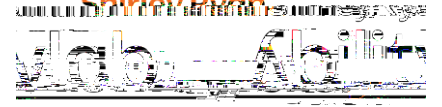


Shirley Ryan





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.

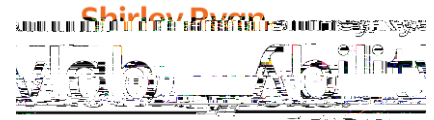
So in our study, we looked at unmet need across five different domains, as you mentioned, and that decision was really left to our judgment and discretion as researchers. So the specific domains we looked at were unmet need for assistance with daily activities, unmet need, for assistive technology, home 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. C

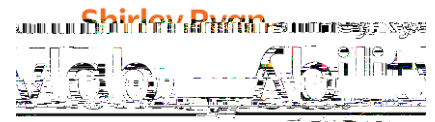


TERESA:

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



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.



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:

Shirley Ryan

