

Interview with Emma Shouse-Garton

51 minutes 17 seconds

Summary Keywords:

siblings, disability, developmental disabilities, support, people, tennessee, folks, council, Evan, sib, absolutely, life, state, tabs, family, medicaid waiver, councils, talk, conversations, experience

Speakers:

Emma Shouse Garton, Alex Schiwal, Jeff Sheen

Alex Schiwal 00:08

Hi, and welcome to the MHDD Crossroads podcast, where we explore the intersection of mental health and developmental disabilities. This week our host, Jeff Sheen, interviewed Emma Shouse Garton, a sibling advocate from Tennessee. We hope you enjoy this episode. Thanks for listening.

Jeff Sheen 00:28

Today I'm speaking with Emma Shouse Garton, the Public Information Specialist for the Tennessee Council on Developmental Disabilities. Emma also leads the Tennessee Adult Brothers and Sisters, or TABS Statewide Sibling Support Network, and is the co chair of the Chapter Development Committee for the National Sibling Leadership Network. All of which we'll talk about in our conversation today. Emma we're delighted to have you here. Thanks for joining us.

Emma Shouse Garton 00:53

Thank you for having me.

Jeff Sheen 00:55

We would love to hear just a little bit about your background and why it is you do the things that you do? I did give a little bit of an intro on some things. But yeah, tell us a little bit about who you are and why you do what you do?

Emma Shouse Garton 01:09

Absolutely. Well, so I live in Nashville, Tennessee. In college, I studied social work and sociology. I had kind of a vague idea, I just wanted to be in some sort of helping profession. In college at Belmont, here in Nashville, I really fell in love with the public policy and social work side of things. Learning how government and public policy and systems had such a direct impact on the lives of people. From a personal perspective, I grew up with two younger brothers who are twins and they're six almost seven

years younger than me. So right now, they're 24 almost 25, and I'm 31. One of them, one of the twins, Evan has autism, and some pretty significant communication and behavioral support needs. So from a very young age, I grew up kind of in a traditional older sister sibling of a person with a disability role in that I was providing a lot of support in peer modeling in Evan's therapy sessions, and a lot of caregiving to help my parents. I also saw my parents get super involved in the disability advocacy community and got to see them really benefit from finding support from other families and parents of kids with disabilities. So, all that to say when I was looking for what a job might look like for me. Out of school, I had done a really wonderful public policy internship at the Tennessee Council on Developmental Disabilities during my last year of school. I was just fascinated at how complicated the disability service system can be, and how agencies like the Council try to help families understand exactly how to navigate those complicated systems, and how to speak up for their loved ones with their with disabilities, and train people with disabilities how to speak up for themselves. I really fell in love with that work and so that's now 8-9 years later. I have really fell in love with the the disability justice rights advocacy movement itself far beyond just you know how my brother and our family is impacted.

Jeff Sheen 04:01

Yeah, and I really appreciate you sharing some of your background. I know the more people we interview, everybody has some kind of personal connection, typically to be working in this field one way or the other. Certainly, you know, I mentioned in the intro that we have interviewed also your mother Janet Shouse. So that was a delightful opportunity to talk to her about her experiences. So, now to be able to talk to you there's a lot I want to kind of discuss. You do a lot of different things. You wear a lot of different hats. I'm excited that you're so passionate about public policy, and that's one of the areas of social work that that really got me interested in things. I also have a younger sibling with disabilities and seeing how the system did and did not work in different parts of their lives was certainly a big part of why I do what I do. Like you said, it's grown well beyond what my experience with my sibling was into a much broader understanding of the disability field in general. So, I'm excited to talk to you about some of those things. I should say that when we were talking about setting up this podcast, you did send us a couple of lovely articles. We'll have those in our show notes. One of them, for the Council, the DD Council Magazine, you have a really nice piece about your experience with your brother, Evan, and that you had his permission to talk about some of his story and things like that. We'll definitely have that link because folks should really take a look at that article. Then at some point, today, we'll talk a little bit about the other article, which is much more recent. That was in an interview that Psychology Today, I believe, that talks a little bit about the sibling perspective and the current covid pandemic. So, we can't pretend that that's not going on. I'm in my basement recording this, and you're at your house, and both of us would probably be in the office at this point in our day. We're kind of entering our fourth month of some pretty serious stuff, isolation and quarantine for a lot of us. So we'll weave that into the conversation too. What I'd really love to talk to you about first is- I'd love to hear about your work with the Sibling Leadership Network, and with the TABS, and kind of what that is all about. For those of our listeners who have never heard of the Sibling Leadership Network, can you just give us a rundown of what's the kind of purpose of that particular organization? How you're involved and how that might be a resource for people that are listening?

Emma Shouse Garton 06:35

Absolutely. So, the Sibling Leadership Network is a national network, really aimed at providing siblings of people with disabilities across the lifespan, whatever information or peer support or encouragement that they need, no matter where they are in their sibling relationships. One of the things that I really appreciate and respect about the SLN is how much they appreciate kind of the diversity of sibling experiences, and how they they try to reach out and provide support to folks who are doing you know, day to day caregiving of siblings with significant needs. You know, living with their siblings all the way to folks who may be estranged from their siblings or their siblings have passed away, and to really respect kind of no matter what our experiences have been or our perspectives about the role that we have in providing support or care to our brother or sister with a disability. The SLN is there to kind of meet folks where they're at. They do some public policy advocacy, for example, a major focus of the SLN for many years is, or has been, expanding FMLA, the Family Medical Leave Act, to include siblings who are providing care to their brothers or sisters with disabilities. There are some situations where siblings are able to benefit from that. But many many siblings would be able to to benefit if some of the definitions in that law were expanded. The SLN does a lot. They do bi-annual national conferences where siblings from across the United States and more recently, even from outside the US, come together to talk about research about the impact of having a brother or sister with a disability. The impact that that has across someone's lifespan and the supports that siblings of people with disabilities need. So often the disability advocacy movement has really centered on the voices of parents of kids with disabilities, and more and more often, wonderfully, also centered the voices of the people with disabilities themselves. But as the SLN often talks about, for most of us, our sibling relationships are the longest relationships any of us will ever have longer than our relationships with our parents or kids or partners. So I think we're a really important voice to have at the table when talking about what support for families looks like, how to support our brothers and sisters in speaking up for themselves, and disability policy and how it impacts people.

Jeff Sheen 09:55

Yeah, thank you so much for that that general overview of the SLN. I think as a sibling myself that idea of this is a really long term relationship, right? I knew my sibling well before I met my partner and had a family of my own. My father's already passed, my mother is getting older. So, I will likely be in my sibling's life well past when my parents are both passed. And that relationship changes throughout the years, there's been more intense caregiving than not, and then more distance, and there's the whole representative payee issue. In some situations, maybe medical or financial guardianship or supported decision making roles or things like that. It is a very rich relationship and it can be a very complicated and very stressful relationship at times.

Emma Shouse Garton 10:51

Absolutely. One major focus area, kind of a thread through most of what the SLN does, is to support siblings in having conversations about future planning with their brothers or sisters. In far too many cases, supporting siblings taking on those additional support roles if mom and dad have passed away and haven't put those supports in place. Far too often, parents of older adults with disabilities may be reluctant to have those conversations about what the future will look like after they're gone. Not all

siblings of folks with disabilities are like you and me, and have jumped straight into the the disability policy world. A lot of folks find themselves in their middle age or older adult years having to all of a sudden learn all of this complicated, you know, Medicaid waiver, Social Security, health care, stuff that their parents had a lifetime to learn. If families don't have those tough conversations about the next phase of life for their family member with a disability, it can really cause a disruption to a lot of things.

Jeff Sheen 12:12

Yeah. I'm thinking, as folks might be listening and want to learn more, what's the best way for anybody to connect with SLM?

Emma Shouse Garton 12:20

Absolutely, so I think their their URL is just siblingleadership.org. If you join that network, anyone is welcome it's not just for siblings it's for sibling supporters who can be anyone as well, and you'll be added to an email mailing list. Where research and resources and all sorts of things will will be sent out. If you are a brother or sister of someone with a disability, I would encourage you to join the closed Facebook group called Sib Net. It's run jointly by the SLN and the Sibling Support Project, which was created by Don Meyer back in the 80s. They helped promote the spread of Sib Shops, which are events for younger siblings of kids with disabilities, to kind of early on get the benefits of that peer support. So it's so Sib Net is a huge international community of siblings. It's a really important resource in place for siblings to post about those really complex service system questions, to post about family frustrations, to post the joys that we experience as brothers and sisters of folks with disabilities, and celebrate those milestones, and really just, it's a great resource for finding support from your peers.

Jeff Sheen 13:57

That's great. That was one thing I was going to ask you about because this is a podcast where we do explore the intersection of mental health and disability. You know, some of the caregiving issues can create additional stress on siblings and can impact their mental health. That was my question, so there is a place to go connect with more of a support group kind of network through this SLN?

Emma Shouse Garton 14:24

Absolutely. I'll always plug the the bi-annual SLN conference, but in terms of a resource for getting that person-to-person peer support if folks are lookingfor support around mental health needs or caregiving stress or that sort of thing I would definitely recommend connecting to Sib Net on Facebook. I may be wrong, but I want to say about 25 states currently have a state chapter of the Sibling Leadership Network. So here in Tennessee I help lead TABS, Tennessee Adult Brothers and Sisters. One thing that I like about the SLN and this network, is that each state kind of picks its own approach to what they want to focus on in terms of supporting siblings. Some state chapters focus a lot on growing Sib Shops and opportunities for younger kids. Some do like advocacy camps where teams with teens with disabilities and their brothers or sisters go to camp together to learn different school skills for life after high school and adulthood. In Tennessee, TABS does a lot of conferences and workshops based

on kind of helping folks navigate the service system and learning all of this youth logistics that people need to know, like the financial planning and future planning and how to navigate Tennessee's service system. I'm hoping that in the coming years, we can focus more on kind of that mental health, interpersonal family dynamics, relationships aspect of things. For example, we're hosting, virtual Zoom TABS siblings meeting in July. That's going to feature a speaker to talk about having tough conversations with families, and how to resolve conflict when parents, or the person with a disability, or the siblings, or all of the above may not see eye to eye on on various things. I would encourage siblings to check out the SLN website and see if their state has a chapter, and if so get involved. There are contacts listed for all of the chapters on the website.

Jeff Sheen 17:03

I'm assuming if they find that their state doesn't have a chapter, as co chair of chapter development you...

Emma Shouse Garton 17:10

-I want to talk to you, exactly!

Jeff Sheen 17:13

Okay.

Emma Shouse Garton 17:14

That's right. Basically, all it takes to start a chapter, you don't have to commit to developing a nonprofit or finding a board of directors or anything. Really all we ask is that you have at least three siblings who are in your state, who are willing to participate and be involved in developing resources or events or support opportunities, and that they're willing to be committed for I think, six months at least. So it's free and easy, and we will help you if you're interested.

Jeff Sheen 17:54

Yeah, that sounds great. I appreciate you talking a little bit about that process. So it's not as daunting as having to have a background in nonprofit.

Emma Shouse Garton 18:03

-Not at all.

Jeff Sheen 18:05

Can you give me a sense, talking about TABS, how big is the network there in Tennessee? How many people kind of regularly participate?

Emma Shouse Garton 18:14

Yeah, that's a great question. It's kind of shifted over the years. So the the council where I work, in Vanderbilt Kennedy Center's University Center for Excellence in Developmental Disabilities, started kind of gathering siblings to create TABS maybe in 2006 or so. For a while there was a paid staff member whose sole job was to really coordinate both SIB shops and TABS activities. So up through maybe 2013 or so, there were annual conferences that attracted about 60 to 70 folks which was great. In the more recent years, we've tried to kind of mix up the types of opportunities that we're offering, more local social get togethers or regional workshops or online trainings. Since we had heard from a lot of folks that they that they can't get away to Nashville for a weekend. I often point out to folks when talking about siblings, we're often referred to as "the sandwich generation", which means we may be at any given point be providing support or care to three different generations: our own kids, our brothers and sisters with disabilities, and aging parents or in-laws. There were a lot of people I think who weren't able to do, you know, weekend conferences. So now I would say, probably a couple dozen siblings remain pretty actively involved in attending events or helping to coordinate and plan the events. I would love to grow that.

Jeff Sheen 20:07

I think I very much relate to the sandwich generation. That was always a concept I was aware of from my social work background, but then the last several years to actually live that and have elementary school aged children at home and aging parents with different things happening. Then, a sibling that every once in a while, kind of hits a rough patch and needs a lot of support to get through that. So yeah, I can imagine trying to get away to a weekend conference. The silver lining of the world we're living in right now, with everything moving online, is hopefully there's still that real sense of connection that people can can cultivate by participating online and accessing resources that way.

Emma Shouse Garton 20:51

Yeah, and we've found this to be true in Tennessee and TABS and I've heard from other sibling chapters, that. But now that we're offering more things, more get togethers virtually, we're attracting a lot of new folks that that we hadn't seen. So I think, yes, silver lining for sure.

Jeff Sheen 21:11

Yeah, it's interesting how kind of time and distance can be mitigated a little bit by the online. You do certainly lose some of that face-to-face that so many of us really value. As far as making due with what we have, it's not bad. We have found in some of the groups that I'm involved with, is members that we've kind of lost track of that have moved away to different places are able to actually join us from all over the country. Some old friends and things in that context has been nice as well and to provide support to each other.

Jeff Sheen 21:45

I am curious a little bit about the other hats that you wear, and that's your work with the Developmental Disability Council. Maybe you can start with a big broad view. I think most folks listening probably understand what the University Center for Excellence is and hopefully have a little bit of an understanding of DD councils. But maybe there's someone that doesn't know what a DD Council is? Like, what's their mission? Can you talk broadly and then maybe more specifically what you do there?

Emma Shouse Garton 22:12

Absolutely. So, the same federal legislation that created UCEDDS, the Developmental Disabilities Act, also created state councils on developmental disabilities. So every US state and territory has a DD Council. The vast majority of councils are connected to government, there are a couple I think are more independent. But our role is really to bring the voice of people with disabilities and families to the policymakers, who are running the programs and creating the policies that impact people's lives. So I think councils are a really unique body in that way.

Emma Shouse Garton 23:01

On our council, we have not only citizens with all types of disabilities all across the lifespan, and family members of folks with all different types of disabilities, but the leaders at all of the state agencies who have programs that impact the lives of people with disabilities. So it's this place where policymakers and the disability community can come together and talk about what's working and what's not working? What are the gaps and the barriers? What policy changes need to really make a difference in people's lives? So we do a lot of leadership and advocacy skills training. Many councils, including Tennessee, run a partners in policymaking training, which is an intensive leadership development and advocacy program for adults with disabilities and family members. It's really aimed at kind of developing this grassroots movement of trained advocates, who know how the service system works and know what they need to do in their communities to make positive change happen. We do a lot around public policy advocacy, and helping families understand what they need in order to live their best lives and to support their loved ones with disabilities.

Emma Shouse Garton 24:31

So, my role at the Tennessee DD Council is in the field of communications, which if you remember I said I studied social work and sociology. So some of it's been making it up as I go along. *laughter* No, but after starting at the Council, this position had been created to really focus on getting people with disabilities and families the information that they need to learn about how different programs work, how to advocate effectively about the council and who we are and how we can help them. I really developed a passion for plain language, and helping simplify what is such a complex system, and and to help break down really confusing and complicated topics hopefully in a way that really reaches people and helps them feel more confident in navigating the service system.

Jeff Sheen 25:40

Yeah, and that's an important piece that we're really trying to focus our efforts around is making sure that the information is available directly to the individual that experiences the developmental disability and mental health issues. Not having everything be written in such a way that they have to rely on others completely to understand what might be being said. So, I definitely appreciate that. I also appreciate the idea that is a big part of social work in many ways is making up things as you go.
laughter

Emma Shouse Garton 26:12

I'll just say from a personal perspective, it's been so interesting to have my brother, Evan, enter the adult service system. You know, he was added to the Medicaid waiver, I guess, three or four years ago and began receiving these disability support services I had spent several years trying to become more fluent in and learn about. You know, hearing the top policymakers in our state, talk about the very best way that they're supposed to be operating and it's been really eye opening to then see at the ground level, from a family member perspective, where those gaps are in communicating to families. What my mom and dad and I have had to try to figure out for ourselves or where we've run around in circles, because no one agency seems to have the answer. I think that's the powerful part of having adults with disabilities and family members with lived experience of the disability world, in agencies and councils. We can bring that real life perspective. We can talk all day long about how things should be happening, but until you're on the front lines and are going through it, you may not know where those gaps are.

Jeff Sheen 27:47

Yeah, I think this kind of underscores the importance of more people understanding if there is something like Sibling Leadership Network and Sib shops and things like that. Because a lot of people are familiar UCEDDs, particularly in this field, or with the DD councils. But not as many are familiar with siblings, the Sibling Leadership Network, and all of those things are going on.

Jeff Sheen 28:09

A lot of us siblings end up actually working in this field in one way or the other, whether we go into special education to be teachers or occupational therapist or physical therapists, because so much of our experience was watching our families interact with these different service providers and agencies that we develop a real strong sense of, "Oh, this could this could work better" or "I love this particular teacher that my sibling had, and I want to be like that teacher." So there's that component of it, but you know, it that's such an interesting thing to maybe amplify the importance of including siblings in these conversations and you did say that. It is so wonderful that we're hearing more and more directly from the individuals with the lived experience. I think we also need to amplify the voice of siblings who play a really important role in this transition from maybe parents being the primary advocate, to the individual learning to be their own advocate, and then maybe still needing some support from someone that really cares deeply about them and has their best interests at heart in supported decision making, and things like that. So I appreciate that conversation. I started on some Medicaid work incentive initiatives back in the day, and there is kind of a disconnect between how the system supposed to work and then what

your sibling actually experiences and that can be very frustrating. Like, "No, I know that these things exist and I'm sorry that the person you talked to at the office doesn't yet know exactly about that." But yeah, it's an interesting experience. It's always lovely to talk to another sibling and just kind of automatically have an understanding. Oh, yeah, I get that.

Emma Shouse Garton 29:58

Yeah, been there done that. I speak your language. Absolutely.

Jeff Sheen 30:03

Yeah, yeah. I think that's important. So hopefully folks listening will check out this leadership network. I do recall a conference with a lot of siblings, and a lot of folks that were involved in that conference were actually working on their PhD programs. They were all doing their dissertation on sibling issues. I was just starting a doctoral program and thinking I would do the same. Life took me in a slightly different direction as far as what I got involved with and life got busy. But that's when I first became exposed to, oh my gosh, there's a whole kind of core group of adult siblings now that I can connect to and get support from. It was exciting, and it was also a relief. To feel like other people get some of the joys and sorrows of being in this particular role, because there are some interesting impacts on your own mental well-being when you know you have a sibling that does require a tremendous amount of the family's resources, either time or money. That does play a role in your growing up experience.

Emma Shouse Garton 31:07

Absolutely, and not even just growing up but I mean for siblings who are going to need support throughout their lives. I mean, for me in particular, I would say the the greatest stressor in terms of my own emotional well-being and mental health is, just to revisit that sandwich generation notion, throughout all of my young adulthood up until now I remain really anxious about what that phase of my life will be like. I'm not there yet. I'm recently married, but my partner and I do plan to have kids and just thinking about will I have enough time and emotional capacity and energy to not only be a good wife, a good employee, a good mom, a good daughter and the fiercest advocate that I can be for Evan. So yeah, I mean, I think it again underscores the value of that peer support opportunity for folks who will understand where you're coming from.

Jeff Sheen 32:27

Yeah, absolutely and I have two other siblings beyond my sister that has developmental disabilities. I think it's been in the last five or so years that we've all recognized, "Oh, Mom and Dad are no longer able to take the lead on these things." And there is still a level of support that's needed to help my sister be safe and navigate some of the complexities of her world. So you have to have these conversations about, "Hey, I'm running at capacity with the issues going on with my own family and I can't step into this right now. Who can? And it does become very complicated and communication and support from other siblings, whether they're in the same family or outside, is really critical. Because it can feel very overwhelming- and very quickly. Sometimes out of the blue, you'll be taking your kids to soccer practice

one day and all of a sudden there's a phone call and there's been a social security overpayment or there's been a glitch with the Medicaid paperwork or the housing subsidy's not there and they're short on rent. And it's like, well I thought we figured that all out and now...

Emma Shouse Garton 33:39

laughter -Didn't we solve this problem two weeks ago? Yes. Always. Or there's been a mental health or behavioral health crisis and somebody needs to come to my house right now and help deescalate things. I'll mention, without speaking for either of my brothers, but my brother Brendan, Evan's twin, who does not have a disability. He also ended up in the helping profession social work field. He actually works in a rehab facility, an aging facility, doing that kind of end of things and couldn't be less interested in the whole disability policy advocacy stuff that both my parents and I are working in. But he has a really different perspective on his sibling relationship as Evan's twin than I do, as the older sister who always kind of felt the future caregiving burden as kind of my primary impact of Evan's disability. He grew up in the same grade and all of his friends knew Evan and that relationship just ended up being so different and the lasting impacts of living through a really tough time in Evan's later teen years, where there were lots of meltdowns and behavioral challenges, mental health challenges, that I was already out of the house for. I was already living on my own and in college but Brendan was right there. So I think it's important for professionals who have a role in possibly bringing siblings to the table to really understand the nuances of the different sibling relationships. Not everyone ends up being super pumped about learning the service system, and being at every IEP meeting, or service planning meeting, and wanting to be involved every step of the way can have a really different impact depending on age and family dynamics.

Jeff Sheen 36:12

Absolutely. I'm just thinking of my own experience, you know, kind of sibling order in the family and all of the interplay between different dynamics. For my own lived experience, I won't talk for my sister or brother who's also in this role, but for me there's been times when I've kind of felt a little bit hypocritical because I do this work in the field, right? And it's because it's a little bit safer distance to work on systems change versus deal directly sometimes with my siblings in crisis.

Emma Shouse Garton 36:44

laughter Absolutely.

Jeff Sheen 36:46

And recognizing the tension there about, I do this work, to hopefully improve things for my sister and others, and yet I can't always go into the burning house to deal with the immediate issue. And I do end up leaving that to other professionals and just kind of have to let go of having to be the one and just say, there's other people that can address this. They're not family but they're trained professionals, and I'm gonna have to let go of that. So I don't know if that's ever been your experience, but that's a big issue that's come and gone for me.

Emma Shouse Garton 37:23

Yeah, I mean, in my job every day, I am in some form or fashion talking about or advocating for the employment of people with any and every type of disability. And we have yet really as a family and a team of people supporting Evan, figure out what on earth that looks like. I mean, it feels kind of like our wheels are spinning sometimes for the past, you know, since he left high school. I've had to kind of come to terms with like I can't go and be Evan's customized employment job developer like I'm his sister. That's not my role, I can be a sister and advocate when there are opportunities to and encourage and provide ideas and brainstorming, but I just don't have the capacity. I have to live my own life too. I can't go in and solve every problem, which is hard.

Jeff Sheen 38:32

Yeah, that's such an interesting place and that does play into the mental health issues for everybody involved. There's a recognition of, if I work beyond my capacity, I do a poor job interacting with my sister in a way that is unskillful and sometimes can make it worse." So knowing that, hey I'm not in a place where I have the capacity right now, and I can try to get other people to step in. That's better for everybody's mental well-being long term.

Emma Shouse Garton 39:04

Absolutely.

Jeff Sheen 39:07

I appreciate that. I want to use this as an opportunity now to, speaking of things coming up, covid pandemic and having siblings that worry about and how are they coping with these changes that they may or may not understand fully. I know that's kind of the gist of the Psychology Today article, but I wonder if you can just kind of give us a little rundown of a couple of things. How is the DD council or TABS kind of responding to this to the folks in Tennessee? And anything else you want to say about how we better support individuals with developmental disabilities kind of navigate this current landscape?

Emma Shouse Garton 39:48

Absolutely. So I'll say that the two fronts, both from kind of a national disability policy landscape and in terms of what the council focused on right out of the gate, the big fires to be put out. We were really concerned about the concept of whether or not in hospital shortages if people, our loved ones with disabilities might suffer negative consequences- might be put at the back of the line. There were several states, including Tennessee, that had policies on the book or guidelines that seemed to suggest that having different types of disability support needs or accommodation needs or diagnoses might really suggest that that they would experience discrimination and triage protocols. So that's been a huge national disability advocacy push and Tennessee's Developmental Disabilities Network, which

includes the Council, and the UCEDDs, and our Protection and Advocacy Agency, Disability Rights Tennessee and the ARC, several federal agencies having conversations with state policymakers about ensuring that disability discrimination doesn't happen in those instances.

Emma Shouse Garton 41:25

Another huge issue has been with all hospitals pretty much enacting no visitor policies. That's a huge concern for people with intellectual and developmental disabilities, who need support from a direct support professional or a family member in order to have their daily needs met or their communication needs met. That certainly was kind of one of my number one fears given that Evan is exposed to several different professionals, DSPs, every day. You know, he's luckily, unlike a lot of siblings of folks with disabilities, he's young and healthy, pretty much but if he were to ever have to be hospitalized, his communication barriers would be such that I would fear that it would end up in him being restrained or sedated if a family member or support professional weren't allowed to be there with him. So, that's been a big issue on the Council's plate. Actually, we just this week got to share that our Developmental Disabilities Agency and the Department of Health issued guidance, instructing hospitals that if patients with intellectual and developmental disabilities need to be hospitalized, that their need for a support person to be admitted with them, was a priority. So that's been a big relief. Then beyond that, I think I've heard from the siblings here in Tennessee through TABS and through our council members that folks are just really struggling with, as we all, with understanding what this disruption to our daily lives is going to mean and how long it will last and how to stay healthy and sane and safe with all of the protections.

Jeff Sheen 43:51

I wanted to follow up on these recommendations. Is that something that we could post, or that other people that are trying to address the same issue in their state, might be able to use as an example? Is that something we could get ahold of?

Emma Shouse Garton 44:04

Absolutely. So I'll mention a lot of states are tackling this at the state policy level. Some states have gotten guidance from their Governors or Attorney Generals directing hospitals to take that same approach of allowing support people to accompany someone with a disability if needed. A few states' protection and advocacy organizations, or P&As, have sued or filed complaints with the US Office of Civil Rights. Because, I mean, I don't know how sad to get, the heartbreaking reality is that folks with intellectual and developmental disabilities are dying alone in the hospital without being able to communicate with their family because the hospital staff doesn't understand the right ways to support them and communicating remotely. So this is a really troubling issue that lots of states are working really hard on, but I would be happy to share Tennessee's new guidance.

Jeff Sheen 45:19

Yeah. There's certainly a very somber component to this, right? And we can talk about system change and all these other things, which are really critically important. And in the meantime, there are individuals that we love and care about that are dying under really difficult circumstances as far as being alone. We've done a series of interviews in the last little while with some folks with lived experience and my good friend Justin, who is a Best Buddies coordinator and that's his passion and his life. He has been attending a lot of different funerals and using his phone to broadcast them to other people that care about these folks. You know, just talking to him, like the reality of that it just takes a minute to even process what that experience is like for him and these other families. So yeah, it's certainly an issue that has all kinds of components. But at the very heart of it is about loved ones, that we care deeply about experiencing really difficult circumstances. So we'll certainly refer folks to the article that we'll post from Psychology Today, where you talk a little bit more about this, would love to have the resources you're talking about to share with other people. I just really appreciate your time and all that you're doing and to have a chance to just talk to you and to get to know a little bit about what you're doing has been really delightful. I used that word a lot when I talked to your mom. It's just so delightful to talk to folks that are so passionate about what they're doing and are just putting their heart and soul into this work. So, I really am grateful for the chance to talk to you about that. I do want to give you a chance if there's anything that you wanted to say today that we haven't talked about, this would be a great time to have you just kind of share any of those thoughts.

Emma Shouse Garton 47:17

There's something I'm really passionate about letting professionals in the disability world know is, the power of peer support for connecting people with disability to self advocacy groups, connecting siblings to sibling support groups, and parents to parent support groups. I think there is so much about the disability experience and the experience of family members, that state programs are just not cut out to address. That Special Education or Voc Rehab or Medicaid waiver professionals aren't even really set up or equipped to meet those kind of interpersonal day-to-day mental health, emotional well-being needs of people with disabilities and families. There is such value and power in connecting people to those resources, not just in a moment of crisis, but the second that you have an interaction with a person with a disability or family make sure that they know about the resources in their community, where they can find some support from people who are on a similar life journey.

Emma Shouse Garton 48:32

I also always enjoy bringing or mentioning when talking about sibling issues, I think something important to remember is that siblings often bring a really different perspective to the table in terms of the strengths and skills and gifts and challenges that a person with a disability might face. You know, your relationship versus a parent child relationship. Sometimes we, as brothers and sisters, can see abilities in our brother or sister that mom and dad may not have considered or have been nervous to kind of push them or the whole dignity of risk thing. I've always been a whole lot more willing to challenge Evan and say, "No, he can make his own snack, I don't need to make a snack for you know, an eighteen year old. I might have to get some instructions." Toreally kind of push for those independent living skills, I think it's a really just a valuable perspective to have that that sibling point of

view at the table if there are brothers and sisters in the picture willing to be there. You know of course not all siblings are interested in being super involved. But if there are siblings in someone's life and you're supporting someone with a disability and trying to figure out what a good future will look like, I really think that brothers and sisters bring an invaluable perspective that you're not going to get if you only have professionals and parents at the table.

Jeff Sheen 50:26

I think those are lovely points to kind of wrap this up with. I really appreciate you taking the time, Emma, and those final thoughts that kind of bring it all back to some of the key points. So yeah, thank you for taking the time to be with us today.

Emma Shouse Garton 50:42

Absolutely. I'm so glad to have been invited and to have had this conversation with a fellow sibling.

Alex Schiwal 50:50

music plays Thank you for listening to the MHDD Crossroads podcast. Make sure to like, subscribe, and share this podcast wherever you get your episodes. Also, make sure to follow us on social media at MHDD Center or visit our website for more resources at mhddcenter.org. Until next time, thank you.
music plays