



## **The Medical Mind Podcast Personal Perspectives on Early Psychosis - Part 1**

### **Voiceover**([00:00](#)):

This is the Medical Mind, a podcast about innovations in mental health care from the American Psychiatric Association. This special episode is co-presented by SMI Adviser, a clinical support system for serious mental illness, and by NAMI, the National Alliance on Mental illness. SMI Adviser is funded by the Substance Abuse and Mental Health Services Administration and administered by the American Psychiatric Association. These podcasts include the real life experiences of people with mental illness and family members. Some of the content includes discussions of topics such as suicide attempts and may be triggering. If you are in need of support at any time during the podcast, please contact the NAMI helpline at (800) 950-6264. Available from 10:00 AM to 6:00 PM Eastern time, Monday through Friday. To receive 24/7 crisis support, please text NAMI to 741741, or call the National Suicide Prevention Lifeline at (800) 273-8255.

The topic for this episode is early psychosis and is the first of a two-part discussion led by Dr. Ken Duckworth. He leads a deep discussion that offers insights for individuals, family members, and mental health professionals. Living with it, loving someone who has it, treating it, the impact of cultural identity and so much more. Let's dive right in.

### **Ken Duckworth** ([01:20](#)):

Hello everybody. My name is Dr. Ken Duckworth. I'm a child and adolescent psychiatrist and the chief medical officer of NAMI, also known as the National Alliance on Mental illness. In today's discussion, we'll be learning from people who have experienced and benefited from the movement towards a public health approach for the treatment of psychosis. So this model called the first episode of psychosis or early intervention in psychosis has grown tremendously in America, and it represents a triumph of how to conceptualize our work with people who are in the early stages of vulnerability. We're going to start with a family member, Donna Fagan. We're also going to be hearing from Iruma Bello. Donna, I want to thank you for joining this and sharing your experience. I understand you also work at an early psychosis program.

### **Donna Fagan** ([02:15](#)):

Yes, that's correct. I live in Texas and I work in a coordinated specialty care program in Texas.

### **Ken Duckworth** ([02:22](#)):

Coordinated specialty care is the specific model that the NIMH has developed to make sure there's a fidelity to a model which has shown benefit for people who engage in that program. Would you mind telling us a little bit about your experience with your family and in your work at a coordinated specialty care program?

### **Donna Fagan** ([02:44](#)):

Yes, of course. I'd love to do that. I'm a person with lived experience, parenting children, adult children with mental health conditions. I'm currently a grandparent parenting two grandchildren that both have mental health conditions, I have raised four children. Of my four children, three of my adult children develop mental health conditions. Of my four children, two of my adult children develop a diagnosis which included psychosis.

**Ken Duckworth (03:16):**

You've had a lot of firsthand experience. Can you describe what things were like before the coordinated specialty care model and after, just in terms of how people think about it?

**Donna Fagan (03:29):**

Yes. The coordinated specialty care model has a number of team members that are providing support to an individual. Whereas prior to that, it was very hard to find any kind of coordinated care for someone. Our early experiences with our daughter when she developed a mental health condition as a child was that we couldn't even find a psychiatrist. And then when we did, there was just one child psychiatrist in an entire city. To see us move from a place of not having access to care or not being able to find care for our loved ones to a place where now you have multiple team members there to assist your family member, that is just leaps ahead for people that have mental health conditions. It's awesome treatment.

**Ken Duckworth (04:22):**

Excellent. We also have Dr. Iruma Bello, a psychologist who is the co-director of OnTrack New York and the clinical training director there. Dr. Bello, can you talk a little bit about this model and what drew you to it in terms of your professional interests?

**Iruma Bello (04:39):**

Sure. I think as you've mentioned, Ken, it's such a shift in the way that we provide treatment and it's leaps and bounds from what we used to be able to offer. I think that really drew me. It's a very innovative way to work with people and their families, and that really puts them at the center of the care. For me, it really brought forth the difference that we can make in people's lives when we take a person centered, recovery oriented, resource rich model to help people early on achieve their goals and really move their lives in a different direction. So when we think about coordinated specialty care, as you guys have described, it's a multi-element approach delivered by a multi-disciplinary team. And that's very different from the way that early psychosis has ever been dealt with.

Usually we would see young people develop psychosis and it was a revolving door in and out of the hospital. Developmentally, it's a point in time when you're, as a young person experiencing, something to think the way that I'm going to get help or that I need help around this is by going to mental health treatment in a very prescribed way. It doesn't really resonate. So I think what's helped in the shift towards coordinated specialty care is it has a real focus on youth and an orientation to what is important to young people. The team is able to offer services in a very flexible way. As Donna was saying, it's a group of providers who work together very closely and coordinate all of the services. So it's not left up to this young person and/or their family who are going through a really difficult time to figure this out and connect the dots.

You have a team that can provide psychiatric care or medication management. They can provide nursing services, psychotherapy based on evidence-based CBT strategies to help individuals manage symptoms and achieve their goals. Then you have a team member who's really focused on helping young people achieve work and school goals and get a ton of support in these endeavors so that they're not having to figure out that space on their own. A lot of our teams have peer specialists, so they get support from someone else who has lived experience to help them figure out what's happening to them and figure out how to navigate this new world that they're encountering.



And then the team has a real focus on supporting families. So providing psycho-education and providing support to the family members. Traditionally, we would see there was treatment for the young person on the one hand and then separate treatment for the families, if at all. What we're trying to do is combine it all in a way that provides a ton of access, provides a ton of flexibility. The model is really driven by what's important to that young person and their family. Nothing is mandatory, but rather it's a collaborative way of approaching care where the goals of the young person are at the center and drive treatment decisions.

**Ken Duckworth (07:50):**

Yeah, it really seems to solve for some of the core problems in the traditional model, in that it's leveraging a person's strengths, it's actively pursuing their goals with the resources to support education or work goals. And it brings the family in early because the family's a linchpin for most people of doing well. Donna, I wanted to ask you about your experience of family intervention and involvement in this coordinated specialty care.

**Donna Fagan (08:22):**

It's interesting what we're doing here in Texas is within our community what we call local mental health authorities. We also have a family support provider role. We call that a family partner. And this has been a role that's been in development for about the last 10 years. Where we've really implemented this role has been in children's mental health, and we use family partners or family peer support providers in other programs like Wraparound. We are already accustomed to providing our services within a team environment. The family support provider role is a very important role in providing help to the family. What we understand is that a person will be more well if their family is engaged, if the family is given access to individuals that explain to them what's going on with their loved one, have interactions with them. The emotional support that can be provided by another person with the same experiences is so invaluable.

And then also in Texas, as we do the family support provider role, that person can also do the psycho-education with the family. We do go through a certification process and have a number of different supports that we can provide to families. Within coordinated specialty care, what we've been doing with our family partners is that we are utilizing the family psycho-education material from the OnTrack New York family resources material. That's a really easy material for a family support provider to provide to a family. It's utilizing that material that talks about what is psychosis, how does it develop, what is recovery, as we're utilizing that material with families, and we can also bring in aspects of our lived experience and talk with families.

**Ken Duckworth (10:26):**

How do people receive your own family lived experience?

**Donna Fagan (10:31):**

We are very careful about how and when we share our lived experience. We do have some mentoring and supervision around that. We want to share our lived experience when appropriate with another family. But I have found that it is invaluable to the family that I'm working with because the feedback that I'm getting from the family is that it's wonderful to know that other people have experienced the same thing, or I felt like I was the only person going through this and I don't have someone else that I can talk to about this.



**Ken Duckworth** ([11:08](#)):

So never worry alone. One of the classic NAMI experiences. And you are not alone.

**Donna Fagan** ([11:12](#)):

You are not alone.

**Ken Duckworth** ([11:14](#)):

The idea that you are part of a large number of people who's learning how to cope and hopefully thrive with this challenge. Dr. Bello, I wanted to ask you a little bit about the model itself. I just heard that Donna is using the OnTrack New York materials. Do you find that professionals want to be involved in this? Do you think this is motivating for people to value people's strengths, help them set goals, and work on a team? Typically in psychiatric training, I'll speak from my own experience, that wasn't necessarily a core principle. So I wanted to ask you about the professional response to this model.

**Iruma Bello** ([11:57](#)):

With young people who are sometimes hard to engage and you are required to do a lot of activities that don't necessarily revolve around having weekly sessions or 15 or 20 minute appointments with a psychiatrist, the ability to leverage your team members and their skillset, and be able to connect with people in a very creative, flexible way, in a way that you have time to try out a lot of things... As you're noting, a lot of the requirements previously of how we thought about individualized care is what is your care node? How many folks are you serving? How many people back-to-back can you see in one day? And it's very much driven by productivity in that way. When you switch to coordinated specialty care, where now your care loads are smaller, most CSE team have a ratio of 10 to 1 when it comes to full-time equivalents of people. You have clinicians with smaller care loads, you have different team members with specialized experience that they bring in, and you have the time and the bandwidth to work collaboratively.

I think what we hear from our team members is that they really enjoy it. It gives them the time and the flexibility to work with people in a way that can really resonate. The main thing that they get to focus on is on engagement. So they're not tied down by this notion of, "I have another appointment and if somebody comes in late, then I can no longer see them." Or, "I am seeing people only in the office." I think on the contrary, the teams are able to see people with multiple team members at once, they can see people in the community, they can see people in the office, they can have longer meetings, shorter meetings. The involvement of the family in this flexible way becomes really important too, because different team members can work with a family in a lot of different ways. I think that the teams find that it's still really challenging and really hard work, but it's very much more rewarding because they have more autonomy and support in working with people and their families, because everything is very much coordinated and integrated.

**Ken Duckworth** ([14:05](#)):

One of the things I was impressed by when I volunteered at the early psychosis program at the Massachusetts Mental Health Center in Boston is how open the individuals usually were to family involvement. That they had recognized that something had changed and they turned to their family. This doesn't always happen later on in people's experience. But my experience with young adults and teenagers was their experience often led them directly to leaning into their families. Donna, can you talk a little bit about that perspective, if you agree with what I've observed on the family engagement?

**Donna Fagan (14:45):**

Absolutely. And what we see sometimes as adolescents are in that transition age group and they're transitioning out of young adulthood into adulthood or adolescence into young adulthood, we see that the community has been giving them information about their rights and their independence and their ability to be able to drive their own treatment, et cetera. But the family, sometimes we feel like we're pushed aside at that point, because at some point we stop receiving communication with treatment providers. But when an individual develops psychosis or a very significant mental health condition, then we do start looking at the family because the family is a natural support for that person. If we're able to engage the family, then like I said before, the individual's going to be more well. And we also want to understand that the family needs recovery too. The family as a whole has walked through some very difficult times and it's much better to see relationships healed in families, and we can sometimes facilitate that within coordinated specialty care.

**Ken Duckworth (15:58):**

In terms of the expansion of this program, worked down to close to 300 programs across America in almost every state. Dr. Bello, tell me a little bit about your vision for the future of this model. What do you see as this model continues to grow?

**Iruma Bello (16:17):**

First, I have to say it's fantastic to see the growth. I remember when I first started working in the first episode area, it was a couple of programs and academic medical centers and that's it. And now there's really an increase in access as there's this expansion, which is phenomenal, because ideally we would be able to serve everyone. In my future vision, there would be an opportunity for anyone who is experiencing a first episode of psychosis to have access to this type of care. We know what makes such a big difference in terms of trajectory and outcomes. And right now, even though we have this huge expansion, we still don't have capacity to treat everyone. So I think that's one goal of expansion.

I think the other goal is this model came from research and it came from understanding its applicability for a certain group of people. What I observe anecdotally, just from working with teams in New York and then teams nationally, is that there are certain adaptations that need to happen in order for it to function and really serve people across different communities and across different groups. My vision would be that the model was also able to accommodate and adapt to the needs of people who are experiencing first episode psychosis across different communities, across different environments, and offer care that really resonates and can engage different groups effectively. I think there's still a lot more to learn in that regard. I see the model expanding not only in terms of people served, but the model expanding and permutations that resonate with what people feel like they need, and that they're getting the types of services from the types of providers that align with their worldviews.

**Ken Duckworth (18:03):**

Thank you. Dr. Bello, is there an easy place in your experience for a listener to know what the closest first episode of psychosis or coordinated specialty care program is? We have them listed on the NAMI website, but I wanted to know if there was another place that you would send people.



**Iruma Bello** ([18:22](#)):

The first one that comes to mind is the PEPPNET network. They have a directory where they have a national map that lays out based on geographic location where programs might be located, and then it has their contact information. For the state of New York on our OnTrack New York website, there's a map with the different teams. And then there's... I can't remember if it's Strong 365, they also have a directory for first episode psychosis programs. There's also the formal networks where I think if people find anything, just reach out to whatever you find, and usually you can figure out how to get connected if there's a program in your area.

**Ken Duckworth** ([19:04](#)):

Yeah, the PEPPNET is based at Stanford, but it has a national directory. Donna, I wanted to ask you a little bit about your professional development in this model. So you're serving as a family resource. Can you talk a little bit about that for people who are interested in metabolizing their own first lived experience into a professional role?

**Donna Fagan** ([19:31](#)):

Yes, so actually when our youngest son developed his early psychosis, which actually led to him taking his life at 21 years old, my husband and I were at a significant loss and we didn't know where to turn to for answers. We really didn't understand entirely what had happened. We're always wanting to know why. And our daughter had early onset mental health condition as a child, but her symptoms were so much different. After we lost our son, we entered into the NAMI family to family education program. We found the most support there than we had ever experienced.

We did have to travel to be able to access that program, but it set us on a path of more understanding, linking with other people that experience, not the same thing, but similar things. After that program, my husband and I, we said, "We have to do this for other people." We felt like it saved our lives. We became family to family teachers, and then ultimately basics teachers and then went on to help start an affiliate in the rural county that we live in. But NAMI has been an integral part of our family's healing and recovery.

**Ken Duckworth** ([20:56](#)):

Giving back is just a huge piece of healthy process for many people. Would you agree?

**Donna Fagan** ([21:05](#)):

Yes. Sometimes giving back is actually part of your own healing process.

**Ken Duckworth** ([21:12](#)):

I wanted to ask you a little bit more about your decision to work in a coordinated specialty care. You had mentioned just how much you've been through, and my heart goes out to you, and what you've made of that to give to others. But how did you become a person who's working at an early intervention program? And tell us a little bit about your job, if you would.



**Donna Fagan (21:32):**

As my husband and I began offering support to other family members within the community, I received a call from someone at NAMI Texas, and they said, "You might be interested in this job that a local mental health authority has available." I looked at it and I thought to myself, "Wow, that sounds like something I would do for free." I did contact them. I was hired. I did go through a training and certification process to be able to provide family support in a community mental health setting. We go through other additional trainings through the year. Because we're in community mental health, like our coworkers, so we do ethics training and HIPAA training, psychological first aid, our community mental health authority makes those trainings available for us as family partners, because we consider ourselves to be mental health professionals. And the way that we do work on a team collaboratively with other team members.

Then sometimes I have to take that hat off when I go back out into community and I'm providing direct service one-on-one family support with another family, because I'm not part of a clinical team at that point. But the role is really not that much different. It's that one person with lived experience providing that emotional support, just giving that other person the opportunity to talk about what's going on with them and talk to a person that has an ear to hear what they're saying in a way that other people can not hear what they're going through. And then being able to provide some of our own stories to provide additional support to that family.

**Ken Duckworth (23:23):**

Excellent. I wanted to ask each of you how you think about your identity in terms of culture, religion, sexuality, race, anything that you think has influenced your work or experience at all, and how do you see this model evolving towards more cultural competence? Let me start with you, Dr. Bello.

**Iruma Bello (23:47):**

Sure. I'm Cuban and I grew up in Miami, so culture and being a person, a minority has always informed not only my world view, but my professional development. I think as a woman and as a Hispanic or Latino woman, I've always had a special interest in thinking about how our treatments impact people of color in a different way or how they generalize or how they actually provide services in a way that is respectful of people's world view. I have always been informed by my ethnicity. I think it definitely impacts the way I relate to people, being able to understand different world views because knowing that my worldview was not the primary one in our country.

But further than that, I received my training in Hawaii at the University of Hawaii. There was a strong emphasis, because of the diversity of the population in Hawaii, there was a strong emphasis on cultural competency. In addition to my own personal cultural identity, my foundation and my training as a psychologist is very much focused on cultural competency. I'm bringing a lot of cultural humility when you're working with people and having a lot of experience working with a lot of different types of people. So coming into the world of coordinated specialty care, where one of the foundational principles is cultural competency in terms of delivering this model was a perfect fit. A lot of the things that we train our teams on is using cultural formulation interviews, for example, which is a tool to understand somebody's worldview. I'm not coming in with preconceived notions around what it's like for young people and their families. Not just about thinking about people's culture, but understanding people's worldview.

**Iruma Bello**

When we're talking about first episode psychosis, we come in with a bio-psycho-social explanation, maybe around what's happening, but that's not necessarily true for that young person, for that family, or for the rest of our team. Being humble and understanding the different perspectives, understanding how people make meaning of what's happening to them from a varied point of view, being able to be open and ask a lot of questions to understand not only that person's perspective, but how to effectively align with them rather than imposing your own interpretation of even a definition of psychosis onto that person or that family becomes super powerful in developing an Alliance and being able to carry the treatment forward.

**Ken Duckworth (26:21):**

Thank you. So Donna, I wanted to ask you if your cultural identity, however you define it, religion, ethnic, any kind of identity influenced your experience of being a family member with individuals who live with this vulnerability.

**Donna Fagan (26:40):**

Yes, culture definitely an impact. We live in a rural county, so there's limited services at our county, and the people within the community, there's a certain amount of stigma that exists around mental health conditions. I found that there's also stigma that exists within my own family around mental health conditions. I came to understand a lot about that and why that is. The older generation in my family, they don't talk about mental health conditions. It's something that is set aside within families that you don't talk about, that you don't make aware, you don't want other people to know that part of your family's story. When you think about it, it hasn't really been that long ago that people were institutionalized. My family comes from that generation of people being institutionalized, so you don't want to talk about the mental health conditions that exist within your family.

My generation is the first generation to really talk about it. When our son passed away, my husband and I made a decision that we weren't going to hide from it, that we were going to talk openly about it within our family. In regards to my daughter's mental health condition, the same thing, we're going to talk openly about it in our family, because ultimately what we want to see is that people within our family receive treatment. Hopefully, with early treatment, I have family members that can find themselves in a place of recovery and be more well, do more things in their life, be better functioning.

**Ken Duckworth (28:20):**

That's quite a powerful statement as well, the idea that you are going to be the first generation to tackle this problem of shame or prejudice that exists in the prior generations. NAMI and the entire coordinated specialty care model is a welcoming idea that you have a place to go. Coordinated specialty care represents the idea that there's a place for you.



**Donna Fagan (28:47):**

I'd like to say something about cultural humility also. This has just been first and foremost in the front of my mind for the last couple of years. We understand about cultural competency. We've received a lot of information and training and dialogue about cultural competency. But when I began to understand cultural humility and that is that I have something to learn from the family that I'm helping, I'm going to be listening to them from that perspective of I have something to learn from them, that I'm not just there to provide them services that I feel like that they need, but I'm actively listening to what they have to say. In regards to people that have serious mental health conditions, being able to provide a family support provider to those family members, that is being culturally responsive to that family. So to have that culture of one person with a lived experience working and helping another person with lived experience with their loved ones, that, for me, is cultural competency.

**Ken Duckworth (29:55):**

Dr. Bello, do you want to add to that or offer your perspective on Donna's remarks?

**Iruma Bello (30:02):**

I think Donna, your perspective is spot on in how we are hoping that all team members are functioning and providing support to young people and their family. This idea that the person has an expertise in their worldview and what's important to them, the team can take that in and work from that premise to help the young person on the family becomes really important. I know we use an example with our teams all the time when we're training or when we're discussing how to think about culture, trying to understand very clearly this notion that how a person identifies goes beyond ethnicity, goes beyond religion, and goes beyond race.

We'll use this example of a team who was working with a young person, and what was really important to this young person was their ability to rap. They were a really good rapper. When the symptoms of psychosis started, they lost that ability. It was really challenging for this young person to want to connect socially with others because they lost that piece of their identity and they felt that it would bring shame and just a ton of negative feedback from peers, seeing him lose that skill. And being able to understand the importance of that and the role that it played in that person's recovery was fundamental in the team helping them move forward. And if they wouldn't have been able to capture that because they would have been focused on the person's ethnicity or focused on the fact that the symptoms of psychosis or focused on whatever preconceived notions they had about their status in the world, they would have missed that.

**Ken Duckworth (31:37):**

And it sounds like that was core to this individual's identity.

**Iruma Bello (31:41):**

Exactly. Exactly. So it's the intersectionality of how people think about all of these variables of identity and then who they are in the world. And being able to capture that, whether it's the individual or with their family members and understand that becomes super important.

**Ken Duckworth (31:59):**

That's excellent. I wanted to ask you what you would advise a young adult who is beginning to have symptoms of paranoia or excessive fearfulness or is hearing voices. How would you advise them to think about their experience and about their care journey? I'll start with you, Dr. Bello.

**Iruma Bello (32:22):**

The first message and the first advice is that there's help and that people do get better. I think with serious mental illness, there's always this message around chronicity. This is forever and your life ends and there's this very hopeless message. So I think the first piece of advice is there's help available and there's help available where you can be in the driver's seat. There's different ways that this help can actually facilitate you achieving your goals, because that's the whole purpose of help, to help you build a life that you want to build, not to just contain symptoms or manage difficulties, but rather to help you move forward in your life. When people are young, they have their whole lives ahead of them. They have so much potential and so much to learn and so much to try out and experiment. And by getting help, you can actually do all those things and pursue all of these dreams that you have. So the first step is to be open to talking to someone about it, and with the right kind of help, knowing that you can achieve your goals.

I would like to give the message to young people on their families, that there is coordinated specialty care, which is an evidence based way of doing this, which respects someone's perspective, which uses shared decision-making and collaboration, and is really centered around the person's goals. Because I think a lot of times people have misconceptions of what it's like to get mental health treatment. And we know that traditionally it's been hurtful, even, and a lot of times young people are scared, and rightly so. So knowing that if you connect with the right type of care, it could be really different. A lot of times people with first episode have had other people in their family experience other types of care in the mental health field, and that actually turns them off from wanting to go get help. So the message is it could be really different. It doesn't have to look like what it looked like for your family member. Connecting with a team to even explore what the possibilities are and giving it a chance could make a big difference in giving you a different way.

**Ken Duckworth (34:39):**

So your point is this is oriented towards your goals and whatever you're experiencing, there's real hope in terms of this treatment model.

**Iruma Bello (34:49):**

And there's no piece of the model that's mandatory. To come into coordinated specialty care, you don't have to say, "Oh, you're going to take medications." I know that's a big issue for a lot of young people. Or you're going to have to come to therapy once a week and talk about your childhood. But rather, this team is going to work with you in a way that you'll find valuable and in a way that really amplifies your voice and what you want and what you need and what your family needs. That's very different than how people are used to thinking about going to any kind of health professional.

**Ken Duckworth (35:18):**

Donna, how would you advise a family who may be concerned about a young adult symptoms or experiences in terms of seeking help, accessing care, finding this model? How might you advise a family who's entering this journey for the first time with one of their children?

**Donna Fagan (35:38):**

Sometimes accessing mental health care can be very daunting. We don't know even who to call to ask for help. Within the program that I work within, I actually do education and outreach to the community. I'm actively working to raise awareness within the community, provide links for other providers within the community to access care or for referrals. I work actively with the schools and the school districts to make them aware of the program. I think there needs to be education provided within the community so that they know that the program exists to start with. In the state that I live in, a majority of people know that there is a community mental health agency that they can go to, but they still don't know what to ask for. I know within NAMI we're working actively to try to get the word out and raise awareness. But generally I think that early treatment is going to equal better outcomes, so we need to work actively with people within the community that have daily interactions with those adolescents or young adults.

**Ken Duckworth (36:54):**

Donna, a lot of families struggle around these issues of self care, setting limits, and balance, and I wanted to get your thoughts on that.

**Donna Fagan (37:03):**

I think it's very important for families to exercise self care within their lives. We want to recognize that recovery as possible. We want to recognize that families need recovery. And much of the time we're extending so much time and energy into supporting that loved one in our life that is experiencing some challenges that we don't often take time for ourselves, and that's going to have an impact on our mental health and our physical health when we don't do that. I do a number of things myself to support my own mental health and wellbeing. I've identified some things like swimming and gardening that I like to do that not only give me an opportunity to relax, but give me an opportunity to get moving with the rest of my body and for my mind to focus on something else. I think self care is really important.

And I think a lot of times, as parents, especially parents of children or young adults, we are only as well as our least well-child. We're going to constantly be in that caregiving mode and it's very hard to step back and take that time for yourself. But sometimes it's very freeing for another person to tell you it's okay for you to do that. You have to focus on the long game and look at what can you do to provide some self-care time for yourself. You really have to be able to sometimes separate yourself from the problems of your loved one and recognize that you're an individual that needs love and support and care yourself.



**Ken Duckworth ([38:46](#)):**

Well, that's a beautiful sentiment to end on, and I want to thank you both, Donna Fagan from Texas, Dr. Iruma Bello from OnTrack New York. We greatly appreciate your contributions and your sharing your experience so that others can learn, and I want to thank you all.

**Voiceover ([39:04](#)):**

That's all for this episode of the Medical Mind. Look for the second part of this discussion led by Dr. Duckworth in the Medical Mind episode list. The mission of SMI Adviser is to advance the use of a person centered approach to care that ensures people who have serious mental illness find the treatment and support they need. Learn more at [smiadvisor.org](http://smiadvisor.org).

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Personal Perspectives on Early Psychosis - Part 2**

**Voiceover ([00:04](#)):**

This is The Medical Mind, a podcast about innovations in mental health care from the American Psychiatric Association. This special episode is co-presented by SMI Adviser, a clinical support system for serious mental illness. And by NAMI, the National Alliance on Mental Illness. SMI Adviser is funded by the substance abuse and mental health services administration and administered by the American Psychiatric Association. These podcasts include the real life experiences of people with mental illness and family members. Some of the content includes discussions of topics such as suicide attempts and may be triggering. If you are in need of support at any time during the podcast, please contact the NAMI helpline at (800) 950-6264. Available from 10:00 AM to 6:00 PM eastern time, Monday through Friday. To receive 24/7 crisis support, please text N-A-M-I to 741741 or call the National Suicide Prevention Lifeline at (800) 273-8255. This episode is the second in a two-part discussion about early psychosis. We continue the conversation with Dr. Ken Duckworth right where we left off in episode one.

**Ken Duckworth ([01:09](#)):**

This is Dr. Ken Duckworth, chief medical officer of NAMI, and we're very fortunate to be having experts who are part of the transformation of the public health approach to psychosis, the idea of staging intervention. You're very fortunate to have Kyran Phillips, who's going to share his experience. Ky, I wanted to see thank you for joining this conversation. And I want to also ask you to introduce yourself, if you would, please.

**Kyran Phillips ([01:40](#)):**

Absolutely. My name is Kyran Phillips, I go by Ky. I am 27 years old. Originally from Pittsburgh, Pennsylvania. I started experiencing mental health issues in my adolescence and then experienced psychosis for the first time at age 21.

**Ken Duckworth (01:59):**

So Ky, can you tell us a little bit about the experience? What did you notice about it? What was your experience of it? Was it scary, foreign, was it not that big of a challenge for you?

**Kyran Phillips (02:15):**

It was honestly overwhelming. At first my initial symptoms that I noticed were just some paranoid thoughts. And then those evolved into full blown delusion. At the worst of it, it felt like I was reliving the same day over and over and over again, just waiting around for things to change. Until I entered a first episode psychosis program, I was just convinced that I was going to continue reliving the same nightmarish day until the end of my days.

**Ken Duckworth (02:50):**

Can you tell us a little bit about the progression?

**Kyran Phillips (02:53):**

It was very difficult to recognize without the language around psychosis to describe it. Many of my friends and family became concerned because I had become withdrawn. I refused to participate in any large group activities. I over-thought most of the things that I said at one point, it got to a delusion that if I did something with my left hand, I was controlling the past. And if I did something with my right hand, I was controlling the future. So that is just a sample of the types of things that you start to experience when it first starts to progress. And then as the delusions stack, the analogy that I use to this day is stacking like pancakes, because they're sticky. So one is relatively easy to cut through, but if you have a stack of, I would say 50, it's going to take some time

**Ken Duckworth (03:50):**

Right. Now for our audience, a delusion is a fixed false belief, that information doesn't alter your thinking. So we've all come to conclusions about something. Then we learn new information and we might evolve our thinking or change our minds. So it sounds like your experience of the handedness, for example, was quite fixed. And there was just a belief that you had that you couldn't be talked out of.

**Kyran Phillips (04:22):**

Yeah, precisely.

**Ken Duckworth (04:24):**

Let's talk a little bit about how you found coordinated specialty care, how your family worked with you to find it, if they did, and then what your experience was in the program?

**Kyran Phillips (04:36):**

I actually got very fortunate to find coordinated specialty care. My mom got a flyer at work from somebody who worked in the mental health system. And at that time we didn't even know what psychosis was. It was still a mystery as to what exactly was going on with me. And I was very resistant. The first encounter that I had with my treatment team was actually quite challenging for myself, because I was brought into a conference room with everybody who would be on the team, including my therapist, my certified peer specialists or CPS, my psychiatrist, the person who ran the actual first episode psychosis program. And again, it was that feeling of just being completely overwhelmed.

I was desperate for help, but I didn't necessarily think that it was to the point where I needed all of these people involved. And partially, the issue with that is my own resistance to getting help. That's one thing that I try to share with other peers, people with mental illnesses, as much as I can in my line of work and in my personal life, is it takes a lot of courage and strength to admit that you have a problem that you can rarely deal with by yourself. And engaging them in that that day was extremely difficult. I was very withdrawn. I didn't want to make eye contact with anybody. I just got very lucky in that I even encountered a first episode psychosis program.

**Ken Duckworth (06:08):**

Are you able to articulate to them, it might've gone better for you had you been interviewed by one or two people? It sounds like the crowd of the team added stress.

**Kyran Phillips (06:18):**

Yes. As the treatment team could see, I was experiencing a multitude of symptoms that was affecting my daily life and my demeanor. And so the leader of the team decided to meet me at a Starbucks several weeks later. Just sitting down with her and her explaining the program a little bit further and saying, "Take this at your pace." It's something that is at will. So at any point, if you decide it's not for you, you can opt out of the program. And that changed my mind about how I wanted to go about this. And I thought to myself, well, why not give it a shot? Things are not getting better. Certainly there's a possibility for them to get worse. I decided that it would probably be in my best interest to take the steering wheel life, so to speak, and make a change and challenge myself to actually participate in what was going on with myself.

**Ken Duckworth (07:18):**

The team leader sounds like really went out of her way to connect with you as an individual. Not in the clinical setting, meet me at Starbucks and let's review it. Because your initial interaction with a lot of people sounds overwhelming.

**Kyran Phillips (07:32):**

I'm still eternally grateful to her kindness in doing that. At that point the program was relatively in its infancy. They were looking for more participants and they told me, you fit the bill. You're within the age range. You live in the right place. I try to advocate as much as I can now for these programs to be more accessible for anybody who needs them.

**Ken Duckworth (07:56):**

Hmm, excellent. It's close to 300 programs across America now. But, as you know, you were fortunate in that there was this movement to create a team-based strengths-based approach through coordinated specialty care, really only in the past decade or so. Once you were engaged in the program, how did you experience it? What was it like for you? What kind of things did they help you with?

**Kyran Phillips (08:24):**

Initially, they made it very apparent to me that it was going to be at my own speed, which was something that I really appreciated. Because, at that time, I didn't know very much about mental health at all. I decided that one of the first things that I wanted to work on was getting back into the workforce. I had actually just up and left my job because of a psychotic episode that I was having and just walked out. So I knew that I was still capable of working, but having that tangible goal of, okay, here's something that I know I'm capable of doing, that I need some support to do. Another thing that I wanted to work on was getting around the dilutions themselves. That was so central to me, because my thought process had just been hijacked, so to speak, by the paranoia and the delusions that I was experiencing, to the point where I could barely function in a conversation, let alone a work setting.

And so those two things were my initial steps into recovering. The most central part for me though, was my certified care specialist. He could relate to me in a way that nobody in my life or in my family or friend group could, it's not even necessarily that he had my disorder, which has Schizoaffective disorder. He suffers from depression. But his ability to say, "I see you, what you're feeling is valid. And I believe that you're experiencing these hardships, and I want to help you overcome them and power you to see the light of the power of recovery and the power of taking charge of your own life."

**Ken Duckworth (10:18):**

And this is something even the best professional couldn't do, unless they also had a lived experience that they were willing to share with you.

**Kyran Phillips (10:28):**

Mm-mm (affirmative). Absolutely.

**Ken Duckworth (10:31):**

So it sounds like the program focused on your goals, which was getting back to work, and had this supportive peer relationship that really made a big difference. Did they involve your family at the program?

**Kyran Phillips (10:46):**

Initially they did not, which was at my request. At the time I'd had a multitude of delusions and paranoia about my own family. And so I didn't want them involved in my care at all. However, they did have a few meetings that my parents were present for. So, that helped facilitate difficult conversations that I necessarily couldn't have with them one-on-one about, okay, this is something that you do that increases my stress. Or as we call it, triggers me. That was absolutely central to my home life. And then my ability to communicate with them as a young adult.

**Ken Duckworth** ([11:33](#)):

So understanding the patterns of communication that we're both triggering and hopefully reassuring was important.

**Kyran Phillips** ([11:41](#)):

Yes.

**Ken Duckworth** ([11:41](#)):

It also sound like they followed your pace. We'll bring my family in when I'm ready for that. Is that right?

**Kyran Phillips** ([11:49](#)):

Yes. That was something that if they hadn't done, I probably wouldn't have trusted the program at all. That integration was something that I greatly appreciated.

**Ken Duckworth** ([12:01](#)):

So this program is trusting you to run the process of when your family's engaged and then provided the conversation with your family, how to support you better. What else did this model offer? Because, traditional treatment might not be able to pull off most of those things.

**Kyran Phillips** ([12:21](#)):

The model presented me with a type of therapy that I had not ever heard of before. I thought to myself, cognitive behavioral therapy, isn't going to work for me because it is trying to reframe my thoughts and how those thoughts evolve from point A to point B. For me, using dialectical behavioral therapy was something that was absolutely central to making my life worthwhile, which is the goal of DBT. Having a therapist who was well-versed in multiple types of therapy was absolutely critical. Having a peer was absolutely critical. At first, me and my peer, his goal was to get me out of the house, and to get me away from a living situation that I wasn't necessarily happy with. The goal was to take me to the mall and just walk around and talk about anything other than the things that were stressing me out. And I could talk about those things if I wanted to. But he would very wisely redirect me towards, okay, what's going on in the here and now? What can you control? What are the things that you're grateful for? And that combination of DBT and having a peer and also the medication, we in the mental health world talk about medication as a tool, one tool in the toolbox, right?

**Ken Duckworth** ([12:21](#)):

Mm-hmm (affirmative).



**Kyran Phillips (13:52):**

I got very fortunate again, and that I only had to try two medications, two anti-psychotics, until I started to see a change. I will self-disclose here, because it's no secret to anybody, that I'm on Abilify. And Abilify is a mood stabilizer as well as an anti-psychotic. So that combination of having a peer, having a therapy session where I could talk about anything that was on my mind, it's very open. I think a lot of people have misconceptions about what they assume therapy to be, where it's this red couch, where you're being psychoanalyzed, but it wasn't. With my therapist, I had the freedom to talk about anything that was on my mind, whether that be delusional things or things that I was frustrated with. At that time I probably couldn't tell the difference, what was the delusion and what was something that was just stressing me out. And then having a peer was totally the keystone into a mental health recovery that I'm still on, but I couldn't be more grateful for the things that I learned along the way about myself and about how I think.

**Ken Duckworth (15:03):**

Really, you're describing the perfect blend of the recovery model and the traditional service model. Because we do know that cognitive behavioral therapy and dialectical behavior therapy have an evidence-base. We also know that medications like Aripiprazole, I'll use the generic term for the same medicine that you're taking, clearly have impact on symptoms for most people most of the time. So the idea that you got these recovery oriented, peer-driven services, and they were connected to a more traditional, but very important set of services that both addressed your experience, your thinking, coping, and also medications to help with the actual biological dimension to the psychosis. Of sounds like it was more or less optimal treatment.

**Kyran Phillips (16:00):**

I feel like I fell into a pot of gold. I didn't notice a change immediately, which is why one of the things that I tell people who are starting their recovery is you have multiple tools in your toolbox and you need to build a wellness, recovery action plan or a wrap to know the things that stress you out. The things that help. If you're standing in line at the grocery store, it's not like I can go employ my coping skill of going for a hike. But I can practice deep breathing or visualization or put my headphones in or change locations to help motivate myself, to separate myself from the stressors and focus on the present and the here and now. You're absolutely right. It was the perfect mix of both of the models of treatment.

**Ken Duckworth (16:50):**

Well, then you discovered a pot of gold is such a beautiful thing to hear. Because, so many people have not had this experience with the early years of their beginning journey with care. Just to be clear, the Wellness Recovery Action Plan or WRAP, as it's called, is yet another recovery tool developed by Mary Ellen Copeland. And it helps people identify triggers and what works for them. And it's a bit of a map for how to go forward. So it really sounds like this program pulled together virtually every tool in the worlds of recovery and the more traditional models to help you.

**Kyran Phillips (17:33):**

Oh, of course. And as I said, I couldn't be more grateful and inspired by their work with me. I can't imagine that there's any roadmap to how to treat somebody who's going through psychosis or schizophrenia or what have you. And it seems like over the years, we've just learned more about it as an illness and learn more about it and how it manifests in people's daily lives.

**Ken Duckworth (17:59):**

Well, it's a tremendous service that you're discussing this, because our hope in this podcast is that there are people out there who don't know, like you didn't know what psychosis is and don't know of this model, which makes a difference for people. I think it's really wonderful that you're taking time to talk about your experience there. Can you tell us a little bit about your connection to the treatment program now? Are you still actively engaged in this? Is this an episode of care that you had that made a big difference, and now you're onto another chapter? How do you think about this?

**Kyran Phillips (18:41):**

I'd say it's a mix, and that it's now in the background. I would say that my experience was probably very episodic. However, because the duration of the program, I'm essentially aged out of it. I recovered so well. I've done multiple advocacy projects for the program that I'm in, in order to try and move the program forward, to lend my voice to something that's so essential to my life. I still am in therapy. I went from seeing my therapist once a week to now seeing her once every month. I am on a monthly injection. So it's very hands-free in terms of medicating myself, because I go meet my nurse and have a conversation with her and get the injection. And that's that.

And then just routine med checks once a month to make sure that I'm not experiencing any new symptoms. And all I can say, as a result of it, is that I am always here to lend my voice to these types of programs, because I think you absolutely hit the nail on the head, and that 300 programs at the start of my recovery. I don't think it was anywhere near that. But we only hope that they continue to evolve and continue to reach people who desperately need them. Because I am just one voice, probably of many who benefited tremendously from a coordinated specialty care program.

**Ken Duckworth (20:14):**

That's great. What's the name of the program that you benefited from?

**Kyran Phillips (20:18):**

It's called ENGAGE. It's run by Wesley Family Services in Pittsburgh, and Allegheny County. And I believe it's open to anybody between the ages of 15 and 26.

**Ken Duckworth (20:32):**

Excellent. So really you described just a terrific recovery pathway. How do you spend your days now?

**Kyran Phillips (20:40):**

Oh, that's a loaded question. I feel more fulfilled in my life than I ever had. As an adolescent I dealt with depression, into my college years, I dealt with anxiety and I think that mix eventually led me to having a psychotic break. Now that I've put all of the depression and anxiety behind me. It's not like I don't struggle on a day-to-day basis from time to time. However, that experience of going through the coordinated specialty care program and having a team of people who believed in me for myself and for my own willpower. Now I spend my days very far, most days from depressant anxiety or delusions.

**Kyran Phillips**

I'm an avid hiker. I like to spend time in the woods. I listened to a lot of music. I hang out with my girlfriend and my cats, which I never thought for myself that I would have made it this far. And to be able to build a more stable, fulfilling relationships. Every now and then I'll plug in a video game and not have to worry about things like delusions that I am actually hurting somebody else somewhere far away by playing them. It's just impacted every aspect of my daily life and given me rewarding coping skills that I probably wouldn't have had if I hadn't engaged in a program like mine.

**Ken Duckworth (22:13):**

That's great to hear. And it also sounds like you're a resource to that program.

**Kyran Phillips (22:19):**

I try to be as much as I can. Advocacy work is something that I'm very passionate about. As an adolescent and a teenager I always thought that I would struggle with my mental health. I never saw positive things for myself. I've now completed certified peer specialist trainings. I'm about to start as a mobile position to the place that I moved to recently. I'm just very excited for the future of myself and the future of mental health as an entity.

**Ken Duckworth (22:50):**

That's great. Giving back is really a big piece of a lot of people's recovery. Becoming a peer leader, you can help a lot of people.

**Kyran Phillips (23:02):**

Just sharing your lived experience and saying, Hey, I've been there. I know what you're going through. I might not necessarily know the specifics of it, but as humans, we all struggle and suffering is part of the human condition, but that doesn't mean that we suffer alone and we have to suffer silently.

**Ken Duckworth (23:19):**

You are not alone. We can help each other through these things. It sounds like your experience with coordinated specialty care is going to have you become a leader in supporting others. The peer leadership roles are still evolving in our society, and incredibly important. Because as you said, the key to your recovery was someone who had walked in these shoes, not these exact shoes, but that they understood what it was like to have a mental health vulnerability. And they were happy to share with you.

**Kyran Phillips (23:55):**

Absolutely. I think it takes a lot of power and courage, but at the same time, vulnerability is true power. You can't get things that you've experienced without being willing to face them.

**Ken Duckworth (24:07):**

Ky, one of the questions I ask everybody is a little bit about how your cultural identity, however you define that, has impacted your experience or your family's experience in any way.

**Kyran Phillips** ([24:20](#)):

Well, that's an interesting question actually, because for me personally, as a person who does not fit gender normative society necessarily, because I actually am a trans male, I knew that I was living in the wrong body, so to speak, for most of my adolescents. Until I had language to speak about it, until I had role models who pioneered the way ahead of me, and my peer who could relate to me and just saying, Hey, I see you. And your identity is totally valid. That wasn't something that I got from anywhere else. It took me a lot of self discovery and self evaluation to figure out, am I having an identity crisis? Is it something that is my mental health? Is there anybody else like me out there? My cultural identity was I think very complex. And that was a chicken or the egg question. Am I psychotic because I'm trans, or am I trans because I'm psychotic?

Having the language to speak about these things and now realize that my mental health was affected by me not fitting a specific mold that was expected of me has transformed my life in every way. I could not be more grateful to have figured that out through the help of other people, and through the willingness of human beings to reach out to another human being and say, I may not know your experience. I may not know anything about you, but I see your identity as valid and true. That was so central to my understanding of my mental health recovery and myself as a person.

**Ken Duckworth** ([26:07](#)):

How did the coordinated specialty care work with you on that particular challenge? Or was that not an active part of your experience at that time?

**Kyran Phillips** ([26:17](#)):

Oh, it was absolutely an active part. That's what I mean by saying that this coordinated specialty care was able to integrate me into my family as somebody who had always been the black sheep, but had had dreams since I was 11 or 12 of being just a man. Until I had people in my corner, validating me saying your identity is not something that is questionable. It's something that you've known about yourself since the beginning of your understanding of yourself as an individual, and having their support and their understanding as well as them expressing to me that it was okay for me to exist as who I was, was very liberating. That's the only word that I can think of about it. Because, until I had people who said, you're not necessarily an outlier, there are other people out there like you, you just need to seek them out and recognize that there's challenges that are going to be ahead, but you are not in any way all by yourself in this world.

**Ken Duckworth** ([27:41](#)):

Great message. Just a great message. Ky, one of the questions I've been asking all these podcasts is if you were a young person beginning to wonder if you were having a psychosis experience, what advice do you have, Ky for that person?



**Kyran Phillips ([27:57](#)):**

My advice would be to accept help that is readily available. And I was fortunate enough that I didn't have to seek it. It's just found me, but it is absolutely central to recovery, to allow other people to come in and not necessarily invade your life as I once thought was happening to me, but to help facilitate the journey of self discovery and the journey of self validation that I had been on for years. There's no roadmap to understanding certain mental illnesses and there certainly isn't a roadmap to understand an identity like mine.

But having people there to say your experience is valid, and what you've always known about yourself is true. It's okay to be different and not necessarily follow a described path or mold that has been around you. Other than that, it's going to be challenging. It's not something that's done overnight. But the work that comes out of a mental health recovering and the people out there who are able to help facilitate a mental health recovery is amazing. I didn't know of any resources when I started my mental health experience, but now that I am a peer and that I know the ins and outs of the mental health system, I am just completely shocked at just how much is available, whether it be a Warmline, whether it be a treatment team through coordinated specialty care, whether it be writing WRAP plan, all of these things are just tools that you can help build a life worth living around yourself.

**Ken Duckworth ([29:52](#)):**

Excellent. That's a great answer. This has been a remarkable conversation, and I can't thank you enough for your generosity both in the time and in sharing your experience. You're going to help a lot of people. I just want to thank you again.

**Voiceover ([30:08](#)):**

That's all for this episode of The Medical Mind. Look for the first part of this discussion led by Dr. Duckworth in The Medical Mind episode list. The mission of SMI Adviser is to advance the use of a person centered approach to care that ensures people who have serious mental illness find the treatment and support they need. Learn more at [smiadviser.org](http://smiadviser.org).