INside the OUTcomes: A Rehabilitation Research Podcast

Episode 11: Developing and Testing Person-Centered HCBS Outcome Measures

SHARON PARMET, HOST:

Today I'm speaking with Dr. Bridgette Schram, a project manager on the Rehabilitation Research and Training Center on Home and Community Based Services at Shirley Ryan AbilityLab, and Dr. Sara Karon, co-principal investigator on the project and a senior health policy scientist at RTI International. Sara, Bridgette and their team, are working on developing a set of measures designed to evaluate the achievement of person-centered outcomes by people who receive home and community-based services. Their work is funded by the National Institute on Disability, Independent Living and Rehabilitation Research. Welcome to the podcast, Bridgette and Sarah.

I'll start with you. Sara. Can you tell us a little bit about what exactly are home and community-based services? And what does that mean for them to be person-centered?

SARA:

Yes. So home and community-based services are HCBS, are services that are provided to people with various types of disabilities that enable them to live in the community. And their disabilities can be emotional, physical, mental health, they can be lifelong or new onset. It doesn't matter. But the focus here is on supporting people to live in the community. It's not very long ago at all that most people with disabilities spent their lives in institutions. And so HCBS is the way to support people so they can not live in institutions, but be engaged in the world and have the lives that they want off the same as anybody without disabilities.

And the kinds of supports they get through HCBS can vary. It can be things like helping people, basic activities, things like getting in and out of bed, bathing, getting dressed, help eating, help preparing meals, but it also can be things beyond that to help people be engaged in the community in the ways they want. Helping them go to social events, have a job, be engaged, whether it's leaders or participants in various social groups.

And then you ask what does it mean for them to be person-centered. So, person-centeredness is a philosophy that drives more and more of how services are provided these days, and it comes out of the disability community, saying that the goal of services is not just to get people out of bed, or into a place that somebody else thinks they should be. But the goal is to really understand who the person is, what they want their life to be, and to have services provided that help them to have the life that they want, in the way that they want.

And to understand that changes, as far as any of us, are our lives change and things we want change. Somebody may have been engaged in working in a sheltered workshop, which is a place specifically for people with types of disabilities, with, you know, they're isolated from the rest of the world, and they're doing work and usually paid very little. And people might say, this is great, I get to be with my friends each day. I'm enjoying it, it's keeping me busy. And then someday, down the road, they may say, hey, you know what, I'd like a new job, I made a new friend who's working out in the community, it never even occurred to me that that's an option. You know, I'd like a new job. And I need the supports to help me figure out what does that mean to get a job out in the community? How do I apply for a job? How do I get transportation there? What is it that I need? So all of that is about being person centered.

And just briefly, a related concept of person-centeredness, is person-directed. And so person-directed supports are having a person really say, this is how I want it to be not just, this is what I want the outcome to be of having this, but here's how I want it to be done. And so I had a friend who had cerebral palsy, and said, You know, when I get dressed, I need help to get dressed, I want my pants put on first, the left leg than the right leg. And I tell my workers that and some of them look at me like, What is difference? Does that make me put your pants on whoever is easiest for me? And the answer is no. You do it the way I've told you to. Because that's how I'm steadiest and safest. And because that's how I like it. I don't need to explain it. And so that's person-directed: that you get to tell the support

workers, you know, how you want your pants put on there, how you like things done, and have the control you want in your life.

SHARON:

Thanks for that intro to HCBS and person-centered and person-directed support.

So the project that you're working on is kind of looking at person-centeredness of those supports and how to measure that. Bridgette, can you talk a little bit about, you know, what is a measure? Why do we need to measure if HCBS are person-centered?

BRIDGETTE:

Within any program, it's important to evaluate to understand how it's doing, if it's doing what it's supposed to and intended. So a measure does just that.

What we're looking for in outcome measures, we want to understand do people have the life that they want, they have these person-centered outcomes and living the lives that they want. A measure then is a way to measure that, understand if it's happening. And it's often done in the form of a survey or an interview. A survey is the most commonly used at a large scale, because it can collect a lot of data and kind of a snapshot of what's happening in a lot of people. So that's probably the most common way for them that you will see a measure take place or an outcome measure.

Last spring CMS released a report that they are a final rule or to set up a rule that with measures ways to understand if HCBS is being person-centered, therefore, it's become a priority. And these measures are even more important than they were before. CMS released a proposed rule last spring, to help improve the measurement of person centered outcomes within HCBS. Therefore, our project falls perfectly within that space. We see our measure kind of filling some gaps of current surveys and measures that exists specifically, we're trying to find a way to include it into the planning process. So it becomes part of the process in order to determine the quality of services. And therefore, we can identify if providers are doing a job, if counties are doing a job, if states are doing a good job. And therefore, people are getting the services that they want and need in order to live the life that they want.

SHARON:

So CMS has a proposed set of measures, they've just proposed this fairly recently, in the last couple of months. And the measures are out there, there's an opportunity to revise those measures based on research and input. And so in your projects, you're developing a set of measures that may one day be used by CMS as part of their proposed measures. But they need to be tested, they need to be rigorously studied and examined to make sure that the measures are measuring what they're supposed to measure that they're useful. They're easy to use. So, Sara, can you kind of walk us through how you began developing these HCBS measures? How did you decide what to measure?

SARA:

So, one important thing is that we have a participant council. And that council is people with disabilities of all types who have received HCBS, and advocates for people who receive HCBS. And they've been advising us throughout this work. They've got the lived experience, and they're very articulate, and they're terrific to work with. So we've met with them, starting out to talk about the issues that were most important to them, when we talked about quality of life. And we talked about person-centered outcomes, what things are important to them. And we helped guide that conversation using various structures that others have developed to think about what are the different types of outcomes of HCBS? Very generally.

And so we met with them, and they identified a lot of different things, a lot of different kinds of outcomes and things that are important to them. And we reviewed the literature, we reviewed the currently existing measures that others have developed, and there are tons of them. There are more than 100 other sets of measures that people have developed. But we reviewed them to find out where were the gaps. And a gap could be simply that, you know, the participant counsel said, here's an important concept. And there are no measures addressing it at all, that would certainly be a gap, or gaps could exist where there are measures but they only have been used in some populations

and not all or they've been developed but they've not been tested and proved to be valid and reliable. That is that we don't really know if these are strong measures that we can count on and trust to give us the right information. So, we found where the gaps are, and then worked more with the participant council to come up with what are their priorities given that resources are limited? What are the most important issues to them. And so based on that, together with the participant council, we identified nine concept areas, a lot of those have to do with choice and control in seven different areas.

We have an area focused on choice and control over diet and nutrition. So that's, you know, what do you eat, you know, how much do you eat, and all that, again, very person-centered, you know, what you eat, and how much can be driven by your culture, your religion, your politics, your health, your finances, all of that we looked at choice and control over money.

Do people have the ability to use their personal money the way they want to buy what they want, sell what they have? And within HCBS some people have financial powers of attorney other people who have legal authority to make decisions about their money for them. And in those cases, do people have the authority to still give input and direct the people who are acting on their behalf?

We look at choice and control over health care. What kind of health care do people want? In that one that can be medications, procedures, you know, alternative health care, can they decide who is helping them make decisions?

We've looked at choice and control over how time is spent, you know, can you decide what to do when to do it? Whether you want to be alone or with other people? Can you change how time is spent? What do you get locked into a schedule? You know, some people love schedules, and some people love flexibility. You know, can you have the choice and control that's meaningful to you.

We looked at choice and control over living arrangement, you know, where you're living, who you're living with, you know, how the space is used, if you can access it, you know, if you're living in the home with other people can you choose when the seas watch TV and all of those things?

Choice and control over meaningful relationships is another area. And that's, you know, can you form the relationships you want? Can you maintain them, and that can be connections with friends and family, with animals, whether it's a service, animal or pet, it can be emotional, you know, meaningful relationships also can be physical and sexual, do people have that ability to make those choices and have control over those parts of their lives.

And the last area of choice and control, we look at is personal expression, you know, being yourself, putting yourself out there in the world and the way you want to be perceived, you know, what you wear, you know, how your hairstyle, how you decorate your home, what music you listen to how you share your politics, you know, all of that, again, reflecting whatever aspects of identity are important to you, you know, your culture of origin, your religion, your sexual or gender identity, your other affiliations, whatever it may be, but can you put yourself out in the world in the way you want to?

And then we have two areas that are not specifically choice and control. One is community engagement, can you be engaged with an integrated into the communities that you care about, and that could be attending events, it could be volunteering, it could be leading or forming a new organization, however you want to be engaged in the community.

And finally, there's dignity of risk. Do you have the ability to make and act on decisions that you want to do, even when other people think they could be risky? And there are all kinds of risks that could be physical, you know, do you want to go skydiving so when they think that's, you know, physically risky, but can you do that if you want, but it can be an emotional risk, you know, starting a new relationship, it could be something that has an uncertain outcome, you know, applying for a job, it's a risk, you're putting yourself out there, you're being judged by others, you may or may not get what you want. But all those kinds of things, can you do that? So those are all the kinds of concepts that we came up with, together with the participant council and where we felt there was a need for new measures.

SHARON:

So, you've got your concepts narrowed down, that's a huge, a huge milestone in the research. And then next steps are to actually develop instruments or measures that evaluate the person-centeredness or the achievement of person-centered outcomes as relates to these concepts. Can you talk about how you went about doing that?

BRIDGETTE:

So, after we had the advice and the guidance of the advisory councils, particularly the participant council, we developed the question items, and like Sara said, we did a lot of looking into what existed, how were these questions being asked already, you know, really dove into the literature to understand how to approach each of these concepts. And from there, we drafted some of what we're calling instruments or item sets, each concept will have its own item sets.

SHARON:

And by item set, do you mean like each concept area has a list of questions to evaluate it?

BRIDGETTE:

Exactly. Yeah, okay, exactly. So, each concept has its own set of item sets or its own instrument, if you will. So each has multiple questions, different sections of questions that belong to it. After we developed what we thought would be the items or the questions that we would ask on these surveys, we then have to test it. So the first wave of testing is cognitive interviews. Cognitive interviews are done with a small sample of people. So we did 25 individuals, we broke it down into make sure that we had a diverse set of voices represented in that in that so we had, we have four disability groups that we identified making sure we want coverage of disability as a giant umbrella category. And so everyone's experiences are different even within these disability populations I'm about to name but it's important to make sure you're considering that we made sure we had at least five interviews from people who identify as having a physical disability, mental health, disability, intellectual and developmental disability as well as an age-related disability. So make sure that as well as diverse voices in including rural versus urban, different race and ethnicity.

SHARON:

Were the people who tested the measures, were they recipients of HCBS, or providers of HCBS or both?

BRIDGETTE:

Great question, Sharon. Yes. So we interviewed 25 individuals that receive HCBS. And making sure we included all our different disability populations within those 25 to increase the diversity of voices and in our sample.

SHARON:

So, how does the testing take place?

BRIDGETTE:

Yeah. So what we did then was we scheduled interviews, we did recruitment. We asked the individuals in that interview all of the questions on the items for each concept. Each interview person did three different concepts. And then again, we asked all the questions in that concept, and asked them to answer it. And as interviewers, we focused on two things. One is, we didn't really care as much in this process, or in this step of the process, what their answer was, we mostly watched how they answered it, in order to understand if our questions were clear, and if they were measuring what we wanted to measure. So that's the main purpose of cognitive interviews is to make sure our questions are clear. And they're measuring what we tried to measure.

How we did that was, we ask them the question, they responded, and if we noticed, we observe their body behavior, you know, if they if they paused, or looked confused, or if they verbally asked, Can you repeat that? Or what does this mean? That meant our question was not clear. So we needed to go back and look at it, reword it and make sure that

it was easy to understand for all individuals. The second piece is, we would ask why they answered the way they did. And what this allows us to do is really understand if conceptually if they're going to the same place that we want them. to go when answering so if we ask a question, they're going off to this one space, where like, that's actually not what we were hoping to get out of this question. We kind of flagged it there again and said, This is something we need to go back to that's not what we're trying to measure with this question, we need to we reword it and make sure that we're going at what we're going after. So those are the two main purposes.

The pilot testing, again, is making sure that we're measuring we're trying to measure at a larger scale. So now we're recruiting, we're in the process of setting up our processes for 400 folks to complete the survey, at least two times. What this does is allows us to statistically analyze our survey and make sure again, that it's valid, accurate and measuring what we're trying to measure. Four hundred folks completed two different periods of time. And again, and that's important, because we want to understand and see if this measure can help us track change over time.

SHARON:

You've drafted the measures, you've tested them, you're now looking to further refine those measures to make sure that they're evaluating what you want them to evaluate that they're clear and easy to understand. As you move through that and get down the line, where do you envision these measures being used?

SARA:

With cognitive testing, we're testing are the questions being understood the way we want them to be understood. And now the pilot testing will move into testing the measures. And the measures are the numbers that we generate based on people's responses to questions, or some summary of that of our people making progress towards the life they want to have, are they getting the supports that they want to have, are those supports working well for them. And so that can come up with a score for an individual. And those scores then can be aggregated for a population. So we could say, this provider is helping 83% of the people they serve to have choice and control over their living arrangements. And the provider down the road is only helping 52% of people have the choice and control they want over their living arrangement. Those measures then that we'll be testing next in the pilot testing to make sure that they are valid and reliable then assuming that they are, we get into the question of how would they be used by whom and for what purposes. And there are lots of different ways they could be used.

Right now, as Bridgette said before, the Centers for Medicare and Medicaid Services has proposed having some HCBS person-centered outcome measures, those would be reported by the state level. So we could compare how different states are doing in different ways that's helpful. States can compare themselves to others and say, gee, we're not doing as well as our neighbor next door. What are they doing that we could perhaps learn from and do differently? But if you're an individual trying to figure out where do I want to be served, you're probably not likely too often to say, I'm going to move to states over because they've got better care there. So you know, state level is helpful in one regard, but it only gets you so far.

Other options are to be able to measure at a lower level. If we go down to the individual level starting there, information could be collected by the care managers by people who are helping to set up people's service plans and help them get there supports they need. And without comparing the persons, anybody else that could give information there to say, Gee, I'm so sorry, sir, we're not helping you the way we should be to be living where you want, how can we do better at that. So on an individual level planning, it could get better, we could then aggregate it to a provider level. And that's something that the states who are the primary payers here through Medicaid may want to do to be able to say, gee, this provider is doing a better job than the other provider. And sometimes states have ways of rewarding providers that are doing better, they may want to do that, or they may want to point it out to another provider, you're not doing so well pull your act together, figure out what you need to do.

It might be something could be analyzed at a regional level, to see if people living in these parts of the state aren't doing as well. And maybe it's because we're lacking certain resources there. And we need to put more resources into the community, improve the transportation system, or whatever it may be.

And as part of our pilot testing, we will be, in addition to collecting information at the individual level, we will be talking also with people at the service organizations and at the states about what would be most useful to them. And

what's most realistic for how they could implement the data, store and analyze what's going to actually be possible for them.

BRIDGETTE:

I wanted to highlight the three strengths that we think our measures could bring to the field. There's kind of three ways that we see or measures currently filling gaps that currently exist. One would be the change over time. So we're trying to develop something that could measure change over time, which again, is more useful at an evaluation and quality level than then cross sectional meaning just one time measurement. So that's one thing that we're hoping that our measure would add to the field.

The second thing is, we are exploring ways that this could be used in in the planning process. That's a lot of questions in the air, you know, things to have to finalize, including talking and, and getting the support and, and getting on board with the providers and care managers. But we do really think this could be a tool that would and could enhance the planning process, if set up correctly, and therefore, ease in some of the feasibility of implementation down the line, because asking an already overworked staff to do more is challenging. And so we're trying to find ways to build measurement into processes that already exist. So we do think we're trying to explore that and think that this, that's a possibility there.

The third strength, I think, is the fact that we're trying to validate across disability populations. So currently, and in research in general, oftentimes, you have to validate it by population to make sure that you know, it is being understood and then measuring, again, what you're trying to measure. So are we are trying to validate across multiple populations, which would mean that it's the same tool across waivers for HCBS. So again, those are three strengths that we have identified that could, we could be adding to the field.

SHARON:

So you mentioned earlier that you are going to be pilot testing the measures, you're looking for 400 participants to engage in this effort. If a listener is interested in being one of these testers, how can they get in touch.

BRIDGETTE:

So in terms of how people can get involved if they want, we are doing testing with, as we've said, 400 individuals, however, we're not seeking 400 individuals on their own. What we're looking for is states that are interested in participating in this, and organizations in those states and organizations in other states that would be interested, we're looking for organizations then who provide services, or care management to people receiving HCBS. And we would look to those organizations then to help us contact the individuals. So if you represent a state or an HCBS, provider, organization or care management organization and are interested in this, please by all means reach out to us, we would love to talk with you.

If anyone is interested in supporting us or participating in our pilot testing, feel free to email me or our general email. So my email is B S C H R A M at SRA lab dot org. They can also email our HCBS grant email at H C B S at S R A lab dot org.

SHARON:

Right, great. Well, thanks so much. This has been a really interesting conversation. I'm looking forward to continuing to follow the research and the progress and to one day see these measures out there in the world. So thanks so much for being part of the podcast.

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host Sharon Parmet, signing off.