

Padres en Acción: A parent training program for Latina mothers of Children with ASD

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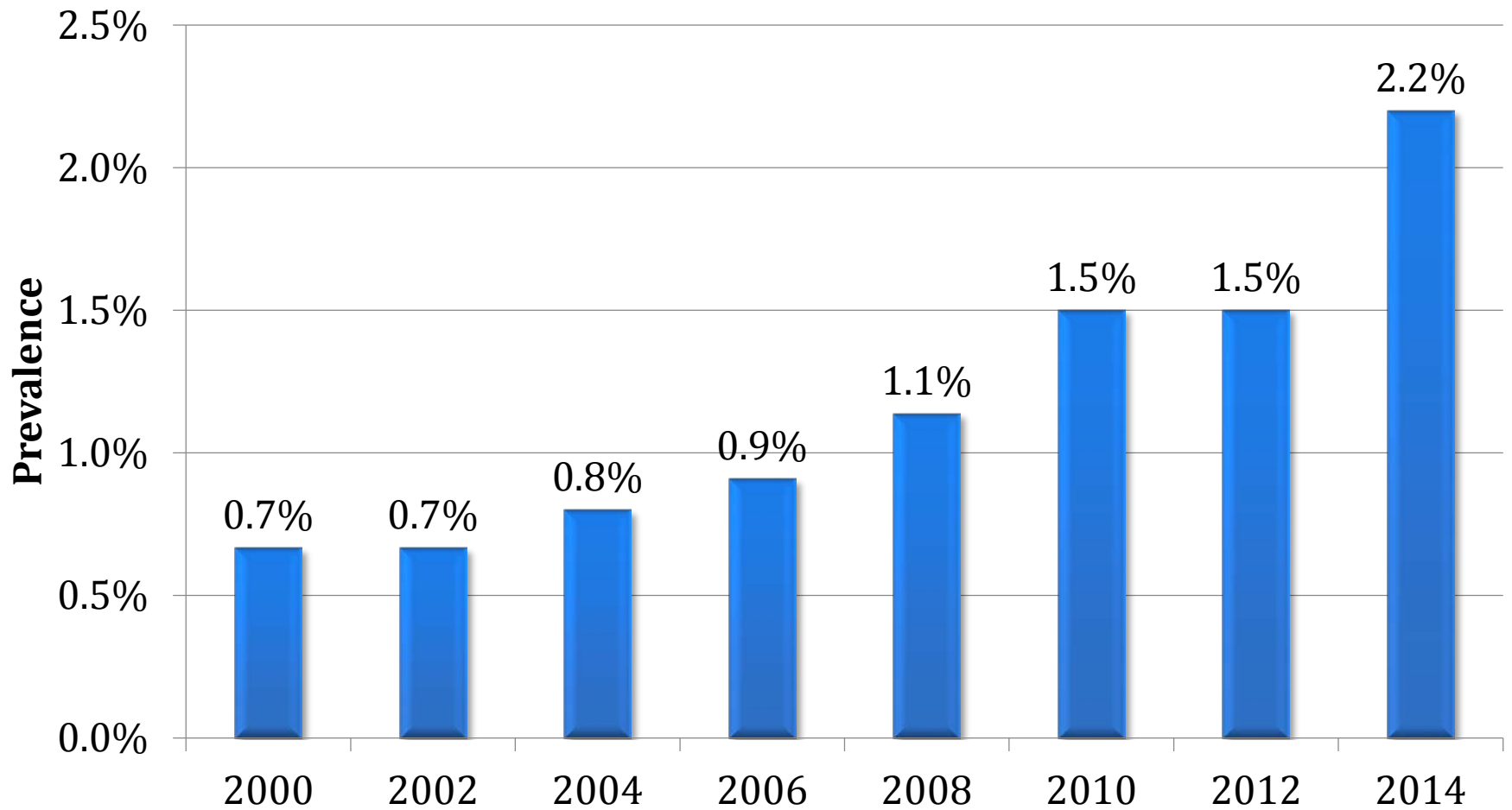
Overview of presentation

- Background
 - ASD prevalence and Latinos
 - Disparities for Latino children with ASD
 - Parent training as an intervention for children with ASD
 - Importance of culturally derived interventions
- Description of the project
- Methods
- Results
- Conclusion

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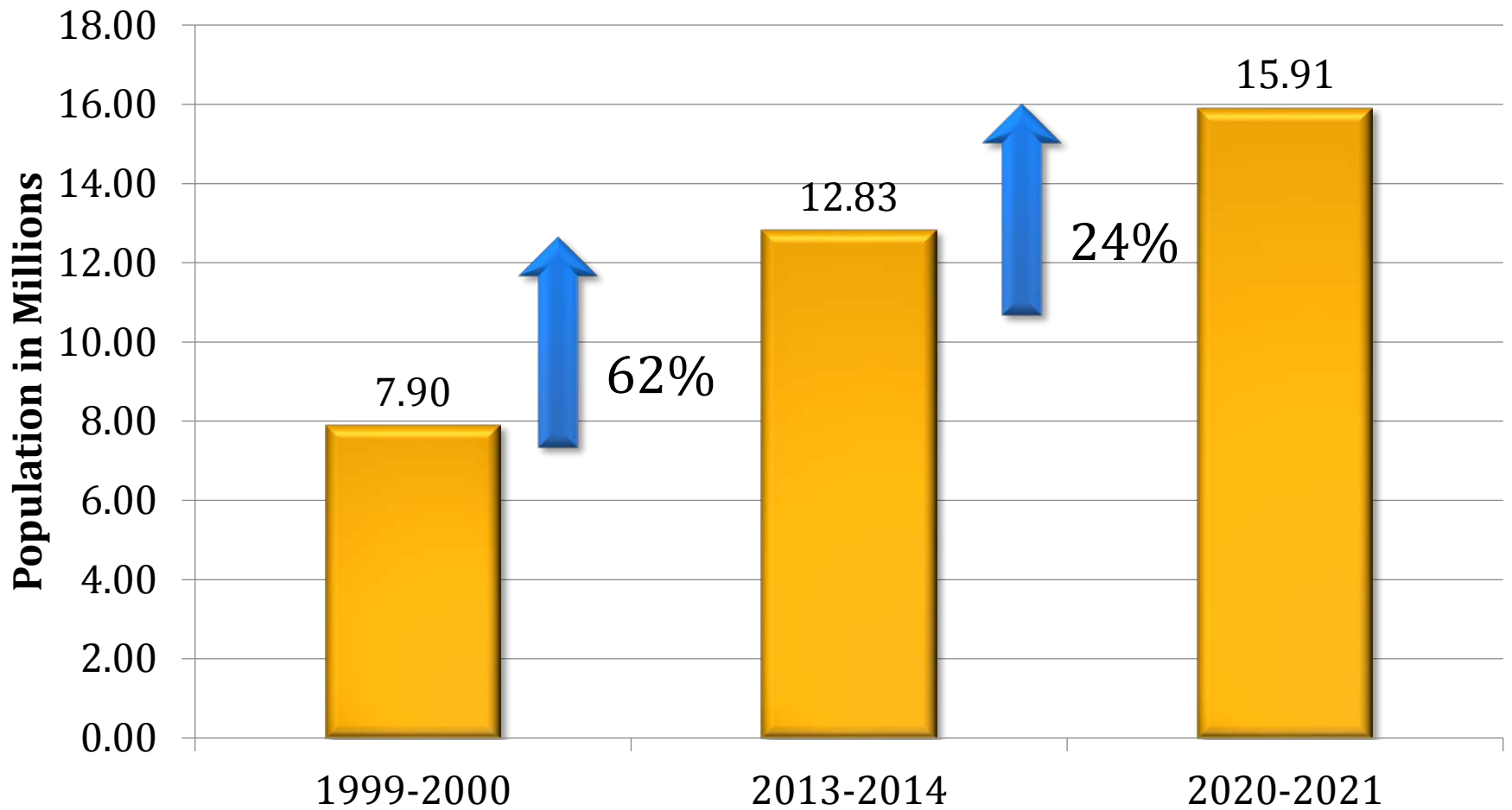


Prevalence of ASD

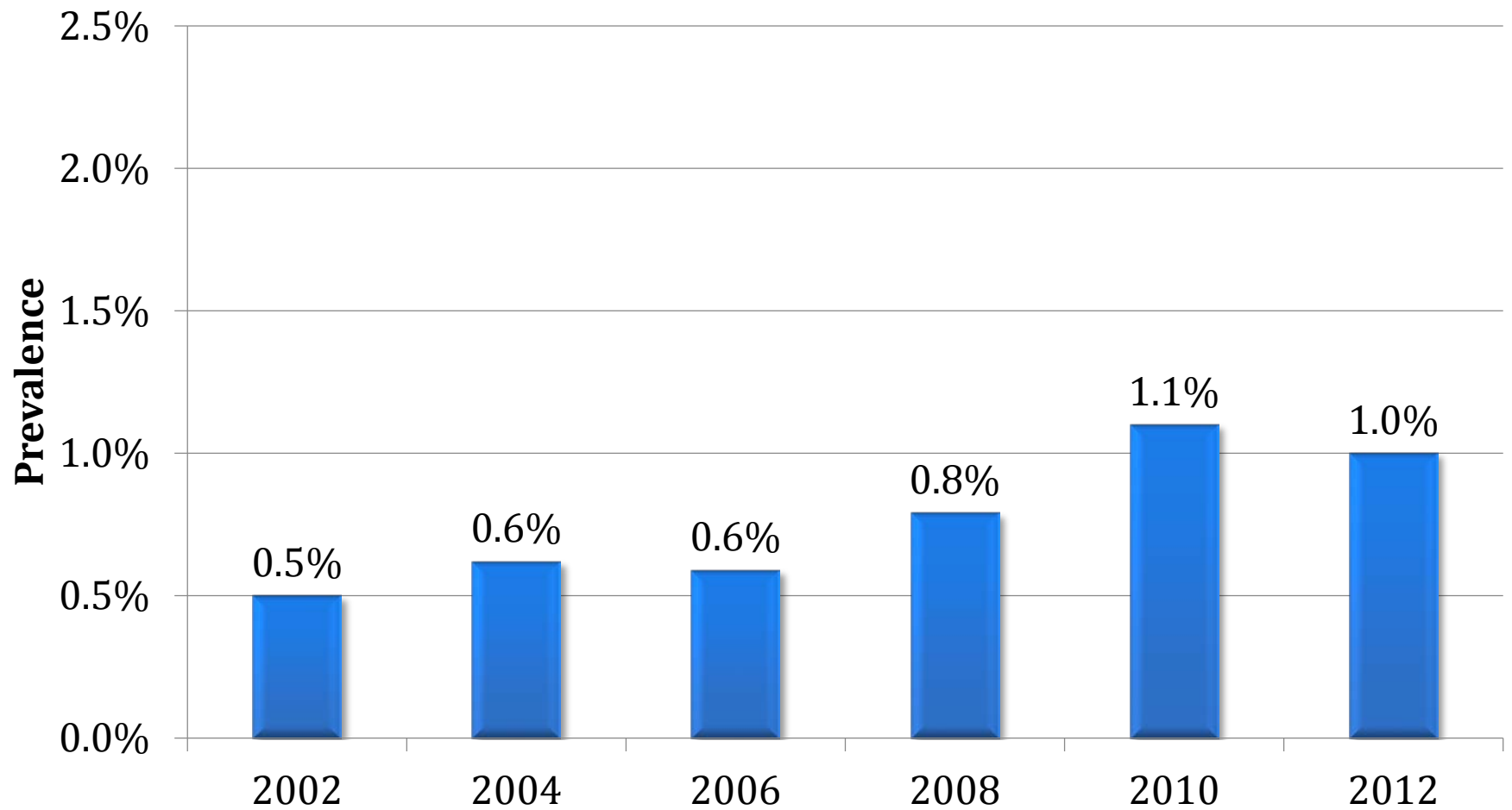


Center for Disease Control (2016); Zablotsky et al. (2015)

Latino Children in United States



Prevalence of ASD Among Latino Children



Center for Disease Control (2007, 2009, 2012, 2014, 2016)

Latino Children with ASD

Diagnosed at a later age



Less likely to receive early intervention services

Less likely to receive ASD diagnosis



Greater uncertainty about treatment

Less likely to receive evidenced-based services specific to ASD



Limits opportunity for improved development

Less likely to receive transition services



Inadequate or lack of future planning

Less likely to have primary care or specialist doctor



Health issues can become exacerbated

Parent training: effective intervention strategy for children with ASD

- Consensus that children with ASD need intense intervention of 24 hours a week or more
- It is argued that parents can be the most effective interventionists because they spend more time with their children
- Most parent training studies have focused on middle-class white families





Equality

doesn't mean



Equity

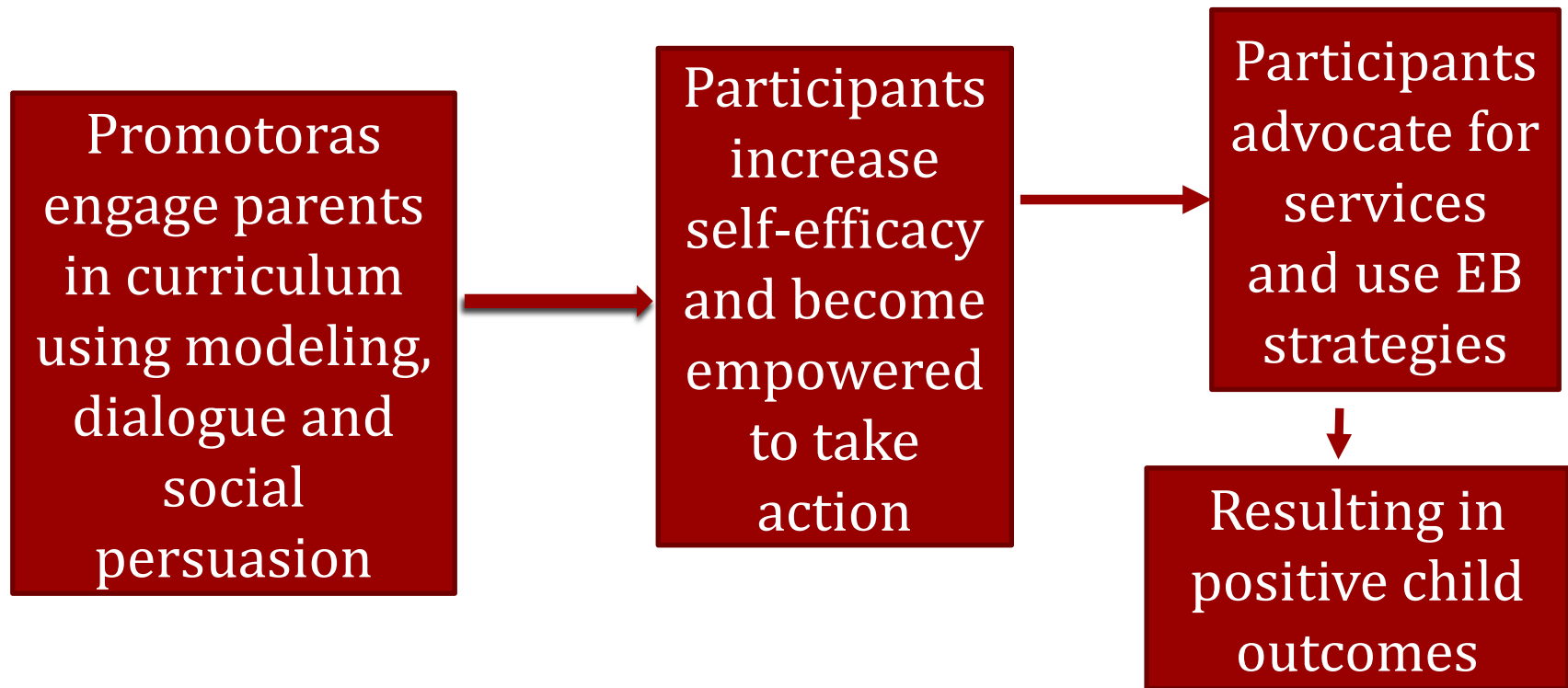
Importance of culturally derived or adapted interventions

- Some disorders are likely to be universal across cultures but may manifest differently in different cultures
- There may be different thresholds for what is considered problematic
- Differences in risk factors
- Also differences in knowledge about particular resources and services available to support children with ASD
- Differences in “flexible resources” that give families access to state of the art treatments

Parents Taking Action project

- Building on the promotora model
- Used community-based approach
- Used Ecological Validity Framework (Bernal et al. 1995) for cultural adaptation
- Combination of empowerment and self-efficacy theoretical framework

Theoretical framework



PROMOTORES DE SALUD MODEL



* Unique to our study

Advisory committee



Community Partner staff



Local social service & medical professionals



Investigators and research staff



Latino parents of children with Autism



Bilingual Autism educator, Emily Iland

- Met several times to review & give feedback on program content

Advisory committee



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

Session	Goal
Session 1 Introduction to the program	Meet the promotora and receive an overview of the program
Session 2 Understanding child development	discuss developmental milestones and recognizing signs
Session 3 Understanding the autism spectrum and your child's needs	Learn about how autism is diagnosed and what autism symptoms relate to your child
Session 4 What works to address symptoms of autism	Learn about evidenced-based practices and how to tell if a practice works for your child

Session	Goal
Session 5 How to be an effective advocate	Learn about the importance of being an advocate for your child and advocacy strategies
Session 6 Advocacy in the school system	Learn about the IEP process and advocacy strategies to use in your child's school
Session 7 Play together, learn together	Learn about the importance of play and ways to engage your child in play
Session 8 Creating everyday opportunities to encourage communication	Learn strategies for enhancing communication through daily routines
Session 9 Helping your child make friends and interact with others	Explore activities parents can do to help their child interact with peers

Session	Goals
Session 10 Challenging behavior is communication	Learn why children engage in challenging behaviors
Session 11 How to reduce challenging behaviors and respond appropriately when they occur	Explore strategies for preventing and reducing problem behaviors
Session 12 Reducing stress and recognizing signs of depression	Learn about risks to parental health and well-being and how to reduce stress
Session 13 Talking about autism to others and social support	Discuss how to share information with others about your child and the importance of social support
Session 14 Looking ahead	Set future goals and explore how to sustain growth. Celebrate completion!

Promotoras de Chicago



Promotora training in January 2015



Promotoras de California



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



- Training included review of IRB required research training
- Curriculum reviewed through discussions and dialogues
 - Engaging promotoras in discussing their own experiences relevant to content



Each receives certificate



Supervision and monitoring



- Promotora Coordinator
 - manages the work of the promotoras through making assignments, receiving regular phone calls and providing encouragement
 - Works closely with study staff on progress of the home-visits
- Fidelity checklist- self report and observations

Study design and method

○ Randomized trial:

- Total of 120 cases (90 in Chicago and 30 in Los Angeles) to be recruited over 3 years
- 60 to receive intervention,
- 60 in control/wait list group (to be offered intervention after 8 months)

- Recruitment criteria: Latina mother of a child with ASD between 1 and 8 years old
- Families receive baseline and 2 follow-up evaluations
 - Includes questionnaire
 - Video-taped interactions with mother and child
 - CARS-2 at Baseline only for severity measure
 - About 70 have been enrolled in the study so far
 - 24 have completed intervention and had baseline and one follow-up; will report on these

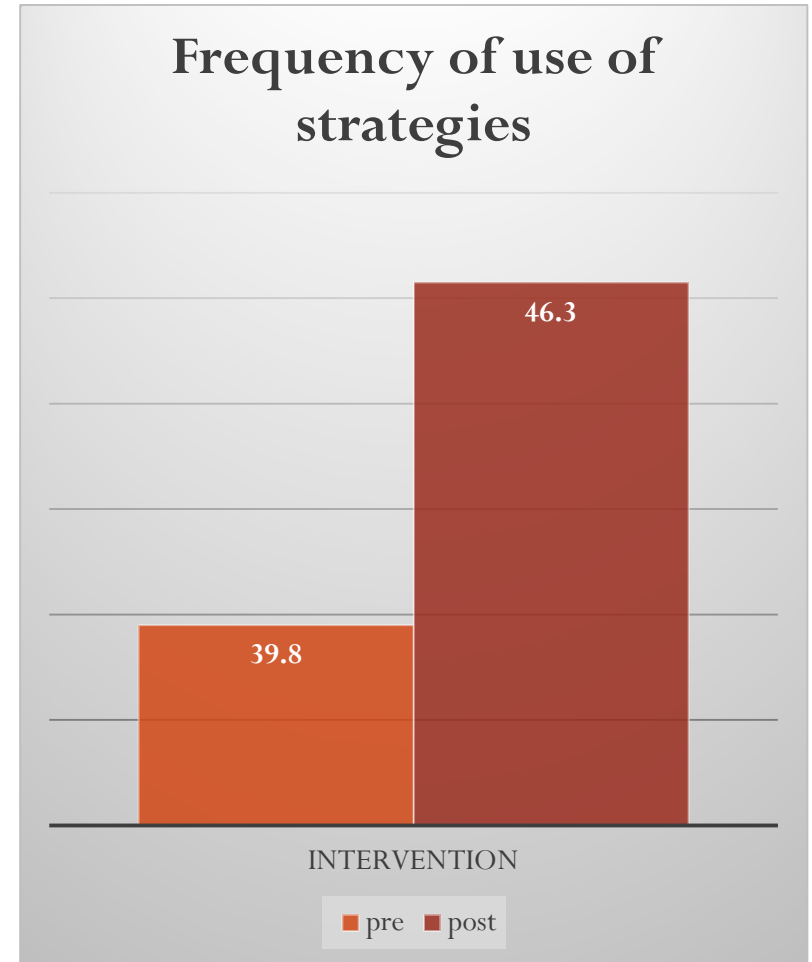
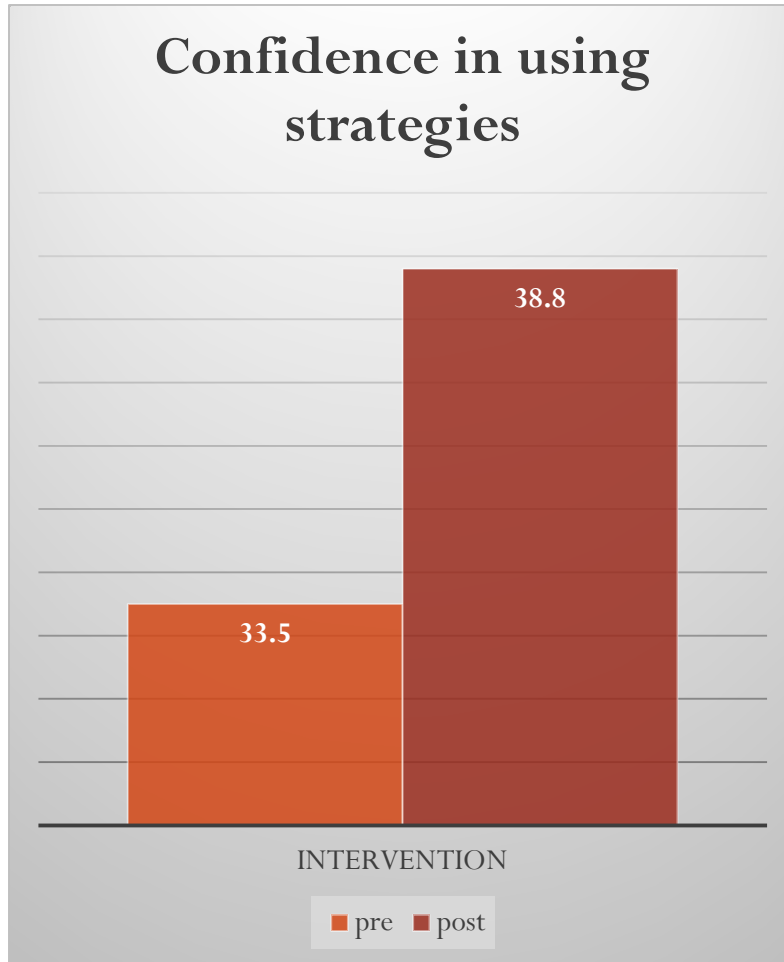
Demographics of intervention group

Characteristic	(n=24)
Mother's age (mean)	38.2 (5.3)
High School +	75%
Income (% under \$20,000)	43.5%
Married or living together	79.2%
Foreign born mothers	95.9%
Child Age (mean)	6.2 (1.8)
Male children	84%
Severe ASD symptoms (CARS)	20.8%

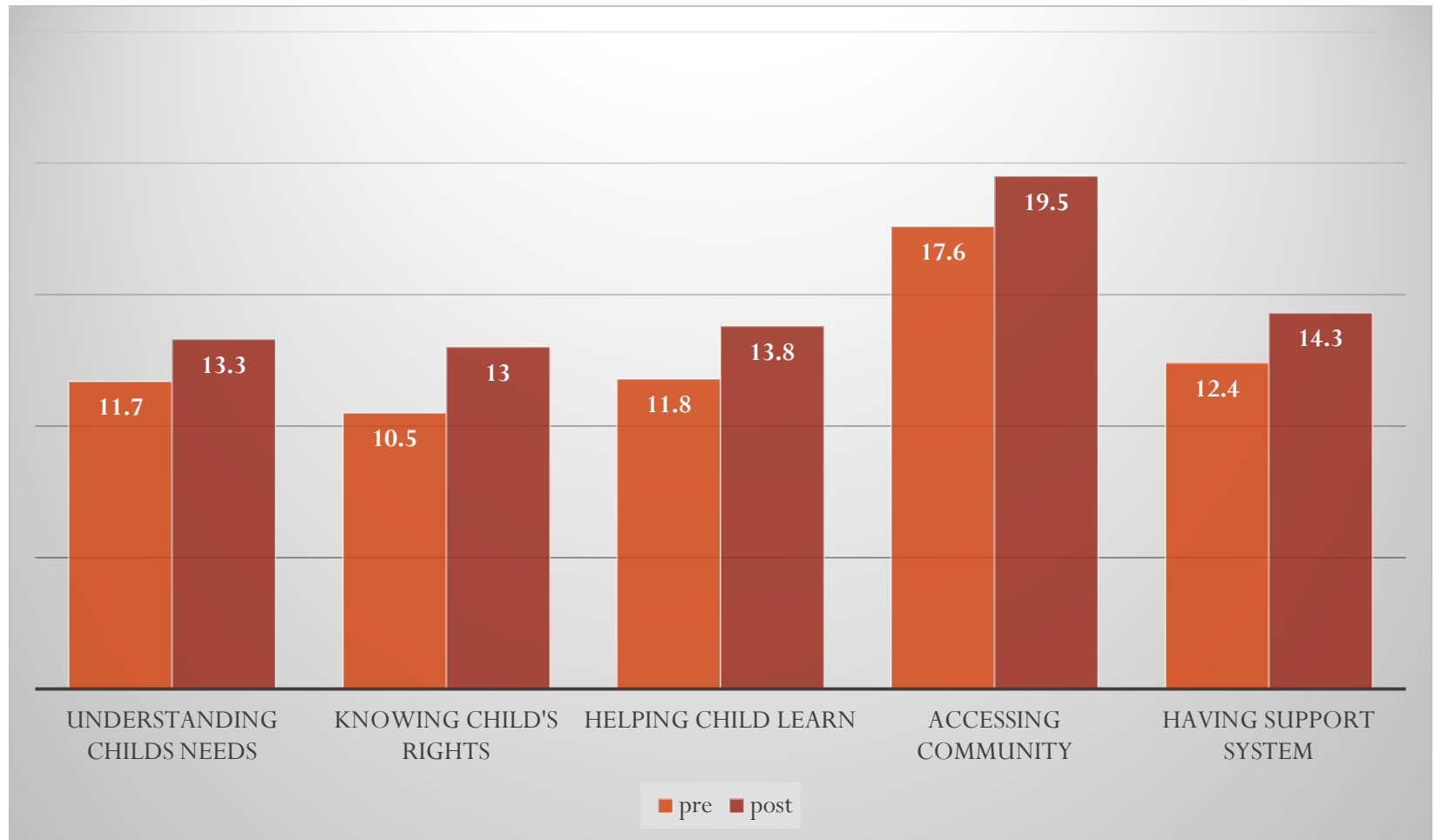
Measures

- Parent measures
 - Family outcome scale including 5 subscales (knowing your rights, helping child develop and learn, accessing community, having support system, understand child's strengths and needs)
 - Confidence in using evidenced-based (EB) strategies
 - Frequency in use of EB strategies
 - Observations of parent play and use of strategies
- Child measures
 - Social communications questionnaire
 - Current service use
 - Challenging behaviors (SIB-R)

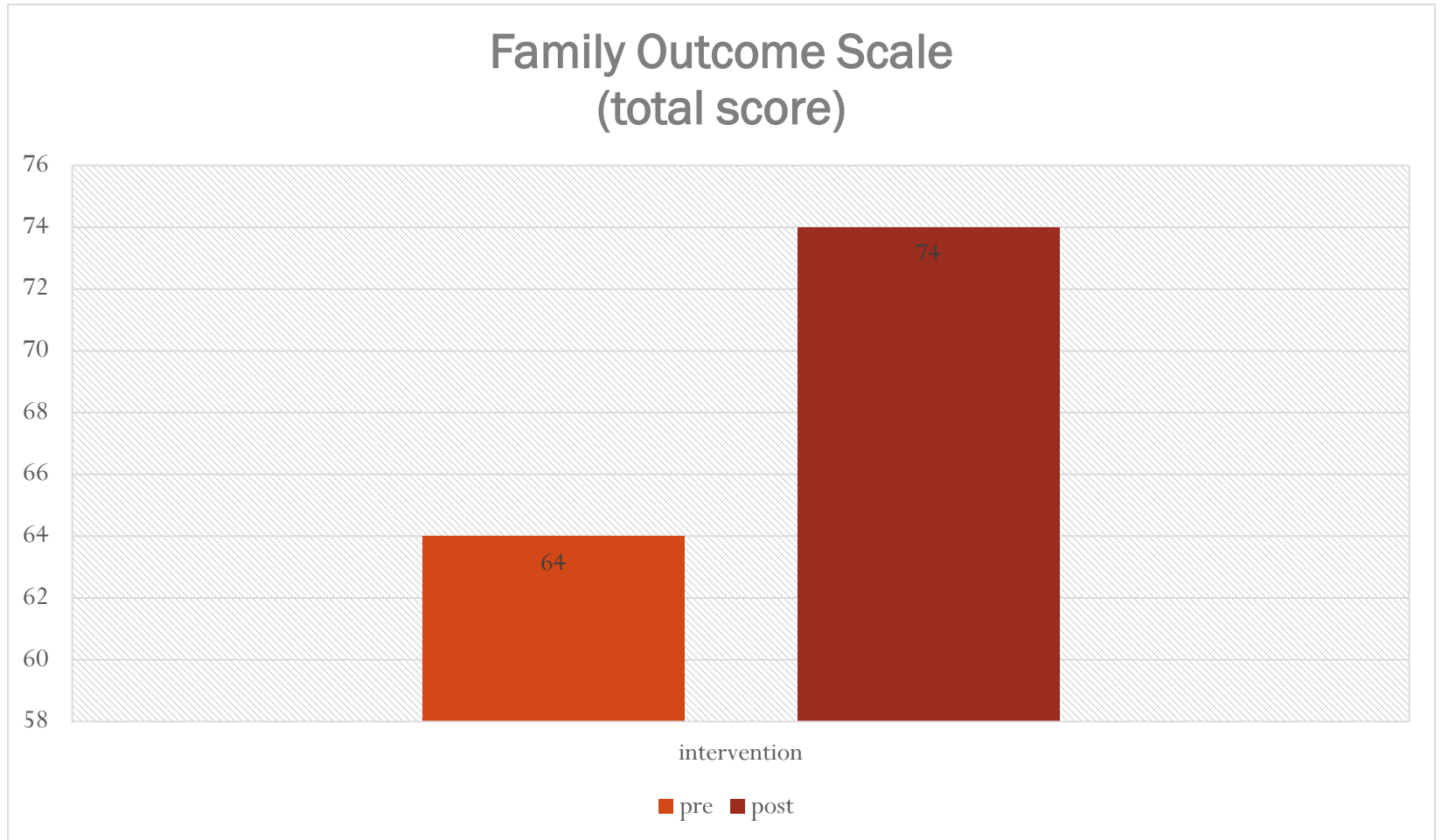
Parent outcomes: using strategies



Family Outcome Survey

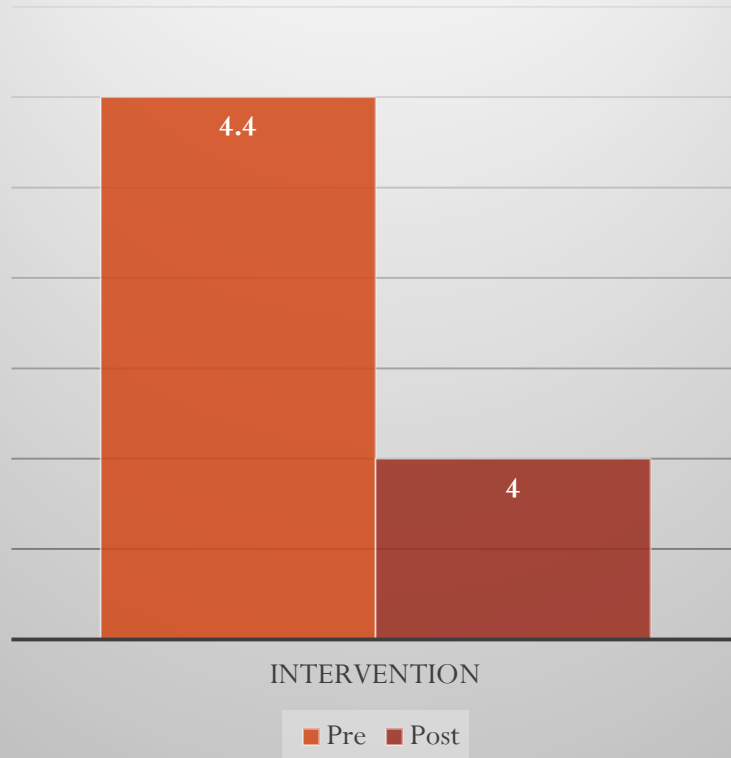


Parent Outcomes

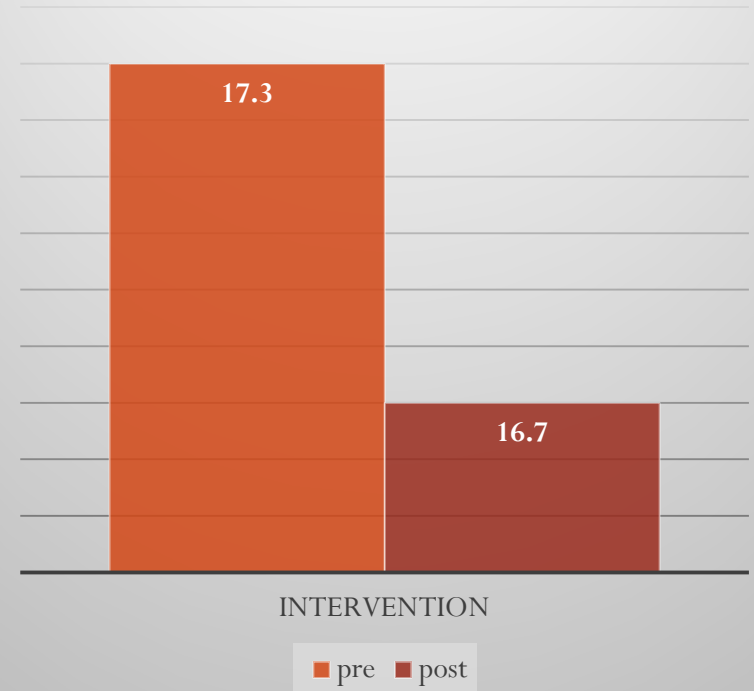


Child Outcomes

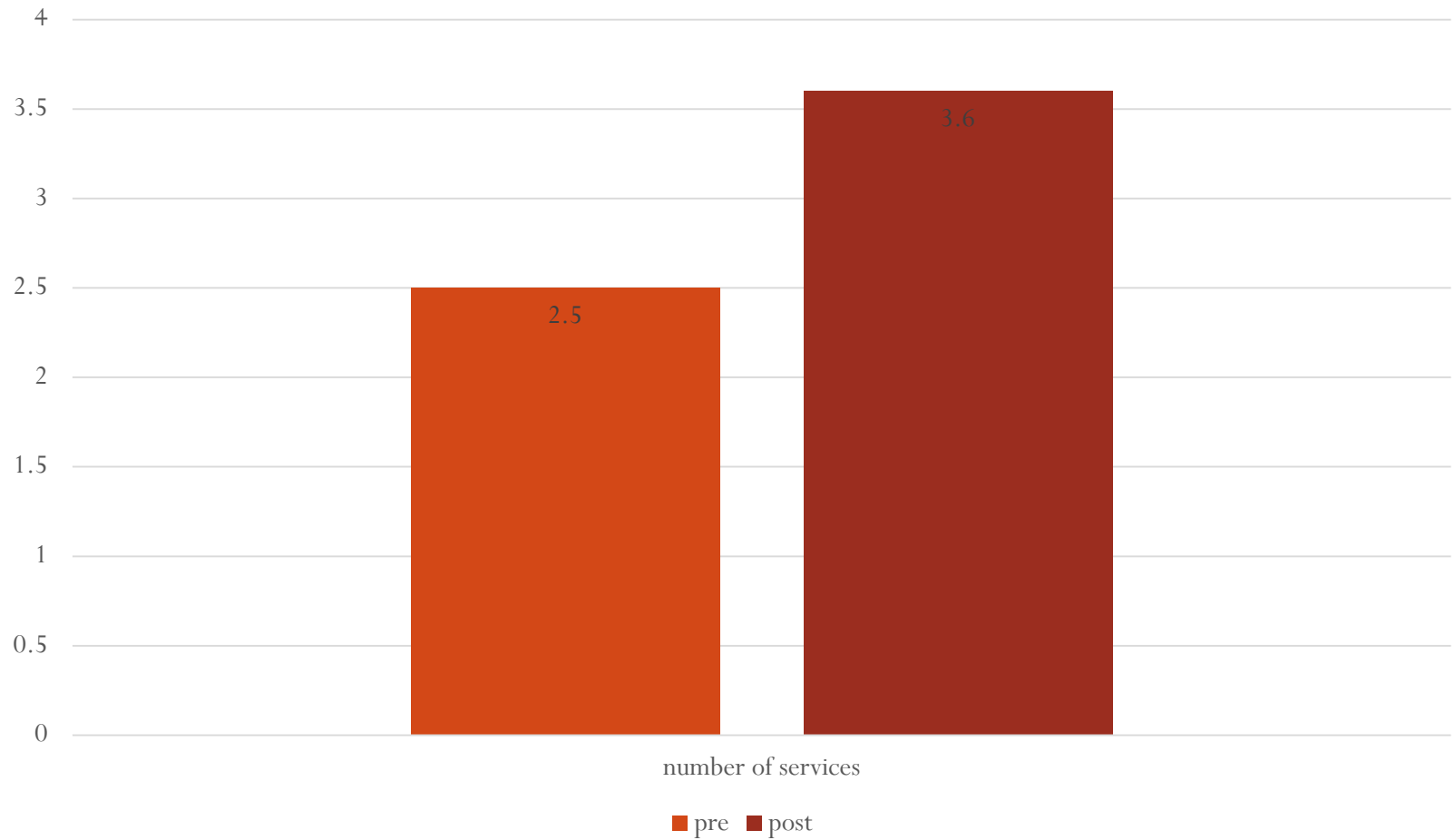
Challenging behaviors (not significant)



Social Communication Questionnaire (not significant)



Child outcome: number of specialty services

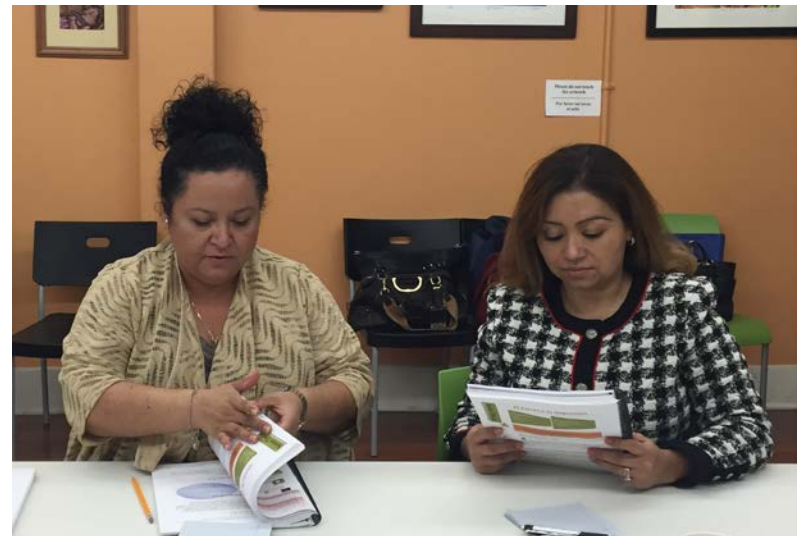


Focus groups with participants

The following themes emerged about the promotoras

- Participants valued promotora's experiences and how they served as a role model
- Dialogue between promotora and participant important
- Participants appreciated the flexibility of scheduling with the promotoras

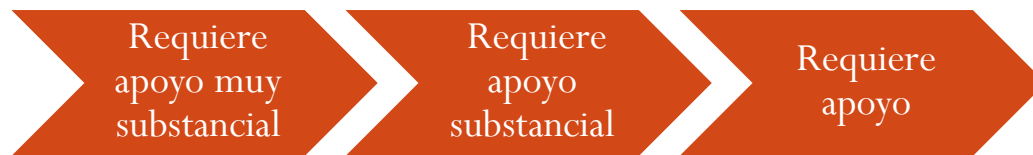
- Participants liked having someone to talk to that doesn't judge them



- Promotoras helped participants build advocacy skills in concrete ways





The following themes emerged about what aspects of the program participants valued

- Participants valued knowing their rights-that they have the right to ask for services
- Valued understanding their child's diagnosis
- Appreciated learning how to communicate with others about their child



Strategies valued by families

- Use of social narratives, picture schedules, and behavioral strategies
- The majority of participants wanted to see a continuation of the program to continue learning and receiving support from the promotora

			
Cepillarse los Dientes	Vestirse	Tender la cama	Desayunar

Conclusion and future research

- Preliminary data shows that this is a promising approach for Latino families of children with ASD
- Will examine this compared to control group when we have complete data
- Will be able to examine by symptom severity and age of child
- Need to analyze the videos, and the 3rd time point

Padres en Acción: Colombia



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