



Pathways to Autism Diagnosis: Lived Experience of Hispanic Immigrant Families



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Team



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Hispanic children at risk for ASD face...



**Lower rates of
diagnosis**



Later diagnosis



**More significant
symptoms**



**Less emphasis on
developmental
concerns**



**Less likely to
receive treatment**



**Lower quality
treatment**

Project Aims

01

To explore **parent's experience** of autism spectrum disorder and early concerns about child behavior

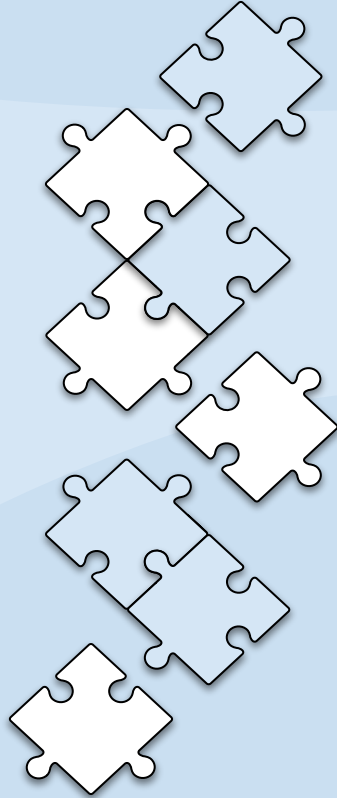
02

To describe **interactions with the US healthcare system** during the screening and diagnostic process

03

To understand barriers and facilitators to **service referral and access** following a child diagnosis

Methods



Qualitative approach

- Realist and deductive

Interviews

- Caregivers of autistic children (informed consent and demographic forms)
- Semi-structured interview guide
- Written in English and translated in Spanish

Directed content analysis

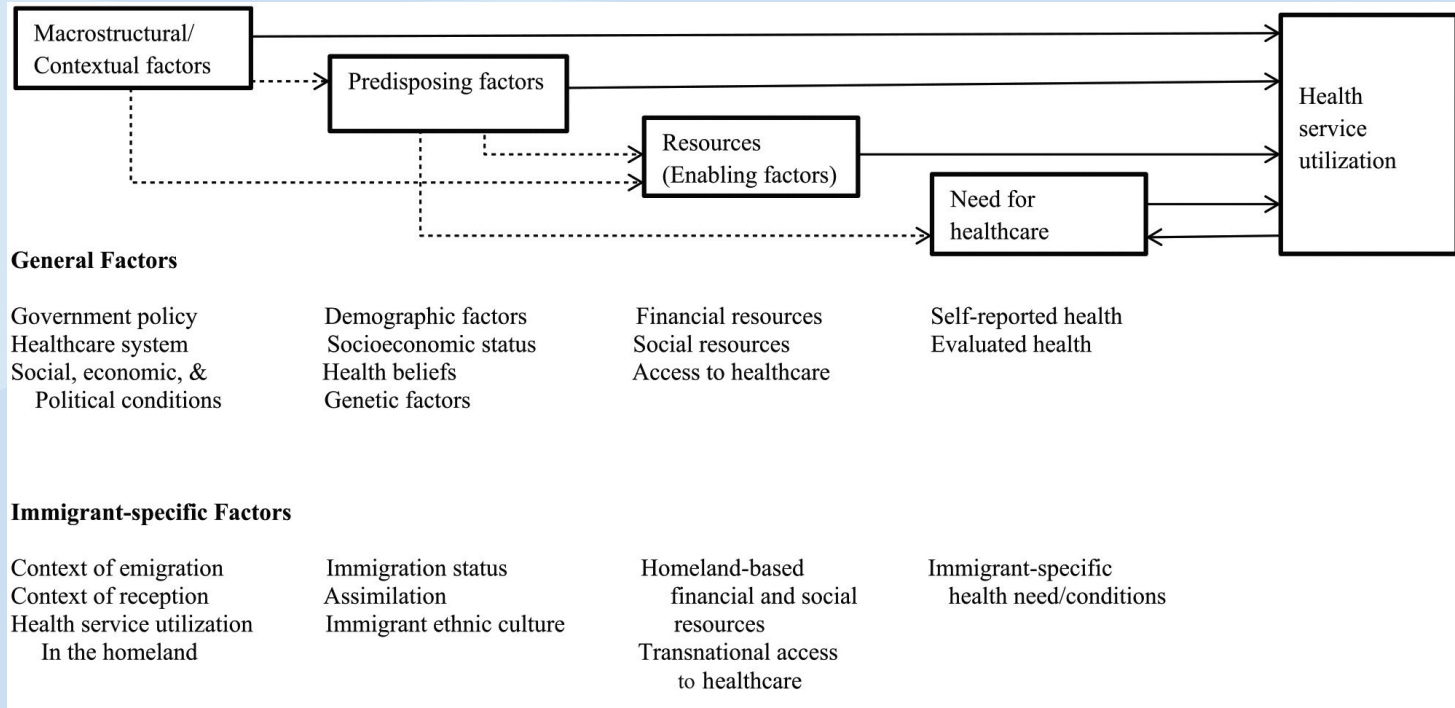
- Theoretical framework independently coded by two researchers
 - Utilizing to code interviews



Interviews

- Maximum of 90 minutes
- Culturally adapted interview guide to Spanish
- Tested questions with practice participant before actual recruitment
- Importance of positionality

Qualitative Coding



Culturally Appropriate Adaptation



CAREGIVERS OF CHILDREN ON THE AUTISM SPECTRUM NEEDED FOR INTERVIEW STUDY

WHAT ARE THE GOALS OF THIS RESEARCH STUDY?

The purpose of the study is to learn more about the experience of caregivers who have a child diagnosed with ASD. We also want to better understand what is working well in healthcare in the US.

WHO CAN BE A PART OF THIS STUDY?

This study is open to primary caregivers of a child (aged 3-17) who has been diagnosed with autism spectrum disorder in the last year. To be able to participate you must have immigrated to the US and identify as Hispanic.

WHAT WILL PARTICIPANTS BE ASKED TO DO?

In this study staff will ask you about your experiences as a caregiver of a child with ASD. This is a one-time interview will last about 60-90 minutes in either Spanish or English. This study will take place virtually with a secure video link or in-person.

Participation in the research study is voluntary and will not affect any services that you or your child may be receiving at CHOP. You are free to withdraw from the program at any time

I WANT TO HELP! WHO DO I CALL?

If you are interested in participating in the study or want to learn more about it please contact:

Stacey Bevan, MA, RN
Study Coordinator
stbevan@upenn.edu
979-676-6838

Visit [Research Discovery Finder](http://Research.Discovery.Finder@www.research.chop.edu/Studies)
[@www.research.chop.edu/Studies](http://www.research.chop.edu/Studies).



SE NECESITAN CUIDADORES DE NIÑOS EN EL ESPECTRO AUTISTA PARA UN ESTUDIO DE ENTREVISTA

¿CUÁL ES EL PROPÓSITO DE ESTE ESTUDIO DE INVESTIGACIÓN?

El propósito de este estudio es aprender más sobre la experiencia de los cuidadores que tienen un niño diagnosticado con TEA. También queremos comprender mejor lo que está funcionando bien en el sistema de salud en los EE. UU.

¿QUIÉN PUEDE PARTICIPAR EN ESTE ESTUDIO?

Este estudio está abierto a los cuidadores principal de un niño (de 3 a 17 años) que ha sido diagnosticado con el trastorno del espectro autista (TEA) en el último año. Para poder participar, usted debe haber emigrado a los Estados Unidos e identificarse como una persona hispano o latino.

¿QUÉ ES INVOLUCRADO EN ESTE ESTUDIO?

Un personal del estudio le preguntará sobre sus experiencias como un cuidador de un niño con TEA. Le entrevistaremos durante aproximadamente 90 minutos en español o inglés. Podemos reunirnos en persona, por teléfono, o le daremos instrucciones para completar la entrevista por video a través un enlace de web seguro.

La participación en el estudio es voluntaria. No tiene que participar para recibir atención médica en CHOP. Puede parar la entrevista en cualquier momento.

¡QUIERO AYUDAR! ¿A QUIÉN LLAMO?

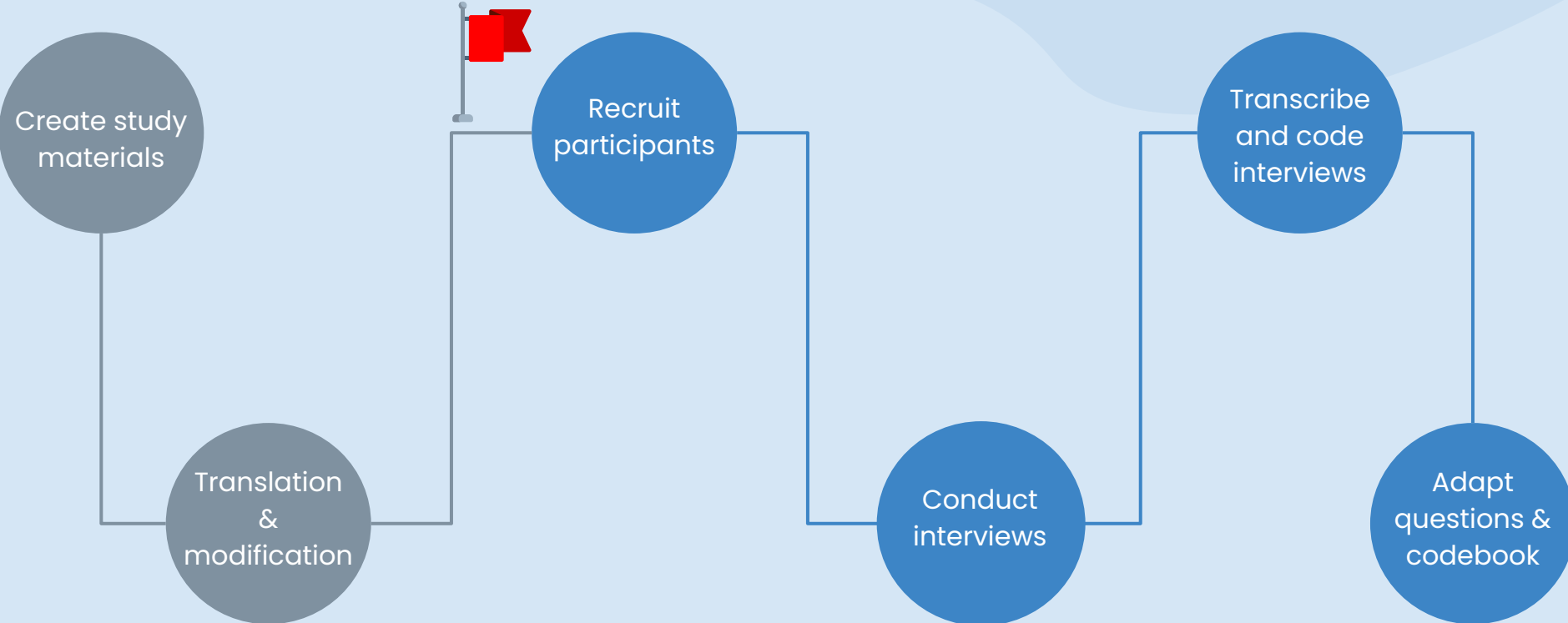
Si está interesado en participar en el estudio o desea obtener más información, llame al:

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[@www.research.chop.edu/Studies](http://www.research.chop.edu/Studies).



Timeline



Implications



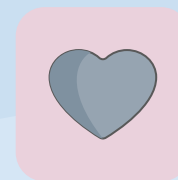
Inform

culturally sensitive
clinical interventions
and improve the
**identification of risk
factors**



Improve

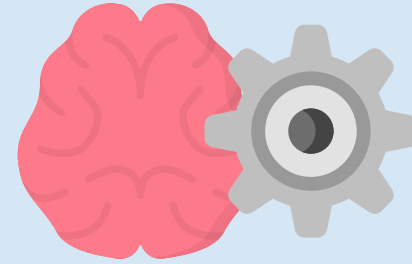
early and accurate
autism diagnoses
through screening
processes in clinical
and community
settings



Support

the creation of
**immigrant and
refugee clinics** to
evaluate and refer for
**mental health
services**

Additional Research Opportunities



Clinical Considerations Paper

- Updating from the last three years
- Clinical considerations for immigrant children at risk/diagnosed with ASD
- Consulted with clinicians
 - Clinical questions
 - Case studies

Sleep Study RCT

- Field visits with caregivers that have at least one child with autism (first 8 weeks)
- Describing and developing clinical care plan for sleeping habits of caregivers and children

Lessons Learned

- Positionality
- Breath of Nursing Profession/Field
- Literature Review
- Writing abstracts
- Exposure to clinical case conferences
- Qualitative and quantitative research participation
- Difference between direct translation and cultural adaptation



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Stacey L. Bevan, MA, RN

Margaret C. Souders, PhD,
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Sleep Study RCT Team

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2023 SUMR Cohort

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Thank you!



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QUESTIONS???

Thanks for listening!