S.I.L.V.E.R. Ask Me Anything: “Helping Older Adults with Psychiatric Disabilities Find Independence: A Hopeful Approach to Planning” with guest expert Erika R. Carr, PhD.

*This call is being recorded.*

Erika R. Carr:

It has been, uh, nothing but a, uh, phenomenal journey of meeting her as a fellow human. And, um, so many connections we have about, um, supporting people with hope and, and having a life of meaning. So, I really, really appreciate this opportunity today, and I feel like we're doing, um, similar work across the US and it's exciting, um, that we're both, uh, involved in this. Uh, so first I'll, I'll just talk briefly and then, um, I, I realize this is interactive, so we will, um, have questions and I want to just get to the heart of what people may be most interested in. Um, but just to introduce myself a little bit more about my work as far as, um, that element that's most important, I think of building hope, um, and, um, doing this as, uh, we work with older adults, or if you are an older adult, um, and my role of, um, directing a positive behavioral support service. So, um, you know, one of the things that we do in positive behavioral supports is, um, see people sometimes when they're having more challenges. So sometimes I see people in an inpatient setting, or I'm called to consult, uh, for our outpatient services and with a team around when someone may be having more difficulties. And we see quite a lot of, um, adults that are older. Um, and in that respect, some of the, the mainframes or the foundations of the work in having positive behavioral supports, and that's why it's named that way, is that we want to, um, honor people's voice their capabilities. It's a recovery-oriented care perspective, so that we're, um, we believe everybody has the right to recover to live life as they want, and as they define, not by what, um, the mental health, um, system defines for them or other people say, but like, what are their preferences or choices? What will build a life of meaning for, for individuals, um, and what can give people the most autonomy and choice? Um, and the part about positive behavioral supports, um, is sometimes I'm consulted on, um, well, every time I'm consulted and there may be a concern going on in a situation, and a team is wondering like, how do we all work together to deal with this concern or this challenging situation for this person? Um, and they may have, you know, other ways of dealing with it or, or other ways that they've, um, worked that haven't been that effective. And so, we kind of come in and try to understand, um, you know, what is the situation here? And typically, maybe I'll get a referral for, well, here's some of the concerning behaviors we have for this person, or the concerns. Um, and I try to come in and kind of assess the situation fully and see, um, what really is going on. And sometimes people will say, well, there may be this challenge I have personally when it's the, the person with lived experience talking about it, or people aren't listening to me. Uh, whereas on the other end, maybe team supports are saying, well, you know, this person may do this all the time, which I'm really concerned about, and we don't know what to do effectively and how to address it. So, um, uh, we try to do two things. We try to, um, uh, build skills on the part of the individual that may be experiencing the situation, and also really build skills on the part of the team that's supporting the person and, and make an environment and supportive network, um, that is conducive for the individual to have the life of meaning that they want and, and do the things they want with the life. So, kind of at the construct of the bottom of that is, um, first kind of identifying what are the goals of the person? What do they want most outate their life? Um, whereas I may have gotten a referral from other, other people related to concerns for the endive to the about the individual, I really want to find out who the individual is, and our team does, um, so that we can see how we can communicate best with them and maybe understand how the challenges are occurring related to communication. So, um, and then the other big part I think is working with all different providers that are supporting the person natural supports. Um, um, it may be related to specific goals the person has, um, and goals that may be even different than what the setting they're in. Um, and how do we all come together to honor the person? So, it's been a really, um, interesting journey. Uh, for me. We've kind of, um, honed our skills in this, and we now have some, um, burgeoning research that is great with helping people stay outate the hospital, um, helping people. Um, we're also starting to analyze this related to recovery concepts of like how much this type of approach helps people, um, be able to more so embody and, um, have a life of meaning that they would like versus then kind of, uh, an experience of patient hood or something like that. Um, and we have some good outcomes. You know, another great outcome we have is that, um, in the inpatient setting, um, in which I also do some work in consultation, it's, it's reduced, um, things like using seclusion restraints, which I always feel like is, is critical because we don't want our, um, inpatient settings to, to cause trauma for people. Um, so I will also, um, kind of just open it now, um, to any questions we have out there, um, and let people shoot some of those, um, out and, and try to make this as interactive as I can.

Lisa Krystynak:

Thank you, Dr. Carr. Yes. Please put your questions in the chat. Um, but also during our registration, um, you were asked if you felt the need, uh, to submit questions in advance. And, um, so while folks are thinking and getting their questions out there in the chat, we'll start with some of those. Um, and then we'll go to yours. So, um, so Dr. Car, one of the questions that, that I have, um, that I want to present is around hope and independence and hope being like the key here. Um, so the question says, um, how do you communicate belief and hope in fostering independence? Especially when, uh, the person that you're supporting or their loved ones may be struggling with the whole idea around this independence, my person is now considered in the age aging population with lifelong mental health, and now all of a sudden, you know, there's something sparking out there that they may want to find some independence, whatever that looks like for them, but they're struggling, the family's struggling. Like, how do you and your team deal with that?

Erika R. Carr:

Absolutely. That's such a, such a, um, helpful question for us to leap off from. Um, I think one is like a, is the groups that you're working with is teaching the value of hope and like the power of it and how, um, how to embody that, how to share that with individuals, um, if someone is, is sparking and having ideas and goals that they want. Um, I think one of the things that we want to emphasize is like, um, we want that most. So how can we all work together to make that goal come true? Um, and we believe you can do this. So I think when people have goals for themselves, if it's goals of independence or it's like, I want to, um, go back and take, um, art lessons, or I would like to get into work again, or I want to reconnect with some family members I've disconnected from, or I want to, um, be in my own independent apartment, um, is like thinking about all the strengths that person has and coming first from this strength space perspective and even listing those out for yourself. Because I think if, um, I do this on every like positive behavioral support plan, I write for my team, because that's part of the implementation process, is kind of writing a pathway for what we're doing with a team, mainly for us. cause if not, we get lost in what we're doing well and, and what we need to do. Um, but like, starting from a strength space perspective, like all the strengths this person has and capabilities. Um, and sometimes it's things that you haven't even thought about. Um, in fact, at times, um, I've seen my team or other teams or family members that may be worn out or, um, and rightfully so at times, um, get worn out by the person that keeps saying, I want to do this. I think I can do this. Um, well, as other people question that, but that can be seen as a strength, hey, this person really knows how to advocate for themself, and they won't give up on it. And I love that cause that shows resilience, it shows advocacy, it shows the communication skills of someone to keep saying what they need and hope and, um, and that hope, um, is something to build on. You know, so how do we, how do we pull people around that? How do we put those central goals of the person in the center? And then even though it seems like some of those things may be really challenging, or it seems like someone's maybe been in a, um, a setting where they've, um, kind of either been in the hospital or they've been in a supportive housing, or they've been even in a nursing home for a long period, but yet they'd like to do something different and live independently, like, or they'd like to have more independent skills or create more, um, hobbies. How do you get towards that goal? I also think it's helpful to, to start with small and short goals, you know, as you work towards that. Um, because, um, even though there may be doubt, um, on some of the team members that are supporting this individual, um, you know, helping people see the incremental steps that that show this person may be capable and setting up things for the person to grow towards those steps, um, and have success. And then that for both the teams that are supporting the individual and for the individual that's in recovery, um, I think success, uh, fosters more success. So as, as someone, um, gradually works towards some of the goals they want and can make some of those things happen, our hope builds as well. We're like, wow, look at that. That's amazing. I can't tell you how many times we've worked with people that have, um, maybe been in the hospital for 10 years or, or 15 years. And then, um, we slowly over, it's one of their goals to get out in the community and live independently and maybe they haven't before. Um, and as we, we start with really sum small goals, right? Like, hey, we're going to get off the hospital unit more because so far, the last six months you've, you've only, you know, been on the, the unit. Um, so let's make incremental goals. Let's go to Starbucks, let's go out on rehab outings, let's do this, let's do that. You know, um, and build kind of that hope within with the individual. And then that the team also sees the independence growing of the person. And so, the next step doesn't seem like that large of a step to climb. And eventually, um, uh, what seems so hard for most of us to me, envision can happen for an event can happen. And, um, that's another thing that we've been studying within our, um, my lab and my program, is that from this perspective, um, we've been able to really help people, um, kind of get out of our systems of care and get into more independent, um, living situations who've been maybe hospitalized for lengthy periods of time. So that's, that's, that would kind of be my answer. And I don't know if that may spark some other thoughts.

Lisa Krystynak:

Thank you, Dr. Car. That was awesome. Keeping that hope alive. That's, you know, our conversations that we have together, uh, the times we've sat and talked is that's the theme throughout it, no matter what we put together. Mm-Hmm. <affirmative> helping that person find that hope and what that looks like for them, and then embracing it. Um, we do have a question, uh, from, uh, Joseph and he asked, um, can you speak to some additional natural supports for older in individuals in recovery, other than the usual ones that we hear about, such as church library, those usual ones that everybody kind of goes to. Do you have any kind of unique ones that you and your team have, you know, uh, discovered or created in your work?

Erika R. Carr:

Absolutely. That's such a good question. Um, and I don't know if this differs for, um, I do think and, and know it differs probably per state, but I don't know some of the things that we've done for wraparound services. Um, there's something, and I'm in Connecticut, so this is the state of Connecticut, and I am not, I should have looked this up before this, but we have something here called money. Money follows the person. That's something that, um, for an older adult I'm working with right now that, um, this is something that, um, is set up where a person can go to the, their home to live, but yet they can have supports where, um, people can come in and work with them so many days of the week based on like the assessment needs of what support they need, whether it's to help support them in, um, you know, going to the grocery store, getting groceries or help support them with, like, their goals on exercise or getting out in the community in other ways. So that's a, that's a support. Um, money Falls, the person that's set up through our, um, man, I don't know whether that's state money or other grant, other grant funded money, um, but the, like, some supports like that. Um, we've had also, uh, through Demas, the Department of Mental Health and Addiction Services. We've had supports where we've had, um, uh, like life coaches that have been supported for people. Um, where, you know, I think this is kind of similar, uh, uh, it's not the same as peer support cause it's not necessarily at all. It could be, but it may not be people, um, not necessarily have lived experience, but it's someone that can serve as, uh, very different than a therapist, but as a life coach on focusing on those goals that people want to have in their life and helping them with their independence and hobbies and activities. Or, uh, it may be things like mobility of like, how do I navigate getting around town and, and going to the places I want to, and doing some of those things with the people. So, um, that has been extremely helpful, um, for many people that I've seen. Um, and we also have some other, um, I would say recovery, I don't know if you mentioned peer support, but we do have money in Connecticut. Um, that is through, uh, peer support that is very helpful where other people with lived experience come and work with people, um, long term. The other thing that we've done from my team, and this is something if you're, if you're a, uh, provider or a, um, you're like on a team and you've maybe been in a, uh, supporting people in housing supports or within inpatient settings, or you're a therapist or you're a social worker, um, you know, a psychiatrist, anyone along these like caregiving continuums, we have, if you're a lived, um, uh, if you're a peer support, you know, with lived experience and you're a part of a team that's thinking about supporting person, one thing that I really recommend is sometimes people are willing to go the extra mile. One thing that we've done with from the inpatient setting with people that have had more long-term institutionalized experiences, we know they mean may need more support. So, we've developed, um, kind of broader teams of, um, people like a bit like a, what I would say is a, um, community titration plan. So, I've set up where someone that's been in the hospital for like 10 or 15 years and we're really, really trying to launch them in the community well, where we'll try to have like a monthly meeting with the individual in recovery. And, um, myself, I'm a psychologist and I oversee the positive behavioral supports. Sometimes I even get the psychiatrist that treated them inpatient to attend once a month, um, and the, you know, outpatient, um, psychiatrist to attend. Or it may just be myself, the visiting nurse, a family member, um, a peer, um, you know, it could be a neighbor, you know, but people that are in that person's lives that can say, you know, how do we think it's going for this person? And the voice of the person to say, how do, how do I feel it's going as I've, you know, transitioned into living into my apart independent apartment. And as they're bridging kind of those first, um, kind of humps, I think of like, what is it like to be more on your own? And how do I navigate, um, finding things I like to do or making friends or, um, finding out how to go to places where I can meet people. Um, and that we've had better success with kind of building this. We'll do it for six months, probably every other week with a meeting. And then, um, we'll fall off to like once a month as we have more success in over a year. And that has shown, uh, better outcomes with our research than not putting that in place for people that have been in, uh, in long-term institutionalized settings.

Lisa Krystynak:

Thank you, Dr. Carr. That was awesome. Um, we also had in the, uh, chats, um, Leanne, uh, also mentioned around the, um, natural supports or other things to consider. Um, she said outpatient recreational and creative arts therapy support, if those are available, you know, in the community or things that I think they have found to be helpful as well as well. Um, we do have another question, um, from Brittany. Brittany said, this is kind of broad, but she wanted, um, to you to speak briefly on your work or interest area on the unique concerns of women with serious mental health. What this looks like, what those unique, um, concerns might be, uh, and maybe some appropriate interventions.

Erika R. Carr:

Wow, that's a great question.

Lisa Krystynak:

<laugh>, <laugh>,

Erika R. Carr:

<laugh> and Brittany. And for others that really, uh, care about this, I would say, um, and I'll put the link up in, in the chat hopefully in a minute, but, um, one thing you can do. So, I helped lead a, um, task force for the American Psychological Association that develops psychological practice guidelines. And I think it can be useful for anybody that's a caregiver provider. It can also be useful for you if you have lived experience, because it can be very validating of your unique experiences as a woman with serious mental illness or serious health concerns that are, or mental health concerns, uh, of like validating your experiences and maybe things that might be helpful for your providers to know, for you to advocate for. Um, but I led a task force to develop psychological practice guidelines for women with serious mental illness and is, um, totally free. It was published by a PA and, um, and 20, uh, I'm thinking 2022. It's either 2021 or 2022. And so, if you just Google American Psychological Association, um, psychological practice guidelines for women, uh, with serious mental illness, you'll find it and pull it up. It'll, it's a whole PDF on it. So that's like a really good resource to go to. But what I would say broadly is, is that we know that, um, women have unique concerns, um, when they've experienced some of these more serious mental health concerns than, um, men. And that, um, they experience, um, uh, more sexual trauma. They experience, uh, more likelihood to have that in the community if you're homeless. So, the addition of that, so you're at higher risk, um, some of these ha things happening within our institutionalized settings. So that's why we have to be really careful and mindful about the use of seclusion restraints when people go in impatient, um, and really thoughtful about the, um, the needs of women, uh, from trauma-informed perspectives, um, and be very careful of like, if there's any challenges this person has is like, how do we help this person be most effective and that we know they can be effective? And what are we doing to help them be effective? And what are we not doing that is not effective on our part that's bringing out something that not may not be helpful? You know, how do we communicate safety for this person? How do we build a safe relationship? Um, other concerns, uh, for women is like, we know that in comparison to men, statistically, um, women who have serious mental health concerns experience more, um, of a lower socioeconomic status. So, um, in comparison to men annually. So, it's, um, and that's, that's sad cause that those changes, I think the, the dynamic of them to be able to, um, uh, support themselves independently. And there are disparities there. So that gap in pay and is the same for, for women with, uh, serious mental illness as it is for women, um, nationwide. Um, you know, there's other concerns, uh, for women related to substance use and it being more likely to be addressed for men than for women, um, with serious mental illness where, um, we may pay attention to that more likely for men. Um, among many of the things, um, you know, paying attention to, um, you know, the women, uh, typically with serious mental illness, um, have had, uh, children at the similar rate or of a higher rate than the, um, the other, you know, people in the US or the world. And, but their parenting concerns or the challenges they've had with, um, at times having to lose custody of their children has gone unaddressed. So those relational concerns and what it has meant to be a mother, um, and maybe have lost their children while they've been, um, intersecting with coming in and out of hospital settings at times, or how the parent will, there's like, this is, um, kind of one of my, uh, things that hurts my heart a lot and, and as a mother myself, is that there's just not enough supports for women, um, that have serious mental health concerns to help them in their mothering needs and their parenting needs. And in fact, the statistics show that the closer they are to, uh, more of our normative, um, kind of, uh, mental health, um, institutions, the more likely they are to lose their children in custody. And that's sad because I think that that means that a lot of women with serious mental health concerns don't seek help. And, um, with due concerns, you know, I wouldn't either if I thought, um, my children were going to be taken away. Um, so that, that shows that we're not, a lot of our mental health care settings aren't approaching that with a culturally sensitive, culturally responsive, um, way of how do we empower women with their best strengths of, um, how do we help them parent well, how do we give them supports that can help them do a good job? And we know that a lot of the outcomes for many children are better if they're able to somehow stay with the parent, um, that is their birth parent. So, but there's few supports to help them with that. So, and even in my settings, um, it's amazing sometimes how, uh, that may be a deep part of someone's depression or lifelong, um, challenges with, um, delusions or psychosis of like the loss they've felt related to that role. Um, and so I think it's important for us to pay attention to that. Um, and in doing all this, I think, um, I think many times, um, you know, women can get overlooked or marginalized in our, our settings. I think, um, historically we know, um, many of our settings, uh, marginalized women, and, um, and it's an important factor to pay attention to is that, that there's so many unique and more culturally responsive, um, approaches that we can have as we work with 'me. And so, I think some of the things as far as interventions is, um, you know, asking about what supports they have. You know, it's important for us to assess for trauma sometimes when people have psychosis or, um, other kind of mental health concerns that seem to take precedence because it's this thing they came in the hospital for, or the thing they seem to be struggling with the most that we don't assess for trauma and they never get the treatment for trauma that they need. But it's a huge, huge component of, um, their, um, their challenge with mental health is that that trauma has been there but never addressed. So that's one of the things that I'm really, um, a big advocate for is that we, um, assess for trauma in a trauma-informed way that is in a preference of the person, and that there's a plan made for how and when and where, and, and what safe way that that can be addressed. Um, because a lot of times that can and not be done well. Um, you know, I think other things too is, um, as, uh, as we think about that is like thinking of the holistic needs of a, of a person, um, especially for women. So, like thinking of these wraparound services that may be effective, um, you know, places for women that may be experiencing intimate partner violence that also help them with, um, getting education. So, there's places that help people, um, that help women that have experienced intimate partner violence, get education, have natural supports to also have housing, um, financial support so that they can get on their feet and, and be more independent. I think this is especially true as you think about older adults and older women that may be experiencing that and feeling even more kind of disenfranchised in such settings. So how could they still advocate for themselves and get out of a scary situation like that? Um, those are just a few tidbits off the top, but like, um, I would say that document, um, is free and you can access it and, you know, a minute off offline. So please pull that up.

Lisa Krystynak:

Uh, I think that Amanda has put that in the chat.

Erika R. Carr:

Oh, great. Thank you so much.

Lisa Krystynak:

Yeah. She found it and put it in the chat, uh, in the chat for everybody. And Brittany says, thank you so much for your insight and for the resource. Excited to check it out. So, thanks Brittany. I check that out. That's interesting. You brought up a lot of good things that, um, I hadn't even thought about, uh, even working with, uh, you know, working with older, our older adults now and thinking about their past traumas or abuses, um, domestic violence and how that, you know, has just lain dormant for all those years. Yeah. And, uh, not, um, you know, at least looking into that being some of the barriers to independence Mm-Hmm. <affirmative> and having that hope mm-Hmm. <affirmative> that they can do what they, they would really dream to do. So, um, I'm going to check that out. Definitely. Thank you.

Erika R. Carr:

Absolutely. Yeah. And we've had many of our older adult women, um, in their late seventies, early eighties, talk about things that you would think maybe they had resolved, but no one ever thought to touch it with them, whether it was like a past rape or a, um, you know, an abortion they had, or intimate partner violence that they experienced with their husband for many years or something. So those things are important for us, and that plays a part in them being well at that age and still being able to, to not feel fear, to feel safe, to trust people, to feel like they could be independent. Um, so those are very important factors.

Lisa Krystynak:

Absolutely. Thank you so much for that. Um, so I encourage everybody to look that up and read about it and, um, really sit and process that because I think, uh, there's a lot of us who get so caught up in that moment of trying to get someone in that independence that we, um, cause there's some housing available or somewhere else available that we, you know, we just get that we get blinders on and we, we can't understand why they're resistant or there, and this is going to go to our next question about isolation. Why does this person keep isolating themselves? And we're not, um, even considering some of those past traumas to, you know, someone's 75 or 80, surely, they've dealt with that. Well, maybe not. I mean, you know, we've come a long way in addressing those things. But those many years ago, 40 years ago, 50 years ago, were we addressing them? Probably not <laugh>. Um, our culture keeps us kind of mm-Hmm, <affirmative> we want to talk about things. So yeah, that's a great point. I hope folks will really process that and dive into those possibilities for folks. But someone, Debbie, uh, ask a question, uh, about older adults who self-oil isolate and mm-hmm, <affirmative>, how do we deal with that? How has your team dealt with that? How do you look at that self-isolation?

Erika R. Carr:

Um, such a good que I had to move my screen because I had a carpenter ant climbing on my leg. I'm sorry. <laugh>. Um, that is such a great question. So, I think, um, uh, you know, I think it's a, a a, um, I think one of the main things would be to try to understand the behavior first. So, like why are they self-isolating? You know, um, is it kind of more personality style? Is it like, uh, maybe they're having more difficulty communicating as things may be changing. Um, you know, everybody as we age, we have some as cognitive challenges that come on. So maybe it, it maybe, it may be, it may be the beginnings of, um, things like dementia. So, an assessment for, for something like that in a culturally informed trauma-informed way that's respectful, um, to see, you know, what may be happening neurologically. Um, but most importantly leaning into when the person will talk. Um, I mean, I have, I have people from, I've worked with people that are older adults and I'm, you know, that are all the way to like selectively mute to, you know, talking all the time, very engaging, very outgoing extroverts. Um, but at times I think that behavior really communicates something about the individual. Um, so is it really you want to find out is it something we really need to change or is it something that they like, like, uh, are they, does it really mean they're depressed or they're sad or they're alone? Or like, hey, this person likes a lot of their, I'm alone and they are an introvert, but, um, you know, you know, and then, and that may be the case. Um, but what, where are the times in their life where they might want to connect more with people? Maybe it's not, maybe they don't have the right outlets to connect in the ways they would like, or maybe they don't know there's opportunities available for them to, um, get out and do things. Um, so this is such, that's like, such a big question, I think. But like, I think most importantly is like, rather than, than pushing an older adult, I think is leaning into like, um, it's kind of like a puzzle. Uh, I do this all the time. I, I do what we call a functional analysis of behavior and try to understand like what is going on for the individual that they would like to self-isolate. Um, you know, is it, is it, um, is it more psychiatric where they may be, uh, depressed, there's a mood issue or they're anxious or they're, um, you know, maybe experiencing paranoia? Is it all of that? Or which we can find ways to address, to work on and help them maybe, um, in therapy at a, at the process that feels palpable for them. And maybe their goal would be that they would like to connect more. A lot of people in society do want to connect more even when they're selectively mute. I've dealt with, um, many people at times that were selectively mute in older adults, that it was on purpose and sometimes it was on purpose because they felt like they couldn't communicate what they really wanted to communicate, or their feelings were so strong, um, they didn't want to communicate it in that way, or they felt like they had not been heard or it hadn't been received well. And so, it was like their statement to the world of like, okay, now I'm not talking to anybody, you know? Um, which is extremely powerful cause it, it holds the rest of us that want to be helpers and caregivers, um, at bay of like, ah, I don't know what to do. You know? Um, but I think even in those times, if someone's selectively new or self-isolating, I think continuing to show up in a respectful way, um, of saying Hi, continuing to build rapport and relationship, I think is the biggest thing. Um, and communicating that you care for that person will build a relationship in which you can get those answers you're seeking, you know? So, I think, um, I think I would go at it cautiously, what I always think is, um, be trauma informed and person centered. Because if you, you come, um, too boldly at someone who may self-isolate, they may, um, in reaction isolate more. So, I think, um, doing it in a steady, kind, respectful way, um, will help you uncover kind of the answer to the question of why are they self-isolating? Um, you know, is it a personality issue where they like to be alone more? Um, would they like to be out more, but they don't feel like they have the social skills to do it, or they have no idea how to get out more and talk to people, you know, or to go to things, or they don't have the ability to go out and do things, or they don't have the money to do it. Um, so it's, it's interesting sometimes where you narrow down the problem to why someone won't do something, and it may be the most interesting answer that you haven't thought of at all, um, and not a big problem to solve. Um, so we've had that happen, um, in some of our cases where it's just like, um, well the person didn't know that you could go to, they would get out and do things more, but everything that people are offering them to do doesn't relate to them at all. They don't have any interest in going to the library or, um, the art club or this or that or this. But, um, when you dug deeper, you found out, oh, wow, well they have this, this unique kind of side interest in crocheting that they've never talked to anybody about, and they were, they're interesting to go to, like a crocheting, um, group. So, I, I always think there's more, more than what we think to the answer is what I would say.

Lisa Krystynak:

Awesome. Thank you. That's, that's, that's good. Um, that kind of leads to the next question that came up, um, around, um, that it just kind of fell. So, I'm going to go ahead and add, this was sent to us, this, we have this from earlier, um, around the environment, um, that could hinder, you know, whether, uh, like you were talking about the isolation, you know, is it the environment? Is it, you know, people aren't hearing, uh, or they don't know how to communicate that. And, um, so the environment could hinder success, um, you know, for that individual. How do, how do you and your team work with systems and teams to ensure that they are most effective in supporting the individual's need when it comes to that environment being the, the obstacle for someone?

Erika R. Carr: ([37:09](https://www.temi.com/editor/t/dMlbq8BGqqzrLOVh3yO-F5ouyWea26cGy4o1HiZSa0pHoQalKJcehZR9OFkrULc9en6qYcBNF-rxx3ZsPtIr7wGHZa8?loadFrom=DocumentDeeplink)):

Absolutely. Such a good question. And I would say this is way more than the individual. Like a lot of times we love to, um, and I say we in the context of like, systems and teams of care is like, uh, because of like the way our systems have been structured, um, you know, we diagnose people, we say they have these psychiatric SY symptoms, they need these medications. And for many, many years, historically, it's been set up in a, like a, a problem first rather than a person first perspective. Um, whereas it's important for us to, to start with thinking about, about the individual and their capabilities and strengths. And in working with the systems, I think you must do a huge, um, I feel like most of my work is on the system is less than the individual, but helping systems and teams think about the capabilities of people. And one of the things I do is, is trying to help switch the narrative. And in the beginning when I'm working on a particular issue, or I'm called in with a situation where people have done things kind of as they might typically do, but they're like, we don't know what to do, so they call me in. And a I really try to first meet with the individual and understand them more. Build rapport, try to find out, I mean, there's a lot of people that may, um, think they know the answer to the problem. I, but I really try to ask the individual and question them and get, gather as much data from their voice as I can. And, um, also gather data from everyone that connects with this individual about like, what may be going on or, or when do you see this person not isolating, you know, when, when are they most effective? Because there's, there's people that are always willing to tell me, well, this is the time when the person like cusses at us all and refuses services and tells us to go, go away, you know? Um, but I like to ask the question of like, well, I know they're not doing this. And they'll say, they do this all the time, I say a hundred percent of the time, like every minute of every hour, every day. And that's when they laugh within me and they're like, no, no, Dr. Carr not that much. And I'm like, okay, when those hours and minutes, when they're not doing this, what do you see them doing? You know, and they're like, oh, well sometimes they play checkers with so and so. I was like, oh really. Wow, that's impressive. So, they like to hang out with people and, but it may be that it's the certain type of people they like to hang out with. Like there may be some people that are too, too outgoing for that person or too, too pushy, you know? So, it's like the style of person. Everybody has preferred people. Like there's some people that I would, you know, not work well with in my life, but other people that I do, some people wouldn't work well with me, so that's okay. Um, so building that for the team, helping them think outate the box. Um, and I come up kind of with like an idea or a hypothesis of ways that I think we might, we might be more effective in serving the individual. And then we try it out. And a lot of times I get a lot of skepticism. I have to say in the beginning, I have even people telling me when I first started this 10 years ago, this positive behavioral support service people said, that won't work. Um, you can't do that. And I even had people one time, and this was about addressing maybe someone's more aggressive behavior, um, even in older adults. And, um, they would say, well, where's the punishment in this? And I was like it’s a positive behavioral support plan. There's no punishment at all. It's all, uh, strengths based. So, um, the idea is to be very proactive and see strengths in people and for us to be proactive. Um, the thing I think is like, once you have an idea of how to help a person or activities that might be more effective and especially ways of interacting, that, that is one of the biggest ones of ways we interact with people. Like the subtle ways of interaction can mean a whole wellspring of a different outcome. And I think that one of the things that's helped the team the most is seeing that it works. Um, and I, like in my beginning years in the system I worked in, there was a whole lot of doubt because I was asking people to do a lot of things differently. But when they start to see things change, and when they start to see the person get better in doing things, maybe they wouldn't do, um, they're like, whoa, you know? And so also the other thing I would say to that, um, and I know I want to save time for more questions, but it's a parallel process. So, for people that are supporting people, we also need to hear when we're doing a good job, right? So, I'm conscientious about telling the team, wow, it's amazing. Like, how did you do that? Like, and telling them, thank you so much, you worked on this, and you were so skillful in what you did. So sometimes they come in feeling very ineffective and like, nothing will work, but then they try something new, we try these new ideas, and they are very effective at also helping people. So that parallel process of feeling supported by someone that has some seniority or is a leader, I'm a leader on my team. Um, and really recognizing them for that. And the more you support your people that are doing the good work to help with that change process, I think that the more effective they are at continuing that journey, and they'll, that'll inspire. Like we've had people sometimes, uh, really struggle with showering as they age or their ADLs, and, but we've gotten super creative and amazing about it. And as I tell people, how did you do that? That's amazing. Like, you're the team member of the month. Or like, sometimes I bring in a pizza party or a, you know, um, that helps people do more of the same

Lisa Krystynak:

Thank you, Dr. Carr. That's, that's great. cause I used in the past work life, I was boots on the ground and it meant the world to me to hear from, uh, especially the clinical team, you know, recognize the unique things that we come up with based on the, the relationship that we have with that person. So, um, being to be recognized, it does keep the fire going, um, because sometimes it, it, it's kind of hard to see success when you're in it every, every day, but have someone on the outside map it out and show the success and, and your contributions means the world. It really does. So, thanks for bringing that out. We are rolling out of time, and we have, uh, a bunch of questions coming in, so, uh, we will do our best to get to all of them. Um, and we might go as in depth as we've been, but we'll try to get to all of them. Um, Marcy asked, um, a question about the main driver in obtaining supports like housing activities in the community, like the main driver or driving forces, that's been your experience?

Erika R. Carr:

Uh, that's a good question. So, in some states it's better than others in that there's a lot of like, uh, state funds or even like community nonprofits that do that. Um, but I also think even if there's not so many, I think, uh, being a team that is willing to look up, um, just about everything and anything, and I think probably in every state there's some type of form of legal representation you can get for people with mental health needs that's free. So that can be a thing too, to advocate for people. So that's, uh, there's, there's state supports, there's nonprofit supports, and there's things I had no idea about, but I've been told about. Um, so being willing to really delve into those things. And it's like popcorn on here, like, um, you know, I'm saying some things, but I'm sure in the chat people are giving other people supports, so being willing to just keep searching and, um, that legal support people can tap into as well.

Lisa Krystynak:

Absolutely. Yeah. A lot of folks are putting some ideas up in the chats too, so I hope people will look at the chats. Uh, some good things are coming through for, uh, ideas and resources, so grab a hold of those, save your chats so you can, uh, go back and look at those later when you have a minute. Um, so our next question, uh, is a very interesting question and has crossed my mind as well. So, um, I, I wish we had more time for it, but we're going to do the best we can. Uh, Graham asked a question about, uh, do you advocate raising and dealing with issues around dying and death? Are these, uh, issues significant for many or just a few? And how do you promote hope in this context?

Erika R. Carr:

Wow, Graham, thanks for the, the big, big question, but I love it. I absolutely love it. I, I do support having conversations around that, um, dying and death and hope, um, because I think we all face it as humans, right? And even though I'm not an older adult yet, I will be. And I also still don't know that that might not happen to me tomorrow, right? In an accident or something, or that I die young from some illness. So, I do, I do think we should talk about that because it's a stage that people are getting to anyway, and they're thinking about, um, and I think we'll go about it in different ways based on personality style. Some people may be willing and able to do it more easily while others will kind of get there in kind of a, a more, um, subtle way. But I suggest we should, um, because it's happening for the person, and we don't want people to wait alone in that. Like, I think they, we do need to help hold that for them. And of like all the older adults that we've been working with and seeing late lately, like I would say we're having those conversations. Some people and people need to voice their, uh, feelings about it, what even in like the last years of their life, whether they feel like it may be months or years or whatever, or days, there are still things that they would like to do. So, I think it's a very important discussion to have, um, with people they feel safe with. I think that's one of the most important things. That may be family members, it may be a peer support, it may be a therapist, um, but a promote having that discussion.

Lisa Krystynak:

Yeah, that's a, that's a good one. <laugh>, that was a good one. Thank you for your insight on that. Um, um, so Janine, um, she wanted to know, you know, your thoughts or your experience with working with OTs. Um, she talks about a tool that they use the interest checklist, which can identify, um, their main interests. She talks about occupations which are very meaningful, uh, and she also gives, um, the UK version, uh, diverse learner options available. She gives that, um, as a way for people to go look at that and research that as well. But her, she wanted to know your experience with working with OTs.

Erika R. Carr:

I've had such great experience working with OTs, they're part of our rehabilitation department, and I tell you what, they have been some of the most positive, amazing people that have wanted to just dive in with this positive behavioral support planning. So, they're kind of, I think the hands and feet of helping us implement this. Thank you for offering that. Um, uh, it sounds like some type of assessment to enlighten us on more things people may have interest in. Um, another one I meant to, um, say earlier is the recovery assessment inventory. And uh, you can Google that, it's free, but, um, the wonderful thing about you putting that out there is that sometimes we think maybe that person who self isolates or is alone or doesn't do much, has no interest in the world. And sometimes it's a problem of we haven't found the right thing they're interested in. And when I get to that crux where no one can tell me what someone's interested in and all they want to do is sleep or stay in their bed, I will try to do something like that. And inevitably, even if I do it at five minutes at a time, I will find something that a person is interested in, and it is unbelievable it. So that's so creative, and I think that's a great tool for everyone to use.

Lisa Krystynak:

Yeah, absolutely. And uh, Leanne, she put out another resource talking about interdisciplinary team members. Uh, so hopefully folks can go out and check that out to recreation therapists who can support and transition. Um, she referred to that as well. And, uh, lots of folks are coming out and thanking you for your insight. Um, so we got, uh, maybe like just a minute or two for one last question, and I think this is a good one. Um, and I know you, Erica, you and I have talked about this a lot, um, in our meetings talking about, um, peer support. And I know that we have, um, we have some peer support specialists that have joined us today, or maybe we'll even watch this later. And I know being a peer support specialist myself, um, we are introduced to many, many environments, um, and it's around the family, uh, engaging family and support. So, um, so how did you, uh, how, how does you, you or your team or both come together, like to educate the family to see the, uh, the capabilities of their loved one, um, how to address their anxiety that they may have about their loved one getting living in the community or getting more engaged in the community, and how have you seen peer support kind of light that up and, and paved the way for that as well?

Erika R. Carr:

Oh wow. I love that question and thank you for all of those on here that are peer supports. You do like the work of angels, I feel like because you do work, um, those, that, those of us that are clinicians or haven't identified as having lived experience can't do. And so, you are the very voice and, um, embodiment of the capabilities of what can happen. So I feel like, um, beyond the team, like the team can do so much and I can do so much, but sitting in that room with family and talking about that you hold hope for that person or sharing some of your story that you feel comfortable sharing of like, Hey, I've been there too and this is where I was, but now this is a path I've gone through and I needed people to have belief and hope in me to get there, or maybe I wouldn't be there. Um, or other narratives you have that are similar, I think I would think, and I, I tell you from my own experience, the families hearing the stories of other people with lived experience and having that advocacy and that support as a person maybe is working on that is probably more powerful than many of these other things that we do. So, um, I would say keep doing that, um, advocate and, and I think it's okay to say, hey, we recognize you have anxiety, rightfully so and so you validate their anxiety <laugh> so they don't feel like it's not valid. Every emotion is valid. We all just have emotions, uh, validate the anxiety, but also say both. And like, I hear your anxiety, and it is possible also that every human has the right to fail. Um, and this doesn't mean the person is going to fail, but it just because you have a mental health experience doesn't take away your right to fail. Like, uh, you know, every other human in life has the right to go and try something next that they would like to do. And so, I think, um, pushing against that thought that some of the families don't even let people try, you know, say just because this person has this experience doesn't mean that they don't have the right to try and learn from the bumps in the road and tell them there will be bumps in the road, because that's part of it. And a bump in a road doesn't mean it's not possible. It's just like how do we navigate around those bumps in the road? Um, so that's some of my thoughts.

Lisa Krystynak:

Thank you. Thank you. You're right. There are going to be bumps in the road, and recovery can happen at any age, at any time. And, um, peer supports can share their experience with family, um, as well. And, um, and that's just kind of a mind-blowing thing sometimes, um, for family to he sees in front of them that success where they, they just couldn't imagine it. And peer supports or living representation of recovery each day, no matter how young or old that they may be, it's, it's just very powerful. So, yeah. Thank you. Um, I just want to thank you Dr. Carr, um, for sharing your, your experience, your knowledge, but most of all your passion, that's what what I fell in love with when I first met you was your passion that you're willing to put on any hat, do your gloves up, pull your pants up, and, and go right out there and work with your, not only the people, but with your teams. And we need more, more people like you out there working like that. Uh, it really makes a difference, and we appreciate you sharing that for us. Gives us hope, <laugh> for sure. Um, but we do appreciate, uh, all your insight. Um, and I want to thank everybody that came out today for all your wonderful questions. Um, I wish we had more time, but we are out of time. Please take time to, um, complete the survey. When you, uh, go off here, there'll be a survey pop up that really, really helps us here at Boston U to figure out what we're doing well, what we need to improve on, and even ideas of things you'd like to see on ask me anything. And, um, we appreciate it. So, I hope you guys have a great remaining of, uh, your Monday and a great rest of your week and we appreciate all the thank you and um, all the things that you have, uh, put out there on the chat, all the great resources. So, uh, thank you so much. But guys, we're going to sign off. So, you guys have a wonderful rest of your day and hope to see you at the next, ask Me anything.

Erika R. Carr:

Thank you so much. Take care everyone.