

Inside the OUTcomes: A Rehabilitation Research Podcast

Episode 12: Kenny's World

LINDSAY DUBOIS:

This podcast is created by the Center for Rehabilitation Outcomes Research at the Shirley Ryan Ability Lab with support from the National Institute on Disability, Independent Living and Rehabilitation Research at the Center for Rehabilitation Outcomes Research. We are dedicated to excellence in health services, research on outcomes for people with disabilities, their care partners, clinicians, policymakers and other stakeholders. You can learn more about our center and stay up to date on our projects by visiting our website in the description like our Facebook page at Rehab Outcomes or signing up for our newsletter.

Hello, everyone, welcome to the first episode of our Home and Community Based Services podcast series. My name is Lindsay Dubois and I'll be your host today. We at the Center for Rehabilitation Outcomes Research hope that this podcast series can be an informative resource about all things home and community-based services. We are so excited to share this episode with you, so let's get right into it.

Today, we are delighted to be joined by Tanya Richmond, who is also co-host in the podcast with us. Tanya is a licensed clinical social worker, certified person-centered thinking trainer and plan facilitator. And she's a partner with Support Development Associates or S.D. A. SDA and Tanya work with organizations who deliver home and community-based services to help to transform their practices and systems into more person-centered ones. Sounds simple, right? Well, as we will talk about more in this podcast, it's much harder than it sounds. You'll hear from Tanya, who will speak on why it is so important for providers to be trained in person-centered planning. And you'll hear from Kenny and Heather. So, Tanya, could you start by explaining to our audience, what do you mean by person-centered practices?

TANYA RICHMOND:

Yes, of course. Thank you. Person-centered practices are value-based. They're a set of skills and they're designed to give people who provide supports and services the skills they need to generate, to explore, to offer options and choices to people. And it's a way for people who are in support roles to have the skills they need to first understand what's important to a person. So kind of what sits at the core of the person in their heart and then explore the choices that connect to those things that are important to that person. So the things they desire for themselves and they prefer, while taking into account those things that are important for the person in terms of their health and their safety.

LINDSAY:

All right, so other than those obvious reasons you just mentioned, why should providers practice person centered skills?

TANYA:

Well, because it's not only the right thing to do, it's the law, the home and community-based services or what we say. The HCBS final rule of 2014 specifically requires person centered planning with people who are who are receiving HCBS services. And many of those services are there in the community there. It's a range of things, everything you can possibly imagine. So the skills and the practices then are the mechanisms that we would ask people to use when they're determining the desire for or the type or the amount of services that someone's receiving and also who provides them. So people have choice about that. And the big change for us to talk about today is a change that's directly connected to home and community-based services. Final rule. And it's because providers are now required to include people in the planning process for services and supports and use a person-centered framework.

And that's a structured framework that allows the person to guide the process. And at the same time, the provider is learning about the desires and the preferences of the person in balance with their health and safety needs. Because historically what's happened is the system and the people who provide services and supports have been the deciders in people's lives. So plans have been more system centric or focused on the capacity of or the convenience or the

ease of service provision. And they focused on what keeps people healthy and safe. But when we only focus on health and safety, we find that people are perfectly healthy, they're perfectly safe, and they might also be perfectly miserable. But because of the expectations in the Final Rule, people and the people who are closest to them are now making their own decisions about their lives. We want a system where people are supported in living the lives they want in their own communities. But we are living in a time, we're living in an era where the demand is increasing and public resources really can't keep up with that demand. And that means that if we're in a provision role, a service provision role, we have to change how we think about how we organize, how we deliver services. And the person needs to be the final decider whenever possible. So if we're going to have real substantive change, not just a flash in the pan and the kind of change that not only meets federal and state expectations, but also improves the lives of people who use services and supports and helps people who manage the organization, use their limited resources more effectively, and also helps people who manage the system learn how the changes that they made are working. We need skills to be able to do that, and our person-centered skills can help us do that.

LINDSAY:

So when we initially talked about doing a podcast around person-centered services and what that looks like in practice, you immediately thought of Kenny and Heather. There was no hesitation. So can you tell our listeners about Kenny and Heather and why you thought they would be the right guests to interview?

TANYA:

Yeah, you know, I met them about eight years ago or so, I was in Connecticut, I was training some person-centered thinking trainers, some of whom came from an organization called Marrakech and Marrakech is the organization that serves Kenny. And Kenny's been with them for a very long time. Kenny actually came with those trainers who were the people who are learning to be trainers, and he was telling stories about his life. And we incorporated that into the training process. And it was through Kenny that I actually met Heather. Heather later came to Marrakech many years ago and she actually provided services. She was a direct support provider. We called DSP earlier in her life and she has worked her way up through the organization and is now the CEO.

But Kenny Gianotti just really impressed me with the stories about his life during that training process. And really the other thing that really impressed me was how the organization had flexed to support Kenny through the years. Now, Kenny is fairly outspoken. He can tell us what he wants and he is not afraid to do it. And I think many of his stories will highlight that for us. But I was really impressed with the lengths to which Marcus had gone to identify what was important to Kenny and to help him have that at the same time that they were helping him be healthy and safe and helping their organization meet all the mandates that they have to meet. So they provide services and supports to Kenny. But in addition to that, they really got to know Kenny and build trust with him.

LINDSAY:

I love that I'm really excited to hear what Kenny and Heather had to say in your interview. So can you tell us a little bit about what to expect and what we're going to hear?

TANYA:

Yeah, so you're going to hear Kenny talk a little bit about his own life, a little bit about his background, things like how he met his wife. He's going to talk to you about his job and his experiences receiving services at Marrakech. And I think he's really the perfect example of what it means to have some choice and control over various aspects of your life and really how his services have changed over time to support his choices in a way that makes his life much more meaningful and really represents a balance in Kinney's life between those things that are important to him and those things that are important for him to be healthy and safe.

LINDSAY:

That's amazing. Let's get right into it.

HEATHER:

So my name's Heather and I started here at Marrakech when I was very young, about thirty, thirty six years ago. I was set out to be a special education teacher and I wanted to know where people that have disabilities and other barriers might live and work after school. So I wanted to be the best special education teacher ever. And so I wanted to know what options there were out there. And this is way before there were cell phones and everything. So I opened up the Yellow Pages. I was at Southern Connecticut State University in New Haven, and I opened up the Yellow Pages and I found Marrakech. I called them. I said, could I come to my internship there? And they're like, yup, come up. So I as a almost special education teacher, I started my internship at Marrakech and I fell in love. And that's where I am. Thirty-five years later than now I'm here. And I took many different positions here. And about seven years ago when I was meeting you was when I was transitioning over to president and CEO.

TANYA:

I've just been so impressed with the services at Marrakech. And, you know, when we talk about person-centered practices, it truly is about building communities where people who maybe have disabilities, the presence of a disability, are surrounded by really strong, meaningful relationships in their communities as much as possible and having control over their resources and having the people in their lives who support them to have more of that control, have that positive control over things. That was one of the things that really impressed me about medication. And through meeting Kenny, through talking with Kenny about his experiences. I know it wasn't always easy, right? You didn't just kind of come into the world. You may have had a person-centered way about you. I think when you approach services because you were very young, you were like 17 right when you first started with Marrakech. And Kenny was a teenager and probably no one was using the term person-centered very much back in the days, as you were saying. But when I think about what I've learned from Kenny, that's why I really wanted to have an opportunity to talk about his experiences today.

Kenny, the stories you've told me over the years have really kind of helped me understand how important it is for everybody to hear stories like you. And like I said, we've talked almost every day for seven years. I can't believe it's been that long. And I just kind of want you to tell everyone about yourself, like, where do you live? Who do you live with? Tell me about what you do, all of those things so that people can get to get to understand your life where it is right now.

KENNY:

East Haven, Connecticut.

HEATHER:

We're in New Haven, Connecticut, eating. Oh, statement, yes. So who do you live with?

KENNY:

My wife.

HEATHER:

Your wife, who I also know, Carla, where did you meet Carla?

KENNY:

Through a friend of ours. Don't tell me you want to know the whole debt hole details about it, I was like a long time ago, close friends and they had a birthday party for her. She goes over there. My friend Golden says, What are you doing to manage? All right. Come to my friend's house for a birthday party. That's sorry, but some girl punches me in the nose because I was looking at her stuff and I had a bloody nose. I run to the bathroom and then crawl and run to the bathroom. Are you OK? And I said, Yeah, I'm alright. And then she said, Who is this kid? He's cute. And then after that the next day and she goes and says, You got something to say to me. She said, How would you like to go out with me and stuff? And then she says, OK, then we went on a date and stuff. We went to Anthony's in Gilbert.

HEATHER:

How long ago was that how long ago did this all happen?

KENNY:

We got married in two thousand nineteen ninety. And then when we got engaged, that was on the Halloween two thousand No. Nineteen nineteen ninety nine this Halloween, a friend of mine gave me tickets for a wrestling match and stuff. We went there for our engagement party by ourselves.

HEATHER:

You're a big fan of wrestling. I know that's the one thing you and I never see eye to eye on. Right. Or one of the many things you and I never see eye to eye on was actually the first thing he taught me about Tonya with a person-centered thinking. Marrakech was always progressive. So I know that there were six bed group homes were very common in the world, five bedroom homes. So we were like, no, it's horrible to live with five other people. Even everyone you choose to live with. It's hard, but that's what they were giving out at that time, like community living arrangements for five or six people. So what we did, we thought we were so smart we were going to check them. So we rented three apartments in a building. So even though it was a five bed home, it was really someone had their own apartment and two people shared an apartment and two people shared an apartment. So they had their space and they got to choose who they were with. So Kenny moves in. He's my age. I'm youngest. I know he's a little a couple months older than me. And he comes in and behind him is tons of like rolled up posters. And they were the Undertaker, which I never heard of from my girls in bathing suits and, you know, all these different types.

KENNY:

Young men and stuff. Yeah.

HEATHER:

Yes. What a typical young man might hang up in that room. And so it was my first experience where my coworkers were like, I don't want to look at those posters. I don't want to you know, I don't want that he shouldn't have that in his room. And it caused me to think about it and talk to Kenny about it and say, it's my room. I'm like, yeah, you're right. It is your room. So we came up with a vision statement. So all new hires and all of our current employees knew that this is their homes. This is Kenny's home, and it's decorated by Kenny. And so if something might offend you or something that you don't want to deal with or something that you don't like, you can work in a different place. But it's not here because the people that we support can furnish their home in any way that they like. So that was like one of our first things that we had to do formally meeting Kenny so people knew what the mindset was and that we support people who have their own decisions on what their home was like.

LINDSAY:

So for you, that was really kind of the beginning of I remember you telling and telling me that it wasn't called person-centered. It was called Kenney's life. And that was kind of the only life there.

HEATHER:

It was. And that's how supports were provided. It was Kenny's life. And I think that's you've told me that you've learned so much about person-centered supports from Kenny. I know, Kenny, one of the things I was reflecting on as you were talking about, Carla, your relationship with your wife, you know, the first thing that you mentioned was she came to take care of you. You had a bloody nose. I didn't know the other part of that story, but it sounds exactly like Carla to be that caretaker in your life. And I know you to be a good caretaker for her as well. And I know when I was getting married myself, you gave me advice about my marriage, which is not very old at this point. And I just have always really appreciated your orientation to your family and the people in your life that you love. And I'm curious about how life is going for you right now. Just in general. How are things going?

KENNY:

Almost everything is good. But I what I want to get the heck out of stop shop. I want to leave that.

HEATHER:

So your current job. You've been there a really long time.

KENNY:

Thirty-four years going on. Thirty-five.

HEATHER:

So what do you do there?

KENNY:

First Stop and Shop, but I push carriages or the porter.

HEATHER:

OK, so has that changed any over the years. Is that what you've been doing all along or not?

KENNY:

They changed because they said that I called out too many times. I think it's so stupid. When they started to have the robots there and I think that was the beginning of the downfall.

HEATHER:

So what kind of robots are these, like self-checkout robots?

KENNY:

They walk around, they roll around the whole entire store and call up when you cleanup.

HEATHER:

So if there's a spill so like Kenny's job, if there was a spill, if there was something, you know, the robot can now clean it up. And when he ever met that robot know Friday night in hysterics saying, I'm getting out of here, they're buying a robot to replace me, they're going to change my hours now because then they started playing with hours and he was not thrilled with that.

KENNY:

Yeah.

HEATHER:

So are you thinking about other things you might like to do?

KENNY:

Oh, yeah.

HEATHER:

What's on your mind about that? What do you want to do?

KENNY:

Well, the minister.

HEATHER:

A youth minister. So I remember talking with you during the pandemic about you missing that because when you couldn't get together in person.

KENNY:

Oh, yes.

HEATHER:

So you're back now gathering in the church?

KENNY:

Yeah, kind of. But it's like I haven't been there for about a week because I haven't the occasion. I don't go back until the 13th of June.

HEATHER:

OK, so you have some opportunities to meet with me, with people again, and I know that's been really meaningful for you, that that your connection to your church has given you a lot of purpose and meaning. We've had a lot of conversation with that over the years. Yeah, so what are your opportunities for getting into the ministry?

KENNY:

If I do, I have to go to seminary school for it first, try to go and check out some schools.

HEATHER:

So have you begun to look at ones you might check out or just think about it?

KENNY:

I want to go to the divinity school that's in Yale. I heard cost a lot of money.

HEATHER:

Kenny called me during Covid, and you were not happy with the person that was supporting you at the time, you're like, I don't want him back. And you don't have to say his name because we're on a podcast, but you don't want him back. And, you know, from that day, that was it, because people choose their own support. Kenny put out to the world that he wanted a man to help support them and someone he could trust. And so every single thing that Kenny wanted out of a support staff I found, except that she's a married woman. And I said, do you want to try? And she's like, absolutely. And we were very happy that that worked out. So that's another thing about Marrakech, is the people that we support choose their own support staff, because that's how you're successful in life. If you are every day opening your door and the person coming in is not someone that you trust or you believe in or believe in you or have the choices, then it's not going to work out. So we just know that Kenny's world is easier. So person-centered sports is an easier way to provide sports because it's through the choices of the person.

TANYA:

It's interesting to me, too, I mean, you're thirty-five years into your job at where you're working now and thinking about a career change, and I think that's always for many of us. I think, you know, you've been in a in a career for a while and you start to think, if I learned everything I can learn here, have I done everything I want to do? So I don't think it's that different that you are looking at a career change, but I love that you have someone who's talking that through with you and what some of the possibilities may be, because I think what happens often and I don't know if you've experienced this Heather or Kenny, but sometimes what happens in the field of disabilities in particular when people are thinking about working, is you get one job one time and you don't get to try other things. And Kenny has sort of run the range of jobs that existed, I think, at that Shop and Stop. So, you know, looking at something else is perfectly a good thing. But in addition to that, he has a lot of support for doing that, which I'm happy to hear. So. I'll be curious to see how that turns out.

So, you know, here's kind of what's on my mind. We've talked about sort of person-centered practices in a in a very vague sense, but not really about what it means to support someone through the use of person-centered practices. And so I know over the time that I've known Kenny, I've heard many stories about often you, Heather, sometimes you were the person that was a part of the story. I've heard about swimming assessments and fire drills and cooking assessments. And I want to hear about the fire drill.

HEATHER:

I think he actually taught the state of Connecticut to waiver things so he could still live in a home where he could have support but not follow all ridiculous rules that he could write the book for.

LINDSAY:

So so tell me about the fire drill since you were a part of that story, the two of you tell us.

HEATHER:

So part of the regulations in Connecticut is that if you do live in a licensed home, which this home was licensed, you have to run a monthly fire drill and everybody from the home has to have a meeting place that's visible and everyone has to meet at the meeting place. And we pick the place as right in front of the building, but to the side so a fire engine can still get into the parking lot. So we had our phony, you know, sirens and the people in all three apartments knew that it was a fire drill. And everybody came out and they're standing at the meeting space except for and Kenny decided, forget about it, forget about it. And that's what he told us.

And I'm like, honey, we have to send this paperwork to the state. And if we don't, you know, evacuate and if you evacuate slow, you're going to have to go to a more supported living place, which you hate. He's like, figure it out. Do you know what he said? Heather, come look out the window. So I look out the window. We're on the second floor. We're looking out the window at the front. And his roommates, the other people that he lived with in the building, were outside at the meeting space with their support staff. And no one else in the building is evacuated. But some of them are looking out the window, too, like Kenny's like. Do you know what I look like, Heather? Do you know what I look like? And I won't repeat it, but I knew what he meant and I didn't know what to do. I was terrified because I didn't want him to get disqualified from living there. I didn't want him to move backwards and he didn't want to move backwards. And he just trusted me enough to say, figure it out. But I'm not doing it. I'm not.

And so in a typical world, what I learned before is, you're right, a big ah for refusal, because that's what you do when someone doesn't do something you want them to do. It's called a reversal. And, you know, he'd probably have a behavior program because he'd refuse. But instead I called and Connecticut was very progressive and we had this wonderful man in charge of licensing named Dan McQueary. And I called him and I said, this is the story. And he told his story. He's not going outside. And I don't blame them. You know, if I when he explained it to me, I got it. And Dan's like, let me get back to you. And the state of Connecticut came up with the evacuation waiver for people who did live in apartment buildings and didn't want to, you know, wanted to fit in with everyone and just and what to do. So what we'd have to do is every quarter just kind of do a verbal test and document it. So he didn't have to have to do it. And then what happened months ago and months after that, there was a fire in the building. And guess who was out first?

LINDSAY:

Yeah, I have no doubt.

HEATHER:

Yeah. And you know what I mean. It absolutely is true that the obstacles often are our regulations. Right? The constraints are part of the rules. And those are important, too, because they do keep people healthy and safe. And that is why we are in the world. But I love that you're able to push back on that Kenny in a way that just kind of helps people understand what your experience is, because standing in the parking lot when no one else is out there, when someone's waving a fake fire alarm, making a fake fire alarm sound, you know, you don't want to be called out that way. And none of us would want that for ourselves. So I think it's great that you have always had a way to help people understand why this matters. And that is one of the things that has really drawn me to you over the years is the way you tell these stories.

KENNY:

I think the state of Connecticut is scared of me, that's what they say, yeah, it's Kenny's world.

HEATHER:

Well, do you think that's always true or do you think you always get everything you want?

KENNY:

Yes, I would I would bet Heather has different impressions about that.

HEATHER:

You know, it says a lot to me that, Kenny, you feel like you get everything you want, and it truly means that people are listening to you and hearing it from your perspective. That's sort of how I hear this. And that, to me is everything. Because for all of us in life, I'm I certainly don't have everything I want, you know, all the time. It's not always my way. But I appreciate it when people hear my perspective about what I want and that I have people I can talk to about that and that it matters to them what I want.

Kenny hated the vans that if he was being picked up from somewhere, when it backs up, it beeps.

KENNY:

Everyone could hear what the heck.

HEATHER:

And I guess he already hated it from the school he went to before he came to Marrakech. So he already had a very adverse reaction to those loud beeping vans like that.

KENNY:

Had a headache.

HEATHER:

And he was at Stop and Shop already working. And one of the job coaches or someone tried to pick you up in the van and, you know, when. And instead they called us and said, Kenny won't get in the van. He won't leave work, he won't get in the van. So I'm like, well, there's got to be a reason because Kenny just doesn't do things to do them. There's got to be a reason. And when asked why, Kenny is like, did you hear that in the whole store? Here's a van. No one else gets picked up from a van that beeps, no one else. So you know what I look like, Heather. I'm good. So. Well, what's the solution? I don't know. What's the solution? I could take the bus like everyone else.

You know, in those days, thirty-five years ago, people with developmental disabilities basically had twenty four seven staffing. Right. So this was all new. We all knew to teach Kenny how to use the bus and then let them come home on his own. And of course, that was a big risk at the time. But so that was interesting. But he just told us what he wanted to do. He wanted to take the bus like everyone else from stop and shop. And that's what we did. Figured it out.

TANYA:

I suspect you probably already knew how to use the bus knowing you. You probably had done it already. He probably taught the person who was supporting him. How do you know?

HEATHER:

And the last straw of that program, which we thought was very innovative considering it was he had his own apartment. But, you know, we had overnight staff, we had overnight people that came in dawn and they had posted. And so they'd come in at 10:00 p.m. and stay overnight in one of the apartments. So God forbid something happened, everyone would be safe. And he's like, now, I don't think I don't think I'm going to let them in my apartment today. That's not happening. Don, you should be with your husband, you know, tonight. You should be there with him. You shouldn't be here watching me. I know what to do in case of an emergency. And I literally didn't let her ex apartment. So I get the call and he explains that, no, I don't I don't need overnight stuff. That's really ridiculous. And, you know, when he said it like that, he was right. He really didn't need her next step. But again, in those days, people had twenty four, seven support. So what are we going to do about that? I called my friend Dan at the Department of Developmental Services, the licensing guy, and I'm like, what can we do about this? And so they did write a waiver for Overnight's and then eventually Kenny just had to find his own place to live. So and we can he developed individualized supports. We developed them. That was it. He's like, I'm going to live in my own apartment and I'm going to tell you what I need help. And so because of CANY America Swade, where most people in America were twenty four seven, supported twenty four, seven, and now this day most people here supported less than twenty four seven. And because we really look at people's needs and wants and desires and try to put things in place where people can be safe but also living the life that they choose.

LINDSAY:

That's pretty impressive. And you know, what I hear most is just this relationship of trust, like you have really developed in a lot of ways. You grew up with one another. You were very young when you met anyway. Right. But you had this trust for one another, I think that you developed over many years. And Heather, a unique ability to really listen to Kenny, who knows best about his life and trust that he knows best about his life. And I'm curious, this is kind of more question for Heather, but can he jump in if you want to? What do you consider to be the essence of person-centered care? You've mentioned many, many things, but what do you think the essence of is and how why does this work?

HEATHER:

I think there's a many different facets of this that make it work besides choice. Like just I always picture the opposite. Imagine waking up and not having a choice. Imagine not having what you want for breakfast. Imagine someone telling you you have breakfast even if you're not hungry. But the dietician says you have to. And if you don't, it might be a phone call or whatever or, you know, I want to spend my money on this pet instead of saving up for something else. So it's just like choice obviously is so important, respect is so important and that fighting with someone is just ridiculous, like telling someone you know better when you don't know. So to me, everything is important when it's a compromise and it's working together and I don't ever have to put my foot down. This is it. And who wants to live like that? I don't think I'd be here thirty-five years if I was telling people how they were going to live their lives, because that wouldn't be fun and it wouldn't work. Or you're not having confrontations and telling people how they should live their life.

LINDSAY:

So I kind of have just a couple more questions. I think this one may be in thinking about how we can wrap this up. When you think about what you've accomplished in your life and in the things that Heather has said about what you did for the state of Connecticut and other people who have disabilities and what their experiences are, what are the things that you're most proud of?

KENNY:

Everything. I think my goals are good, like I tell people how it is and they say, no, what you tell the truth, because my whole life I had I was picked out when I was a kid and everybody who will pick me one day apologize to me. I'm sorry for being rude to you. It's just that it.

LINDSAY:

You've certainly shown a lot of people what's possible. I think. And it's hard not it's hard not to respect what you've accomplished, and I think when people hear about your story, it has a way of just kind of helping them not only understand what your experiences are, but where they may be wrong in their thinking about people with disabilities.

HEATHER:

Absolutely. And Marrakech. Every time someone does something that's very choice and risk and everything. I always think I'm always thinking. If it wasn't for me, I don't know if I'd have the stomach for this. We had two people that we supported, had a baby three years ago and they're supporting a bit. And we were terrified. We're like, oh, yeah, what are we going to do? And they're great parents and he's running around and singing and he's wonderful. And we have had other people get married since Kenny broke the mold. And we just had people, you know, go on vacation or do things that maybe in other programs wouldn't be able to or, you know, some agencies don't want to support anything that might be risky. And to us, life is risky. And we have to weigh out everything and make sure that people are living the lives they choose or else they're not going to be happy.

LINDSAY:

So. So, Kenny, any last words, anything you want to add about?

KENNY:

I'm trying to save lives, that's what I'm trying to do.

LINDSAY:

I think you have changed lives, you've changed my life for sure,

KENNY:

And Heather's, but there's one thing Heather and I, ever since I came to Marrakech her entire life, brother and sister and stuff, we have a bond that will not break. That's amazing.

HEATHER:

Yeah, I say it all the time. Everybody should have a friend like you. We all need a friend like you. Maybe I don't say it to you enough, but I do believe that. Yeah.

LINDSAY:

Well, Tanya, I can understand why you immediately thought of Kenny when we talked about doing a podcast on person-centered practices, you know, Kenny's life and the things he shared with you touched on so many critical aspects of what it means to be person centered and all of the challenges that can arise from that. I want to take a few minutes with you to just reflect on some of the themes we heard Kenny address. The first and often one of the most important in conversations about home and community-based services is the big one, choice and control. And more specifically, I think respecting Kenny's choices and letting him decide how his staff should support him. I think the fire drill story was such a great example of this. What about that story stands out the most to you with respect to this very tricky idea of choice and control?

TANYA:

What stands out to me about that the most is the way Marrakech was willing to support something that represents a risk and that that is really hard for providers to do sometimes. But they did it thoughtfully. They did it while keeping what matters most to Kenny in the center of the decisions they were making. But it also occurs to me that Kenny is able and he's willing to push back on things that don't make sense to him. And if they don't help, if those decisions don't help him may have a life that represents that balance as he sees it, he's going to push back. But not everyone is, Kenny. So our job, if we are in a role of service provision, is to really think about every person individually, including people who maybe don't tell us with their words what matters most to them, because we need to ensure that the decisions we make on their behalf then reflect that balance. That's not an easy thing, but it's a very necessary thing.

LINDSAY:

Absolutely. Yeah. One of the other key themes that I heard in some of Kenny's stories and I know is another common theme for HCBS is community inclusion. You know, Kenny wants to be able to participate in his community equitably the same way that you and I might. But to do that, Kenny, does need some support. So, for example, Kenny commutes to his job and he needs support with transportation to this job. I know you've heard that story before, but when you think about community inclusion and that story, what do you think about.

HEATHER:

So the bus stories are really good example of how it's not about having something separate or special for Kenny. He's very sensitive to the fact that he wants to be living a normal life where he's not singled out. But it's rather about making sure that public transportation is accessible to everyone, not just him. So if Kenny's able to change his job in the future, like he's looking like he wants to do, this, of course, is going to impact those supports that he needs to be included in the community.

LINDSAY:

I imagine that having him have those skills to be able to use public transportation as opposed to having sort of a special system will only help him make any of those transitions more successfully.

HEATHER:

Absolutely. And it doesn't just help Kenny. It helps everyone. So, you know, having systems be more inclusive is not just about Kenny. It's about everyone in that community.

LINDSAY:

Definitely. The last thing about community inclusion that I want to get your reaction to is this idea of meaningful inclusion. So one term that I've seen a lot is this concept of meaningful day services. And those are services that focus on developing, maintaining or building skills that people need to be independent. A big part of those conversations are focused on competitive, integrated employment. And Kenny, like many of us, has a lot to say about his job and his goals for something a little bit different. So can you talk about that and how meaningful community inclusion can be so impactful when it's done right?

TANYA:

Absolutely. You know, Kenny, I'm not sure how many jobs he's had in his life, but sometimes when people are using services and supports, we tend to approach employment as one job one time. So there's not a lot of pressure to look at other options. Kinney's also had a change in the nature of his job, and I think that's in part due to covid. But I think it's important to Kenny that he had the opportunity to explore how to make other changes to employment so that it can be more meaningful to him. He's not really liking what he's doing right now. And I think when we talk about meaningful services for people, we often think that as long as people are out and they're busy or as long as they're employed, that's enough. But it's not if it's not connected to the things that people care about the most, the things I say that the stuff that's important to them sits on their heart. So it keeps them happy, comfort and satisfied, fulfilled uniquely who they are. So if it's not connected to that, then it's not enough. And it's it's one thing to be on an outing. But if it's still not connected to what they care about, it's just filling up their time.

LINDSAY:

I think that's so true. You know, looking back over everything we've heard today and everything you've touched on, I think Kenny has made it open and closed case for person centered services, respecting choice and control and facilitating supports for both equitable and meaningful inclusion in communities. But we both know it's not so black and white. You know, many home and community service providers really struggle to support these person centered practices. Why do you think that is?

TANYA:

Well, because we can get trapped into focusing on health and safety, particularly when we're not taking into account the things that matter most to the person. So if we focus all of our energies on bubble wrapping that person against all harm, you know, they're going to be safe. They're going to be safe from harm, but their lives are not going to have quality there. They're likely not to have purpose or meaning. So if people get everything they want without understanding the consequences of choices, without boundaries, they can be set up to be hurt. And that's hard for providers to to balance that so people can be healthy and safe, as we said, but they also can be miserable at the same time. And that's unacceptable. But it's not an easy thing to to negotiate that some of this comes down to attitudes of providers and even to an extent more generally, attitudes of society. So we see that there's a medical model of disability which really treated people with disabilities as people who needed to be fixed or as objects of charity. And that has a lasting impact on the perceptions of the rights of the capabilities of people with disabilities by the non disabled majority. We also see a lot of examples of paternalism or people who provide services thinking maybe that they know what's best for someone. Often that comes from a good place, but it's misguided. So they don't respect the independence of the person or the autonomy of the people who use their services and supports. And sometimes we see staff who maybe haven't been trained to know how to listen for what's important to people so that they can honor those things when they're supporting people to make choices and make decisions in their lives.

LINDSAY:

Yeah, that's that's absolutely true, and I think, you know, people are often unaware of these attitudes, they're often more implicit or internal than they are explicit or conscious. And that makes it really hard to address because you're you're not even aware of those subtle beliefs that you have of thinking of this person as maybe not as capable. So I've also heard you talk about compliance, pressure and positive pressure for providers of home and community based services and how sometimes the regulations or the policies that exist are a huge barrier to delivering person centered services.

TANYA:

Yeah, you know, we see that very often with people that we work with. And Kenny had some great examples and Marrakech was able to find workarounds. I'd like to say that was a simple thing. Like they just thought of something new and tried it, but truly they tried things over and over. And I think sometimes people forget that this is not as simple as flipping a switch. It really is trial and error, using judgment and creativity and keeping in mind at all times that we are in the world also to to protect people from harm. But, you know, thinking about going to the State Department and asking them for a formal exemption, that's a big thing. And some providers may not even really know that they can do that. Connecticut is really progressive in that sense. And I'm not sure that that story would have had the same ending somewhere else. But there are pockets of good practice all over the U.S. and that's why it's important to have positive pressures to that. We're doing things for the right reasons. It's not just the law, the compliance pressure, but it is because we want to have a better life. And if you if you extrapolate by that, you know, to all the people who are using services and supports, how do we individually help each of those people have a life that represents more of that balance from their perspective?

LINDSAY:

Yeah, I recently got to hear Alison Berkoff, the director of the administration on Community Living talk about choice and control and something that she said about choice and control that I thought was really profound is this idea that choices are incremental. So for someone who has been living in one setting for a long time, who has been told that they don't have the skills to do something independently, you can't just ask them one time if they want to try something new and expect them to say yes, whether that's living arrangements or activities in the community, you know, people need to go and they need to see these other options and have that experience that's hands on in exploring those choices. She also said that person centered planning is a constant conversation. And I really loved that. And I think that's the centerpiece of true, meaningful community inclusion.

TANYA:

So that's a that's such an important reminder choices, not a one and done sort of thing, I know in my own life I get to research when I have a choice to make. I get to ask people who care about me. I get to look for examples of the options that align with those things that are important to me. So informed choice really requires understanding the options and testing the waters a little bit. And sometimes systems that serve people with disabilities are unaccustomed to doing that. So that's certainly part of the barriers where we see to exercising choice and control.

LINDSAY:

Absolutely. All right, so I want to end this conversation on a high note, can we talk a little bit about some calls to action and what can our listeners do to help make the system more person centered? So I want to start with individual providers of home and community based services. What can they do to provide more person centered services?

TANYA:

Well, they can make sure their staff gets trained in person centered practices. And it's not just the people who provide the direct services, but everyone from the administrators to the janitor really should understand about the balance between important, too and important for. In addition to that, there's lots of resources like the learning community for a person centered practices which you can reach at TLC, PCP, dotcom or in caps or seek you out, all of whom are working in to further person centered practices in the U.S.

LINDSAY:

Great. All right, what about provider agencies and organizations? What can they do to change the system?

TANYA:

You know, individual and systems, levels, they have to work with one another, so, you know, never before in our history have we had a blind policy at the highest level with values based practice on the direct one to one level in such a way that people can have balance in their life, as they describe it, for themselves. So this is really a watershed moment for people with disabilities and chronic conditions and the people who care about them. At the highest level of our system, leaders have participated in person centered thinking, trainer training, and then they've used what they've learned to change expectations for how services and supports are developed and delivered. And that became the HCBSS final rule. So now states have taken up the charge and they are clearing obstacles to service and support provisions so that the people who are doing the work in the organizations can do it with confidence and they they can be in compliance at the same time they are doing the right thing.

LINDSAY:

So, as you mentioned, not everyone is able to be as vocal about their goals and the things they want from their services as Kenny is. So what would you tell someone who receives services and maybe wants to have a conversation with their provider about some changes to those services? How should they get that conversation started?

TANYA:

One thing that comes to mind is that the learning community for persons in our practices has a template for something we call a one page description, which is it's a warm introduction to a person and it is just one page. It's a good, simple first step to a person centered introduction. And it's a way to help people who may be providing services and supports get to know a person and kind of lean into them. It always includes what we like and admire about the person. So it's strength based and its approach. And in addition to that, it tells us what's important to the person, what's that stuff that sits on their heart? And it tells us about the supports they need to be happy, healthy and safe. So it describes for us the balance, and it does that in a very brief summary. And for resources like that, you can check out that TLC PXP dotcom website I mentioned and also see Roar's Facebook page, where they'll be sharing additional resources from a person centered perspective.

LINDSAY:

Well, Tanya, thank you so much for talking with me today and for interviewing Kenny and Heather. This was such an insightful discussion. I feel like I learned so much. And I think it's really great to hear that person centered practices are possible with the right supports.

TANYA:

Thanks so much for letting me come and share something I'm really passionate about.

LINDSAY:

Special thanks to my colleague and podcast guru, Niveda Tennety. And thanks also to our team at the Center for Rehabilitation Outcomes Research for their feedback on this project. If you liked this podcast or have feedback for us on what you want to hear next, head to our Web site at sralab.org/research/labs/cror Or check us out on Facebook by searching for at [rehaboutcomes](https://www.facebook.com/rehaboutcomes).