

Episode 25: Mental Health Crisis - Is Anyone Listening? YOU Matter



Note: This is a machine transcription. Please excuse any punctuation or other weirdness:)

Intro:

Having a mental health issue can be scary leaving you filled with anxiety or just finding the courage to reach out especially if you are in a dark place can be difficult as well.

Also trying to figure out where you start to get the help you need and can you afford it? There are many people who are struggling with mental health...you are not alone, there are resources...YOU matter!

Get Savvy...Demystifying Healthcare – 30 second commercial

Are you tired of the high cost of healthcare? Are you overwhelmed trying to navigate a complicated healthcare system?

Welcome to Get Savvy...Demystifying Healthcare weekly podcast where we take complicated healthcare topics and make them simple.

Imagine if you could stop feeling paralyzed with fear and frustration and instead be empowered to make smart healthcare decisions for you and your family.

Get Savvy with your host, Sandy Kibling, a healthcare professional changing how healthcare knowledge is shared.

What we will discuss:

- 1) Mental Health Story - Matthew's Story.
- 2) Addressing the stigma around getting mental health support.
- 3) What Matthew did to improve his own Mental Health?

Sandy

Hello everyone, and welcome to Episode 25: Mental Health Crisis...Is Anyone Listening? You Matter.

We hear the stories every day of the need for more mental health services, especially in light of recent headline news of shootings in our schools, churches, and other public venues.

I also hear from mental health providers of how they are trying to provide mental health services up against a healthcare system that doesn't always provide the support that is needed. For consumers, it can be a depressing and a dark place. How do you find the care and the strength you need?

I'm delighted to have Matthew Dickson on the show today. Matthew helps people with mental illness in developing countries so they can get access to basic mental healthcare at MindAid.ca the world's first website with all the organizations working on mental health in developing countries on one site.

These organizations use models of basic mental healthcare that are low cost, proven, effective, and scalable. Some of these organizations have been endorsed by Bill Clinton, Forest Whitaker, Arcade Fire, Ashley Judd, as well as Zach Williams, son of Robin Williams, and Tim Shriver, founder of the Special Olympics. Matthew, welcome to the show.

Matthew

Thanks for having me on, this is great.

Sandy

You and I talked initially about mental health and in fact, your own journey. Can you start by sharing your story?

Matthew

Yes. I'm 51 and live in Eastern Canada. I grew up here and traveled across Canada by bicycle when I was 20. I had so much fun on that trip, and I wanted to do more fun stuff like that with my life, but at 22 I was diagnosed with schizophrenia and that threw a bit of a curveball into my life.

I voluntarily went to get help as I wanted to get myself better. I got on the medication and stayed on it. I did what I could to get myself better. There's probably a million things I could have done better, but I tried my best to work on my recovery.

I noticed an improvement in my health every single week for 27 years, and it was on February 11, 2021 during the pandemic when my symptoms just stopped. For the next year and a half or so I was kind of in a state of shock. It literally felt like I was being blindsided, pummeled, hit from behind...for 27 years dealing with systems and then just have them stop.

I had feelings of peace and contentment. I had full, complete thoughts of punctuation at the end of sentences, not run on sentences. I could actually think properly about things and that's how I've been ever since. The shock of processing this has been wearing off in the last many months and I'm starting to really enjoy life, enjoy my own brain.

When I was first diagnosed and first went out, one of the first symptoms I had with the disease was it felt like I had a brain transplant. Like I literally had gone through an operation and had someone else's brain put into my skull and I was thinking their thoughts and they were making me do and say things that just weren't me. The old saying your mind isn't your own. That's how it felt like for me. And that's that feeling stayed with me from severe to mild over almost 30 years. Now it's like I've got my own brain back.

Sandy

Wow, that is an amazing story. One of the things I think about with mental health is I hear so many people talk about that there's such a stigma around getting that help and support needed. You talked about wanting to live a better life and wanting to reach out. How did you find the strength to get past that stigma that sadly exists today?

Matthew

So I had full acceptance of what I was going through. I don't know where that came from. It came out of nowhere. I mean, to be honest, I was sitting in the psychiatric ward. I went to get help. They started asking me questions and trying me on different medications.

After a while they said we think you've got schizophrenia, and Matthew hopefully we can get you better. I was left thinking well wow, that's a bombshell to drop on somebody at 22 or for any age. I didn't know what I was going to do. I was sitting there and I thought well I can either take my life or I can try to fight this. What should I do? I thought about it, and a few seconds went by. I weighed the pros and cons.

All of a sudden I said, I'm going to fight this. I'm like, OK, now that you've decided that, Matthew, how are you going to do it?

Matthew

So again, a few seconds went by and I thought it came out of nowhere. I said...I accept the fact that life is going to be really bad for a while. I absolutely accept that and I'm going to put my life on hold. I accept the fact that things are going to be bad.

I asked a nurse previously.... I said how long do you think it might take before I feel better and she said sometimes it takes people a couple years. I don't know where she got that number but that's all I had to go on in 1994. There wasn't much literature on schizophrenia back then. There still isn't. There's books on depression and mental health, but I didn't have much to go on and I said I'm going to put my life on hold.

I accept the fact that things are going to be bad for a long or for at least a couple years. If when two years comes and I'm better, I will pick my life up from where I left off and move on.

There was no Plan B, so if two years comes and goes and I'm not better, what's going to happen? That was my plan. It was literally the words going through my head, word for word. I said, well, Matthew, you've got this plan. When are you going to start? I thought, I'll start now.

I said, what can I do? What activity can I do right now? I was in the psych ward. I said, well, maybe I could go into the TV room and watch, some sitcom or something that's on on TV. OK I'll do that. I'll go over and see what's on TV, so I got up out of my chair and started walking across the floor. It was a very purposeful walk. It was sort of like running the gauntlet, like head down, bullets firing at you firing at your head sort of thing.

I will never forget those steps, those first few steps across the floor. It's was the start of a very long, and terribly terrifying journey.

Sandy

How brave you were to make that choice. Something you said that came to mind is about the journey. We think about that climb. I'm reminded of a time when I used to ride my bike and I know you cycle as well. I was on a tour in France and we were climbing up Col de Tourmalet which was nothing but switchbacks. Straight up. I remember at one time feeling very tired and looking up at this person way up on the switch backs that looked like the size of an ant. I thought I am never going to make this, but you know I eventually got to the top one switch back at a time, but mentally getting through that was tough. What I like about what you said is just everybody thinks so big and not trying to put words in your mouth, but it's that step by step process...one day, and one moment at a time approach. Would that be a fair statement?

Matthew

Yes. It's just seconds at a time, minutes at a time. In the early years of my recovery, I would look at my watch every 5 minutes to see, how much longer I had to go to get through the day. My goal was to get through the day. In the early years, of my recovery, I would wake up in the morning and the pain would start to set in. I felt no pain when I slept. When I woke up, it would just sink into me and I'm like, no no. I don't want to go through those again, but I had to because I committed myself to fighting this.

The first thing I thought was give me the strength to get through this day and then I would start. I looked at my watch every 5 minutes to see how much longer I had to go, whether it was watching a TV show every 5 minutes, look at my watch, how much, how much longer just holding on there. With schizophrenia, one of the symptoms is difficulty sort of planning, organizing, that sort of thing. There's other people with schizophrenia who say the same thing.

You still have part of your thoughts going on just fine...you think I will go for a walk now or what do I want to eat? Maybe I'll have a banana or larger thoughts like do I want to go back to school or do I do I want to take this job? There are a lot of thoughts going through your head, but they're bombarded by a lot of other thoughts that are very aggravating and annoying.

Sandy

I admire your discipline in doing that. It sounds like you had care providers who provided that care and medication, but did you also have a support system to kind of help you on this step-by-step approach?

Matthew

There is this a man Shakara and he's from Harvard. He spoke at the UN and said every country when it comes to mental healthcare is a developing country. You have to think about that for a while. I had to think about that for a while.

I was and still am in a country in Canada with a developing countries mental healthcare system. So there could be more resources back then and now. The support for me, was the hospital, I thought there could have been more going on there, but the staff were all just basically putting out fires. I was also in a group home for three years in the mid nineties. Everyone's trying to do their best, but things are underfunded and under-supported. I guess I shouldn't really complain too much. I had it fairly easy compared to other people. I mean I was making progress in my recovery.

I was working at about three or four years into my recovery, I had a full time job. I bought a house in early 2000. I bought my first car in 2000 and so I one thing I would tell people starting out with schizophrenia, maybe other mental illness too, is that it can be really bad in the beginning. It's hard to imagine.

When the pain is so severe, it's hard to imagine anything other than that. It's like listening to a song. It's hard to imagine another song when you're already listening to a song, it's hard to put that in your head. But it's sort of like that with trying to think of a pain that's not as bad as the pain you're already in. You're sort of focused on the pain you're in at the time.

But I want to tell people is that the pain can lessen. It may not go away entirely right away or as soon as you want, but it can lessen and that will allow you to keep going further much further than you thought.

So 2 more years came and went. I was one year into a group home and I would spend another 2 years in that group home. What I thought was my original goal of lasting for two years that turned into 27 years of recovery. If you told me back then when I was in that pain in my first year that I would live through this for 27 years. I would be like, I can't do that.

I am reminded that Navy seals are taught in their training that they are capable of 20 times more than they think they are. And they say that's not a scientific number, but it gets across the point you're capable of much more than you think. They're shown that in their training to be taken to the brink of physical and mental exhaustion. They say, I can't move another inch. I can't move another muscle. I'm done. They are told...You're not done. Not only do you have 5% more, 10% more, you've got 20 times more than you think you do. They get them to get up and keep moving, keep doing whatever their training is.

I feel mental illness is the same thing. Now I'm no Navy SEAL, but I feel like I have been at that breaking point. It's shown me, to say yes, you can get up and keep going, even if it is just sitting in a chair watching TV or lying in bed doing nothing. Carrie Fisher, the Hollywood actress, Princess Leia from Star Wars, she had bipolar and said that people with mental illness should be given awards. Medals for bravery, courage, because it's a real battle.

Think about what people with mental illness force themselves to go through that somebody could be serving you as a cashier. Do you know what it takes for them to get up that morning, to put on their shoes, to get dressed, to eat breakfast, to go to work? To sit there at work and do all those things you have to do at work all day long with mental illness, You give them your credit card and say bye, you should be giving them a medal if you knew the battle they are going through.

Sandy

So true. We don't know what people are going through. We hear it all the time, but I think we should assume good intent because you never know the what anybody else is going through and lead with listening and understanding and kindness.

You talked about in 2021 that you had a breakthrough. You talked about a turn of events for you that must have been just amazing. Do you know what was the root of that cause of that awakening, that paved the way for a new you?

Matthew

No idea. I noticed an improvement in my health every single week until about 2012, and then the improvement started happening more often than once a week, sometimes once a day or even twice a day. What happened in my brain was clarity, more lightheartedness, not so much heavy heartedness, sort of more better emotional feeling would go through my body as I would have these clear thoughts and they might have lasted for 20-30 minutes, something like that.

It's just I'd just be sitting there or doing something and I'd just have this clarity. It's kind of like in math class, they are trying to explain a problem to you and you just can't get it. Then either you look in the back of the book, but you still can understand how they got the answer. The teacher is trying to explain a certain way and then they finally h/she finds a way to teach it so that you can understand it. It's like an aha moment. That's what I was having all the time. They don't know for sure what happens with schizophrenia in the brain. They can see some of it on scans and other tests and research, but they don't know for sure.

So I don't know what was happening to my brain, but all I know is if there were neurons not firing and now they were starting to, they were slowly starting to fire. My only analogy, and this could be totally inaccurate, but it's like if you're going through the jungle, hacking away the brush with the machete, trying to make a trail, well, it's kind of like that's what I was doing for my neurons. I was trying to clear all these trails in my head that I had for the first 20 years of my life. I was hacking away making trails for like almost 30 years and then came to the end of a trail. Oh look at that, I've come to the other side.

Sandy

So question for you regarding your journey. I know you're in Canada and I'm in the US but we all know the healthcare system is broken. In our earlier discussion, I believe I mentioned that I deal with physician groups with contracting all day long and I have many mental health groups and the lack of funding and what these groups are up against any given day is ridiculous and impacts them trying to help people.

We hope that better reform comes, but it I think it's a reminder of what you shared about your journey and that is being your own advocate and being proactive in your care or partner along with the providers that are trying to help you. I think this becomes so important because it's just as you stated, you were in a group home but everybody was so busy putting out fires and there you are. So it sounds like it really becomes important to get the help you need, but it is also balance with you being your advocate and leading your path to recovery. Would you agree?

Matthew

Yes. A great resource for being your own advocate is in this book called the *Survivor Personality* by Al Siebert. I have it listed on my website, along with my best mental health tips, I've got books and resources on there that I highly recommend people go look. It's the easiest way to get into my head of ways to get yourself better.

I've read books for 20 plus years. I had to improve my own mental health. Al Siebert, the author, studied people who'd gone through the Holocaust, natural disasters, cancer, alcoholism, cancer. He said people fall into 3 categories, one with a diagnosis saying you're going to die in so many months from this disease, say from cancer. This group says, I accept the fact that I'm going to die and this is my time and that's it and they don't fight. The second group says, Doc, I'm going to fight this and I'm going to do whatever you tell me to do to get better. The third group says, Doc, I'm going to fight this. I'm going to listen to what you have to say, but then I'm going to get a second opinion, and then a third opinion and a fourth opinion. I'm going to take my recovery into my own hands, and they are sometimes labeled as difficult patients because the doctor will be trying to do something and that patient is saying no, this is my body, I'm the one in charge here. You're not going to do that to me.

It's tough for people with schizophrenia and it can be difficult to do that for yourself a little bit. I mean you can, but it's one of the symptoms of schizophrenia I've read is difficulties self directing, let alone other directing. It's difficult to just take charge of your life like that. That is sort of planning, prefrontal cortex thinking, organizing part of your brain. It's hard. Plus yourself esteem is so low. It's hard to say this is what I want and this is the way it's going to roll.

A lady on CBC radio here in Canada, she said that she works with people with mental illness and that you have to take them and say now we're going to do this and you do something for a little bit and then you say now we're going to do this. A step by step process. When you do that for a little bit, and I felt the same way. It's like I can do stuff, but don't leave me alone for long periods of time, whether that's hours or days or weeks, whatever. Just keep coming back to me and pointing me to do small tasks, but just keep coming back and pointing me in the right direction. That's how it was for me.

So advocacy, for yourself is great.

The other thing I wanted to mention is that. There's a man in Nova Scotia, Canada. His name is Todd Leader like leadership. He's got a book called *It's Not About Us*.

He talks about how to transform the mental health and addiction system here in Canada. I would argue other countries could probably follow the same methodology. He radically transformed his area of Nova Scotia's mental health and addiction system. He got wait times from 5 to 8 months down to three weeks, one week, or least sometimes. The book is about how the mental health addiction system is bureaucracy centered. It needs to be client centered.

When a patient, or someone who's looking for help walks into an office, into a clinic looking for help, how many seconds is it before someone talks to them and starts asking them about how you can help them? Do you get them to fill out forms or put them in a waiting room and then another waiting room? For example, there's all sorts of things he talks about in the book like phone calls when someone phones a mental health line is the first thing you say if you are taking a crisis call is to tell person to call 9-1-1 or do you put that client first and listen. It's about getting the mental health system client centered.

Sandy

I that's really great stuff. We live in a system where providers are paid on quantity and not quality of care. Those sound like amazing resources which I will make sure and link to in the show notes. I know my listeners will greatly benefit. I want to kind of turn just a little bit because one of the great things that you're doing is your work with Mindaid. I was hoping you could share with us a little bit more about what Mindaid is and what your goals are?

Matthew

Thanks. I started Mindaid in 2018. I don't know why I never went looking for content on mental health in developing countries until this random Ted talk bubbled up into my Google Feed one day in 2017. It was a Ted talk by Vikram Patel. Back in the nineties, Patel said, we've got all these basic physical healthcare manuals, on how to treat someone with a broken leg or pneumonia or whatever, and where there's no hospital for hundreds of miles around, why don't we do this for mental illness? So he did. They've got models of basic mental healthcare where there's no doctor around, or no hospital. How do you help somebody with their mental health? These models are approved by the World Health Organization (WHO). They are low cost, proven, effective and scalable. The WHO is trying to figure out the best way to roll them out to the masses. In the meantime, I found groups that are using these models of basic mental healthcare with success.

They've been working for many years, well, the last 20 years or so, and they've been helping thousands of people in developing countries get their mental health back, which is huge especially if you're living in poverty and you can't get out of bed to feed your kids, this can be magnified in developing countries.

Sandy

That's great! I also believe you're doing a bike across Canada to help support this initiative. I was hoping to hear more about that.

Matthew

I've been chomping at the bit to bike across Canada again. I just love it. Some people might think I'm just stupid, but I don't know why it might be a curse. I just love traveling, exploring places, especially by bicycle.

I finally feel like I've got the health to do this and I leave in June. I've got a web page for it on my website. I plan on getting into Newfoundland in late August. I hope it works out. I'm trying to organizing it. If not, I'll try it again next year. I would love to have this be an annual event.

The other thing that I've been trying to do is when I made my domain name of Mindaid.ca back in 2018 I thought, this could be like a Mindaid concert, like Live Aid, Band-Aid, Earth Aid, Farm aid back in the eighties and nineties, all those big mega concerts. A few weeks ago I started making some headway towards that. I started reaching out to some people in the music industry, the musicians, singers saying look, what do you think of this for a Mindaid concert? I'm starting to get some good feedback from people saying all this is a good idea Matthew so I'm working on that. I don't know much about putting on a concert, I'll be honest, but I'm hoping that other people with the skills in those areas could help do this and I can help out in whatever capacity. I'm very excited about that this, so those are sort of my two biggest ideas.

Sandy

I was talking with someone about the healthcare system and again, whether you're US or Canada or in a third world country, with no health care. It's going to take heroes, truly. It is about people rising up. Healthcare consumers, saying I've had enough and people like yourself getting others on board in the music industry to help and bring awareness. Reforms is not going to happen in a bureaucratic run system. It's going to have to be people doing things like you're doing today.

I think that's really essential and I look forward to following your journey. You mentioned that Minded has been endorsed by some key leaders like Ashley Judd, Bill Clinton, has that been helpful for you?

Matthew

It's been helpful for me when I talk to people about them because these organizations, most of them are fairly small. They're not the size of like UNICEF or World Vision or anything like that, but they still do great work. I keep with those big names behind them. It just gives credibility to them and endorsement. I haven't reached out to those specific celebrities or people of influence. I have chatted a little bit with Zach Williams, Robin Williams son online a little bit.

Sandy

My husband's was a big fan of Robin Williams and so it's nice to hear his son is so kind to lift up the cause. It's really enlightening to hear your story and how you've overcome and I really appreciate you sharing your story and what you continue to do. I will make sure and provide those links so people can follow your story and help in any way they see appropriate as we close. I wanted to leave the final thoughts to you that you would like to share with listeners.

Matthew

Well, I had an idea earlier in this conversation. I'll just throw it out here to the world. Sitting here talking to you and having another conversation about our bad mental healthcare systems around the world. At some point you say, you know, enough is enough, just enough is enough. The climate March they had a handful of years ago, one of the largest marches and rallies for helping out the environment and people organize these things. They say some of the biggest changes in the world have happened because of people taking to the streets.

I thought, we've been hiding in the shadows for decades, probably centuries with mental health. Is it time to take it to the streets? Can we get more funding for mental health systems and get them operating correctly and not poorly?

We want to be proud of our mental healthcare systems. We don't want to be complaining about them and shaming them. If we can get them better, we'll be the same people working them 10 years or 20 years down the road. Olympic athletes talk about visualization and I'm thinking, can we visualize a better mental health system?

These athletes spent hours in the dark with their eyes closed visualizing their best performances for sports. If we do this with our mental healthcare system, saying, look, we want this to be great. We want to be something, for example, where I live, there's a good cardiac unit. So you want to go to that city, that hospital, then you do. Is it possible to say this about a mental healthcare system? It's happened in Nova Scotia. He's got a great mental healthcare system there. So it's possible.

I also want to say that the models of basic mental healthcare that they're using in developing countries, they've piloted some of them in America with success.

One of the groups that I steer people towards basic needs in the US. They did a pilot project in an urban area in Detroit, I think, and New Mexico and a rural area in New Mexico, and they had success there. Another group, the one that Ashley Judd has narrated, a promo video for, they're called StrongMinds. They help women with depression in Africa working in Uganda and Zambia, I believe. They've created StrongMinds in America in the last year.

They've taken the same model of basic mental healthcare and they're using it in America with success. These are low cost proven effective scalable methods and I'm just trying to tell more people about it.

If people want to have me speak or whatever please reach out to me. I'm trying to talk more and more about this because there are people here in North America and others in developing countries that are desperate. They're desperate for help. I was desperate for help.

I spent years desperately trying to save my life. I don't think we talked about desperation enough. I mean, it's sad, but I know what desperation is. It's like being circled by sharks and a lifeboat comes up to you through your friends who would ask "Matthew. How are you doing? Do you want to come for ice cream with us?" I'm thinking...I'm tracking these two worlds of terror and a nice, normal, ordinary day and I have to walk in both worlds and it's terrifying and it's frustrating thinking, I've got to do all this normal ordinary things, yet I want to scream out at the top of my lungs.

Please, somebody save me. Save me. Get Me Out of this mess now. Throw me a life jacket. Get me into the boat with you. I want to go party and have a good time. Get Me Out of this. Yet there are millions of people in every single country around the world today, every single country who are desperate just like I was for help.

There are ways to help them with these basic models. These models of basic mental health care, can be rolled out and we can help. Should we take to the streets, have rallies with thousands, of people to bring awareness. Mental illness affects so many people, a large percentage of the population. Can we can we do this?

Sandy

I so love everything that you said. I cling on the word desperate. If you heard in the US and I'm in Colorado and we had another school shooting. To your point, of people rallying, I was so proud of these high schoolers who went to the Capitol to protest and to say listen to me. The sad part was only a few of the state representatives came out of their office to listen to them.

And so I say it again every day people lean on, and trust the healthcare system I think the healthcare system is working for them in some cases and I do believe that many try to do good but there's a lot of bureaucracy and politics that don't allow for good and it's evident in what we see today.

I could not agree with you more and people need to read those books you recommended and reach out like you've mentioned...it takes one person at a time, but we can rise up because there are so many people desperate for help that can't get the help that they need.

Matthew

We've been hiding, whispering behind closed doors for decades about our mental health issues. Whispering, whispering about it. In the last 10 years or so, we've been talking slowly more and more about mental health. So this is new for us, talking openly in the grocery store of all places, the sidewalks, or a cafe. We're actually using the words mental health in public and having conversations with sometimes strangers about. It's happening. To take it one step further whether it needs to have people in the streets thousands of people in the streets for this or not, it's growing and we need to keep running with it.

Sandy

Well you've been through it, you've lived it. I can't thank you enough for being on the show today and sharing your story and being open about your most vulnerable moments, because you never know who needs to hear this. Thank you for bringing to light so many things that we need to think about differently. I appreciate you Matthew and am grateful for your time today.

Matthew

Thank you, you're welcome and thanks for having me on.

Sandy

It was great having Matthew on the show. I appreciated him sharing his story and I hope it helps you. Matthew mentioned some resources that I will link to in the show notes.

I hope that you are enjoying our guest series where we are covering lots of topics and meeting amazing people along the way, sharing their healthcare stories.

In our next episode, we rescheduled Miles Wakeham who is sharing his healthcare journey from an immigrant's perspective and how he had to wait years before getting a much needed surgery.

Until then, Get Savvy.