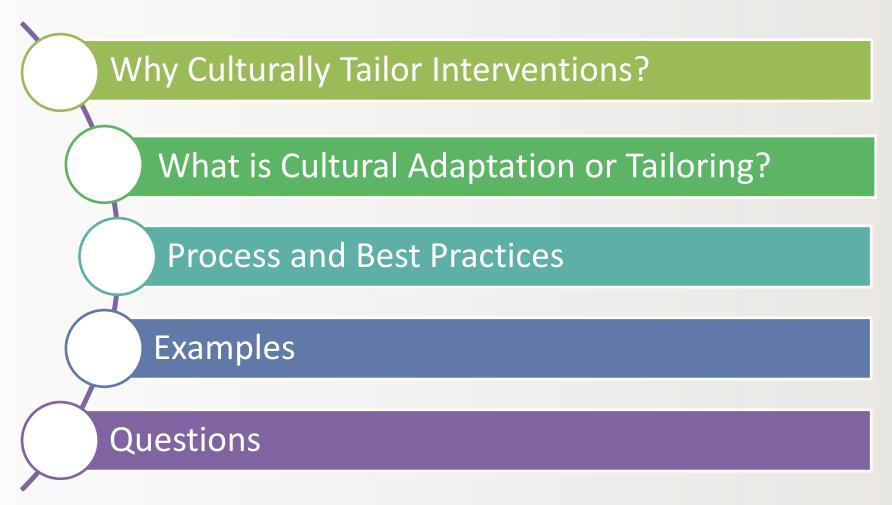
# The Process to Culturally Tailoring Interventions

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## Overview of presentation

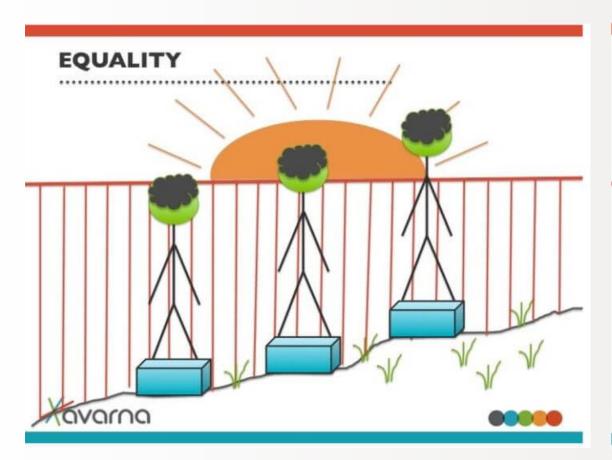


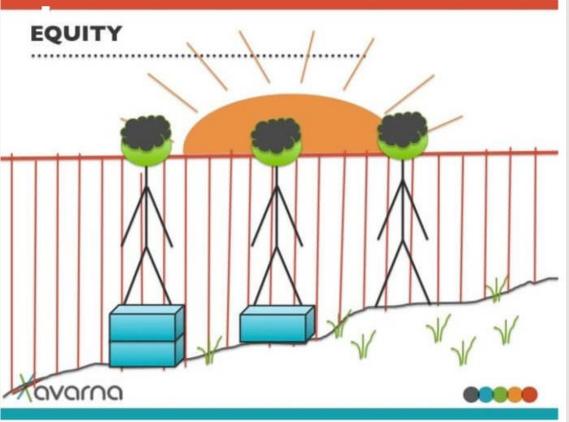
## Before we begin...

- I would like for you to think about these two points as we go along:
  - How you might use the ideas/concepts presented in your studies, or future/current professional practice
  - Additional ideas or examples that you've observed

## Why culturally tailor interventions?

- Most evidence-based interventions are not tested with culturally diverse populations
- Diverse groups have unique needs and often fall through the cracks of service and healthcare systems
- Interventions tailored for specific populations, needs and outcomes can address these needs and reduce disparities





## What do we mean by cultural tailoring an intervention?

- Ensuring an intervention is culturally responsive to the group you plan to serve
- Can be creating or developing a new intervention that is culturally tailored or culturally adapting an existing intervention to a specific group



## Models of Cultural Adaptation

- Surface level adaptation
  - Identified sociocultural needs of the family
  - Use bilingual/bicultural staff
  - Use of culturally specific interpersonal styles

- Deeper structure approach
  - Also embed values, practices, traditions that reflects helpseeking behaviors and view of the world
  - How social, cultural,
     environmental and historical
     factors influence health related
     behaviors & practices

# Best Practices in Developing or Adapting Culturally Tailored Interventions

- Involve Stakeholders
- Consider using peer-based recruitment and delivery methods
- Create/adapt/translate materials for the specific group
  - Ensure content is relevant and salient to group
- Ensure accessibility and reduce effort and barriers
- Consider using the Ecological Validity Framework

## Involve Stakeholders

#### Stakeholder advisory board

- Families/individuals who would benefit from the intervention
- Community & school practitioners working with the population
- Community advocates

Adoption is increased by compatibility and level of complexity



Diffusion of Innovation (DOI) Framework (Rogers, 2003)



## Include a Paid Bilingual and Bicultural Peer Mentor, Navigator or Interventionist

Situation within organization

Outreach, Recruitment

Endorsement by community member can support adoption in community

Help with delivery of intervention



### Adapt and translate materials/intervention

#### Consider length, number of sessions

Cost

#### **Engaging materials**

• Minimize text, visuals

#### Culturally relevant themes

- Family activities
- Images
- Content specific to group



Diffusion of Innovation (DOI) Framework (Rogers, 2003)

## Accessibility/reduce effort

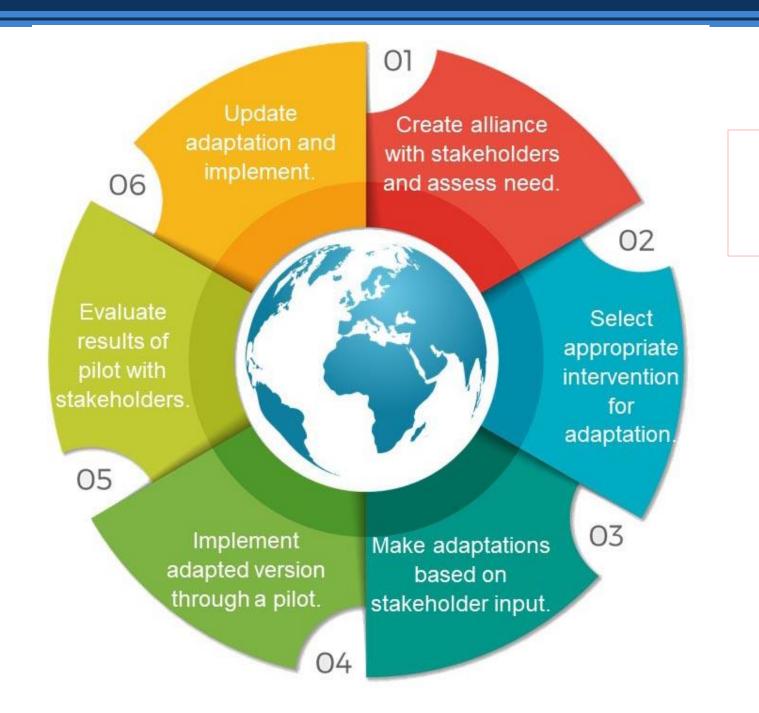
Family homes or near where families live

Close to public transportation

Snacks, childcare provided

Smaller groups of families to promote connection/discussion

Consider home visits which overcome several barriers



Cultural Adaptation Process

# EXAMPLES OF CULTURALLY TAILORING AND ADAPTING INTERVENTIONS

## Parents Taking Action

 Intervention created to address disparities for Latino immigrant parents of children with Autism

Formed Advisory
Committee

Used Ecological Validity Framework

Used Promotoras de Salud

## **Advisory Committee**



Community Partner staff



Local social service & medical professionals



Investigators and research staff



Latino parents of children with Autism



Autism expert

 Met several times to review & give feedback on program content

## **Advisory Committee in Milwaukee**

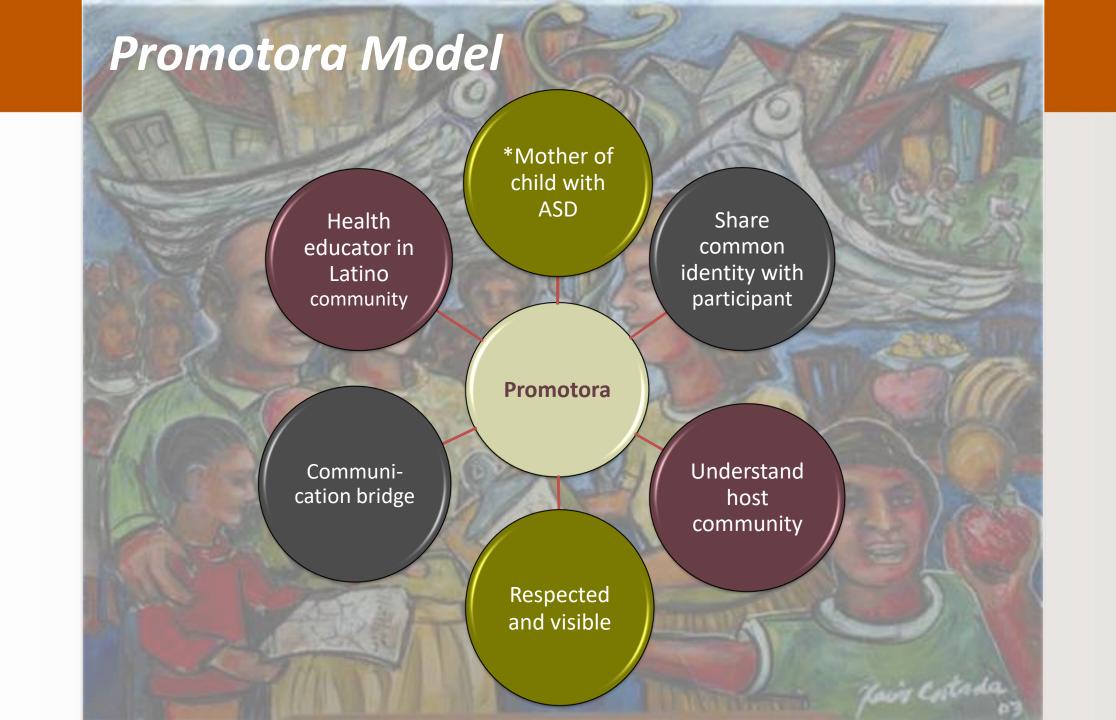


## Ecological Validity Framework for Cultural Adaptation (Bernal)

Dimension	Incorporation into intervention and materials	
Language	Materials created in Spanish and English, promotoras native Spanish speakers	
Persons	Promotoras from same cultural and geographic community	
Metaphors	Common Spanish sayings or "dichos as well as storytelling were incorporated into the manual	
Content	Incorporated cultural values such as familism and personalismo	
Goals	Goals for parent and child that take into account sociocultural context	
Methods	Flexible and foster relationship building and including the family	
Context	Home-visit model overcomes barriers to participation such as transportation and child care	

## Curriculum: 14 Sessions

Psychoeducation	Advocacy & Parent Support	Evidence-based strategies to help children learn
Understanding child	Parent advocacy in	Using play,
needs, autism,	schools &	enhancing
evidence-based	community,	communication,
practices, and	reducing stress, and	reducing challenging
challenging	increasing social	behaviors
behaviors	support	









- Training of Promotoras
- Held in group format, 4-to-8-hour blocks
- Total of 32 hours of training
- Provided meals and compensated promotoras for training time



## Promotoras role

- Being a role model and having shared experiences
  - "I believe the most effective aspect was to have someone to talk to about the problems they are facing, someone who understands them and doesn't criticize them."
- Having discussion and dialogue with participants
  - "It's a very mutual conversation."
- Providing emotional support
  - "it is possible for them to cry and talk with me about what is going on and how they feel."

## Promotoras role

- Teaching advocacy skills and providing resource information
  - A promotora indicated that the participant did not know they had the right to ask for services for their children
  - They reported that some parents knew of certain services but did not know how to access

#### **Parents Taking Action**



Promotora Manual

#### **Parents Taking Action**



Participant Manual

#### Padres en Acción



Manual Para Promotoras

#### Padres en Acción



Manual Para Participantes

#### **Materials & Structure**

- 2-hour sessions
- In-home weekly visits
- Manuals (English and Spanish, promotora and participant)
- Videos & Novelas
- Visual resources
- Session activities
- Home activities
- Community resource guides
- CDC materials

#### Session Two **Understanding Child Development** Key Terms Key Terms Key Terms Greet the participant and welcome him or her to session two: Juso. Understanding Child Development Thank you for keeping our appointment. Today we will learn about the way young children grow and develop, which is called child Check-in: development. Some of the information that we will see today will also be helpful in thinking about the development of brother, sisters, or cousins. (the child's name) Today we are going to look at three tools that will help us understand how children between 1 and 3 years of age develop. The first tool is a picture dictionary. We will look at this picture dictionary to understand the development of young children. In particular, we are going to pay special attention to how babies learn to relate to others, communicate, and play. We will notice the age

- Key terms
- Instructions to Promotora
- Check in with participant
- What promotora should say

- Objectives of session
- Framing of issue
- Saying or "dicho" as icebreaker

range in which certain skills usually develop. Then, we will test our understanding with a matching activity.

#### **Objectives**

- Talk about child development
- Practice the stages of child development with a picture dictionary
- Review information from the Center for Disease Control
- Talk about the M-CHAT

Latino families of children with developmental delays or autism face many obstacles in getting help for their children. Latino children do not always get the help they need, or get help after many more doctor visits than white children. In fact, Latino children are under-diagnosed and underserved in school and service systems across the country. One of the main obstacles is the lack of knowledge about child development and warning signs for autism.

Before we talk more about child development and the red flags of autism, I would like to share a saying that says,

"Little by little, one goes far".

Do you agree with this saying, why or why not?



Questions to generate discussion



Results of study: Compared to the control aroun

Parents feel more empowered/confident

Parents use more evidencebased strategies

Children access more EB services

Reduction in social communication problems

## Adaptations of PTA

For Black community in Baltimore

In California to reduce disparities in Regional Center system, San Diego

Internationally in Bogota Colombia

For Chinese immigrant families in Chicago

## Adaptation of PTA to Serve Parents of Black Children with ASD



## **Baltimore Team**

- Lead by Sarah Dababnah at the University of Maryland, Baltimore
- Primary collaborators
  - UMB Social Work Community Outreach Service; Dr. Wendy Shaia
  - Community Advisory Board
  - Collaboration with local initiative,
     Brown on the Spectrum



## Pilot Study Aims & Methods

- 1. Engage key stakeholders in the local adaptation and implementation of *PTA* for caregivers of Black children with autism in low-income Baltimore neighborhoods; and
- 2. Pilot *PTA* and identify participation barriers and facilitators.



# Aim 1: Advisory Group Engagement and *PTA* Adaptation

- Changes to PTA program manual
  - Modified first session to begin with a story of an individual with autism in Baltimore
  - Added photos of Black children and families
  - Reorganized manual to present child-directed play, communication and child behavior earlier
  - Recorded new video narrations
  - Included resources on police interactions
  - Revised manual with Baltimore-specific resources

## Meet Malcolm & Wendy



#### Objectives

- · Read Maloolm's story
- Fundamete you self with the general information and topics that we will explore during the program



#### Malcolm's Story



To continue, we will talk about the story of Malcolm, a young man with autian who is on the way to success and a happy life.



When Michaeles are been in James y 1990, bit consider Violands (etches are for prefer bully. As an inflat, Michaeles was hiring all his milestones training. However, around 14 months, all his vocalizations stopped and he became a very policy even. He would also stonesch and flap his hands. Violands which Michaeles, yellow the what to the The probaticions to Mi Violands. "Give it time." After those viola, Violands demanded arcusers. The deston referred the family to Mit Wishington Pediation Propriet, where a panel of professionals tested Malocian. They diagnosed Michaeles with strain. Tolands had saves beaut of strains, not large arrows with the daubility. Mit. Wishington set up speech appointments and sensory food appointments. Michaele that stured the Program for Amittic Learners (PALS) at a local elementary inflood. Violands was happy Michaele to receiving the help he needed, and decided to go back to work. However, no dayone centers were valued to accommodate has special needs. The family continued with PALS and Haltmore Inflant & Toddien program and he was those years old, when he transhored into Raltmore Cay Priving Schools.

At their first Individualized Education Program (IEP) meeting, Yolands insisted on the consect charaffection. The advocal recommended he be charaffed as "developmentally delayed." Yolands, stood from and Midwales was charaffed as being surious. With this diagnosis, the applied for the

## Aim 2: PTA Pilot Delivery

- Three Parent Leaders delivered the program to seven caregivers. All parents received case management from a LCSW or master's level social work intern.
- Caregiver characteristics:
  - All Black mothers
  - Two mothers were single; the remaining lived with someone or were married
  - Majority of participants had a high school education or less and had household incomes less than \$35,000

# Program facilitators: Parent support & Relevance to Black families

- In-home service delivery often revealed and allowed us to address material needs (e.g., food insecurity).
- Regular program and Parent Leader check-ins were commonly cited as facilitators to participation:
- "We normally try to maintain life by ourselves. So, I mean, even when we didn't have a meeting, [my Parent Leader] would reach out...Sometimes we just need that little question..."
- All parents reported the program was relevant for their family, with most citing the focus on Black families:
- I think [PTA] was relevant because a lot of the times in African American communities, the disparities...I feel it get pushed under the rug in this country....[my Parent Leader] and I...actually spoke about that, not enough attention is put on African American families, and what we go through...

## Program Challenges

- Caregivers frequently canceled or missed appointments (41%) and only three completed all 14 sessions (mean completion = 10 sessions).
- COVID-19 related shutdowns and other challenges exacerbated existing barriers. Financial incentives to keep scheduled appointments were ineffective

## Common reasons for cancellations:

- appointments for child and household needs (e.g., child therapy, SNAP benefits)
- caregivers' health issues, which included routine illnesses (e.g., colds) as well as extended hospital visits due to childbirth and surgeries for life-threatening medical conditions, gun violence, and other emergencies
- moving and housing instability (e.g., evictions)
- busy work schedules
- school closures
- lack of reliable transportation (e.g., which extended their time doing errands such as grocery shopping)

### Flexible Scheduling: Barrier, facilitator, or both?

- All caregivers reported PTA's flexible scheduling (e.g., meeting on weekends or in community locations) facilitated their participation:
  - "95% of programs won't [offer times outside of typical weekday work hours]. It's either, 'You do it the time that I can give you, because that's the time that I have opening, or you can't do it at all.' And that's just how it is. And that doesn't work."
- The average time between sessions was 35 days (ideally seven).
- Some parents felt it was unnecessary to be on a weekly schedule:
- "[PTA] give[s] us time to actually embrace it, learn it, fill it out and see if it works, if it doesn't work....as a single mother doing this, it takes a lot of patience. And with patience, you need that space in between to actually be able to cooperate with the child but incorporate everything that you need inside."

## Next Phase now in progress: Scale up with Developmental Behavioral Clinic on project to recruit from waitlist

Developmental Behavioral Pediatricians actively involved

- in recruitment through the DBP waitlist
- In helping families with arranging care for additional needs
- and in participating in the analysis and interpretation of data



## Other Cultural Adaptations

For families in Bogota,



For Chinese immigrant families Yue Xu at University of Illinois Chicago

## Questions?

How might you use ideas of developing culturally tailored interventions in your profession or future profession?

## Thank you to our funders

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