

Taboo Topics Among Refugees | CPD Blog

JoLynne Lyon

03/17/2017

If you're gathering information, fostering leadership and spreading awareness about a taboo topic across cultures, there is one thing you don't want to do: Sound like the all-knowing, arrogant American. Dr. Eduardo Ortiz, a researcher from the Center for Persons with Disabilities, was sure of that before he even began a project that ultimately shared awareness about disability among refugees in Salt Lake City. So he and other project leaders began their work by carefully choosing the research fellows who would work directly with refugee communities. They found two multi-lingual, educated women who were not born in the United States. "By being a native Lebanese-American citizen who attended a French school and then married a Peruvian Latin-American citizen, I turned out to be a good link who can build bridges," Mireille Karam quipped during a presentation at the Associated University Centers on Disability conference in Washington, DC. She reported on the experience last December, and she was one of the fellows who worked among six refugee communities in Salt Lake City.

Still, she said, the project had some barriers to overcome in any language. "Disability is a very difficult subject to deal with," she said. "Lack of education, different cultures and backgrounds didn't make this work easy. It made some of these communities like shatterproof shells. We worked hard to learn about their particularities, needs and challenges." In addition to the CPD, the project brought in University Neighborhood Partners at the University of Utah, and the Utah Regional Leadership Education in Neurodevelopmental Disabilities, which builds leadership across health care disciplines in five states. Team members worked together to foster leadership, but most of all, they focused on bringing out information from people within the communities themselves. They conducted six focus groups among the 50,000 refugees who have settled in Utah. Rather than hire interpreters in academia, they found interpreters from among the refugees and trained them in research protocol. The result: better access to the people they were trying to reach. "We wanted to prepare the connection with them, that they could trust us," said Helene Kalala, a research fellow from the Republic of the Congo who worked on the project. While it was time-consuming, the approach helped to overcome barriers to language and build relationships within the targeted communities. And together, the research team discovered that cultural attitudes vary with regard to disability—so much that the whole concept could be tricky to define across cultural lines, and especially if the disability was not an obvious physical impairment, like autism. Those differences may help explain why the prevalence of autism spectrum disorder is more than 600 percent higher in white American communities than in other racial or ethnic groups.

"Some of them will define disability based upon religion, based upon culture," Kalala said. "For them, disability is like, this person has a disability because it is a curse from God. ... They thought they would stay home and do some ritual and go to church. Then it would go away. They don't really believe it is a disability and it can be cured or, for instance, to look for services." Being a refugee—or even belonging to a minority—can be isolating. Being a refugee with a disability intensifies that isolation, said Dr. Teresa Molina, the University Neighborhood Partners' Associate Director and a co-investigator on the project. "It prevents them from being more able to look for resources and to integrate their own people with disabilities." Some families were reluctant to admit that disability even existed within their members. "Some women will notice disabilities with their children, and they will stay silent," Kalala said. "They don't want to talk about it because they believe their husband would like a wife that does not give birth to a child with a disability." "I think the stigma comes from the lack of information," Molina said. "I think that a strength that many of these communities have is that yes, they deny it socially, they don't integrate disabled people, but they do take care of them. At home it becomes a given, this is what he can do, this is what she is able to do, and she is welcome at home." The researchers also found that some cultural practices might also affect disability within families. "It's very common that people in some communities marry cousins," Ortiz said. "There are some issues related with disabilities in the children of these marriages." Some of the refugees they met had also experienced terrible things, opening up new questions about mental health across cultural lines. "Some of them come from a war place, and they have family members who are struggling with that," Helene said. What's more, trauma made the mental health effects worse for some, said Molina. "Particularly those coming from war

zones, they perceived their mental health as disabling. ... Not knowing where to go, not knowing what to ask, not even knowing how to prepare meals in this environment. It's not that there was a long history of malnutrition or things that they felt they couldn't perform in their previous environment, but in this environment they were caught by surprise by their own reactions." Ortiz also wondered if, in places where trauma is commonplace, it is just more socially acceptable to talk about disturbing things. One thing he was certain of: while this particular project is over, the conversation about disability among refugee cultures needs to continue. He is working to start a new project that will help the effort become more self-sustaining. After gathering information, the group assembled and distributed information that was tailored for each community. For those cultures where marriage between cousins is common, they offered information on how some disabilities are inherited, and how to access services. "We created information that says, you have resources you can use," Ortiz said. "We can't tell them, 'You must do this,' but we can tell them, 'Here, we do this.' ... At the end they were thankful for the information that we were sharing."

Molina agreed, "More is needed, because communities need to know about resources, particularly," she said. What's more, when the project was done, people from communities that had not been included in the study came to her, asking if similar information could be presented to them. The team also spoke to groups about the development of a typical child. "When we talk about the earlier signs of, for instance, autism, we also talk about the development of a child, from birth to when they go to school," Kalala said. "They understood, and with that we can tell them about the earlier signs of autism. It was something new to them." Along the way, Ortiz said the group learned from the people they set out to serve. "This relationship is both ways," he said. "They are learning, we are learning. ... Their way of life is different. It creates more questions to follow up and understand." For example, the concept of marriage and family changes across cultural lines. For some cultures, a marriage is a union between families, not just between two individuals. Changing the place of residence may affect how the refugees view family, and it may not. But Ortiz said our service systems needs to be able to see families from different points of view so that they can be more effective. Molina was impressed by family loyalty to their own members who had a disability. "There were not any mention of institutionalization," she said. And caregivers worried about what would happen to their loved ones if they were no longer able to provide care. Ortiz came away convinced that first-generation immigrants are an underused resource, both inside and outside the disability world. He remembers a young woman in one of the focus groups with obvious leadership potential. "Her expectations were very high, but they were shaped by her experience," he said. "We need to go beyond the accent, beyond the dress, to the strengths, that for whatever reason, we have the chance to use."