

Episode 2.7 – Supporting Families with Disabilities with Karen Thompson, Director ASK Resource Center

Mike Hoenig: Well, hey, everybody, it's Mike Hoenig from the Iowa UCEDD the Iowa University Center for Excellence in Developmental Disabilities, here with another episode of Disability Exchange. Disability Exchange is a podcast dedicated to elevating the voices of people with disabilities and their families. We are very pleased to be working in partnership with the Midwest Public Health Training Center. They are a part of the University of Iowa College of Public Health. They do an excellent job of producing these podcasts and just helping us to keep things flowing smoothly. We really feel that centering and elevating the voices of families and people with disabilities is a key component of what we do at the UCEDD, and we have a very, very exciting guest who's going to share lots of ways to elevate those voices. But before we bring her in, I'd like to welcome and introduce my co-host for today's episode, Laury Scheidler. Laury?

Laury Scheidler: Thank you, Mike. It's a pleasure to be here with both Karen and you. I am one of the practicum students here at the UCEDD working to my degree as a social worker, and I get the pleasure of working with Mike and doing these podcasts.

Mike Hoenig: And you have a personal connection with disabilities too, right?

Laury Scheidler: I do have a personal connection. Thank you for bringing that up. I'm also a mother of 15-year-old son with autism and ADHD, so I've had the pleasure of getting to know the world of disabilities from a personal standpoint.

Mike Hoenig: And hopefully those of you listening have listened to our episode featuring Laury and her son James, who did an outstanding job educating us about many things, including World War II history. So, without further ado, I mentioned that we have an exciting guest, and Karen is somebody who I have worked with for many years in different capacities. She's, among other things, the director of the ASK Resource Center in Des Moines. So, Karen, I'd like to welcome you to the show, Karen Thompson, I guess I should say, I'd like to welcome you to the program. So please go ahead and introduce yourself and tell us a little bit about your work and activity within the family and disability advocacy movement.

Karen Thompson: Sure. Thanks for inviting me, Mike, and I appreciate the introduction and I'm happy to be here. And as Mike said, my name is Karen Thompson and I'm the executive director of ASK Resource Center. I've been with ASK for 14 years now, and as such, I'm a parent advocate and I'm also a self-advocate. My journey with disability started a long time ago, back when I was six years old, so like, oh, 15 years ago. There's a wink there. You can't see my wink but let me wink to that. Might have been a little bit longer ago than that. But I had difficulty reading when I was a child, and long story short, ended up with a diagnosis of dyslexia, and that happened to be in 1976, just as 92-142, which is the law that preceded what we know as Individuals with Disabilities Education Act today when it was being implemented and coming into place.

So, I was very lucky that I received support and services in my hometown. I was also lucky because my parents were well-connected in the town, especially well-connected with the school district. My dad was a minister of one of the three churches in our town and two of the principals attended our church. And so my family knew the education world, and everybody respected everybody, and things went very well for me. So even though my prognosis was that I wouldn't be able to attend college, nobody listened to that. And there were some struggles and trials and tribulation through the whole thing, but in the end, I was exiting special education by the sixth grade. I did well academically beyond that point. College was not a problem for me. And so, from that point forward, really, I had my legs in self-advocacy. Today, I'm

a mom of two. I'm blessed with two kids who also have abilities to learn differently, and so my work in disability is something that has permeated my life from my degree into my original work. When I first stepped outside of college, I was a job coach and then a supported employment supervisor, moved into some rehabilitative counseling work, did a little bit of work with Iowa Department of Public Health, and then landed at ASK Resource Center. So both from the lens of a parent advocate and a family advocate, this role fits me very well, and the work at ASK fits me very well.

Mike Hoenig: Wow. There's a lot to digest there, Karen. And one of the things that I want to go back to start, kind of follow up on a couple of things that you said, that the law had just come into place, what, like the year before you were diagnosed, and I was also one of those students. I think I'm old... Oh, in fact, I know I'm older than you, but I remember the law passing and things changing. For those of you who are out there listening who don't know, I am blind and attended a residential school and ended up... Because I had started in 1969, the transition back to the public school would've been really difficult, and so it didn't happen, which is a whole other story. But I think it's really interesting, Karen, that if it had been just a few years earlier, or if your parents hadn't had a connection and were so well respected within your community and within the school district, outcomes, or certainly expectations, would've probably been completely different for you.

Karen Thompson: You're absolutely right, unfortunately. I was placed in self-contained special education classroom when I was a first-grader to learn how to read and write and a little bit with mathematics, although I struggled more with reading and writing. And I don't remember exactly how many classmates I had in that self-contained room, but somewhere between six and nine other people were probably with me, and of those, there were a couple whose diagnoses and symptoms and the way their disabilities played out was very, very similar to mine, or they had other disabilities entirely but their outcomes didn't necessarily need to be different if they would've had the right supports wrapped around them. And yet our outcomes were drastically different, dependent upon whether or not the kids had early intervention, access to the supports and services that they need, and teams that would wrap around them, and those teams needed to include both the school and the family. So, it makes a huge difference, and that's exactly what ASK Resource Center does as the parent training and information center for the state of Iowa and the Family to Family Health Information Center. Our role is to train parents in advocacy and their rights and responsibilities so that they can be meaningful participants in the teams and helping those teams and systems move things forward for their kids with diagnoses.

Laury Scheidler: So, I heard you mentioning that the outcomes were different for yourself versus some of the others that were in that same classroom with you. What did you see as the main difference between the resources that you had available compared to what they had in that same classroom?

Karen Thompson: Honestly, it came down to family and professional partnerships, an ability to work together, an ability for there to be maintaining of what we were working on for me in the home and in school. For me, there wasn't so much a healthcare component for it, because the diagnosis was dyslexia, but for some of the kids that were classmates of mine, there were pieces that were related to that, and so then you would've needed the healthcare professionals on board as well. And so, the ability for everyone to work together as a team, and then once I got to middle school and high school, even though I wasn't in special education anymore, my prognosis followed me. It was in my record, and there were things that were predetermined for me, and I had to advocate for myself. I had parents who expected me to do well and to advocate for myself, from the point of my diagnosis forward, as a matter of fact. Actually, for us, disability also was involved in our life one generation before me. My dad suffered a massive stroke when I was very little, I was one, and his prognosis was that my mom should

institutionalize him, and she chose not to do that. And they said that he wouldn't be able to really do much of anything. Well, by the time I can... I have memories of him. He was reading and riding and driving. We equipped the car so that he could drive. He held a job from time to time. It was a very massive stroke and a significant acquired brain injury, so he couldn't fully speak ever again. He speaks in phrases. And I promise there's a reason why that's important beyond his own life and our experience with that and working with professionals, but sometimes having different ideals than they do about what you're going to move forward with and what the prognosis can look like in the end. But then when I got my diagnosis and prognosis, I remember he looked at me. We were sitting in the office with the neuropsychologist who diagnosed me, and he was the one who told my parents, "Don't expect to send her to college. She won't be able to do it." And my dad turned to me, and he goes, "We'll see. Okay?" And just those words, I knew his expectation of me was no different. My mom felt the same way. She expected me to advocate for myself. She told me, "Your studies will be longer and harder than other students, but we expect you to do what you need to do to become a contributing citizen." And so that's what I did.

Laury Scheidler: Oh, it sounds like you came from an amazing family of strength.

Karen Thompson: There were definitely components of our family that we were well-prepared and well-equipped to deal with this.

Laury Scheidler: Great.

Mike Hoenig: Boy, I'm learning so much here, and I know we're kind of diverting, which is great. I love just having this conversation. But so, what I think I'm hearing then is that dyslexia was considered by those professionals and neuropsychologists and teachers and so forth as an intellectual disability, if they didn't think you'd be able to go to college.

Karen Thompson: It very much was. That's an important point. And this was a number of years ago, and at the time the prognosis was don't plan to send that person to college. We have since really debunked that one, right? But now we're on that same threshold with other diagnoses, Down syndrome, autism spectrum disorder. There are a lot of other diagnoses now that are at the place now that I was at when I was in school, and so let's don't write those things off. I even think about kids who are nonverbal, and we think that they aren't taking information in or they can't understand or they can't read or they can't learn. Hmm, are we sure? Or is it that our science and our technology and our ability to understand how to teach them hasn't yet caught up with how they learn?

Mike Hoenig: And we do know a few situations where perhaps people that are non-verbal have gone on to college, but it's been with all kinds of supports built in, and there are all kinds of... The supports are great, but there's still so much doubt and questioning about whether they truly had an experience that was meaningful, and did they learn what they say they learned, and that would be a tough situation to be in.

Karen Thompson: Mm-hmm. I agree. You know, you think about the difference between somebody that we experience as non-verbal and we have respect for like Stephen Hawking, Dr. Stephen Hawking, right?

Mike Hoenig: Right.

Karen Thompson: And we're around kids all the time that look similar, that behave in similar ways, but we have a different preconception about what that might mean for them than what it means for him. And so always challenging ourselves in that way is important. Teaching parents to have high expectations and to trust what they know. My parents did trust what they know. They also understood how to respect and work with the professionals, and how to expect respect back from the professionals. The professionals and they already had a tight foundational relationship. That played a role in their ability to find their way through differences of opinion. All of these things matter so much. They matter as much as the policy and the procedure and the guidelines and everything that's in place to deal with kids with unique needs and how to help them move forward. Their relationships and ability to move through differences of opinion and what to do next matters just as much.

Laury Scheidler: So, Karen, I am curious. I hear you talking about all of these things that need to come together to advocate for students and their success. So how does ASK work with parents to help instill those skills to advocate for their children?

Karen Thompson: Yeah, great question. Thank you for asking it. So first, ASK Resource Center stands for Access for Special Kids Resource Center, and we were founded back in 1997 by two moms who ran into each other in the grocery store and had kids with unique needs with them. And so they were able to identify with each other as moms who were probably experiencing similar things, and one of them had a background in political organizing and the other one had a background in social work, and they were able to talk with each other about how even for them it's difficult to navigate, to understand what they need to understand, to navigate systems, to know exactly what they need to do to help their children. And they thought, if that's the case for us, it must be the case for others. And so that was back in the day before social media, so the first version, so to speak, of ASK was a local resource and support group. It grew very quickly, and they realized that they needed to form a nonprofit entity and begin to spread the services and supports across the state. And so, in 1998, we became the parent training and information center for the state of Iowa, and that is a federal grant that we hold that the funding rests inside the Individuals with Disabilities Education Act. There is a parent training and information center, a PTI, as it's called, there's at least one in every state, and some states have more than one. There's a funding formula for it. In Iowa, there is only one, and through that particular grant that's kind of one of our foundational grants, the supports and services that we offer to parents through that is largely around training. So that can be online training. We do webinar series around unique needs, disabilities, navigating supports and services, behavior planning, mental health, all those kinds of things. The law, understanding what it says, what it means. So, webinar training. In-person training, we'll come to support groups, we'll come to conferences. We also hold a conference of our own, the Together We Can conference, and it's the first Saturday in May each year, so it's kind of our largest training event in the state. Then we also offer one-to-one support, one-to-one assistance. So, we have on staff professional advocates. So, these are people who are family members with lived experience, they've walked the walk themselves, and now they're there to help other families do the same. They're trained up in all of the laws and guidelines that are relevant to families, such as things around special education, 504 plans, the Rehabilitation Act, Workforce Innovation Opportunity Act, Medicaid waivers, all those kinds of things. So, when families call in, they can receive one-to-one support from them. We have a mentor service as well, which is other families across the state that offer emotional support, navigational and informational support. That's a volunteer service. So, we'll link a family member who has been there, done that, with a family member who's about to go do that, and they work together, and we just sort of help support that connection along the way. So, I would say that those are our two main ways that we're regularly communicating with families person to person, and then the other piece is information dissemination. So, we have a couple of websites, askresource.org and transitioniowa.org, and through

those you will find all kinds of resources, events, and support that we're sharing out for families, and then also an e-news, a Facebook page, all of the typical ways that we can share out that kind of information. If there are things that we can find that other people are providing that are good resources, we will share things out from others. And we also build a lot of fact sheets, brochures, training vignettes from our webinars, little splices of shorts, we call them, information that help families, and we're posting that information in each of those ways on a regular basis.

Mike Hoenig: Yes, they are. I can attest to that. For many years, some of you may know I manage the disabilitytraining.org website, and I think ASK was our lead provider of stuff, and sometimes there was too much stuff. We would do a post, and it would just say, "Resources available from ASK," because they truly, when they say they're the ASK Resource center, they are. And so, I would encourage any of you that, whether you're parents, family members, or maybe you know somebody that has a kiddo or a young adult with a disability, please check them out, because they put their money where their mouth is, as they say, and really provide some amazing resources, and they just keep coming. It's not like some websites where you might go, and they're there and then they're not there or they're outdated, and they do an excellent job. One of the things, Karen, the ways that I got all that information was through the mail outs, and what's the best way for people that would want to get on that mailing list?

Karen Thompson: Right. So to get on our e-news, you can go to our website at www.askresource.org, and in the footer of any one of the pages, you'll see a sign-up for our free e-newsletter, and you just put in your name and your email that you would like it to go to and you will receive the e-news. It goes out twice a month, highlights usually a number of things that are going on at ASK Resource Center, but we also have a lot of partner organizations, CDD being one of those, but a lot of other organizations. If we know of trainings or new pieces of information that are being shared around the state, we'll list it in the e-news. Then we use that to also springboard onto our social media. So, if you don't want to sign up for the newsletter, although I would suggest that you should, it's the best way to get everything kind of at one time, but you can also like the Facebook page and you'll receive most of the information that way. We also have it available in plain text, so if you're somebody who would rather receive the information in the mail, we can put it in plain text and mail it to you. We can send it to you in a Word document. So just let us know if you would like to receive it that way instead. You can do that by calling us or emailing us.

Mike Hoenig: That's great. Lots of options.

Laury Scheidler: [inaudible 00:21:27]. Karen, for being the only one in the state of Iowa to do what you are doing, and it sounds like there are so many wonderful aspects and supports in place, do you ever find that there's like a capacity concern to be able to keep up with the large number, being the only resource in the state?

Karen Thompson: Yes. So, two things to say about that. There are lots of other partner organizations out there who do components of the same work we do, so we try really hard to keep our fingers on what are other people doing and not doing the same things that they're doing. If we can share out a resource that somebody else is already doing well, we will do that. But there is also a capacity issue. A lot, especially our one-to-one, our individual assistance or what we call the Ask an Advocate helpline, there is always a wait when a family calls in and they have a question about a school meeting for an IEP, or a school meeting for a 504, or a child has been suspended or expelled, or they have a waiver question. We have a second grant, the Family to Family Health Information Center, so some people know us as the Family to Family, some people know us as the PTI, but usually people just know us as ASK, or ASK

Resource Center. But people will call in with those healthcare questions too. You know, "I have a child with cystic fibrosis and we're about to hit truancy, but he can't be in school because there's too much flu in school and he really can't be exposed. What do I do? How do I put that on the 504?" Or, "I need to have a controlled med at school. What does that look like? How do I work with a school on that?" Those are things that we do through the F2F, as well as helping families navigate waivers and Medicaid, and all of those things, we are far beyond capacity in this state in terms of people who need help navigating those things. So, one thing I would say is, be patient with us. Know that we're not a crisis center and we are a small shop, so if you call in, it might be a few days or even a week before you hear back from us. We go first come, first served when we're calling families back, and we also talk to providers. If you are a provider and you have a question and you think it might match up with 10 or 15 of your families, we'll provide technical assistance to providers as well. So, feel free to give us a call and we can coach you through some things with your families. But that's also the reason why we created the Mentor Network, so that we would have a sprinkling of parents all across the state who can help each other.

Laury Scheidler: The Mentor Network, is that a volunteer situation for individuals that they can become mentors for ASK?

Karen Thompson: Yes. Yeah, you can be a part of the Ask Each Other Mentor Network, and so we run trainings twice a year for people who want to become mentors. If you're interested in becoming a mentor, you can shoot us a message and let us know. The easiest way to do that is to go on the website and use the Contact Us form, and there's a piece of it that says, "Are you interested in becoming a mentor, or would you like a mentor?" And you just click on that piece, and it'll walk you through the questions. And oftentimes, people both are mentoring someone else, and they're receiving mentorship or need one-on-one support for whatever they're dealing with next in their life, because those of us who navigate these systems and the supports that our kids need, we know with every new change in life, there's the next thing that you need to figure out how to do. And so, you might be able to help somebody with early childhood at the same time that you need support for post-secondary transition services. So oftentimes, people are doing both, and then you take the training, and as long as you really feel comfortable and want to commit to being a mentor and we feel like you're ready for that, then we sign you up for mentorship, and when there's a family that we can connect with you that you match up with well, then we do that.

Laury Scheidler: That's wonderful that you offer those resources.

Karen Thompson: I'm glad you think so. The mentors also run what's called the Ask Each Other support group, and that's currently, it's a Zoom once a month support group that you can just jump on. It's for families only, they can jump on, and they can talk about anything they want to talk about. We kind of have prompts and things set up so that if nobody brings an issue forward, we have something we can share. But generally, the mentors run that, and families can bring anything they want to an Ask Each Other support group and kind of help each other through it. So that's an option as well.

Mike Hoenig: That is terrific. Karen, one of the ways that I have had the pleasure of interfacing with ASK in recent years has been the Youth Leadership Academy, which is a, right, at this point anyway, it's still a virtual training offered during the summer for students, young adults roughly 14 to 21, although we've expanded that age limit a little bit on occasion. Many agencies are involved in that initiative, and ASK is assuming a greater and greater role, which we are very grateful for. So first of all, I just want to say how much we enjoy working with you on that.

But then in terms of the question related to it is I've noticed even through the Youth Leadership Academy, the Together We Can conference that you mentioned earlier, that you have also really added young people with disabilities to the people that you reach out to, not just as technical assistance for families, but working directly. So, talk a little bit about how that started and your commitment to that, because it's obviously very strong.

Karen Thompson: Yeah, that's a commitment that we wanted to have. It's been on the radar screen for a very, very long time. Obviously, as children move into middle school and high school, they need to be, what we call have self-determination, right? They need to understand their diagnoses, their unique needs, and how to advocate for themselves. And parents can't always be there to do that for them, nor should they be, because as kids get older, they're going to come up with their own answers and ways that they want to advocate for themselves and shape their own lives and futures, just like any other child. So parents need to start to take a backseat, still be there, still help, but largely it needs to be the child learning how to run their own supports and services so that they can do that successfully on their own, or if they're not somebody who can be completely on their own, they can run as much as they can on their own, be as independent as possible and as contributing as possible to their own decisions in their own life. And so, it's always been on the radar screen for ASK, but about seven years ago, it became something that was also dictated to the Parent Center network through the PTI grant. So as our grant renewed, they said, "Okay, no more just working with families. We also want you working with youth and youth leaders now." And it took a few years for them to add any funding to that that would help support that, and of course, that was the piece that we needed. Our resources were already tapped working with families, and in recent years there have been opportunities to grow funding streams through vocational rehab, through Family to Family, through a new parent training and information center grant that comes from rehabilitative services administration, and then also some state funding through the Iowa Department of Education. So, we braided all of those funding supports together in order to begin to work more with the youth that we were already touching because we were working with their families. And so, in that came a self-advocacy strand of the Together We Can conference, being able to support the Youth Leadership Academy both with funding and with staffing support for that. It's one of my favorite projects. I love connecting with the youth and working with them. And Mike, I'm so glad you're staying involved with that, because you're one of the best trainers. You really know how to engage those youth leaders.

Mike Hoenig: Well, thanks. I'm going to miss my partner in crime though, Bill from the DD Council. Boy, we played off of each other so well, so-

Karen Thompson: You do.

Mike Hoenig: ... maybe we'll have to hire him back for a week or something. I don't know.

Karen Thompson: That's what I think too. I think we need to subcontract with you both, because you two clearly know how to engage youth.

Mike Hoenig: We have fun.

Karen Thompson: Yeah, so the Youth Leadership Academy happens every summer, and you kind of already gave some of the criterion for it. It is currently on Zoom, it's two hours a day, and we train youth on, let's see if I can get them all. There's self-determination, civic engagement, goal setting, leadership, and networking. And then once they finish, they get to have a graduation together. And so, it's a great

opportunity to begin to develop skillsets with youth. From there, they often participate in the Together We Can self-advocacy strand at the conference that we hold in May. We also ask youth to serve on our planning committee for that and other self-advocates as well, not just youth. And then that's really a funnel. We see that as a funnel that needs to go into the adult system that exists for self-advocacy. So, we use those opportunities to try to get those youth and young adults prepared for and willing to participate in things like the Iowa DD Council and all of the different initiatives that are going on at Centers for Disabilities and Development. We talk about them being able to participate in LEND, the Make Your Mark conference with DD Council, the SOAR conference with the larger self-advocacy network that spans across multiple states. So, it's a funnel to prepare new self-advocates to move forward.

Mike Hoenig: Well, we are so excited to have your involvement too, Karen, and as much as I hate to say this, we are coming to the end of our time here. And I think you know Judy Worth, one of our facilitators from last year and just one of our highly respected folks within the UCEDD, and so we have come up with a closing question in honor of her, and that is what is your superpower? So, if you could pick one of your many superpowers, what would you say it is?

Karen Thompson: I think in terms of the context that we've been talking about, my superpower, and it's probably even the superpower of ASK as an organization, is to be a resource and a connector, right? Our job is to empower people with the connections and the information that they need to be empowered in their own lives.

Mike Hoenig: Well, that's perfect. That's awesome. And it's showing 5,000 people how to feed themselves rather than feeding them all once. I know that's kind of mixing analogies, but I think we get the point.

Karen Thompson: Yeah, definitely.

Mike Hoenig: Yep. So Laury, any final thoughts before we let Karen go and put a wrap on this one?

Laury Scheidler: I am just amazed at everything that you're doing for families across the state of Iowa, and as a parent of a son with these special abilities, or learn differently, I like the way that you put that earlier, Karen, I appreciate even more so what you are doing, and also not only leading families, but leading individuals to advocate for themselves, I think, is so important. And I just want to thank you and your organization for all the work that you're doing out there.

Karen Thompson: Well, thank you very much. And the main thing that we look for is to make sure that families know about us, because of course, the one budget all small nonprofits don't have is a marketing budget, right? So, I really appreciate the opportunity to come today and share a little bit about my story and my passion and who ASK is and what we do, and I hope that that will help spread the word to others so that they can find us sooner when they need the services and supports that we offer.

Mike Hoenig: Thank you so much, Karen, and thank you to all of our listeners. Join us again soon for another episode of Disability Exchange.

Caitlin Owens: Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for

Disabilities and Development at the University of Iowa. Special thanks to Kyle Delveau for the music contribution.