

*COMMUNITY PARTNERSHIPS AND AUTISM  
INTERVENTION FOR UNDERSERVED  
CHILDREN THROUGHOUT COVID-19:  
PROMISING PRACTICES FOR HEALTH  
EQUITY*

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# *Padres En Acción*/Parents Taking Action

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

**Legal, Economic & Socio-Cultural Parameters  
(Scope Conditions)**

**Health Care & Educational  
Systems Domains**

**Federal, State, and Economic Policy**

- health care policies
- mental health care policies
- education policies
- immigration policies
- regulations at state and federal levels
- market forces

**Operation of Health Care System and Provider Organizations**

- provider burden
- design of services for Latino children with ASD and their families
- workforce diversity
- organizational culture and climate

**Provider/Clinician Factors**

- use of guideline concordance care
- attitudes towards and perceptions of clients
- provider's training and resources
- gender, race, and ethnicity

**Interface of  
Community & Treatment Systems**  
Domains Linked Through Mechanisms

**Health Care Market Failure**

- lack of availability, accessibility
- institutional bias
- limited financing

**Restricted Pathways to and of Care**

- Differential pathways into mental health care.
- Poor patient-provider interaction and communication
- Mismatches in mental health and autism service offerings; minority service needs

**Poor Clinical Encounters**

- lack of community trust
- erroneous expectations
- limited workforce availability
- limited provider training to treat Latinos and autism.

**CUMULATIVE  
DISADVANTAGE**

**Disparities in Health Services Outcomes**

- later diagnosis
- burden of ASD on family
- mismatched treatment
- misdiagnosis
- functioning
- quality of life

**Community Systems Domains**

**Environmental Context**

- poverty/wealth
- residential segregation
- isolation
- health programs available

**Operation of Community System and Social Networks Sectors**

- community perceptions of health service; mistrust in service providers
- family cohesion and support
- caregiver's recognition of health problems
- perceived effectiveness of health care system
- previous healthcare experience

**Individual Factors**

**Child**

- gender
- race
- ethnicity
- ASD symptoms severity

**Parent**

- acculturation
- language
- beliefs
- prior experience
- documentation status
- health literacy
- SES

# Parents Taking Action

(Lopez et al., 2019; Magaña et al., 2017; Magaña et al., 2020; Zeng et al., 2022)

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 <i>dichos</i> , storytelling, & <i>novelas</i> included.
Content	The protocol and manuals incorporated cultural values such as <i>familism</i> (needs of family comes before individual) and <i>personalismo</i> (relationship focused).
Goals	Goals were realistic and specific to the parents and their child with ASD.
Methods	<i>Promotora de salud</i> 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.

*Ecological Validity Model (Bernal et al., 1995)*



*\*specific to Parents Taking Action*

# Parents Taking Action

(Lopez et al., 2019; Magaña et al., 2017; Magaña et al., 2020; Zeng et al., 2022)

Session
<b>Session 1: Introduction to the program</b>
<b>Session 2: Understanding child development</b>
<b>Session 3: Understanding the autism spectrum and your child's needs</b>
<b>Session 4: What works to address symptoms of autism</b>
<b>Session 5: How to be an effective advocate</b>
<b>Session 6: Advocacy in the school system</b>
<b>Session 7: Play together, learn together</b>
<b>Session 8: Creating everyday opportunities to encourage communication</b>
<b>Session 9: Helping your child make friends and interact with others</b>
<b>Session 10: Challenging behavior is communication</b>
<b>Session 11: How to reduce challenging behaviors and respond appropriately when they occur</b>
<b>Session 12: Reducing stress and recognizing signs of depression</b>
<b>Session 13: Talking about autism to others and social support</b>
<b>Session 14: Looking ahead</b>

# PROCEDURE

- Targeted recruitment of underserved mothers of children at-risk or diagnosed with ASD or SCD ages 1-8
- Recruitment through service agency referrals, support groups, and word of mouth
- Participants randomized into an intervention (Intervention Now) group or a control (Intervention Later) group.
- Intervention: 14 sessions, 2 hours, PTA psychoeducation
- Baseline assessment and two follow-up assessments for all families.
  - 4 months and 8 months post baseline



# PTA Implications and Findings

- More equipped to be self and child advocates
- Increased caregiver efficacy suggests that mothers may also be able to exhibit more effective parenting (Jones & Prinz, 2005)
- Suggests they will be more involved in developing their child's skills and managing their child's behaviors (Hastings & Brown, 2002).
- PTA program is a promising culturally informed intervention that can be delivered in a cost effective manner.

# Pandemic Influences

- At the onset of COVID and throughout, parents of autistic individuals were concerned about the effects of the pandemic as they affected the behavior and socialization of their children (Lutzer et al., 2021).
- COVID-19 elevated the need for collaborative, innovative, and virtual forms of intervention for autistic individuals Smile (2020).
- To deliver intervention services to children with DD, creativity and innovation that engaged community-based professionals and/or technology became necessary considering COVID-19 restrictions (Jeste et al., 2020; Sohl et al., 2017; Zwaigenbaum & Warren, 2021).



# PTA interventions affected by COVID

- Parents Taking Action (PTA) program for Diné (Navajo) parents and guardians (parents/guardians) of children at-risk of or diagnosed with autism spectrum disorder in Northern Arizona (Co-PIs: Lindley, Henderson, & Lopez).
- Parents Taking Action Chinese (PI: Xu; Details of the major adaptations of the intervention are outlined in Magaña et al., 2021).
- *Padres de Niños con Autismo Como Técnicos en el Análisis Conductual (PACTO)* or Partnering with parents of children with autism in early behavioral intervention (PI: Dueñas).

# Community partner impacts

- challenges connecting via e-mail and social media (e.g., Facebook) with local chapters and other organizations such as healthcare clinics.
- increased provider burnout and inability to engage with new projects during the pandemic may have played a role in the challenges our research team experienced engaging new community partners.
- challenges in connecting with institutional and regional government entities and in building trust through networking electronically.
- frustration with increased reliance of technology and decreased face-to-face interactions.

# Promising community engagement strategies

- build strong partnerships prior to beginning programs to withstand unexpected changes.
- invite and sustain invitations to community partners to contribute to programming.
- understand and explore own positionality as they impact interactions with community partners.
- create and maintain flexible expectations with research, partners, and families.
- have a trusted community member champion project to a potential partner organization facilitated engagement by the given organization.
- diversify organizational partnerships to include service providers from community-based settings such as at school, healthcare clinics, and home.

# State, & Federal Policy Implications

- State

- Mental Health Services Act, Family Empowerment Centers, and regional centers
- Arizona Rural Network Development Planning Grant Program
- Medicaid Managed Care Organizations (MCOs) for internal investments in CHWs.

- Federal

- American Public Health Association (APHA) Community Health Care Worker Policies
- Early intervention services and Title V/Maternal and Child Health
- Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorder Research; Autism Cares Act .
- Title II of the DD Act , titled Families of Children With Disabilities Support Act of 2000, addresses issues of family support, developed by the Administration on Developmental Disabilities.
- Coronavirus Aid, Relief, and Economic Security Act (CARES Act) and American Rescue Plan Act of 2021, both of which provided a variety of funding channels to support CHW programs and the direct hiring of CHWs.
  - CDC's National Initiative to Address COVID-19 Health Disparities
  - HRSA's Community-Based Workforce for COVID-19 Vaccine Outreach program

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