

# UNDERSTANDING THE RESPITE CARE EXPERIENCE OF LATINX FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

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# Project Partners

- Loyola University Chicago
  - Monique Ridosh, PhD, RN
- PADRES E HIJOS EN ACCIÓN
  - Non-profit in Dane County dedicated to supporting Latinx families of CSHCN
  - Helped inform cultural relevant questions and interpret results



# Children with Special Healthcare Needs (CSHCN)

“Those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

*(HRSA MCHB)*

# Disparities in Respite Care

- Respite Needs Are Unmet for Latinx Families
- Prevalence of unmet needs 2x greater in Latinx families (compared to Non-Hispanic white families)
- Cultural and linguistic barriers
- Gap in resources for racial and ethnic minorities
- Research is needed to create culturally and linguistically appropriate respite interventions

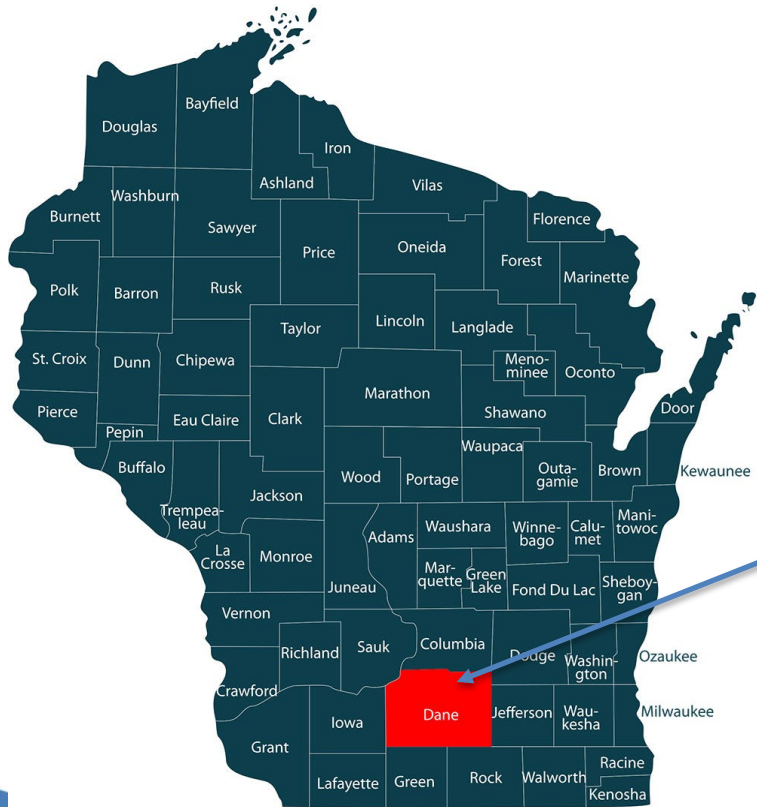
# Study Purpose

The purpose of this pilot study was to better understand the experience and needs of Latinx families of children with special healthcare needs, specifically related to respite care



# Method

- Mixed-method pilot study
- Community-engaged research
- Anonymous Online Qualtrics Survey
  - English or Spanish
  - Incentive (drawing for ten \$100 gift cards)
  - Option to participate in interview
- In-depth, one-on-one, semi-structured interviews
  - Conducted virtually or in-person
  - English or Spanish



# Project Location

Dane County  
Wisconsin

# Eligibility Criteria

- Parent or guardian of a CSHCN (under 21 years of age)
- Self-identify as a member of the Latinx community
- Read, write, and speak English or Spanish
- Live in Dane County, Wisconsin
- Can tolerate an hour to hour-and-a-half interview
- Have access to an internet connected device (i.e. computer, tablet, or smart phone)
- Are willing and interested in participating



# Survey Measures

- Demographics
- Global Family Quality of Life Scale
- Family APGAR (Measures family functioning)
- Perceived Stress Scale (PSS-10)
- Experience with respite

\*Translated to Spanish and back-translated by study team

# Validation of Spanish Measures

- Validated in Spanish
  - Family APGAR
  - Perceived Stress Scale (PSS-10)
- Will conduct validation
  - Global Family Quality of Life Scale

# Semi-structured interview guide

- Questions informed by the literature, professional experience, and input from community partner
  - Rewarding and challenging aspects of care
  - Family quality of life
  - Stress
  - Support
  - Respite (experience and recommendations)

# Analysis - Survey Data

- Exported from Qualtrics
- Imported into SPSS statistical software
- Descriptive statistics
- Correlations
- Regression analysis

# Analysis – Interview Data

- Audio recordings transcribed verbatim
- For confidentiality purposes, names are removed during transcription
- Thematic analysis of transcripts with consensus coding from at least 2 members of the research team
- Preliminary results will be shared with *PADRES E HIJOS EN ACCIÓN* to help validate our interpretation of the findings

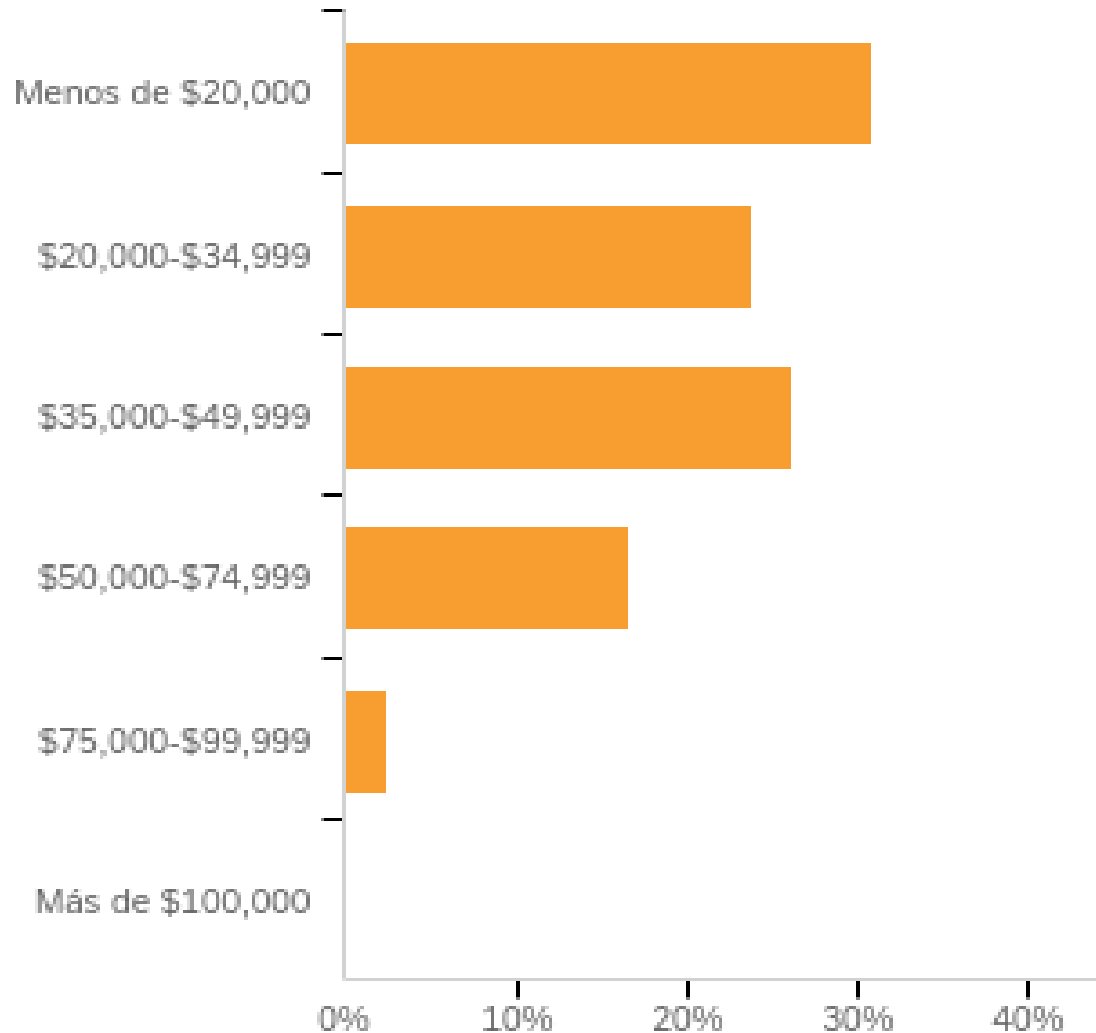
# Preliminary Results

- Barriers to online survey
- 48 paper surveys completed
- 3 interviews completed to-date



# Most respondents were:

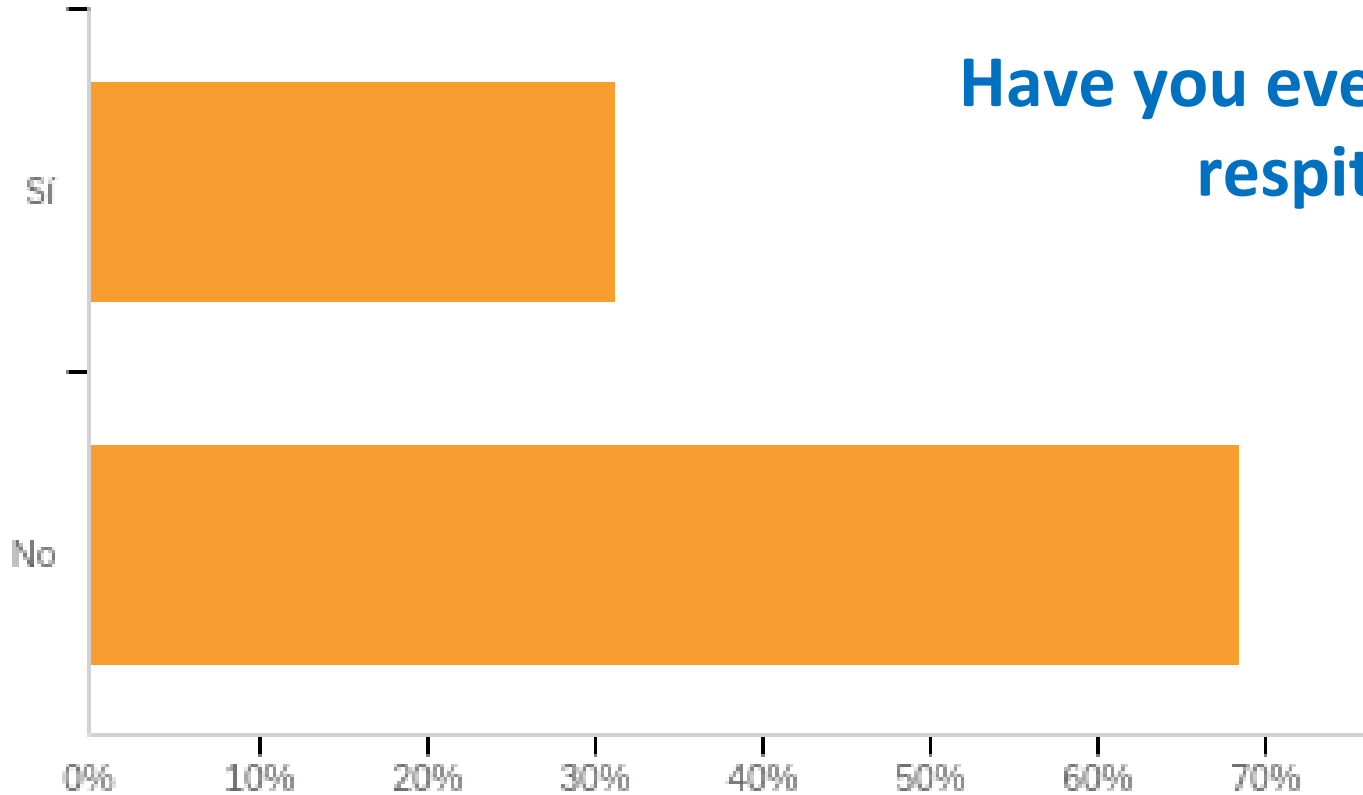
- Married (60%)
- Female (80%)
- 40-50 years old
- Had high school diploma or GED (40%)
- Working full-time (43%) or unemployed (30%)



## Annual Household Income Range



# Have you ever received respite?



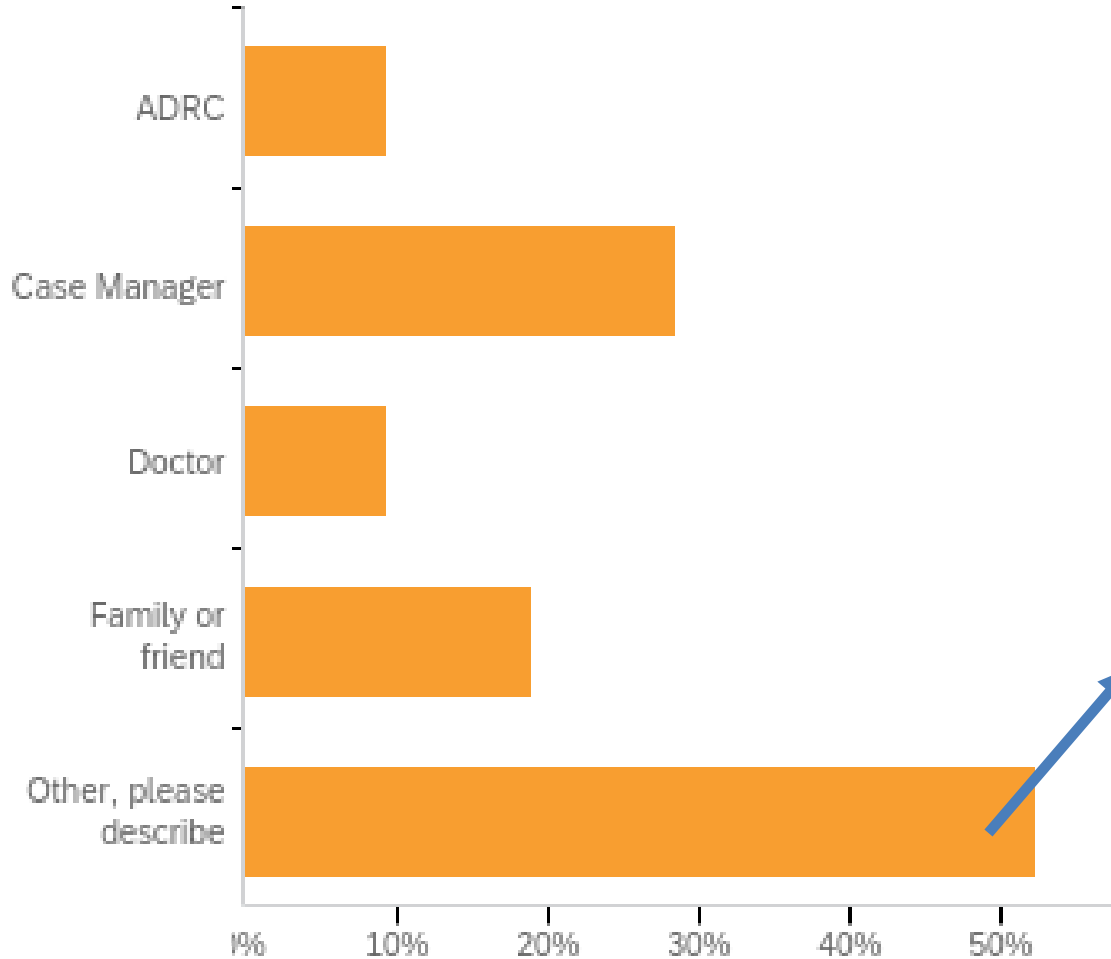
# Why haven't you received respite?

- I don't know what respite is
- Not having full legal status
- My son is not a citizen
- I prefer to take care of it myself
- I didn't know this support existed
- I haven't heard of it

**Only 4 respondents  
(8%) are currently  
receiving respite**

# How did you learn about respite?

Most learned about respite from PADRES E HIJOS EN ACCIÓN



# Respite Access

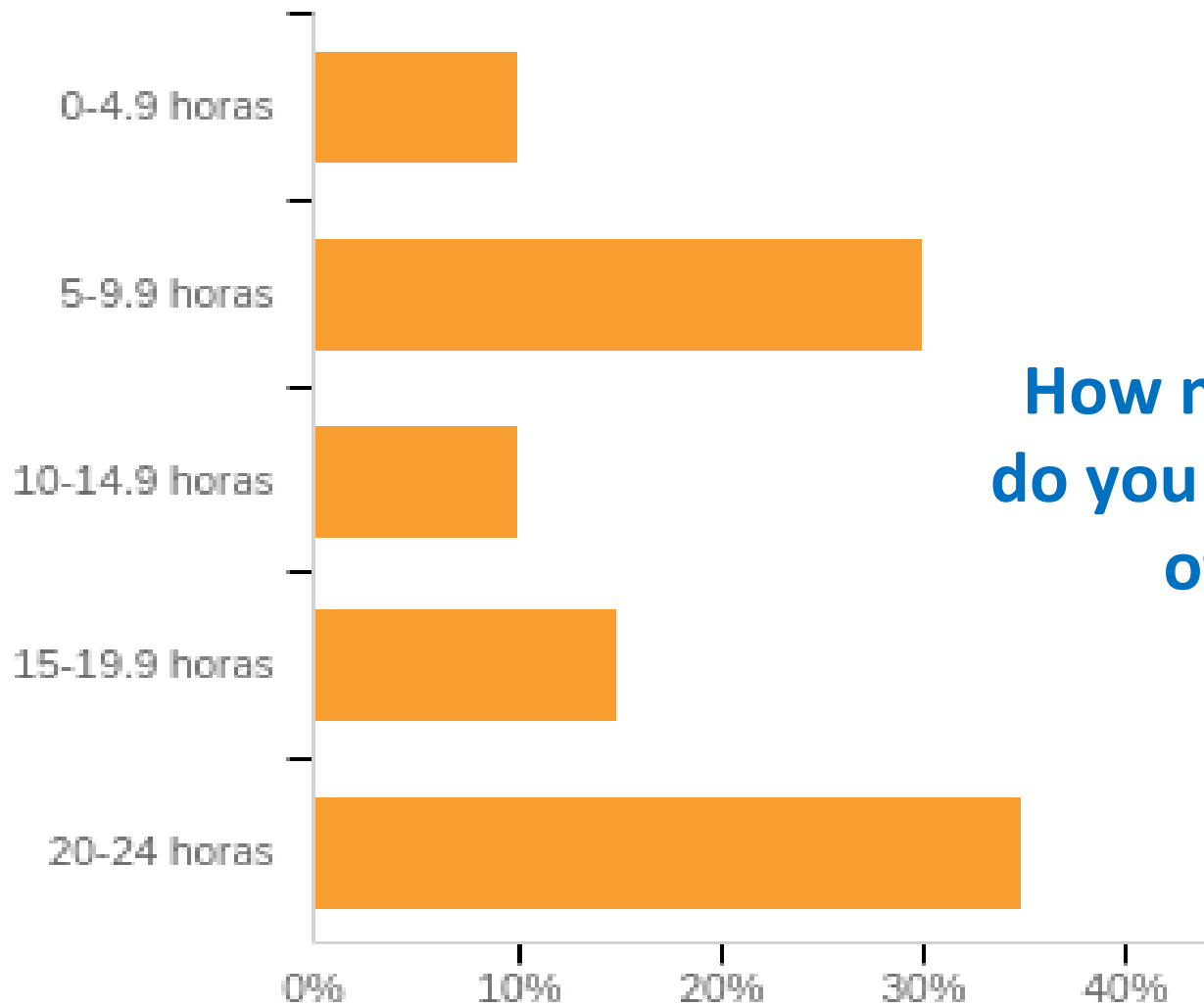
- Provided mostly in the home
- Provided on an as needed basis
- Funded by public/government funds
- No transportation provided
- 46% were on a waitlist for services
- 47% reported reduced or no respite during pandemic

# What barriers or challenges do you face in receiving respite care?

- My son's behavioral
- There are no workers
- It's a long waiting list
- My son's citizenship
- Language
- I don't know how or where to get it

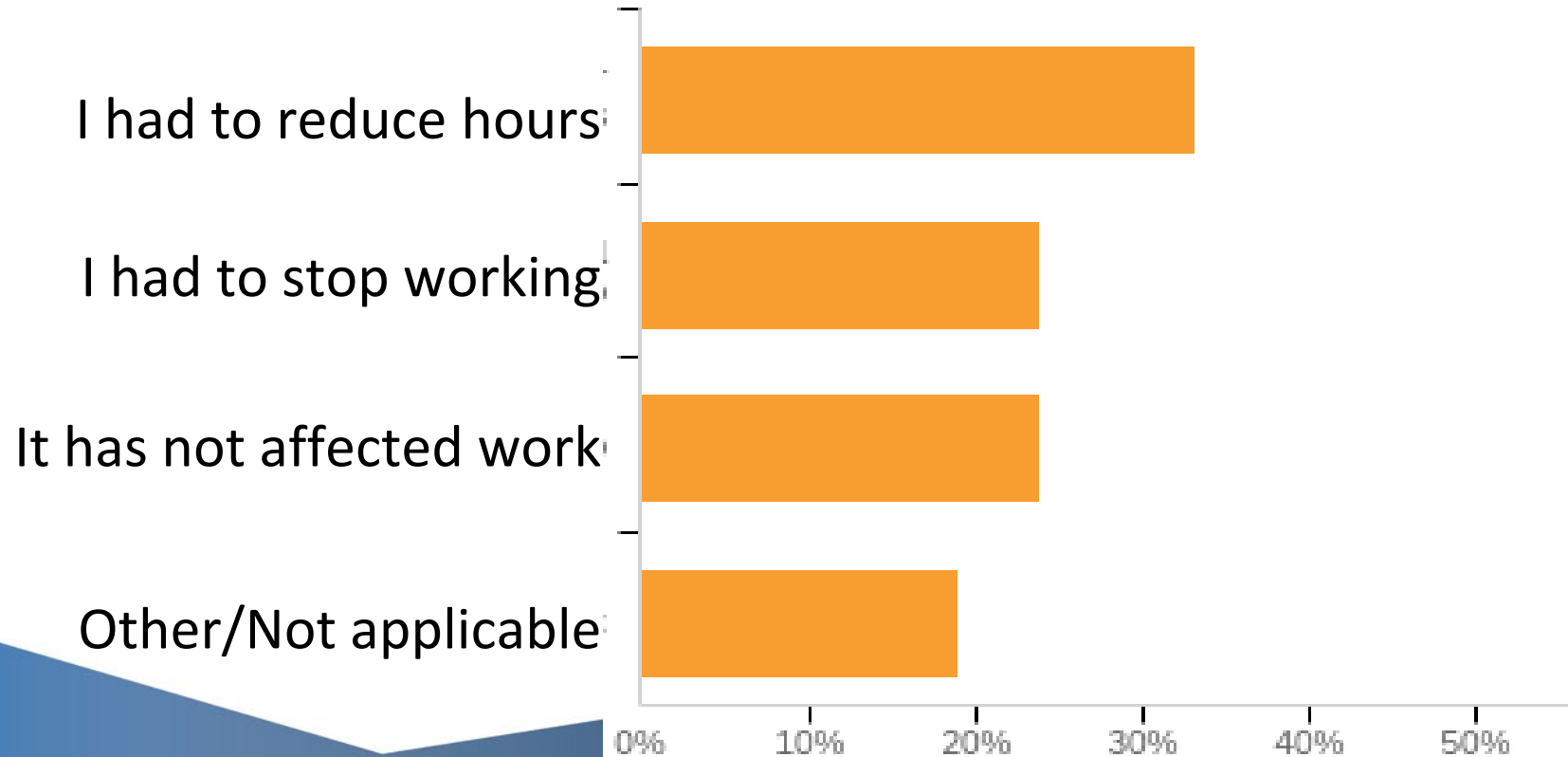
# CSHCN Results

- Most respondents had 1 CSHCN and 2-3 other children
- Average age of CSHCN was 14 years old
- Most common diagnosis was autism (~75%)
- Most children were diagnosed by the age of 5



**How many hours a day do you spend taking care of your child?**

# Has caring for your CSHCN affected your employment?





# Next Steps

- Conduct additional interviews
- Additional analysis and validation of measures
- Apply for funding to conduct a statewide or national study
- Collaborate with *PADRES E HIJOS EN ACCIÓN* to develop a culturally and linguistically appropriate respite intervention to improve family and caregiver outcomes among Latinx families of CSHCN
- Share findings to inform recommendations for funding and public policy at the State and National level

# THANK YOU!

To learn more about the work of  
PADRES E HIJOS EN ACCIÓN, visit:

<https://padresehijosenaccion.org/>

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