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PERCEPTION OF DISABILITY BY DIVERSE CULTURES

Present: Dr. Rooshey Hasnain

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>> -- for inviting me to speak. This is a very important topic in regard to looking at how we can bridge the gap between foreign-born consumers and the U.S. disability services. What I hope to accomplish today with your help is --

(Sneezing)

>> DR. ROOSHEY HASNAIN: -- introduce a notion, a concept that may be helpful for the work that we're doing with people with disabilities and their families who are from diverse cultures. And that's also inclusive of people who are from indigenous populations, who are from the actual English-speaking communities as well, when we look at the issues that are going to be discussed in the presentation.

I really actually welcome comments and questions as we move along through the PowerPoint presentation. My biggest challenge today is to be able to cover and get to the

cultural brokering framework, which really helps to understand all the factors that come into play when we're working with people with disabilities who are from diverse cultures. So a heavy emphasis based on my own experiences and experiences of my colleagues here at the Institute for Community Inclusion, is mostly on immigrants, refugees, and newcomers, but it can certainly be applied to all cultures.

With that, I'm hoping that folks will be very open to sharing comments and questions as I move along. I will be going quickly in the beginning, to cover some important issues, but just to give you an overview of what we're hoping to accomplish today is, I'm looking at wanting to introduce some outreach strategies that can promote the active inclusion of people with developmental disabilities from diverse cultures in regard to the work that you're doing as a UCEDD. I'm also hoping to promote this -- as a means, as a tool to really increase -- for people with disabilities. And finally, to really look at, well, how can we use the cultural brokering process as a means to incorporate in systemic systems-related work that we're doing. How can we incorporate it into our organizations, into our UCEDDs.

As many of you may be very familiar, President Bush's New Freedom Initiative addresses the very fact that person with a disability has the absolute right to live independently, enjoy self-determination, make choices, pursue a quality of life just like any person without a disability. However, what was pointed out in the New Freedom Initiative is the fact that people from diverse cultures, particularly the most underserved and unserved populations are not quite reaching those particular outcomes, so we're going to be looking at ways that we can actually minimize some of those barriers and really facilitate the cultural brokering process between a consumer and a provider that can really achieve the positive outcomes that we're trying to achieve with people with disabilities.

A lot of what I'm going to be touching on is our focus and link to community-based ethnic and immigrant-serving organizations, and a lot of what I mean by that is that the Institute for Community Inclusion where I'm presently based, a lot of our focus has been, "Well, how can we connect to the diverse communities here in the state of Massachusetts?" Those communities who are not necessarily knocking at your doors for the services and resources that you have available.

Given that, one of the things I was hoping to actually ask the listeners is: How much connection do you have to the diverse communities in regard to your UCEDDs, in the different states that you represent. Are you actually linked to the underserved/unserved populations within your communities? That's something that we need to look at. And this is a mission and a focus of the work that we've been doing at the institute is looking at how you can diversify and work along in partnership with grassroots community agencies to really reach the heart to serve individuals with disabilities who may be in need of resources and supports.

Who are the unserved and underserved in our communities? What comes into mind? And this is a question for any of you who are on this call with me. Who comes into play? When you think of unserved/underserved? Anybody?

>> My name is Carmen and I'm calling from Puerto Rico.

>> DR. ROOSHEY HASNAIN: Puerto Rico?

>> Yes.

>> DR. ROOSHEY HASNAIN: How wonderful. It's probably much warmer there than it is here.

>> Oh, it is. It's very warm. And I'm pleased to be here today virtually. We in Puerto Rico, our population is an underserved population in the United States, as you may know. But here in Puerto Rico we are the majority. And so we have some underserved populations specifically that are more so geographically isolated, in a way.

>> DR. ROOSHEY HASNAIN: Uh-huh.

>> We have two islands that are close to Puerto Rico that are municipalities, and the people that live there express that feeling of disconnection.

>> DR. ROOSHEY HASNAIN: Right.

>> With the process. Actually, one thing that we have observed in our -- in a project that we have right now going on in these communities is that many people choose not to have their children be diagnosed so that no one knows that their children have disabilities because these are such small communities, so everyone knows everyone, and the notion of having a disability is still met with much stigma.

>> DR. ROOSHEY HASNAIN: And that's --

>> So one thing that we're trying to do is reach them.

>> DR. ROOSHEY HASNAIN: That's a very good point and we're going to be touching on that further down the presentation there.

But in terms of, you know, the isolated groups within Puerto Rico and how people may not disclose or even recognize or perceive their family members having a disability, those are issues that come into play. One of the things I just wanted to point out here when I asked the question about unserved/underserved, that can be actually comprised of a variety of groups such as people who are homeless, geographic differences, those who live in rural communities versus urban communities because that also has an impact on being able to access resources and supports.

It's also inclusive of people who may be HIV/AIDS at-risk youth. So we take a very global approach when it comes to unserved and underserved in our communities. However, for the purpose of this presentation, what I really want to focus on is the ethnic, racial, and linguistic groups that we have worked with over the years, and if you go to the next slide, communities we serve, these are just an example of some of the groups that we have been working with here in Massachusetts, and you can see that, you know, philanthropy United States, Chinese, Bosnians, Middle Easterners, Latinos, it's a very expansive group and it also includes indigenous populations such as African Americans, Native Americans, and if you look at that diversity that's presented here on the slide, I'm curious on, well, are your UCEDDs quite linked to these types of diverse groups? Yes or no?

>> Well, you do it.

>> (inaudible).

>> DR. ROOSHEY HASNAIN: I'm sorry. I didn't quite catch your comment there.

>> I work with (inaudible) commission in Boston and we work with people who are (inaudible).

>> DR. ROOSHEY HASNAIN: So you have been working with people who are unserved and underserved?

>> Yes.

>> DR. ROOSHEY HASNAIN: Where are you based?

>> Boston, near you.

>> DR. ROOSHEY HASNAIN: I'm sorry?

>> Boston.

>> DR. ROOSHEY HASNAIN: I'm sorry, I didn't catch that.

>> Boston. B-o-s-t-o-n.

>> DR. ROOSHEY HASNAIN: In Boston.

>> B-o-s-t-o-n.

>> DR. ROOSHEY HASNAIN: Boston, right?

>> Yeah.

>> DR. ROOSHEY HASNAIN: Yes. I'm sorry about that. Yeah, in terms of the underserved, I mean, there is -- so was that -- did anyone actually get that, the whole comment or question? Because I'm -- I want to make sure I address it. Mat, did you get that?

>> I got most of it. I got most of it.

>> DR. ROOSHEY HASNAIN: Because I didn't quite catch all of it because of his hearing impairment.

>> I have CP. We work with people who are underserved.

>> DR. ROOSHEY HASNAIN: Okay. So you are working with people that are -- that are underserved.

>> Yes.

>> DR. ROOSHEY HASNAIN: So the point being is that there is a variety of groups that exist in our neighborhoods, in our towns and cities, and what we need to do is as an UCEDD, how can we do better outreach to those communities and bring them on board in partnership with interventions and the kinds of activities that we're trying to promote in looking at improving outcomes for people from diverse communities.

Let's look at some demographics. Foreign-born individuals. It's really important to just take a -- a snapshot look at demographics. And based on the slide here, according to the U.S. census, approximately 33.5 million foreign-born people live in the United States, and that's representative of 11.7% of the U.S. population.

Do you think that's an accurate representation of the percentage of people that actually live in the United States? 11.7%? Because it's not. It's a very underrepresentation of how many people from different countries actually live here in the United States.

So that's something for us to look at in regard to -- in regard to --

(Phone ringing)

>> DR. ROOSHEY HASNAIN: -- funding issues, and, well, who are the diverse communities in your local neighborhoods? And how can we address issues --

(Phone ringing)

>> DR. ROOSHEY HASNAIN: -- related to -- I'm not sure why I have a phone call that's coming on my PowerPoint presentation. Are folks having that on your end?

>> Yes. If someone could place their phone on mute. If your phone isn't on mute, could you place it on mute, please? Thank you. There you go. Go ahead.

>> DR. ROOSHEY HASNAIN: Thank you. I'm not sure what

that telephone ringing sound is but ...

(Phone ringing)

>> DR. ROOSHEY HASNAIN: In regard to the percentage issues, then, it's important to look at the fact that, you know, 53.3% are coming from Latin America, and so on, but these are not representative percentages, and it's up to us as UCEDDs to see what we can do to develop the tools and the surveys to see, well, who really is representative in our communities, in order to look at the funding opportunities that exist. And we can pursue.

Now, there are some significant barriers and roadblocks that come into play between the disability service system and individuals with disabilities who come from diverse cultures. And it's important to look at, well, what are some of those barriers from a systemic service system point of view?

I've presented a few examples here on the slide where things like use of service jargon can really actually cause a roadblock when you're working with foreign-born individuals. Service jargon such as "supported employment" is a concept that is not translated into another language.

"assistive technology."

So what can we do to minimize some of the service jargon when communicating with consumers with diverse cultures?

We also need to look at the fact that, you know, as an UCEDD, are we linking and connecting to local leaders in diverse communities? And that's where it's really important to look at the fact that a lot of the disability service systems may not be doing a very good job with their outreach efforts in these unserved/underserved communities. We don't really want people to come to our doors, we can't expect that to happen, because of the challenges of being able to be informed of the services that are available.

So what can we do to inform the diverse communities of service system resources that are available to them? And a mechanism to do that is that we go to the communities, rather than expecting them to come to us initially.

It's also important to look at, you know, what kinds of tools and skills are connected to the disability service system? What are they based on and how are you assessing people with disabilities who are from diverse cultures in regard to their needs and their outcomes?

Are there other kinds of barriers that come into play from your own experiences for any of the listeners? And these are from the systemic point of view, so we're looking

at the barriers that the systems have placed to make it harder for people from diverse cultures or from any culture, for that matter, to enter and access the supports that they may need in order to pursue a good quality of life.

Another thought that comes into play is: Illegibility criteria and how when a person has a certain kind of disability, there are certain kinds of agencies that you may be connected to. However, what if you have multiple disabilities? You may have to go to one -- more than one agency, and often you do.

Well, there are different forms that are involved in that process. That's a barrier in itself.

So those are the kinds of things we need to think about, but on the other end of things, it's important to look at, well, what are the barriers and some of the roadblocks when we're working with consumers who are from diverse cultures? Language and communication is -- is huge, but it's not the only factor that influences the outcomes for people with disabilities.

So we're needing to look at, well, what are the language and communication issues, and is it -- is it simple enough to have bilingual or multilingual staff involved in these processes? That's one solution. But that's only a tiny solution to what this whole process and this presentation is about. It's looking at all the factors that come into play. Such as the lack of awareness to the service options that are available in the state or in the country, because many of the foreign-born individuals are coming from countries where there is no infrastructure, disability infrastructure for services and supports. So people don't know how to access those kinds of services, let alone understand the different options that they have to choose from.

Perception of disability, that came up earlier and we're going to touch on it in a moment. But you can see sort of these barriers that come into play. If you go to the next slide, if you look at some of the findings, research-related kinds of findings in the literature that exist for people with disabilities from diverse cultures, you see a common pattern that emerges which links to the higher rates of acquired or birth disabilities and that could be, you know, poor access to health services, more at-risk, having fewer access to resources and less knowledge, like I had mentioned earlier. But there's also

a heavy emphasis on qualitative studies, which are very, very important. What can we do to bring in more empirical studies into play?

Other things that have been noted, again, is the fact that there is insufficient and ineffective outreach by mainstream service systems, so what can we do to change that and to get ourselves out in the community to really inform folks of what their options are? In regard to resources.

And also, the fact that if you look at the current service system and program staff, we often find that they're not typically from culturally ethnically and linguistically diverse backgrounds but that's slowly changing. So what can we do to bring in more people who are representative of the diversity of people that we're actually serving in our consumer populations? And we can do that through maybe recruiting and educating high school students, middle school students, of career opportunities at an earlier age in terms of the disability field and rehabilitation and so on.

What does "disability" mean in diverse communities?

That's a -- that's a huge issue in itself. That could be a -- a very interesting conversation to spend an hour on. However, we don't have that, but it's important to just point out that there are differences that exist for individuals and how they view their disability, how the family may view or perceive the disability of their family member, how the community and, of course, our service systems define "disability."

And all of those can be related to causation of, you know, was it through birth or folk explanations that may have caused the disability, or some spiritual connection that relates to how people view disability.

So these are the kinds of things to really look at, and let's just look at two examples, for example. For the work that we've done in our -- in the diverse communities regarding how disability is viewed, for example, for some individuals who are from Somalia. Allah or God determines whether or not a child will be disabled and this cannot be predicted or altered. So if some individual from Somalia really believes that a child with cerebral palsy may not be able to pursue employment or post-secondary education because of these beliefs of, you know, things can't be predicted or altered and their belief that there is no expectation for their child to pursue adult life outcomes

in these areas, what do we do as service providers to handle those kinds of perceptions?

Another example of what we found is individuals from some Asian communities, more specifically a Vietnamese woman shared her experience of seeing a friend of hers who had really true beliefs that her child had a disability because during the time that she was pregnant she actually was in view of certain animals that were -- were present and that resulted in her child having a disability.

So those kinds of things could be related to taboos that people have in regard to how disability is perceived.

We'll be talking about more examples as we get to the model, because that's really where I want to head as we move forward with this presentation. And what really truly works for us to be more inclusive of people with disabilities. And this leads to the actual slide of the cultural brokering model.

Now the culture brokering concept is a concept that is actually a principle that has existed for centuries and basically it's a -- it's a process that involves a specific spokesperson, a person that serves as a liaison between the consumer and the links that she or he has to the systems and the individuals that are involved in this person's life. The cultural brokering process, given that it has existed for years where a person was able to acquire goods, for example, from the peasant societies in order to address the needs of their village people, this same person was very familiar with the culture of the actual government to be able to negotiate the kinds of things that the village peasant people needed to be able to make a difference. So what we want to do is apply this cultural notion, cultural brokering notion, to health/disability-related kinds of issues and processes that come into place. Given that this is the first time that we're applying it to disability and rehabilitation kinds of processes, we've been applying it for five years, and providing it to service providers throughout the United States as well as in other countries such as Canada and France where the model is set up, the framework is set up, because there's some need for some cultural brokering process that needs to come into play because there's been some kind of breakdown between the consumer and the service provider.

I'm just going to review what we have here on -- on the slide in regard to this framework.

There's three stages that come into play. Stage 1,

Stage 232 and Stage 3. Stage 1 is where the breakdown actually has come into place between a consumer and a provider.

How many of you have had situations where a consumer does not come back to your actual follow-up meeting? Once you have them involved with your specific service. Has there been a time when they don't show up or come late to a follow-up meeting? Anybody?

>> Yeah. I think people are just afraid to say yes.

>> DR. ROOSHEY HASNAIN: Because that's something that's very common, and that's an example of a conflict or a breakdown, that there's a conflict that has occurred, therefore resulting in difficulty in accessing or using services, or a breakdown in the connection.

So the cultural brokering model provides an opportunity for us to really understand, "Well, what is the root cause of -- of the actual reason why the consumer cannot show up, and that's where the intervening conditions come into play.

If you look at some of the intervening conditions, such as type of disability -- that being visible versus invisible, an apparent disability can make a difference on how a person is viewed versus a disability that's not so noticeable.

Communication, nonverbal versus verbal. The age of the consumer or the age of the provider. Cultural sensitivity. Time. All of these factors are factors that the cultural brokering model and framework looks at.

What's unique about the model is that you're looking not only at the relationship between the consumer and the provider, but the brokering process looks at the different levels that come into play when it comes to achieving the positive outcome that you're trying to achieve with the specific individual with a disability.

Meaning that you're looking at the relationship between the consumer and the provider, but also the connection that the consumer has with his or her family, the connection that he or she has with the community, both the mainstream community and maybe his or her own community that they represent, and how they're connected to the systems. The service systems.

And that's where all these different intervening conditions come into play.

Gender, power/powerlessness, economics, bureaucracy, politics, networks, stigma. These are some of the factors. There's many other factors that come into play. What do

you think is missing here, when you think about the work that you're doing with the consumer? What else would you want to know about the individual? What other kinds of variables are important to look at?

>> (inaudible).

>> DR. ROOSHEY HASNAIN: How the consume certify connected to the community?

>> Yes.

>> DR. ROOSHEY HASNAIN: Yeah. That's a big one. So that's --

>> (inaudible). Neighborhood group can become more educated.

>> DR. ROOSHEY HASNAIN: Communicating is also a huge one, so language issues.

>> (inaudible) become (inaudible).

>> DR. ROOSHEY HASNAIN: I'm sorry, I didn't catch that comment.

>> I grew up in (inaudible) Maine and I was (inaudible) community.

>> DR. ROOSHEY HASNAIN: How they're connected to their community?

>> Yeah.

>> DR. ROOSHEY HASNAIN: Yeah.

>> Yeah.

>> DR. ROOSHEY HASNAIN: Yeah, absolutely. So these are -- I mean, that's an excellent example, that how much are they connected to their own community and how can we increase the level of integration that they have into the mainstream community when we talk about foreign-born consumers.

>> Yeah.

>> DR. ROOSHEY HASNAIN: So this model, you can see that there's intervening conditions that can be a positive and facilitative aspect of achieving a positive outcome or it could actually be a hindrance to achieving a positive outcome, depending upon the intervening conditions in regard to all the different layers that come into play.

So the brokering model, you have Stage 1. You look at the intervening conditions which are the various factors that are linked to the consumer with a disability, and really understanding what they're coming from and why they came into the U.S., what kinds of connections do they have, and then it's up to us as a broker, as a provider, to come up with some creative interventions and strategies that can achieve Stage 3, which is the outcome that you're trying to

achieve with the consumer, whether it's employment, whether it's post-secondary education, and establishing those connections.

Let's look at a specific example so this makes more sense, because right now it's -- it sounds very abstract. Does anyone have any questions or can I just go ahead with this example? And then hopefully we can have more of a dialogue about this process.

Now, again, the framework is set up that it's more of a problem-solving mechanism, that there's some kind of breakdown that has taken place between the consumer and the provider.

Here's an example of a family that we worked with from Somalia, and again, you have Stage 1, Stage 2, and Stage 3, and intervening conditions.

Often you start with Stage 1, because there's a breakdown between the consumer and the provider, and in this case, for this particular family from Somalia, this is what took place.

After numerous missed and late appointments, daughter is determined that she qualifies for services. However, the parents and the daughter fail to respond to the follow-up meetings for the service placement, and the counselor who was involved with this family recognizes the need for intervention.

So what do you think is the breakdown here in Stage 1? Does anyone have a thought of what the breakdown could be here? It's a quiet group.

Well, the breakdown --

>> Communication.

>> DR. ROOSHEY HASNAIN: I'm sorry?

>> I would say that there might be a cultural breakdown, meaning that -- meaning that the service people may not understand entirely what this family is going through, and so I would say the cultural sensitivity would be an issue. There might be -- there might be some issues due to the fact that there's a female involved. In some cultures, females might be viewed as a group that don't necessarily deserve services in some cultures, whereas the male is dominant. There might be some issues there.

>> DR. ROOSHEY HASNAIN: Mat, can I just say something before you go on? You mentioned gender.

>> Yeah.

>> DR. ROOSHEY HASNAIN: It's really tricky. This is what's tricky about the actual framework is gender is an

example of an intervening condition. Meaning intervening conditions are factors that can be facilitative or they can serve as a hindrance to the cultural brokering process in order to actually achieve Stage 3, which is the outcome that you're trying to achieve. That's what most of our work is involved in is how to really meet that outcome, based on the consumer's needs and desires.

In this case, when there is a breakdown, or the perception of some kind of cultural brokering that needs to take place, it has to do with the fact that there is some kind of breakdown between the consumer and the provider. In this case, it is the fact that at the did not show up for the follow-up meeting, that they failed to show up for the follow-up meeting.

Now, one can assume that it's because they didn't care. You know, sometimes that's the thought that comes into place. What the cultural brokering model does on this -- in this situation, and what we're trying to promote is, that's often not the case. The blame is not on the family or the consumer; the blame is on the system.

What is the root cause to the reason why they didn't come back? And what the cultural brokering process does, and you pointed out gender, gender is an intervening condition and, yes, that could influence how a service provider and a consumer interact. But then there's many other interventions -- intervening conditions that also come into play.

For this particular family, however, let's just review some of those intervening conditions that we came up with when we applied the cultural brokering framework. And that is, in this case, the Somali young adult daughter was labeled with mental retardation. By the service system.

Now, mental retardation, this label that was given by the service system, was a label and a diagnostic kind of condition that made no sense to the Somali family. It made no sense. And it goes back to my earlier slide that I quickly sort of touched on s that there's different perceptions that a consumer or their family may have in regard to their disability. So that was one issue in regard to what we discovered, that it -- that the understanding of what mental retardation really means made no sense to the family.

>> Yeah.

>> DR. ROOSHEY HASNAIN: However, that's what the system came up with, our system.

Another issue that came up is that this family was very fearful of the government. They were fearful that their daughter would be taken away, and that she would be placed in a hospital, separate from them. A big part of that is because this family was from Somalia, they actually had a very strong fear to government, and a real high mistrust to government because of their situation in their own country, so that's another issue for us as the system service provider. We need to understand that those intervening conditions are very real, and that influences how a person may behave. In this case, that was another intervening condition that came into play.

Family is poor and parents speak only Somali. So they didn't have the English ability to really communicate and understand what this really meant in regard to services, supports, the meaning of the disability, and the label of mental retardation, a cognitive disability. So that was also something that came into play.

Family wants to care for daughter and they had no expectation for her to work. That's the belief system that they came from, based on their cultural background. No bilingual, bicultural rehab counselor was present initially when -- when this family came into play with the service system here in Massachusetts.

The service system can offer flexible funding. Now, flexible funding here in Massachusetts is offered by the department of mental retardation. So that was something very positive for the family, where they could use funding to support their daughter to achieve some positive outcomes that could be useful for her to pursue. And then the rehab system as a whole, very committed to diversity here in Massachusetts.

So you can see from this example that in their intervening conditions, there's both positive and some -- or facilitative kinds of conditions, and then some conditions that can be a hindrance to the cultural brokering process that we face. When working with consumers such as this.

So you can see that the intervening conditions, there's a combination of factors that come into play, and what the brokering model framework helps with is Stage 2, which is: What can we do to intervene to minimize some of those barriers that come into place, and really maximize the opportunities to be able to work with the consumer to achieve Stage 3? A positive resolution.

So if you look at Stage 2, there are certain interventions that come into play, and this is where you can be very creative, and this -- this is an opportunity to be culturally appropriate to the ways that you go about working with consumers who are from diverse cultures.

In this case, these are some of the strategies that the counselor used to work with the Somali family, and their daughter. The rehab provider was able to identify a bilingual, bicultural counselor from an other area office. That's one step that was very helpful. Because communication and language, that's an intervening condition, and what can we do to speak the same language of the consumer, so we can do the best that we can to understand what the needs are, and also offer them the options and opportunities that are available by the U.S. service system.

Another intervention that was done was there was a sensitivity training that was conducted within the service system. For all the service providers that were linked to this rehab office system. Which was very helpful for many of the administrators, since there was providers who are dealing with the issues of people with disabilities from a variety of backgrounds that they were constantly challenged by in order to achieve the outcomes that they were trying to achieve.

Another intervention was that information was discriminated to the entire Somali community, rather than just that family alone. Why do you think information was disseminated to the entire Somali community in that particular area of Massachusetts?

>> Because they were unified -- under-identified.

>> DR. ROOSHEY HASNAIN: Because they were under-identified, which I think what you're saying, in a sense, is the way I'm understanding it is that many Somali families in that community may also have a family member with a disability, so they would gain from hearing this information. Is that --

>> Yes.

>> DR. ROOSHEY HASNAIN: Is that what you were referring to?

And that's exactly why we disseminated this information to the entire Somali community is not only to inform other families who may be interested in the resources that are available, if they happen to have a family member with a disability, but also because it's less stigmatizing. Many

families who have family members with disability may have very strong feelings of stigma or shame associated with having a child or a family member with a disability, which leads to further isolation from being integrated into their community or for the -- into the mainstream community, let alone accessing external supports that they may want to use. So that's something for us to think about is: How can we minimize some of those fears, those stigmas that come into play from some individuals from diverse communities.

Also, the counselor was able to connect this family to other family members -- to other families who have family members with disabilities, which was really helpful for this family who was very isolated initially. And then finally, the flexible funding was used to fund -- to fund the family to attend a conference in order to learn more about how the U.S. system is set up with family supports and resources that are available to them based on the fact that they have a child with a cognitive disability. So the end result of this whole process, this evolving process is that the family was able to receive in-house respite services which they did not even know was something that was available to them. They did not know what respite services were until it was introduced and explained. And then it was something that the family really wanted to pursue.

The daughter became very involved in an integrated recreational program and was able to develop friendships through that, and she was not isolated like she was before. And then the parents became very involved with the family support network within that actual neighborhood, and became very actively involved with the Somali community in disseminating information and being helpful over, you know, weeks and months of working with them, helping other families who were in the same situation.

So you can see that the framework, the cultural brokering framework, is set up in such a way that it serves as a tool to help organize and to think about all the multiple factors that come into play when working with a person with a disability and if that person with a disability is from a diverse culture, there's so many other layers of factors that come into play that can make the brokering process easier or harder to be able to get to the kinds of outcomes that you're trying to achieve with the individual.

Does that make sense? It's a lot and it's very hard to

do this over a teleconference phone call.

>> However, there are three key things that are available on-line, and they key things -- you can actually use these case studies within your community or within your organization and use those case studies and use this model and see if you can actually work through it. It might be -- it might become -- it might actually make more sense if you actually took those three case studies and actually worked through the actual model, and so I would recommend that all -- that everybody on this phone call actually read over those case studies and actually try to work through the issues that are presented through those case studies, and with that in mind, Rooshey, you have until -- until 4:15 to go through the rest of the presentation, and -- but I just wanted to let you know that we approximately have 14 minutes, around that time.

>> DR. ROOSHEY HASNAIN: Okay. Wonderful. Well, I'm hoping that -- I'm curious if people have comments. One thing I really do want to emphasize about the cultural brokering model, and definitely looking at the case studies that are also provided on the side there, the case studies, I mean, that's really what's helpful in looking at how do you apply a specific case to the actual model, and you can use those case studies or any case study in regard to the work that you're already doing at your UCEDDs, based on the work that involve people with disabilities and their families. One thing I really want to point out about the framework is, like I said in the beginning is the cultural brokering model has not been used in a disability rehabilitation arena before. It's been introduced through training mechanisms and through case studies and workshops that we offer to different groups who are interested in this, and being able to have more interactive kinds of facilitative kinds of opportunities to discuss it, because there are so many factors that come into play.

However, in the ideal world it would be great to use this framework in a proactive way versus a reactive way. The way that we have introduced it over the years is more reactive, that being Stage 1, that there's a breakdown between the consumer and the provider, a breakdown that they failed to come to the follow-up meeting or they showed up late, three hours late.

What I propose is, what can we do to completely eliminate Stage 1 and take a more proactive approach and really take the time to understand who the consumer is that you're

working with, and looking at the intervening conditions that come into place. Those that are facilitative, as well as those factors that cause a hindrance to the cultural brokering process, and what can we do in regard to minimizing those roadblocks and coming up with interventions to really maximize the outcomes that we're trying to achieve with -- with individuals with disabilities.

So I just wanted to really bring out that point, and I'm curious if anyone has comments, agreements or disagreements. Do you think this framework can be helpful for the work that you are doing currently with people with disabilities?

>> Hello?

>> DR. ROOSHEY HASNAIN: Yes.

>> I just wanted to say -- this is Carmen from patriotic again -- Puerto Rico again.

>> DR. ROOSHEY HASNAIN: Yes. Hello.

>> I think one thing I think the framework is very interesting. I'm sorry I couldn't get ahold of the slides so I'm just listening to what's going on.

>> DR. ROOSHEY HASNAIN: That's trickier. Sorry.

>> But anyway, any systemic view I think is very important. One thing that I was thinking about when you were talking about the sensitivity training and these other techniques that one might use, strategies that one might use to help the staff --

>> DR. ROOSHEY HASNAIN: Yes.

>> -- is that one thing that I think as a Puerto Rican would be very important is that when we talk about diverse ethnic and cultural groups, we really need to know that within these groups, there's a great diversity. And -- you know --

>> DR. ROOSHEY HASNAIN: Absolutely.

>> And sometimes what I've seen -- and, you know, it's been my experience, in some sensitivity training, we kind of pull out stereotypes and that, too, can be kind of tricky because then you might be expecting things that aren't necessarily there, and I think that the -- the framework that you presented is interesting because it gives a systemic view so that you will look at more than one thing, and that you would look at perhaps what this family -- what is the meaning that this family places upon what's going on in the service delivery. Like, for example, here in Puerto Rico, for some people -- which is

not for everyone, but some communities, especially people that are in public housing, that are lower-income, home visits are not a good strategy because people do not welcome people -- strangers coming into their homes. It's sort of a -- an invasion of privacy.

>> DR. ROOSHEY HASNAIN: And that's -- that's an important point, and that is exactly what the cultural brokering process does is it recognizes the fact that each individual is an individual, despite the fact that they're part of a certain group. That it really actually customizes trying to understand where a consumer is coming from, and how he or she is connected to his community, her community. But the family, the community, and the service systems. So that example that you're bringing in is a really good one, and what the framework would do is, well, what could be done differently that could much more accepting for the family to be able to get this information? You know, a neutral place like a faith-based institution, for example. Let's say if they're very heavily linked to their church, for example, or temple, you know, depending on their affiliation and spiritual linkage, would that be a meeting place? For people to learn more about resources and supports, rather than one's home. Because the privacy issue is a big one.

There are differences in the world views and perspectives of people who are foreign-born who are from other cultures, because they tend to inherit a more collectivism approach to life versus how the systems are set up here in this country, which take more on a -- an individualistic kind of approach, and privacy is a big aspect of that individualistic kind of world view. Versus a family who may be very collective in their thinking and have a real strong group orientation where sharing information is much more accepted. So that's a -- an excellent point.

And it shows and brings all the different kinds of layers that we really need to think about, and again, it looks at the assets and the strengths of people that we're working with that we need to work with to really maximize those assets. But then look at some of the roadblocks and barriers that come into play through the interventions, which are Stage 2. Of the framework.

So thank you for that comment.

Any other --

>> This is Lisa from Los Angeles.

>> DR. ROOSHEY HASNAIN: Yes.

>> And I'm a bit concerned -- I think I understand the intention about the language, the jargon, the service jargon, and I -- English is my second language. I was born in Hong Kong, and I guess I'm one of those 1.5 generation people, and basically I think it's a disservice if you don't educate people what the service jargon is, because, I mean, to give a -- another example with the IRS, anybody who goes into accounting, those -- the people who go into the IRS are people who get C grades. They're not the creative people. They're the people who are good at taking -- following directions, and, you know, in the rest of the support system that we have in the government, it's going to be pretty close to that because the good people go to industry, et cetera. You know, start their own businesses. So in a way it's -- it is inflexible, much as we would like it not to be, and to empower the people to be able to use it rather than to be used by it, you know, sort of as a non-thinking entity I think is the right way, and to -- I mean, as you said, the way it is translated is the most crucial part. Like explaining --

>> DR. ROOSHEY HASNAIN: Ultimately, yes.

>> Right. And that's where the key is, but, you know, even in the dominant culture, this is a whole new world to us.

(Laughter)

>> And we learn these words and phrases also, you know, just as anybody would in any other situation. You know, what I'm trying to say?

>> DR. ROOSHEY HASNAIN: The point that you're bringing out, just so I can clarify, if I may, it's not to necessarily take away from teaching and informing and educating the diverse communities about the services that are available, because ultimately we do need to explain what assistive technology means --

>> Right.

>> DR. ROOSHEY HASNAIN: -- what supported employment means versus segregated models, for example. It's more initially we need to be mindful of the fact that, you know, how we get into the -- the notions of using acronyms when we're talking, because we're so much part of the service system. I think it's just really important for us to be mindful of when we are introducing and trying to inform diverse communities, that we try and explain what we mean by the service and supports that are linked to the service jargon. And then, yes, inform of them of what supported

employment is, rather than assume that people really understand what supported employment means. So it's a two-way street. You know, trying to simplify the language and also inform. So you're building the capacity of individuals and families to really be advocates for themselves, but it's hard to be an advocate for yourself if you don't really grasp what some of the service jargon may mean.

>> Well, I don't agree. I've never been in a (inaudible). I have (inaudible) more harm than good for people.

>> DR. ROOSHEY HASNAIN: If we use service jargon, that it does more harm than good.

>> (inaudible) I have (inaudible) I --

>> DR. ROOSHEY HASNAIN: Yeah. I didn't -- I think I got some of it, that you're --

>> I have (inaudible) had (inaudible) people.

>> DR. ROOSHEY HASNAIN: That ultimately that we're trying to help people and inform them through use of simple --

>> I have (inaudible) about (inaudible).

>> DR. ROOSHEY HASNAIN: That you have some doubts about the services?

>> Yeah. (inaudible) give money, give people so they can (inaudible) their own (inaudible).

>> DR. ROOSHEY HASNAIN: And that's something -- really the bottom line of the framework is, you know, what can we do in each individual and each family will need different sets of strategies and different intervening conditions that come into play in order to -- to do what we're trying to do in regard to our work with people with disabilities.

I mean, the bottom line in regard to this is that you can consider it a toolkit, of sorts, and a very person-centered planning approach to the work that we're doing with people with disabilities.

So for some of the comments in regard to service jargon, for example, some -- you know, what can we do to address it in ways that people can really understand it, but also inform them of what these things mean so that they can actually adapt to what is used in the service systems currently, so they can be familiar with those kinds of things.

If we move ahead with the presentation, I think I have a few more minutes. I think I have about --

>> (inaudible).

>> DR. ROOSHEY HASNAIN: Can I continue? Is that all

right?

>> Yes. We approximately have 8 to 10 minutes.

>> DR. ROOSHEY HASNAIN: Okay. Wonderful.

>> So if you could -- if you could give your closing comments, that would be great.

>> DR. ROOSHEY HASNAIN: What I would like to do is in the remaining slides, which is actually another, you know, component of the cultural brokering model is, the Stage 2 is really critical. That's where, you know, we need to look at all the different levels of maximizing the positive outcomes of working with people with disabilities. Based on where they're coming from, and what their beliefs are in terms of what's successful.

So there -- the Stage 2 is, you know, not only establishing the trust and rapport and maintaining and linking individuals with disabilities to various resources and supports, but it's really -- really the key is, how can we start developing partnerships and collaborations with community-based immigrant and cultural organizations that exist in our neighborhoods. Like I had said in the beginning that outreach is key, and we need to start those relationships not when a grant comes in, but before a grant comes in, and work in partnership with trusted gatekeepers, build those connections so you can really develop culturally competent, culturally responsive services that really address the needs of diverse communities that we've been talking about for this -- for this presentation.

A lot of the work that we have done has been in partnership with community-based immigrant serving organizations and the reason why we've been working with them are they're really the gateways to the underserved/unserved communities that we're trying to work with. They're the cultural experts. They can help us to develop our interventions, to develop our evaluations, to develop the research tools, to develop the various mechanisms that we need to consider, so that we can really be inclusive of people with disabilities from all backgrounds.

If you look at the remaining slides, the key is how can we develop innovative, culturally competent interventions, and what I have provided here are just some examples of what we mean by networking and I know there was a comment made earlier about networking, and this is really important: Who is the consumer connected to? In terms of traditional versus nontraditional networks and how can we

really engage the grassroots communities in order to inform and really empower people with disabilities from diverse cultures in accessing formal or informal supports to achieve employment outcomes, to achieve post secondary education outcomes, to be linked to leisure and recreational and spiritual and religious activities, just like anyone else without a disability.

So you can actually review some of these kinds of interventions beyond this actual teleconference presentation, but because of time I want to make sure that there are no pending comments or questions that people have in regard to the cultural brokering framework. I'm really hoping that this framework can be useful for the work that you're currently doing with people with disabilities, and that it can help you to organize and look and think about all the factors that come into play for the individual with a disability, and that you consider it a systemic issue; that it's not only individuals and families and communities, but what can we do to improve our systemic systems so that we are really universally accessible to people who are most in need of the services and supports that we're trying to offer folks.

So those are the closing kinds of remarks that I really wanted to place, but I wanted to give people another opportunity to make comments in respect to do you think that the brokering model may be helpful to the work that you are doing at your UCEDDs, and do you think it could be something that can be infused into various work and projects that you're currently working on?

>> Hi. This is Dianna from maternal and child health bureau and we are also trying to promote cultural brokering, but I have a question.

Do -- have you had any experience or do you have knowledge of any state or community where different systems have come together, such as public health, mental health, you know, whatever, but those agencies or programs have come together and have -- you know, to develop a concerted cultural brokering effort so that it's not just one agency putting resources out --

>> DR. ROOSHEY HASNAIN: Right.

>> -- but that everyone is, you know -- well, people are combining resources.

>> DR. ROOSHEY HASNAIN: It's happening more and more in practice. However, you know, in terms of documentation, you know, I think it's a really good point. Yes, there

are -- we're doing it here in Massachusetts. We're doing -- but other groups throughout the nation are trying to link up to other networks to really see how could this be of assistance to the consumer, ultimately.

The cultural brokering model is -- is new, like I had mentioned. What we really need to do is take it to the next step. Some people have been using it once they have gone through the -- the training and have found it useful for some of the individual cases that they've been working with. What we really need to see is, well, does it really help operationalize all the different players that come into place when working with a consumer? This is the work that we need to start developing now, to extend what we already know, which seems to be helpful from people's feedback, and follow-up, after they receive a cultural brokering training.

The next step is, does it really actually make a difference when a service provider goes through the training and really thinks about all the cultural brokering components? Does it really actually link back to the consumer? Does it actually lead to improved outcomes for people with disabilities. If that answers your question.

>> Thank you.

>> Hey, Rooshey?

>> DR. ROOSHEY HASNAIN: Yes.

>> If anybody has questions, could they send you an e-mail?

>> DR. ROOSHEY HASNAIN: Oh, yes, please. My contact information, if you go to the end of the presentation, I have provided resources where you can access some additional resources on cultural brokering and how it's linked to some of the work that we've done with CIRRIE and some other articles that have come about, as well as resources through the association of University of centers on disabilities, but you can also contact me. Please contact me. I would be happy to talk further about this. This is a very important issue, and one that's very difficult to do in an hour and 15 minutes, because it does require a dialogue. But I hope that it was helpful for those of you who actually put up with me for the last hour and 15 minutes. But, yes, my e-mail or by phone. Rooshey.hasnain@umb.edu.

>> Excellent. And Rooshey, you already have your first e-mails on the way, so check your e-mail after this conference call.

Unfortunately our time has come to an end, and I'm -- and I wanted to thank Rooshey for participating in this conference call, and I want to extend a thank you to all of you for attending today's conference call. I really think that this -- that this model could be very useful, simply because it doesn't require research. It simply makes you reach out to the nearby community and just simply get to know them. And that's key within itself. So I wanted to thank all of you for joining us today, and if you have any questions for Rooshey or me, we will be more than willing to answer those questions. With that in mind, I wish you all a good afternoon, and Rooshey, thank you very much.

>> DR. ROOSHEY HASNAIN: Thank you for your time. Thank you for the opportunity.

>> Thank you.

>> Thanks.

>> Thank you.

>> Have a good afternoon, guys.

>> DR. ROOSHEY HASNAIN: Good afternoon. Bye-bye.

>> Bye.

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(Teleconference ended at 3:15 p.m. CT)