

INNOVATIONS CONFERENCE -- SAMHSA

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GOLDSTROM: So today I'll be speaking about engaging mental health consumers in services, research and evaluation. By mental health consumers, I'll broadly be speaking about youth and young adults and their families and adult mental health consumers as well as people who've recovered from serious mental health challenges.

Over time, CMHS has internalized the values and beliefs that we all benefit from the involvement of consumers in not only research and evaluation, but all of our activities. We recognize that being a consumer doesn't preclude you from being a top-notch researcher. There are many people who are both.

The third bullet, "Nothing about us without us", is a slogan taken from the Disability Rights Movement. The mental health consumer movement, which was modeled on the civil rights movement, has adopted this slogan, and it is now integrated into all of our center's activities.

Today, there are many different definitions of what participatory action research is, and it's called different names. I believed you used something with the word "community" in it. But, basically, I'll just take this very simple definition, where participatory action research refers to a process whereby the researchers and stakeholders collaborate in the design and conduct of all phases of the research process.

In our case, we engage consumers, probably the same cadre of people from the beginning of the process through the end, rather than just interjecting people at different steps. So let's talk about some examples.

First, with respect to the specification of research questions, involving consumers helps us to better identify where the research gaps exist. We can simply ask people "what helps you in your recovery?". In our work, that simple question has led to research on adjuncts to traditional mental health services.

For example, mental health consumers told us that what helps them in their recovery, many of them, is self-help. So we responded by doing and supporting research on peer providers and consumer-operated services.

As a result of this, today, peer providers are being certified and being paid for by Medicaid in many states, and consumer-operated services have been designated as evidence-based practices. With respect to design, consumers can review and refine our instruments and procedures.

Specifically, they can ensure that we use people-first language, which is something we can talk about later. Jargon is eliminated, cultural and

linguistic issues are considered and in question wording. With respect to data collection, consumers make excellent interviewers.

Many can establish a rapport with respondents who feel much more comfortable sharing honest opinions with people who share their experiences. This helps not only with data quality, but it also helps with the recruitment and retention of people's participation in the process.

In terms of data analysis, consumers can look at the data and provide context that non-consumers miss. Finally, engaging consumers widens the dissemination of the research findings to the groups of which they are a part, and consumers can provide advice on how the findings can be applied in diverse communities.

By blending research findings with their own personal stories of recovery, presentations by researchers can broaden interests to much wider audiences, including the media. So what are the challenges to implementing participatory action research?

Some of these challenges are the same challenges that we face in all aspects of our life: time, not having enough time, and not having enough money.

Because participatory action research is an iterative process and inclusive of many stakeholders, there needs to be sufficient time for feedback at each phase of the research process. Further, at the onset, we need to have developed trusting relationships.

Regarding money, we need to offer people fair and reasonable compensation for their time and expertise. If academics are getting consultant rates for sharing their knowledge and experience, so should consumers.

Also, many consumers need cash advances to attend meetings. They can't just ask for reimbursement later. So we have to be prepared to provide cash advances. With adults, sometimes we have to be prepared to consider child care; and with youth, we have to consider bringing adult support with them.

Also, it's important not just to include one consumer, a token consumer, in discussions. At least it's recommended that at least two consumers be part of any piece in the project.

Another challenge is the historic mistrust of health research, which we probably all know about, emanating from Tuskegee and, even more recent revelations about the use of research for not very positive purposes. Stigma is a challenge we face, because many highly qualified people don't want to self-identify as mental health consumers, and we're missing out on having their input into the research process.

Something as simple as arranging a meeting can create humongous challenges. You talked about how transportation, it's two hours, you know, just to get somewhere to participate in a meeting. We tend -- when I say we, you know, CMHS, many of us here, tend to work from 8:30 to 5:00.

However, adult mental health consumers are working from 8:30 to 5:00 on their jobs, and youth are -- and young adults may be in school. So we have to figure out ways to work around those challenges.

And now, a little about activities within my branch. We fund something called the Children's Mental Health Initiative, which is described on this slide. But what I want to point out is that one of the principles of this initiative is that our work be youth-guided.

So by youth-guided, we mean that youth are not only guiding their treatment decisions, but they're also participating in governance, service delivery and evaluation. So how does this -- how do we apply to evaluation? Well, the National Evaluation created an advisory team of youth.

The team wrote out its own mission and named itself and they call themselves YADA, Youth Advisors Driving Action. Engaging youth in this way is a win-win situation. We profit by their participation and their voice and learning directly from them, what they find to be important. And they gain skills that can promote their recovery.

And here's a list of some of the ways that we overcome challenges associated with engaging youth. We communicate with them, for example, through social networking sites, such as Facebook and Twitter and via cell phones. And in a focus group, we had youth who were telling us that even youth who are couch-surfing or homeless will still go to a library and use their -- and look at their Facebook.

So we think that we're reaching a pretty broad audience youth, if we can just use those methods.

So there are many resources available from a wide variety resources, to help you, if you want to engage consumers, adults, youth, families in research. These are just a couple of examples. And here are a few websites that you can -
- contain more relevant information.

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