

# VALIDATION OF THE ADI-R WITH LATINO POPULATIONS

Sandy Magaña

# DISCUSSION OVERVIEW

- ⦿ Background on the issue
- ⦿ Previous study with adolescents and adults:
  - brief description of study examining comparison between whites and Latinos in on the ADI-R
- ⦿ Current NIH R03 study examining ADI-R for Spanish speaking Latinos
  - Preliminary results
- ⦿ Overcoming diagnostic issues

# BACKGROUND

## ⦿ Research shows:

- Some groups are less likely to be diagnosed with autism than Whites in US
  - CDC data show that some minority groups less likely to have a diagnosis of an ASD in their health records
  - Does not necessarily mean lower prevalence
- Reasons for Disparities in diagnosis
  - Limited information about DD and autism in different immigrant and minority communities
  - Financial and insurance barriers
  - Lack of multi-lingual speaking clinicians
  - Diagnostic instruments not validated for different groups

## ◉ Additionally

- Instruments are needed to accurately assess autism among different cultural groups
  - Keeping in mind different contexts; I.E. context may be different between countries like Spain versus Latin American Countries versus US Latinos even though the same language is used.
- Whatever the country or context, education levels need to be taken into account in adaptation of instruments

# DIFFERENCES IN DIAGNOSTIC PATTERNS BETWEEN LATINOS AND WHITES WITH AUTISM

- ◉ Published in the Journal of Autism and Developmental Disorders
- ◉ Co-Author- Leann Smith
- ◉ Data from 2 studies:
  - AAA Adolescents and Adults with Autism
    - ◉ NIA (R01 AG08768) PI Marsha Seltzer
  - Latino families of Children on the Autism Spectrum
    - ◉ Center for Disparities in Health at UW-Madison School of Medicine and Public Health
    - ◉ Institute on Race & Ethnicity
    - ◉ Waisman Center

# PREVIOUS ANALYSIS & CURRENT STUDY

- ◉ Focus on ADI-R as one instrument that needs to be validated for Latinos
- ◉ There are many others that should be validated, but have to start somewhere
- ◉ Cultural differences may be more relevant (than for example with the ADOS) because it relies on interviewer coding of parent responses

# AUTISM DIAGNOSTIC INTERVIEW- REVISED

- ⦿ Considered to be “gold standard” in assessing and diagnosing autism
- ⦿ Standardized, semi-structured investigator-based interview for caregivers of persons with autism
- ⦿ Evaluates 3 functional domains:
  - Language and communication
  - Reciprocal social interaction
  - Restrictive and repetitive behaviors

# ADI-R SPANISH

- ◉ Spanish version used back translation and iterative methods
  - Currently in clinical use
  - Validity of ADI-R not established with English or Spanish Latino populations
  - Valid use of instruments requires more than translation
    - Obtaining cultural equivalence is important
    - Items must have same meaning across cultures

# METHODS: SAMPLE

- ◉ Sample of 48 Latina mothers and 96 non-Latino White mothers matched on:
  - Whether they were verbal
  - Had an intellectual disability
  - youth or adolescent between 10 and 21 years old
- ◉ Sample from studies conducted in Wisconsin and Massachusetts
- ◉ Latino sample:
  - 85% of mothers were foreign born
  - 69% were interviewed in Spanish
  - Majority of mothers of Mexican (33%) or Puerto Rican (41.7%) descent
  - Remainder from Caribbean, Central or South American countries
  - Majority of children born in the US

# METHODS CONT.

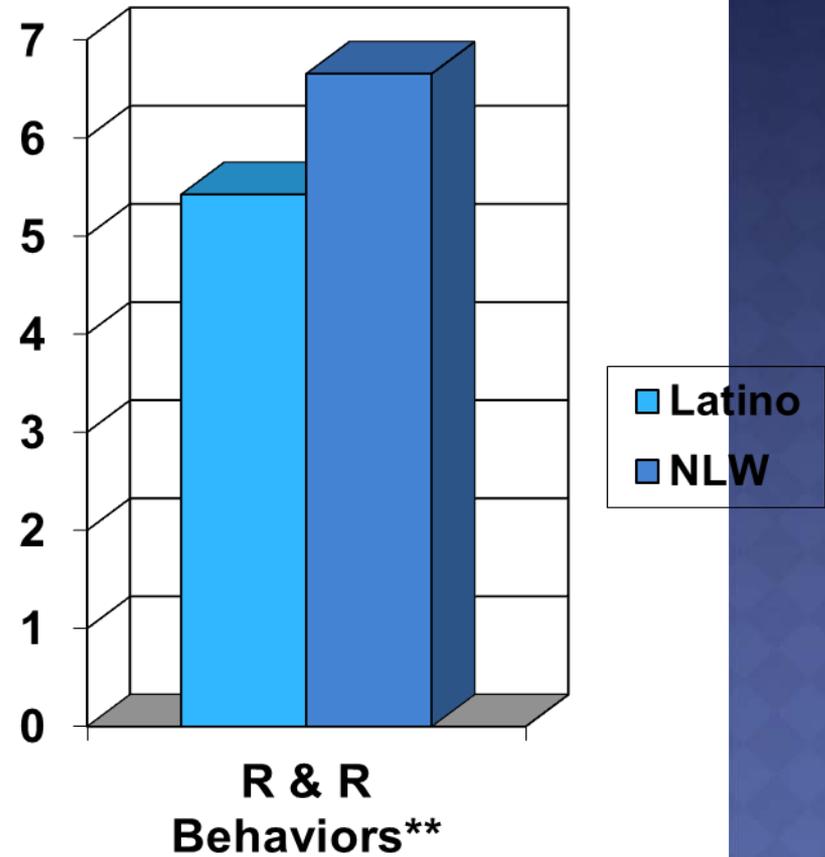
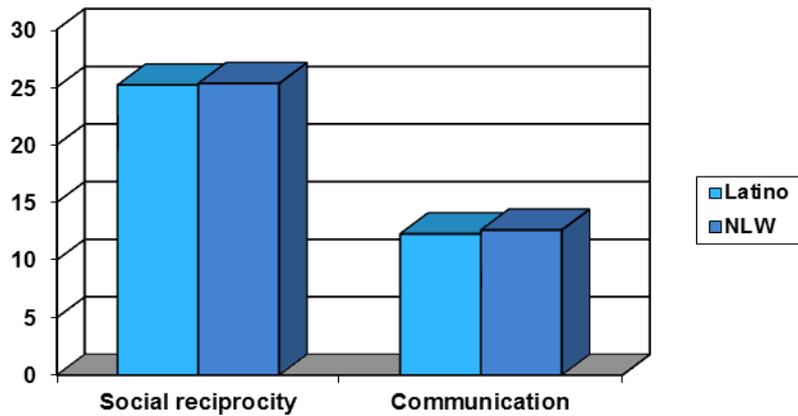
## ⦿ Procedures:

- All participants interviewed in their homes
- Interviewers trained by researchers certified in use of the ADI-R for research
- Interviews conducted in language of preference

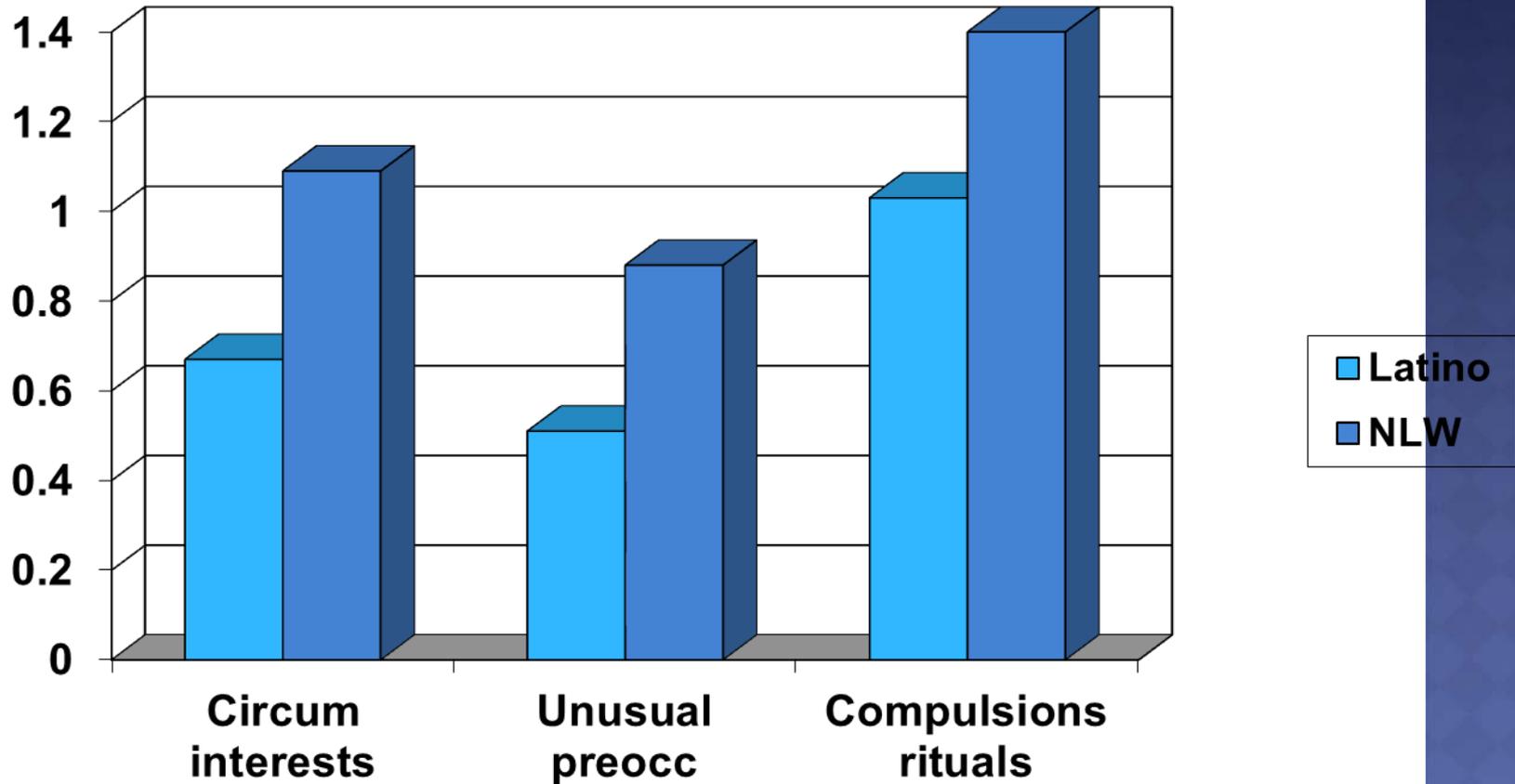
## ⦿ Measures

- ADI-R
  - Used 36 ADI-R items that comprise diagnostic Algorithm
  - Interviewers code caregiver descriptions as
    - 0- no abnormality
    - 1- possible abnormality
    - 2- Definite autistic type abnormality
    - 3- Severe autistic type abnormality
  - Scores of 3 recoded to 2 (as done in diagnosis determination)
- Other demographic information gathered in questionnaires:
  - Education, gender, intellectual disability, child age

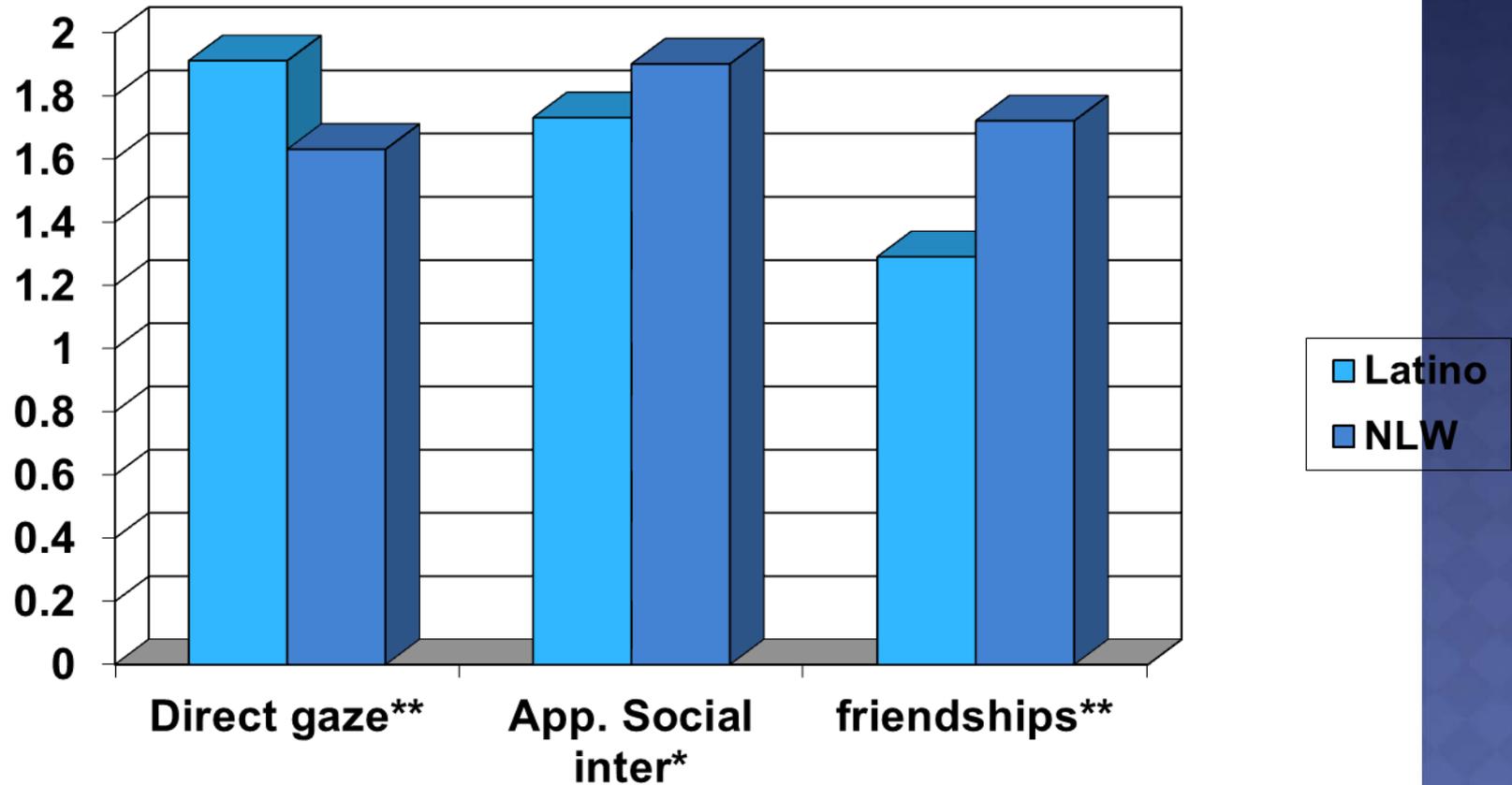
# RESULTS: LIFETIME SUMMARY SCORES ADJUSTING FOR MATERNAL EDUCATION



# DIFFERENCES IN RESTRICTIVE & REPETITIVE BEHAVIORS



# DIFFERENCES IN SOCIAL RECIPROCITY ITEMS



# SUMMARY OF RESULTS

## ◉ Findings

- No differences in summary scores for social reciprocity, verbal and non-verbal communication
- Some differences in social reciprocity items (mixed directions)
- Significant difference in restrictive & repetitive behaviors summary score (Latinos less impaired)
- Similar means across groups for the vast majority of items

## ◉ Practical Implications

- Have to learn more about whether we are measuring cultural differences in parental expectations
- Or actual differences in behaviors
  - In this case is the difference due to cultural contexts?

# AIMS OF NEW STUDY

- ◉ Replicate with Spanish speaking families validity study conducted in 1994 by Cathy Lord for the ADI-R
  - Aim 1. To assess the reliability of the Autism Diagnostic Interview Revised (ADI-R) Spanish version among Spanish-speaking parents of children with autism and intellectual disabilities
    - ◉ Assess interrater reliability of interviewers

# AIMS

- Aim 2. To investigate the validity of the Autism Diagnostic Interview Revised (ADI-R) in a sample of Spanish-speaking parents of children with autism and intellectual disabilities
  - Sample- 25 children with ASD diagnosis, 25 children with other DD or delay, ages 4-16
  - Diagnoses based on established algorithms will be compared to a clinical diagnosis to assess discriminant validity
  - Items and summary scores will be compared across 2 groups of children

# AIMS

- Aim 3. To investigate the meaning and perceived severity of symptoms in relation to the norms of participant's family and culture
  - Open ended questions about what symptoms and issues initially concerned parents about their child, and what symptoms are presently more bothersome to the parents and family will be analyzed using qualitative methods.
  - This analysis will provide information that may help in the interpretation of quantitative findings.

# AIM 2 IS FOCUS OF PRESENTATION

## ◉ Challenges in methodology

- Did not have funds to conduct diagnosis ourselves
  - ◉ Gold standard is to have children evaluated by 2 clinicians who come to consensus on dx
  - ◉ Study in Madison: goal was to ensure all kids seen at Waisman Center where consensus dx is routinely made
    - Problem is most of the kids recruited were not seen at Waisman in the past and had to be referred
    - Long waiting lists, some kids still not seen when I left Madison
  - ◉ Study in Chicago, families seen at a variety of clinics who conduct evaluations differently

# PRELIMINARY RESULTS

- Have conducted 34 ADIs in Madison and Chicago
  - 21 have a diagnosis of an autism spectrum disorder
  - 9 have another diagnosis
    - 3 with Down Syndrome, 2 with ADHD, 4 with ID
  - 3 had no diagnosis at time of interview
  - Average age: 9
  - Percent male: 73.5
  - 53% of diagnoses were confirmed with medical records (still in the process of collecting)

# ALL CATEGORIES

	All ASD	Autism only	Other ASD	Other diagnosis	No diagnosis
Meets All ADI criteria for autism	16 (72.7%)	13 (86.7%)	3 (42.9%)	5 (55.6%)	1 (33.3%)
Meets all but R&R behaviors	3 (13.6%)	1 (6.7%)	2 (28.6%)	2 (22.2%)	1 (33.3%)
Did not meet ADI criteria	3 (13.6%)	1 (6.7%)	2 (28.6%)	2 (22.2%)	1 (33.3%)

# DIAGNOSTIC VALIDITY

Of ADI	Sensitivity	Specificity	Positive predictive value	Negative predictive value
Autism only	86.7	47.4	56.5	81.8
All ASD	72.7	41.7	69.6	45.5
Of clinic dx				
Autism only	56.6	81.8	86.7	47.4
All ASD	69.6	45.5	72.7	41.7

- Sensitivity- proportion of those with ADI AD among those with clinical AD (true positive rate)
- Specificity- proportion of those with ADI non-AD among those with clinical non-AD (true negative rate)
- PPV-proportion with clinical AD among those with autism AD
- NPV- proportion with clinical non-AD among ADI non-AD

# NEXT STEPS FOR ANALYSIS

## ◉ Discriminate validity

- Will compare each domain and each item between those with and without dx of autism

## ◉ Reliability-

- have had 3 interviewers who are reliable at 90% level with trainers
- Will conduct reliability checks within our reviewer group on 10-20 cases

## ◉ Qualitative- what was first noticed

- 5 out of 6 said language delays, 1 said child did not want to socialize with other children
- Average age first noticed: 2

# IMPLICATIONS

- ⦿ Keeping in mind data is preliminary
  - Learned that Latino children are not receiving consistent clinical diagnoses
  - some children may not be given clinical diagnosis of autism when then should, or are getting clinical diagnosis of autism when they shouldn't
  - Difficult to determine diagnostic validity of ADI-R with out sufficient resources to ensure consensus diagnosis

# ENSURING ACCURATE DX OF LATINO CHILDREN

- Observed the following problems in clinical dx:
  - Clinics that do not have bilingual clinicians
  - Clinics that have bilingual clinicians who are not trained in gold standard assessment tools
  - Clinicians who do not conduct assessments because tools are not validated in Spanish
  - Spanish speaking parents who receive accurate diagnosis often know little about what it means years later
    - Clinics need to provide written and verbal information in Spanish

# BEST PRACTICES FOR DIAGNOSIS WITH SPANISH SPEAKING PARENTS

- Hire bilingual clinicians and provide training in autism assessment (if not already trained)
- If bilingual clinicians are not yet trained, have them pair up with trained clinicians to conduct assessments together
- If no bilingual clinicians, conduct assessments with a trained interpreter when needed-this is better than not conducting at all
- Biggest issue is communicating with parents on the diagnosis, treatment and follow-up