



# Reducing Racial and Ethnic Disparities for Children on the Spectrum

Sandy Magaña, PhD MSW

Professor in autism and neurodevelopmental disorders



Why is it important to examine and address disparities?

Research on racial and ethnic disparities among children on the spectrum

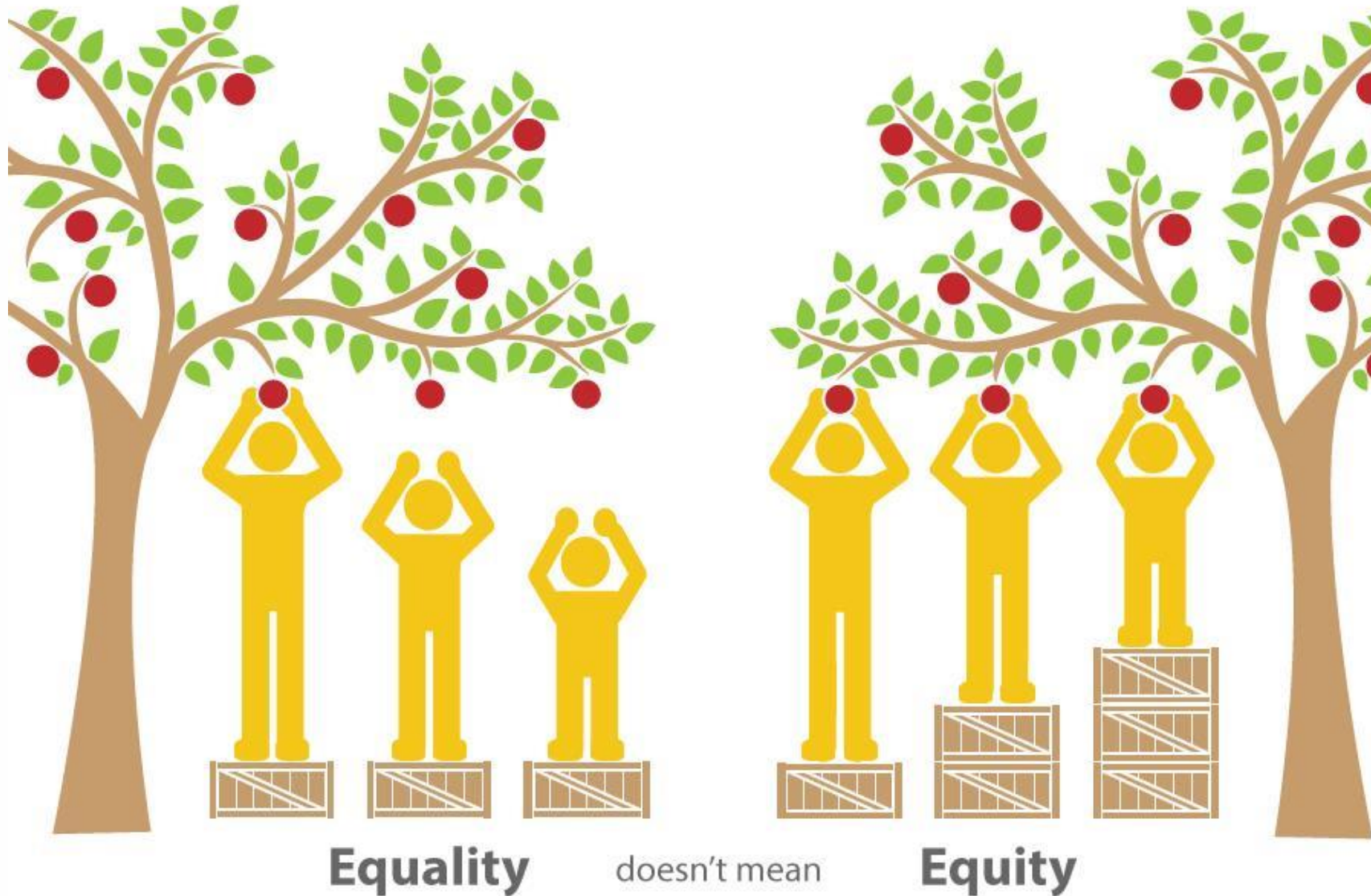
Examples of Interventions to address disparities

- Parents Taking Action
- Current study: ASPEN



# What are Health Disparities?

- Not all health differences are health disparities
- Health disparities are health differences that adversely affect socially disadvantaged groups
- Generally according to race/ethnicity, religion, nationality, socioeconomic resources or position



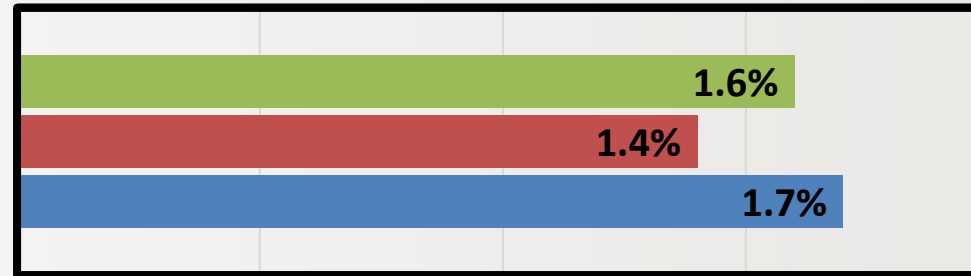
You may have seen this graphic before. Some have said it needs an update to reflect structural inequalities versus individualizing the problem



## Disparities in Diagnosis

### CDC 2014 Prevalence Rates

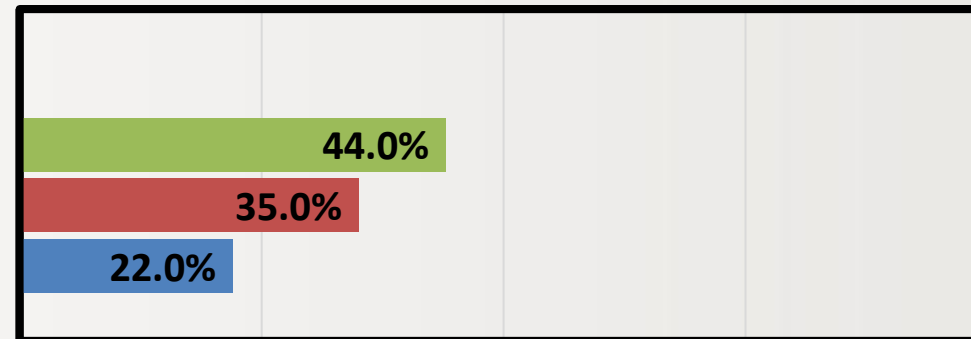
Autism Spectrum Disorder



0.0% 0.5% 1.0% 1.5% 2.0%

### CDC 2014 Prevalence Rates

Autism Spectrum Disorder +  
Intellectual Disability



0.0% 25.0% 50.0% 75.0% 100.0%

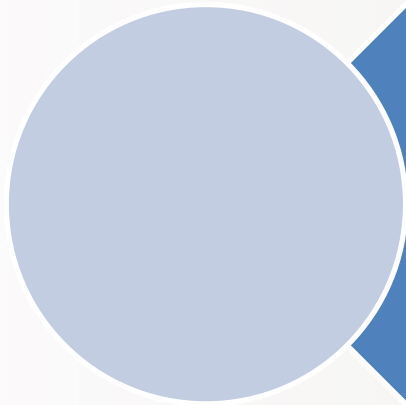
■ African American

■ Hispanic/Latino

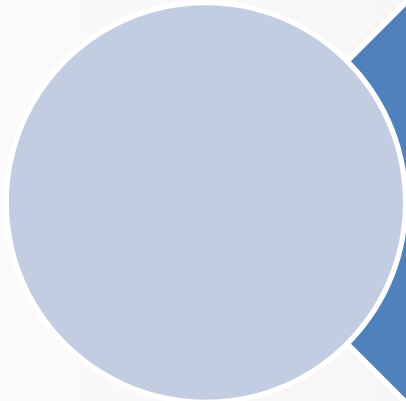
■ Non-Hispanic White



# Disparities in diagnosis



Black and Latino children are diagnosed later than White children (Mandell et al., 2009)



Black children are 2.6% more likely than white children to receive misdiagnosis such as conduct disorder or ADHD (Mandell et al., 2007)





# Other disparities related to diagnosis

Mandell, 2009

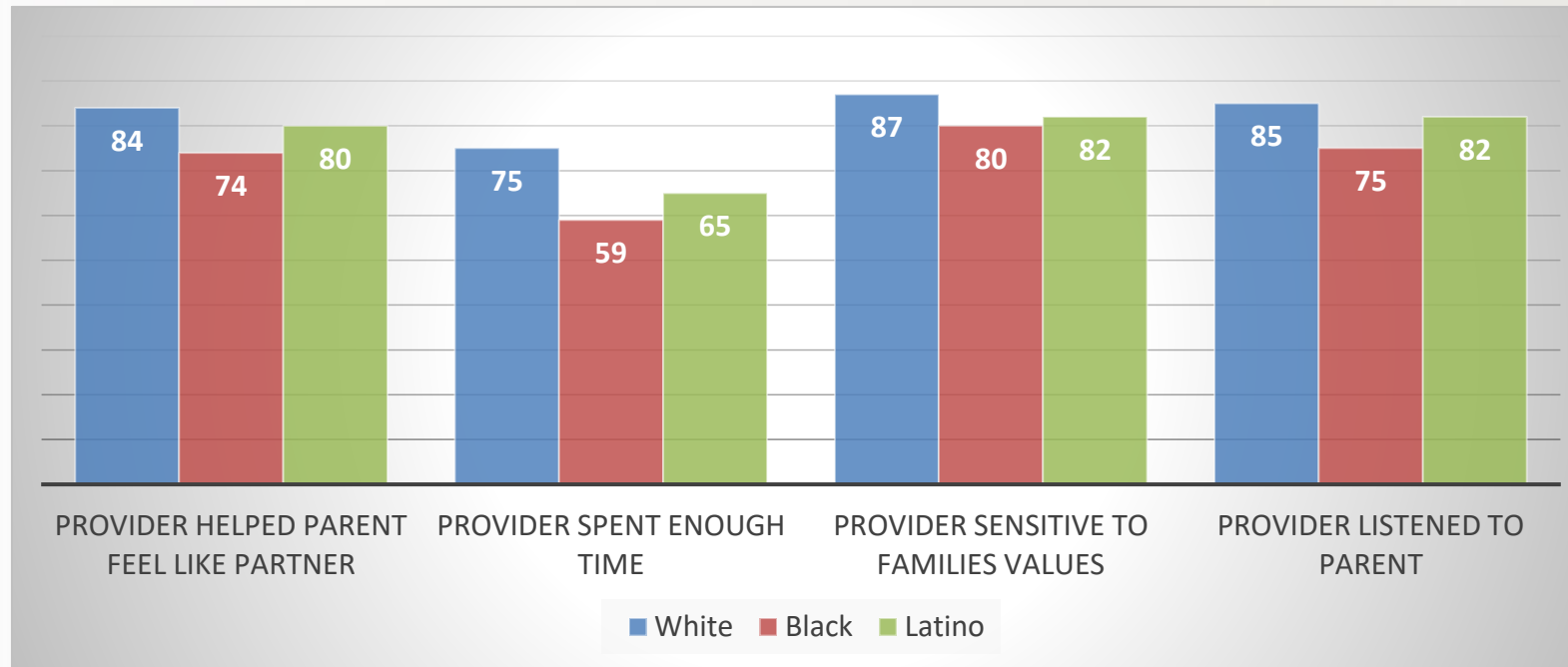
Black and Latino children are diagnosed later than White children

Mandell 2007

Black children are 2.6% more likely than White children to receive misdiagnosis such as conduct disorder or ADHD

CDC

Low-income children are also less likely to be diagnosed and diagnosed later

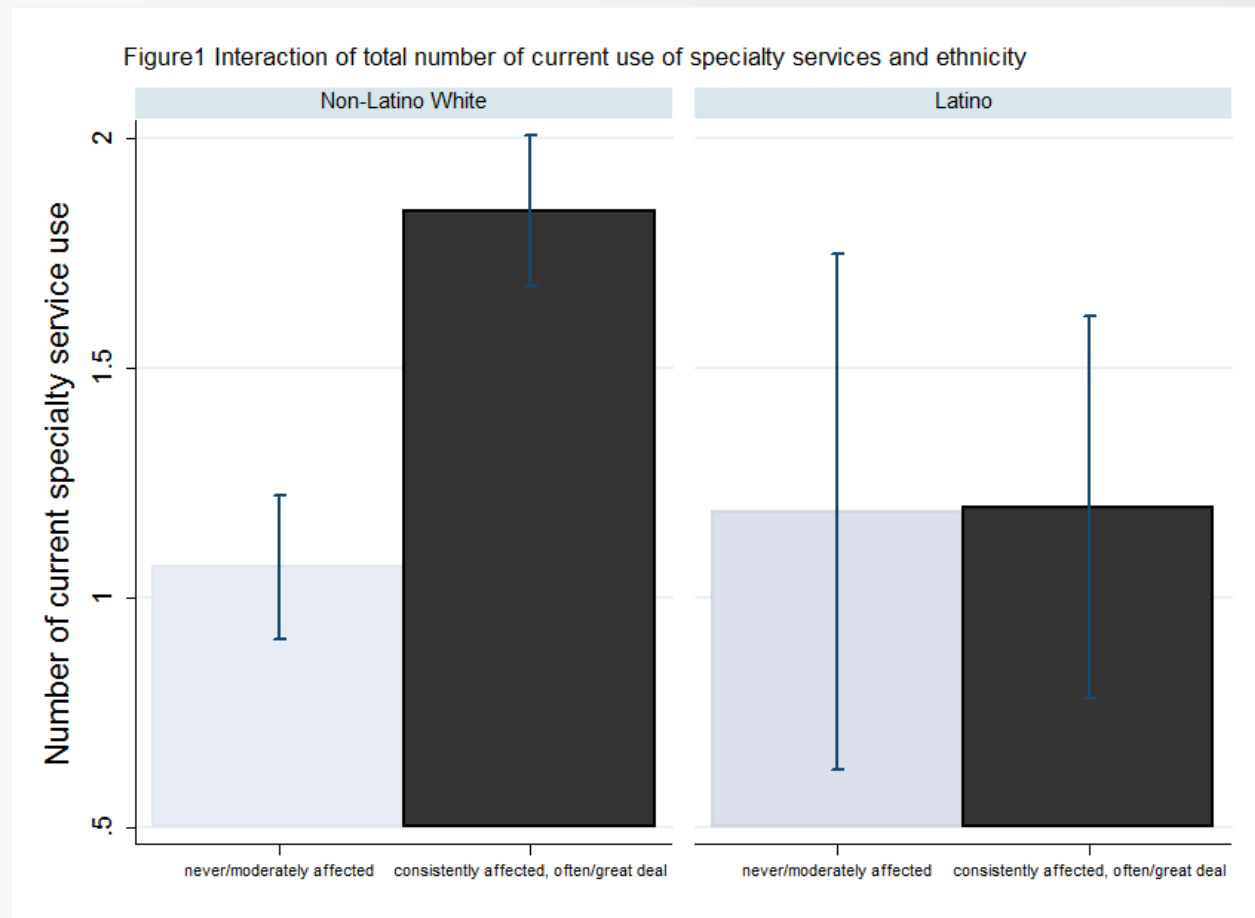


Magaña, Parish, & Son, 2015





## Pathways study on service use and severity of children with ASD (Magaña, Parish, & Son, 2016)





# Ways to Reduce Disparities

- Culturally tailored interventions that help to empower families on an individual and family level
- Interventions that provide training to providers to reduce disparities
- Policy level interventions



## 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



# Parents Taking Action

- Intervention created to address disparities for Latino parents of children with autism





Ecological  
Validity  
Framework for  
Cultural Adaptation

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

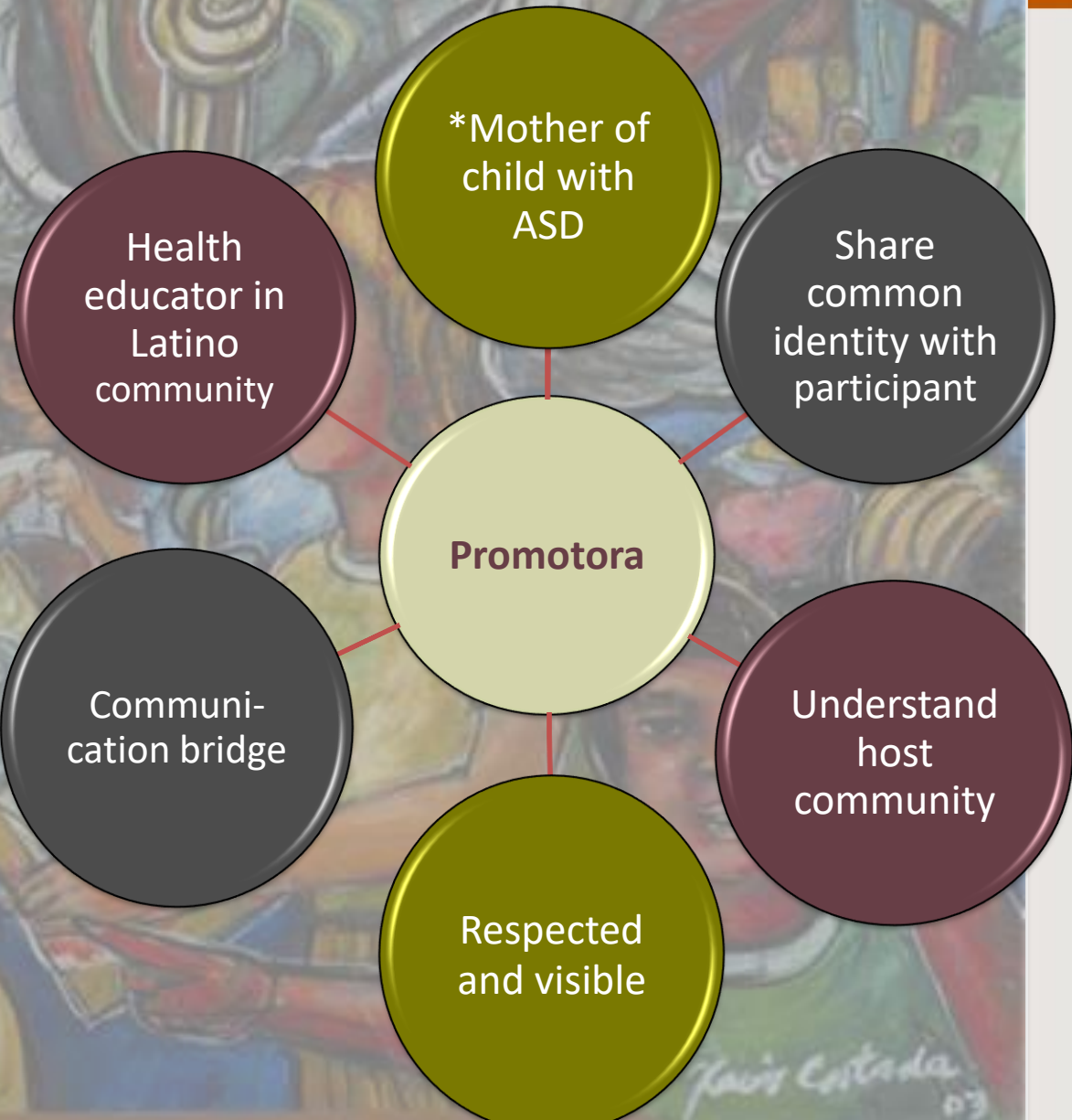


# Curriculum

Psychoeducation	Advocacy & Parent Support	Evidence-based strategies to use with children
Understanding child development	How to be an effective advocate	Play together, learn together
Understanding the autism spectrum and your child's needs	Advocacy in the school system	Creating everyday opportunities to encourage communication
What works to address symptoms of autism	Reducing stress and recognizing signs of depression	Helping your child make friends and interact with others
	Talking about autism to others and social support	Understanding and reducing challenging behaviors



# Promotora Model





# The University of Texas at Austin Steve Hicks School of Social Work







## Materials & Structure

### Parents Taking Action



*Promotora Manual*

### Parents Taking Action



*Participant Manual*

### Padres en Acción



*Manual Para Promotoras*

### Padres en Acción



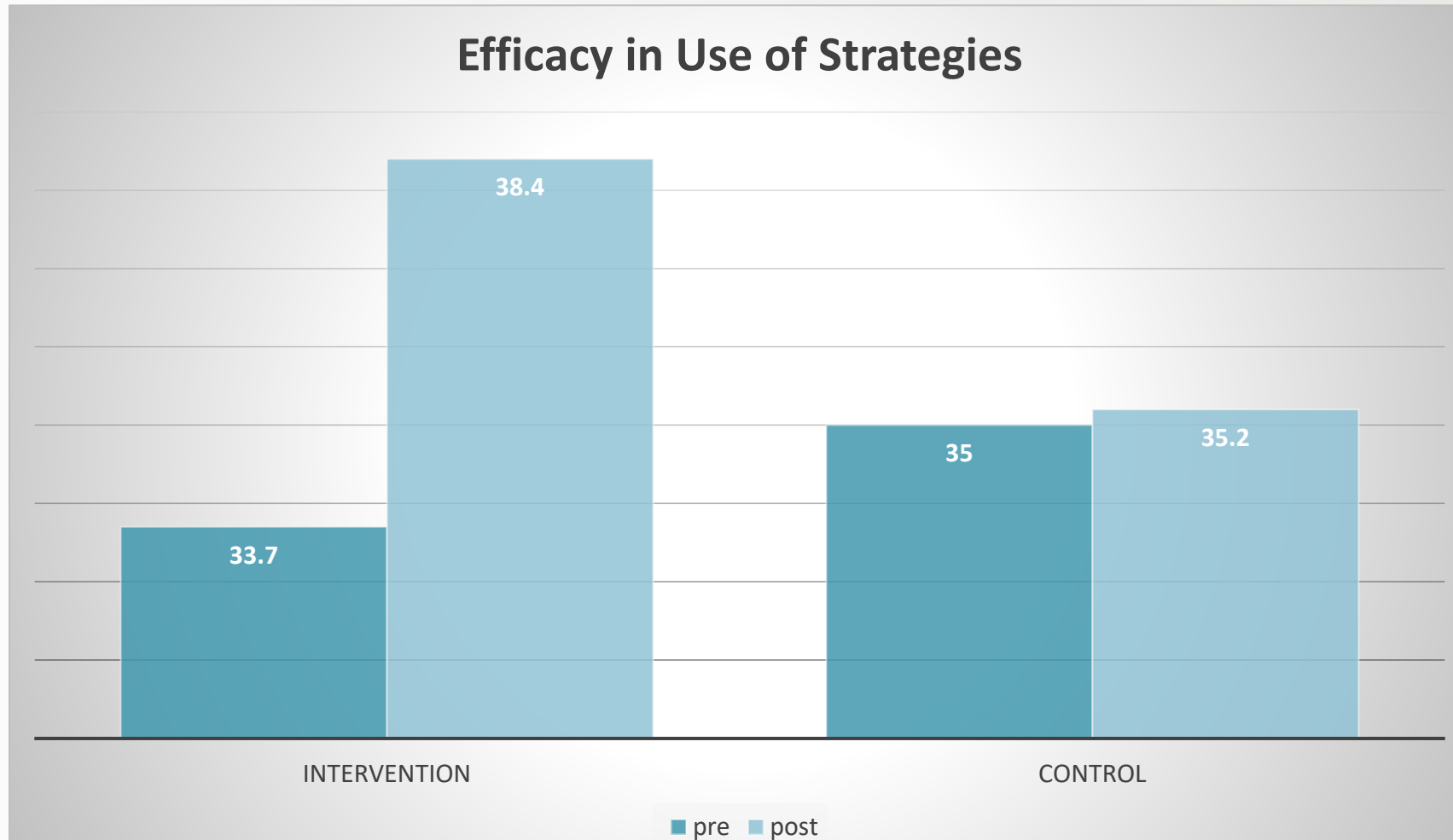
*Manual Para Participantes*

- 2-hour sessions
- Weekly In-home visits
- Manuals
- Videos & Novelas
- Visual resources
- Community resource guides
- CDC materials
  - ASD
  - Depression



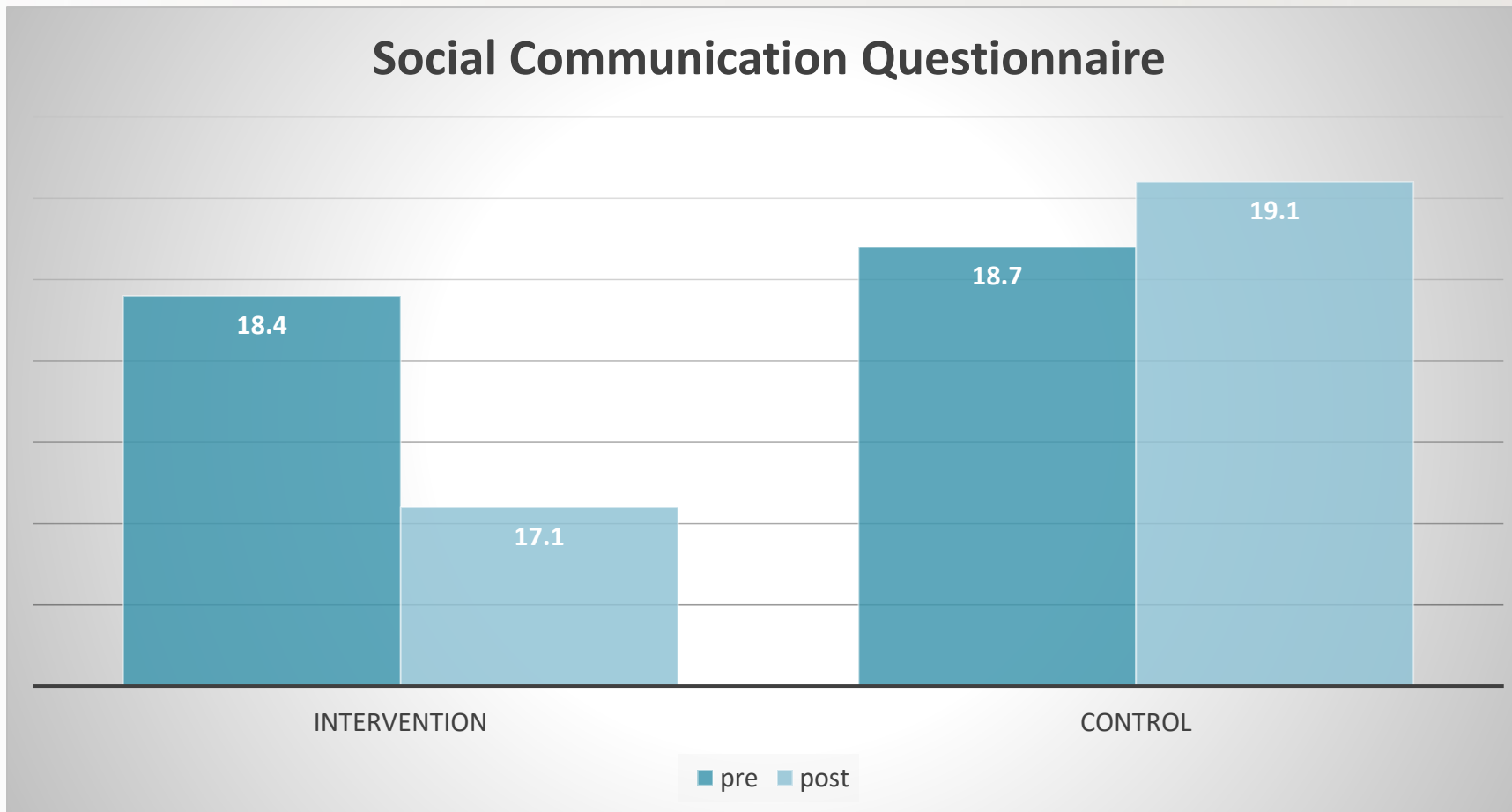
# Maternal Outcomes

## Efficacy in Use of Strategies



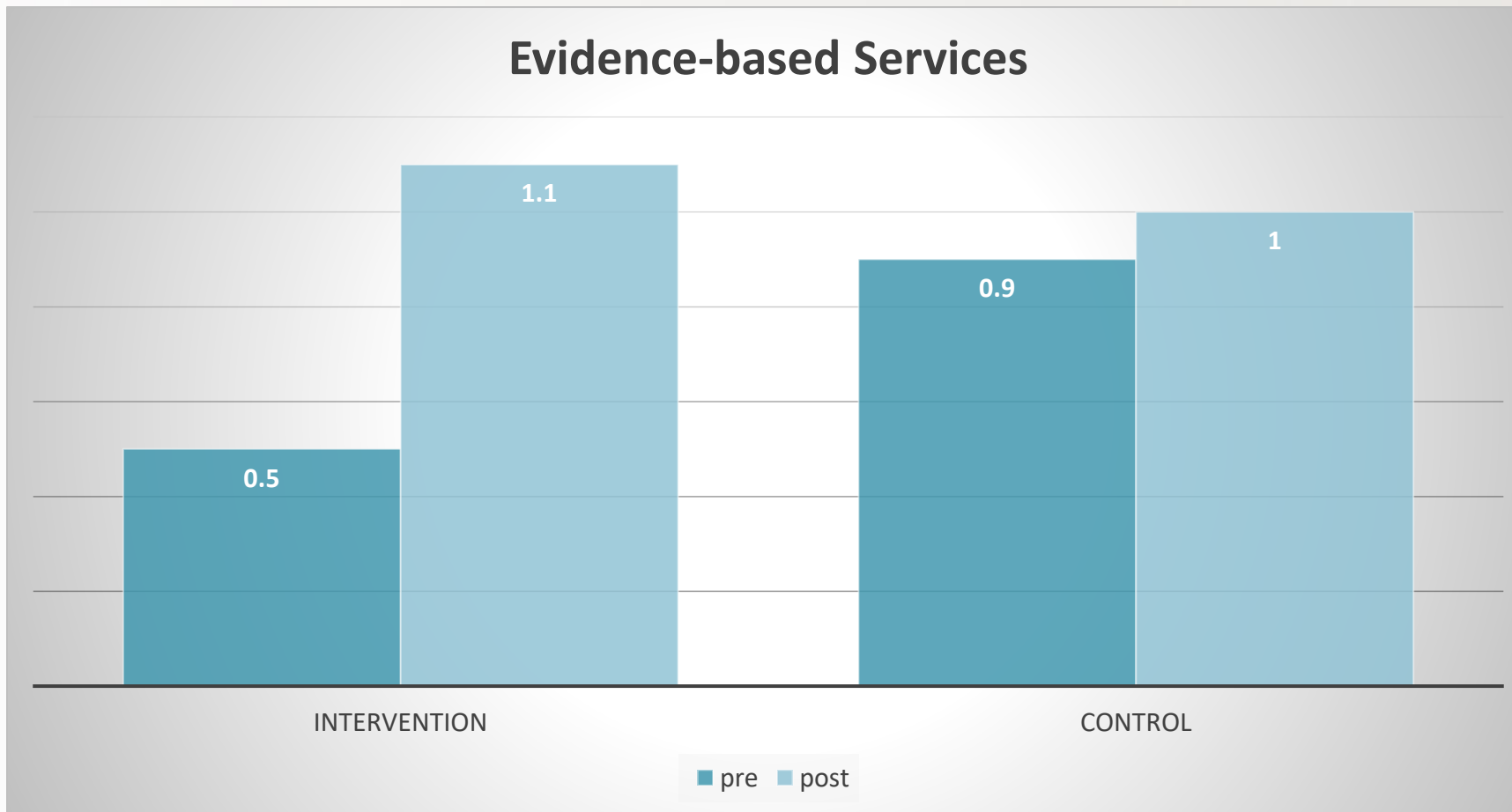


# Child Outcomes





# Child Outcomes







# Summary

Parents feeling more empowered



Parents using evidence-based strategies



Children accessing more EB services  
Reduction in social communication problems

## Adapted for Black families

- Led by Sarah Dababnah at the University of Baltimore
- Conducted focus groups of Black parents of children on the spectrum and Black professionals on content and delivery
- Conducted pilot study with 10 families, all were from low-income neighborhoods in Baltimore

# Used 5 components of SHARP framework (Shaia, 2019)

- SHARP identifies five components necessary to address in working with individuals and communities impacted by poverty and/or oppression:
  - 1) **S**tructural oppression impacting the individual or community
  - 2) **H**istorical context of the focus community
  - 3) **A**nalysis of the provider's role, either to disrupt or maintain the status quo
  - 4) **R**eciprocity and mutuality in the relationships between the provider and client, and between the client and others in their community
  - 5) **P**ower in individuals' ability to engage in individual and collective advocacy to change their own circumstances

# Using Sharp Framework for PTA

- Engaged Parent Leaders in the current study as teachers, advocates, and supporters in order to disrupt service systems which place caregivers purely as service recipients, instead of as knowledgeable, powerful, and capable of providing high-quality services to others.
- Project aimed to (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) deliver *PTA* and identify participation barriers and facilitators.

## Some of the changes made

- Changed both the order of sessions
- Revised the first session to begin with a story a young Black man with autism in Baltimore
- Revised and verified the manual and resource guide with additional local and national resources
- Added photos of Black and African-American children and families
- Recorded new video narrations with Black speakers, changed names and families in stories to be more appropriate for community context
- Included information on police interactions to the advocacy session.

# Facilitators and Barriers Identified

## Facilitators

- Flexibility in appointments
- Parent leaders- that they peers- from their community and having child with ASD
- Case management to address immediate needs
- Having someone go “step by step” and checking up on them

## Barriers

- Cancellations due to
  - Housing instability
  - Health issues
  - Phones out of service
  - Lack of transportation which delayed other chores and activities



# Adapted for Chinese immigrant families

- Graduate student, Yovia Xu from University of Illinois at Chicago culturally adapting for Chinese immigrants in the US for her dissertation
- Asians are the fastest growing racial/ethnic group
- Nearly 6 in 10 Asians in 2015 were foreign born
- Model Minority Myths
- Chinese American is the largest ethnic group

# Why PTA for Chinese Immigrant Families

- Autism was first described in Western cultures, and only later recognized elsewhere
- Both communities consist of large number of immigrants
- Shared values such as collectivism and Familism

- Yovia held focus groups with Chinese providers and parents to determine what changes to make to the program

# Change to Mode of Delivery

- Persons: Professionals
- Format: Group online learning led
- Delivery: Online

Weekly one-hour group learning

Weekly pre-recorded lecture videos that last 1 hour

# Major Modifications of Content

- **Replace** the story of Tom with two family stories
- **Emphasize** tools to track child outcomes
- **Add** myths on bilingualism and autism
- **Add** individualized family goal setting and plan of action
- **Add** a brief meditation for every session
- **Move** the session of social skills to the end



# ASD Screening and Parent ENgagement (ASPEN) Program

# ASPEN Leadership Team



Principal Investigator  
Texas State University

Sandra B. Vanegas, PhD



Co-Principal Investigator  
University of Texas at Austin

Sandy Magana, PhD, MSW



# Focus of ASPEN Program

- Parent chooses goals that are important to them
- The training on strategies follows a systematic order
- Training includes practice and observation
- Training includes support and problem solving
- Strategies focus on daily routines, natural environment

# ASPEN Intervention Topics

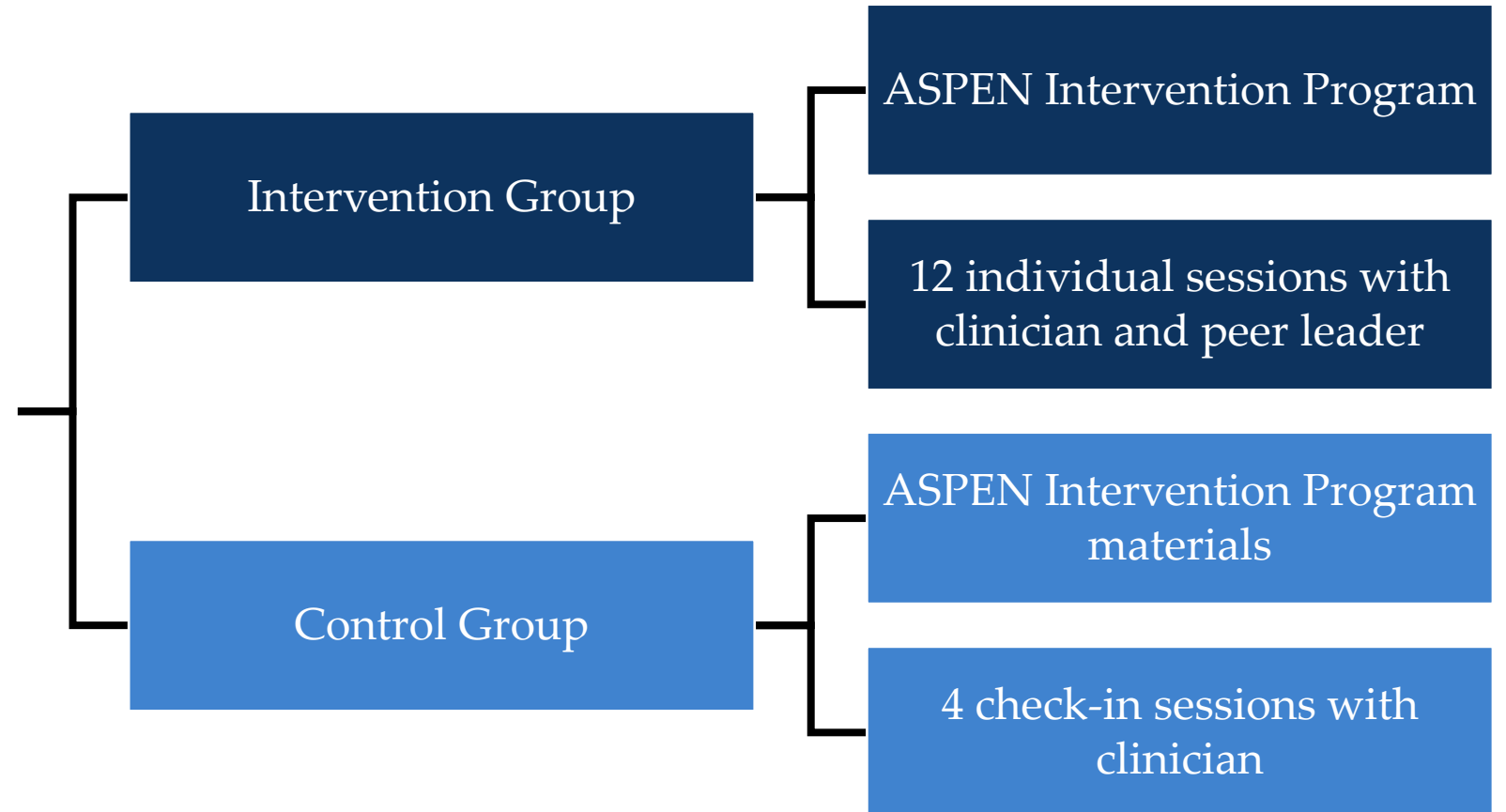
Session 1	Taking Care of Yourself	Session 7	Creating Opportunities for Communication
Session 2	Foundations of Development and Learning	Session 8	Introduction to Behavioral Strategies
Session 3	Foundations of Social Interactions and Play	Session 9	Teaching Expressive Communication
Session 4	Foundations of Language and Communication	Session 10	Teaching Social Imitation and Play
Session 5	Creating Playful Interactions	Session 11	Addressing Challenging Behavior
Session 6	Providing Support for Communication Development	Session 12	Overview of Program

# Participant Eligibility

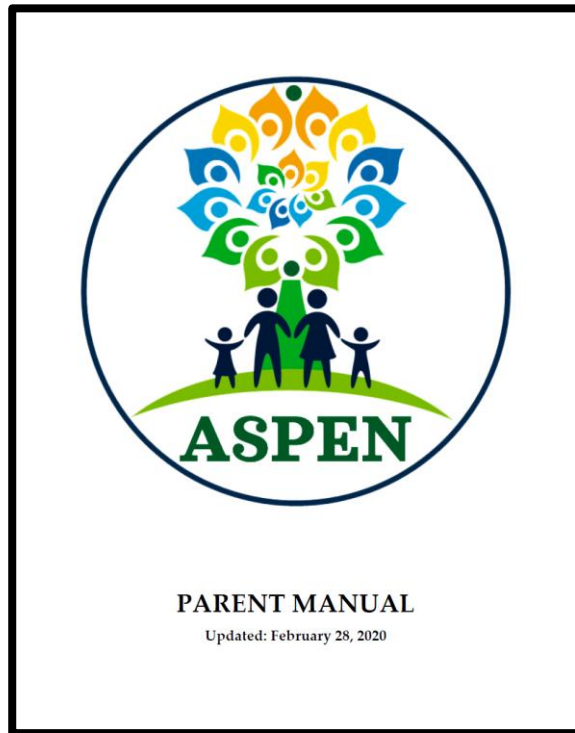


- Age
  - Child is between 18 months – 6 years
- Autism
  - Child has an Autism diagnosis/ educational classification OR
  - Child is at risk based on ASD screening
- Low Resource Household
  - Medicaid
  - High School or Lower Education
  - Household Income is  $\leq$  200% of the FPL

# Participant Randomization



# ASPEN Program Materials



**ASPEN Program  
Manual**



**Disability Services in  
Texas**



**CDC Developmental  
Milestones**



**Visual Supports**

**ASPEN Resource  
Packet**

# I'm interested, what's next?

Fill out the ASPEN Interest Form:  
<http://bit.ly/ASPENInterest>

We will call you to complete the eligibility screening

If eligible, schedule assessment

Randomly assigned to intervention or control group

Receive ASPEN Program materials and program based on group

Complete an assessment when you finish the ASPEN Program and 3 months later



# Contact Us!



Email:

svanegas@txstate.edu



Phone/Text:

(512) 693-9765



Facebook:

<https://www.facebook.com/ASPENProgramTX>



Twitter:

@ASPENProgramTX

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  - Matie Ovalle
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  - Jesus Plascencia
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