TED & CEC Collaboration Podcast Special Series: Interview with Colleen Diedrich

Unknown Welcome to a special series of the TED and CEC Collaboration Podcast. In this series, we hear the stories of families, educators, and researchers who may be impacted by proposed changes to the Department of Education, IDEA funding and Medicaid. Today, I am joined by Colleen Diedrich. Colleen is a registered nurse and a full-time caregiver for her 17-year-old son, Ian, who was born with a rare chromosome abnormality. Resulting in significant developmental and physical disabilities. He thrives with the support of school-based therapies, in-home supportive services, and Medicaid. But as he nears adulthood, she worries about policy changes that could cut essential services, impacting his education, care, and future. Her daughter, a college sophomore pursuing a Ph.D. in psychology, recently experienced the effects of federal funding cuts when her NIH summer research internship was canceled. Alongside her husband, she advocates for disability rights, equitable access to resources, and the importance of maintaining vital programs that support individuals with disabilities and their families. Welcome, Colleen. Thank you. Happy to be here. Glad to have you today. I'm excited for you to just be able to get your story out there and share a little bit more about who you are and why this topic is so important to you. So why don't you go ahead and kick us off with Just a little background about who you are, your family, and why this topic is so important to you. Well, thank you for the introduction. Um, you, you generalized it well. I'm a mom of a severely disabled, um, Son, in addition to, um, our daughter. She's a sophomore at UCLA studying psychology. Um, our son is a 17-year-old Um, with significant disabilities. Um, we found out early on that he has a rare chromosome abnormality. Um, we live here in Northern California and we've been grateful to, we actually sought out a school district, um, that could offer Public school offer all of the services that he would need to, um, to meet his potential. So currently he has a long list of services including occupational therapy, physical therapy, speech therapy. He has music therapy because he really responds well and learns with the aid of music. Um, so that's where he's at now. He is seventeen Um, he's in kind of a special day class with a life skills program. So under his current program, um, he can stay until he's twenty-two Which we're really grateful for. Um, I think jumping right into what we're most concerned about is, um, with the disillusion or major changes to the Department of Education, um, And protections, um, to IDEA and these individualized programs, we wonder and worry that that program would be no more, the transition program that would keep him in control. In this school with all these necessary supports until he's twenty-two And so if that were the case, he's technically considered a senior. So we're facing the fear of will things abruptly come to an end, potentially. Yeah, that is, it's a fear a lot of people I think have right now. I've been speaking with folks, other parents who have shared that same fear. So you're certainly not alone in that. Um, I want to just take a step back a second because you said, you know, you knew early on that Ian had this, um, this chromosome abnormality. And so can you talk about how old was he when you did find out and maybe, um, just a little bit about the services he has received probably from a very young age, maybe even before school started. Sure, yeah. So we found out shortly after birth that he had this rare chromosome abnormality. And, uh, we were connected with the regional center here in California. We have regional centers. Um, and a social worker came out and, um, helped provide us with a list of resources and connected us to, um, Medi-Cal, uh, which is You know, secondary insurance, we have private insurance through employers, um, but secondary insurance that would help fund, um, you know, extenuating medical costs for him. Also, um, services such as early intervention, um, we had in-home PT, OT, and speech from a very young age, um, as he was not meeting his milestones. Um, so this was hugely beneficial because we were just completely overwhelmed. Um, this was, you know, we had our daughter who was always just, she was You know, advanced and easy and um, definitely didn't know what to expect or how to prepare. Um, the regional center really was, um, was so beneficial. We were so grateful to be connected with them. They also, through Medi-Cal, um, he qualifies for nursing. He has a lot of medical issues, so he's G-tube dependent. Um, he's fed with a gastrostomy tube. So we had in-home nursing when he was young, um, to help support, to support us there. Um, so yeah, it was a lot. I can't imagine navigating all of that with, without those resources. Um, the early intervention services started almost right away, I would say about six months of age. And then he started with the school district at three, um, because children with special needs and disabilities are able to enter like a preschool program at the age of three to start, um, Catching them up, if you will, or providing the extra services and resources that they need to prepare them best to to enter into school. Thank you for sharing that. Um, just thinking a little bit about those services that you were provided from such a young age, thinking about the therapy services, um, your in-home nursing. You know, I assume your background as a registered nurse, you knew how to do all of those things probably or had at least some knowledge of some of the care that Ian needed. would you just share a little bit about for maybe people who don't understand what it's like to have a child with such a significant disability And for people who might think, but you're a nurse, like, why couldn't you just provide that care? Could you shed some light on that and maybe the toll it took on your family and why those services were so critical? Sure, yeah, it's really interesting because I actually have a previous degree, not in nursing, and before I had kids, I had decided that I wanted to go back to get a nursing degree, so I earned a second bachelor's. And my RN, um, and then I have my kids. So I kind of combined that with my business background when I went to work and I worked in clinical research. And so I did that for just a couple of years before I had my daughter. And then when I had my son, um, I'd always expected to go back to work, um, after having some time off with my babies. And after I had my son, um, I, I was just so grateful to have had the education for the terminology just to kind of understand all of the information that was being thrown at us. Be able to ask the questions, um, be able to have conversations with the medical providers and understand it on a little bit better of a level. But in terms of, you know, assuming that I was so much more prepared As a mom to handle, um, this news of what life was suddenly going to look like or to know how to help him meet his potential. Um, I was just as clueless as, as anybody. Um, and it was very, very difficult. And sometimes that was almost a hindrance because people would make those assumptions, um, in the family. Oh, it couldn't have happened to, you know. A more perfect mom. This was meant for you. This was your fate. This was so, those were kind of hard things to swallow um, when I, we still needed a lot of support as well. So No matter, you know, what the circumstances. Yes, we're grateful because we have educations and we have resources and, um, you know, we, we have a strong family bond and a good marriage and my husband is a great involved dad. Um, even with all of that, it's, it's still often survival mode for families like ours. It's very difficult. Thank you for sharing such a personal story and, and your experience with that because I think that is one of the important things as we continue to share stories such as yours and Ian's. That I think will help people understand the types of impacts that will happen if we have funding cuts and especially in the Department of Education as a whole thinking about IDEA. We've had conversations about Medicaid and I'm sure Medi-Cal in California. I assume that's your kind of a local, um, insurance coverage there. But just thinking about all of these pieces, um, for people who might not be familiar with some of those services that Ian receives, what are some of the things that you What do you think will be most impacted by cuts in the Department of Education or the funding streams like IDEA, Medicaid, and that sort of thing that would really impact the services that he's able to receive at school right now? Well, again, I kind of already touched on it right now for us personally, um, our biggest concern is that that transition or life skills program that would allow him to stay in school until he's twenty-two Um, that that would go away. Um, that would be hugely impactful because he, he's not, he's So severe that he's not going to be able to work in the community or go to college after high school. And there are very limited day programs for him because of his extensive needs. Um, this school would provide him a productive place to go where he's continuing to work on his, um, Mobility that he has. He gets physical therapy twice a week. He has a one-on-one aid that helps him move around the, um, The school campus and environment. Um, he's working on a speech device using eye gaze. Um, so he's continuing to learn skills that are going to help him into adulthood. If that suddenly stops, you know, I really worry that there's no place for him in the community. He's going to suddenly be home. And I think, I think the, the bigger issue also that is so hard for families like ours Is this general attitude and disrespect coming from our administration about our children and family members being such a burden, financial and otherwise? And kind of the attitude that um, they really shouldn't be in the community. They don't deserve the same rights. Um, so just, just worried about that, about the attitudes about having him out in the community. Um, and will he always have equal access to, to be in the community? But going back to school, yeah, really just concerned about losing that program, um, specifically. And then also just losing uh, all the therapies that he needs. He needs a lot of support at school. And it's already difficult. Um, you know, funding has always been an issue for special education. And so, um, having further or further cuts or abolishment to those programs would be devastating for our kids. Absolutely. Um, you mentioned, you know, the, the worry regarding attitude and I think that's an important thing to bring up. Have you experienced Any of that, you know, personally with Ian out in your community where you are feeling as though the attitude has shifted since this new administration. That's a good question. You know, as a mom, I've toughened up over the years. When Ian was little, um, it was really difficult to ignore all the stares. Um, but I embraced it early on and used it as an opportunity to educate, um, other people. And then if little kids were staring, you know, I know they were just curious kids. And so, um, I would help connect and answer questions and introduce Ian and, um, and so I always looked at that as an opportunity and, and didn't feel resentful towards it. Lately, I do feel a little bit more on edge, um. I think the reality of knowing that um, that almost half of our society potentially Voted to support this administration makes me worry um, a little bit more and feel a little bit more sensitive when I do receive looks. Um, have we received anything overtly You know, rude, uh, yet. No, but I, but I do worry about it more and more as he's out in the community. He can be loud. He's in a wheelchair. He drools. You know, he brings attention to himself. Um, so it is something that's in the back of my mind for sure. Yeah, I'm sorry that you have to deal with that. It's just not something that I think many of us, um, maybe even think about on a day-to-day basis. And so I just, it's, it's really helpful, I think, to share your story and. Help people understand some of those fears that you have as a mom and I think just like any other parent right we want our kids to feel welcome and feel like they have a place wherever they are whether it's in the community or in their school with peers. Out in public. And so I'm sure Ian would want that for himself as well. So I appreciate your vulnerability. No, no problem. I want to back to you talked a lot about the school where Ian's at and mentioned at the beginning that you sought this school district out because of the services it provides but it's a public school. Um, how did you find the school and was it a burden for your family to get into and from the school? Did you have to move? Can you talk a little bit about that? We did. We did have to move. So we were in a smaller district, um, smaller community. They were definitely willing to work with us in terms of Ian's needs, but because of the population and the limited number of students that needed as many supports as our Ian did, It really would have been, um, kind of paving the way and doing so much legwork to kind of create a program. And so we had heard of and learned about, you know, this larger district in the Sacramento area that had a large population of special needs students. They had a specific school that could offer the nursing that he would need since he was medically complex, um, at the time. And also had so many needs. And so we started doing some investigation. We had a former therapist that had gone to work at the school and kind of helped give us some insight. And so at the time we felt like, um, that's what we needed to do. So we did move, um, a couple towns away and got reestablished. We were kind of in a foothills area and he is, um, physically disabled and in a wheelchair and we lived on a real hilly street and so we needed to be somewhere that just was more accommodating, um, down in the flatlands and easier access. Yeah, absolutely. I think that's an important piece too to think about just equity and funding for education in general because You know, I live in a rural community in Iowa. And so, you know, kind of a similar situation. We have lots of services available at our local public schools. But maybe not to the extent to which someone like Ian might, you know, be able to thrive in that environment. So just thinking about, um, some of that, that access for kiddos with Um, disabilities and getting them the supports they need. And for some families, you know, moving maybe isn't an option. And so how do we continue to advocate for equitable funding so that we can have these types of services? And I think about even, um, in my area, you know, physical therapy in the town where I live, you would have to travel fifteen to thirty minutes just to see a physical therapist if it wasn't available within, you know, your school day. And those types of things. So it's, it's just really interesting to be able to talk to people who have been able to find such fantastic programs, you know, within a community to be able to get those services in school. Um, just kudos to you guys for seeking that out and, you know, making such a big sacrifice for your family and, um, being able to do that. So thank you for sharing. Absolutely. One of the things I wanted to ask a little bit about just shifting a little bit. When you shared initially with me, uh, you talked about your daughter who is, um, pursuing a degree in psychology and was doing, going to do a summer research program. Um, internship and her funding was cut for that. Could you talk a little bit about that as well? Yeah, so Ava is a sophomore at UCLA, as I mentioned. She's a psychology major. Um, one of the internships that she was most excited about was with the NIH in DC area. And she had made it through the uh, the application process and was getting ready to interview, so she hadn't received the offer yet. But, um, at the time where the, she was expecting the interview to be scheduled, she got a personal letter apologizing that, um, the program was going to be terminated, need to be terminated due to funding cuts. Um, so they aren't offering that research internship program at all this summer as a result of the funding cuts. She has another one that she has interviewed for, um, But it's also heavily funded, I believe, by the CDC. So she's a little bit worried about the status of that as well. So, we're just realizing it from both ends. Um, you know, she's in a field um, that is heavily involved in research and education and So feeling the hits on, on both sides. So it's pretty upsetting. I'm sure that's hard as a parent when, you know, you have a child who's so excited about, you know, a research internship and being able to pursue her passions and, um, feeling really disappointed that maybe those avenues aren't going to be available. Yeah. Talked about, you know, hearing all of these different pieces, you know, Department of Education, NIH. Could you talk a little bit about from a medical perspective? So cuts maybe to Medicaid. Um, or if IDEA shifted under the Department of Health and Human Services, um, kind of what changes might you expect in Ian's care or work? What would be some of the things that you could be, that could be impacted by those cuts? Yeah, that's another big stressor and area of concern for us. Here in California, and we're aware that California, um, Is, is one of the better, um, providers for in-home services for families with kids with disabilities. So we have here what's called in-home supportive services. That's funded through Medicaid, um, partly through Medicaid. And it offers, um, so kids that otherwise would be institutionalized or need full-time care, um, Um, there's funding given to families to bring those services into the home so we can hire, um, Uh, workers, support workers, whether they need nurses or otherwise one-on-ones to come in and help us care for our kids and keep them comfortably at home. These are. Considered, you know, they use these terminologies that I don't love, but institutionally deemed children that otherwise would have been institutionalized. So that's the way that the state, um, you know, reallocates that money, um, away from institutionals or institutions. Yeah, into, um, into the families. So that is really concerning as far as us thinking about, um, If we lost that funding, you know, I don't work because I care for Ian full time and we're grateful to receive some extra income to continue to do that. Secondly, a lot is tied to Medicaid. So his nursing services, um, that's tied to Medicaid. Um, What else were we just talking about? The secondary insurance coverage. He's needed multiple surgeries. He has a lot of orthopedic needs, so he's needed twelve spine surgeries. foot surgeries. So anything that our private insurance, after we cap out of our private insurance and all of the co-pays, um, Medicaid helps families out so that we don't go into Um, um, healthcare debt. So it's just a lot. Absolutely. You mentioned Ian being able to be in school until he's twenty-two through the transition program. And you don't anticipate he'll be able to work in the community post-graduation. Um, for some, some students who are able to work or potentially live in Group home facilities where they can get part-time jobs and such. Would you anticipate Medicaid would also impact kids who are maybe living in group homes? You mentioned institutions as well, but for some who can live semi-independently, I would assume some of that funding comes from services such as Medicaid. Absolutely. SSI, um, Medicaid, uh, the regional center here in California, all of those things support kids with their living situations as adults, whether it be That they stay in home and they provide them, you know, financial supports there to stay with their families or some sort of semi-independent or group home type living situation. Yeah, and I think that's an important piece. You know, we talk about wanting the best for our kids and, you know, helping them to achieve as much as possible and, you know, continuing to have those high expectations and so providing the types of services that Like transition education through the age of twenty-two and opportunities for work post-graduation and living semi-independently or in group facilities. Provides kids with that opportunity and young adults with that opportunity to really get that experience they maybe wouldn't have otherwise. So I think those are important distinctions to make. You've talked about, you know, your concerns and these funding streams. So I just, you know, I wanna ask a little bit about your support system. So you've talked about, Um, services, but how have you been supported yourself as a parent, as a mom, as a caregiver? Um, for Ian, what groups do you reach out to and how do you get support to just really kind of fill your bucket back up? Yeah. Um, the biggest support probably comes from the other families and moms that are in the trenches with me. So, um, I have a couple of good friends who Ian has gone to school with their kids, um, for years. Um, And, um, you know, they just get it. There's a lot that, that overwhelms my friends that don't, you know, have this. Yeah. Sorry about that. Um, that don't live this life and sometimes I feel like when I open up or become vulnerable or overshare People just aren't quite sure how to respond, which I get it. I would be that way too. It's a lot. Um, so having these friends who live it and get it and are changing diapers of their sixteen year olds and seventeen year olds and Worrying about these things, um, that's my biggest support. That's where my, the most support comes from. Um, it can feel pretty lonely sometimes, um, even with, I'm sorry, I have a cat who just broke in. So, um, yeah, even with family members, sometimes, um, just the assumptions that are made, um, And my husband and I, we were really grateful again that we do have a good family bond and support and so maybe we make it look easier than what it really is. Um, and so I can't blame people for, for making those assumptions. So it really is important to have a connection with people who kind of live something similar. I'm glad you found that community. I think that's important for people to have that support system. So, and I'm sure it is difficult, you know, when people, even when people maybe feel that compassion and that empathy. Even for those of us who don't know what it's like, it's hard to help you feel heard, I think, in some of those situations. So it's important to have that. So we we've talked about a lot of complex issues and potential shifts that could happen and the fears surrounding those. What do you think right now is most important that people are advocating for? So what are some of the things that you would like people to continue to advocate for right now with this administration? Well, you know, to be honest, I thought about this and I think about this every day because I'm a firm believer that, um, We have to do more than just complain. But I think a lot of people are feeling a little bit shell-shocked and overwhelmed. As we've kind of brought up, there's so many things we're worried about, whether it's from Medicaid cuts or whether it's from the Department of Education and the changes that are going to happen there. Whether it's the attitudes about, um, special needs in the disabled community in general. So, so much has happened so quickly. And I think that we're all still, our heads are spinning a little bit. Plus our families are in survival mode anyway. So I'm not sure we're at the place yet where we know tangibly what to do. Um, a lot of people are just kind of waiting and seeing. Like, what are we going to be facing to know what we need to do? So right now, um, as I mentioned, like, my friends that are in it with me, we're all talking about Um, I follow Disability Rights California. I try to just read up and know what's potentially coming so that we can organize, but it's a really good question. I wish I knew how to, um. Make more of an impact. We're already a small and tired community. Um, not as small though as you might think. I think that we just don't have a loud voice, so. I think that's important because like you said, you are already kind of pulled from, from lots of different angles, right? As a mom, as a caregiver, and that's a really difficult place to be in and then try to add one more thing on your plate. So yeah. When we think about, you know, some groups, you mentioned the Disability Rights California. Are there other advocacy groups or legislative groups who you follow to try to stay up to date? Um, or that you're involved with to try to know what's happening right now. Um, in terms of, you know, disability rights, not so much. Um, you know, I follow Heather Cox Richardson, I think she's a great source of information. Um, but in terms of local advocacy, no, we feel lucky that where we live, Um, and here in Northern California and in our district were pretty well supported. So, um, um, I feel some security there. Um, that at least at the state level and our local level, um, we're pretty well supported, but no, um, nothing else organized at this point. Yeah, I agree. Heather Cox Richardson gives great updates. I, you know, it's, it feels really factual and, um, everything's so timely. And so I think that that's a great, that's great advice. What, what is some advice that you have for families, maybe other parents who are just kind of looking for ways to get involved or what can they do? How can they find their own communities? What What would you tell them? I think the biggest thing, um, again is connection. Making the effort to get to know, to reach out, go have coffee with, um, the parents at your kid's school. It's really difficult in special ed because a lot of our families come from different areas. Um, you know, it might be a school within our district, but it's not necessarily your neighborhood school. And so, and then a lot of our kids are bussed in. And so you don't have the pick up drop off thing where you're getting to know these families. We are maxed out with therapies, with medical appointments, with, you know, our lives. So it kind of hinders the opportunity to really form those bonds that you do with the parents of your typical kids on the soccer field or at the PTA meetings or whatever. But I say that's, it's so important um, to find just that camaraderie and that understanding and that support. Um, is really make that effort. And it's not easy. I mean, I, I don't connect as much as I do, but now that I have the bond with even just two or three, um, It just feels so important to me that I always have somebody that when things get really rough, we come together. We're, I have two or three friends and all of our kids are going to be aging out of the school, um, system. Within two to three years of each other, we're already talking about what can we come together to do to create something meaningful for our kids after they age out of school. Um, some kind of like a co-op or co-op type program or collaborative program. So, yeah, I think just connection. That's great advice and I love the idea of a co-op and thinking about how you can create those kind of sustainable systems for kids beyond high school. That's an amazing opportunity. And I think something that could take off, um, you know, if you guys figured out how to do that in your area, maybe others would start to, you know, catch wind of that and do that themselves. So it's such a cool opportunity. Thanks a lot. Colleen, I've had a really great time talking with you today and just loved hearing about all the things that, you know, you are sharing and in the You know, the passion that you have for bringing light to, um, the disability community. So I want to just ask you kind of some last thoughts. What are What do you want our listeners to know about you, about Ian, about, um, these potential changes and just kind of some, some last pieces, last words of wisdom maybe. Yeah, I mean, you know, my idealistic self and as a mom to a severely disabled kid, um, differences make communities stronger and they make people better. And having our kids, um, visible and in the community, um, is good for everyone, um. You know, our typical aged daughter, I feel, is so amazing as a result of growing up with her brother. Her friends would tell you the same thing. They're so happy to know Ian. There's quality of life there, um. He's lovely and engaging. He's hard. He has a lot of work. He needs accommodations. But that's what makes us better human beings. My fear is just again with the attitude of our administration and the survival of the fittest mentality that our kids will be devalued and if they lose resources even for families like ours that You know, have Decent jobs and some resources, we will be strapped and we will not be able to afford to um, give him what he needs and our kids will be, I, I fear we're gonna go back into the dark ages where our disabled kids are Shunned and stuck at home. So really just, um, just thinking about the fact that, that, um, society is better with, with differences. And

I worry so much about Uh, what's happened with DEI and all of a sudden inclusion is a bad idea. Um, so I just appreciate the opportunity of telling Our story and I'm hopeful that even if you don't have a disabled family member, um, that you'll think about your friends and neighbors that do. That's great advice and I think a little bit of empathy and compassion can go a long way and that inclusion is so important so thank you for those words because I think It's a great way to leave our audience today. So thank you, Colleen, for joining me and for sharing your story and best of luck to your family. Thanks, Tammy. I appreciate it.

Jamie Nelson Thank you for tuning in to this episode of the TED and CEC Collaboration Podcast. We hope you found our discussion enlightening and inspiring. Remember, change begins with awareness and advocacy is the catalyst for progress in education. Keep exploring. Keep advocating and keep pushing boundaries to create a brighter future for exceptional learners everywhere. Join us next time as we continue our journey of discovery and action in education. Until then. Stay informed, stay engaged, and keep advocating for what matters most. We want to take a moment to express our gratitude to the incredible individuals who have contributed to the TED and CEC Collaboration Podcast. First and foremost, a big thank you to the TED organization and CEC for their collaboration and support in making this podcast possible. Your commitment to special education advocacy and policy is truly inspiring. We also extend our heartfelt appreciation to our guests for sharing their expertise, insights, and passion with us. Your perspectives have enriched our conversations and inspired action. A special thanks to our production team. Danielle A. Waterfield, University of Virginia. Caitlin Criss, Georgia Southern University. Nancy Welsh-Young, Ph.D. Alison Kearly, University of Alabama. And Jamie Nelson, William Penn University, for their dedication and hard work behind the scenes. From researching topics to editing episodes, your contributions ensure that each podcast episode is informative and engaging. we want to acknowledge the contribution of the production equipment and software provided by William Penn University. Without the tools and technology that enable us to record, edit, and distribute this podcast, None of this would be possible. And finally, we want to express our gratitude to you, our listeners. Thank you for tuning in, for your support, and for being advocates for positive change and education. Remember, The work doesn't end here. Let's continue to collaborate, innovate, and advocate for a brighter future in education.