INside the OUTcomes: A Rehabilitation Research Podcast

Episode 5: Unmet Needs and the Importance of Data in HCBS

SHARON PARMET:

Welcome to INside the OUTcomes: A Rehabilitation Research Podcast from the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. I'm your host, Sharon Parmet.

This is the second of our episodes focusing on home and community-based services and was recorded and hosted by Lindsey DuBois, formerly a project manager in the RRTC on Home and Community-Based Services with the Center for Rehabilitation Outcomes Research. Lindsay completed this episode before moving on to take a job at the Human Services Research Institute where she is a research associate studying healthcare inequities among vulnerable populations. Lindsay co-hosted this episode with Tanya Richmond, a licensed clinical social worker and certified person-centered thinking trainer and plan facilitator. Tanya is a partner with Support Development Associates, which works with organizations that deliver home and community-based services to help them incorporate person-centered practices into their service delivery. I'm now going to step aside and let Lindsay introduce her guests. I'll see you on the other side of the episode.

LINDSAY DUBOIS:

Today we are joined by Teresa Nguyen and Natalie Chong from Brandeis University. Teresa Nguyen is from Denver, Colorado. She identifies as a Vietnamese American woman with complex medical needs. Her pronouns are she her and hers. Teresa received her Master of Public Health from the University of Colorado Anschutz Medical Campus, and her work is focused around health care policies and systems improvement for vulnerable populations. She has experience in both federal and state level health program and policy development and is currently a researcher at the Community Living Policy Center at Brandeis University. Teresa believes that equity and access to programs and policies is critical to the well-being of people with disabilities and weaves her strong relationships with the disability community into all aspects of her research and work. Natalie Chong was born and raised in South Florida and is a Chinese American woman. Her pronouns are she her and hers. She is a doctoral candidate at Brandeis University's Heller School for Social Policy and Management, where she studies health policy and health services research. Her research interests include aging and health policy issues that impact older adults. She is also a research assistant at the Lurie Institute for Disability Policy, contributing to research on the quality and outcomes of home and community-based services for people with disabilities. Welcome, Natalie, and Teresa, thank you for joining us today.

NATALIE AND TERESA:

Thanks for having us.

LINDSAY:

So to begin, I'm going to ask if you can give our audience a brief overview of long term services and supports and in particular, Home and Community-Based Services.

NATALIE:

Thank you, Lindsay, for that introduction, and we're so glad to be part of this podcast.

So long term services and supports also known as LTSS refers to a very wide range of health and social services that are provided to individuals with disabilities who may need assistance with everyday activities. Some of these activities may include getting around the house or outside the home, bathing, dressing, medication management, and preparing meals.

While long term services and supports are not direct medical care, these supports and services really help users health and well-being by ensuring a safe living environment. They also assist with management of chronic health

conditions and help coordinate health services as well. In the US, there's an estimated 12 million people that are in need of LTSS.

In general, when we talk about LTSS, there are two general buckets that people refer to. So the first bucket of LTSS is the more traditional form of care which is provided in institutional settings such as nursing homes, as an alternative LTSS can also be provided at an individual's home or in other community based settings. And these services are called home and community-based services or HCBS. For short.

As I mentioned earlier, traditionally LTSS was provided in institutional settings. But over the past few decades, the balance of services has shifted to HCBS. So currently, more than half of all Medicaid LTSS spending is now devoted to HCBS.

HCBS allows individuals with disabilities to get the supports and services that they need in order to live independently to participate in their communities, and to age with dignity and respect.

So that's my broad overview of LTSS.

LINDSAY:

Thanks, Natalie, we know that there's a really significant need for home and community-based services. Can you share a bit more about what you know about the quality of home and community-based services in the United States?

NATALIE:

Sure. So quality is a really broad concept or construct. And so when talking about it in terms of HCBS, I like to divide it into two groups. So the first I guess, sub topic within HCBS, quality is around access. So questions around are people getting the services that they need at all? And are they getting enough services to meet their specific needs?

One important thing to know about HCBS and Medicaid programs in general, is that states have significant flexibility in designing their systems. And this includes everything from what sub populations are eligible for services, the scope of services, etc. So the picture of who gets what is really different across states. And most states also cap their enrollment in HCBS programs. And that results in a long waiting list for many people in states that maintain waiting lists. So there's a significant group of people that are eligible for HCBS in their states, but right now cannot receive services because the amount of services are capped are individuals who can participate in those services are kept.

The second bucket of quality, I like to think about is the outcome of services and supports that individuals are receiving. So once individuals have access to HCBS, how well do those services actually support people's participation in their community? In their relationships? How much are people actually involved in designing and directing those services according to their unique preferences and goals.

So in terms of these metrics, too, I think there's considerable room for improvement across the board across the landscape of HCBS. But also, it's important to remember that if you see, you know, a, say, certain national metric around the quality of services and supports, there's likely a huge variation across states in terms of the quality of the services that they're providing.

LINDSAY:

That's really helpful context. Thank you. And I like the way you describe quality as both access and outcomes, I think both are incredibly important for, you know, looking at the system and how to make the system better. So I think that's a really nice way to frame that out.

I want to talk a little bit more about some research that your team recently published. And in that article, one of the main findings was that 80% of home and community service users report having an unmet need at least one domain, I thought that was really staggering. I definitely did not expect it to be that high. So I wanted to ask if you were surprised at all by this finding about how well or not well, in this case, HCBS services are meeting the needs of users? And if you could tell me more about that.

NATALIE:

Yeah. So when we were preparing to do the study, and looking at prior research in this area, we found a huge range in terms of prior estimates of the prevalence of unmet need in this population. So in the studies, we looked up, unmet need and HCBS ranged from about 25% to about 60%. So given that really large range, to be honest, I wasn't really sure what to expect in the specific data and the specific definitions of unmet need that we were using in our study.

I think it's really important to recognize that there's no single definition for unmet need. It's kind of like a nebulous construct that we use. We know it's important, but we don't always agree with a single definition on how to measure unmet need, or how to operationalize that measurement in the data that we collect. So I think it's safe to say that every survey measures unmet need differently. And I think that variation in how unmet need is measured is particularly pronounced in the world of HCBS.

Because the range of services that is provided is broad, the services are supposed to be tailored to meet the unique needs of each individual. And besides that, HCBS serves a very, very wide range of, of individuals. So we're talking about a huge range of people with very different needs. There are people that have disabilities, or related to injury, there are people that have disabilities related to aging, and also different health and chronic conditions, as well as people with intellectual and developmental disabilities.

So in our study, we looked at unmet need across five different domains, as you mentioned, and that decision was really left to our judgment and discretion as researchers. So the specific domains we looked at were unmet need for assistance with daily activities, unmet need, for assistive technology, home modifications, transportation, and finally, unmet needs with respect to sufficiency of services for meeting each user's needs and goals. So it's really important to recognize that, you know, as researchers, we landed after, after many discussions on these five different domains. But, you know, one could imagine including more domains and asking about unmet needs in other areas beyond those five. So the more domains you include, likely the more unmet need you're going to detect within your study.

I think it's also important to recognize that there needs to be a balance between asking questions around unmet need, that are too specific and too broad. So you want to leave room for the subjective view of the person answering the question. But you also want to measure things that can lead to action that can lead to a response from the HCBS system. But you also don't want to restrict it too much. And leave the set of possible areas for unmet need to be too small. And basically, you'll end up missing the more qualitative picture of unmet need.

So my takeaway from all of this is that it's really important when you're reading different studies and different analyses about unmet need to really dig into how the researchers measured, unmet need to get a better understanding of is the idea of unmet need, that I have in my head, really what the person or the group of people are measuring in this study. There is no one definition. So it's really important to read a range of studies to kind of get this more comprehensive picture around unmet needs.

LINDSAY:

Yeah, I think it's really important what you're emphasizing about it's not only about what you measure, but how you measure and unmet need. In particular, it's vital to measure what those are. Can you just briefly share a little bit more about the current state have data on Home and Community Services and specifically, data looking at the needs of people who use services and whether those services are working well for people?

NATALIE:

Yeah. So nationally, representative data in HCBS, is really hard to come by. And I think it's safe to say that there's currently no uniform source of person reported data that is collected across different programs across different states, in a nationally representative way. And part of this is because of the nature of the structure and administration of HCBS. And Medicaid in general. Each state runs and monitors their own programs separately. So the data that we do have is typically limited to a single HCBS program or single sub population. So for example, just older adults, or just the younger population, or it's just looking at a single state, and the data we use in our study is definitely subject to some of these limitations of so we use data from the National Core Indicators Aging and Disability survey. And while this survey is multi state and multi program is not nationally representative, nor is it even representative of each state's HCBS population.

So at this point, it's one of the best sources of information we have. So we work with it. But there's definitely a lot of innovation and a lot of work and collaboration that needs to be done. If we want to measure HCBS quality and collect data at the national level.

Another challenge that we have in terms of data is the lack of longitudinal data. So that's data that is collected across time in the same group of people. Let's say you're interested in the effectiveness of a certain design or a set of services in HCBS. And you want to know, okay, well, was this effective? Is it achieving the goals that we had hoped that it would, but without longitudinal data, so measuring a baseline in a post, it's really hard to determine, you know, was the results that we're seeing a product of the specific program design or demonstration then that we're

experimenting with or was it due to something else. So the real world is really messy. And I think that it is a challenge to collect longitudinal data and to tease out the relationships that we're interested in. But it's still worth pursuing.

And I just want to mention that in the limitations that we have with survey data, one source of information that we can fill that gap with is with qualitative research. So qualitative interviews can be really important for getting a more nuanced understanding of what is going on in the different programs and with different evaluations of HCBS programs. And finally, I just want to mention that because everything is so different across states and across programs, you know, maybe we're not meant to actually compare different programs, right? Like, maybe we're just meant to look at all of the different experiments that are going on across states, and then figure out, okay, out of these experiments, what looks like it's the most promising in terms of providing the high quality HCBS programs that we want to see implemented.

LINDSAY:

Natalie, that was really interesting. I feel like you gave me a lot to think about, especially with your last point that, you know, maybe we're not actually meant to compare, because maybe we've been using it kind of wrong, or maybe that's not the best way to use it in the sense of making comparisons. And in fact, that's not giving us enough insight, because as you said, the world is so messy. That's really I think, a lot to ponder and really insightful.

One thing I did want to just ask, can you share with us kind of where you think this type of research needs to move forward? You know, what it should focus on how we should do things differently from a research perspective, in order to be able to address some of these challenges and implications you raised? I know, one thing I heard you mentioned was making sure data is really actionable. But there might be other things that kind of come to mind for you as the most crucial next steps for research in this space moving forward.

NATALIE:

Thanks, Lindsay, for that question.

Yeah, as a researcher, you know, spending time really in the weeds with different data sources, and wishing that surveys would have asked questions differently, or identify their samples differently. And working with all of that and publishing your manuscript. After a few days, you know, what, when the project is done, you feel really relieved, but then you think about Whoa, like, who is actually going to read this, read this study, read this analysis? And what does it actually mean, for people that are receiving these services? And how does it actually help?

And I think the evolution of research is a really humbling process, to think about how your study is only just a drop in the bucket right, of just getting at understanding what is going on? And not even at the at the level of like, how do we improve things? Right?

So our study just looked at, you know, what is the state of unmet need? And how does that relate to certain user outcomes? But it doesn't necessarily answer, How do we how do we bridge the gaps? And so thinking outside of surveys, and the quality of the data that we have.

One interesting thought that has crossed my mind is, why don't we use the assessments and care plans that are already being implemented and created and discussed with users and their case managers and their caregivers to get, you know, how do we improve the gaps in their care? How do we design services and supports so that they do actually meet the needs and goals actually, support community participation, etc.

TANYA:

Thank you so much, Natalie.

So Natalie told us about the variety of HCBS services and how states can design their systems to address need. And she also talked about how there is no single definition for unmet need.

So there are many system characteristics that impact whether services our meeting needs, and a variety of health and human services can be provided. And it varies by state according to how they've customized things. So these programs are designed to address the needs of people with functional limitations, who need assistance with everyday activities, and are often designed to enable people to stay in their homes rather than moving to a facility for care. Teresa, I know you've previously worked with the state of Colorado and had a key role with their Money Follows the Person program. Can you tell us a little bit more about that?

TERESA:

Yeah, sure. Thank you so much, Tanya.

I guess to start I'll give a really brief background about Money Follows the Person and its goals. The Money Follows the Person program really enables state Medicaid programs to help Medicaid beneficiaries who live in institutions such as nursing homes, regional centers for folks with developmental disabilities, folks in mental health institutions, really helps those folks who live there to transition into the community with their choice, and gives folks with disabilities and older adults more choice and deciding where to live and receive long term services and supports.

And how this is done is Money Follows the Person provide states with enhanced federal matching funds for services and supports to help these folks move from the institution to the community. And the program was really designed with four goals in mind. The first goal is to increase the use of home and community-based services, and to reduce the use of institutionally based services. The second goal was to eliminate barriers in state law, state Medicaid plans, and state budgets that restrict the use of Medicaid funds so that Medicaid eligible folks can receive support for the appropriate and necessary long-term services and supports in a setting of their choice. The third goal was that money follows a person is designed to strengthen the ability of Medicaid programs to provide home and community-based services to people again, who choose to transition out of institutions. And lastly, the fourth goal was for this program to establish procedures to provide quality assurance and improve HCBS. I was hired on as the community liaison for Colorado's Money Follows the Person program. And my role was to primarily figure out how to increase the community's awareness of our program in Colorado, but also to understand kind of in the behind-the-scenes work, why our number of transitions to the community was so low when we started out. And so eventually, the position evolved into a lot of outreach and training, to skilled nursing facility staff, to transition coordination agencies, to families and then to folks with disabilities.

LINDSAY:

Thanks for that context, Teresa, and working with states across the US around transitions. It is very interesting to hear about the different kinds of barriers to access people may experience or the difficulties and the challenges that might follow. As people try to transition into the community. What are some of the advantages and the disadvantages in using the Money Follows the Person model from your perspective?

TERESA:

Yeah, you know, a lot of this has to do with things that Natalie has already talked about.

Every MFP program can vary by state, they are able to design it in whatever infrastructure kind of works with their state structure already with Medicaid. And so I would say state flexibility is both a benefit and a challenge to Money Follows the Person. An example of that is states may choose the populations in which they focus on during transitions. So they could choose to primarily focus on people with physical disabilities, or older adults, or people with intellectual and developmental disabilities, or people with mental health disabilities. So there's, again, you know, if states have more infrastructure to support one community versus another, that can leave a big gap in community living and community participation. And then in addition to kind of choosing populations to serve, states can also choose to focus on different types of facilities that meet what they already are having success with. So, you know, I mentioned they can focus transitioning from skilled nursing facilities into the community, mental health institutions to the community, or, you know, regional centers for people with developmental disabilities. And so that could also create a big challenge in either leaving a gap in a certain population or a certain setting in which transitions are really happening. So that's, that's kind of one pro and con is the flexibility that's available to states, something that can be difficult that states have to wrestle with MFP is that there could be a waiting list issue for participation in the Money Follows the Person program. Well, again, just depending on the state could be due to lack of funding or lack of a HCBS waiver.

When folks utilize Money Follows the Person, there are always a limited number of participants slots. And as Natalie mentioned, most waiver programs are capped. And so this creates a waiting list. And the whole goal of MFP is to utilize HCBS services. And so there's still the waitlist issue to begin with, to really implement an innovative program like this. I guess the last difficulty that states may have or folks may have in utilizing and implementing MFP. Is that just like what's the state flexibility to choose who they serve and where they want to focus their energy on in Settings, the specific benefits within MSP are not identical in all states. And so, you know, some states could offer pure support as a transition service, where some states may not opt for that based on data and historical successes with the service. And so that can we look at inequality of the transition and utilization of MFP funds. So those are just some of the challenges and benefits to MFP.

TANYA:

So, Teresa, it sounds like between states being able to choose populations that they serve, waiting lists, which can be challenging, and also just the variety or the differences between the states and the benefits that people may have access to. It really adds a layer of complexity to what Natalie told us about what we measure and how we measure. And if we know that states can really differ in the ways in which HCBS are delivered and paid for, what do you think about the impacts in terms of the quality of services, and ultimately, maybe the outcomes for home and community-based services users?

TERESA:

Well, I think it really comes down to person-centered planning, and kind of to what degree that plan is followed and developed to be customized to fully meet an individual's needs.

Natalie talked about quality being really related to access to a lot of the services and then the outcome of services and supports that are provided. And so I think access is kind of the key here, when we're talking about service characteristics and how that may impact quality. Again, some of the services, you know, that really can impact whether a person can participate in their community in their relationships, and have a successful quality of life and the community are really basic services that many people take for granted in home personal care, related to hygiene and health, employment supports, you know, that working really contributes to quality of life and truly access to positive health care outcomes, and access to quality health care, different assistive devices can be accessed through HCBS, and also home modifications.

And so if these services aren't unified across states, that really can be a determinant in the quality of services and service delivery that a person may receive. And so you know, that would impact what I've talked about with person-centered planning, in terms of what is available for them to even utilize in their plan, what can they request or identify as a need based on what is available within their state infrastructure. And so, again, the differences in state models can really affect service quality. And then, of course, with person centered planning, I think that historically, we have been focused on whether a plan has been developed or if it exists. And I think we need to move beyond that in terms of really going back to ideally, the person with a disability who developed the person-centered plan to really gauge if that truly is being met, if their needs within the plan are being met, and then leave space for the individual to talk about their gaps as well. I don't know if we do a good job right now on assessing that and giving people a space to really discuss challenges. I think there's a lot of fear there.

TANYA:

Theresa, I really agree with you, I think, you know, we do spend a lot of time paying attention to whether or not people have a person-centered plan, but we don't spend as much time paying attention to the kinds of outcomes that mean their lives are better.

So different models can really facilitate or be a barrier to using Person Centered approaches. And home and community-based services generally fall into two categories. So there's the health type services, and there's also the human type services. And they may offer a combination of both types of services, but they don't necessarily offer all the services from either category. Can you tell us what you know about how these service delivery models impact people having the person centered supports they need and achieving those outcomes that they desire?

TERESA:

Yeah, well, I would like to start with just there is much needed research around this area. And so in the little data and research that we know, there is a lot of evidence actually out there that self-direction, the model of really again, allowing the individual who needs the services to really self-direct manage their services really contributes to better health outcomes. And so we know that that is a successful model.

The next step is how do we utilize this as the majority model across states. So that's, you know, one way that we know, service models can have a positive impact on outcomes, there is a little bit of evidence that integration of care. So integrating long term services and supports and acute healthcare needs, contributes to better health outcomes. But again, it really depends on how these programs are designed within the system that is already developed in the state. And so we really need further research on how to really integrate care, in terms of the community care and the long term services and supports, and then looking at from a queue or immediate healthcare needs, and how can we focus on merging those two service models to really meet somebody where they're at. And then of course, we know

that through the research that Brandeis was facilitating with person centered planning, this can also contribute to better health outcomes, as well.

TANYA:

And to me, this really highlights that need for consistency about the way we measure things and what we measure.

TERESA:

Absolutely.

LINDSAY:

This was a really fascinating discussion. Thank you both for joining us and having this conversation today.

Before we let you go, can we finish with some calls to action? One potential call to action that I've heard both of you touch on is improving the quality of HCBS and specifically the data that we collect in order to understand how it's working and that that's a major element is making sure we have the best possible data. When we think about research there's always the idea that research is intended to be the evidence basis of decision funding, etc., so it's really critical for a number of reasons to have that great data and what I think I heard you both touch on is how can we collect data that reflects person centered outcomes in particular and not simply what we think the services should be but rather a person's perspective of the services. SO can you guys talk a little bit about the policy landscape of HCBS right now, and I acknowledge you've touched on this a little bit already, but how that directly impacts quality of services when we think of the policies and how they're set up right now.

TERESA:

So this is Teresa. I can go first. I would say we just received news last week where Centers for Medicare and Medicaid Services announced that they are releasing the first ever HCBS quality measure set to promote consistent quality measurement within state Medicaid programs. And so this, I think, sets the tone for the policy landscape moving forward for how we improve data collection around quality measures of HCBS. This measure set us really intended to provide more information to the public on the quality of HCBS and allow states to measure health outcomes for people who rely on long term services and supports in Medicaid but in a unified way. We talked about how it has been really varied and that it's hard to come to a consensus when data is collected on what quality means for folks in different states and different programs within HCBS and Medicaid and so I think that is really exciting. And so the next step would be to see a majority set of states really look into these measures and collect information consistently to see if this is kind of the way to go in terms of measuring HCBS quality.

LINDSAY:

Absolutely, yes, thank you.

NATALIE:

So I think in terms of policy picture in HCBS there are several things going on. So one area where there's a lot of attention is with MLTSS which stands for managed long term services and supports. And under MLTSS is that states can contract out the administration and accountability of HCBS to specific managed care organizations and this is a form of value-based payment where many sates operate under a capitated system where they give managed care companies a certain set of funds to provide HCBS services and supports to the populations in there state. And then these organizations are also held accountable for certain quality metrics. The interesting thing right now is that MLTSS has been taken up by a lot of states and I think the jury is still out on whether this model of care is actually beneficial or an improvement from what the current design of LTSS administration and financing and quality measurement. So that's one area where policy has moved forward but it's still unclear about whether or not that's LTSS services and HCBS in particular should be administered.

Another area where policy can step in in in an area Teresa just mentioned about the CMS measure set that was recently announced. So moving beyond once we can agree or reach some kind of consensus on OK, these are the specific areas we should measure quality within HCBS and this set of measures provides a good picture of what we want to see in terms of outcomes and access to move towards public reporting of these measures to introduce a new layer of accountability. If the public is not going to see these measures, are systems going to be incentivized to actually improve their performance on this set of measures. And public reporting has been adopted in many other

contexts, for example in acute care settings. And there have been different studies in those contexts that look at the effect of public reporting and there is some evidence that public reporting of data and quality measures actually drive some improvement in outcomes.

TANYA:

So getting data and changing policies is certainly important, but these types of large scale changes often take several years to establish. Are there other short term or immediate calls to action for improving the quality of the HCBS system to reduce unmet needs, in your opinion?

TERESA:

Yeah, I can go first. This is Teresa. We talked briefly about self-direction and looking at an increased usage of self-direction models in the delivery systems I think could really improve quality in the short-term basis, but also really involving people with disabilities in data collection. I think I mentioned earlier a fear when people with disabilities are asked how their services are being met and delivered and I think that part of that is just trust or mistrust, I guess, of state officials, staff of agencies, all because understandably their care relies on these people to get the best quality of care so the fear of saying something bad or negative and having a negative impact on outcomes is really real. So involving a third party or community-based organization or group of individuals with disabilities or advocates to help understand and collect this data I think would provide a pretty different experience for the folks who receive services and also provide a rich context of data that we can utilize moving forward to reduce the number of unmet needs and also to ensure that quality is being addressed in a meaningful way.

TANYA:

Those are great points, Teresa. It's really about increasing trust and helping people feel more conformable of being part of research that impacts them in life. Natalie, what do you think?

NATALIE:

I just wanted to add to what Teresa mentioned about self-direction. What's interesting is that the COVID-19 pandemic has in some ways provided a natural experiment for self-direction and we know that self-direction really took off during the pandemic. It afforded individuals a lot of flexibility in terms of deciding who they wanted to be in their home providing care. And so self-direction, the ability for people to decide who they want to hire, how they want to train and supervise individuals, and even budget authority, meaning that people can actually make decisions about how they want to spend a bucket of money in terms of who they want to hire, what equipment they want to purchase – all that flexibility can really provide a huge opportunity in terms of filling the gaps in the needs that individuals have that are unique to themselves.

So as researchers, we have this idea that this is the gold standard and we discuss how to measure the gold standard but then do people who are actually receiving these services know about the ideal situation that they should be advocating for that their caregivers should also be made aware so that they can advocate on their behalf.

TANYA:

And Natalie, I'm certainly a proponent of person-centered planning and practices myself. We know that it's not just the required thing to do, it's the right thing to do and what we should be measuring is if people's lives get better as a result of the work that we do whether were providing HCBS services or not.