Promotores de salud: Perceptions about cultural appropriateness and usefulness of the "Autism Promotor Manual"

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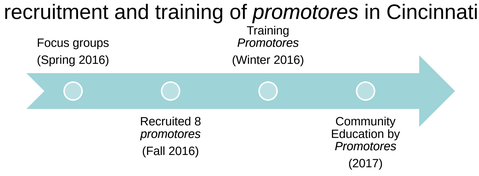
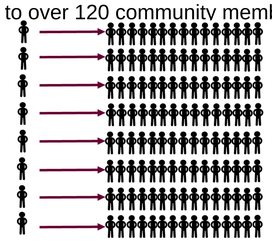
INTRODUCTION

- There are many health disparities for Latino children with autism spectrum disorder (ASD):
  - Diagnosed at later age
  - Less likely to receive evidence-based services
  - Less likely to have primary care/specialist doctor
  - Less likely to receive transition services
- *Promotores de salud:* lay health educators or peer leaders, live in the same neighborhoods in which they work, trusted and capable of influencing hard-to-reach communities. They are becoming critical participants in prevention, health promotion, and the care delivery in Latino communities
- Initial phases of this project have focused on recruitment and training of *promotores* in Cincinnati:



- Thus far, 8 *promotores* have provided education about ASD to over 120 community members:

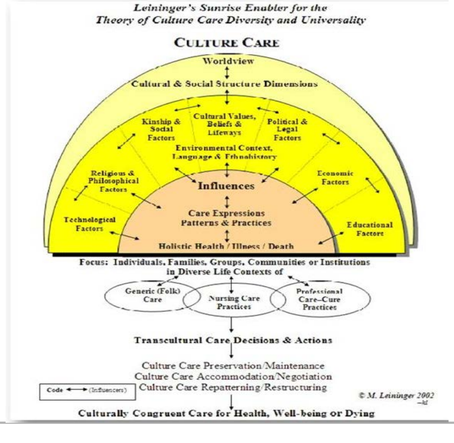


The aims of the current project are to:

Aim 1: to understand if the tools used in the *promotores* study were culturally-appropriate, met their knowledge expectations, easy to use/read, and applicable to the Latino Community in Cincinnati

Aim 2: to develop an adapted curriculum in partnership with the *promotores*

FRAMEWORK: Culture Care Theory



METHOD: Qualitative Focus Groups

- **Research design:** Qualitative Focus Groups underpinned by Cultural Care Theory
- **Setting:** Local community organization (St. Carlos Borromeo Catholic Church in Cincinnati)
- **Data analysis**: Focus group session was analyzed using NVIVO, with themes abstracted from the patterns.
  - Focus group session was translated and transcribed from Spanish to English
- **Key participants:** 7 Latino promotores
  - Primarily female without previous experience with ASD (*n*= 5)
  - Country of origin: Guatemala (*n*= 3), Mexico (*n*=3), Nicaragua (*n*=1).

RESULTS

Culture care for Promotores trained to increase ASD awareness in Latino community members expressed:

Theme 1:Characteristics of being promotores

- Supporting their community by acting as a resource

"That's something you can do, get the person's number, get help... because you have the resources, we know people who can help."

- Empathy about the community issues

"Because sometimes as a Hispanic, you just arrive, you don't know anyone, you get depressed because of the situation and the confinement, change, work, child care."

- Depending on other *promotores*

"It helps us a lot, is to have another partner…if someone got stuck, there was someone to help."

- Empowering others to seek help and being non-judgmental, in order to be a trustworthy *promotores*

"When we were giving the talk with parents, they felt like they were very strong and like they were more in the mood to seek help."

Theme 2: *Strategies to training promotores*

- Preparing as a team and modeling after others

"A good thing that you also did was that... to look at each other's presentations. That helped a lot."

- Researchers providing support for mastering content such as advocacy and navigation skills

"That can help us, strengthen the group and expand, talk more about the issue so that we can help the population because there are many people here who need support."

- Increased knowledge of community resources

"If you give them a list of names, they don't know where to go or with whom. But if we tell him his house or San Carlos, he's gonna give that help. It's like you are more specific."

RESULTS (continued)

Theme 2: *Strategies to training (cont.)*

- Simplifying and standardizing materials (e.g., training manual, expert presentations, videos and testimonials)

"A lot of statistical data. A simpler scheme and more examples would be better. Examples of autism. Like she said, videos."

- Providing economic incentives for the community members

"Many people only go when they see that they are going to be given something."

All in order for the *promotores* to be prepared and confident in the content.

Theme 3: Barriers to being trained as *promotores*

- Lack of confidence in knowing about developmental disorders and broad resources

"One of the confusions we may have had, personally, is sometimes knowing each phase, or each development. For example, in the developmental phases it said Down syndrome. There was kind of a mix-up of all that. The program's name involves the autism spectrum. But we're not just focusing on autism…They trained us about a little bit of everything."

- Confusion about use and purpose of the training manual and procedures

"When we made the presentation, (other promotore) and I had a little confusion, as she said, because we didn't know what came first. We gave our presentation and that time they corrected us saying that we had to talk about developmental disabilities."

- Confusion about teaching advocacy skills

"I think that those 8 steps of advocacy should be broken down more... make it clearer by applying them to a particular case.

- Misunderstanding technical terms

"The technical word is 'autism spectrum disorder' but also in English, when we talk to parents we don't say the autism spectrum, we just say autism."

RESULTS (continued)

Theme 4: Cultural Diversity

- Expressions of diversity in meanings and beliefs related to knowledge
- Experience with individuals with developmental disabilities
- Differences in having a lived or learned experience

DISCUSSION

- A focus group with *promotores was conducted to* understand if the tools used were culturally-appropriate, met their knowledge expectations, easy to use/read, and applicable to the Latino Community in Cincinnati.

➢ Promotores' feedback encompassed four major themes and will be utilized to revise the training materials:
  - ➢ Consider depth in ASD vs. breadth in training on DD
  - ➢ More videos
  - ➢ Personal testimonials from parents
  - ➢ More specific to Cincinnati area

➢ Future directions include further examination of the Promotores' written feedback and the promotores training other promotores (i.e., Train the Trainer).

➢ Our study is limited to the experience of this group of *promotores* recruited from the Cincinnati area.

Acknowledgments

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