

Interview with Janet Shouse

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SPEAKERS

Janet Shouse, Jeff Sheen

Jeff Sheen 00:04

(music plays) Welcome to the Mental Health Crossroads podcast. I'm your host Jeff Sheen, and today I have the opportunity to talk with Janet Shouse from the Vanderbilt Kennedy Center. Janet has been a previous guest as part of a panel on participatory action research for our podcast episode released in April. So I'm delighted to talk to Janet again on an individual basis to talk about some of the work that she's been involved for several years at the Vanderbilt Kennedy Center. So Janet, thank you so much for joining us again.

Janet Shouse 00:38

Thanks for having me.

Jeff Sheen 00:40

I am very excited to talk to you today. I know from our previous discussions, that you wear a lot of different hats, and that you have been involved in a number of projects. So I'm wondering if we could start by just you giving us a brief overview of how you came to be working in the disability field. I know that you have some lived experience as a mother of a child with a disability, and so love to have you include that part of your story as well. So give us a little bit of background on you.

Janet Shouse 01:12

Okay, well, um, I was actually a newspaper copy editor for many, many years here in Nashville, Tennessee. And we have a son with autism, who is now 24, and my husband and I got very active in the disability community almost immediately after Evan was diagnosed. My husband took a more prominent role in terms of working on boards and being board chairman and that sort of thing. And he worked with our local Autism Society for a number of years and then he worked with the Autism Society of America, and now is working with the ARC Tennessee. I did more of the behind the scenes stuff I served as what we call it county contact for our local Autism Society so that when families got a diagnosis, I'm going to talk them through what the diagnosis meant or if they were moving to our area, what kinds of resources were available and that sort of thing. Ran support groups for families, because I worked evenings I had my days free to do a lot of this work.

Janet Shouse 02:26

I started at the Vanderbilt Kennedy Center as a member of their community advisory council, as a parent of a child with a disability. And then in 2009, the newspaper I worked for decided I should explore my opportunities elsewhere as they were going through several rounds of layoffs. And so the Kennedy Center was just starting a project, the director of the Kennedy Center Elizabeth Dykens at that time, was starting a project called the Parents Stress Center Intervention project in which she was going to do two different interventions with parents of kids with disabilities. One based on positive psychology, one based on mindfulness. And she announced at the Community Advisory Council meeting that she was getting this grant. And they were going to try to hire, this was during the economic downturn of 2008-2009. And they were going to be hiring unemployed parents of children with disabilities to do the interventions, because they felt like it was important for the people providing you interventions to have lived experience. Because it's one thing for a professional to tell you well, you need to do this and this and this to reduce your stress. And the families can say, 'Yeah, but you don't live my life.' So they wanted parents to be able to say, 'Well, you know, this actually works even if you have a child with a disability.'

Janet Shouse 04:02

So I was recruited to do the positive psychology intervention, even though I really didn't have much experience in psychology. But I had asked during the community advisory council meeting, would they like to employ me? And Dr. Dawkins said, Well actually Janet, we thought of you, which I thought was her just being gracious in this big meeting. But I found out later that actually they had thought of me for this position. And so I spent three years with this project. We did two years of both the mindfulness and the positive psychology, and actually published a paper in pediatrics about primarily the stress on mothers of children with autism. Because that was the the primary group that we had the largest group we had were mothers of children with autism. And we found that while both interventions worked, the positive psychology worked really well during the time that the classes were meeting, that support group meetings were meeting. But if people actually incorporated the mindfulness into their lives that that had a greater longer term benefit.

Janet Shouse 05:31

And then at literally the day after that project ended, I was hired for the IDD toolkit. And the idea behind it was to take tools that had been created in Canada, through their Developmental Disabilities Primary Care Initiative and make them more accessible. They were current at that point, in a book that was distributed throughout Ontario, Canada, as Ontario closed its developmental centers. They, the government, was concerned that the primary care physicians in Ontario would not have the knowledge and experience because these people had been getting their care in these large developmental centers. They wanted to get some training out. So they sent out these books and they did some training in-person and online. And then one of the figures in that training was a guy named Dr. Tom Cheetham, who came to Tennessee as the director of health services for our department of intellectual and developmental disabilities. And he saw the same need for knowledge and training and experience here that he had seen in Canada. So he helped us get a grant from the, what was then called the Special Hope Foundation, which is now called the WITH Foundation, which stands for Working Inclusively

Together for Healthcare. So we were able to, in agreement with the folks from Canada, to take their tools, which were based on consensus guidelines that they had created and put them online.

Jeff Sheen 07:23

Janet, let me stop you there for just a minute. We're going to get more into the toolkit in a little bit more detail. But you said a couple of things in this in this overview that I wanted to circle back to. So you start this work at the Vanderbilt Kennedy Center. As a parent, you don't stop being a parent during this time that you're taking on this new role, right. So you're going through these developmental stages with your children, including your son with autism, as you're also advising other families and parents about your experience. How was that working for your family at that time? What were maybe some of the unique challenges that you felt you were facing? Or what was the strategies that you were using to kind of do all of these things? Because you also referenced your husband was involved with boards and it sounds like both of your careers kind of shifted into full disability field focus pretty early on.

Janet Shouse 08:22

no, John has maintained his work as an engineer.

Jeff Sheen 08:26

Okay.

Janet Shouse 08:27

All of his advocacy and disability work is strictly within a volunteer realm. So he spends lots of hours outside of work. Although his his company has been very generous in allowing him to do some things during work hours, but he also ends up taking a lot of vacation time to participate in like national conferences and such.

Janet Shouse 08:56

Fortunately, because of my work, a lot of times what I love to do and what I get paid to do fall in the same realm. The big issue for us was because I worked evenings for many years, we only needed childcare a few hours in the afternoon. Suddenly, I was working a day shift 40 hours a week. And so making sure that we had childcare was a huge barrier, because my child was not able to go to a regular daycare setting, like that they before and after school care. And then, of course, in our state, as I'm sure as in many others, school aged daycare ends at 12 and my son needed supervision and care. Welll he still does, at 24. So finding childcare providers to look after him was a was a big challenge over the years. But it allowed me to have stories to share in our parent mentor meetings, because I was living some of the same struggles that the families themselves were dealing with.

Jeff Sheen 10:27

Sure and I think that's what such a powerful part of the University Centers for Excellence on Developmental Disabilities you said, which the Vanderbilt Kennedy Center is, have done a great job for the most part of including parents with this lived experience to work on projects geared towards other parents so that there was that rich expertise of the lived experience that you were able to draw on and also to build empathy and cohesion and to be able to let the other families know 'I get this I understand this because I live this too.' But I have the opportunity to help kind of maybe you navigate this system and, and things like that which I'm sure was helpful as you started your work on the the health care for adults with intellectual and developmental disabilities toolkit that you've started to reference. So I would love to talk about that in a little bit more detail, you kind of give us a little bit of the backstory with Dr. Cheetham and some of the materials from Canada. But if we can dive into that, I'd love to hear more about your work on this toolkit, kind of what its primary purpose is and maybe we can go from there.

Janet Shouse 11:37

Okay well, the website is very simple. It's www.iddtoolkit.org. And it is primarily aimed at medical providers, so some of the language is, for lack of a better term, highfalutin. It'll mention, for example dental caries, which most of us refer to as cavities. It uses the medical terminology. But it helps physicians and nurses and physicians assistants to think about when they encounter an individual with an intellectual or developmental disability. Maybe some of the differences they need to keep in mind, because while everybody needs regular ol' primary care, people with IDD often present additional barriers and also have additional conditions that most individuals don't present with at say 20 or 30.

Janet Shouse 12:48

So the toolkit is broken down into really four major sections. One is called general issues, which there's a section on communicating effectively, because we know that many people with IDD have communication barriers. In some instances, they may not use language, they may use an alternative communication device. They may have, may not be able to read, either because they they don't have vision or because they don't have the intellectual capacity to read. So learning to communicate effectively with people who have communication barriers. There's a couple of sections on informed consent one kind of walking you through what it is. And then there's also a checklist to run through to see if the person you're working with is able to give informed consent, because that's sometimes is a concern for medical providers. There's a section about adaptive functioning and levels of intellectual and developmental disabilities to give people who aren't really aware of the various levels.

Janet Shouse 14:04

I will say this, some of that doesn't work very well, because my son, his IQ score would have him be in a higher level, but if you look at the communication abilities that are listed with that he doesn't have those communication abilities. He has extremely limited abilities to communicate either verbally or with a device. So, there are some discrepancies, but that gives you kind of a broad idea. Then there's organizational office tips. So how to set up your office to be accommodating. You know, are there physical barriers if someone's coming in in a wheelchair, or their sensory issues for people who may be

extremely sensitive to maybe crying children or long waits. Then there's what's called a today's visit form, which we understand most medical providers have electronic medical records and that's not really going to fit in very well with them. But for some folks that may help guide their visit. And families can print that off and walk through that with their loved one to make sure that they're really focused on a particular issue rather than coming in with a whole boatload of things to talk about. Because we know medical providers have limited time to see most patients. The average office visit is two minutes. And for most of our folks, it generally takes longer than that.

Jeff Sheen 15:45

Well, and Janet, I'm just looking at that particular tool right now. And it's certainly a printable form that a family or an individual could fill out ahead of time and looking through it. It's actually something that would benefit it's kind of universal design, right? It would benefit most people to walk through these, these kind of questions about what the main health concern is for the day, and to keep you focused. I know that when I go to the doctor's visit, I often forget all of the things that I wanted to ask. So I do take my own little notes. But then here's a form that many people could use, either parents are individuals to help them remember the things they did want to ask during their 15 minutes with the doctor so they could stay focused. So shout out to this is just a great little tool for most of us to use. So I'm curious and I want to get back to the rest of the toolkit, because this is a great to have somebody that was involved with it do this overview for us. When did this first come online?

Janet Shouse 16:43

It came online in January 2014.

Jeff Sheen 16:47

Okay, so we've been around for about six years now with this. I was reflecting on that, because back in around 2005 I was doing some focus groups with local dentists here in Utah. About how they were serving children with Down syndrome, or autism and kind of what their lived experience was as a dental provider, dental care provider. I would have loved to have been able to refer them to this, but it was about 10 years too soon when I was having those conversations.

Janet Shouse 17:20

Sorry about that.

Jeff Sheen 17:21

Yeah, it's- no, we appreciate that it's here now and so I'd love to have you kind of jump back into to the other three sections that you were talking through?

Janet Shouse 17:33

Well, the next session, the next section is about physical health issues. There's a cumulative patient profile, which again, in the days of electronic medical records is probably not all that useful, but it could help guide the way you set up your EHR (electronic health record). There's a preventive care checklists for females and one for males and there are specific things to watch out for for people with intellectual and developmental disabilities on that preventive care checklist. And one of the things we know is that many individuals with intellectual developmental disabilities do not get the preventive care that most of us get. One thing I was stunned to learn not too terribly long ago is that people who receive state Medicaid services with Medicaid waiver services actually are more likely to get preventive care than individuals who still live at home with their families. Which as a family member, I was like, Wait, what? How can that be? But the state often mandates how often people have to see a medical provider and they have to get routine checkups and they have to get routine vaccinations. And sometimes as family members we think, is it really worth the hassle to do this because maybe my loved one doesn't do well at the doctor's office or doesn't do well with that kind of exam. And so, you know, they seem like they're okay, do we really need to do this? And I would encourage families and everyone to get the regular preventive care that all of us should be getting.

Jeff Sheen 19:37

Yeah, that's a that's an excellent point. I appreciate you pointing that out. And then I know there's this Cheetham's Checklist is I'm assuming that's referring back to to Tom, Dr. Tom Cheetham.

Janet Shouse 19:48

Dr. Tom Cheetham was a family physician, who worked more than 30 years specifically with individuals with intellectual and developmental disabilities. He actually started out as a house manager for a group home in Ontario, Canada. And then he became a family physician and worked both in a large developmental center, which at one time, I think he said held about 2,000 people. And then he also had a private practice in which he pretty much emphasized work with adults with IDD. And that checklist really talks about if someone's having some kind of behavioral issue what to think about. He talks about blaming the drugs first, because many of our loved ones take a lot of drugs. Sometimes they take drugs to fight the side effects of other drugs, which then can lead to additional side effects. But he talks about, you know, looking at pain, looking at is it possible that they're constipated? Because he actually recounts an instance of where a patient has died, because the gentleman was constipated and he did not recognize it in time. He was just a fabulous man he passed away about a year and a half ago, and we missed him terribly. But he created that checklist kind of on his own, and we just thought it was such a good checklist that we wanted to include that as kind of a hat tip to Tom and his work.

Janet Shouse 21:38

Yeah and I think that's a nice piece of his legacy to have on here and kind of a tribute to his work. You know, certainly some of that was probably on the very front end of a lot of these conversations and working with these families and individuals. I want to just pause here for a minute and just for those of you that are listening to this podcast, it's probably a really great opportunity. If you can, if you're not

driving or doing other things, to have the website actually open as Janet kind of runs us through and you can be clicking on these different things. We'll certainly post these links to our show notes. But I'm just having I've got it here open as well while we're talking. And so as Janet's referring to these different things, I'm able to click on them and look at them briefly. I would encourage our listeners if you're in a spot to do that that might be a nice way to listen to this particular episode is with that particular website open. So the next thing on here is the is the health watch tables. And I know that you've had a big part in that and so really like to spend some time, maybe particularly the autism on the you could run us through how these are developed and their kind of purpose and role.

Janet Shouse 22:43

Well, this is my actual favorite part of the toolkit are the Health Watch Tables. They are created in Tom's language, a review of body systems, so it walks you through. The first section is about eyes, ears, nose, and throat, and then it goes on from there. And I'm just going to click on one so I can walk through it more easily. And it does give things both for children and adults, because the Canadian guidelines and the Canadian tools that this is based on, they deal with family physicians. Now, those are the gatekeepers in Canada's health care system. So while our work is primarily targeted to adults, the Health Watch Tables also include language about things to watch out for for children.

Janet Shouse 23:42

So in the first column are considerations. Then in the second column are recommendations for the medical provider to think about in terms of these considerations, and so under autism, under children it says hearing. recurrent otitis media is common Well, that's recurring ear infections. And as a parent of a child with autism, I can tell you we had ear infection after ear infection after ear infection. Then it suggests, you know, visualizing the tympanic membrane at each visit. Well that means checking the hearing by using a little device that measures how flexible the eardrum is. Referring to an otolaryngologist if the ear infection continues. Screening vision and hearing regularly. Checking for nasal allergies. These are all things that that are more prevalent in this population that if you're not familiar with you may not be aware of so it walks you through things. Dental caries are common and individuals have sensory sensitivities may not be thorough in their tooth brushing. And restricted diets may predispose some to dental caries. Again, that's cavities. And I don't know how many of your folks have experience with people with autism, but Evan is what we refer to as a crunchy sort. He eats nothing that requires a spoon, no soup, no pudding, no yogurt, no ice cream. Fortunately, the things he likes to eat are not highly sweet. So we haven't had a lot of problems with cavities. But there are many folks with autism who only eat like five or six spoons and depending on what those are, those could easily lead to cavities.

Janet Shouse 25:45

We have a section on sleep because that's a big issue among people with autism. Gastrointestinal issues is the next one. Then it talks about sexual function and musculoskeletal systems. Neurology, seizures are relatively common in people with autism and you need to be alert to that. Tic disorders are more common. There's a section on mental and behavioral health, and then infectious disease and

immune deficiency. That's an issue for many people with autism. Then it talks about etiology or the origins. And we don't yet at this point know a lot. We know it is a heritable trait, but we also know there are some environmental factors. And then the last category is others, which says up to 50% of individuals with ASD may also have an intellectual disability. So each of these Health Watch Tables, walks you through those considerations. And there's one for Down syndrome, fetal alcohol spectrum disorder, Fragile X, Rader-Willi Syndrome, and something I had not be aware of until I started working on this. And that's 11 or 22Q11.2 Deletion Syndrome, which is kind of a, again, it's a spectrum, depending on how much of the chromosome is deleted. But Autism is often a frequent part of that syndrome as well. But this is just a really good thing.

Janet Shouse 27:29

This is good for families and for medical professionals to just be aware of some of the things like for example, fetal alcohol spectrum disorder. It talks about how oftentimes individuals with this syndrome will appear much more competent than they really are. And unfortunately, they will end up involved with the judicial system because it seems seems like they are more capable of making good decisions than maybe they actually are. And that was not something I was aware of when I started working on this project. So that was very enlightening to me.

Jeff Sheen 28:16

I appreciate that you pointed out that this is information that is great for you know, it's geared towards primary care providers. But it's also very helpful for family members and individuals. I was looking through and I just want to point out to the listeners, as you look at these, you know, Janet was the project coordinator on this toolkit. They had an advisory committee and these are well cited, academically well cited materials. And it looks like on the Autism one there was 15, 16 PhDs MDS with expertise in these different areas that reviewed and made sure and vetted these these materials. So certainly they are well cited and from very reputable sources. So I think that that's an important thing to point out to those that are using these resources. And I noticed that in each of the watch tables, there's a section on behavioral mental health. And then you also have a separate section on the on the homepage of behavioral mental health issues. Maybe we can talk a little bit about that section now.

Janet Shouse 29:18

Yep, that's the next section. And there are several different things. One is the initial management of behavior crises in primary care. So if you're, if you're having a behavioral crisis, and you're dealing with a primary care physician, this gives them information on how to deal with that. It also has been used by I know at least a couple of state intellectual developmental disability services offices, and in their work. There's a risk assessment tool for folks with IDD.

Janet Shouse 30:00

And then two things I really, really like there's a behavior problems and emotional concerns checklist for providers, but then there's also one for caregivers and families. And the thing that I like about it, the

provider checklist sort of incorporates the information from the family or the caregiver. But if you look at it, it talks about first of all, you know, what is the person's developmental disability? What is their level of functioning? When did the behavior start? When were they last at their best? And then it gives you an idea of whether the risk is significant. Is it aggression, is it self injury, and then it talks about other things like, has there been changes in the person's mood, their bowel or bladder continents, their sleep, which I work with a neurologist who's a sleep specialist so sleep is always one of those questions. She asks first, has their social involvement changed? Has their self care changed? And then it talks about, you know, would you know, if the person is in pain? How would you know if the person's in pain and then changes in the environment. Sometimes people have behavior issues, because of changes in their routine in their environment.

Janet Shouse 31:42

And then, do they have vision or hearing problems? Maybe the reason they're not doing what you're asking them to do is they can't hear you asking. They're not being non compliant. They're just not hearing you. And then as we've heard for many, many years, that Evan's behavior issues may stem from his inability to communicate accurately what he's thinking and feeling. But that is probably true, we still haven't found that magic device or system that he seems to want to use to communicate with us very well. But, you know, for some people, giving them the right device can make all the difference in the world, in their ability and their desire to communicate.

Janet Shouse 32:37

Is what's going on around the person too stimulating or are they bored, stiff, you know, some people act out because they're bored. They don't- they're not being incorporated in the activities of the day, whatever those are, and so they're going to get attention some way. Or they may be overwhelmed by what's going on. And they may be, quote unquote, acting out, because they're overwhelmed. And it just walks you through some things that we may not always think about. One of the things is the individual beginning to recognize that they're different from their peers? Particularly like in high school, and in that transition age, if they've had siblings go off to college or their peers are going off to college. And they're not going off to college. They're either staying in a transition program in their high school, or they're staying at home. They may be being really emotional or behaviorally challenging, because they've seen their friends and their siblings go off and do things they're not allowed to do. So I think it just really helps people think about why might this person be had be having either emotional or behavioral concerns in ways that maybe everybody doesn't think about? So that's one of my favorite parts.

Janet Shouse 34:20

Then there's a psychiatric symptoms checklist, which is really quite simple. It just walks you through, is this person showing symptoms of these various disorders? And when did they start? And how long have they been going on? And how severe are they? There's an antecedent behavior consequence chart for anybody who's involved in behavior analysis. This is like class number one, but for many people who aren't involved in that, and there's even one that's been completed so that if you're not

familiar with how to complete such a chart, you can. There's a couple of sections on crisis prevention and management. There's a planning tool, and then actually a form to complete.

Janet Shouse 35:09

And then there are a couple of sections on psychotropic medication. There's one talking about the issues involved, because unfortunately, a lot of our loved ones receive psychotropic medications, not because they have a psychiatric condition or a mental health condition. But because it's a way to modify their behavior. And what we find out is oftentimes, it doesn't do a lot to modify their behavior. But sometimes it's the only thing that people know to do. So this section walks you through, thinking, why are you doing this? Why are you prescribing this? And then a checklist that if you do prescribe it, what are you trying to change? Is it effective? Are you monitoring? Are you titrate? Are you dosing up slowly, because it's the best advice is to start slow, go low, and then work your way up. Because many of our folks have a heightened reaction to medication and what you would start as an average dose for an average individual may be overwhelming to someone's system. So that's kind of a broad overview.

Janet Shouse 36:28

Then there's a couple of other things I do want to point out. We have online training available. And it's in the middle of this homepage. One is for healthcare professionals, and they can receive an hour and a half of CME credit by watching our eight pretty brief video modules. And then there's a little short pretest and post test with each one and then there's training for individuals, families, conservators and other caregivers. There is no CME for that. It's just if you want to watch and there are pretest and post test with that too, but mainly just to kind of drive home the kinds of things we want. And the fun part about that is our patients are people with intellectual and developmental disabilities. In most of the videos, they are playing people who are more communicatively challenged than the individuals are themselves. But we felt like since that's one of the things that we believe causes medical providers to have greater concerns about serving this population we wanted to give those we kind of wanted to highlight that as part of the issue involved. But we had some great actors, play our patients and then you would get to see me as a direct support professional and a parent, and you also get to see Dr. Cheetham in action. And he's wonderful. And then my colleague, Dr. Beth Malow, who is also playing- she plays a really ratty doctor in one video. She was a good doctor in a couple of others. So.

Jeff Sheen 38:24

That's great and I noticed to the right of the homepage, there is a little remembrance section for Dr. Tom Cheetham. So I would encourage folks to review that as well. Janet, this has been so helpful to have someone so involved in the development of the toolkit as well as how you interwove your own lived experience with these issues as you talked about these different tools. I appreciate that you pointed out your kind of favorite part as far as the behavioral problems and emotional concerns caregiver checklist. I think that's incredibly helpful, but what a real treat to have you as the person project coordinator on this walk us through this tool. I know that the MHDD project that that I'm a part of has listed this in our on our resource page inside it and reference people to go here. But that makes me think about just kind of a wrap up question is how has this -how have you seen this being utilized thus

far? And what plans if you need you have to hopefully expand the number of people that access this resource? Because clearly as you've gone through it with us, there's a tremendous amount of very helpful, very accessible information here that I think more and more people need to know about. So, talk to me a little bit about how it's been used so far, and kind of maybe what plans are for the future?

Janet Shouse 39:47

Well, I have done trainings across the country about the toolkit, which sounds a little weird. I actually did a conference a couple of years ago to more than 400 people. The ARC of New Jersey invited me up because they have a mainstreaming medical care conference each year, which is fabulous. And the coordinator called me and asked me if I wanted to be the keynote speaker. And honestly, when she did, I was like, 'Wait, do you know who you're talking to?' And she said, 'yeah.' And I said, 'and you want me to be the keynote speaker?' And she said, 'Yeah, about the IDD toolkit.' And I'm like, 'Oh, okay.' And I was thinking, how on earth did she find me? Well, she found me through an ECHO project that was being done out of New Jersey, that I had been connected with through Dr. Malow. So I went up and presented to 400 people about the toolkit, but I've also done conferences all across Tennessee. And we have worked with the American Academy of developmental Medicine and Dentistry, which is a wonderful, wonderful organization that if you're not connected with and you have any interest in this field, you should connect with. They have put us on their website.

Janet Shouse 41:19

One of the things we have just added in the last day or two is there's a red little banner at the top about Coronavirus resources. These are specifically for adults with intellectual and developmental disabilities so it's easy to read explanations of the Coronavirus. Video. Short simple videos about washing your hands appropriately. I try to think of the kinds of things that would appeal to my son. So this is obviously not for everybody but for people who need those easy read. Those graphics, those visual supports, and I try really hard not to overwhelm people. Because so much of the time when I go to resources for families and individuals, you'll find like 85 things. And at that point, I'm just so overwhelmed. I don't even want to click on any of them. I try to be really judicious about what I share. I try to make it pretty clear as to what, what it is that you're going to be looking at.

Janet Shouse 42:43

So we have a social story about the pandemic. We have a little graphic about why community participation is limited at this particular point in time. And we are hoping to complete a couple of new Health Watch Tables we've been working on one on cerebral palsy, which has been asked for for several years. And then we're also getting ready to do one on Rett Syndrome. We hope to have those up fairly soon. The folks in Canada have released new guidelines that the tools were based on, and we will be linking to those new guidelines very shortly. They are updating some of their tools and those will also be linked from our homepage. I'm always willing to talk about the toolkit, because I think it's it's very helpful. I appreciate the opportunity to talk about it today.

Jeff Sheen 43:57

I think it's been a very lovely conversation and very educational. I think it's impressive that you've been able to put up so quickly some Coronavirus specific resources and we'll certainly probably use some of our MHDD resources, social media to help push some of those things out because that is so needed.

Jeff Sheen 44:15

Right now, I did want to circle back because we had an earlier conversation and do another shout out for the American Academy of Developmental Medicine and Dentistry. Janet described this conference as akin to the same level of energy one would find that their favorite concert from their favorite musical artists, and for me, that would be Pearl Jam. And for Janet, that was John Denver. So if you're into either of those bands, that's the level of energy that is at those conferences. So I think that's an impressive endorsement. I also wanted to do just, as we wrap up, Janet, the other part of been getting to know you it's been so delightful as you've connected me and refer me to your daughter, Emma, who works for the Tennessee Developmental Disabilities Council. And I'm going to be reaching out to her because we'd love to bring in a sibling perspective to some of these issues. And so I'm excited to do that. I know our producer Alex and myself are both siblings of individuals with developmental disabilities. And so it's a it's a topic and an area that we're familiar with. And I'm excited to talk to Emma. And you gave me permission as her mother to reach out to her. So I look forward to that.

Jeff Sheen 45:34

As we wrap up, are there any other thoughts that you didn't get to express that you'd like to share with our audience?

Janet Shouse 45:40

Well, I didn't talk about the other hats I wear.

Jeff Sheen 45:42

This is true. And I think you wear enough that we might have to do a series of podcasts with you. Because that reminds me I have lots of questions about the positive psychology and mindfulness projects and where those materials might be. Do you want to say what what's kind of happened with those projects?

Janet Shouse 46:00

There are materials for sale, for groups to do the mindfulness and the positive psychology. I would have to get the website. I don't have that off the top of my head. But those are available.

Janet Shouse 46:19

I also work on a project called Tennessee Works, which is trying to improve the employment landscape for people with disabilities across Tennessee. And as part of that work, I write and coordinate a blog. Now some of those blogs are Tennessee specific, but some of them are broader. And we do have readership outside of Tennessee. My focus there is primarily on families and individuals with intellectual and developmental disabilities. But sometimes I take that broader and it's supposed to be the intersection of disability and employment. But again, I take that broader and I sometimes include things about health care, and Medicaid waivers, and that sort of thing. And if anybody wants to go there, it's www.tennesseeworks.org. And if you want to go across the top, there's a Rise to Work blog tab. And you can see our archive of blogs. One of the most popular has remained something I pretty much fired off in a moment of desperation called the dignity of risk, which if folks are not familiar with. Not that I'm wonderful writer, but it's a topic that I think families and individuals themselves need to be aware of. And like I said, it's been one of our more most popular enduring blogs.

Janet Shouse 47:53

I also work on a project called the Center for Dignity in Healthcare for People with Disabilities. And right now we're doing a gap analysis on what are some of the discrimination issues and bias issues that people with disabilities face in healthcare.

Janet Shouse 48:11

And I'm also working on a project with Dr. Beth Malow through the Department of Defense to try to improve health care for adults with autism. Specifically, we're going to be launching an ECHO project which ECHO stands for Extending Community Healthcare Outcomes. We use Zoom video conferencing, with a team of expert clinicians as our hub team. And then we invite community healthcare providers, either physicians, advanced practice nurses or physician assistants, to join us from wherever they are in the country to do case presentations, and brief didactic presentations about issues that are common in adults with autism. So where we'll begin recruiting for that project, it's the ECHO itself launches in November, and we will be recruiting soon for that project.

Janet Shouse 49:18

So, we're trying to improve healthcare in a number of different ways. As you mentioned, that's something I'm pretty passionate about. And one of the reasons I love AADMD because that's a group that that's their sole focus. And so...

Jeff Sheen 49:40

You know, that really is and all kidding aside probably enough material to do a whole series of podcasts with you. So what we'll we will do is we'll be sure to put all of the different links to the projects and resources you mentioned in the show notes. We'd encourage folks to look through those until we have a chance to interview you again, about one of these other hats that you're wearing. Again, Janet, thank you so much for taking the time to spend with us today and to talk specifically about the toolkit. And all

of the other things you're involved with. It's it's been a real delight, and it's one of the fun parts about this job is getting to meet new people and connect with them and make some friends and learn a lot of stuff along the way. So thank you.

Janet Shouse 50:22

Well, I appreciate the work you all are doing because mental health in this particular population is a pressing issue that doesn't unfortunately, get a lot of attention. And a lot of providers don't really have a good idea of how to approach our loved ones. So the work that you're doing is extremely important. And I am delighted to be able to talk with you and share a little bit about what we're doing and want to do whatever I can to support the work that you all are doing

Jeff Sheen 50:57

And we certainly appreciate that endorsement and look forward to working with you and another folks at Vanderbilt Kennedy Center and others around the country. To all do our part to elevate these conversations and make progress in this area. So thank you, Janet. We'll talk with you soon. (music plays)

Jeff Sheen 51:17

Thank you for listening to the MHDD Crossroads podcast, where we explore the intersection of Mental Health and Developmental Disabilities. We hope you enjoyed our conversation with Janet. All of the resources mentioned in this episode and a full transcript of the episode are linked in the show notes. If you liked the content we provide make sure to subscribe, listen, and share wherever you get your podcasts. Remember to follow us on social media at MHDD Center for more great information.