

*Pictures removed from this slide deck for participant anonymity

Autism Diagnostic Process with a Bilingual, Low-Income Latinx Community in Los Angeles: Barriers Families Experience and What We as Providers Can Do to Help

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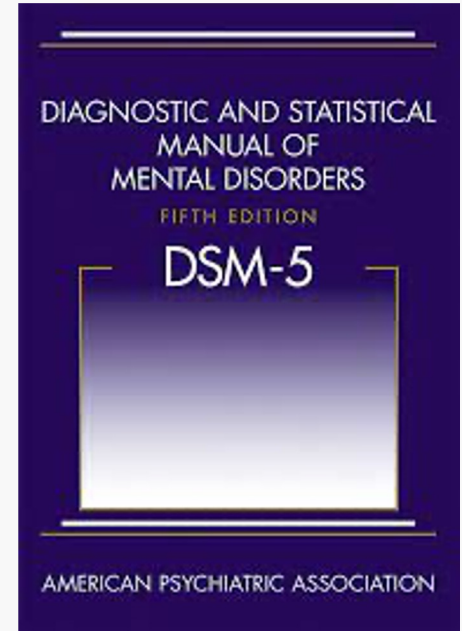
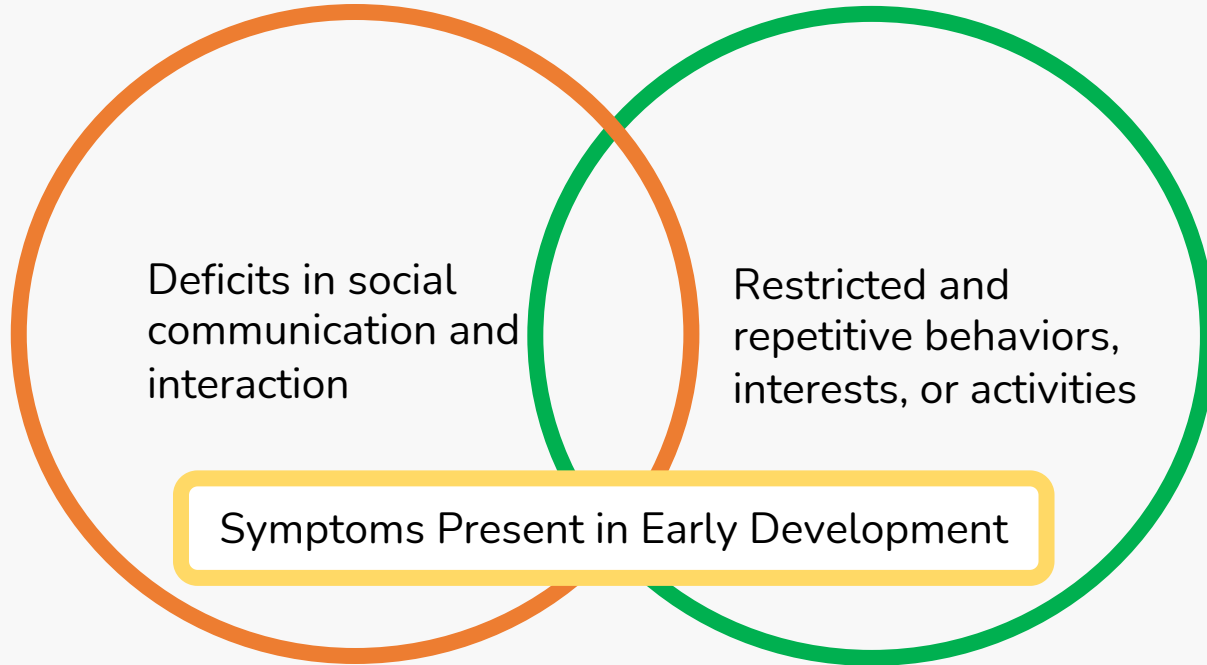
University of California, Los Angeles

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Learning Objectives

1. Identify barriers that bilingual, low-income Latinx families in the greater Los Angeles area experience related to early diagnosis and service acquisition
1. Strategies that providers can use to support access to early diagnoses and individualized and targeted treatment

Autism Spectrum Disorder



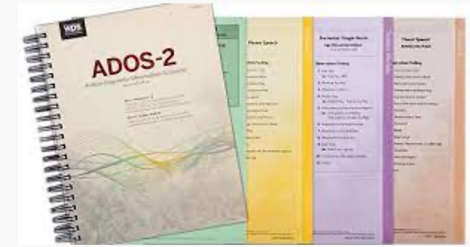
The Diagnostic Process

High quality comprehensive autism assessments should include the following:

1. Direct observation of the individual being assessed
2. Caregiver and (teacher/provider when possible) interviews and questionnaires that capture the individual's developmental history and current behaviors such as:
 - Social communication
 - Restricted interests, repetitive behaviors
 - Adaptive skills
 - Behavior problems
 - Language use
3. Cognitive testing

The ADOS-2

- The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) is a clinician-administered, standardized, semi-structured observation used to inform a diagnosis of autism
- Different modules for different age levels and expressive language abilities
- Used in several contexts such as school and clinics
- Translated to many languages including Spanish, but not validated



Latino Population in the U.S.

- Latino population = largest minority (19% of population)
- Spanish is the most common language other than English (U.S. Census Bureau, 2022)

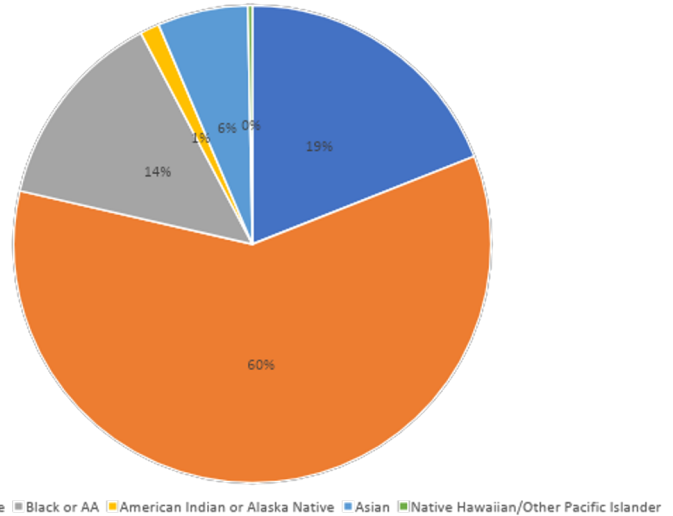
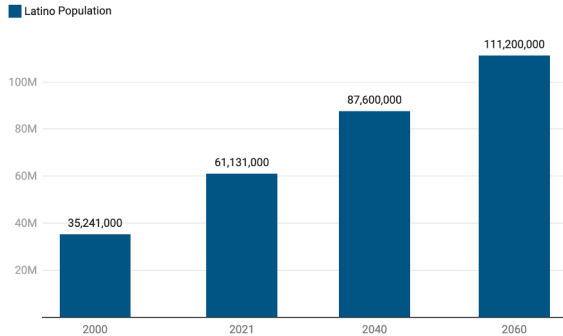


Figure 1. Projected Growth of the Latino Population by Number and Share, 2000-2060



Bilingualism and ASD



- Belief that two languages would confuse children with ASD (data has not supported this belief)
- Majority of the literature is cross-sectional and has focused on comparing language abilities (both expressive and receptive) between bilingual and monolingual children
- Limited research on the use of the ADOS-2 with bilingual populations

Hypothetical case:



A family of a child who is 24 months old is referred to a clinic to be assessed for ASD. Parents speak mostly Spanish and the primary language in the home is Spanish. The child is attending daycare, where he is exposed to both Spanish and English. The child's older siblings speak both English and Spanish with each other, and the child is exposed to English on his electronic devices. The child speaks in single words, sometimes Spanish and sometimes English. The clinician is unsure about how to approach the assessment of this patient. Should they:

- A. Do the assessment in English
- B. Do the assessment in Spanish (or refer out if clinician doesn't speak Spanish)
- C. Do it in both English and Spanish (or refer out to someone who can do both)

Research Questions

1. Will the presentation (severity of symptoms in social affect and restricted and repetitive behaviors) differ depending on their dominant language and language of the ADOS-2 administration?
1. Will bilingual individuals be correctly identified as autistic if the assessment is done only in English or Spanish?

Participants

Our goal is to recruit about 100 participants from early childhood to adulthood with different expressive language levels

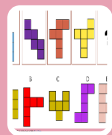


Recruitment



- Schools, regional centers and local autism associations such as community non-profits that work with the Latinx population in Los Angeles
- The Center for Autism Research and Treatment (CART) and the Tarjan Center
- Autism resource fairs
- Community based clinics
- Word of mouth

Time 1



Cognitive
Assessment



ADOS-2 (Spanish
or English)



BESA



BOSA

Time 2



ADOS-2 (Spanish
or English)



BOSA

Time 3



Feedback



Reports

Incidental Findings

Barriers

- Limited access to evaluations and services (long waitlists, no availability)
- Misinformation (age of diagnosis, levels of ASD, strengths and challenges, language level, co-occurring diagnoses of ID, service acquisition, virtual/quick evals)

What we as providers can do

Cultural Sensitivity

- Clinicians (language, relatability, family systems approach)
- Materials (dolls, books)
- Clinical questionnaires (online vs in person)
- Consent and compensation (for research)

Communication

- Ensuring information is delivered in an accessible way (language and formality)
- Phone calls as the primary mode of communication, text, email (though usually not preferred)
- Flexibility about time of communication
- Letting participants call in from flexible locations
- Being responsive

Flexibility

- Siblings being present (toys, snacks)
- Location
- Space where the ADOS occurs
- Dinner time

Feedback

- Language
- Discussing strengths and challenges, not focusing only on the diagnosis
- Concrete and individualized recommendations
- Calling providers to verify they are taking clients, that it fits the families' needs
- Emphasizing re-evaluations, especially for younger children

1. **Centro regional:** Se recomienda a la familia de [Name] que se haga cliente de su centro regional local bajo la clasificación diagnóstica de trastorno del espectro autista dado el diagnóstico de TEA de [Name] y los retrasos en su desarrollo y funcionamiento adaptativo. Los servicios y recursos que no están cubiertos por su seguro médico pueden ser proporcionados por el centro regional. Aunque es probable que muchos de los servicios de [Name] se cubran a través del distrito escolar, será útil a largo plazo que [Name] siga siendo cliente del Centro Regional durante toda su vida para seguir teniendo acceso a los servicios. Este informe debe compartirse con el Centro Regional local de la familia.

Llame al Centro Regional de Orange County al (714) 796-5354 o mande un correo al intake@rcocdd.com.

2. **Plan Educativo Individualizado.** [Name cumple los requisitos para un IEP en virtud de la elegibilidad del trastorno del espectro autista. Los padres de [Name] deben ponerse en contacto con el colegio de [Name] y solicitar que sea evaluada para establecer su IEP. Este informe también debe ser compartido con su escuela para informar de las modificaciones apropiadas a su IEP. Recomendamos especialmente lo siguiente: terapia del habla diaria en persona, apoyos visuales para ayudarlo a seguir instrucciones y actividades en la clase, y rutinas estructuradas y predecibles.

3. **Análisis aplicado del comportamiento (ABA):** El ABA es un tipo de intervención que se utiliza con niños con discapacidades del desarrollo. ABA puede utilizarse para mejorar una serie de habilidades, incluidas las relacionadas con el lenguaje, la socialización, el juego y la vida adaptativa. [Name] se beneficiaría de un proveedor de ABA que individualizara los objetivos para aprovechar los puntos fuertes de [Name] y centrarse en las áreas con dificultades. El centro regional debería de ayudarlo a acceder ABA ya que sea cliente. También puede contactar a TASKids al 714-683-5876 para ver si aceptan su aseguranza.

4. **Servicios de habla y lenguaje:** Dados los retrasos de [Name] en el lenguaje en comparación con compañeros de edad similar, [Name] se beneficiaría de intervenciones intensivas de habla y lenguaje para desarrollar sus habilidades de lenguaje expresivo y receptivo. [Name] debería recibir 1 hora diaria de tratamiento centrado en el desarrollo de su comunicación.
5. **Terapia de interacción entre padres e hijos (PCIT):** PCIT es un tratamiento basado en evidencia diseñado para ayudar a los niños con conductas disruptivas a aprender a controlar su frustración. PCIT a menudo se conceptualiza como un programa de formación de padres porque el terapeuta proporciona a los padres instrucciones sobre cómo guiar y dirigir de manera efectiva los comportamientos de sus hijos, establecer límites, disciplinar con calma y restaurar sentimientos positivos en sus interacciones. [Name] y su(s) cuidador(es) se beneficiarían del PCIT para tratar la desregulación emocional y el comportamiento oposicionista de [Name].
- El Child and Guidance Center (CGC) es un proveedor de PCIT en el Condado de Orange County: 714-953-4455
6. Los cuidadores de [Name] también podrían considerar participar en los siguientes grupos de apoyo para padres:
- Un grupo de apoyo mensual específico para padres de niños con trastornos del neurodesarrollo ofrecido a través del Centro de Autismo y Trastornos del Neurodesarrollo de la UCI.
 - o Se reúne cada tercer jueves del mes de 6pm a 7:30pm.
 - o Teléfono (949-267-0442), Correo electrónico: Marlene Cuevas: mcuevas3@hs.uci.edu
 - Zoom Webinar- Autismo 101 con CHOC Thompson Autism Center
 - o Costo: \$20 por familia
 - o Fecha: El último martes de cada mes
 - o Teléfono: 949-267-0200, Correo electrónico: centertraining1@uci.edu
7. **Reevaluación en 1-2 años:** [Name] es todavía joven y esperamos que muchos aspectos de su comportamiento e interacciones sociales cambien en los próximos años. Por lo tanto, recomendamos que permanezca en la lista de espera del Centro de Autismo y Trastornos del Neurodesarrollo de UCI y que reciba una evaluación completa en un centro clínico.

1. Modified cognitive behavioral therapy (CBT) for ASD. We strongly recommended that [Name] work individually with a clinician who can provide modified CBT for individuals with ASD. We recommend that her treatment include helping [Name] practice coping skills to ameliorate symptoms of anxiety and depression, social skills training (e.g., helping her pay attention to the social feedback others are giving her), and weekly assignments to continue to help her develop greater independence with her activities of daily living.

[Name] and her family could consider contacting Resilience Psychological Collaborative, Inc, as this clinic has two licensed CBT providers with experience treating autistic individuals experiencing symptoms of anxiety and depression. <https://www.resiliencepc.com/about-us/> (805) 703-5330

[Name] may also consider engaging in short-term, virtual CBT treatment delivered by a psychology trainee (16-24 sessions) at the UCLA CAN Clinic. To be placed on their waitlist, please use the following contact information: Contact: 310-794-4008 or canclinic@mednet.ucla.edu.

2. Social skills intervention and activities. A social skills program is strongly recommended for [Name] to build confidence in her interactions with others. The treatment should be based on explicit skill-building. [Name]'s family should also be included in learning the specific strategies in order to support her skill development outside of the clinic setting.

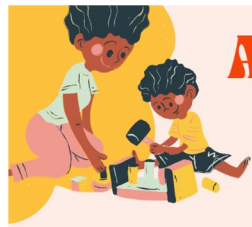
One such program is the UCLA Program for the Education and Enrichment of Relational Skills (PEERS®), which is a 16-week evidence-based program for young adults with social challenges. In particular, [Name] should consider joining PEERS for CAREERS, a program focused at supporting individuals with career related social interactions. Phone: (310) 267-3377/ Email: peersclinic@ucla.edu.

3. Continued Medication Management. [Name] is encouraged to continue medication management with her current provider to address symptoms of depression. Medications should be maintained in conjunction with psychotherapy. Under appropriate management, medications are expected to continue to help [Name] better engage in and benefit from other treatments.

3. Continued Monitoring. [Name] and her providers should continue to monitor her social, emotional, and behavioral development. If adequate progress is not being made or if new concerns arise, a change in her treatment regimen may be warranted.

Myths

- “They aren’t looking for services”
- “They aren’t committed”
- “They aren’t interested in research participation”
- “Families think speech therapy time is a time for them to vacuum or wash dishes”



Are you or your child Spanish-English bilingual AND have autism (or think they may have autism)?

YOU MAY BE ELIGIBLE FOR A RESEARCH STUDY AT UCLA THAT WILL ADMINISTER THE FOLLOWING AUTISM ASSESSMENTS IN YOUR HOME OR COMMUNITY:

- ✓ ADOS-2
- ✓ Caregiver Interview
- ✓ Cognitive testing
- ✓ and more!

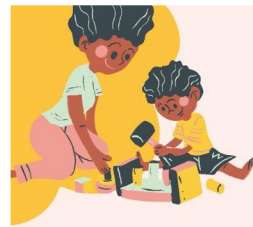
You can receive up to \$100.00 in compensation!



**FOR MORE INFORMATION EMAIL
MTAFOLLA@MEDNET.UCLA.EDU**

Protocol ID: IRB#23-000535 UCLA IRB Approved Approval Date: 5/2/2023 Committee: Medical

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Tu o tu hijo tienen autismo (o piensan que tienen autismo) Y son bilingüe en Español-Ingles?

PUEDES SER ELEGIBLE PARA UNA INVESTIGACION CIENTIFICA EN UCLA DONDE RECIBIRAN LAS EVALUACIONES DE AUTISMO SIGUIENTES EN SU CASA O EN LA COMUNIDAD:

- ✓ ADOS-2
- ✓ Entrevista al cuidador
- ✓ Evaluación Cognitiva
- ✓ y mas!

Puedes recibir hasta \$100.00 en compensación!



**PARA RECIBIR MAS INFO MANDA CORREO A
MTAFOLLA@MEDNET.UCLA.EDU**

Protocol ID: IRB#23-000535 UCLA IRB Approved Approval Date: 5/2/2023 Committee: Medical

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Thank you!

Special thanks to the families who have participated and shared their stories with us!

This project would not be possible without our PI, Dr. Catherine Lord, and support from WPS.

Special shoutout to Juliette Lerner for all of her help!

For questions or referrals, please email
mtafolla@mednet.ucla.edu

Questions?