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Parents taking action: Reducing disparities through a culturally informed intervention for Latinx parents of children with autism

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ABSTRACT

Latinx children with autism spectrum disorder (ASD) are underserved in part due to a lack of culturally relevant evidence-based services. We conducted a randomized control trial to test the efficacy of a culturally informed parent education intervention to address this gap. We assigned 26 Latina mothers of children with ASD to receive the intervention immediately ($N = 12$) or after all assessments were conducted ($N = 14$). All participants received baseline and follow-up assessments. Repeated measures ANOVA revealed significant improvement in child and parent outcomes for the intervention group compared to the control. This intervention is a culturally tailored way to address disparities in services for Latinx children with ASD.

KEYWORDS

Latinx children and parents;
autism spectrum disorder;
randomized control trial;
community health workers

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social communication and interaction difficulties and restricted and repetitive behaviors (American Psychiatric Association, 2013). ASD has been a growing public health concern with a prevalence rate of 1 in 59 children affected (Baio et al., 2018). Research indicates disparities by socioeconomic status, race, and ethnicity among children with ASD in age of diagnosis and access to services (Durkin et al., 2010; Harstad, Huntington, Bacic, & Barbaresi, 2013; Mandell et al., 2009). Baio and colleagues (2018) reported a persistent gap in ASD identification, with Latinx children less likely than Black and White children to be diagnosed with ASD. When diagnosed, Latinx children are diagnosed later and receive fewer services than their non-Latinx White counterparts receive (Magaña, Lopez, & Aguinaga, 2013; Palmer, Walker, Mandell, Bayles, & Miller, 2010). For Latinx children who receive services, parents report lower quality and appropriateness of care (Zuckerman et al., 2017). Latinx parents report many barriers to ASD diagnosis and care, including cultural and linguistic competency

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of service providers, parent knowledge of ASD, and access to information and resources (Lopez, Xu, Magaña, & Guzman, 2018; Magaña, Lopez, Aguinaga, & Morton, 2013; Zuckerman et al., 2017). It is critical that culturally tailored interventions are designed with these barriers and needs in mind to improve outcomes for Latinx children with ASD and their families (Lopez, 2014). In this article, we present data about a randomized control trial of Parents Taking Action (PTA), a culturally informed psychoeducation program for Latinx families raising children with ASD. California was selected as a setting for the RCT given the large Latinx population, increase of ASD diagnoses, and recognized disparities in services among Latinx children with ASD.

Latinx children comprise a substantial proportion of children (51%) in California, with proportions of 60 to 89.5 in 14 of 58 counties (Kidsdata, 2017). Similar to the national prevalence rates, the rate of ASD in the state has increased considerably. Yet, Latinx children have lower rates of ASD than White and Black children in California (Becerra et al., 2014). In 2017, 21 regional centers had documented 86,863 consumers diagnosed with ASD as well as an additional 51,558 Early Start consumers too young for diagnosis (California Health and Human Services, 2017). Regional centers are nonprofit private corporations contracted with the Department of Developmental Services (DDS) to provide or coordinate services and supports for individuals with developmental disabilities. Disparities by race, ethnicity, and income status in the authorization of services and expenditures have been a consistent issue within regional centers. DDS purchasing data show Latinx consumers, the largest racial/ethnic group of regional center consumers, have the lowest amount of authorized services and expenditures than all other major ethnic/racial groups served by the regional centers (California Department of Developmental Services, 2016). In 2013 fiscal year, the average spending on services for children 3 to 17 years of age and diagnosed with ASD varied across racial and ethnic groups. The average service expenditures for Latinx consumers was \$9,571, which is considerably less than expenditures for White consumers, which averaged at \$11,480 (Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016). A needs assessment of 96 Latinx mothers caring for a child with ASD in California highlighted psychosocial, health care, economic, and political barriers to accessing services (Iland, Weiner, & Murawski, 2012). Legislative and public scrutiny led the Senate President to appoint a 20-member Taskforce on Equity and Diversity for Regional Center Autism Services in 2013 (Vismara, Giovati, & Tadeo, 2013). The task force was developed to identify recommendations to reduce the disparities by race, ethnicity, educational background, or socioeconomic status. Recommendations from the task force emphasize improvements to cultural and linguistic competency, flexibility and creativity in service provision, partnerships with consumers, their families, and community-based organizations, and enhanced data collection and oversight on equity and diversity issues (Vismara et al., 2013). PTA is a culturally informed psychoeducation intervention for Latinx families of children with ASD, which addresses each of

these recommendations and was highlighted in the committee report as an innovative method of addressing the disparities in regional center purchasing data. On a broader level, PTA aligns with the concerted effort of the Interagency Autism Coordinating Committee (2017) to identify interventions to reduce disparities in diagnosis and treatment by race, ethnicity, and other socioeconomic factors.

Intervention description: Parents Taking Action

PTA (Magaña, Lopez, & Machalicek, 2017) is a culturally tailored psychoeducation program designed to address disparities for Latinx children with ASD and their families. PTA is culturally informed based on collaboration with community-based partners including an advisory committee, and the use of the ecological validity framework (Bernal, Bonilla, & Bellido, 1995). The ecological validity model emphasizes eight cultural domains of concern in the adaptation or development of interventions for diverse populations. The domains include *language, persons, metaphors, content, concepts, goals, methods, and context*. Each domain was considered by the advisory committee and incorporated into PTA to improve the cultural and linguistic competency and ecological and external validity. In PTA the *language* dimension was included by utilizing promotoras who were native Spanish speakers to implement the program and by providing the materials in English and Spanish. *Persons* was addressed through the inclusion of promotoras who were from the same cultural and geographic communities as participants. We included the use of *dichos* or common Spanish sayings into the PTA content to address the *metaphors* dimension. Cultural values were built-in to PTA to meet the *content and concepts* dimensions. For instance, *familismo*, or the needs of family comes before individual, was incorporated into PTA. The *goals* dimension requires that goals are culturally appropriate and a collaborative process between therapist and client. Thus, the goals were specific to parents of children with ASD and realistic in the environmental context. The procedures for achieving treatment goals comprises the *methods* dimension. In PTA, *methods* are addressed by utilizing the *promotora de salud* model as well as being flexible to foster relationship building and the whole family. Finally, the *context* dimension must consider the social context of the participant and intervention. Home visits in PTA reduce many barriers to program participation for Latinx families, such as transportation and child care. In addition, promotoras adapted to the context of the environment of the participants.

A *promotora de salud*, or community health worker model, is used to implement PTA. A promotora is a lay health educator from the target community who provides health information to other Latinx people after receiving training in the health topic. The promotora model is considered cost-effective and culturally relevant to access marginalized groups and disseminate evidence-based information to them (Rotheram-Borus, Swendeman, & Chorpita, 2012). Interventions

using the promotora model have been found to improve parenting behaviors (Williamson, Knox, Guerra, & Williams, 2014) and enhance the care and health of Latinx women and their families (Early, Burke-Winkelmann, & Joshi, 2016). In PTA, promotoras are required to be Latinx mothers of children with ASD, fluent in Spanish, and leaders in their community, which introduces a peer-support aspect to the intervention.

Parent training approaches to intervention for families of children with ASD have been shown to enhance children's social behavior and communication ability (McConachie & Diggle, 2007). Parent training is also effective at reducing parent mental health concerns (Matson, Mahan, & Matson, 2009), improving parent knowledge of ASD (McConachie & Diggle, 2007), and parental self-efficacy (Whittingham, Sofronoff, Sheffield, & Sanders, 2009). Moreover, improving parental self-efficacy may lead to greater improvements of overall parenting behaviors when faced with challenging behaviors (Jones & Prinz, 2005).

The content of PTA includes understanding the diagnosis of ASD, identifying evidence-based treatments, learning advocacy skills, and learning evidence-based approaches to enhance social communication skills and manage behaviors for children with ASD including principles of applied behavioral analysis (Magaña et al., 2017). Incorporating the ecological validity framework and parent education using peer-based promotoras to deliver evidence-based information are innovative and necessary to providing linguistic and culturally competent intervention to Latinx families of children with ASD.

A feasibility study of PTA with 19 Spanish-speaking Latinx mothers of children with ASD indicated that mothers reported improvements in their understanding of ASD, their child's strengths and needs, how to help their child develop and learn, and knowledge of their child's rights. They also improved in having support systems, accessing the community, and in efficacy using the evidence-based strategies (Magaña et al., 2017). We also found promising changes in child outcomes; children reduced impaired language between pretest and posttest. Participants in the pilot study emphasized the role of the promotoras as essential to their change by providing emotional support demonstrated by listening to participant problems and instrumental support by helping participants to navigate services (Magaña, Lopez, Paradiso de Sayu, & Miranda, 2014). While the findings were promising, the pilot study was a single-arm design. Therefore, a control group is needed in order to determine efficacy of the intervention.

Purpose and research questions

Relevant to data on disparities in California but independent from DDS and California regional centers, we conducted a randomized controlled trial of the PTA program in California to determine its utility in reducing documented disparities there. Our research questions were (a) Are there differences between pretest and posttest on child outcomes for participants in the treatment group

compared to those in the control group? and (b) Are there differences between pretest and posttest on family outcomes for participants in the treatment group compared to those in the control group?

Methods

Participants

Parent-child dyads were recruited from community organizations providing support to children with developmental disabilities and support groups for families of children with ASD within the Los Angeles area. The community organizations and groups distributed invitation letters and brochures in both Spanish and English to potentially eligible families. To be eligible for participation, participants were required to be of Latin American descent, living in the targeted geographic location, and the primary family caregiver of a child with or at risk for ASD between one and eight years of age. Children were required to have an ASD diagnosis or be at risk for ASD determined by the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999). We limited the geographic region within Los Angeles because the city is so large, and we wanted to make sure participants were in driving range for our promotoras as this was a home-visit intervention. Interested parents contacted study staff by mail or phone. Those who met eligibility criteria were scheduled for an informed-consent visit. At this visit, study staff reviewed the informed consent document in the preferred language of the participant. The majority of participants preferred to use Spanish ($N = 22$, 84.6%). All of the participants were mothers. Twenty-nine mother-child dyads completed the baseline assessment. Children were diagnosed with or at risk for ASD. Following a baseline assessment, dyads were randomly assigned to an intervention-now ($N = 14$) or intervention-later ($N = 15$) group. The present article includes only data for the 26 mothers and children who completed the baseline (T1) and follow-up assessment (T2). Two mothers in the intervention-now group left the study for personal reasons before completing the 14 sessions or further assessments. One mother in the intervention-later group decided not to participate after receiving the randomization selection. Thus, we have an 86% retention rate in the intervention-now group and 93% retention rate in the intervention-later group.

Baseline demographic data, including t-tests, and chi-squares for the intervention-now and intervention-later groups, are included in [Table 1](#). The only significant difference between the two groups is in child sex. The intervention group includes 75% male children while the control group has 100% male children. Overall, children are about five years old, and the majority were born in the United States. Most mothers were born outside the United States (Mexico [$N = 17$], Guatemala [$N = 1$], Cuba [$N = 1$], El Salvador [$N = 2$], Peru [$N = 1$]) and reported family income as under \$40,000.

Table 1. Participant Demographics by Intervention Group.

	Intervention Now (<i>N</i> = 12)	Intervention Later (<i>N</i> = 14)	Critical Test Value ^a
Child			
Age	5.1 (1.9)	5.5 (2.1)	-.50
Sex Male	9 (75)	14 (100)	3.96*
Social Communication Score ^b	19.1 (5.1)	20.6 (5.1)	-.80
ASD symptom severity ^c			1.41
Minimal to no symptoms	4 (36.4)	6 (46.2)	
Mild to moderate symptoms	3 (27.3)	5 (38.5)	
Severe symptoms	4 (36.4)	2 (15.4)	
Maladaptive behaviors general ^d	-11.3 (9.8)	-16.9 (14.4)	1.10
Total typical & evidence-based services	2.8 (1.5)	3.7 (2.7)	-1.10
Mother			
Age	40.6 (5.1)	37.4 (6.1)	
Education			2.20
Less than HS	2 (16.7)	6 (42.9)	
HS	3 (25)	3 (21.4)	
More than HS	7 (58.3)	5 (35.7)	
Annual Household Income ^e			.97
Less than \$20,000	2 (20)	2 (15.4)	
\$20,000-\$39,999	5 (5)	9 (69.2)	
More than \$40,000	3 (30)	2 (15.4)	
Unemployed	8 (66.7)	7 (50)	.74
Married or living together	10 (83.3)	8 (61.5)	1.47
Born outside of United States	11 (91.7)	12 (85.7)	.22
Poor or fair health	6 (50)	5 (35.7)	.54

Notes. Values are mean (*SD*) or number (proportion); ASD = autism spectrum disorder.

^at-test for continuous values, chi-square for categorical values; ^bSocial Communication Questionnaire (SCQ) total score; ^cmeasured by the Childhood Autism Rating Scale (CARS2-ST); ^dbased on the Scales of Independent Behavior-Revised (SIB-R) Generalized Maladaptive Index; ^edata missing for three cases.

**p* < .05.

Measures

Child measures included the Modified Checklist for Autism in Toddlers (M-CHAT), Childhood Autism Rating Scale, 2nd Edition Standard Form (CARS2-ST; Schopler, Van Bourgondien, Wellman, & Love, 2010), Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996), Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003), and service use questions. Parent measures included the Family Outcome Survey-Revised (FOS; Bailey, Hebbeler, Olmstead, Raspa, & Bruder, 2008), efficacy in using the evidence-based strategies, frequency of using evidence-based strategies, and the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). With the exception of the M-CHAT and CARS-2, all measures were assessed at T1 and T2.

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 1999) is a parent-report screening tool of 23 items to assess risk for autism spectrum disorder (ASD). The M-CHAT is a screener designed to identify children 16 to 30 months of age who should receive a more thorough assessment for possible early signs of ASD or developmental delays. If a child fails more than three items or

two critical items, they are considered at risk for ASD and should be referred for diagnostic evaluation for ASD. Examples of critical items are “Does your child ever use his/her index finger to point, to indicate interest in something?”, “Does your child respond to his/her name when you call?”, and “Does your child imitate you? (e.g., you make a face—will your child imitate it?)”. We used the M-CHAT to determine eligibility for participants who did not have an ASD diagnosis. If they were considered at risk for ASD, they were eligible for the study. The M-CHAT has been translated into multiple languages including Spanish.

The Childhood Autism Rating Scale, 2nd edition Standard Form (CARS2-ST; Schopler, Van Bourgondien, Wellman, & Love, 2010) is an autism rating scale designed for use in education, research, and clinical settings by trained examiners. The scale is used to identify children ages two years and older with autism and distinguishes between mid-to-moderate and severe autism. The scale is comprised of 15 items across five domains for determining autism including social interaction, communication, restricted patterns of interest and stereotyped behavior, sensory issues and associated features, and thinking style and cognitive issues. Examiner ratings are based on direct behavioral observations. Rating values for all items sum to produce a total raw score. Each item has seven possible responses, weighted from 1 to 4, with .5 increments (i.e., 1, 1.5, etc.). The sum of weights for endorsed responses determines ASD severity. The range for each severity category in children age 13 or younger is Minimal-to-No Symptoms: 15–29.5, Mild-Moderate Symptoms: 30–36.5, Severe: 37 and higher. We utilized the CARS2-ST as a measure of ASD severity based on 10 minutes of direct behavioral observation and interaction with children during the baseline assessment. For this sample, the internal consistency value for the overall score was 0.90. The CARS2-ST was used at T1 only to determine level of severity of the child ASD symptoms. The CARS2-ST is only available in English; however, the examiners who are conducting the assessment use the observation scale; it is not read to participants. The principal investigator and examiners in the research team received training in the CARS2-ST prior to conducting assessments. The research team was comprised of bicultural and/or bilingual examiners, who were able to interact with children in Spanish as needed to illicit behaviors and were able to score the child on the rating scale in English.

The Scales of Independent Behavior Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) was used to measure child-challenging behaviors. The SIB-R is comprised of three domains of behavior, which include two or three categories of adaptive and maladaptive behavior. The domains and categories are internalizing (hurtful to self, unusual or repetitive habits, withdrawal or inattentive behavior), externalizing (hurtful to others, destructive to property, disruptive behavior), and asocial behavior (socially offensive behavior, uncooperative behavior). Parents are asked to indicate if their child engaged in each behavior in recent months by responding “yes” or “no.” For behaviors marked “yes” respondents are asked to indicate the frequency and severity of the behavior. Frequency is rated on

a Likert scale ranging from 1 = less than once a month to 5 = once or more per hour. Severity is rated on a Likert scale from 1 = not serious to 5 = extremely serious. Frequency and severity ratings are matched with a “part score” specific to frequency, severity, and the general maladaptive index or each of its subscales (internalized, asocial, or externalized maladaptive indices). The age of the child also has a part score. The part scores are summed and then subtracted from 100. The maladaptive behaviors index value can range from +10 to -41 and below. The level of seriousness of the value ranges from “normal” (+10 to -10) to “very serious” (-41 and below). The SIB-R was already available in Spanish and used with Latinx parents by previous researchers (Blacher & McIntyre, 2006; Magaña, Schwartz, Rubert, & Szapocznik, 2006).

The Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) Current Form is a 40-item yes-or-no-parent-report screener that evaluates communication skills and social functioning in children who may have ASD. The SCQ Current Form focuses on the child’s behavior over the most recent three-month period. Items rated “yes” are added for a total raw score. The SCQ has a good discriminative validity with respect to the separation between ASD and non-ASD children across all IQ levels. Scores above the cutoff of 15 suggest the individual is likely to have ASD. The SCQ was previously translated into Spanish. Mothers completed the SCQ at each time point in the current study. We used the SCQ as a measure of ASD symptoms rather than as a screener. Chronbach’s alpha for the current sample is 0.88 for the total overall score. The SCQ was completed at T1 and T2.

The Family Outcome Survey-Revised (FOS; Bailey, Hebbeler, Olmstead, Raspa, & Bruder, 2008) measures family outcomes expected to change through participation in early intervention programs for children with disabilities and their families. The FOS includes five outcomes: understanding your child’s strengths, needs, and abilities; knowing your rights and advocating for your child; helping your child develop and learn; having support systems; and accessing the community. The FOS is comprised of 24 items, with four to six items per outcome. Responses range from not at all (1) to completely (5). Items are summed for each outcome, and a total FOS score is produced by adding all items. Mothers completed the FOS-R at each time point in this study. The FOS was previously translated and validated in Spanish (Olmsted et al., 2010). The internal consistency values for this study were 0.78 for understanding strengths; .80 knowing rights; .79 helping child develop and learn; .67 having support systems; .77 accessing the community; and 0.91 for the total overall score.

The number and type of services used consisted of 20 service questions in the baseline and follow-up questionnaires. Mothers were asked whether their child was currently receiving a given service. We summed yes responses for two categories—evidence-based (EB) and typical developmental disability (DD) services—to determine the number of services children received at each time point. EB services consisted of alternative or augmentative communication services,

naturalist interventions, social skills training, applied behavior analysis, parent training, sensory integration therapy, video modeling, picture exchange communication, voice output communication aids, pivotal response training, and social stories. Typical DD services included occupational therapy, speech therapy, physical therapy, nutrition/feeding consultations, respite care, psychiatric services, psychological services, recreational therapies, and case management or coordination.

Efficacy in using the intervention strategies was measured with 11 Likert scale items developed by the research team to assess caregiver efficacy in the use of the evidence-based strategies included in the PTA curriculum. Sample items include “I feel confident modeling for my child what I want him/her to do,” “I feel confident in evaluating whether an intervention will be helpful to my child,” and “I understand the purpose of antecedents/behavior/consequences (ABC) chart.” The items were developed, translated, and back-translated by the research team. Responses ranged from 1 = strongly disagree to 4 = strongly agree. Responses were added for a total efficacy score and higher scores indicate greater efficacy in using the strategies. For this sample the Cronbach’s alpha was .86.

Frequency of using intervention strategies was measured with 14 items assessing how often caregivers used the evidence-based strategies included in the PTA curriculum. The items were developed, translated, and back-translated by the research team. Responses ranged on a 4-point Likert scale from 1 = never to 4 = always. A sample item is “How often do you immediately reward your child for positive behaviors?”, “How often do you use prompting to encourage your child to do what you are asking him/her to do?”, and “How often do you provide your child with different choices to prevent challenging behavior?”. Items were summed for a total frequency score, with higher scores indicating greater frequency of use. The Cronbach’s alpha for this measure was .85.

Depressive symptoms among mothers was measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D includes 20 items that rate the frequency of depressive symptoms within the past week. Responses range on a Likert scale from 0 = not at all to 3 = five to seven days. Sample items include “I had trouble keeping my mind on what I was doing” and “I talked less than usual.” Four positively worded items are reverse coded, then all items are summed for a total score. Higher scores indicate higher levels of depressive symptoms. The CES-D was previously translated into Spanish and validated among a Spanish-speaking population (Ruis-Grosso et al., 2012; Soler et al., 1997). The Cronbach’s alpha in the present study was .92.

Study design and procedures

This study used an experimental design with randomization into an intervention-now and an intervention-later group. Parents who agreed to participate signed the informed consent for themselves and their child and were scheduled for a baseline

assessment. The intervention-now group was immediately connected to a promotora to receive PTA after the baseline assessment. The intervention-later group received usual care and was offered the intervention voluntarily after all data collection was completed. Usual care for the children in our study consisted of service coordination by the regional center. Through service coordination, regional center clients are connected to appropriate services. Most of the children in our study were receiving weekly speech and occupational therapies at baseline and very few were receiving intensive autism-specific services.

Those in intervention now received two follow-up assessments (after completing the program and four months following). The intervention-later group was offered PTA after four- and eight-month assessments. All procedures were approved by the California State University Long Beach and the California Health and Human Services Agency–Committee for the Protection of Human Subjects. [Figure 1](#) displays the randomization procedure.

Promotoras conducted 14 home visits immediately following the baseline assessment of mothers who received treatment now. The sessions were comprised of the following content:

- (1) introduction and learning about our children;
- (2) understanding the autism spectrum and your child’s needs;
- (3) what works to address the symptoms of autism?;
- (4) how to be an effective advocate;

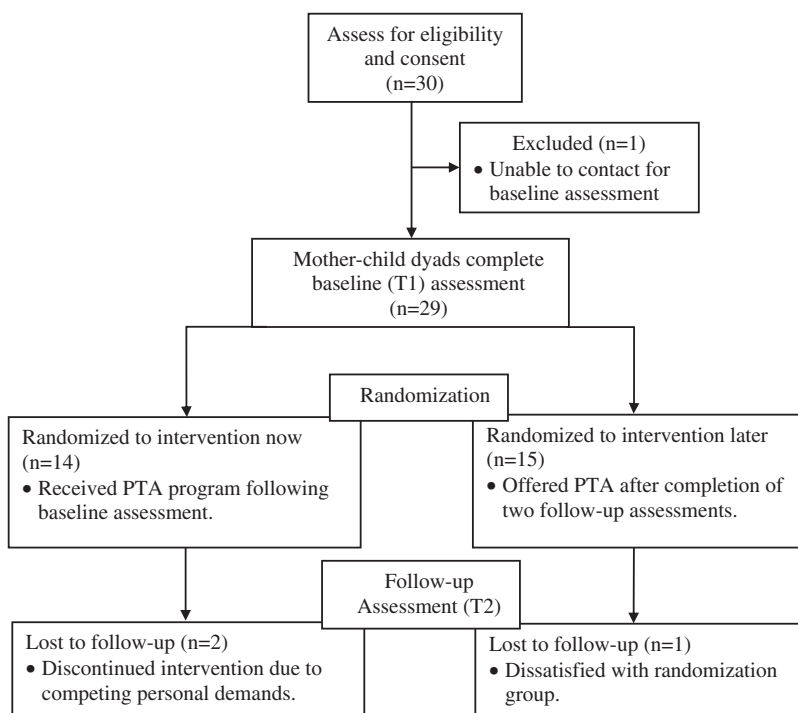


Figure 1. Enrollment and retention flowchart.

- (5) advocacy in the school system;
- (6) talking about autism to others and social support;
- (7) reducing stress and signs of depression;
- (8) overview of strategies for working with your child;
- (9) play together, learn together;
- (10) creating everyday opportunities to encourage communication;
- (11) helping your child make friends and interact with others;
- (12) challenging behavior is communication;
- (13) making challenging behaviors less likely and responding appropriately; and
- (14) looking ahead.

Six promotoras were identified by the community-based organizations we partnered with. All promotoras were Latinx mothers of children with ASD, ages eight and up. The promotoras received about 48 hours of training on the material before implementing the intervention with families. In the training the program content and materials were presented, discussed, and role-played. Study staff also reviewed the research protocol and the fidelity checklist with the promotoras. Promotoras completed the 15-item fidelity checklist after each session with intervention-now families. A similar form was used by study staff and the promotora coordinator to complete two fidelity observations for each intervention-now family. A promotora coordinator was identified to serve as a liaison for the primary investigator and promotoras. The promotora coordinator is a co-author of the PTA program, bilingual, mother of an adult child with ASD, familiar with the geographical area, and is an advocate in the target community. The promotora coordinator maintained a role in facilitating the training, debriefing sessions with promotoras, tracking the progress of promotoras throughout their cases, and completing fidelity observations. As key personnel for the study, the promotora coordinator completed the appropriate human subjects training required by the institutional review board.

Study participants received a manual to follow along and for their future reference, and a folder of additional resource information about the topics and resource/service directories. Promotoras and participants developed a compatible schedule to meet for each session.

Data analysis

The data included in this study are from the baseline (T1) and Time 2 (T2) assessments. T-tests and chi-square analyses were conducted to assess for differences in the demographic variables between the intervention-now (treatment) and intervention-later (control) groups. Next, paired-sample t-tests were conducted to determine whether there were differences between pretests and posttests for each group. Morris and DeShon's (2002) method for effect size calculation was used for

all outcomes to adjust for the dependence between pretest and posttest scores. A repeated measures analysis of variance (ANOVA) was conducted to assess whether the change from T1 to T2 was significant between the intervention-now and intervention-later groups for each child and parent outcome. Data analyses were completed using SPSS version 24.0.

Results

Child outcomes

As shown in [Table 1](#), there were no significant differences at baseline between the treatment group and the control group in social communication, maladaptive behaviors, and severity of autism symptoms, indicating that the two groups were comparable at baseline. The Social Communication Questionnaire (SCQ) score for both groups exceeded the cutoff of 15, for “likely to have ASD.” The proportion of children in each of the CARS autism severity groups was similar between the intervention-now and intervention-later groups. The SIB-R maladaptive behavior index of the treatment-now group averaged -11.30 and -16.9 in the control group, indicating both groups had marginally serious maladaptive behaviors at baseline assessments.

Results from paired-sample t-tests show that the children in the treatment group significantly decreased in the SCQ score (indicating improved social communication) between pretest and posttest. The effect size of this change was substantial at a Cohen’s d of 1.1. The treatment group also significantly increased in typical DD and EB services from pretest to posttest and had a large effect size (see [Table 2](#)). The control group did not significantly change from pretest to posttest for any of the child outcomes.

For a more conservative analysis of the results, we used repeated measures ANOVAs (see [Table 3](#)) for child and parent outcomes. For child outcomes, the effect of time in the repeated measures ANOVA demonstrated that children’s social communication (SCQ) score decreased for the pooled sample, and the effect of time by group was significant, indicating that the change was significant for the treatment group and not the control. The number of typical DD and EB services children received increased significantly for the pooled sample from T1 to T2. The time by group interactions indicated that the change between pretest and posttest was significant for the treatment group compared to the control. The treatment group increased by 2.3 services while the control group increased by half a service.

Parent outcomes

Paired-sample t-tests show that there were significant improvements in many of the parent outcomes between pretest and posttest for the treatment group (see [Table 2](#)). Except for depressive symptoms, the intervention group had

Table 2. Paired-sample T-tests for Study Outcomes.

	Intervention Now (n = 12)		t ²	Effect size ^e	Intervention Later (n = 14)		t ²	Effect size ^e
	Pre-test	Post-test			Pre-test	Post-test		
Child Outcomes								
SCQ Score ^a	19.1 ± 5.1	13.7 ± 4.6	4.6**	1.3	20.6 ± 5.1	21.1 ± 6.2	-0.5	0.1
Maladaptive Behaviors ^b	-11.3 ± 9.8	-6.7 ± 7.0	-1.2	0.8	-16.9 ± 14.4	-12.4 ± 14.4	-1.7	0.6
Typical DD & EB Services	2.8 ± 1.5	5.1 ± 2.6	-4.7*	1.7	3.7 ± 2.7	4.2 ± 3.1	-1.8	0.5
Parent Outcomes								
Understand child's strengths & needs ^c	10.9 ± 2.9	13.8 ± 2.3	-2.9*	0.9	12.0 ± 3.4	12.7 ± 3.3	-1.4	0.4
Know your rights ^c	8.8 ± 4.3	14.2 ± 3.7	-5.1***	1.5	10.7 ± 5.0	10.9 ± 6.3	-0.2	0.1
Help child develop & learn ^c	10.9 ± 3.1	12.8 ± 3.3	-3.6**	1.0	11.4 ± 3.5	11.8 ± 3.7	-0.7	0.2
Have support systems ^c	10.5 ± 5.0	13.3 ± 5.5	-2.5*	0.7	12.4 ± 4.4	12.9 ± 4.7	-0.6	0.2
Access community ^c	14.9 ± 5.5	19.7 ± 3.2	-4.3**	1.5	16.9 ± 4.8	16.8 ± 4.7	0.1	0
Total family outcome score ^c	56.0 ± 18.0	73.8 ± 14.9	-5.7***	1.7	63.4 ± 15.2	65.1 ± 19.0	-0.8	0.3
Efficacy in using strategies	33.4 ± 5.5	38.5 ± 5.2	-2.8*	0.8	34.6 ± 6.2	35.4 ± 6.3	-1.1	0.3
Frequency of using strategies	39.8 ± 6.8	44.8 ± 6.0	-4.0**	1.2	42.0 ± 7.0	43.1 ± 8.3	-0.8	0.2
Depressive symptoms ^d	20.8 ± 12.2	14.5 ± 9.0	2.2	0.7	16.4 ± 12.2	15.5 ± 8.8	0.4	0.1

Notes: Means and standard deviations reported. ^aSCQ total score; ^bSIB-R Generalized Maladaptive Index; ^cMeasured by the FOS; ^dTotal CES-D score; ^eCohen's d reported, 0.2 = small, 0.5 = medium, 0.8 = large (Cohen 1988); *p < .05. **p < .01. ***p < .001.

Table 3. Repeated Measures ANOVA for Child and Parent Outcomes.

	<i>df</i>	Time		Time*Group	
		<i>F</i>	η^2	<i>F</i>	η^2
Child Outcomes					
SCQ Score ^a	1,24	10.3**	.30	15.0**	.38
Maladaptive Behaviors ^b	1,24	1.4	.06	0.2	.01
Typical DD & EB Services	1,24	25.8***	.52	10.8**	.31
Parent Outcomes					
Understand child's strengths & needs ^c	1,24	10.9**	.31	3.9	.14
Know your rights ^c	1,24	15.2**	.38	13.0**	.35
Help child develop & learn ^c	1,24	9.1*	.28	4.3	.15
Have support systems ^c	1,24	6.0*	.20	3.3	.12
Access community ^c	1,24	12.3**	.34	13.1**	.35
Total family outcome score ^c	1,24	29.5***	.55	20.3***	.46
Efficacy in using strategies	1,24	9.8**	.29	5.4*	.18
Frequency of using strategies	1,24	10.5**	.30	4.1	.15
Depressive symptoms ^d	1,24	3.8	.14	2.1	.08

Notes. ^aSCQ total score; ^bSIB-R Generalized Maladaptive Index; ^cMeasured by the FOS; ^dTotal CES-D score; * $p < .05$. ** $p < .01$. *** $p < .001$.

significant increases in all parent outcomes from pretest to posttest. The effect sizes for the majority of parent outcomes for the intervention group were large. While change in depressive symptoms was not significant, the effect size was medium to large and clinically meaningful. The intervention group decreased in depressive symptoms from 20.8 to 14.5 and the CES-D cutoff score for being at risk for clinical depression is 16 (Radloff, 1977). The control group did not have any significant changes from pretest to posttest for parent outcomes.

The repeated measures ANOVA (Table 3) for parent outcomes indicated that understanding children's strengths and needs, knowledge of rights, helping children develop and learn, having a support system, access to the community, and the total family outcome score increased between pretest and posttest for the pooled sample. Similar results were found for efficacy in use of EB strategies, and frequency of using EB strategies. Observation of mean differences indicate that the changes were greater for the intervention group compared to the control group, as seen in Table 2. Time by group interactions were observed for knowledge of rights, accessing the community, total family outcome score, as well as efficacy in use of EB strategies, indicating that the increase was significant for the intervention group compared to the control group for these outcomes.

Discussion

This study focused on testing the efficacy of a culturally tailored parent educational intervention for Latinx parents of children with ASD in a Southern California community. The focus of the intervention was on empowering parents and reducing disparities in knowledge about ASD and services for their children. The intervention provided evidence-based information to help

parents better understand their child's condition, and give them knowledge and skills to help their children develop and learn. Participating mothers were randomly assigned to an intervention-now (treatment) group or an intervention-later (control) group. Our findings found that parents in the treatment group improved in empowerment-oriented outcomes such as knowing their child's rights and accessing the community, compared to the control group. They also increased in their confidence in using evidence-based strategies with their children and in the frequency of using these strategies. While the focus of the intervention was on the parents, we found some significant improvements in the children as well. There was a significant reduction in social communication deficits for the treatment group compared to the control group. Important to the issue of reducing disparities, we found that children in the treatment group showed greater increases in the number of services currently received compared to the control group.

Despite the fact that more Latinx children are diagnosed with ASD now than in the recent past (Centers for Disease Control and Prevention, 2018), Latinx children are diagnosed later and receive fewer services than their non-Latinx White counterparts receive (Magaña et al., 2013; Palmer et al., 2010). Care that is received is often perceived by parents as inappropriate or of poor quality, which may be due to factors including a lack of cultural and linguistic competence of service providers (Zuckerman et al., 2017). Taken together, such disparities can have a far-reaching negative impact on the child, the parents, the family, and society as a whole.

It is not possible to reverse this problematic situation without high-quality research into effective interventions specially designed to meet the unique needs of the Latinx community. This is especially true given the fact that Latinx families, particularly immigrant families, often face multiple barriers to diagnosis and treatment including language barriers, limited social capital to navigate services, low levels of information about ASD, and potential bias on the part of pediatricians (Zuckerman et al., 2014). Latinx families have magnified needs and fewer resources to meet the needs of their children with ASD than other non-Latinx White children. This state of affairs may be exacerbated by the national or local political climate at any given time, even when the Latinx child with ASD is an American citizen. For example, in California, the diagnosis of ASD among Latinx children was found to fluctuate depending on immigration policy (Fontaine & Bearman, 2011), and these same policies may affect service use as well.

PTA was carefully crafted to overcome identified barriers including limited information available to Latinx parents, language barriers, and lack of knowledge and skills related to advocacy. The very program name Parents Taking Action captures the essence of parent education and empowerment. The use of an ecological validity framework and elements of program design that were customized to this population include cultural and linguistic

competency, flexibility and creativity in service provision, partnerships with consumers, families, and community-based organizations, enhanced data collection, and oversight on equity and diversity issues.

In addition, content was tailored to the needs of Latinx families, not only providing key information, but also redressing misinformation they may have due to limited knowledge about ASD in their communities. The emphasis on evidence-based treatment options provided a strong framework for parents to advocate for services, with measurable results. Learning ways to improve their child's communication, socialization, play and behavior, and feeling empowered to do so resulted in increased use of the strategies, and improvements in quality of life for the child and family.

The peer-support aspect of PTA is another unique and impactful feature of the program. The PTA promotoras were Latinx mothers of children with ASD, well-educated about ASD and service systems, and leaders in their community. The relationships that developed between the promotoras are consistent with the Latinx value of *personalismo*, meaning that the culture is people-oriented, with great emphasis placed on personal relationships (Zea, Quezada, & Belgrave, 1994). These relationships were mentioned as a positive aspect of the program by the study mothers and promotoras alike (Magaña et al., 2017). Having peers provide the educational program may overcome some of the fears families have regarding immigration issues as they develop trust with their promotoras.

While this study used a randomized control design, there are limitations that should be noted. First, the sample size was small, thus limiting the generalizability of findings to a larger study population. Second, the sample was majority immigrant mothers of Mexican descent, therefore not representative to all Latinx families. Furthermore, because the study was conducted in California, the developmental disability service system may be very distinct from those in other states, which may affect the results of the study. Finally, all measures were self-report, which could lead to social desirability bias. However, a potential inflation of outcome results would likely occur in both the treatment and control groups, which helps to mitigate this limitation.

The evidence described in this article demonstrates that PTA is an effective intervention for Latinx families of children with ASD in Southern California, resulting in improved family outcomes and access to services. The program model holds great promise for Latinx families in other locations, as long as it is carefully tailored to the needs of a specific community. There is clearly room to expand PTA as an educational program for Latinx parents whose children have disabilities other than autism. Finally, 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.

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