

# That's Inclusive!

## Episode 14 Transcript

### **Episode title: Mental Health and Disability Collaborative Care**

In this episode Isadora talks with advocate Kelly Ehrhart and Julie Lago of Center for Life Management about the collaborative care model that is changing the way disabled people with mental health needs receives care in our system.

Vanessa Blais (VB): Welcome to That's Inclusive! Where we talk about disability and what it means to live a full life, engaging in our communities.

What does that look like? And how can we work together to make our world a more inclusive place?

IRL: Hi everybody and welcome to That's Inclusive where we have conversations with the DD Council on inclusive community-based lives. I'm here today with Kelly Ehrhart and Julie Lago and we're going to talk about supports and services for people with developmental disabilities who also have co-occurring mental health conditions and what are some models that seem to be working for those folks. My name is Isadora Rodriguez-Legendre and I'm the Executive Director at the New Hampshire Council on Developmental Disabilities. And, I'll hand it over to Kelly to introduce herself.

KE: Hi. I'm Kelly. I live in Nashua, New Hampshire. I have a mental illness. I also have ADHD, depression and I also am on the autism spectrum.

IRL: Welcome Kelly.

KE: Thank you for having me.

IRL: Yah, it's great to have you. And Julie, would you like to introduce yourself?

JL: Sure. I'm Julie Lago. I'm the Director of Collaborative Care at the Center for Life Management. We are the community mental health center in Region 10 and together with Community Crossroads, we co-founded the Continuum of Collaborative Care model which we're really excited to share with you today.

IRL: Yah, we're really excited to talk about this model. The first question that I have kind of leading into a conversation about the model is a very general question about why it's important to have quality services for people with developmental disabilities and mental health conditions. Kelly, do you want to take that one?

KE: Yah. I'll take that one. I think that it's important that both of, like, I have a mental illness that I get good quality care in that department and also in the developmental disability department. Because if you don't have quality care, like I haven't been to the psychiatric hospital since 1998, which is a very long time, you won't be able to stay out of the hospital or function on your job – I have 4 jobs – or, do the things you want to do. Like do yoga, go to the library, be a member of your community. You can't do that if you have symptoms of your mental illness overwhelming you. Or if you don't have a nurse to prescribe your medications so you can take your medication. 'Cause if you don't take your medication, you wind up in the hospital not functioning well. And at the age of 31 I was actually diagnosed as having depression and medicated but before that time I wasn't. So I didn't really experience good quality mental health care. I experienced no quality mental health care. No mental health care at all. And so in 2014 I was not given services for my autism. So, I had no services for developmental disabilities either. I was born in 1966, so that's a long time to be without services.

IRL: Yah. It sure is.

KE: I've also lived in three states- Illinois, Virginia, and New Hampshire. When I came to Nashua, that's when I got services for developmental disability

IRL: So, shout outs to New Hampshire then!

KE: Yes. I lived in Rochester, New Hampshire. I didn't get any services through their agency. And it was a mental health, developmental disability agency. I won't name it because I don't want to call them out. But, actually they knew I had autism, but they gave me a psychiatrist and I had a diagnosis of hoarding, so they decided that I didn't really—I couldn't have a therapist from then because of that. I had to go an hour and half to Portsmouth to see a therapist actually.

IRL: That's very interesting that they would deny you services for one thing because of another thing. We were just talking about how important it is to unsilo the services and supports that people might need and provide that kind of holistic approach and wrap around services.

KE: Yah, I go to Harbor Care. They have doctors there, pediatricians, they have a dentist. I see a doctor outside of there through Solution Health. But, I do have my dentist there because she takes the Medicaid dental benefit. And it's also sliding scale. And on my Medicare health plan, I have dental benefits through there. So, I have triple benefits in a way. I have Medicaid, Medicare and a sliding scale.

IRL: Yah, so would you say health is important to you?

KE: Yes, health is very important to me. Because when I went for my wellness visit which is what Medicare pays for, they gave me recommendations and I looked at the recommendations and I said I've done all these. Except for one. They said get nutritional counseling and then I told my doctor I needed a referral for a nutritionist. I'm going to see them in December.

IRL: Great! I definitely know that you're a strong advocate for what you need and you've had a lot of success getting people to really recognize that you deserve to have all the supports and services that you need to be an integral part of your community, which you are.

KE: Yes. I think that not everyone gets that because they don't know how to speak up for themselves. I'm also the President of People First, in my second term, so we try to help people learn how to advocate for themselves and

advocate for other things besides themselves like, self-advocate leadership team, they're working on housing, transportation, computer skills and community living, computer literacy and things like that. Basically, that's important, too.

IRL: Wonderful. So, Julie, can you tell us a little bit about the Continuum of Collaborative Care model? How it came about and what direction you see it going in in the future.

JL: Sure. I appreciate the opportunity to be able to talk about this. I always say that I could talk about this for days and days at a time so we'll try to make it short and sweet. The Continuum of Collaborative Care came to be, I think, out of necessity. My background is in developmental disabilities. I've worked in the developmental disability field since I could get my working papers, which is a long time ago. When I came to New Hampshire, I still worked running the day program for a little while and then I said I'm going to switch it up. I'm going to come to community mental health and work as a therapist. And try something new. And when I came to the mental health center, the Center for Life Management, I realized we're not really starting over like I thought. There was a lot of redundancy in services. We were doing a lot of the same things as developmental services but just calling them different names. So, we had treatment plans at the mental health center. They had ISAs, so Individual Service Agreements at the developmental services agencies. We had quarterly reviews – they had quarterly reviews. So I'm sitting there thinking – why are we being redundant? Why are repeating and how many times were people going to have to tell their story over and over and over again? As a family member of someone who is living with a developmental disability, I thought, what is it my family member would want? Would she want to repeat her story over and over again? So, we joined together with Community Crossroads, who is our area agency, we've always had a great relationship with them, we paired together and said, where do we overlap? We literally drew a venn diagram. We drew our mental health services on one side and our area agency services on the other and we said where are we overlapping and how can we come together to decrease redundancy and improve efficiency in service delivery for people who experience dual diagnosis? After piloting with thirteen individuals over ten years ago now, we've served probably over four hundred people with dual diagnosis. The goal is

for people to be seen as people. Pretty much that simple. Let's not treat people for one diagnosis and send them one place. But let's say- Hi, Kelly. What are your needs and talk to you about what your individual needs are verses—well, let's talk to Kelly about her depression or Kelly about her autism—but really, what makes Kelly, Kelly. And that's the important piece. So, we've had some great success. Community Crossroads is imperative. Jen Chisholm is their Executive Vice President and she's my partner in crime over there. But working for two agencies that have been so supportive to make sure that we're looking at whole person approach to care has really been important.

So you asked about the vision. The vision is for this to be the expectation and not the exception. We don't want people to get differences in experiences based on where they live. We know that we live in a great place, in New Hampshire, we want there to be a quality in service delivery across the state of New Hampshire. So with the Continuum of Collaborative Care model, offering trainings and support, we're hopeful. We're hopeful that we will be able to achieve that with our continuing partnerships.

IRL: It sounds like it's almost a no brainer. For so long systems have been so siloed in New Hampshire and it's thinking about trauma informed care for example. And how frustrating it can be for people to tell their story over and over again. Especially if they're having negative experiences or they feel like people aren't hearing what they're saying or aren't addressing their needs. You talked a little bit about that too, Kelly. About people hearing what you're saying and giving you what you're asking for instead of skirting around your needs, your person centered needs are. You definitely have talked about how important it is to be person centered. Can you tell us a little bit more about what person centered services mean to you?

KE: Person centered services is seeing the well me, like we talked about, the mental health and also the developmental disability aspect of my care. And also I'm part of New Hampshire Developmental Services Quality Council and we have a subcommittee which you don't have to be on the Council to be part of the committee, but we're doing person centered planning and bringing it to state and saying you're not doing it correctly. Because, you say an ISA is person centered,

Individual Service Agreement, but it's not. It's not like me choosing my goals, or me choosing a methodology of how I meet that goal. I'm actually going to have one in December and we're writing my goal—I said, I want a work goal. And I want a self care goal. I want to incorporate yoga into my Individual Service Agreement, and I also want to integrate my business that I have that with my four jobs I want to be able to keep track of my money better with my business income but concentrate on that. Not necessarily my personal finances because I think I have those down. But, making sure – I'm on contract with different places, make sure I get paid when I'm supposed to be paid and that sort of thing. I don't want to not get paid for my work and then they would just tell me why they haven't paid me and not actually say 'we're sorry', this is when you should expect payment.

IRL: Would you say in your experience that the ISA process is from a strength based perspective?

KE: No, it's not. It's actually like, what can Kelly not do? Because I was reading it and she said something, my service coordinator said that because of my taking on my fourth job, that I'm getting more disorganized. I'm like, well that's not true because I didn't get my fourth job until November 15 and she's writing this before November 15. I don't feel like I'm getting less organized as I've taken on new jobs because in September 2022, I was actually working four jobs because I was working with the Institute on Disability on the Dream Big project, training DSPs about giving their client's choice, that was the IOD was one job. I worked for the Developmental Disabilities Council with Isadora on the Dream Big job. I had my Marshalls job and I had my Bureau of Developmental Services Quality Council job. So, I wasn't disorganized then. Everyone that knows me or sees my apartment I'm jealous because of how organized you are, they say that. Or like people when they nominate me for awards, she's very organized. They don't say she's a mess. She's got to clean up her place, or something like that.

IRL: You definitely seem like you have your stuff together.

KE: That's what everybody says. Or how do you do all that you do with your four jobs.

IRL: It seems like you prioritize really well and you have a lot of strengths to bring to the table. It's unfortunate that service agreements seem to focus on what people can't do rather than developing the skills that they do well.

KE: Like my service coordinator wanted me to do yoga at home. I said no, take that out. Delete it. I'm not doing yoga at home. I take a class a week and I want to be out with other people when I do yoga. Not just do it in front of YouTube – yoga by Adrian – or whoever. I want to do it in a class. The teacher can see if I'm doing it correctly or not. And other students are there, not that I talk to them or make friends with them, but at least they're there and I'm there. I'm out of my apartment.

IRL: That's fantastic that you're able to really be an advocate for yourself in that way. And did you get yoga?

KE: Well actually, the Bureau of Developmental Services refused to pay for yoga, but I applied through the Harry Greg foundation and I got a ten class pass, which is for ten classes and it's good for a year. And then they had a black Friday special, which I found out 'cause I went to the class on Saturday, after Thanksgiving so I bought five class by my money. I got twenty percent off so I paid twenty percent less than the regular price and I have six months to do the five classes and a year to do the other ten classes. And if I take a class a week, that should take me about two and a half or three months.

IRL: That's fantastic.

KE: Next time I'm going to do better. I'm going to ask for twelve unlimited monthly passes which are eighty-eight dollars a month and only take a class a week, 'cause I can only do so many classes because I can only take gentle yoga because I have a heart condition. So I can't be doing extreme or vigorous exercises and things like that.

IRL: Wow. So, I love your story Kelly because it really highlights and showcases how when things are important to you, you can advocate for yourself. You can

push people, even when you have someone say no, to have the tenacity and creativity to go to someone else and say this is something that I really want and I really need it for my health. And, how can I get it?

KE: Yes. My therapist wrote a letter and my primary care doctor wrote a letter and it just wasn't good enough for BDS. They wanted something from a physical therapist saying that I needed yoga and that it was medically necessary. They can't do that without losing their license. So I said well – it's like a road block—I have to get over the road block or around the road block, so I did. It's a grant.

IRL: That's fantastic. So Julie, when the Continuum of Collaborative Care model is working well, what does that look like for people?

JL: I love that you said working well. Because that is what we focus on. The questions that you were asking Kelly, I'm sitting here saying – don't jump in! don't jump in! Because the very basis of the model is asking people what's going well. It's really, really important, and so when we're doing our training, we say we're going to kick the "how are you?" to the weigh side. And so when we first greet people, not how are you, but, what's been going well since the last time we met? Taking a strengths based approach is really important. If we start to focus on what's going well, you've already identified skills. It is about modeling for our community partners. When I say our community partners, we identify those folks as our direct support professionals, our home care providers, natural supports -- family members, neighbors, your yoga instructor. Anybody that's important. But when things are going well in the Continuum of Collaborative Care, the individual and the teams are doing the work. We really want this to be a client centered, or a person centered, team based model. So the individual that's in services is at the lead of their team and that's exactly how it should be. They may be working on a certain skill set, whether it be in therapy or functional support services or any of the many services we provide at a community mental health center. But then, being in a teaching role to their team and saying, here's what I'm learning about my symptoms. So we're doing teaching about mental health symptoms, but being in the teaching role to help their teams learn what mental health symptoms look like and feel like to them. What warning signs and triggers might look like or feel like to them. And then, most importantly, what skills are we utilizing and



how can teams support those skills. Because what I do in the four walls of a therapy office, that's really hard if it stays in those four walls. But I'm more likely to work my skills with the support of a team. So even with me at home, I'm more likely to work my skills with the support of husband, my mom, maybe even my kids telling me what to do because they like to do that. But it's not about telling me what to do. It's about prompting me, encouraging me, recognizing what a great day looks like. And recognizing what a not so great day looks like and maybe having the tools of how to support me and encouraging me with how to make that better. So I think what it would look like for the Continuum of Collaborative Care to be going well is for teams and individuals to be on the same page for wellness and for a positive future. For everybody at the table, I always think of an ISA – an Individual Service Agreement – and how many people can be at the table. What it would mean for the Continuum of Collaborative Care to be going well, is for every person at that table to understand the hat that every other person at that table wears. So if Kelly were to come in and talk about that employment goal, everybody there says I understand that my role as Kelly's therapist is to help her with symptom management to get to that employment goal. And her service coordinator's job is –and everybody will understand the role of everybody else at the table so we can pass the baton. But also work in complete cohesive partnership all with Kelly at the lead of the team. So, we've had some great success. Like we said earlier, the goal is for that to be the expectation in New Hampshire and not the exception.

IRL: It definitely sounds like it reduces duplication of services if everybody's in the room and on the same page and taking a piece. And that the individual is deciding who is going to support them in what way in the community as well. Because they know an important part of being inclusive is that we are always looking for natural ways that we can build our social skills, our teams and people with similar interests and passions. That is really amazing.

JL: It's been a situation where we've seen the individuals who've participated in the Continuum of Collaborative Care model really shine. They have found their confidence because they understand their symptoms in a better way. Sometimes people would come in and not understand what anxiety is. They would show their anxiety but they didn't have a word to put to it. We have a lot of people

that would come in labeled as having [inaudible]. And one of the things that we specialize in is clinical behavior work. And that really is unique and I am disappointed to say it's unique because I don't think it should be unique. But clinical behavior work is focusing on the whole person. So, how do mental health symptoms impact behavior and vice versa. So understanding that when any of us feel anxious or depressed, our behavior will change. But for you or I, we might not be labeled as behavioral, we might be understanding of our mental health symptoms. But unfortunately, for people who are living with intellectual and developmental disabilities or acquired brain injury, that's not necessarily the case. We place far too many labels. So we've taken a clinical approach to behavior services and we have clinicians who author behavior plans. Our goal is to look at the whole person. When we see the outcomes, we see clients who have found their voice. And at times, we've had individuals who don't want to talk about their disability. Don't want to talk about their mental health diagnoses. And that is absolutely ok. And then they'll come forward and say, this is something that I'm proud of. It helps explain who I am and what I'm experiencing. But it doesn't change how you should treat me. And they have a voice.

IRL: You're giving people the tools and resources to really develop a language to communicate how they're feeling. To be able to identify their own feelings and also tools and resources for them to work on symptom management themselves. I know that when I go to a physical therapy appointment, my first question is I want you to show me what I can do at home to identify when things are getting bad so that I can build the skills that I need so that I don't have to come back here. And so it is about identifying the symptoms and finding a manageable plan for however I can address my own needs to be able to do that. And if I need help from other people, and professionals that I know where they are, how to ask for that help, and that prevents more serious conditions in the future.

JL: It does. It has drastically impacted our numbers for psychiatric hospitalizations and emergency services utilization and it's really because people are on the same page. Everybody is working, they've identified the plan because our individuals identify their plan. We do what's important to the individual, not necessarily what's important to the team. At the end of our sessions, so we often use a model of therapy that we call bookends therapy and it is the support system

coming in at the beginning and the end of session with a ton of autonomy right in the middle. And when we're wrapping up that session, besides what's going well, the most important thing to wrap that up is asking our individuals, what was the most important thing we talked about today? That often gets missed. What I think the most important part of that session is and what they identify the most important part as, those might be two different things. Their take-away is the important part. And from that take-away, we can then share that with their support system, whoever that may be. And they identify who that support system is. But we can then plan to share that and then the individual, based off of their communication or their desire at that time, but they can share that with their support system. And when they are doing the sharing, you get the buy-in. Because it doesn't become "Julie said, well Julie said you need to go for a walk when you're pacing". Then that's punitive. You didn't do what Julie said. It's not about what I am saying. It's "hey, remember last week when we were in Julie's office? You mentioned when you were pacing it's gonna be helpful to go for a walk. Wanna try that?" We're doing everything with a client centered approach. It's going to improve buy-in. We're going to be able to better assess insight, know what we have to work on next time. And most importantly, help people have a voice. And we're taking therapy to a next level. Therapy for us is not just individuals that can participate in talk therapy, or sit here and chat like you and I. We utilize communication devices. A lot of our therapy is done sitting on the floor and playing games and sometimes it doesn't feel like it's that traditional therapy. But it is the most beneficial therapeutic work I have ever done because remaining people where they're at, we're getting creative. We have white boards on every wall – we're drawing away! It really is just such a blessing to be able to do this work and help people have that equality of service delivery.

IRL: So, Kelly, I know that you went to a training, supported in part by the DD Council, where you learned about the Continuum of Collaborative Care model. And I know that you immediately wanted this model in life. So, what stood out for you about the Continuum of Collaborative Care model? Why have you become such an advocate for it?

KE: I think I'm such an advocate for it because I went to the three day training. I was the only person that had services through the DD Council or services through

the Bureau of Developmental Services on the DD waiver. But I realized, basically in the last [inaudible], how do I get this in my area? We don't have this where I live. Why do we not have this where I live? I want it to come to where I live. I shouldn't have to move to Salem just to get this model. I have family here in Londonderry and things like that so I'm not just going to pick up and move. When I have a sense of community where I'm at in Nashua. And I asked my service coordinator, do I have clinically informed service coordination. And she asked, what is that? She doesn't even know what it is. We're obviously not doing it. You mentioned same page, same team. I was actually in the Stepping Stones and that was the name of the article. I think they spelled my last name incorrectly, but that's ok. I want other people to know about it. I was interviewed for that article and Julie is actually going to be going to my individual service agreement. She is not my therapist, but she is a therapist. So my therapist is also going to be attending. Someone from PLUS is going to be attending and someone from PLUS said, well how many people are going to be there? I said, I don't know. It's probably going to be a lot because my service coordinator is like, how many people have you invited? A lot of people because I want my supporters to be there. And we're going to have it on Zoom because it wouldn't be appropriate for my therapist to come over to my apartment and have it in my livingroom so that's why we're having it on Zoom.

IRL: And again, it speaks to you identifying something that seems to be working somewhere else and saying I need that too, and advocating with the people that you need to to be able to get that.

KE: At first they said I couldn't get Continuum of Collaborative Care if I was in participant directed managed services. I said, that doesn't make any sense. Because participant directed managed services means that I get to choose my money. I get money say from the Bureau of Developmental Services through my DD waiver. I choose to spend it on yoga and they decided to not spend it on yoga. But I can choose to maybe get a grant for yoga or maybe go to Isadora and get a grant so I could learn computer skills. Or go through, I'm actually working with vocational [inaudible] to get Microsoft application skills, so I could learn that. Yah, I'm gonna learn that. I still need to learn now to open a Zoom meeting and

to close a Zoom meeting. 'Cause sometimes we have trouble with that in People First.

IRL: Those are all great skills to have. And I think that one of the benefits of having a model like this working in your life is that you have all the people that have the resources and the information that you need to bring your ideas to fruition. And I think that's what this is all about. True person centered services is about individualized needs and not, we can't do that, but how can we do that?

KE: Right. I was kind of surprised because it seems like the opposite of what participant directed managed services is. You're in charge of your services, not the traditional models. You're not in charge of your services. Your service coordinator is. And at first I wasn't allowed to be on participant directed managed services because I'm so interdependent, I don't like the word independent. I didn't have enough money in my budget to pay for the portal for participant directed managed services.

IRL: Oh, that's interesting.

KE: I was like, oh, how do I get more money? I have to figure that out.

IRL: I really want to take this opportunity to thank you both for coming on the podcast and talking about what quality services can look like for people that have developmental disabilities and co-occurring mental health conditions. I do think, I appreciate Julie, what you said about the model kind of arising out of the need that you saw. And I definitely have seen that need. And I am definitely an advocate for this model being implemented statewide so that no matter where you live, you can get these whole person, wrap around person centered services provided to you in a way that is meaningful for you and for whatever, whomever the people in your life are at that time. Is there anything else you want to share before we close?

KE: No. Advocate for yourself and others. 'Cause some people say that people with autism only think of themselves. I don't think that's actually true. They do think of themselves but they think of other people, too. They just don't maybe

know how to express it because of their communication difficulties and things like that. That's what I would say.

IRL: Thanks Kelly. Anything else Julie?

JL: I think it's important for people to know, I don't think the statistic is shared enough, that people with intellectual and developmental disabilities are statistically more likely to experience severe systemic mental illness than those without intellectual and developmental disabilities. And I think it's our responsibility as mental health providers or professionals in the field, to look at whole persons. And know that experiences are real for everybody. We support individuals with acquired brain injuries as well. And there is no harm in doing assessments and asking the questions. So I just think it's really important that we continue to focus on the whole person. And if we do that, I'm really excited to see what's to come. And thank you so both of you. You've both been such phenomenal advocates with the DD Council and Kelly standing up at the three day training series that we did and using your voice so much since then. So for both of you, I'm just so greatly appreciative and I know Jen is as well.

IRL: Thank you, again, both for coming on That's Inclusive! And we'll see you next time.

Vanessa Blais (VB): Thank you for joining us today. I'm Vanessa Blais and this was a production of the New Hampshire Council on Developmental Disabilities produced by Isadora Rodriguez-Legendre, and Vanessa Blais with many thanks to Josh Hardy and rest of the crew here at Concord TV. We love to have guests with differing perspectives. These are personal, and do not necessarily represent those of the DD Council.