

Episode 19: Interview with Mark A. Smith

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Speakers: Alex Schiwal, Mark Smith, Tatiana Perilla

Alex Schiwal 00:09

Hi, and welcome to the MHDD Crossroads Podcast, where we explore the intersection of Mental Health and Developmental Disabilities. In this episode, Tatiana interviews Mark Smith. He's from the Nebraska UCEDD and also sits on the advisory board for the Mental Health and Developmental Disabilities National Training Center. We hope you enjoy this interview.

Tatiana Perilla 00:30

Hello, everyone. Thank you for joining us on the MHDD Crossroads Podcast. I'm joined today by Mark Smith. He is a member on the MHDD advisory board. Mark, I think you would do a better job of introducing yourself than I would. Can you introduce yourself to our listeners and tell a little bit about your various professional roles that you've had in the disability field?

Mark Smith 00:53

Hi again, I'm Mark Smith, middle initial A. I work at the Monroe Meyer Institute for Genetics and Rehabilitation. It's the University Center for Excellence for Developmental Disabilities, as well as the LEND, the Leadership Education and Neurodevelopmental Disabilities, for the state of Nebraska. We're located at the University of Nebraska Medical Center. I've been on the staff here, I served as a faculty member, coming up on about 20 years. My training is in school psychology and a lot of that work that I did was much less focused on the traditional role of school psychologists, that being assessing children for eligibility, and much more focused on children with behavior disorders. I also have experience in working with adults with intellectual and developmental disabilities with behavior disorders, private clinics, and service provider settings and quite a few in the community. Primarily, I'm also a parent of a young man with intellectual disabilities and have a younger sibling with intellectual and developmental disabilities. The whole disability piece has been part of my life, all through my career going back to growing up. It's really had an impact on my life and career in a major way. A lot of the work that I do here at Munroe Meyer is less focused on clinical work and around behavior, behavior

management, behavior disorders, and is much more focused on leadership, policy, and family support.

Tatiana Perilla 03:06

Thank you. Speaking of which, you just mentioned that you're a sibling as well as a parent of individuals with disabilities. I was wondering, are there ways that you've found that your experiences as a sibling and as a parent have helped you in your professional work?

Mark Smith 03:23

I don't know if it's necessarily helped, other than it kind of guided me in certain directions. A lot of folks that I talk to that find out that one of my kids [has a disability] - I have three kids, I have two girls and my son- and find out that I'm a parent will say "Well, did you go into this work because you found out you're parent?" I probably went into this work more as being an older sibling. When I was making career choices and looking for employment after school, my experience with my younger sister really guided me in some ways. Now, I do have to say that a lot of the work I do is in family support but also in advocacy policy and legislation. My work in that latter area was really guided in some ways by the birth of my son. He was born right around the time that Early Intervention services were being started all across the country. That guided me towards working in early childhood services and working with families with young children. It had its impacts. I can't say that it helps in that... Like, when my son was born, I felt like, I kind of know my way around disabilities. That was a little bit of hubris, I think, because I didn't have the experience of being a parent of a child with a disability up to that point and the learning curve was a little steep. I was on the other side of the table talking to professionals like myself, and dealing with some of the issues that those families dealt with. I think my experiences were typical for anybody. I always had an interest in psychology, and I think my relationship with them influenced me in certain directions.

Tatiana Perilla 05:53

I was curious if there are ways you think disability policies and services can be improved? Either because of personal experiences or from your professional experiences.

Mark Smith 06:04

Let me take one step back for a second, Tatiana, based on what you said. One thing that it really has helped, in terms of being a parent, is when I'm working with groups of parents. Then we're all parents, and the similarity of experience, in terms of some of the challenges of raising a child with a disability, is something that we have in common. I work on several national workgroups where that is the focus. It gives me entree into some discussions with some tremendous national leaders, so I feel really fortunate. But without that, I would kind of be on

the outside looking in. Your follow up question to that, though, was... Could you repeat it? I'm sorry.

Tatiana Perilla 07:05

No, no worries. I went on for a little while. It was asking if there are ways that you've seen, either from personal experiences or professional experiences, that you think disability policies can be improved? Or disability services.

Mark Smith 07:17

Well, that's a long question that might require a very long answer. What is going on nationally is a movement towards focusing more on the individual as the guide for their own services, when we talk about adults. The whole issue of transitioning, from family-focus for children to adult-focus, it's kind of a mixed bag out there. That can be problematic. In the state that I work in, in Nebraska, we have a huge waiting list. We have a lack of specific resources to help folks be successful in the community. That's my main focus, how do we help individuals become or remain successful, in terms of their ability to benefit from community living. There is a lack of, I think, leadership that is focused on addressing that. I think there's some siloing and there's some fragmentation. What we see from a number of years ago is a lot of different disability-specific organizations that do a very good job, but they're kind of siloed away from others. When you talk about the fact that 20% of all Americans at any given time would have a disability, any kind of disability, that's the largest minority in the country. Yet, there's really a lack of willingness, or interest, or emphasis to collaborate and work together to try and improve policies. Again, to help people be optimally successful, to have the supports they need, and to have the services they need.

Mark Smith 09:57

I always look at it in terms of, we're all interdependent. The joke I make is that I wouldn't do my own dental work. I would go to a dentist, and of course in my community there are numerous dentists I could choose from. A person with specific disabilities may not be quite so fortunate, may not have as many choices, or any choices whatsoever. A great example in Nebraska is as we move out of the metropolitan areas, the urban areas of the state, into the rural areas we run into areas where there are no services at all. One of the challenges that my program faces is trying to reach out to those individuals. There is just a plethora of issues. But I think it all comes back to this idea. People with disabilities are out there. They have needs. How do we ensure that communities are prepared to have the services and supports to help those individuals be successful?

Tatiana Perilla 11:10

Thank you, I appreciate that response. I like how you mentioned rural areas, because I think that is a big challenge. I know I grew up in a rural area and having to drive multiple hours just to get somewhere. Because although we have those services available in town, it doesn't guarantee that they're going to be the best providers maybe for your situation, whatever services you're looking for. So you might have to drive far away, even if you do happen to have someone there. I really liked that you touched on that. I was also wanting to ask you about schools, because you mentioned that you were a school psychologist. What are some ways that you think schools can better support students with disabilities who have mental health conditions?

Mark Smith 11:56

Well, you just added a factor in there. One is the issue of training for educational providers. I have run into numerous circumstances where teachers might not have gotten much, if any, preparation in terms of their education and their experience in working with kids with challenges. Some of that goes back to the issue of kids with intellectual and developmental disabilities and the behavior issues they might present. There are some disabilities that fall within that category, where behavior problems are part of the disability. On the other hand, you might have a child that has an intellectual disability, but also has a diagnosed mental health disorder. In either case, teachers are immediately challenged to find the level of support needed to ensure again this idea of how can we make that child successful in the classroom and in the school.

Mark Smith 13:21

In terms of therapies, in terms of monitoring, in terms of the environment, one of the ways that I've worked in the clinical work that I've done over the course of my career is to really try and build plans where the environment leads that child towards better choices, in terms of the kinds of behavior that they exhibit in given circumstances. I've worked with teachers that are just terrific and just know. I don't know if that came to them naturally or if they were just really well trained. But they get it and they are able to set up their classrooms or other parts of the school day for that child, where we're able to get a lot accomplished. Some of the issues that are leading to behavior concerns and exhibiting behavior problems are mitigated. Other teachers are like, 'this isn't what I signed up for. I don't know why I have to deal with this.'

Mark Smith 14:42

In fact, the nexus of policy and behavior, one of the things we're dealing with in my state, is that there's a big push to really open the doors to a lot more restraint and seclusion in classrooms, on the part of our legislature. They're being encouraged to do so by some educators in the state and there are no safeguards in place. So a lot of the work that I'm doing is to say, 'Unless you improve this and look at the law, as it exists now the IDEA... As well as, how do we try and deal with problems before they start as one option? How do we de-

escalate? How do we not set kids up for problems in the first place?' So we're working with our legislators to try and put together a package of practices that are more supportive of appropriate behavior versus just reacting in a heavy handed way to problem behaviors. It's been an interesting couple of years on that front, in my work.

Tatiana Perilla 15:58

That's great that you're working on that, though. Are there ways that families can support schools to better help students?

Mark Smith 16:07

Yes. There are a couple of things, I think, that are very straightforward. One is communication. If the what's going on within the school setting and what's going on at home don't ever overlap in terms of information, that can lead to more problems. Also, there are certain things a parent can do in trying to mitigate behavior issues that the teacher can't do and vice versa. A parent can't come into the school building and deal with the issue. It really is the educational personnel's responsibility at that point. So that's one.

Mark Smith 17:00

There are certain approaches to addressing problem behavior where you can have a collaboration occur between the teacher and the educational personnel in the family. That leads to much better outcomes for the child. But I think, first and foremost, is no secrets. It has to be out there, especially for kids that have really challenging behavior. If they're exhibiting maladaptive behavior, if they're aggressive, or self injurious, or destroying property. It takes a village, all of the people that are addressing that with that child need to be talking. If they're siloed apart, your chances of success diminish markedly.

Tatiana Perilla 18:02

Yeah, you're right. I think it's that collaborative approach.

Mark Smith 18:05

One of the things we know about intellectual developmental disabilities is that kids' behaviors tend to respond to what's going on in the immediate setting. So if it's markedly different between home and school, they're going to behave differently across those settings. Then, your chance of making progress on something that might be leading to behavior problems, it goes down. If they're getting consistency across settings, at least in terms of expectations, in terms of responses, in terms of setting up the environment for success... We're dealing with a population of children that typically generalize poorly. Sometimes we have to build that generalization into the plan so wherever that child goes, they're seeing the same kind of responses to them as they make choices. It just raises the chance for success significantly.

Tatiana Perilla 19:19

In the past, you've worked with caregivers, as well as individuals with disabilities, when they're experiencing service transitions. How did you help people locate services? And just what does that process look like?

Mark Smith 19:40

I think the more you can do before actual transitions take place, the better it is. Again, that really goes back to that last comment I made. That ability to generalize to new circumstances can be challenging for a lot of the people that we work to serve. If they have behavior problems, then we're looking at coping with new circumstances as being a potential challenge so practice, practice, practice as you move. Look at moving from one setting to another, a child who's transitioning out of their parents home or someone who's transitioning between service settings, as much as they can get literal practice in doing that... Then, we try to occasion the situation for the person to have success by how we set it up, that we're planful and we look at what potential triggers might be in place. We look at what potential rewards or payoffs might be in place. As much as we can set the person up to successfully go through that transition, the better chance we have of the person going through the transition without major disruptions or without acting out.

Mark Smith 21:17

How much practice does it take? A lot. Yeah. One of the things that has always been a challenge, that I've had to deal with clinically, is the issue of staff turnover whether it's in educational settings, whether it's in disability provider settings. Every time a staff leaves and is replaced by a new person, it's kind of like you're starting over, in terms of developing the relationship. That can be very stressful for people that lack specific coping skills and so number one, you try and teach coping skills. Two, you try and provide supports where that person struggles to learn those coping skills. Three, you try and work through transitions in a real planful way, so staff is well prepared and that person is familiar with that individual. They just don't walk in one day and start saying, here's what you need to do as part of your bedtime routine, you know. They already know that person, and they have started to form that relationship. Because you start over every time. Even for adults that have gone through it a number of times, you still have to be planful. That's something I have always emphasized in my work. The more you plan, and the more you plan things for that individual, the better chance you have for success, irrespective of the circumstances.

Tatiana Perilla 23:10

Thank you. I think that's great, the practice and preparedness that you're talking about. Because transitions are hard. I think it's when our expectations don't match reality... So practicing beforehand, I think can really help set somebody up for success, like you were saying.

Mark Smith 23:28

It's true for anybody, I think. When I work with families... Families are pretty resilient, until you really throw a curveball at them, they lose a particular support, there's a tragedy in the family, loss of a loved one, or one of the caregivers loses their job. That's when we really see distress hit. It's those unexpected situations with families. The same is true for people with disabilities when we throw things at them willy nilly and it's unexpected. If you're talking about folks that have a behavioral or mental health disorder, that's very often a time when you see acting out behavior. It's kind of a loss of control of your environment. We all seek to have some control over our environment, that's never perfect. A person with a disability is just at a disadvantage.

Tatiana Perilla 24:45

Thank you. This next question I'm actually very excited to ask you about. Can you tell us about community inclusive practices? What were some of the main takeaways that you learned from your research about promoting community inclusive practices?

Mark Smith 25:04

Interesting question. One of the things that led me to my work was, when I started in my career, the job that I had transitioning people out of institutional care. They had grown up there. There was a court case, as there were in many states, and they didn't shut down the institution but they went from approximately 2000 people to a couple of hundred. We were busy getting folks out into the community and getting them situated with places to live, places to work, and the other parts of what communities have to offer in terms of recreation, in terms of choices about what you want to do with your life. It was challenging because folks were used to a very regimented lifestyle, where you ate at this time. One interesting thing that I found, the men that I worked with all carry keys on their belts. They would have like 100 keys, I mean it'd be just a ton of keys. I didn't understand, why would you carry around keys that didn't even work? Well, that's what the staff did at the place they lived. They were emulating the people that were the authority figures in the place that they lived, so to be cool or an important guy you wore your keys on your belt. It was fascinating.

Mark Smith 27:14

But one of the main takeaways that I would want to share is that people with disabilities that have co-occurring mental health or behavioral health disorders are typically the ones that are most at risk of not staying in the community. There's a definite need, all across the country, to ensure that- And we're not talking about the large majority of folks that have IDD [intellectual and developmental disabilities], we're talking about a percentage. But without specific supports that are targeted towards people that have co-occurring conditions, the chance of them not being able to stay in the community is enhanced.

Mark Smith 28:10

A lot of the work that I did was about, how do I mitigate this problem so this person doesn't have to go into a more restrictive setting. That was one piece. Working with individuals with co-occurring conditions was especially critical, having people that could specialize in addressing their needs was critical for them to stay in the community. Without it, we would see people going back into institutional care.

Mark Smith 28:46

My experience with institutional care is not a very positive one. I had many friends with intellectual disabilities who moved out of the institution, and we would talk about their experience. It wasn't a pleasant place. It was like 'just because I was born this way I have to live in this place', it didn't seem to be a very reasonable rationale for institutional care. When in fact, when we brought them into the community, they thrived. And we're thrilled that they could have a home of their own and a job. We asked one of our self-advocacy groups several years ago, what do you really want in life? And it's a job. It's like, 'Wow, well, anything else that you're interested in?' 'Transportation, so I can get to my job.' I mean, we're not talking about extravagant or off the beaten path expectations. They wanted to be able to work and make money and buy some of the things they wanted to buy. It wasn't rocket science.

Mark Smith 30:08

But to go back to that issue, one of the things that I found was that if you do have supports, and this counts for people that have co-occurring conditions or just have intellectual disabilities, there is no real need to continue with major congregate care types of settings. Individuals with disabilities, if given reasonable levels of support, and sometimes reasonable can be quite a bit- for example, if they have major medical needs or if they have mental health needs- but regardless, they can be successful in the community. If we are planful, if staff have a pretty good idea of what they need to do, if a person has a stake in it that they know what they need to do, it can work for just about anybody. There are a few folks that have very, very severe mental illness in addition to intellectual disability, and the community is just not safe for them. That doesn't mean you take away all their choices and you consign them to an institution that's basically 100 miles from anywhere. You treat the issue, and you try and get them to the setting where they can have the most success possible with the fewest restrictions possible. And I mean, for me, we're talking like five individuals, and I've been in this work for about 25 years.

Tatiana Perilla 32:09

It makes sense. Yeah, let someone pick out the goals that they want to achieve and give them the supports to get there, they're going to work to achieve those goals.

Mark Smith 32:20

One of the things that I found in reviewing the researches I was working clinically, this was several years ago, but there was some wonderful data about offering choices. You can mitigate major problems by just... A great example is, I would be working with an individual in a work environment and they were having problems. It was threatening their ability to stay there, so there was a real concern on the part of the team that was working with this individual that we need to get this dealt with. I had read some of this research, so we tried a little plan where we said on occasion this individual could ask for a break. If they asked for a break, we'd say, 'Okay. Take five, kick back, and just take it easy. But then we'll need to go back to work. Then, if you need a break later-' Because you didn't want to have a break every five minutes and then nothing got done all day. Well, it was the exact opposite. The person was empowered by the control their ability to ask for a break gave them. So, they'd ask for two or three breaks a day and the problem behavior plummeted. The person was much more successful. It wasn't a perfect fix, but that whole idea of giving the person a little control... They did a lot more work than they were doing prior to that, and that was with the breaks. So it was like, 'Oh, now we know.' It was really interesting. That and just taking very positive approaches...

Mark Smith 34:46

There was a whole school of thought back in the day of using very limiting approaches, physical restraint, seclusion. I'm not saying that people can ignore safety. Actually, safety is the first priority. But on the other side of the coin, 90% of your work needs to go into teaching and positive reward-focused approaches, where you're teaching skills and you're rewarding the exhibition of those skills. If you're smart about it and you get a good idea of the purpose that problems are serving, it's way doable. Now, that doesn't mean you don't have to have somebody there, keeping an eye on things, and ensuring that the person's continuing to do well. But we've been able to move away from so much hands-on by just putting in things like de-escalation practices, and putting the person in charge of the plan, and being very positively focused in terms of our efforts.

Mark Smith 36:11

And especially being very purposeful, and this is true especially in educational settings, about teaching what behavior is expected. We would work with professionals that felt like, and I'm over characterizing but this really was the case, they felt like they should know better than to do that. My immediate question was, why should they know better? If they're not doing it, if they don't know to do it, then they don't know better. So why don't we help them know what to do that's better? We know how to teach, we know how to practice, we know how to individualize study and work, and teaching for individuals, let's get to work on it. The difference is just staggering. When children know what's expected and they know that it leads to the outcomes that they really want to see happen, that's the choice they make more often than not. I want to again say that everything's [not] a panacea and that it's perfect and that it doesn't take effort in maintenance of effort... But conversely, those children or those adults in their

community settings, whatever the case may be, are experiencing a lot more success and success breeds success. That's why I really make an emphasis of that, that as a person sees themselves doing something that leads to the outcome they expect or preferred, they tend to do it again. Maybe not always, but more often than not. Ideally, increasingly more often over time.

Tatiana Perilla 38:22

Yeah, it makes sense when you think about that. I remember being in school and learning about Person-Centered Planning, and the benefits are it increases motivation and determination when they get to pick it. Using that strengths-based approach makes everything seem more achievable and it just helps increase success in the long run.

Mark Smith 38:38

Yeah, it can be challenging at times, because there's that whole locus of control. We're moving from family locus, with children, to the individual being the locus of control as an adult. Sometimes that's a lot. I mean, I don't always make good choices and I've been practicing making choices for a long time. I can tell you one thing for us, for my son's mother and myself, we started working with choices with him when he was five. It wasn't willy nilly. It's like, do you want the motorcycle or do you want the sports car? No, we put the choices within the context of what was in front of him, within his immediate world. Because that's another thing that we deal with, that issue of immediacy. But now he is very good at making choices and will tell you all about them, if you ask him. When I give him a choice when I'm able to with, you know, we could eat here or we could leave and eat later and go there. He'll tell you exactly what's on his mind, and I honor that. Because if I give someone a choice and then I take it away, what's the message there? You really don't have any choice, you really don't have control. So I just try to be careful about what I offer, because I'm going to have to live with that. Whether it's what I have for dinner that night or what we might be doing on vacation, it just depends on the situation.

Tatiana Perilla 40:38

We have come up to our last question, actually. What are some suggestions you would give to a parent or a sibling of a person with a disability, who is interested in becoming more involved in advocacy? How can they start?

Mark Smith 40:54

What suggestions? First, I would deliver a message and I would say, we want you. *Laughter* There it is. The challenge that we face at times is that we need people in the position to advocate. I teach Leadership Series as part of my work. Advocacy doesn't have to be calling the White House or calling a senator, it can be something in your local community, you want to

have help establish better respite options for families. I mean, it can be big or small. We just, please, we need more hands. There are so many opportunities. I work at a university center, there are opportunities here for individuals that want to. For example, our community advisory board is parents and people with disabilities and some professionals, and they have an impact on what this program does. As is the case with our Developmental Disabilities Council, or our Protection and Advocacy Agency, or our state Arc, or the local Arc chapters, or the PTA. There's just so many opportunities. It's a just matter of getting connected to somebody who can help get you to where you want to go, in terms of the change you want.

Mark Smith 42:41

I don't say to people who find themselves in positions of being the caregivers of a person with a disability, or have a disability, or are a family member of a person with a disability that there's a requirement that you be an uber advocate. Because sometimes you hear that. Part of that is because we've seen the Julie Becketts, and some of the tremendous parent advocates out there that are like, I could never do that. That's not the expectation. The expectation, first, is you have a choice if you want to get involved. I really encourage you to get involved, but it is your choice.

Mark Smith 43:33

And the second is, there are so many things, that whatever you bring... You know, one of the things in working with family groups, especially at a higher level like I've had the chance to work federally... One family group that I was working with, and this was early childhood, we had somebody who was really good with computers. So, they helped with the website. We had somebody who was a physician, and that person really talked about medical practice policy as it relates to early childhood and families. My background was working on state interagency coordinating councils and with National Technical Assistance Centers. So, what I talked about was how do we provide technical assistance to programs, parents, providers, personnel preparation centers, and universities. We just emphasized that whatever we brought as our personal strength, that's what we worked on. I would say there are very few people that don't have strengths that they can bring to advocacy for people with disabilities.

Mark Smith 45:00

The other thing to say is that we're not like treading water here. I wish we could just kind of take a break. But I've been at this for a while, and it seems like every time we take a step back and don't try and move forward- in terms of finding ways for people with disabilities to even be more successful, or to have better practices, or to develop ways of researching things that lead to better outcomes- we tend to slip back. It's not like we just go so far, and then we wait, and then we go forward again. The second that we don't keep moving forward, things tend to start slipping back. That's why we need more hands and more people, so that we're not in a situation where 'I just can't do this one more day.' And then we see practices and processes slip back.

Mark Smith 46:15

There's kind of a built-in inertia to public policy. We're just not there yet. I made the comment earlier, we have 6,000 people in services in my state and we have over 2,000 waiting that are past their due date to be served. Now, can we just throw money at that and make it all get better? If we could have, we would have. We need to work smarter, not harder. We need people in the room that can bring their knowledge, experience, and skills to bear.

Mark Smith 47:01

The other thing is that if you're a sibling or a parent, it's cool to hang out with other siblings and parents. Because they have that experience in common. They're more interesting, I think, in that they've dealt with challenges in their lives, in terms of their family member. You just do. There are challenges, whether it's lots of doctor appointments, or educational, or whatever the case may be, not enough hours in the day. In my son's case, it was not getting enough sleep for the first eight or nine years of his life. Because he only slept about four hours a night. As you talk, you just have this common feeling of, 'Yeah, we're there too and it's okay.' It's not so much a matter of being supportive, it just kind of happens. Just the chance to sit and talk and have a cup of coffee, you just walk away feeling a little bit more energized. If you're working to try and make changes that improve the lot in life of people with disabilities, that makes it easy to get out of bed in the morning for me.

Mark Smith 48:41

I heard a saying one time by a gentleman named Boyd, it talked about the process. The first part of the process the parent might go through is, why me? I get this diagnosis for my child, and it's like, how did I? What did I do to get put in this position? But if they can take the bull by the horns and try and move forward, they get to the stage of, why my child? Why did my child deserve this? And some of the challenges they're facing in their life. I like the DD act. I forget which act it is at the federal level. But it talks about disability being a natural part of the human experience and that's really true. Furthermore, people that have co-occurring conditions, it's a natural part of the human condition just like people that don't have intellectual disabilities that might have mental health challenges. That's just part of life in our country, in our world. I can get a dentist, but I can't find a specialist for my son, for a particular reason. That's a community problem. That's not my son's problem. He deserves the support he deserves and services, because he's a human being like anybody else. He's more alike other young men his age, than he is different. It's a matter of identifying those resources. That's a process that's been going on, going on 50 years. We're just not there yet.

Mark Smith 50:51

If you're out there and you're interested, Dr. Wappet knows how to reach me. Have him connect us. I work with parents and providers and people with disabilities across the country. I

had a parent call me from North Dakota, which is not close to Nebraska, it's far away. They said, 'Well, I didn't know who to call. I was looking at websites, and I saw your name. I really need help with this.' And it's like, 'Well, you need to call my friend Evelyn. She's in North Dakota.' And they're like, 'Oh, I only live 20 minutes from...' 'Well, go talk to Evelyn, because she's right there and I'm in Nebraska far away.' There's a network of people in your communities that are like you, and they would welcome, and you might have some fun. The choices are yours. You can do a lot, do a little, do nothing at all. That would be my suggestion. Do a lot, do a little, do nothing at all. But choose.

Tatiana Perilla 52:22

Thank you. I think that's a great message. Thanks for joining me today. Before we stop, I want to give you the chance if there is anything that you wanted to mention that I didn't bring up that you think is important?

Mark Smith 52:37

First of all, the work that the center is doing is so critical. The Utah State, Alaska, and Kentucky university collaboration on mental health and intellectual disabilities is so critical, because we don't have enough people that have training to work with those folks. It's a specialized set of skills. One of the things we run into in my state is that our disability providers find out the person has mental health or behavioral health issues, and they say, 'We can't deal with that.' So, they go to our mental health providers and they say, 'That person has an intellectual disability, we can't handle that.' So, we better figure out who's going to handle it. I think the work that's going on within the center is exceptionally critical. The fortunate thing is we're talking about folks that are very good at what they do.

Mark Smith 53:49

I would finish with, people that have challenges, they're people first. Those were the words I was searching for. Whether they have a mental health or behavioral health disorder, or severe medical needs, or have just an intellectual or developmental disability, they're first and foremost people. And they're protected under the law, just like we all are. And the thought occurs, it's like why do they deserve that? Because we all deserve it. Whether that's a choice in where one lives, who one lives with, where you work, those are the human rights that are guaranteed to all of our citizens. We can never lose sight of the fact that the people that we that we serve, and I say that through our work, are people first. We would think well to keep that in mind, at every point of the journey. Because it really is a journey, and it's just living.

Mark Smith 55:12

One of the things about policy, I had commented about earlier, we need to always keep moving forward in our work towards trying to improve the rules that we live by in our country, in terms

of working with people with disabilities, including people that have co-occurring conditions. That is that one of the things I've been concerned with in my life, that living in our country is not a dress rehearsal. Every time we run up against something that slows us down, or blocks us, or is an issue. We hear from policy makers, 'Well, we're working on it, we're going to get to that.' My message immediately is my son's life is going on right now anyway. And he needs this so while you're kind of thinking about maybe starting on a solution to this problem, his life is going on. He doesn't get a do-over when we all decide how we're going to deal with this. A lot of times I get told 'You're very passionate.' Although, I also get told I'm pretty calm. I don't know which one it is. But the passion comes from how there's always going to be an emphasis on we need to keep moving forward, because life is not a dress rehearsal. People's lives are going on. If their needs are not being met, you don't get a do-over. Because without that, people slip through the cracks and that is the absolute worst circumstance. For example, when somebody because of the fact that they have a mental illness in addition to an intellectual disability, can't find any help and then they slip through the cracks. Lord knows where they wind up. They don't get that they don't get that time back. There are no do-overs. I would share that, because that also has really been a motivator for me.

Mark Smith 57:38

That is probably, going back to one of your earlier questions, how my experience with my son has helped me in my work. Because I can see him going through his life. We've had struggles at times ensuring he would get what he needs. We'd get put off and then we have lost time. He'll never get that back. They'll never get an opportunity- time is the enemy in that way. But I'm not expecting people to just have the answer. It's just a matter of... Things go better if we keep working, if we keep pushing, if we keep advocating whatever word works best. That's the best we can do to ensure that people don't slip through the cracks. We're not in a position of saying, 'Well, we'll get to that.' It's like, no, we're getting to that and we're going to try and make it happen. When you can say, 'I'm really doing what I can do, the best I can,' then that whole issue of life is not a dress rehearsal is attenuated.

Tatiana Perilla 59:02

I appreciate that. Okay Mark, thanks for sitting down with me today, and thanks for everyone else that joined us on our podcast.

Mark Smith 59:12

Thanks, Tatiana. *Music*

Alex Schiwal 59:13

Thank you for listening to this episode of the MHDD Crossroads podcast. Make sure to look at the show notes for more information about today's episode, and visit our website at

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