

Personal Perspectives on Early Psychosis (The Medical Mind Podcast)

EPISODE 1

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.

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The topic for this episode is early psychosis. It 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: 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: Yes, that's correct. I live in Texas and I work in a coordinated specialty care program in Texas.

Ken Duckworth: So, 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 a 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: 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, but I have raised four children. Of my four children, three of my adult children developed mental

health conditions. Of my four children, two of my adult children developed a diagnosis, which included psychosis.

Ken Duckworth: 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: 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: 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: 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 multidisciplinary 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 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 kind of 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 psychoeducation 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: 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: It's interesting. What we're doing here in Texas is, within our community mental health, or 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 and 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 psychoeducation 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 psychoeducation 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, then we can also bring in aspects of our lived experience and talk with families.

Ken Duckworth: How do people receive your own family lived experience?

Donna Fagan: 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: So never worry alone. One of the classic NAMI experiences, and you are not alone. The idea that, you know, 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 team? Typically, in psychiatric training, I'll speak from my own experience, that wasn't necessarily the core principle.

So, I wanted to ask you about the professional response to this model.

Iruma Bello: 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 minute or 20 minutes 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 load? 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 switched to coordinated specialty care, where now your care loads are smaller, most CSC team have a ratio of 10 to one 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 on their families, because everything is very much coordinated and integrated.

Ken Duckworth: 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: 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 developed 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: In terms of the expansion of this program, we're 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: First, I have to say it's, 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 it 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 in 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: 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: 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 informal 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: 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: 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 were 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 were experienced 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: Giving back is just a huge piece of a healthy process for many people. Would you agree?

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

Ken Duckworth: 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: 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, in the way that we do work on a team collaboratively with other team members. Then, sometimes I have to take that head 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 cannot 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: 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: 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 view 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 and 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 foundations 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 world view. 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 world view. 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: 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: Yes, culture definitely had 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 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: 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 existed 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: 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: Dr. Bello, do you want to add to that or offer your perspective on Donna's remarks?

Iruma Bello: 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 in their family. This idea that the person has an expertise in their worldview and in 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 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 the 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: Yes, and it sounds like that was core to this individual's identity.

Iruma Bello: 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: That's excellent. I wanted to ask you what you'd 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: I think 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 are different ways that this help can actually facilitate you achieving your goals.

That's the whole purpose of help, to help you build a life that you want to build. Not to just kind of 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 and their families that there is coordinated specialty care, which is an evidence-based way of doing this. It respects someone's perspective, uses shared decision making and collaboration, and is really centered around the person's goals.

I think a lot of times people have misconceptions of what it's like to get mental health treatment. 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. 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, a different way.

Ken Duckworth: 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: 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: Donna, how would you advise a family who may be concerned about a young adult's symptoms or experiences?

Ken Duckworth: 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: Sometimes accessing mental health care can be a 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, we know 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: Donna, 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: I think it's very important for families to exercise self-care within their lives. We want to recognize that recovery is possible. We want to recognize that families need recovery and much of the time we're expending 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. 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 continue in that caregiving mode and it's very hard to step back and take that time for ourselves. 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: 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.

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.

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