

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

Parents Taking Action: A New Program to Empower Latinx Parents of Children with Autism Spectrum Disorders

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

Up to 1 in 59 U.S. children has an Autism Spectrum Disorder (ASD). ASD is a developmental disability that affects how people communicate and process information. Young children with ASD may benefit from a variety of specialized services to help them develop and learn new skills. Past research has found that children of Latin American descent, or “Latinx” children, are less likely to be diagnosed with ASD than non-Latinx children. Research has also shown that Latinx children who are diagnosed with ASD tend to be diagnosed at older ages and receive fewer autism-related services than non-Latinx children. Latinx families may have difficulty finding and understanding information about ASD or accessing services due to language or cultural challenges, such as needing to communicate with caseworkers who do not speak Spanish or are not familiar with cultures of Latin America. In addition, traditional ASD services may not match the cultural values of Latinx families.

In a recent NIDILRR-funded study, researchers tested [Parents Taking Action \(PTA\): A Parent Training Intervention for Latino Immigrant Families](#), an innovative program designed to educate Latinx parents about ASD and strategies for supporting their children. PTA, which was developed by the same research team under a previous study, is delivered individually to families in their homes by fellow Latinx mothers of children with ASD, called “promotoras”, who provide peer support and information in a culturally relevant way. The researchers tested the impact of PTA on parents’ confidence and empowerment, children’s social-communication skills, and services received by the families.

Researchers enrolled 26 mother-child pairs in a study of PTA. The participants were of Latinx descent with most of the mothers having immigrated to the United States before their children were born. The children were diagnosed with ASD or had signs of ASD, were 1-8 years old, and were receiving services from a community organization serving children with developmental disabilities in Los Angeles, CA. The participants were randomly divided into two groups: a PTA group who received the PTA program, and a wait-list control group who received only their usual services and were offered PTA after completing all study requirements.

The participants in the PTA group had a promotora visit them in their homes about once a week for 14 weeks. The promotoras were mothers of older children with ASD and leaders in the local Latinx community. The promotoras built personal relationships with the families and presented them with information about ASD. Major topics included understanding ASD, learning self-advocacy skills, navigating services and supports, promoting children’s social-communication skills, and strategies for

responding to challenging behavior. The materials were available in English and Spanish and incorporated common cultural sayings and expressions to enhance the cultural relevance. Twenty-two participants requested the program in Spanish and four requested it in English.

Both the PTA and control groups completed questionnaires at the beginning and end of their participation in the study. Then the mothers in the PTA group completed the final questionnaire after the last PTA session while those in the control group completed the final questionnaire four months after the start of the study. The questionnaires were provided in the language preferred by the participants. First, to measure the mothers' sense of confidence and empowerment, the mothers answered questions about how much they felt they knew their children's rights; the degree to which they understood their children's strengths, needs, and abilities; and their level of access to the community. The mothers also answered questions about how often they used various strategies to support their children, such as modeling communication skills or rewarding them for positive behavior, and how confident the mothers felt in using these strategies. Second, to measure changes in the children's social-communication skills, such as conversation and social interactions with friends, the mothers answered questions about their child's level of these skills displayed over the past 3 months. Finally, to measure service use, the mothers indicated which of 20 services their child was receiving, such as occupational, speech, and physical therapies as well as specialized autism-related services.

The researchers found that the mothers in the PTA group reported an increase in their confidence and empowerment over the course of the study, but there were no changes for the mothers in the control group. In particular, the mothers in the PTA group reported improved knowledge of their rights and having more access to their communities at the end of the program than at the beginning of the program. Further, the mothers in the PTA group reported improvements in their children's social-communication skills over the course of the study, but there were no changes reported by the mothers in the control group. Finally, both groups reported an increase in the number of services their children received, but the mothers in the PTA group reported receiving more services on average than the mothers in the control group. The mothers in the PTA group reported an increase of about 3 more services, while the mothers in the control group reported an increase of about 1 more service.

The authors noted that the PTA program may have helped the families in this study overcome many common challenges facing Latinx families of children with ASD. The program was delivered by community leaders who shared the mothers' culture, language, and experiences raising a child with ASD. These leaders may have served as role models for the mothers who received the program, offering peer support and creating lasting connections to the larger communities in which the families lived. In addition, the program was delivered in the mothers' native language and in the family home, reducing challenges related to transportation or childcare. Finally, the program

reflected Latinx cultural values such as personalismo (relationship building) and familismo (importance of the family over the individual). Thus, the PTA program may have helped Latinx mothers to feel accepted, supported, and empowered when securing services for their children and working with them at home to support their development. Future research may be useful to develop and test similar programs for other ethnic groups, or with families of children with other disabilities besides ASD.

[To Learn More](#)

This study was also supported by the NIDILRR-funded Rehabilitation Research and Training Center on Family Support, which hosted a webinar with the research team to talk about Parents Taking Action, including how the program was created.

<https://fsrtc.ahslabs.uic.edu/2016/05/19/pta-webinar/>

A New Beginning for Ana and her Family (Un Nuevo Amanecer Para Ana Y Su Familia) is a Spanish-language disability awareness program (radio novela) that tells the story of the Chavez family from their child's diagnosis of cerebral palsy to her first job as a young adult. <http://www2.waisman.wisc.edu/cedd/familysupport360/novela.php>

[To Learn More About this Study](#)

Lopez, K., Magaña, S., Morales, M. & Iland, E. (2019) [Parents Taking Action: Reducing disparities through a culturally informed intervention for Latinx parents of children with autism](#). Journal of Ethnic & Cultural Diversity in Social Work, 28:1, 31-49. This article is available from the NARIC collection under Accession Number J80525.

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.