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[Kyra Baker] You're listening to Collab Chats, a Podcast from the Temple University Collaborative of Community Inclusion.

The collaborative is part of Temple University in Philadelphia, Pennsylvania and we've spent the last 15 years on focusing on full and meaningful community participation of individuals with serious mental illness. The collaborative receives funding as a National Rehabilitation Research and Training Center from the National Institute on Disability, Independent Living and Rehabilitation Research. I am your host, Kyra Baker.

Today we're talking with Dr. Judith Cook, an internationally recognized authority on mental health services research, specifically the study of clinical and rehabilitation outcomes of children and adults receiving community-based care. She directs the Center on Integrated Healthcare and Self-Directed Recovery along with numerous grants focused on intervention science and psychiatric epidemiology. She designs and implements innovative programs to enhance health and behavioral health of vulnerable populations. She works with federal, state and local authorities on behavioral health service system redesign and alternative financing strategies. Her recent work focuses on randomized controlled trials of evidence-based practice treatments for serious mental illness and outcomes of individuals with co-occurring mental illness and chronic medical conditions. She consults with Institutes of Health, Social Security Administration, Department of Labor, Government Accountability Office, Substance Abuse and Mental Health Services Administration and Veterans Administration. She is currently the principal investigator for the first national study of the prevalence of psychiatric and substance use disorders among women living with HIV and or AIDS.

Welcome Judith and thank you for talking with me today.

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[Judith Cook]

Thank you it's nice to be here.

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[Kyra]

Can you tell me a bit about what got you into mental health services research?

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[Judith]

Sure. For about eleven years I was the research director of a large community mental health program in Chicago called Thresholds and Thresholds served people with mental health

disabilities using the psychosocial rehabilitation model and this model focuses on recovery through achieving normative adult roles. So what this means is that people were helped to get jobs, to live independently in the community in their own houses or apartments, to attain further education, to develop a satisfying social network and participate in their communities and to take care of their physical and mental health. So, studying all those outcomes was a tall order and it led me into figuring out ways to measure not only changes in people's abilities in all those different areas but different methodologies that would best capture those changes.

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[Kyra]

That is quite the experience that you have, and you're currently the director of the Center on Mental Health Services Research and Policy. How did the center start and how has it evolved over the years?

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[Judith]

Well, I was recruited to run the Center at the University of Illinois at Chicago's Department of Psychiatry in 1995 and soon after we arrived, we were awarded our second five-year rehabilitation research and training center grants from the federal agencies NIDILR and SAMHSA and we also won other grants, such as a multi-site study of evidence-based supported employment and another multi-site study of children's mental health care in fee-for-service vs. managed care environments through the years. Since then, we've been fortunate enough to receive additional grants, contracts and cooperative agreement Awards that allow us to engage in our investigations and expand what we've studied and how we studied it.

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[Kyra]

That's really amazing. And how long has the Center been operating now? You started there a few years after it started?

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[Judith]

The center has been operating since 1995.

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[Kyra]

I'd like to talk about one of your recently-published research articles called "Mental Health Self-Directed Care Financing Efficacy and Improving Outcomes and Controlling Costs for Adults

with Serious Mental Illness". Can you describe the self-directed care model you tested in this study?

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[Judith]

Sure. Self-directed care is a model that was originally proposed by the federal government, specifically the Centers on Medicare and Medicaid financing. They were interested in ways that people with disabilities, in this case not including mental illness, but physical disabilities and the elderly and people with developmental disabilities could have greater self-determination in service utilization in the community. So, what they asked was the following question: What if we spent the same amount of money that we would spend by giving the money directly to a service delivery agency but made that same amount more flexibly available to the person him- or herself, so that they could choose what service providers they wanted and what if we also allowed them to make some home modifications to accommodate their disabilities to purchase some things that would directly improve their health and just overall in general have more control over the service delivery dollar and they proposed that this model should have four components first that a person-centered plan be developed; so, that's very different from a treatment plan. This is a plan that lays out how an individual views their life and what kind of life they'd like to have and it focuses as much on what's right with their life as what's wrong with their life and in particular deals with what's referred to as a circle of support and that's people in the individual's environment, only some of whom are service providers, who are going to help them achieve the elements in their plan. Now, in addition to the person-centered plan, the CMS suggested that a budget be created so that the individual would be able to track how they were spending the service-delivery dollars and what kinds of goods that they wanted to purchase and other services. They also wanted a service broker who is not a service provider. It's somebody that helps you use the self-directed care plan but the service broker would be like when you buy an insurance, you know, to do car insurance, you might go to an insurance broker and they don't represent one specific insurance company. They can pick and choose between different companies to help you pick the best car insurance or home insurance and that's what a broker does, they're not employed at a particular agency or in a particular service delivery arena. They help the participant choose what kinds of services they want in a conflict-of-interest-free environment. That was very important to the federal government. And finally, the last component was that an organization called a fiscal intermediary would actually be the organization through which the Medicaid dollars would flow so that it would go from the federal to the state and then into the budget so that the individual could spend the money. People don't actually get the money in the mail but they get, you know, at this chance to make the plan and the budget and have the budget approved and then the brokers help them purchase services or purchase goods in a variety of different kinds of ways. So, that's basically how self-directed care works.

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[Kyra]

How do people get the money?

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[Judith]

There's a variety of different ways. In the Texas self-directed care program which I studied in the article you talked about earlier, people were given debit cards and they, uh, we loaded money on to those debit cards in the same way that you would do it with any debit card right before a person was going to make a purchase and then we were able to monitor online when the purchase was made and that happened in that particular way. And sometimes the fiscal intermediary is directly paying service providers so the services are being purchased in that way.

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[Kyra]

Okay, and these four components that you just described, they were put forth by CMS?

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[Judith]

Yes, pretty much.

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[Kyra]

I had a question about the circles support component. Who is involved in the circle of support?

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[Judith]

Anyone that's in the individual's environment who they feel that they can count on or ask for support and help in reaching the goals in their person-centered plan.

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[Kyra]

Okay, so these are natural supports and not service providers or practitioners?

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[Judith]

That's a good question. So, the circle of support can include anyone. So, it includes service providers, but most people serve a circle of support is broader than that, so it might include neighbors, it might include clergy, it might include friends and family members. So, it's a broad circle of people that can be counted on to assist the individual, sometimes in really informal ways, to achieve the goals and their person-centered plan.

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[Kyra]

I wanted to talk a little bit more about the Texas self-directed care program that you just touched on briefly. You designed this for this for this study?

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[Judith]

Yes, yes that's correct, we designed it actually with the surrounding community in the Dallas and surrounding County area and we designed it as a collaboration between my University and the Texas Department of State Health Services program on mental health and we included peer organizations and family organizations, the service providers, the managed care company that was in the local community and then also the local mental health authority-the North Texas Behavioral Health Authority. We all designed it together.

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[Kyra]

How did the staff work with the participants?

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[Judith]

Well, the service broker staff in this program were called advisors. They like the name "advisors" more than "Service Brokers" and they helped the FCC participant use the program so they enrolled the person into SDC and provided them with an orientation because it is a very different way of receiving services. They help them develop their person-centered plan and create a budget that would go along with that. They were responsible for taking the budget to the Program Director and having it approved and then they help the person spend their money through purchasing services or goods and supports. A critical role of the advisors was to suggest what we call service substitutions in self-directed care and this is the idea that you can substitute for more formal services other things that will help the individual reach the same goal. So, one kind of service substitution is to substitute an informal service for a formal service; so the formal service might be you going to your mental health center's exercise group where the informal service might be getting a gym membership and working out at the local gym, which by the way, you know, leads you to participate in your community much

more so than what you might do at a mental health center. Sometimes a service substitution is to take a traditional service and substitute a non-traditional one; so a good example of that was getting support from a peer rather than a case manager. People did both, but there was this opportunity to make the choice. You could also get services from service providers who were in the private system, not just the public system, so that was another kind of service substitution.

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[Kyra]

What kinds of things did you see people purchasing?

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[Judith]

They purchased a lot of different things. They bought the traditional services such as psychiatrists and case manager, peer supporters and psychotherapists, but they also bought things like communication devices like cell phones and data plans and internet access; they purchased transportation aids such as bus passes and taxi cab fares, and one gentleman bought a used bike to get back and forth to work for their jobs. People bought tools and uniforms or paid for trade licenses or certificates. Several people didn't have clothing appropriate for a job interview so they bought business casual clothing, and to work on their physical health, people purchased access to a gym or health club, athletic shoes. We had some people that only had flip-flops to wear on their feet or services from a personal trainer. We asked people to spend 60% of their budget on traditional services and 40% budget on non-traditional services, but we were willing to flex that if they were making good progress and had been spending their money in a responsible fashion. So, by the end of the program, some people were spending most of their money on traditional services and others were spending their money on non-traditional services. What really mattered though was that anything they purchased had to be tied to a recovery goal. That was critical. They couldn't just buy something because they wanted it, they needed to, let's say, get a cell phone because they needed to return calls from potential employers and to stay connected to their families for social interaction and community participation.

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[Kyra]

Right, it couldn't be just any new outfit; it would be, maybe an outfit to go to a job interview.

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[Judith]

Exactly.

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[Kyra]

And it's really interesting too, how all of the non-traditional services that you mentioned are all things that very much promote community participation and occasion...

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[Judith]

Yeah, I really think that a lot of what self-directed care does is it enables people to accomplish the same goals through engagement in their community and using natural supports and accessing things that they wouldn't normally have access to because of lack of finances.

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[Kyra]

Why don't we see the self-directed care model being used in more states?

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[Judith]

That's a really good question. Because it is widely used for people with other kinds of disabilities; the elderly and even, like, at-risk youth for example. So, I think one of the reasons is that people have traditionally had the misperception that people with mental health difficulties aren't good decision-makers and, as a result, the thought that they would have control over financial resources, for some people, is a stretch. I think that people that work directly with individuals that are in recovery from serious mental health conditions realize that this isn't the case. But, I think it's a stigma that persists and maybe explains why this is one of the last groups to get to use this kind of model.

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[Kyra]

What significant findings did you identify from the study?

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[Judith]

Well, the first thing that we found was that people's outcomes were better in SDC than in the control condition and the people in the control condition continued to receive services as usual using, you know, the regular service delivery system in the area where the research was mounted. So, people in SDC had more hopefulness; they had a greater sense of recovery from mental illness; they had more feelings of self-efficacy, of being able to take action and influence their life; they were less likely to experience somatic symptoms, which are the physical signs of distress, like heart palpitations and feeling weak in parts of your body; they

were less likely to feel those things and that might be because a lot of folks did spend at least part of their budget on wellness and physical health aids and services and supports. But, in addition to all of these positive outcomes, they spent no more money on average, than people in the control condition and, for some specific kinds of services they actually spent less money. So, they spent less money on social skills training, for example, and they spent less money on case management. Interestingly, they spent more money on psychotherapy, which was not a service that they could get easily through the Community Mental Health System, but, overall, it was a budget-neutral model. That's another feature that CMS insists (on)...that self-directed care adhere to. So, what it's really all about is getting better outcomes for the same service-delivery dollar.

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[Kyra]

I remember you saying a few minutes ago that CMS wanted to use this model to promote self-determination. Did you find that that happened?

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[Judith]

Very much so. People in the self-directed care program also scored higher on a scale that measured whether they were being served in environments that promoted their autonomy, which is just another word for self-determination. And, you know, people in the control condition were in service-delivery environments that they rated as much lower in promoting their choice and autonomy and self-control.

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[Kyra]

What suggestions do you have for people who would like to start self-directed care program?

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[Judith]

Well, our Center created a free product that shows you how to do just that. It's called the Self-Directed Care Implementation Manual and you can get it on our center's website at www.center4healthandsdc.org and that manual takes you through the steps of forming a planning committee to bring SDC to your local area and garnering the support of key stakeholders like the funders of services in your local area. The manual also tells you how to staff an SDC program, how to create policies and procedures, how to evaluate it and it provides examples of the paperwork that you'll need, like the person-centered plan and the budgets that will help you be able to run your self-directed care program.

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[Kyra]

It's a really thorough manual; anyone wants to implement this.

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[Judith]

Yes

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[Kyra]

That's fantastic. Well, thank you so much for talking with me today Judith. We really appreciate it.

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[Judith]

It was a real pleasure, Kiera. Thank you.

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[Kyra]

Thank you.

00:21:22.100

[Kyra]

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