

A Primer on First Early Episode Psychosis: Where to Begin Improving your Practice?

MELODY RIEFER, Moderator

Good afternoon, folks. Thank you for joining us for this webinar on Recovery to Practice. We're happy that you could be here with us.

This and all the Recovery to Practice webinars are funded by the Substance Abuse and Mental Health Services Administration. We're grateful for this support and the opportunity that it creates to help the behavioral health and general healthcare practitioners improve delivery of recovery-oriented services, supports, and treatments.

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Now we do have a couple of housekeeping details to go over before we begin.

Feel free to use the participants' Chatbox that is on your screen to request information from each other. But, if you need technical assistance, be sure and put that question in the box that is labeled "Tech and Topic Questions."

Also, if you have questions for the presenter or for any of us who are part of the RTP staff, be sure and put those in the Tech and Topic Questions. In that way, we're able to be sure that we can answer as many of your questions as possible. We will, at the end of the presentation, be conducting a Q&A with the presenter, and so your questions will guide that content.

Also at the end of the presentation, I'm going to tell you how you can get either a Certificate of Attendance or Continuing Education hours for your attendance.

It will be helpful to note that during the presentation, when you see an endnote or a reference, those will correspond to a document listed on the reference slide or in the Downloads pods.

And lastly, on the left of your screen, below our pictures, or my picture right now, you'll see a box that is labeled Captioning Information. If you would like to have live captioning on your screen in real time, copy and paste that link into a URL box in your Windows, and you'll be able to see and make it available.

Also, in the Participant Chat there is a live link that you can click on. That might be easier to access the closed captioning.

Now, let's all get to the reason we're here.

We're interested in what you are thinking, and I want to ask you a couple of questions quickly. So right below the PowerPoint slides, you will see two questions. Yes or no. Simple to answer. The first is, how many of you work with people who are in the TAY, Transition Age Youth, age range? And that is generally defined as between 16 and 25 years of age, give or take. And then the second question, does your program use any specific interventions for first or early psychosis? And, again, yes or no. A quick vote.

And as you answer these questions, you might want to look to see what your colleagues are putting in. And if you see right now, there is a bit of a discrepancy. So, a whole bunch of us, 89%, work with people in the Transition Age Youth age range, but about 75% of us are not providing any specific intervention for first and early episode psychosis. Now those aren't exactly tied together because, of course, not everyone who is young will experience early psychosis, but it is an indicator of perhaps a need for the information that is going to be shared on this webinar.

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So, with that, let's go ahead and transition back to the presentation. And I want to tell you about our presenter.

Lisa Dixon is a Professor of Psychiatry at the Columbia University Medical Center where she directs the Division of Behavioral Health Services and Policy Research and the Center for Practice Innovations, which goes by CPI, at the New York State Psychiatric Institute.

Dr. Dixon is an internationally-recognized health services researcher with over 25 years of continuous research funding for the National Institute of Mental Health, the VA, and various foundations.

I have had the pleasure to work with Dr. Dixon over the past several years in various capacities, but she is also a Steering Committee Member for the Recovery to Practice initiative. And we're really lucky to have somebody with her experience and expertise be able to speak directly to us today.

So, I'd like to welcome Dr. Dixon. Dr. Dixon, it's all yours.

DR. LISA DIXON

Great. Thanks a lot. I'm very excited to be here and to present on this webinar.

When I hear myself being introduced, I always say to myself, well they're not really saying the most important thing about my life experience in the introduction, and so I like to share that myself, which is that when I was in college and a medical student, my brother, who was also a medical student, developed schizophrenia, and, you know, this was a really traumatic, and stressful, and scary, and horrible time. And, you know, my brother remains suffering with this illness, and he has just not gotten a break. So for me, in sort of working on this problem and the challenges that schizophrenia presents, it's a very personal – very personal – has very personal meaning. And that time of onset was very, you know, it was a very difficult time, and I sort of swore to myself that if I could do anything, that I would try to make that experience better for the individuals living with schizophrenia and for their families. So, that's just kind of a little context about me, where I'm coming from.

So, I'm going to be trying to cover three topics. It's going to be ambitious in 35 minutes, but I will try. I'm a New Yorker and I talk fast, so hopefully I won't be talking too fast.

So, I'll start with the RAISE studies: how did we get here? And RAISE is the NIMH program that kind of has set up the expansion of what we now call coordinated specialty care, which is the treatment model, the evidence-based treatment model, for individuals with early psychosis.

And so, then the second part will be what are the key components of coordinated specialty care.

And then just a few comments at the end about what next and how to sustain and build.

Okay. So now I'm able to move the slides.

So just to start with, you know, a basic description, make sure we're all on the same page when we talk about schizophrenia and psychosis. We know that psychosis itself is not a diagnosis. Many, many illnesses have psychosis as a symptom. So, we want to be kind of careful in kind of thinking about this whole, you know, this new set of services and approaches that we are – have some precision of language.

So schizophrenia is a diagnosis that includes the symptoms that you can see here. Again, delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behavior, and negative symptoms. So you don't need all of those, but you do need to have a psychotic symptom to have a diagnosis of schizophrenia. Again, those symptoms are not just there, you know, it's not that they just exist, but that

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they are associated with a decline in functioning. And it turns out that a number of people have psychotic symptoms and they do just fine. It's much more common in the population than we once thought.

But in this case, in people with schizophrenia, there is an impact on the individual's ability to function and meet their life goals, at least initially, and it lasts at least six months to make the diagnosis of schizophrenia. Schizophreniform disorder would be an illness that lasts less than six months.

And there are other diagnoses that are slightly less – that are part of this whole coordinated specialty care movement, but I think in general it's best to think of this as schizophrenia-related illnesses.

And so, what is the big picture? What did I learn when I was a medical student many, many, many moons ago? We know that the prevalence of schizophrenia is about one in a hundred. It varies slightly across the globe. The incidence, however, is much lower. And it's important to understand that. Prevalence is the percentage of people in a population that ever had the illness, and incidence is new cases. So, the incidence is somewhere around 15, ten to 20 per hundred thousand. And men get it slightly more than women, or boys slightly more than girls.

And it starts right in the middle of that Transition Age Youth population. So the fact that many of you, or most of you, work with Transition Age Youth, you, you know, really this is the time of onset of schizophrenia.

And then the numbers that you see, that hospital bed data from long-term care days, those are estimates. But it's all to say that at least up until recently, schizophrenia exacts such a huge toll on, again, people and also on the system. And this – I mean, part of what I want to communicate in this presentation is that what we're hoping to see, and what I think we're starting to see, is that this can change. And that this very discouraging view will be giving way to more optimism and hope and well-lived lives.

So it's important in understanding how this evolved in the United States to know a little bit about the RAISE study. And prior to the RAISE study, you know, there had been quite a lot of research across the globe, in Australia, and UK, and Scandinavia, and Canada, other parts of Europe that we're beginning to kind of conceptualize schizophrenia as a sort of illness with stages and the idea being that if we could engage people and provide them with the right treatment early in illness in the same way that we do for other illnesses like cancer and diabetes, that we might be able to get a better outcome. And the United States was a little behind in this work, and so the RAISE study was – the RAISE program was funded by the National Institute of Mental Health. And I just love – I love this image because it says what the IMH was intending to do with RAISE, Recovery After an Initial Schizophrenia Episode, this initiative seeks to fundamentally alter the trajectory and prognosis of schizophrenia through coordinated and aggressive treatment at the earliest stages of illness.

This program was not intended just to incrementally improve and reduce this symptom or that symptom, but it was ambitious, and intentionally so, that it was going to change the world, change the United States at least, for people with schizophrenia.

And there were two studies that were funded, and I'm going to talk a little bit about them. I don't, you know, I don't want to – we're not going to go into detail, but the first study was a randomized trial. It was the RAISE Early Treatment Program Study. Thirty-four sites across the United States. Seventeen were randomized to provide NAVIGATE or the EGP-studied version of coordinated specialty care. A very important study.

And then the second study was the RAISE Implementation Study, which I was a part of, and I'm also going to talk a little bit about as well. This was more of a demonstration study where we were able to do some qualitative work and work focused on long-term dissemination implementation of the model.

And in order to really understand the impact and the importance and the scientific foundation for this movement and this really change in the system, you need to understand two key findings of research.

And I've already kind of alluded to one, which is this notion of the importance of early intervention.

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The first foundational scientific finding for this shift in transformation is that longer duration of untreated psychosis is associated with poorer short-term and long-term outcomes. That is to say, what is duration of untreated psychosis? This is the time between the onset of psychosis and treatment. And in my brother's case, this was probably close to four years as he was a young man applying to medical school, getting into school, failing out of medical school, you know, be invited back, and years and years of not receiving any treatment.

And so that's the first foundation, that longer DUP, worse outcome. And this is a very robust finding globally.

The second key scientific finding to which the RAISE studies contributed, and, again, we'll talk about that, is that treatment with coordinated specialty care, again which we'll discuss, is associated with better outcomes.

So, two things. Longer DUP, worse outcomes. And treatment with coordinated specialty care, better outcomes.

So, what about this duration of untreated psychosis? What do we know about it in the United States? In the RAISE early treatment program study, that study with 34 sites across the nation, found as follows: that the mean, or the average, DUP of the over 400 individuals in their study was 196 (inaudible). One hundred ninety-six. That's almost four years. That's four years without any treatment for someone who is experiencing psychosis.

The median DUP was 74, so that's a little bit better. But, again, a year-and-a-half. And almost 70% had a duration of untreated psychosis of over six months. And just to give you some context, what we're shooting for now is a three-month DUP. So we are really, really far off the mark in the United States.

And in the RAISE study that we did, the RAISE implementation study, we were able to do a – we did a qualitative study that asked young people and their families about their pathway to care. What helped them – what contributed to them getting care more quickly and what length of care. And so this is really from people themselves, what they told us. And, again, I can't go into this in great detail, but I think that what you can see is in the first part of the pathway, this is the time before help seeking. Things like misattribution. Not understanding what was going on. Thinking it's substance use. Thinking it's just growing up. That contributed to a longer DUP.

Stigma. Also, I mean, again, not surprisingly contributed to a longer DUP.

And then this notion of self-reliance, that I should fix it myself. I should be able to manage. I should not need help. I am a teenager. I'm a young adult. You know, this is my challenge in life right now is to separate.

And so, those three factors together, in different amounts in different people, contributed both to delays in help seeking and then really delays across the whole pathway.

And then after someone sought help, there were at least four health service factors that contributed to a longer DUP. Or a shorter one. Either way. If it went well, it was shorter. If it didn't go well, it was longer.

One was interpersonal connections. Being respected. Being heard. You know, being taken seriously.

Quality of care. Again, making the correct diagnosis. Having the right medication. The right amount of medication.

Family involvement. When families were alienated, things didn't go well. When families were engaged, they did.

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And then care transition. This notion that, you know, often young people would have a hospitalization, and then at the time of discharge they would be lost. That connection to positive, respectful outpatient care wasn't made.

And this was all upon this sort of cloud of uncertainty which was this sense that people didn't know what was happening. They were afraid. They didn't know where to turn. They didn't know what was serious and what wasn't.

And so, I think you can see here, and I'm, you know, the fact that many of you are providers in the community of Transition Age Youth, you know, we can see what we need to do to reduce that duration of untreated psychosis.

And so, you see this is kind of a schematic of the pathway to care that helps us to consider what to do when. So, we have onset. We have help seeking. And, again, help seeking can be with a counselor, or a minister, or a pastor, or a social worker, or a teacher, or an aunt, or a trusted friend. Help seeking isn't always with the clinical, you know, medical world.

And then from there we have referral to mental health services. And then now we have this great opportunity to get people to what we now call early intervention services.

Okay, so now – so we've talked about the duration of untreated psychosis and the pathway to care. We've got to shorten that.

The second scientific foundation of this whole movement of this – what we hope is a transformation of the system – is the fact that this coordinated specialty care, when compared generally with usual services, (inaudible) people do better. Okay.

So, what is coordinated specialty care? And I always like to sort of divide it – or divide it into sort of two categories of things that you need to understand.

The first is it's a multi-element model. There are several services embedded in this model. So what are those services? What are those components? Case management. Supported employment and education. Psychotherapy, which we typically think of as more cognitive behaviorally-oriented psychotherapy. And the RAISE (inaudible) study, the individual resiliency therapy was the psychotherapy.

Family education and support. Very important for this group of youngsters. Or young people. Again, but family education and support that appreciates the developmental stage of these young people.

Again, pharmacotherapy and primary care coordination. We mention primary care because we now know that these young people come with more than their share of medical problems given their age.

So we have the treatment component, and then we have how they are tied together, right? And so it's not like these treatments are in different buildings disconnected from each other, but they are delivered in a team-based model, with specialized training, community outreach, a real focus on client and family engagement such that if, you know, we expect ambivalence. I mean, who would want to get these services anyway? I mean, who wants to be in that situation? So, we understand ambivalence. That's normal. And we work with people to go where they are and always leaving the door open. There's mobile outreach. Crisis intervention services. And a key thing that we'll be talking more about later in the webinar is shared decision making. This notion that people get to choose, you know, with information, which components of the model they want, which ones they don't want, and that can change over time.

Okay, so this is just a schematic of the RAISE connection program. So this was the RAISE implementation study. Again, you can just see the conceptualization of the treatment component. And I want to point out something here that's very, very important. In the original conceptualization and early on in coordinated specialty care, often, you know, peer support, or peer counselors, were not necessarily in the program. Now in many programs they are. I think many programs see having a peer support counselor or peer worker as being critical to the model.

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But I just – I almost show you this for historic reasons. This is almost seven or eight years old now.

And you see that it's somewhat of a service-intensive model. There were about three-to-four STE say for 30 to 40 clients. And we think now maybe a one-to-ten kind of ratio is the way to go.

One of our investigators – I'm not going to give you all sort of the data from the study, but I wanted to share with you some of the results of our qualitative study on engagement, because engagement is everything. Or at least most everything. Because it's getting, you know, making that connection. You know, creating a program that our patients who we're serving want to be a part of.

And so, Alicia Lucksted, as a part of the RAISE project, did this qualitative study, and what she found, again, talking to clients, talking to our individual service recipients, you know, what made this program engaging or not for you? And so they told us individualized care. Focus on my (inaudible) and respect. That was important. Program attributes. Team structure. The setting and location in a friendly, accessible place. Medication management where they had a say in what was offered to them and what they took. Active outreach.

They told us that family member influences could both promote and deter engagement. Often, you know, (inaudible) the majority of times family members were supportive, but certainly there were times when family members did not support the person's being a part of the program, and so that was something that the young people had to struggle with.

And in terms of the personal attributes, again, they did talk about ambivalence, which sometimes led to engagement, sometimes, you know, diminished engagement. Self-concern tended to improve engagement.

Again, the self-reliance, we've already talked about.

And the symptoms could, again, both promote or deter engagement.

I do have some quotes from the study.

I guess what's been good about the program is hearing the counselors talk and saying this is not defining who you are. This is an event in your life. You can still get on with your life. You know, there may be some differences, but you can still do it.

Like when I was in the other program I told the doctor all the problems with my medication. I couldn't change the medication. I had to take it. It was terrible, you know. And now my doctor works with me. Like if something is not working, you know, we'll try something else.

And, again, it's more of how they can help you individually, more than just saying that you need help and kind of giving you what they think you need. It was really more of listening to me and, you know, relating to me. If I was having a bad day and the voices were just overwhelming, they could kind of tell, I guess, and they would ask me. And I would be like, yeah, I just can't handle it right now. And then we would talk about something completely different other than my symptoms but still like relating to me.

And, again, this is what people – these are the kinds of things that people said, things that were important to them in engaging with the program.

And this is a slide that shows data that I'm really proud of. We were interested in whether our clients experienced shared decision making in the work as a team, and this was one of the ways that we evaluated whether we did.

And so we asked, when you and your Connection team, and this program was called Connection, have talked about your treatment, how much did you feel that decisions about your treatment were joint decisions between you and your Connection team? And what you see here is that almost everyone said

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at least a little. A little over 50% said a lot. Another, say, 20%, 25% said a moderate amount. And then a chunk, ten percent, said a little.

And, of course, we'd love that to be even more, but, you know, I think like this is – this is the question that I always have in my mind when I see patients myself is what would – how would they answer this question. And we want individuals receiving service to answer this question by saying, yeah, these were joint decisions. These were joint decisions.

So, I want to touch on the RAISE Early Treatment Program study because this is really the definitive study in the United States on the effectiveness of coordinated specialty care. So, again, remember, coordinated specialty care, better than usual care for individuals experiencing early psychosis. And what this study found was, again, that the Navigate clients, individuals receiving coordinated specialty care, were more likely to remain in treatment, experienced significantly greater improvement to quality of life and work, were more likely to be in work and school, and had fewer symptoms.

And this is the only sort of really nerdy slide that I want to show you in this webinar because it's a really, really – I think it's a very – it sort of demonstrates the two key points that we're trying to make. And what this does is it takes the results of the RAISE EPT study, the study of Navigate, and it looks at the findings as a function of duration of untreated psychosis. So how did people do who had shorter DUP? How did people do who had longer DUP?

And this the control condition in green. And what you see here is the dotted line is longer DUP, the solid line is shorter. And you see there's no difference. There's no difference between longer and shorter DUP with the control condition.

But now let's look at Navigate. Okay. And this is – the orange dots are Navigate. And the Navigate clients with the longer DUP were no different from usual care in terms of their quality of life and functioning. It's – the curves are almost parallel. But in the case where the Navigate clients had the shorter DUP of less than a year-and-a-half, they did way better. Okay. And so there was an interaction between DUP and outcome. And this underscores the importance of these two things that we're working to do. And that you guys here who are working with Transition Age Youth is to reduce the duration of untreated psychosis and provide coordinated specialty care. And when we do that together, we get the most impact and help people the most.

So, again, the goal is to reduce DUP and provide early intervention services to promote long-term recovery and reduce disability. And instead of this kind of pathway to care, which was the unfortunate kind of pathway that my brother experienced complete with the police and the emergency room and the inpatient unit and drop out, we don't want this. We want to put a big X through this. We want something that looks more like this and maybe even, you know, providing services earlier. But we have onset, we have rapid health seeking, to special early intervention services.

So, I'm going to spend the last 11 minutes and 16 seconds, because that's how much I have left, talking about some of the guiding principles and clinical concepts of coordinated specialty care.

And, you know, many of you may know about different programs. There's ESSA (sp), there's STEP (sp), there's the BEST (sp) program, there's PEER (sp). There's a variety of coordinated specialty care programs, and I want to emphasize that I'll be, you know, some of what I'm going to be showing you is a little bit kind of more tied to the program that I've been involved with, which is OnTrackNY, but I – by no means am I implying that it's only in OnTrackNY. These are shared characteristics of coordinated specialty care programs.

So, we start out with this notion of recovery, and then we get the question, what do you think recovery might mean to someone who has only recently started experiencing symptoms of psychosis. And, you know, because we tend to think of, you know, when we think about recovery we think of people as sort of, you know, more having a little bit more experience with illness. So we have to kind of, hmm, what does this mean?

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And so, our answer is we need to frame recovery for young people. We must contextualize psychosis with an age-appropriate questioning about goals and life. And you all who work with Transition Age Youth know that. You know about that questioning, don't you?

We must walk with the client, help the client formulate an understanding of what the problem is and how I can be a part of the solution, you know. And, of course, we're highly influenced by Pat Degan (sp), as you'll see.

We must adopt the client's metaphor of illness to explore goals. You know, most of our clients don't sort of say, well, oh, I have schizophrenia and psychosis and so I need help with that. You know, people have a different understanding of what is happening to them, and that – we must adapt to that and go where they are. You know, we have our understanding. Professionals have their, you know, and individuals – we all have our own understanding.

We need to reduce stigma and emphasize resilience in an active individual recovery journey. I can't tell you how many times I've heard people say to me that when they think they may have psychosis or they hear this word schizophrenia, that they think that all these things are automatically going to happen to them. Violence and homelessness and things that are just, you know, appear in their minds, but it's just so – we have to really move beyond that and help them understand that this is stigma.

And we have to provide the same recovery messages to the client's support network.

And this is just one of my most favorite references in the work. Again, I'm sure that some of you have seen this. This is the notion of person-centered care. And Pat Degan kind of illustrates, you know, how individuals – an important sort of, I don't know, way to think about how people experience illness, and what that means for the provision of person-centered care. So, this notion of, you know, the goals of the individual and the perspective of the individual being supported as opposed to the goals of the system. And so, you have this notion of me, with psychosis, or taking medication, saying I feel sedated, and the psychiatrist saying, you are not psychotic. I'm still hearing distressing voices. You are not shouting at voices any more. I can't think clearly on this medicine. You are not thought disordered.

And, again, you can read the other sort of contrasts.

And I think what – when I see this, what I understand is that, you know, the psychiatrist isn't wrong, not wrong, but the psychiatrist is not looking at the world through the eyes of the person experiencing the illness and its treatment. And that in order to do this effectively, to really connect with people, we have to understand the "me" perspective.

We do shared decision making, as mentioned earlier. And what do we mean by that? Shared decision making is a process by which professionals and individuals with illness or consumers arrive at a decision that is informed by evidence, and informed and influenced by the individual's preferences and values.

In a shared decision making, there is a clear decision to be made. The decision making preference is evaluated. And, again, that's very interesting because not everybody necessarily wants to have the same amount of input into their decisions, treatment decisions, and sometimes people want to have more input into one kind of a decision or another kind of a decision. And, you know, decisional preference isn't necessarily static. It can change over time.

I mean, I personally think we should be sort of trying to cultivate that decisional preference and helping people feel more comfortable playing a role in their decision.

Information is presented in a usable format. Information provides the range of evidence-based alternatives. And that's, again, the job of the professional to make sure that that individual understands the alternative, and the information must be presented in a manner that is clear. Information includes strength of the evidence. There's a procedure to weigh options. And a decision that is at least clear, if not agreed up on by all parties. And I like this, too, because as a clinician, it helps me to sort of think about or

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almost monitor myself. When you're doing care decision making, there needs to be team talk, so that we're a team, you know, we're working together on this. There's a decision to be made.

And then there's option talk. These are the options. If you're not having option talk, presenting different choices, then you're not doing shared decision making.

And then you have decision talk where you're beginning to discuss, you know, go this way, go that way. What are, you know, how do I feel about a particular decision.

So this is kind of a schematic of shared decision making.

And this gets kind of really deep into some of the very nuanced issues in applying shared decision making. And, again, this comes from Pat Degan, who really has been such a leader in our field. And she talks about balancing the duty to care with the dignity of risk. And this notion that, you know, professionals have this duty to care, regardless of what choices an individual makes, regardless of where they are. And yet – as well as kind of need to respect the dignity of risk. When you're giving people the right to make choices, and make their mistakes, that's how we learn.

And, you know, considering the neglect versus over protect continuum. We do this great exercise where you are working with someone and you try to come up with the lowest neglectful alternatives and then the most over protectful alternatives, and somewhere, you know, perhaps the correct or most reasonable approach is somewhere in between.

And then, again, as Pat says, and this gets a little bit controversial, but the notion that, you know, the presence of non-negotiables, and so, again, as a clinician, if I think that someone really is in danger, I need to do what I need to do. Just because somebody may require some aspects of, again, you know, what we might call involuntary treatment, it doesn't mean – it doesn't wipe away the need to proceed as much as possible with a shared decision making and recovery-oriented frame. And there may be questions about that, but, you know, it does happen and it's something that we have to deal with.

Cultural competence, again, is an important component. And here I'm sure that you all have had a number of different presentations on cultural competence. But this is extremely important, particularly as, you know, many, many different cultures have a very different understanding of psychosis and what its causes are, and so we need to almost, you know, almost more important here than in other work, you know, be understanding of where people are coming from.

Appropriate medication and medical care. I've already alluded to the importance of paying attention to individual's medical status with high rates of smoking, diabetes unfortunately. And, again, in medical care it's shared decision making. Lowest effective doses. Keeping things simple. And giving people choices. Giving people the evidence, but giving people choices. Both choices in terms of type of medication and then, you know, whether to take medication or not.

And supported education and employment may be the most important – maybe second to the peer support – maybe the most important piece in the model. It's, again, integrating focus on education and employment within the treatment. Having that supported education and employment worker at the table with the client, with the family, talking to the rest of the team. This is not having the vocational specialist across town. This is fully integrating this effort into the person's treatment. And in our experience, having supported employment and education is often the key to getting people to engage with the program because often it is what people want help with. They may not want help with their thinking, with their psychosis, if they even, you know, if it's not something that they think is a problem. Often people see that they may be having problems with school or with their friends or with their jobs.

Again, family support and intervention. This is where, again, I feel that we have to start with having a person-centered approach to family-supported care. But we want to talk with our young person about, you know, what are their preferences? Are there things they don't want us to talk about? Are there things they do want us to talk about? And then we move to this family-centered approach where, again, we try to

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provide the family and the consumer the kind of family support that works for them. And we offer family psycho education, we offer groups, but we also offer flexibility.

And again psychotherapy. This is, again, in the Navigate model this is individual resiliency therapy, which is really an amazing, excellent – has a wide breadth, covers a lot of topics. And, again, a cognitive behaviorally-oriented approach for psychotherapy.

So that's just kind of a bird's eye view of each of the different treatment components. We have a long list of challenges moving forward. We are clearly not there yet in optimizing the model. We can do better. We need to do better. We have to develop and train the workforce. We have to solidify the financing model. We have to develop strategies to reduce DUP. We have to figure out how long this work is required and how to sustain the benefits. And we have to empower the community and individuals to demand these services.

I'll stop there and turn it over to Melody for Q&A.

MELODY RIEFER

Thank you, Dr. Dixon. You are from New York and can talk fast. I'm a real, live Southerner, so you'll feel some slow talking and then some quick talking.

But we have some excellent questions, and I want to – and I'm glad that we have a bit of time to explore these. But I think that it's helpful to know that the work that's being done through the NIMH and RAISE studies and projects really are happening at the right time. That we have some excellent things in our favor. Because funding streams want data, and these studies provide the data. And it's critical to be able to offer it to them. And that there is some good advocacy happening from folks with first person experience. And that there is also some good policy support, but that needs to be happening with a focus on expansion of services because there are pockets of excellence that exist, but we want those to become widespread so that the duration of untreated psychosis can be decreased as much as possible.

And that gets to some of the questions that are asked by our audience members.

So, some folks asked specifically how can we help pediatricians identify or explore or respond to the reports of psychosis. As one person said, you know, they're just lost and don't know what to do. So how can we in behavioral health help pediatricians when somebody shows up at their door experiencing psychosis?

DR. LISA DIXON

Sure. So I think that there are two parts of this challenge. One is just whether the pediatricians or general GPs, primary care physicians, whether they actually recognize the problem as psychosis. I mean, that's a broad problem in primary care, and across a lot of other settings, you know, is recognition of psychosis.

And I want to say that it's not surprising that it's hard to recognize because psychosis is not all that common. So a good pediatrician will, you know, should be able to recognize ADD or depression or anxiety. But psychosis, particularly in young people, is relatively uncommon. So they may not see it very often. And so one of the tasks is to educate. And we are developing tools. I think that there are, and internationally there are different training protocols for pediatricians and, really, again, for the general behavioral healthcare workforce. And there is, you know, what is psychosis. You know, what are some of the commonly-observed symptoms and problems.

And one of the things that I – another example of how to help pediatricians is like in New York we have this thing called Project Teach where pediatricians who, you know, are sort of stymied, I think I've got this

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right, with a situation, they can call for help so that you can get this kind of real time consultation. And I think that that is kind of a promising strategy that, again, to sort of – when a pediatrician does see a situation that they don't understand or they're not sure, maybe they can, again, get consultation.

MELODY RIEFER

The second part of the question is that, you know, once they recognize it, what do they do?

DR. LISA DIXON

Yeah.

And that's where we, you know, particularly where we have coordinated specialty care programs, we need to be doing outreach and engagement into the communities of these practices, of these schools, and making sure that these potential referring entities know who we are, where we are, and how to reach us.

MELODY RIEFER

Okay. That's great. And a segue to a very much related question but more specific to the school system because that's where young people are. And so can you speak to either how coordinated specialty care intersects the education system or if there are any programs or effective, workable solutions for early intervention or managing care in the education system.

DR. LISA DIXON

Yeah, you guys are asking really good questions! It gets complicated. So, let me – I'm going to kind of, again, tackle this from a couple of different angles.

There is – so Bill McFarland developed the PIER program, and I can't – it's P – I – E – R, and I don't remember what it stands for. So there are models that have pretty well-specified strategies, you know, to go into schools, to interact with the various settings, again, where people with this problem might show up. Now here's the challenge. The challenge is that – I mean, the good news is that I'm here talking with you today about an early psychosis intervention. That's the good news, right?

But what's the bad news? The bad news is that I'm not talking to you about a fully, you know, fleshed out, articulated strategy with evidence-based approaches for every young person who has a problem or who may need some help and assistance.

And why am I saying this now? The reason I'm saying it now is because we get back to this issue that I already mentioned that the actual incidence of psychosis, and particularly non-affective psychosis, you know there's psychosis associated with schizophrenia as opposed to depression, or substance use, or bipolar disorder, is not that high. Okay. And so it's 15 per hundred thousand, but only a chunk of those are going to be kids. Some of them are going to be 20 year olds, 21 year olds, 23 year olds, 25 year olds. So the actual number of young people, say in high school, who are developing this is very low. And so, you know, when you talk to teachers, and they need protocols, it's very hard for them to remember from one person to the next if they see this once a year, twice a year, you know. And so it makes, you know, it sort of suggests the fact that what we really need is a way to sort of integrate a much more sort of, you know, a program for whatever, school-based mental health, or a school, you know, school informing and

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educating teachers and working with the school systems that doesn't necessarily focus on (inaudible) psychosis of the non-affective type, but really hits kind of all the issues that (inaudible) deal with.

So it's kind of a conundrum. I mean right now we have this very powerful evidence-based approach that, you know, we're, you know, in some ways we can think of this as kind of the leading edge. And so, yeah, we can do training, we can approach schools. But I would just say that we have to be mindful of the fact that the problems that schools, and school teachers, and guidance counselors in high school and middle school are seeing are not so much the non-affective psychosis but rather depression, anxiety, you know, the kinds of things – the more common disorders. And so that's why it's challenging. And I can't give you the perfect right or wrong answer. We have the situation that we have.

And so the statistically more common diagnoses would be seen in earlier education, and just as a follow up, are there models for secondary education, so at the university level or community college where maybe people who are struggling, and so they opt to go to perhaps a less intense college experience, any resources that you are familiar with or would the PIER model by Bill McFarland, which, by the way, I provided a link for in the Participant Chat, are you familiar with any for the university system?

So let me just also make a comment about PIER because I want to make sure that people understand this and I don't want to introduce confusion.

The thing about PIER is that it is also – it's focused not just on informing and engaging and identifying young people with psychosis. It is also focused on identifying and engaging young people who would be so-called at risk for psychosis.

And, you know, the discussion of whether that's, you know, of that versus just focusing on people who have already developed psychosis is probably beyond the scope of this webinar.

And different communities are choosing to do different things. And it's, you know, it's a lot of dialogue about this.

But I just want to make – I don't want anybody to be confused by that point on this webinar. That they're both, you know, the focus only on individuals who have already developed psychosis is kind of one pathway. And the inclusion of people who have not developed psychosis but who may be considered at risk is another pathway. And PIER, specifically as a project, is focused on the sort of at risk and the population with psychosis.

In terms of other specific programs, I confess that, you know, I am not aware of like, you know, maybe there are. They're probably different, sort of in different areas, people have come up with sort of different specific named approaches. But, you know, I don't see this as – I see this as a lot of common sense. I mean, you know, what do we need to do? We need to provide information. We need to make it accessible. It needs to be understandable and clear. You know, we can't use a lot of jargon. We have to get in there and talk to people, and, you know, have an online presence, you know, a mine map, I think the Yale Step Program. And there's a lot of stuff out there online, so if people on this phone call are saying, well, I don't want to do this in my community. I would like to spread the word we have – we're either developing an early psychosis program or we have one. I would suggest that, you know, Nashbit (sp) and ESSA, and, you know, it's easy to find a lot of resources, and what you want to do is look in your community and try to figure out, you know, what are the strengths and needs of your community and what is most needed, you know.

But this is not – there's no magic to this. This is about basic bread-and-butter, educating people, tackling stigma, providing information, and then access, you know, so that if someone actually does call and does need a service, that there is someone on the other end of the phone who is going to know how to talk to people.

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MELODY RIEFER

Yeah. That's really helpful. And I think that you're correct. I mean, if we just reflect on how we started this webinar with the two questions about are you serving young people or young adults, Transition Age Youth, compared to do you have specialized programs for Transition Age Youth, that there is a huge gap. And that there is a number of programs and studies to explore.

We are almost out of time, and there are still a slew of questions. But what I want to be sure and let people know, first of all is that your research and study, and your commitment to this topic, Dr. Dixon, is really valuable. And I thank you for your time. That it's not just this hour that you've given us, but the preparing for this presentation and your continued work in Recovery to Practice. And I'm appreciative of that.

That this work fits smoothly into SAMHSA's ten principles and four dimensions of recovery in behavioral health. And that that work has to be focused on integrated healthcare. And that Recovery to Practice itself is an initiative that is looking at the expansion and integration of recovery-oriented behavioral healthcare that is delivered in all kinds of service settings, and that's inclusive of general healthcare settings.

Towards that end, we are, as we move toward wrapping up this series on Transition Age Youth, going to be looking very specifically at integrated healthcare for the remainder of this fiscal year. So next month, which is just right around the corner, on May 3, we're going to have our – actually that's – let me make sure I'm saying this right. On May 3 we're going to wrap up the Transition Age Youth series. Then in June we're going to start with the integrated healthcare series. So there's a lot to pay attention to and a lot where this information begins to overlap and be connected because people overlap and are connected. We start out as young people. And with any luck at all, we grow up and need that support into healthcare for adults.

So as Recovery to Practice looks at this, we want to make sure that we are involving the various disciplines, whether it's the American Psychiatric Association, or the American Psychological Association, or the Council on Social Work. We've begun to work more closely with occupational therapy and the National Association for Addiction Professionals, who, by the way, are the sponsoring organization for the Continuing Education hours that are available for people who have participated in this and other Recovery to Practice webinars. So you can click on the link or you will receive a follow-up email immediately after this webinar to take a quick quiz and be able to get the Continuing Education hours. Or be able to download a Certificate of Participation if you don't need the actual hours.

So folks, thank you so much for your participation, for your great questions. Dr. Dixon, thank you for your expertise and your willingness to share it with us. I think it's been a beneficial webinar, and I'm going to look forward to our next webinar on May 3 at 1:00 focusing on motivating others through voices of experience, with representatives from Youth Move National so that we can hear from young people specifically about what they are looking for as Transition Age Youth.

Y'all have a great day. Thank you for your participation. This concludes our webinar.