledge and say, "There's actually a lot out there. We can think really creatively."

Sheli: Yeah, so my mother-in-law is 95 and my father-in-law passed away last year. And she lives in St. Louis. We live in Kansas City. And she asked us to put cameras in her home because she doesn't want to move out. So, she wakes up in the morning and she turns her camera on and says hi to my husband and checks in and says goodnight; and it gives her a sense of security.

Not everyone wants that, right? But it allows us to have those different supports. A \$200 system from Costco is supporting us to do that. So, there are different ways to provide that support. And we have a caregiver challenge both in the sense of paid caregivers and family caregivers. And not everyone needs 24-hour oversight all the time.

So, it's like you said about thinking about that. So, a housecleaner is a family support. It gives them time to go do stuff as a family or do other things. So, thinking about those things are really important. And when we used to talk about family support, we used to say it's what the family

needs. Like, the family might need tires to get their child to an appointment so that the parents can go to work.

Amelia: Right.

Sheli: Like, there's this whole... You can't disconnect some of those things. And so, there's some, I think, real opportunities if it makes sense for families like how we are creating generational living situations. Housing is a situation. You know, when we bought our house 5 years ago, I was like, was it universally designed? What if I need it or my parents need it, right?

Amelia: Yes.

Sheli: And so, you start thinking differently, and you can't do that when you're 70. You need to think about it younger.

Amelia: Absolutely.

George: Okay. I feel like this conversation could go on and on.

Amelia: So many things to discuss.

George: Yeah. But Sheli, this is great. If people want to learn more about you, about your programs, where can they go to find out?

Sheli: Well, I always say that there's this big portfolio of projects that we support here at UMKC Institute for Human Development. And I think if you live in the state of Missouri, we have a Missouri Family to Family resource center and that should be your go-to place if you're serving families. And maybe you don't have time to do it. They can match a family to another family member, they can provide information all over the state about diagnoses, about services and supports. So, definitely go to our Family to Family website.

The supportstofamilies.org webpage has that national Community of Practice that I'm talking about. But the other thing that came out on that same website is from the national agenda work that we do, we continue to have policy conversations at the federal level. So, 4 times a year, we have these policy learning collab calls where we continue to discuss the national agenda and how that's impacting federal policies across the countries and in the states. And anybody can join those calls.

And then lastly, you mentioned the LifeCourse tools. So, if you're a family member or a professional or a director, a leader, you can get on that website. There is a form you can fill out if you're a family wanting to figure out how to do it yourselves and you can't navigate the website. You'll be directed to our staff at the Family to Family that will help you navigate a plan for yourself. But if you're a professional organization that wants to figure out how to integrate that into your programs or organizations, you can also get information around training and technical assistance on that.

I do have to do a plug. Every year in Kansas City and coming up in April 2024, is our annual Charting the LifeCourse Showcase. So, that'll bring together probably about 500, hopefully more, people from around the country, hopefully other countries as well. And they'll talk about how they're using it for education, early childhood, person-centered planning, how they're using it to support families, how they're using it to support self-advocates, self-determination and leadership development. And we call it a showcase because it does have conference breakout sessions but it is very collaborative, high energy and people [are] just really excited about... They talk about it being a network and a movement and just feeling like really pushing the agenda across all systems.

Amelia: Yeah, absolutely.

George: Well thank you so much.

Sheli: Thanks for having me.

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.