



AUTISM SPECTRUM DISORDER

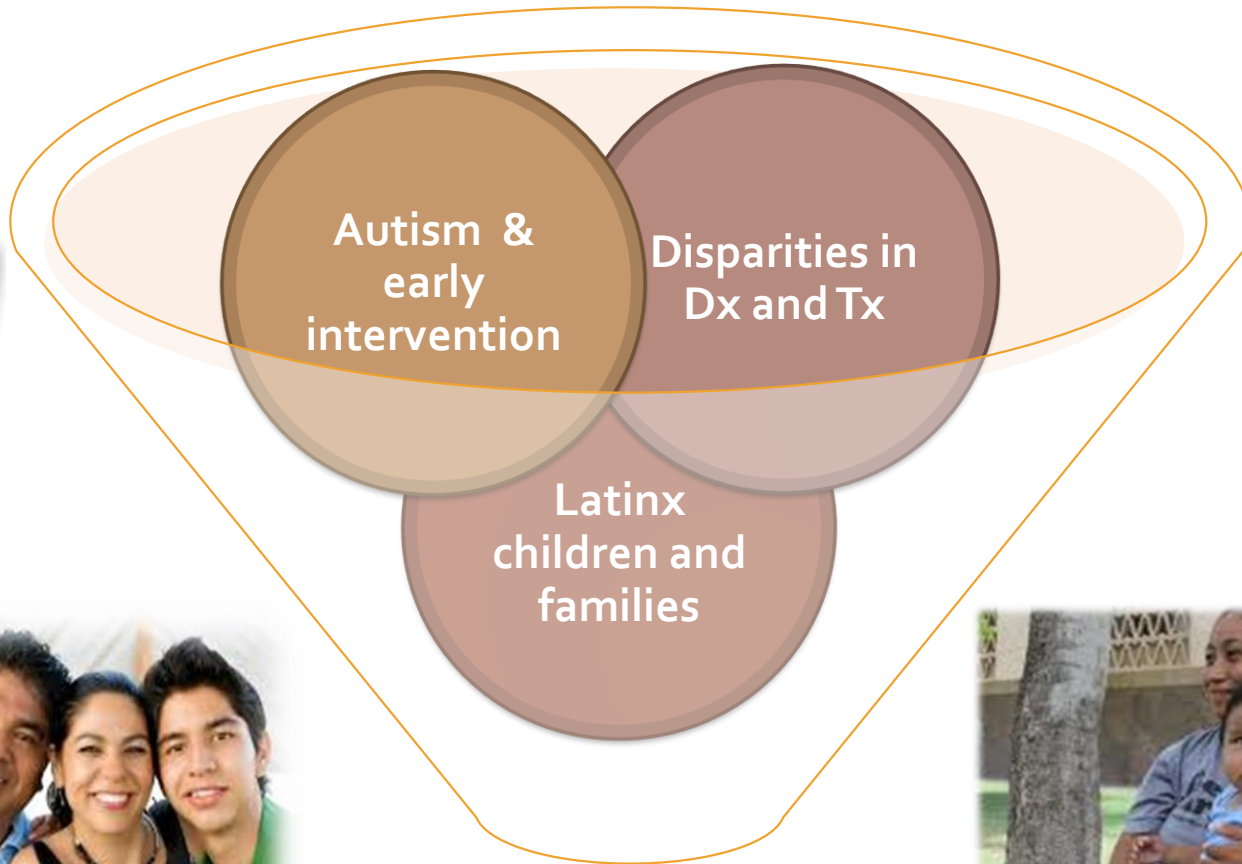
AMONG LATINX CHILDREN: FAMILY

INCLUSIVE TREATMENT PRACTICES

Kristina Lopez, PhD, MSW, MS, MA

Arizona State University

School of Social Work



Exploratory research, Outreach, Awareness, Culturally informed intervention

How many people have or now work with Latina/o/x families?

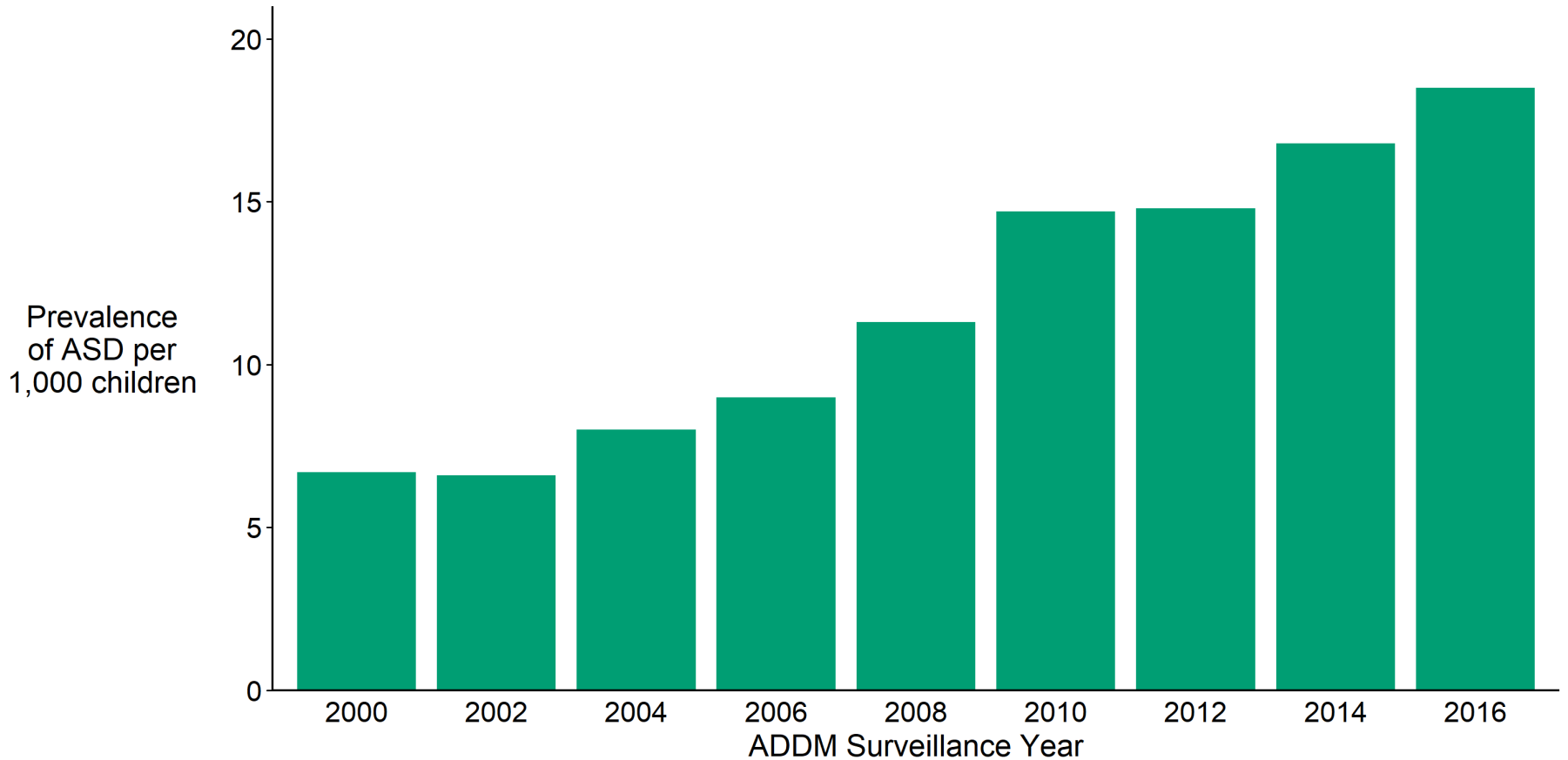
- A. Currently working with the population
- B. Have work with the population in the past
- C. Training to work with the population
- D. No specific experience or plans, but want to know about the population.

Outline

- Autism Spectrum Disorder
- Significance of the Issue
- Case Example: Parents Taking Action
- Implications for Research and Practice
- Q and A

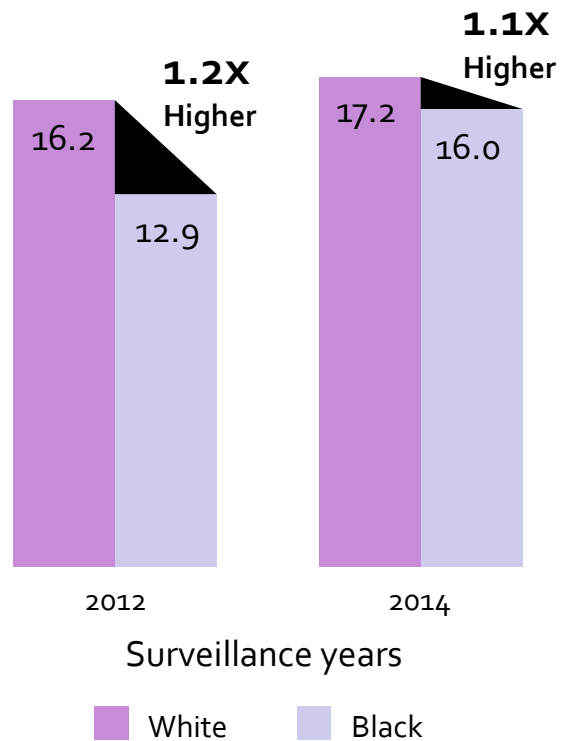
Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by surveillance year

Autism and Developmental Disabilities Monitoring Network

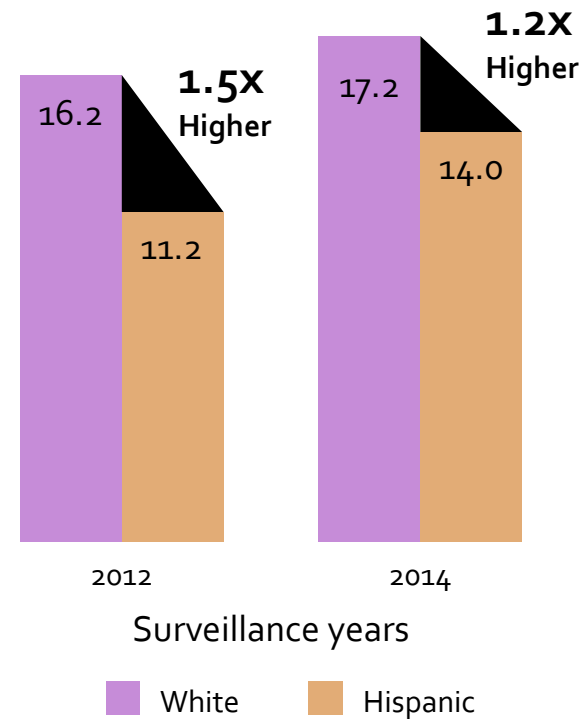


Prevalence by Race and Ethnicity

White to Black

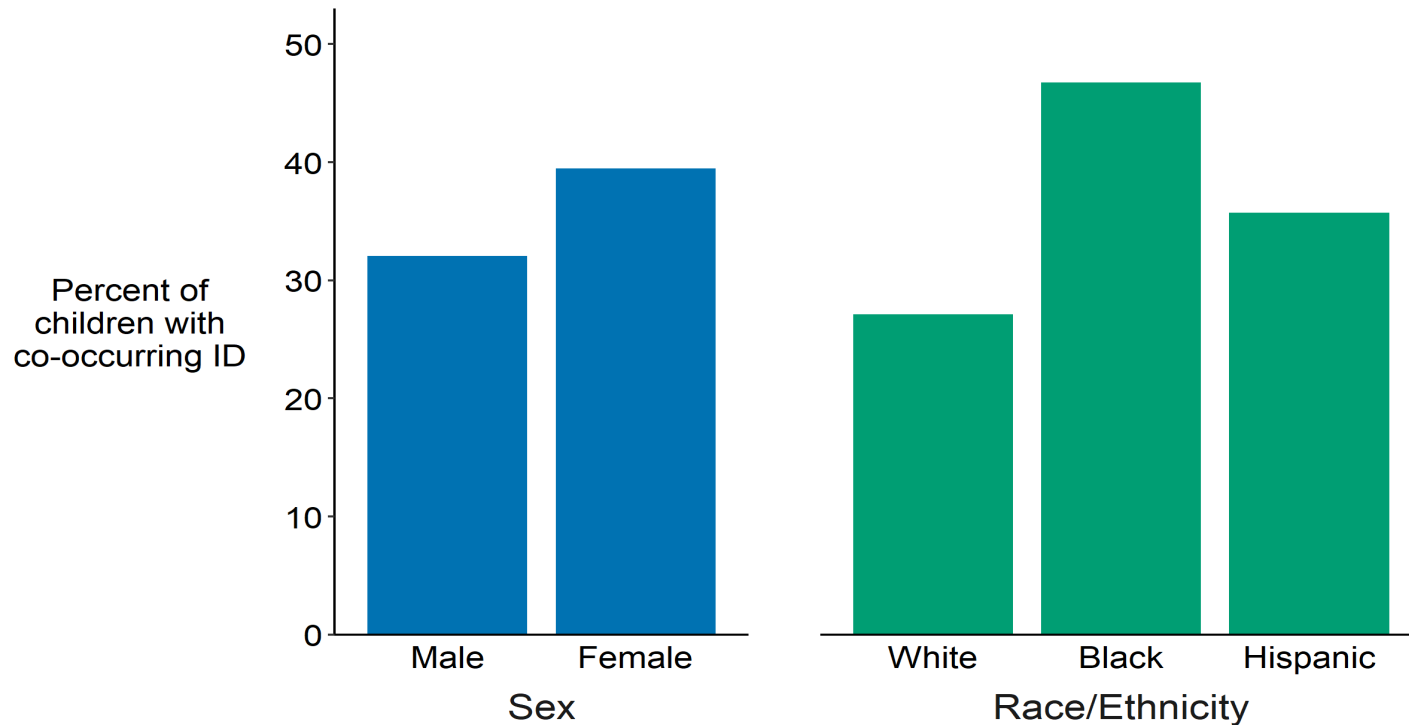


White to Hispanic



Percent of children aged 8 years with autism spectrum disorder with co-occurring intellectual disability*, by sex and race/ethnicity

Autism and Developmental Disabilities Monitoring Network, 10 sites†, United States, 2016



* IQ score ≤ 70 or examiner statement of intellectual disability in a comprehensive evaluation

† Missouri is not included because it did not collect IQ information on at least 60% of children with ASD.

Significance of the problem

- The prevalence of any developmental disability is lower among Latinx children compared with children in all other race and ethnicity groups (Zablotsky et al., 2017).
- Compared to White children, Black and Latino children have more difficulty accessing specialty care (Bethell et al., 2011).
- For Latino children who receive services, parents report lower quality and appropriateness of care (Zuckerman et al., 2017).
- Families of Black and Latino children with special health care needs consistently report their provider does not spend enough time with them (Coker, et al., 2010) or listen to them (Magaña et al., 2012).

By 2030 ASD will cost _____ in care.

A. 434 million a year

B. 589 billion a year

C. 359 million a year

D. 983 billion dollars a year

Autism Spectrum Disorder Cost

- Total base-case costs of \$223 (175–271) billion/year are estimated in 2020; \$589 billion/year in 2030, \$1.36 trillion/year in 2040, and \$5.54 (4.29–6.78) trillion/year by 2060, , substantial potential savings through ASD prevention (Blaxill et al., 2021).
- Disparities in early diagnosis and intervention could have cascading effects on both families and children and societal costs (Elder et al., 2017; Zwaigenbaum et al., 2015).

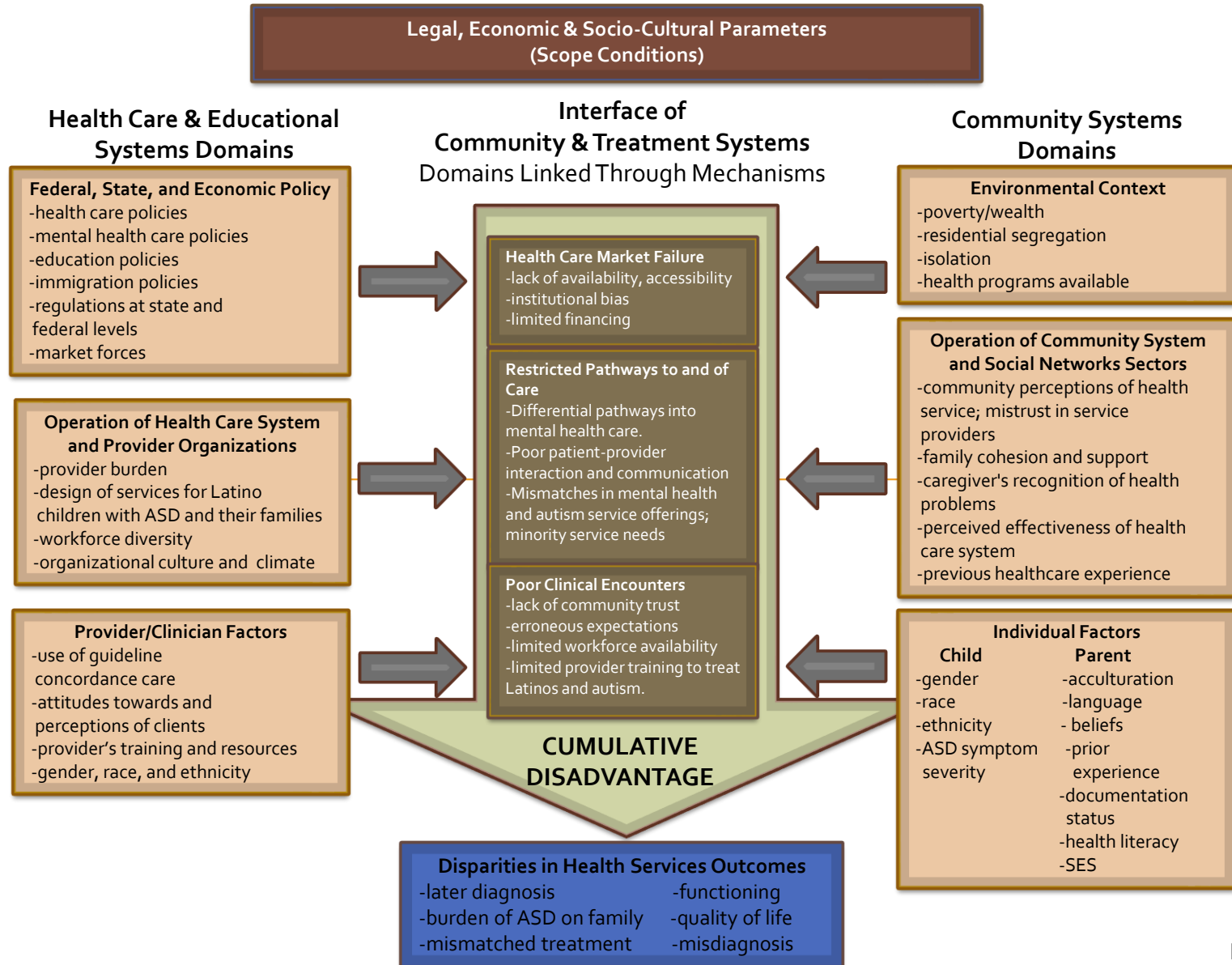
Socio-cultural Framework for Health Service Disparities (SCF-HSD)

- Health disparities are
 - “racial and ethnic differences in access, health care quality or health care outcomes that are not due to clinical needs or the appropriateness of treatment” (Alegria et al., 2011, p. 364).
- Disparities are exacerbated by barriers to access of health care systems in addition to the reduced quality of services and lack of culturally sensitive treatment and service providers.

Factors at the _____ level(s) produce barriers to diagnosis and treatment among Latinx children with ASD.

- A. Caregiver
- B. Provider
- C. Community
- D. All of the above

Modified Socio-cultural Framework for Health Service Disparities



Barriers to Best Practices

System

- Availability of cultural and linguistically relevant awareness, screening, outreach, diagnostic and informational materials
(Grinker et al., 2015)
- Access to health insurance
 - Income requirements
 - Citizenship requirements
- Cost of assessment

Barriers to Best Practices

Provider (Mandell et al., 2009)

- Inadequate screening practices
- Slow response to parental concerns
- Cultural and linguistic competency
- Awareness of early symptom manifestation
- Bias
 - Referral
 - Ascertainment

Barriers to Best Practices

Family (Lopez et al., 2018; Magaña et al., 2013; Zuckerman et al., 2017)

- Socio-economic status
- Education level
- Health literacy
- English language use
- Knowledge of ASD
- Stigma

Culture in Care

Culture is operating constantly in care settings and interactions with families, influencing:

- How service providers diagnose and manage care for children and families
 - Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R/F; Robins et al., 2009)
 - Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000)
 - Autism Diagnostic Interview – Revised (ADI-R; Rutter et al., 2003)
 - *Any psychologist or psychiatrist can diagnose using whatever methods they find effective (DSM-5).*
- How families receive and respond to diagnostic and treatment protocols

Cultural Humility

- Lifelong process of self-reflection and self-critique
- Never mastered—it's an ongoing process, shaped by every encounter we have with every person, as long as we maintain an open mind and heart (Fahlberg, Foronda, & Baptiste, 2016)
 - Active listening
 - Based on the families lived experience
 - Reflexive practice

A RANDOMIZED WAITLIST CONTROL GROUP OF A CULTURALLY TAILORED PARENT EDUCATION INTERVENTION FOR LATINO PARENTS OF CHILDREN WITH ASD

Magaña, S., Lopez, K., Salkas, K., Iland, E., Morales, M., Garcia Torres, M., Zeng, W., & Machalicek, W. (2020). A randomized waitlist control group of a culturally tailored parent education intervention for Latino parents of children with ASD. *Journal of Autism and Developmental Disabilities*, 5(1), 250-262. <https://doi.org/10.1007/s10803-019-04252-1>

Background

- Higher ASD risk among Latino children (Fountain & Bearman, 2011), yet lower odds of documented ASD classification (Mandell et al., 2009).
- 110% increase in ASD diagnoses between 2002 & 2008 (CDC, 2012).
- More likely to receive an alternate diagnosis and/or receive a later diagnosis (Magaña et al., 2013).
- ASD diagnosis among Latino children continues to lag significantly behind that of non-Hispanic children (CDC, 2020).

Research Questions

- Do participants in the intervention group show greater levels of empowerment, more confidence in using evidence-based (EB) strategies, and greater frequency in using EB strategies after receiving the intervention compared to participants in the control group?
- Do children whose mothers received the intervention demonstrate fewer challenging behaviors, less impairment in social communication symptoms, and greater use of evidence-based services compared to children of mothers the control group?

Padres En Acción/Parents Taking **Action**

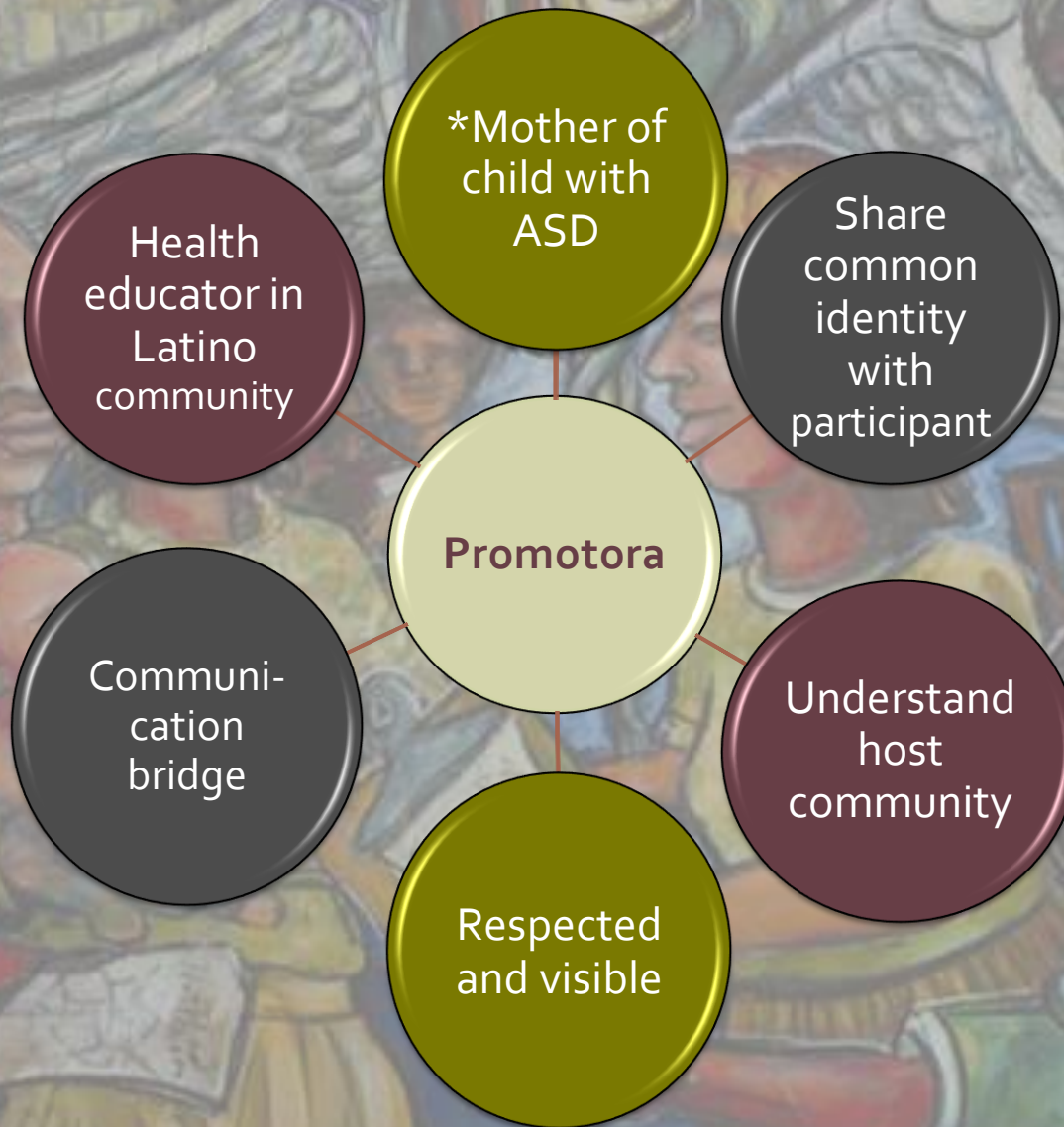
- Rooted in previous studies identifying the informational needs of Latino families (Lopez, 2014; Magaña et al., 2013).
- Parent participation in early intervention is critical to enhancing outcomes for children with ASD and reducing parent stress (Estes et al., 2014).
- Culturally informed psychoeducation intervention for Latino parents is necessary (Magaña et al., 2017).

Ecological Validity Model

(Bernal et al., 1995)

Dimension	Incorporation into intervention and materials
Language	Materials were in Spanish and the delivery was provided by native Spanish speakers.
Persons	Cultural matching: use of promotoras from a similar culture and the same geographic community as the participants.
Metaphors	Common Spanish sayings or dichos, storytelling, & novelas included.
Content	The protocol and manuals incorporated cultural values such as familism (needs of family comes before individual) and personalismo (relationship focused).
Goals	Goals were realistic and specific to the parents and their child with ASD.
Methods	Promotora de salud model used, flexible scheduling, and fostering relationship building and including the family was essential.
Context	The home-visit model overcomes barriers to participation by eliminating the need for transportation and child care. Promotoras adapted to the context of the participant's environment.

Promotora Model



Luis Cortada

Curriculum

Session 1: Introduction to the program

Session 2: Understanding child development

Session 3: Understanding the autism spectrum and your child's needs

Session 4: What works to address symptoms of autism

Session 5: How to be an effective advocate

Session 6: Advocacy in the school system

Session 7: Play together, learn together

Session 8: Creating everyday opportunities to encourage communication

Session 9: Helping your child make friends and interact with others

Session 10: Challenging behavior is communication

Session 11: How to reduce challenging behaviors and respond appropriately when they occur

Session 12: Reducing stress and recognizing signs of depression

Session 13: Talking about autism to others and social support

Session 14: Looking ahead

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
- In-home visits
- Manuals
- Videos & Novelas
- Visual resources
 - Activities
 - First, then
 - Schedule
 - Token economy
- Community resource guides
- CDC materials
 - ASD
 - Depression

Research Design

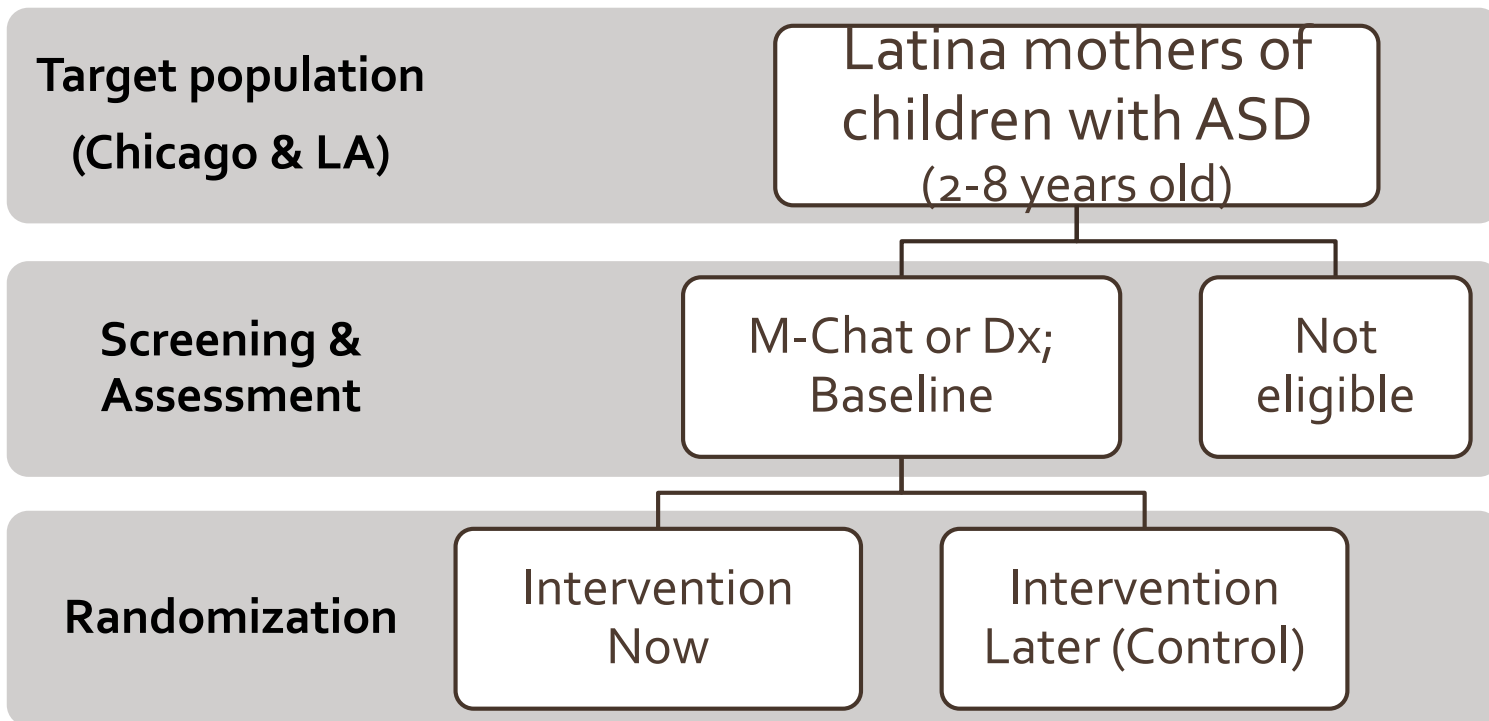


Table 1. *Sample Demographics*

	Intervention	Control	Test value ^a
Mother characteristics	n = 55	n = 55	
Mean age (SD)	37.3 (6.0)	36.6 (6.5)	0.6
Married or living together (%) ¹	42 (76.4)	36 (66.7)	1.3
Level of education (%)			4.4*
Less than high school	16 (29.1)	25 (45.5)	
High school	18 (32.7)	18 (32.7)	
Any post secondary education	21 (38.2)	12 (21.8)	
Annual household income (%) ¹			2.6
\$19,999 or less	19 (36.5)	16 (29.6)	
\$20,000 -39,000	22 (42.3)	31 (57.4)	
\$40,000 or more	11 (21.2)	7 (13.0)	
Employed (%)	13 (23.6)	20 (36.4)	
Foreign born (%)	45 (81.8)	50 (90.9)	1.9
Good/excellent health (%)	29 (54.7)	36 (65.5)	1.3
Child characteristics	n = 56	n = 58	
Mean age (SD)	5.3 (1.8)	5.2 (1.8)	0.3
Male (%)	46 (82.1)	52 (89.7)	1.3
CARS Severity (%) ¹			0.3
Minimal to no symptoms	18 (33.3)	20 (35.1)	
Mild to moderate symptoms	14 (25.9)	18 (31.6)	
Severe symptoms	22 (40.7)	19 (33.3)	

Instruments

Childhood Autism Rating Scale, 2nd Edition (CARS2ST; Schopler et al., 2010)

- ASD severity level

Social Communication Questionnaire Current (SCQ; Rutter et al., 2003)

- Social communication score

Scales of Independent Behavior-Revised (SIB-R; Bruininks et al., 1996)

- Measure of maladaptive behavior

Instruments

Family outcome survey-revised

(FOS; Bailey et al., 2008)

- Family outcomes expected to change through participation in early intervention programs

Efficacy in Use of Strategies

- Caregiver self efficacy for using strategies taught in PTA.

Frequency of Using Strategies

- Frequency of using strategies taught in PTA.

Table 2. Linear mixed effects models: SCQ

Social communication quotient	Model 1			Model 2		
	β	SE(β)	T-value	β	SE(β)	T-value
(Intercept)	18.71	0.75	25.10***	22.71	1.70	13.34***
Time 2	0.42	0.54	0.77	0.80	0.51	1.56
Intervention Group	0.20	1.06	0.19	0.27	1.05	0.26
Time 2*Intervention Group	-1.88	0.81	-2.31*	-1.55	0.77	-2.00*
Minimal to Moderate ASD				-2.83	1.07	-2.64*
Child Aged 2-5				1.28	1.03	1.24
Chicago Region				-1.75	1.17	-1.49
Total Typical & Evidence Based Services				-0.55	0.18	-3.13**

*** < 0.001 ** < 0.01 * < 0.05 + < 0.1

Note: ¹Model 1 N = 110; ²Model 2 N = 107 due to missing data for minimal to moderate ASD

Reference groups: Time 1; Control Group; Severe ASD; Child Aged 6-8; Los Angeles, CA Region.

Table 3. Linear mixed effects models: Efficacy

Efficacy in use of strategies	Model 1			Model 2		
	β	SE(β)	T-value	β	SE(β)	T-value
(Intercept)	34.82	0.74	47.21***	35.51	1.60	22.19***
Time 2	0.31	0.76	0.41	0.23	0.78	0.30
Intervention Group	-0.73	1.04	-0.70	-0.90	1.05	-0.86
Time 2*Intervention Group	4.14	1.12	3.71***	4.05	1.15	3.52***
Minimal to Moderate ASD				-0.92	0.94	-0.98
Child Aged 2-5				-1.84	0.90	-2.04*
Chicago Region				0.60	1.02	0.59
Total Typical & Evidence Based Services				0.13	0.20	0.67

*** < 0.001 ** < 0.01 * < 0.05 + < 0.1

Note: ¹Model 1 N = 110; ²Model 2 N= 107 due to missing data for minimal to moderate ASD

Reference groups: Time 1; Control Group; Severe ASD; Child Aged 6-8; Los Angeles, CA Region.

Table 4. Linear mixed effects models: Frequency

Frequency of using strategies	Model 1			Model 2		
	β	SE(β)	T-value	β	SE(β)	T-value
(Intercept)	41.13	0.99	41.34***	41.21	2.34	17.61***
Time 2	2.04	0.86	2.37*	1.90	0.89	2.15*
Intervention Group	-0.76	1.41	-0.54	-0.68	1.48	-0.46
Time 2*Intervention Group	3.16	1.28	2.47*	3.16	1.32	2.39*
Minimal to Moderate ASD				-1.20	1.43	-0.84
Child Aged 2-5				-0.30	1.37	-0.22*
Chicago Region				0.52	1.55	0.34
Total Typical & Evidence Based Services				0.15	0.27	0.56

*** < 0.001 ** < 0.01 * < 0.05 + < 0.1

Note: ¹Model 1 N = 110; ²Model 2 N= 107 due to missing data for minimal to moderate ASD

Reference groups: Time 1; Control Group; Severe ASD; Child Aged 6-8; Los Angeles, CA Region.

Table 5. Linear mixed effects models: FOS

Total Family Outcomes	Model 1			Model 2		
	β	SE(β)	T-value	β	SE(β)	T-value
(Intercept)	62.16	2.22	28.02***	60.42	5.00	12.08***
Time 2	5.34	1.81	2.95**	4.79	1.86	2.58*
Intervention Group	0.22	3.14	0.07	-0.04	3.15	-0.01
Time 2*Intervention Group	3.96	2.70	1.47	3.33	2.77	1.20
Minimal to Moderate ASD				-1.30	3.07	-0.42
Child Aged 2-5				-6.29	2.94	-2.14*
Chicago Region				4.31	3.33	1.29
Total Typical & Evidence Based Services				0.86	0.57	1.50

*** < 0.001 ** < 0.01 * < 0.05 + < 0.1

Note: ¹Model 1 N = 110; ²Model 2 N = 107 due to missing data for minimal to moderate ASD

Reference groups: Time 1; Control Group; Severe ASD; Child Aged 6-8; Los Angeles, CA Region.

Conclusions

- Demonstrated clinical value, significant reduction in social communication deficits for the treatment group compared to the control group.
- Parents in the treatment now group increased in efficacy in using strategies and frequency of using EB strategies as compared to the treatment later group.
- Increased caregiver efficacy suggests that mothers may also be able to exhibit more effective parenting (Magaña, Lopez, & Machalicek, 2017).

Conclusions

- PTA is a cost effective, culturally informed program for Latino families with demonstrated outcomes for both children and parents.
- PTA informs practice models and the understanding of socio-cultural factors influencing disparities among Latino children with ASD and their families.
- The model may be useful for other ethnic and cultural groups, as long as the program adaptation takes unique needs and obstacles into account and engages the community to find solutions together.

Limitations

- Limited sample size
- The sample was majority immigrant mothers of Mexican descent, therefore not representative to all Latino families.
- All measures were self-report which could lead to social desirability bias.

Takaways

- Family inclusive practice includes outreach and intervention.
- Family inclusive practice is essential in working with Latinx families.
- Parents can be more involved in developing their child's skills and managing their child's behaviors (Hastings & Brown, 2002).



Contact Information

Kristina Lopez, PhD, MSW, MS, MA

Assistant Professor, School of Social Work

Arizona State University

411 N. Central Ave., Office 822K

Phoenix, AZ 85004

(602) 496-0073

Klopez27@asu.edu

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