

Communication Access Realtime Translation (CART) captioning is provided to facilitate communication accessibility. CART captioning and this real-time file may not be a totally verbatim record of the proceedings.

Live captioning via *ExpressConnect* Conferencing, LLC

SPEAKER:

Good afternoon and welcome today's SAMHSA sponsored webinar titled 'You are Not Alone: Building a Life with a Diagnosis of Mental Illness'. Presented on behalf of the National Alliance on Mental Illness also known as NAMI.

Today's presentation will be recorded and the recording link, slides, and a certificate of attendance will be sent via email to everyone who attended today. Closed captioning is available and can be viewed by clicking the CC at the bottom of your screen or clicking the link in the chat pod to view in a separate window. We also have an ASL interpreter who should be spotless on your screen.

During the presentation, please add your questions and comments in the chat box and questions will be asked out loud for the presenters to answer at the end of the presentation. When the presentation ends, please take a few moments to complete a brief survey that will show in your browser as you exit the platform.

Thank you again for joining us and I will now turn it over to today's presenter.

DR KEN DUCKWORTH:

Thank you, hello, everybody, I'm Doctor Ken Duckworth, chief medical officer for NAMI. I want to thank you for joining and just introduce myself, I became a psychiatrist (indiscernible) and nobody was going on Oprah talking about their mental health vulnerabilities and recovery.

In that spirit, I wrote NAMI's first book, 'You are not alone,' the first to ask real people how they had learned to live with a mental health condition and how they had fostered their recovery. I also interviewed family members for how they had fostered the best communication and strategies with their loved one so asking professionals really common questions like, do I have to take these meds forever, and how do I seek help?

The book was a USA bestseller and all the proceeds go to NAMI, so I promoted with no guilt. This was fairly radical, given most books written by psychiatrists have anonymized composite people. In hanging out at NAMI for 20 years, I got such a feeling that there were thousands of people who had generated and if it from helping other people, and this was a new way to think about this.

I wanted to write this book where lived experience is treated as expertise and I'm happy to say a lot of publishers were interested in that idea and I was told by one publisher, "You couldn't get people to use their names," I only shared volunteers story and where they live because I ran out of time.

I was right, NAMI is right, real people sharing their experience is powerful and compelling. You will meet three remarkable people from our book who were stars in the journeys of recovery chapter and you will be able to hear from them and talk with them.

I will introduce them briefly, but you will learn a lot from them. I encourage you to ask questions because we will have a nice conversation. The first person is Chrissy Barnard, Chrissy volunteered from NAMI Wisconsin to share her story. What she taught me was extremely compelling about how she found a journey that worked for her.

Chrissy is a leader in the peer support movement and I want to thank you, Chrissy, for being our first speaker today on your recovery journey.

CHRISSY BARNARD:

OK. Thank you for having me here today. My name is Chrissy Barnard, I have my bachelors degree from Lakeland University, and biology psychology with a business administration minor. I've worked my current job for 14 years, I enjoy spending time with my dogs, Roxie and cuddles and my cats Kitty and Mickey, and taking care of my house. Teaching community Ed classes, and participating in everything NAMI.

When I look back, I can see the signs of my illness starting in high school. I would get up at 6 AM, go to school all day, do extracurriculars, watch a basketball game, do yearbook stuff until 2:00 AM, do homework and then go to bed at 4:00 AM, get up at 6:00 AM and then go back to school.

However, I did not seek help for the depression until college because I'm ashamed and thought my family and friends would not understand. Yet I had difficulties graduating college on time because my moods were so variable. I would have highs of reckless driving, \$1400 shopping sprees, not sleeping at night, followed by crashes of depression and not getting out of bed or showering for days.

Also, I have ruminating thoughts about what a failure I was at suicide attempts, multiple suicide attempts. According to my records, I've had 33 hospitalizations, which is led over a dozen encounters with law enforcement. Only one of those was a positive experience.

During most of those experiences, I was willing to go to the hospital voluntarily. One year, I was in the hospital every month but the month of August. From January to May, I was admitted to one of the state hospitals. Not only did I lose my sense of self, I lost my job, my home, my pets, control my finances, ability to make choices for my healthcare, elation chips, but mostly my sense of self and who I was as a person.

Despite those losses, I finally got an accurate diagnosis of bipolar, Zaidi, PTSD, and borderline personality disorder. That's when I moved back home to Wisconsin and found someone owing to work with me as a partner. He made suggestions on my road to recovery.

I remember him telling me that I knew my body and triggers best and better than anyone ever would. When I found changes, I would send him messages to the portal saying to him, I'm vacuuming at 2:30 AM and I think I need to have my medications adjusted. He built a very trusting relationship with me because he was so patient centered and he allowed me to have control and like I felt like I was in control of the situation. And of my life.

When medications needed to be adjusted, not only did he not change medications continuously but rather sometimes, he would find a larger dosage change of my antidepressants would help control my mania and depressive episodes, rather than consciously doing the yo-yos of different medication changes.

Now I have a new provider and we follow the same process of changing the dosage of my medications because it's been so effective for me and I have to say, I have not been hospitalized in well over a decade. I don't anticipate it happening anytime soon.

My psychiatrist, when I moved back to superior, suggested I put a space in it DVT program that was true to fidelity and participate in it NAMI peer support groups. I did intensive DVT for two and half years and now I see my therapist every other month, and that my very first NAMI support meeting, I was given a road-map to recovery. They were like, "Do you have a psychiatrist? The therapist and one that works for you." I had peer supporter that group and they were such an amazing group.

Now that I've learned about NAMI and recovery itself, I was able to take my experience and turn it into passion and take that into action to help others. I am now the executive director for NAMI Lake superior South Shore and peer respite, which I founded. I co-facilitate the NAMI support groups and I co-chair the NAMI peer leadership Council and I'm on the state Board of Directors and a trainer for the interim voice program.

I'm also part of the NAMI national leadership Council as well. I'm a mental health first aid instructor and I was appointed by Governor Avery himself. I'm a member of the state of Wisconsin DHS recovery implementation task force committee, and a member of Disability Rights Wisconsin Council, which is advocacy for people with mental illness. I'm a member of the Douglas County mental health coalition and I was the grant coordinator for the County cares team.

I'm a certified peer specialist with indiGO. In 2019, I received the Wisconsin peer of the year award and I received essential health volunteer award in 2022 and 2023. And the lifetime achievement award for bringing the mental health programs and services to

northern Wisconsin in 2024 from essential health. I received the badger award in advocacy from independent living centers in 2022 and 2024.

I'm most proud of getting the Gloria Huntley award for NAMI national for my advocacy work at the state and local level. Today, I still continue to advocate for mental health because I know that recovery is possible and hope really does save lives. Thank you for listening.

DR KEN DUCKWORTH:

Before I introduce our next speaker, you sent me an email made my day a few months back, could you tell people what you accomplished in your advocacy role?

CHRISSY BARNARD:

Just a couple months ago, I got 988 signs put on the bridges connecting Wisconsin and Duluth Minnesota. After number of individuals unfortunately took their lives and some of them on the same day. I knew one of those individuals, so it was really important to me that we start advocating and putting out resources where people can see them everyday.

36,000 people a day drive across one bridge, so I figured this is a great way to educate, and public awareness, and help people when they are in crisis. Just last week, our department of Health and Human Services (unknown name) agreed that we will have our NAMI pure respite funded, it just has to go to the county board for approval but will be the second NAMI that has a peer respite in the country, which I'm very proud of because we need services in our community because we have no inpatient services and no crisis services and no crisis response team.

To me, it's really important to be promoting and supporting our individuals with mental illness.

DR KEN DUCKWORTH:

Fantastic, Chrissy, you will get the opportunity to ask Chrissy questions in the Q&A, I encourage you to do so because her journey has been remarkable. Josh Santana, an amazing person that I also met, I asked for volunteers from NAMI Massachusetts state who they were and what they had learned.

Again, the book is about lived experience and I read about this remarkable man who is a musician, a real estate agent, and all-around generous soul who also taught me about how his dog made a difference in his recovery. That was one of the questions that came in before this webinar so I want to ask Josh to discuss that little bit.

Thank you, Josh, for everything and for participating in this webinar today.

JOSH SANTANA:

Wonderful intro, Ken, thank you so much! I'm excited to be part of this today. Let me tell you a little bit about me so you get a bit of an understanding. I have a very long history with mental illness, from as young as five years old, I've had a lot of energy as a child.

I got kicked out of preschool, in fact, for assaulting a teacher. My mom eventually had to promise to put me under psychiatric care and I had to have a professional to go back into mainstream school. My upbringing Wisconsin up and downs, I had a lot of issues still and I started to experience very severe depression starting around seventh grade.

That was incited through a coming out process that I had to do because I identify as gay and I don't (indiscernible) as much as seven pills a day that were prescribed to me at seven years old. That was seventh grade and that was the first time I had to go to an emergency psych center for suicidal thoughts.

Every year since that, I have had depression that came with suicidal thoughts and it wasn't until around sophomore year of college that I had my first year without that major depression but I still battled a lot of behavioral issues. Excessive energy, manic episodes, and it was tough to get through college, it took me a long time, six years. Had to take some time off, it was very hard to focus, throughout my up ringing, it was an ED HD diagnosis with a new diagnosis, NOS, not otherwise specified, until I was 18 and I got a bipolar diagnosis.

Throughout that, it was all really tough. I have my worst manic episode when I was about 23 years old. I had a break with reality, really dangerous thoughts and through this time, I was still very heavily medicated. Experience a lot of sedation from anti-psychotic medications, so it was a lot of up and down.

Where it really starts coming around for me was 2018. I had an interesting experience when I met up with a friend of mine from high school who said, "I have this dog and she's looking for a new home." I was still in college at the time and I told her I was not allowed to have a dog. She told me to meet her, and that first day that I met my dog, I was like, whoa, I have never met another dog that matches my energy. She's an Australian Shepherd, they are very high energy breeds.

From that moment, I knew I wanted to keep her, I snuck her in my dorm room for the rest of my time in college, they didn't find out until I left, so that was fortunate. What my dog did for me was huge. This is where it started to turn around for me.

I adjusted my lifestyle, I started having more regular routines, I had to take care of something else which forced me to make sure that I was OK first. I had to eat regular meals and it was nice to have a dog partner say, "You're having lunch, I'm having lunch to," One of my things it triggers my mania is not eating. I actually get more hyper and distracted, I don't get hangry like most people, I get wired.

That's one of the things my dog help me with. In addition, exercise, she she's a high-energy breed and needs to go out, which forced me to get out into nature and on long walks. I took her out into the White Plains of New Hampshire, we do 4000 km together.

I know some but he asked a question about dogs and for me, she is now and ESA, emotional support animal, so I can go wherever I want with her. Am a renter and a landlord can't discriminate against my dog regardless of the pet policy, they have to let my dog in. That's something that having the right providers has helped with so they can have an ESA letter to help that happen.

One of the things I failed to mention up until this point is how music has played a big role in my life. I started music when I was about eight years old on the violin, and that's something that initially gave me an outlet for my excessive energy and destructiveness in class. I have played ever since, I still play, actually. After my first manic episode in the middle of college, I went to go study music, and now all of a sudden, I couldn't play music because I had to take time off and go to recovery.

Things that helped me get back into the music was joining the meeting orchestra. It was the first of its kind, the only orchestra in the world cater towards erasing the stigma around mental illness, so around 50% of the members live with a diagnosis, about 50% don't, and are just supportive.

Having an example of a community like that that uplifts its members and gives in summing the latch onto, it really helped me and did wonders for me. Going and playing music every week, going in knowing that I could maybe not be feeling great that day but I won't be judged, and all the other opportunities that come with it.

(indiscernible) events across the country to play, we've done Lincoln Center, it was a psych event in New Orleans, in Washington DC, we have an upcoming one in New Jersey, so everything that came without really help me stay steady on my recovery journey.

Couple of other things I want to mention.

I started to recognize that I was entering recovery from a mental illness because I was more aware of what to look out for. Along with my providers, I would be very detailed and keeping track of my moods. I want something was inching towards mania or something, or depression, I nipped in the bud right away because I was able to and kept good track of everything.

This allowed me to be a little bit more consistent. Waking up at the same time everyday and examples like that. Once I started being able to empathize with others, too, and say that I know exactly what they're going through and being able to recognize it and other people, that's when I was like, I know what I have to do now.

That's why I consider myself a mental health advocate because I have been through all that stuff and when somebody else has been through it, I want to help them. It wasn't all easy,

especially with the people around me. Something I wish that they knew were the behavioral trends that came with my diagnosis because I think being able to separate your behavior and thoughts with who you are as a person was huge for me.

My diagnosis does not define who I am anything it's so important for people recognize that. That's something I wish the people around me knew more so they wouldn't attribute my behavior to who I was and would be able to put it aside and recognize who I am.

Beyond that, I've had so many providers throughout my recovery and one of the things I wish more of them recognized, and Ken Duckworth does this extremely well, and Chrissy mentioned this too, people know themselves better than anybody else.

I think providers are starting to shift that mindset of "I've studied this, I know you are going through," They are trying to shift and ask for the perspective from other people. That's what I want people to take from today, empowering the patient to know that they are the most crucial tool in their recovery.

DR KEN DUCKWORTH:

Thank you, Josh, for everything. Josh taught me a lot about the role of animals and one of the reasons I wrote this book is because I knew there were more things than I had been trained. I went to a fancy program, I trained with amazing professionals, I love research and psychotherapy, meds are great too and the right places and the right times and right doses.

I knew that things like how a dog could make a difference in recovery had never been taught to me and that was one example of dozens of lessons I learned from rural people. Josh, you came to the meat to orchestra. Again, could you talk a little bit about this integration of your musical talents with your experience of living with a mental health condition and how the meat to orchestra fits into that?

That's how I found you.

JOSH SANTANA:

Absolutely. What's interesting about me too is how I discovered it. I briefly mentioned this, I went to college to study music. Throughout the beginning part of my college career, it was specifically education and studying to become a teacher and I did teach for a while.

As part of one of our lessons in whatever music Ed classes, there was a professor who discussed me to orchestra. As an example of how you could build a community music program. I understood it in passing, did OK in that class, but years later, when I went to my first manic episode and I had to withdraw, I was at a loss and I didn't have anything to play, and that's what previously sort of kept me going.

It went ding in my head, that's when I joined and on my first day, I was having a manic episode and was digging my fingernails into my legs and I was really putting pressure

against myself on the seat. Then I felt understood, they all saw me as a person. Having that weekly rehearsal and the different opportunities to play in concert with the orchestra, I played with them since 2018, and I have now been manic episode free since 2018 as well. They played a huge role, they now have affiliate organizations throughout the country and different countries as well. I think one in Europe and there's been documentary on the orchestra as well.

I think there's a French public station that did a documentary in Australia, if I remember correctly. It's awesome, I love it.

DR KEN DUCKWORTH:

Thank you, Josh, I encourage you to think about questions related to recovery journey, music, participation in using your animal as a resource and also the difference between yourself and your diagnosis. You are not your diagnosis. Might be handy to know your diagnosis and to anticipate some things but that is not a definitional construct.

Our third and final speaker today is Tera Carter. Tera, I met through NAMI Georgia in the course of my travels in writing NAMI's first book, I met with different NAMI groups and I simply asked people, would you like to share your story and what you learned along the way?

Tera was finishing up becoming a specialist on crisis team, you all know that Georgia has been the national leader on statewide mobile crisis team and Tera told me a beautiful story about she was able to use her own lived experience dealing with someone that she had visited on a crisis.

I think Tera has moved on to other things but I was very interested in her joining us now and sharing her experience. Tera, thank you.

TERA CARTER:

Thank you, Doctor Ken, and I'm so happy to speak with you all today. I am in the Atlanta area and I met Ken while he was working as a crisis responder in the state of Georgia so I did respond crisis calls in our community and it's something that I really enjoyed but it did end up moving on and I am now working at a residential community called Skyland Trail, in the city of Atlanta.

I had the opportunity to become us certified peer specialist with meantime trained in the field and my role serves a dual purpose there. I do work on the clinical side right teach psycho-education classes and I also get the honor to (indiscernible) with our clients as well. I teach things like the wellness recovery action plan, I teach a class on healthy relationships, I also teach a class on identity and insight.

The other great thing about my job is that I get to continue a relationship with our clients once they graduate because I do serve as the alumni coordinator and I oversee the

programming by coming up with amazing opportunities for our retreats enrichment and support we do on a weekly and monthly basis. In sharing my story, it's a little different from the stories you've heard of Josh and Chrissy as it relates to the fact that I received my diagnosis much later in life.

At the age of 39 years old, which takes us back to the year 2013, that is when my life became unmanageable. I didn't understand why, what was going on at that time? I was having more problems with sleep. I've had problems with sleep my whole life but because that was my normal, I didn't see it as something that was "Wrong."

I found myself being top, sometimes not sleeping for a day or two days. Racing thoughts, really not able to get my (indiscernible), and I really struggled with my memory. Forgetting things that was causing disruptions at my job and also at home. It was also during this time that because my racing thoughts were so detrimental to my mind, I started using alcohol as a means to calm my brain down, that's what I thought it was doing, that's not what it was doing but I thought it was doing that at the time.

I would drink something in the morning and at night when I came back home from work. During that time, I was in the music industry and a time, it was chaotic. I was married at the time and had three teenagers but I was traveling all throughout the US and abroad with an artist from this musical.

With that going on, flying across different time zones, then some of the challenges that were coming up in my marriage at the time, by October 2013, I was in complete shambles. I ended up going to a mental health facility, my husband at the time took me, and it was there I found that I was living with bipolar disorder.

A lot of times, individuals struggle with accepting their diagnosis but for me, when Doctor (unknown name), asked me what it's like to live with bipolar disorder, (indiscernible) but when my mood would drop down, that's when I wasn't able to do some things. One of the reasons I wasn't able to identify that I was living with depression is that I was still able to go to work. All those years, I was able to go to work and do the cooking and the cleaning with the kids but I felt that my energy was lower. I wasn't able to do the same amount of things that I was able to do when my mood was high.

So I get the diagnosis. At the time, my physical health was in shambles, and one of the things I get to tell my clients now is that if your mental health is suffering from long period of time, it will eventually affect your physical health and that's what I had going on. I started having seizures, my adrenal glands are drained, and it was very much a long-term situation of healing that I went through and I remember Doctor (unknown name) telling me, "Tera, I think this will take you 3 to 5 years before you can work full time again."

I looked at him and was like, that's not going to work. At the time of this crisis, my husband was laid off, I was the only person working at that time, we had three kids that were all

teenagers and so I was like, I don't know how we will make it as a family if I'm not able to work.

Me being hardheaded, I decided after I was feeling better that I would try to work again. Long story short, I tried three times to work against my doctor's orders and each time, I am about falling into a depressive episode. That was a hard lesson for me but one of the things I learned as it relates to what is life look like in recovery for Tera, my life began to not be overruled by the symptoms and challenges of my illness.

I have less depressive episodes, we fixed the sleep issue and with that fix, I haven't had a manic episode since 2013. But I noticed the depressive episode would come about when I was under high capacities of stress. I began to see the correlation between my environment, my work/life balance, and also whether or not I was in a healthy relationship or toxic relationship and how those had a direct effect on my mental illness.

I'm a very firm advocate of being able to find the balance with work and putting in the work to be able to have healthy relationships and romantic relationships and friendships. Those two things were really big in my recovery. After I made the decision to stop going against the doctor's orders and accept the fact that you're not going to be able to work, I'm a woman of faith and that's what kept me having hope saying that I don't know how we are going to make it, I don't know what we will do, but I will trust God that it will work out and when I submitted to that, it's when I started seeing a shift in things.

NAMI was a lifesaver for me during this time because even though I couldn't work, I was able to volunteer, I started leaving support groups, which was phenomenal for me and it was really the foundation of me being able to build myself back up to a place of confidence where I would be able to work.

It was in the fall of 2019 that my doctor was like, "I feel like you're ready now." Mind you, during that time, I put in for disability twice and was declined because they felt like I was still too functional, even though my therapist and Doctor were saying, "You can't work," I couldn't get approved for disability because the judge felt I was too functional to get it.

My family ended up making do but what happened is that my kids as teenagers, when they turn 16, they began to work and I had to get past my pride because my kids were helping to take care of me. Over 30% of my husband's income at the time was being spent on medications, doctors visits, all of these things.

I remember one time after my son turned 16 and start working, I remember crying (indiscernible) he sold his PlayStation because one of the medications was going to cost us \$300. He sold that PlayStation on his own so they were able to get that medication for me.

We rally together as a patient -- family, yell, and that's one of the things I really feel like it's been very valuable in my recovery, having a very tight support network was important for

me. Educating myself on what I needed and the things I need to do in order to be in recovery with this diagnosis of bipolar disorder.

What did it mean to have bipolar disorder? What are the computing factors to it? I believe education is empowerment and so the more that I learned, I felt like the more I was able to start implementing in my own life in order for me to be able to sustain myself and keep myself balanced as it related to my own mental illness.

I'm a firm believer that a lot of us need medication. When I started this journey, y'all, I was on six different medications. Now, I'm happy to say that I'm only on one that I believe that goes along with how I've been able to take care of myself. Healthy sleeping and eating habits, being able to get my workouts in, having a healthy social life and healthy work/life balance, those things come into play as well. I have been happy with my treatment team and a lot of people don't get to say that they've had the same psychiatrist since I got diagnosed.

That is my story. Doctor (unknown name) has stayed as part of my team, my psychiatrist, and (unknown name) is my therapist and she is been amazing. Since you all are providers and I would like to share, my psychiatrist will always listen to what I have to say about the medications I was taking.

About four years and my diagnosis, I had a very bad reaction to lithium. I was taking lithium and it was working great, even though (indiscernible), in the hospital, we made a decision that we would try another mood stabilizer. At that time, I had been doing research and I wanted to try a supplement called (unknown term), I asked that if I could try lithium or a tape first, then I would try another stabilizer first.

I purchased the lithium (unknown term), I went to see the doctor, we looked at it and talk through it, we came up with how many I would take her day and here we are five years later, that was something that has been very beneficial to my ongoing recovery.

I say that to say that my psychiatrist was willing to hear me out and allowed me to really be an integral part of my treatment. It has paid off for me and now he offers it to other patients that he has as well. I really love that about my treatment team.

I have an amazing group of friends, some live with mental health conditions and others don't but they have been very supportive in my journey. My job is very supportive of my journey as well, and they are really big on not just talking the talk but walking the walk as it relates to work/life balance so I am able to be myself and able to take days off when I don't necessarily feel that great and I don't have to worry about it coming back on me.

One of the things I think my family would have benefited from knowing at the time is that a lot of times, when we come out of treatment, the perception of our family members is that

they are done with treatment now, they will be just fine. They will be healed, and that's far from the truth.

We come out of treatment stabilized but sometimes, it takes us a little while longer for those symptoms to not show up anymore. That was something that I wish my family understood. Also understanding the fact that (indiscernible) does affect some of our behaviors and we live in a society that tends to judge behavior.

Because of that, it was difficult at times to get them to understand that what you see is a symptom of the illness, it's not directly connected to who I am as a person. We got to work through it and it has been very helpful.

I will say in closing that now, I've been at Skyland Trail for four years, it's been an amazing opportunity for me but I am also a national trainer for NAMI. I get to teach people from all over the nation on how to train, I train people to become support group facilitators, I train people on how to present their story, I have really gravitated to speaking so I'm a keynote speaker at other conferences, workshops, seminars related to mental health. I have been able to build myself in that area.

Next month, I will actually be doing that full-time and Skyland Trail part-time, so that's an exciting part of my growth that I am really enjoying and am excited about. Also next month, I will be a natural credited wellness coach as well. My journey will continue but one of the biggest things I learned during this time was that everything we went through as a family prepared us for two of my children, who ended up having a diagnosis for bipolar disorder as well.

My two youngest children, Isaiah, who is now 24, and (unknown name) is 23, both were diagnosed with bipolar disorder at the age of 21. Because we went through what we went through as a family, we knew when symptoms started to come up with them. I am passionate about sharing, going to churches and meeting with church leaders of what this looks like so that it will be stigmatized.

I'm very happy to be here, I'm excited for my growth and I know that I have a lot more that I will accomplish in the years to come. Thank you for hearing my story.

DR KEN DUCKWORTH:

Thank you so much, Tera. Someone mentioned that selling your PlayStation was a great example. Before we ask questions, I want to address some of the questions in the group chat. There was a mention of lack of insight, also known as (unknown term), I want to recommend to you the NAMI convention June 11 and 12, Javier (unknown name) wrote that book, he will be one of the keynote speakers.

I also want to commend to you the NAMI ask the expert webinar series where we have a library of 70 talks covering everything from supported employment to creativity and

recovery to the latest data on clozapine and the changes to the rams requirements. If you go to the NAMI website, you can find out information on ask the expert series and thank you so much for entering that into the chat.

If you want to connect with each other, I encourage you to put your information in the chat. There's just under 400 of you and I will be able to get to all the questions. Kristin, you asked if the NAMI convention is virtual, it is very short money, might be \$30, something like that.

We have topics on everything from recovery to peer specialization to AI and mental health. The list of element on clozapine, there's a lot to work on that I would say NAMI continues to cover. The convention is in Tera's backyard in Atlanta, but this year's is virtual. You can join from anywhere in the world. I saw this people from all over the world in on the conversation.

That's the NAMI convention, virtual registration, go to the NAMI website, you can find out how to register, it's two days of really remarkable information and conversation.

A couple of questions I wanted to ask people, how are you getting involved with NAMI before I asked the questions, go to the NAMI website. There's a link to all 660 or so NAMI affiliates and you can find one near you. I had a woman today email me about question in North Carolina and I was impressed that there are 25 NAMI affiliates in North Carolina.

If you want to become a peer, teach family to family, a peer resource, teach peer to peer, it's all there. Let me ask a question to all three of you. What has been like to share your story publicly? This is the thing that's radical about our book. This is our project, what was that like for you? Has that been a challenge for you?

Not everybody wants to be so public with their journey but you're clearly in a place where that's good. Let me start with Chrissy, what's it been like for you?

CHRISSY BARNARD:

It's been very empowering. I feel like I've in control of what's happening with people's opinions because I set the tone of the conversation. It's my story and I'm sharing it and I'm in control. It's very empowering.

JOSH SANTANA:

Similar to that, I first had the courage to be open about my diagnosis through having the community that was the orchestra. Because I had that as an example of no stigma, that was the whole point of it, that empowered me, in empowered me to be more open about it.

TERA CARTER:

I would say for me, piggybacking off of what Chrissy said, it's been very empowering for me as well. I see it as part of my recovery and representation is important as well so I feel like

it's important for people to see someone who looks like them share their recovery story so they can have the same sense of hope as well.

I have definitely enjoyed the opportunities that have been given to me.

DR KEN DUCKWORTH:

Fantastic. Let's talk a little bit more about animals. Dogs seem to come up a lot, Josh, when you mention that, people lit up on that. You taught me that your dog taught you to help manage and regulate your schedule living with a bipolar diagnosis. There's a whole literature on this, there's a whole social rhythm therapy, the whole thing.

The theory behind that is that people with bipolar disorder have difficulty with self-regulation. Nobody's fault, it's just information, but let's talk about how coda help you manage your schedule. This is providing evidence-based therapy.

JOSH SANTANA:

Absolutely. I grew up in a pretty chaotic household. A lot of people with mental illness have. I never really learned from anybody how to properly routine myself. I think having been exposed to my dog really help with that. I had to get up early morning or what was my punishment? Fits in the house.

I had to feed the dog because if not, she wouldn't survive. Piggybacking on what I had to do with her, I would do on me. If she ate, I ate. If she had to go for a walk, I went out for a walk with her. I think it provided an already embedded routine that she needed. I just kind of piggybacked right off of it (Laughs)

DR KEN DUCKWORTH:

Anybody else have troubles with animals? It came up a lot in the chat and that was one of the questions in advance.

CHRISSY BARNARD:

I have two dogs, so I find them just as valuable because they are super helpful for me as well. They start begging me to go to bed around 9:00 PM, they're like, "Mom, come on, let's go to bed." Maybe I better stop what I'm doing. They actually help me get to bed on time and get out of bed and there's so many perks to having animals.

They snuggle with me when I'm feeling bad and things like that so I find it very helpful.

DR KEN DUCKWORTH:

Becoming a peer specialist is different in every state. What has becoming a peer specialist meant to you? And how do you do it in your respective state? Terri, let's start with you. Georgia has been a leader on peer specialist since the 1990s. Right out of the gate, peer specialist transform the landscape and it all really came from the leadership in Georgia. Let's start with you.

TERA CARTER:

Thank you, Ken. As a certified peer specialist, I went to the program in 2020 and it was composed of an ED our training class that we went through that talked us through how to share your story, ethics, the purpose behind being a certified peer specialist, how to be able to work with clinicians and so after that 80 week training, we have to take a test that we have to pass in order to start practicing as a certified peer specialist.

I've had the opportunity to do community work as a crisis worker and being able to work in a clinical setting on the residential side has been great. I get to meet with clients, I have a caseload, no more than 10 clients that I meet with every week and we talk about a wide array of things, whether support in a relationship, whether it's how I go about things that help me in transitioning out and going back to work full-time, it's been up-lifting to work in this capacity.

I do believe in the state of Georgia, they have changed the training and is now only 40 hours here in Georgia.

DR KEN DUCKWORTH:

Chrissy, can you talk about Wisconsin?

CHRISSY BARNARD:

Certainly. Wisconsin is, I believe, forget hours now. It's shorter and they keep adding material, and then you have to take hours of homework. You have about four hours of homework. And then you have a special project that you have to do for the next day, which last eight hours, to present projects.

Then you have to pass the state exam and I took it, it only had a 60% pass rate but now the two questions that everyone has the worst score on, they take those out and that has helped Passmore peers and make the test more fair.

It's amazing and we have to have 20 hours of CEU's every other year.

DR KEN DUCKWORTH:

Thank you, Chrissy. There was a question about the keto diet. This is emerging research, not hard science. There's a researcher from Stanford who will be presenting at the NAMI convention, which is virtual, on the potential impact of the keto diet on the symptoms of people who live with schizophrenia and bipolar disorder.

Again, don't throw your medicines and go on a keto diet, but this is a creative area of research and we want to support better research and better answers. I think that's really important.

I wanted to ask all three of you, how NAMI has helped you. If you'd care to take that up?

CHRISSY BARNARD:

I guess I'll go first. NAMI not only gave me the peer support group to start with and the road-map to recovery, which is like finding providers and things like that and getting peer support and making sure you have a stable regimen, whether it's medications if you do medications or self-care.

They also taught me about recovery and helped me to learn more about myself and my own diagnoses and then getting involved with NAMI at the higher level with our affiliate and everything really helped me learn leadership skills so I can better help others. That is help me succeed to where I am today.

DR KEN DUCKWORTH:

Tera?

TERA CARTER:

NAMI has helped me tremendously. One, it helped me as it relates to starting to educate myself on what it meant to live with mental health issues and also my family members, we have a class called peer-to-peer and family to family, I've taken peer-to-peer, my family took family to family and then it was also instrumental in me gaining the confidence that just because I was living with a mental health condition didn't mean that I didn't have the strengths that I had, and NAMI help me to see what the strengths were and I could still use them even if I was still working in the music business.

I felt like I became more competent leader becoming a trainer and being able to do presentations and being in front of people. It was all a game changer for me in getting my confidence back while also being able to help my community as well, it's been instrumental for not just myself but my family members.

DR KEN DUCKWORTH:

There are other ways to promote recovery, NAMI is not the only way, there are other organizations. Josh, you seemed to have benefit a great deal from the meat to orchestra. Again, the diversity of pathways to putting your life together. Music, a dog, the orchestra. Can you tell me a little bit about how the community has been a difference for you.

JOSH SANTANA:

Community for me is huge, I think it was the missing element. Since I was five years old, I was taking meds and had a psychologist, I have therapy the whole time but I never had a community that understood the struggles I was going through. I don't see many other examples of how community mental health organizations are put together but the orchestra was definitely that for me.

I mentioned before, about half the people in the orchestra live with a mental health diagnosis and half do not enter to support it. I think coming into the same room with one common goal, to play music and erase the stigma of mental illness was huge for me.

DR KEN DUCKWORTH:

Fantastic, we are down to the last couple of minutes, I want to give each of you a chance to say one thing that you like people to take away from how you built your life living with a mental health diagnosis, what were the key elements? Chrissy, would you begin, please?

CHRISSY BARNARD:

For me, the key elements were DVT, peer support, and having stable routines.

DR KEN DUCKWORTH:

Great. Josh, what would your closing comments be?

JOSH SANTANA:

Let's see... I think, one, empower yourself to take care of your journey. Two, lifestyle, routines, all of that is more crucial than people think. Three, to round yourself with the people around you that will continue to uplift you. Put yourself in spaces where people will uplift you.

DR KEN DUCKWORTH:

Tera, you talk a lot about faith and family and also one good provider. Do you want to develop this one last comment to close out this entire session?

TERA CARTER:

Absolutely. I would definitely want to leave you with support is a big component of long-term recovery. Having the right people that are part of your village, collaboration with providers and family members, one of the things we started doing is that I have a collaboration call. My psychiatrist and therapist are on the call, a friend in recovery is on the call, and my family members.

We all meet together once a month, so collaboration is a powerful thing and also faith, because if it wasn't for my faith, I do believe that I would've lost hope. Thank you.

DR KEN DUCKWORTH:

So I think you can see there's a lot of different ways to get through the recovery journey but there are recurring themes of support, collaboration, and engaging with others. I want to commend to you [again our little book, NAMI old Max -- NAMI's book](#) has gotten wonderful reviews on Amazon and it's all because people in the book share their stories.

I interviewed 130 people for the book and everything a person at the NSAID at the end, they were so glad that if one of their story could help one person, all of it would've been worthwhile. Hospitalizations, the attempt to take one's life, desperation's, whatever he

went through. Person after person said that so that's why the book is so powerful and why I think it will be an enduring piece of the NAMI portfolio.

I want to thank you for joining today, if your provider, we love providers. We love providers who know about NAMI. If you're a family member, NAMI was founded by family members, out of the love and desire to get things right. If you're a peer **or liver the mental health condition, NAMI has been uttered and -- tremendous growth** spot for peers.

If you're young person, **NAMI has another -- entire next-generation gut** youth and young adults more involved in NAMI. I just want to thank you all, regardless of your background, for learning from our three experts, Chrissy Barnard, Josh Santana, Tera Carter, I want to thank SAMHSA and NASMHPD for asking NAMI if we'd be willing to participate in this. We of course, jumped at the opportunity.

Thank you all for joining, very grateful to you, hope to see you at the NAMI convention June 11 and 12th, virtual. Take a look at our ask the expert if you want to get more specific information on one specific question and I hope you all have a wonderful day. Take care.

SPEAKER:

And thank you to all of our centers, and NAMI and SAMHSA, for pathetic though. As a reminder, complete the evaluation. Thank you all for attending and you may now disconnect.

Live captioning via *ExpressConnect* Conferencing. LLC.