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Diné Parents Taking Action Project: Findings from the Qualitative Study & Program Adaptation

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Study Purpose & Aims

Parents Taking Action is a parent education and training program that employs a community health worker delivery model to educate parents about autism and train them about strategies to help their child with social communication and challenging behavior

This project aimed to:

(1) Conduct interviews with Diné parents and guardians of children with autism about their lived experiences and preferences for Parents Taking Action,

(2) Adapt the Parents Taking Action program for Diné families, &

(3) Conduct a pilot trial of the adapted intervention to determine its feasibility & acceptability

In this poster, we describe key findings from Aims 1 and 2 of the Diné Parents Taking Action project. Succinctly, cultural adaptation requires many voices and raising autism awareness may be a first step in helping more Diné families access services and support.

Background

What is Autism?
Autism Spectrum Disorder (ASD) is a chronic and complex neurodevelopmental condition that affects ~ 1 in 36 children (Maenner et al., 2023).

Racial and Ethnic Disparities in Access to Autism Services
Timely diagnosis and access to services can optimize health for children with autism. Children of Color including those who are Indigenous experience persistent inequities in access to timely autism diagnosis and services (Magaña et al., 2013, Liptak et al., 2008; Travers & Krezmien, 2018).

The Navajo Nation
In Coconino County, approximately 28 percent of individuals identify as Indigenous (United States Census Bureau, 2022) with the largest federated tribe in the region and in the United States being Diné ("The People", Navajo). Despite such a large population, little is known about Diné parent/guardian experiences raising children with autism.

Parents Taking Action
- Psychoeducational/parent education & training intervention program developed by Sandy Magaña, PhD, MSW and colleagues (2014)
- Rooted in the Ecological Validity Framework (Bernal et al., 1995)
- Originally developed for Latin parents of children with an intellectual or developmental disability (IDD), then narrowed to focus on parents of children with autism.
- 12-14 lessons; delivered in weekly to monthly intervals (in English, Spanish, or other languages)
- Evidence-based: Improves maternal understanding of autism, confidence & frequency of use of evidence-based practices, child social communication & number of evidence-based services received. Also builds social connection & support between families.
- Has been/is being adapted for different ethnic groups (e.g., Black families)

Methods

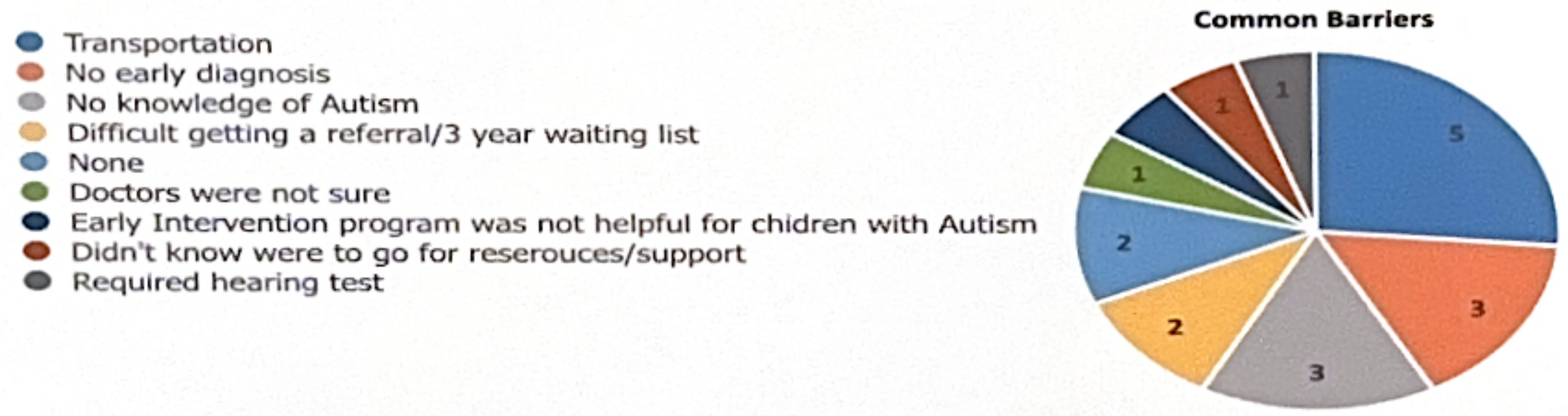
Community Advisory Board (CAB) comprised of 13 Individuals who are Diné parents with an autistic child or who deliver autism services in/around the Navajo Nation provided input monthly or every other month from 2021-2023 on program adaptation and implementation.

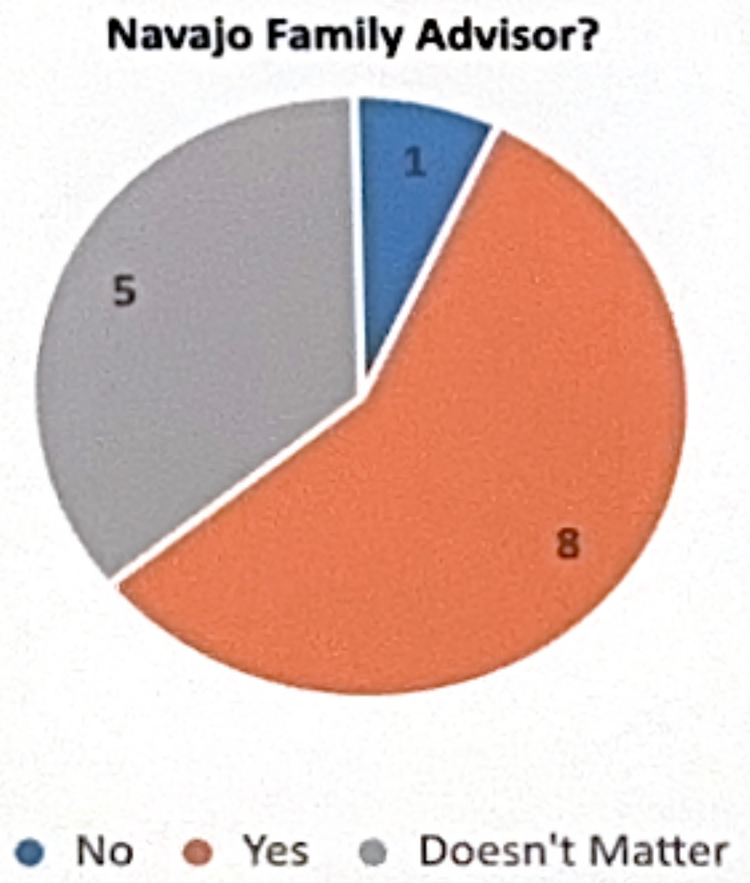
Aim 1: Semi-structured, in-depth interviews with 15 Diné parents of children with autism
Aim 2: Interview data & input from CAB subgroups gathered using the Ecological Validity Framework; interpreter helped to translate educational materials into the Diné language
Aim 3: Pilot trial of the adapted Parents Taking Action program evaluated with a pretest and two post test surveys. 3 community health workers (family advisors) trained to deliver program & 12 parents enrolled

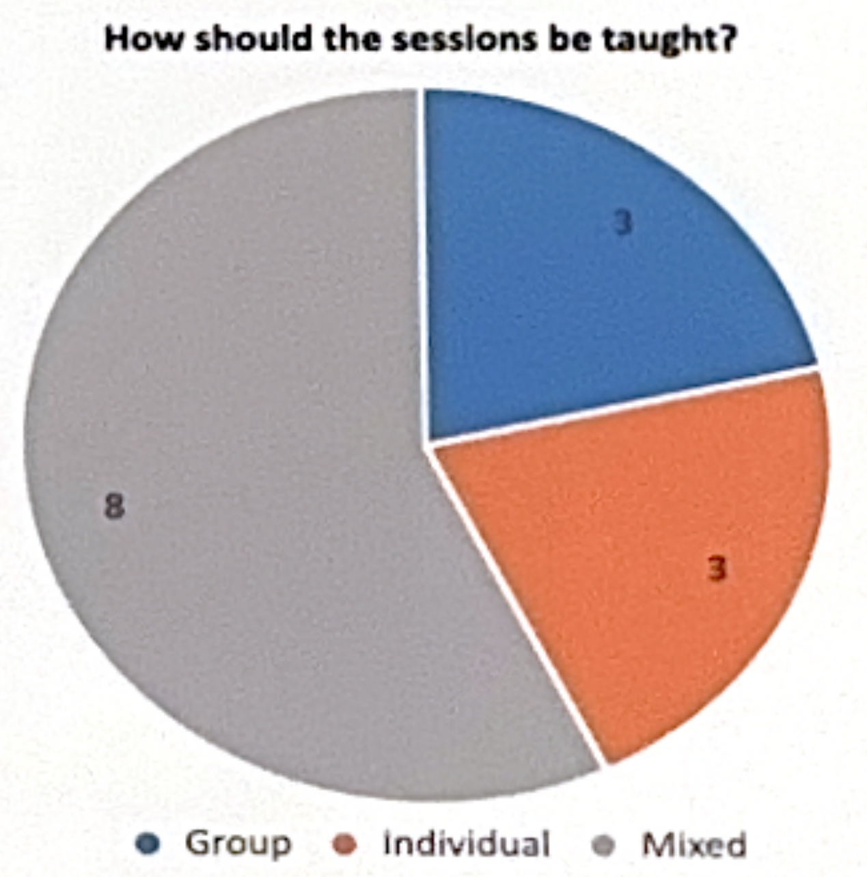
Aims 1 & 2 Interview Data Collection Procedure
- Verbal consent acquired
- 13-month recruitment & data collection period, 2021-2022
- Brief survey on participant sociodemographic characteristics conducted that was verbally administered
- In-depth interviews were conducted by a Diné research team member via telephone or Zoom, audio recorded, & transcribed
- Participants received a $30 payment.
- Directed content analysis was performed NVivo.
- Themes for Aims 1 & 2 discussed by CAB.

Results

Preliminary Interview Findings







Adapted Lesson Topics & Pilot Status (March '23)

Adapted Parents Taking Action Lesson Topics
(1) Understanding child development
(2) Understanding the autism spectrum and your child's needs
(3) Play together, learn together
(4) Creating everyday opportunities to encourage communication
(5) Challenging behavior is communication
(6 & 7) Responding appropriately to challenging behaviors
(8) Helping your child to make friends and interact with others
(9) What works to address the symptoms of autism?
(10) Stress & depression
(11) How to be an effective advocate in school and at home
(12) Building social support and looking ahead

Participants	Completed Lessons
P1	1-11
P2	1-6
P3	1-3
P4	-
P5	-
P6	1-8
P7	-
P8	1-12
P9	1-7
P10	1-12
P11	-
P12	1-2

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Community Advisory Group
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Project Interpreter – Julius Tulley

Community Partners
- Department of Diné Education, Navajo Head Start, Growing in Beauty (Navajo Nation Part C Early Intervention Program), Flagstaff Unified School District, Western Navajo Agency Council, Central (Chinle) Navajo Agency Council, Fort Defiance Navajo Agency Council, Eastern Navajo Agency Council, Northern Navajo Agency Council, & University of New Mexico Navajo Birth Cohort Study, Navajo Nation Early Childhood Coalition, North Country HealthCare

Parents Taking Action Developer
- Sandy Magaña, PhD, MSW

Discussion

Findings
- 12 overarching themes identified including factors about access to services, access to treatment, and how to improve services
- Factors affecting access to services included the sociocultural environment, the health care system and the environment
- The rural nature of the Navajo Nation contributes to poor service access for Indigenous neurodivergent children (Bishop-Fitzpatrick & Kind, 2017; Travers & Krezmien, 2018; Sullivan, 2013; Aylward et al., 2021)
- The Diné culture does not have a word for disability or autism.
- Traditional Diné medicine is pluralistic and may involve the presence of traditional healers and special ceremonies as a complement to western or mainstream medicine (Connors & Donnellan, 1993). So, a translated description of autism has been developed through this project.

Limitations
- Our study is a one of a kind research that has involved Diné parents who have a child with autism, which has limited our resources and articles that specifically support our study.
- Due to the timeline of this study, our recruitment may be affected by COVID-19; and Diné families not being exposed to recruitment information due to limited to no internet access

Conclusions
- Diné parents commonly struggle to access autism services, and these challenges were magnified during the pandemic.
- Programs that utilize community-based social care models for Indigenous individuals with disabilities show promise for reducing pronounced and persistent health disparities (Puska et al., 2022).
- This project illustrates how an existing evidence-based parent education and training program was adapted to be more culturally responsive for Diné parents of children with autism.
- Greater education and training about autism is still needed for Diné families and communities.

Future Directions

- This study's findings may aid health professionals and policymakers in their efforts to support families that have a child with autism in Diné and other Indigenous communities.
- In applying similar types of community-engaged, culturally responsive models of family-oriented education and training, progress toward equitable health outcomes for children may be better sustained and spread.

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