

Cultural Competence in ASD Assessment and Diagnosis

Amy Esler, Ph.D., L.P.
Sheri Stronach, Ph.D., CCC-SLP
October 24, 2013



UNIVERSITY OF MINNESOTA

Driven to DiscoverSM

Learning Objectives

- Learn about differences in autism spectrum disorder (ASD) prevalence across cultural groups
- Discuss identified barriers to identification of ASD for diverse families
- Understand research on racial/ethnic differences in characteristics of children with ASD
- Discuss how culture might impact behaviors important for diagnosing ASD



ASD as a neurobiological disorder

- Defined completely on the basis of behavior
- No neurobiological marker yet
- Assumed to result from several causes, but with a strong genetic component
- Includes a tremendous range of difficulties
- A lifelong disorder, though prognosis is improving

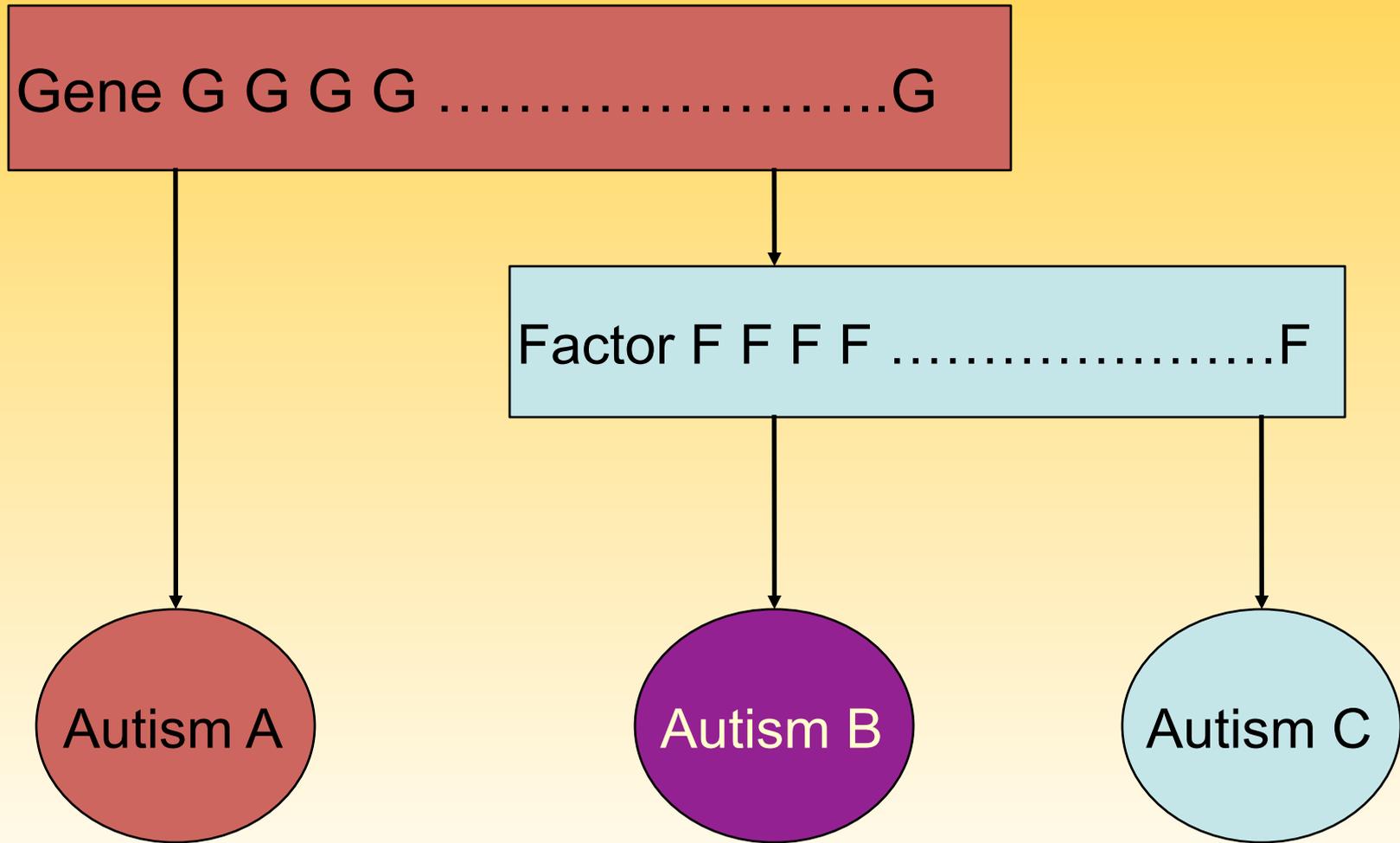


Etiology of ASD: Genetics

- Enormous resources have gone into molecular genetics of autism in the last 15 years
- Initial findings indicated high concordance for some kinds of ASD within identical twins, but not DZ
- Recurrence in families with one child with ASD is 18%
 - Finding from the Baby Sibs Research Consortium (Ozonoff et al., 2011)
 - Also associated with higher rates of speech-language and other impairments in sibs (Messinger et al., 2013)
- A few replicated findings from genome scans and association studies



There are probably multiple autisms



ASD has often been treated as a culture-free disorder

“There is no other developmental or psychiatric disorder of children (or, perhaps of any age) for which such well-grounded and internationally-accepted diagnostic criteria exist.” --Cohen and Volkmar

“Then why is there still so much confusion about what is and is not autism?” --R. Richard Grinker



Early cultural “research”

- Kanner:

There is one other very interesting common denominator in the backgrounds of these children. *They all come of highly intelligent families.* Four fathers are psychiatrists, one is a brilliant lawyer, one a chemist and law school graduate employed in the government Patent Office, one a plant pathologist, one a professor of forestry, one an advertising copy writer who has a degree in law and has studied in three universities, one is a mining engineer, and one a successful business man. Nine of the eleven mothers are college graduates. Of the two who have only high-school education, one was secretary in a pathology laboratory, and the other ran a theatrical booking office in New York City before marriage. Among the others, there was a free-lance writer, a physician, a psychologist, a graduate nurse, and Frederick's mother was successively a purchasing agent, the director of secretarial studies in a girls' school, and a teacher of history. Among the grandparents and collaterals there are many physicians, scientists, writers, journalists, and students of art. All but three of the families are represented either in *Who's Who in America* or in *American Men of Science*, or in both.



Kanner, con' t

- “One other fact stands out prominently. In the whole group, there are **very few really warmhearted fathers and mothers**. For the most part, the parents, grandparents, and collaterals are persons **strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people**. Even some of the happiest marriages are rather **cold and formal** affairs. Three of the marriages were dismal failures.”



DSM-5 Autism Spectrum Disorder

- Two core symptom domains:
 - (1) Deficits in **social communication** and social interaction
 - (2) **Restricted, repetitive** patterns of behavior, interests, or activities



Social Communication

1. Deficits in **social-emotional reciprocity**; ranging from abnormal social approach and failure of normal back and forth in conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
3. Deficits in **nonverbal communicative behaviors** used for social interaction; ranging from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to total lack of facial expressions and nonverbal communication.
5. Deficits in developing, maintaining, and understanding **relationships**, ranging, from difficulties adjusting behavior to suit various social contexts; through difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

...Culture-dependent?



Restricted, Repetitive Behaviors

1. **Stereotyped or repetitive motor movements, use of objects, or speech** (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. **Insistence on sameness, inflexible adherence to routines, or ritualized patterns** of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, needing to take same route or eat same food every day).
3. **Highly restricted, fixated interests** that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. **Hyper-or hypo-reactivity to sensory input** or unusual interest in sensory aspects of environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

...Universally atypical?



ASD Prevalence Across Cultural Groups



Ethnicity, Race, & Culture

- Ethnic Group:** a group of individuals who share a common language, heritage, religion, or geography/nationality
- Race:** historical classification system based on biological features, e.g. skin color
- Culture:** consists of social practices, beliefs, values, and behaviors that members of a group use to communicate and interact





Prevalence Estimates

CDC ADDM Network estimates:

2000: 1/150 (6 sites)

2002: 1/150 (14 sites)

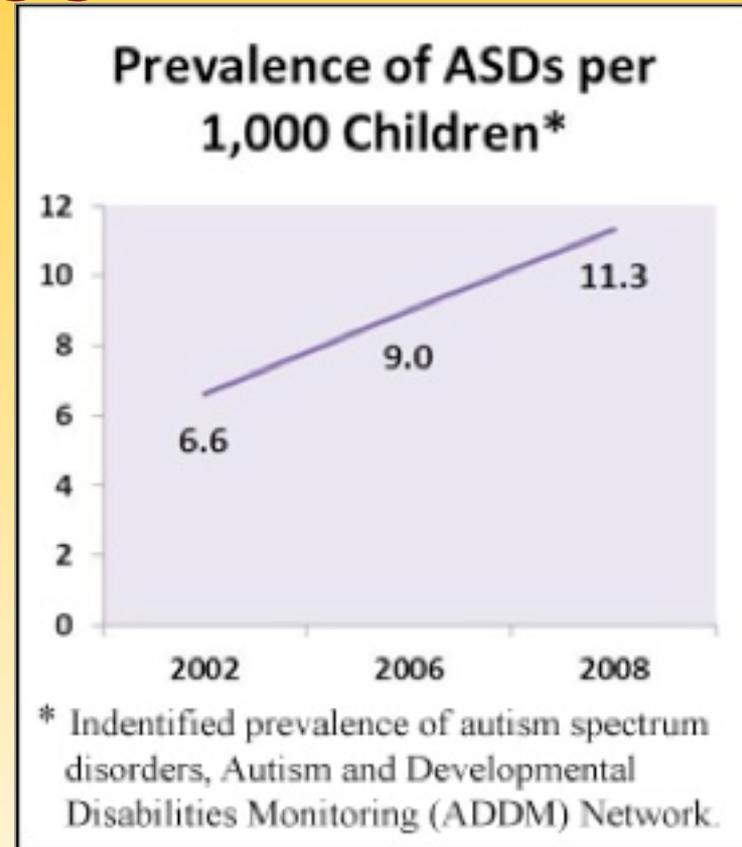
2004: 1/125 (8 sites)

2006: 1/110 (11 sites)

2008: 1/88 (14 sites)

Other estimates:

1 in 38 in South Korea (2006)
(Kim et al., 2011)



Truly rising rates or better identification?





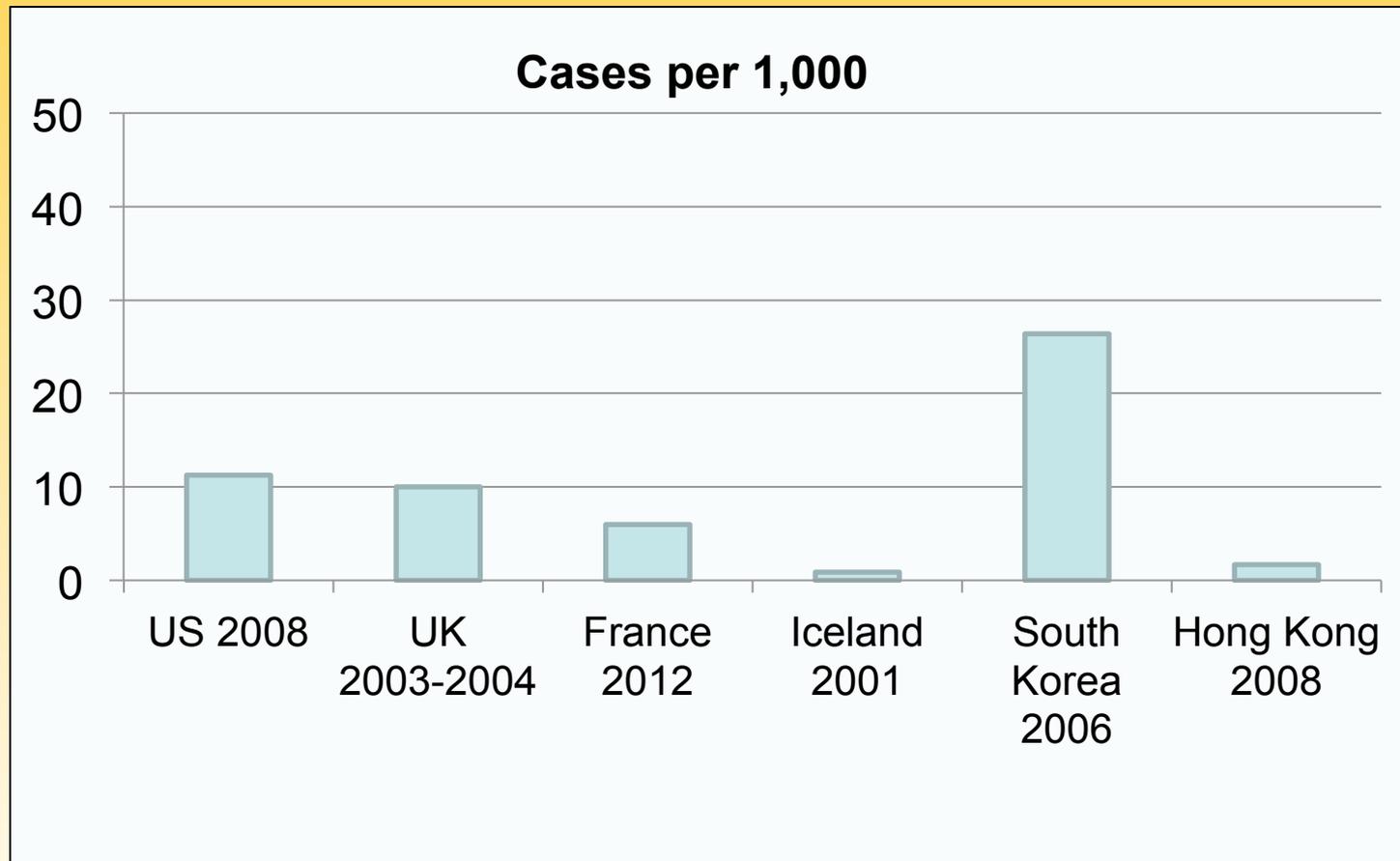
Demographics of ASD

- 4.6 times more prevalent in males than females (CDC, 2012)
- Intellectual Disability: 37% males, 46% females
- Present across race/ethnicity
 - White-to-black: 1:1.2
 - White-to-Hispanic: 1:1.5
 - Black-to-Hispanic: 1:1.3
- Average age of diagnosis
 - All ASDs: 69 months
 - Autism: 48m, PDD: 44m, Asperger: 75m



Evidence for cultural differences?

Prevalence across countries

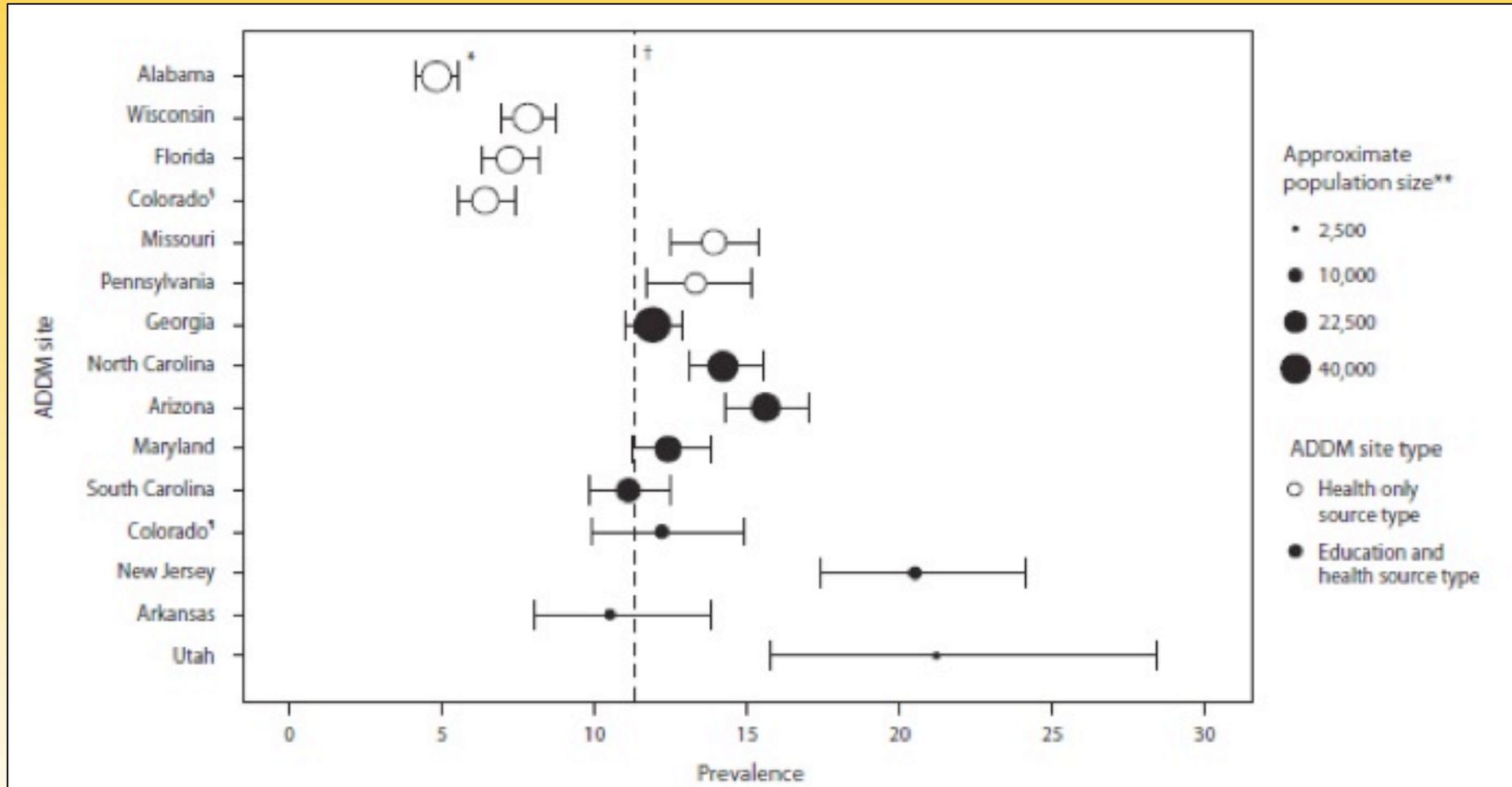


Methodological differences account for differences in prevalence across countries

- Accuracy affected by increased child mortality, poverty, health
- Some cultures may group ASD under another category
- Inconsistent medical record-keeping
- Integration of children with disabilities into society can affect ascertainment



Prevalence differed across CDC sites



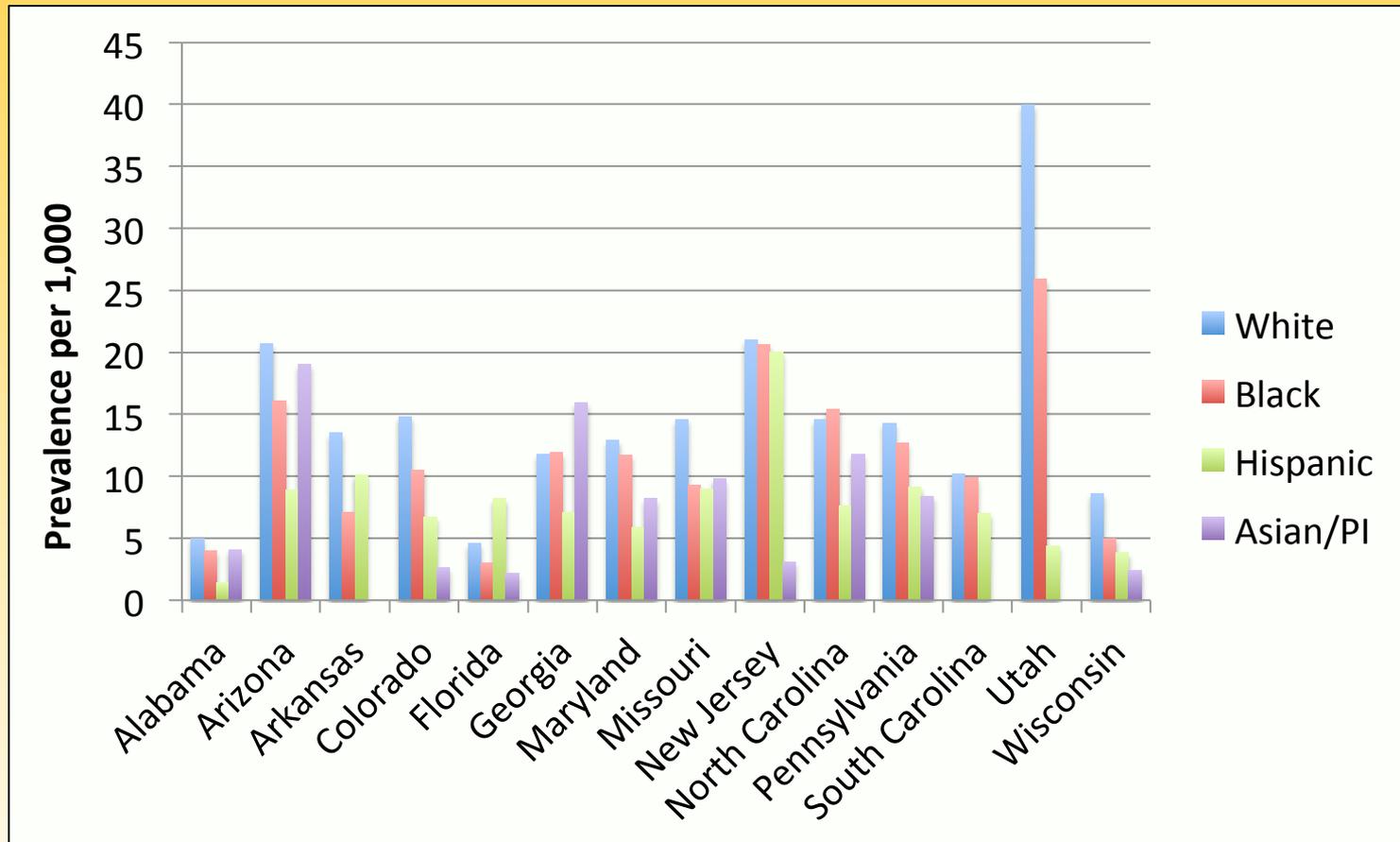
Cases per 1,000



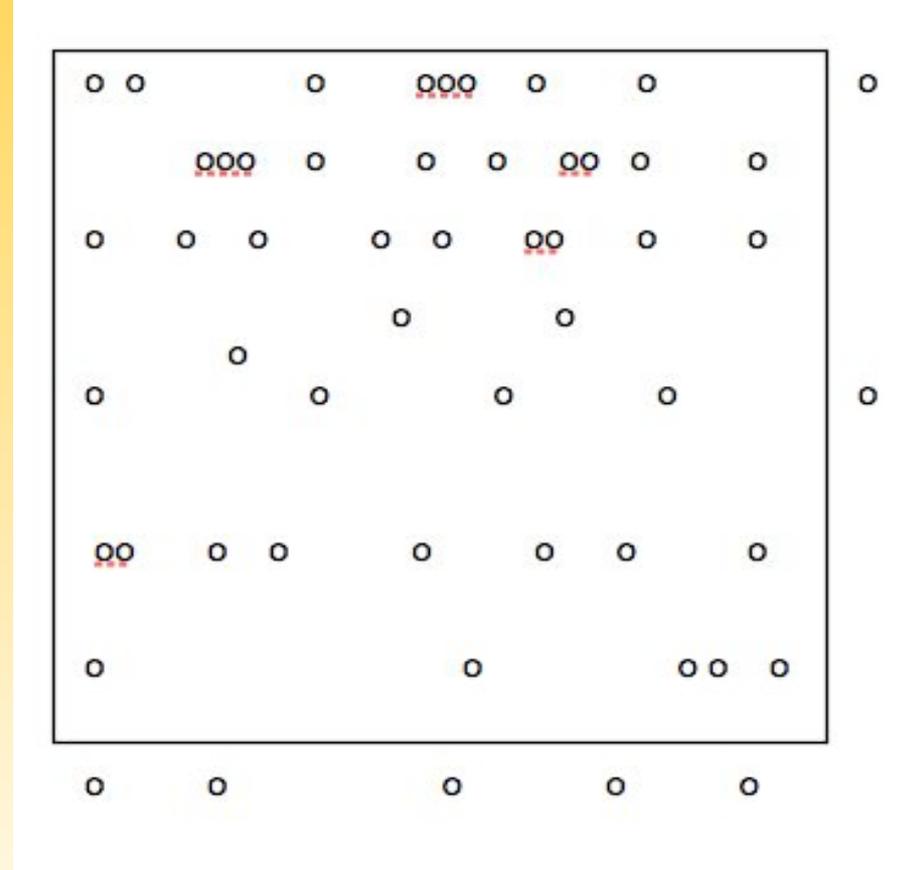
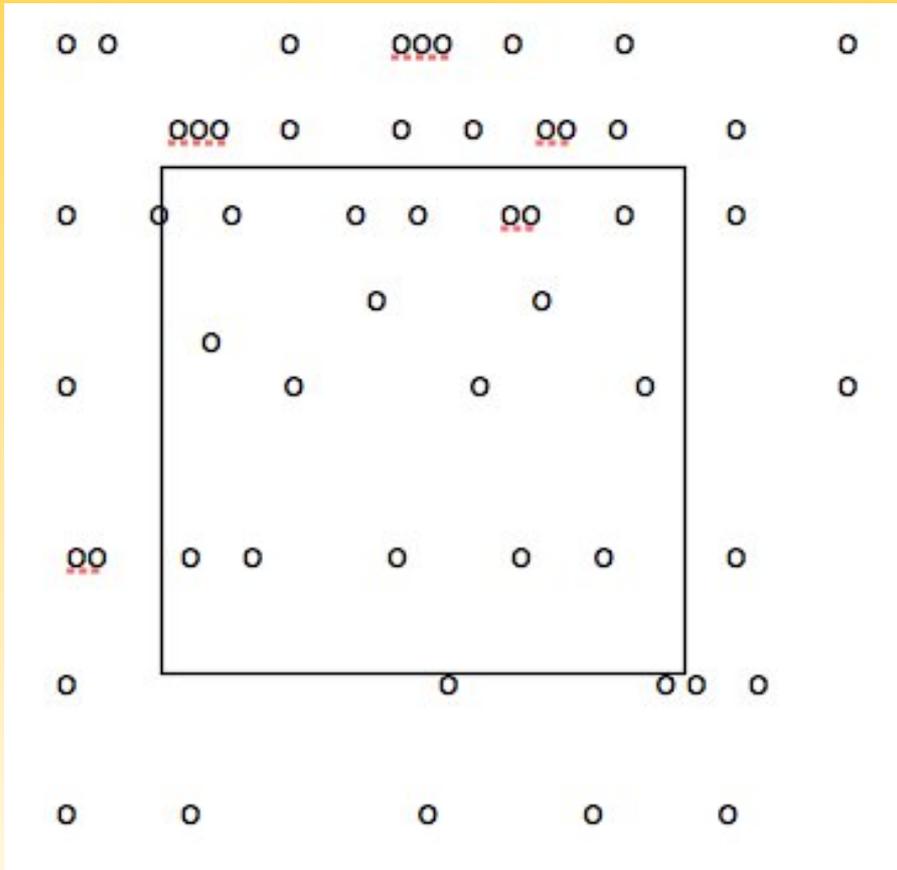
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Prevalence Differences by Ethnicity

CDC Sites 2008 data

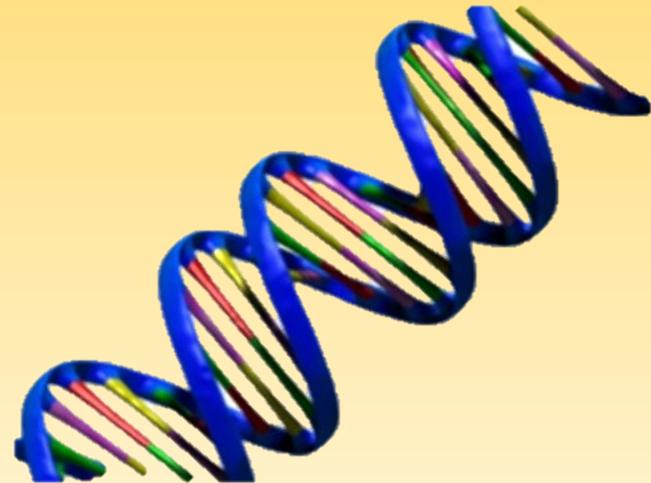


Identification Accuracy Makes a Difference



Genetic factors may contribute to variations across cultures

- ASD may have different liability alleles for different populations
- What is learned from one population may not transfer to another
- Consanguinity
- Environment and risk factors interact with genetics



Immigration as a risk factor?

- London study:
 - Caribbean and African immigrants 8-10x higher rate
 - Asian 2-4x higher
- Sweden:
 - Increased prevalence of ASD among Somali immigrants
 - All had co-occurring Intellectual Disability
- Stress of immigration, or related to factors within the home country?



Barriers to Identification of ASD



Disparities and Growth



Black and Hispanic children are diagnosed with ASD later and less frequently than Non-Hispanic White children

Black and Hispanic children are more likely to live in poverty and less likely to receive early intervention services

The Hispanic population of the United States is growing four times faster than the general population

Interpretation of Behavior

- Medicaid-eligible children in Philadelphia:
 - White children diagnosed 1.5 years earlier than African American and 2.5 earlier than Latino
 - African Americans spent more time in treatment before diagnosis
 - African Americans 3x more likely to be misdiagnosed with a behavioral disorder before being accurately diagnosed with ASD
- Parent reporting?
- Prejudices and misconceptions among clinicians?



Stigma

- Parents of children with ASD in South Korea
 - More likely to seek services without using insurance to maintain confidentiality
 - Believe that apartments would sell for less if a child with ASD had lived there
- Stakeholders in South Africa
 - Demonstrate embarrassment in admitting the use of and belief in traditional healers
 - Conflicted between anxiety over spiritual causation and “western” diagnosis of illness

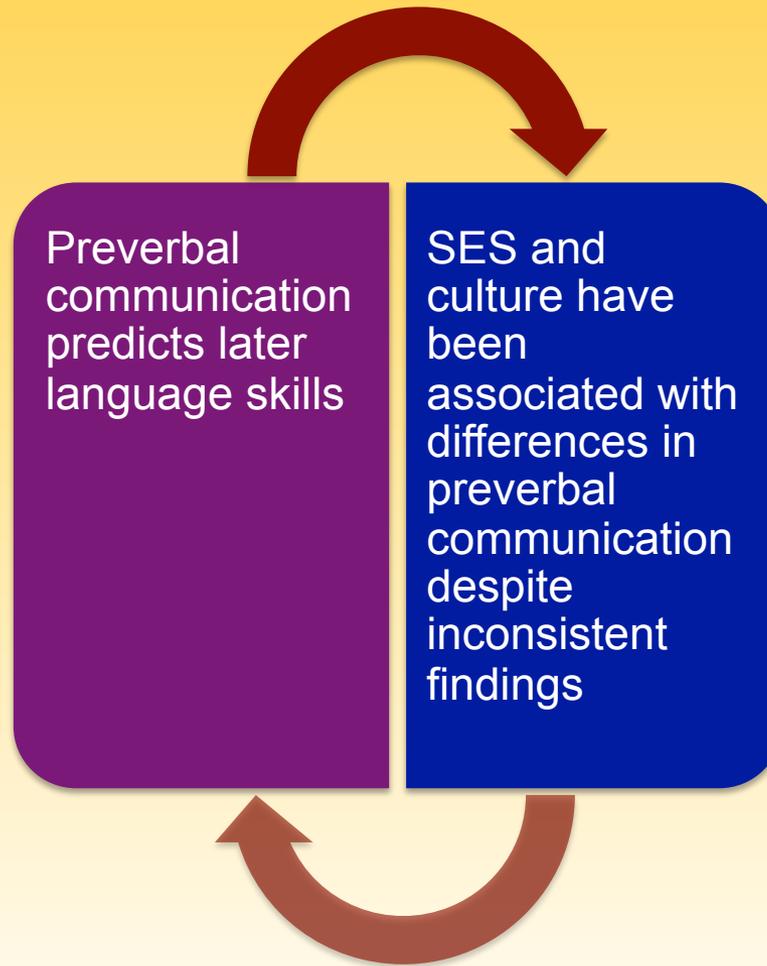
Other Potential Barriers

- Lack of knowledge about development
 - Zulu focus group participants demonstrated little understanding of social and cognitive milestones in children from birth to age three
- Lack of cultural norms for development
- Priorities for short-term survival or other medical conditions

Research on Racial/Ethnic Differences in Characteristics of ASD



Early Social Communication



Social Communication in ASD

- While impaired social communication is one of the two core domains ASD, we need to know more about preverbal communication in ASD
- Rate of communicative acts, vocalizations, and gestures predict language outcomes in children with ASD

Racial/Ethnic Differences in ASD

- Few racial differences in social communication or autism symptoms have been observed in older children with ASD



- Tek and Landa (2012) found differences in language and communication across minority ($n = 19$) and non-minority ($n = 65$) toddlers with ASD

Purpose of Stronach, 2013 Study

- Examine social communication profiles across diagnostic status
 - ASD
 - Non-ASD
- Examine social communication profiles across race/ethnicity
 - Non-Hispanic White
 - Non-Hispanic Black
 - Hispanic White



Research Questions

- Are there group differences across diagnostic classification and racial/ethnic categories on measures of
 - Observed social communication skills on the Communication and Symbolic Behavior Scales (CSBS) Behavior Sample?
 - Parent-reported red flags of ASD on the Early Screening for Autism and Communication Disorders (ESAC)?
- What are the relationships among age, maternal education, observed social communication skills, and parent-reported red flags of ASD?

Participants

- $N = 364$ toddlers
 - 18-36 months
 - North and south Florida
- 3 racial/ethnic groups
 - Non-Hispanic White, Non-Hispanic Black, and Hispanic White
- ASD and non-ASD (TD or DD)
 - Confirmed using ESAC, ADOS, and clinical judgment



Measures

- CSBS Behavior Sample ($n = 364$)
 - **7 Cluster Scores:** emotion & eye gaze, communication, gestures, sounds, words, understanding, and object use
 - **3 Composite Scores:** social communication, speech, and symbolic
 - **Total Score**
- ESAC ($n = 327$)
 - **Total score based on 30 questions**



Demographics

ASD (n = 195)

| Demographic | non-Hispanic White (n = 120) | non-Hispanic Black (n = 35) | Hispanic White (n = 40) |
|---------------------|---------------------------------|--------------------------------|----------------------------|
| Age at BS (M, SD) | 21.07 (1.99) | 20.69 (1.64) | 24.88 (5.81) |
| Males (n, %) | 100 (83.33) | 31 (88.57) | 34 (85.00) |
| First Born (n, %) | 57 (47.50) | 14 (40.00) | 17 (42.50) |
| Age at ESAC (M, SD) | 21.81 (4.51) | 21.16 (5.58) | 25.06 (6.26) |
| Mother Ed. (M, SD) | 15.03 (2.59) | 14.57 (2.13) | 13.45 (3.93) |

Non-ASD (n = 169)

| Demographic | non-Hispanic White (n = 106) | non-Hispanic Black (n = 39) | Hispanic White (n = 24) |
|---------------------|---------------------------------|--------------------------------|----------------------------|
| Age at BS (M, SD) | 20.23 (1.77) | 21.00 (3.10) | 23.75 (4.04) |
| Males (n, %) | 68 (64.15) | 25 (64.10) | 15 (62.50) |
| First Born (n, %) | 37 (34.91) | 17 (43.59) | 9 (37.50) |
| Age at ESAC (M, SD) | 21.89 (4.86) | 22.93 (5.41) | 23.72 (4.97) |
| Mother Ed. (M, SD) | 15.55 (2.80) | 14.05 (2.10) | 10.54 (5.76) |



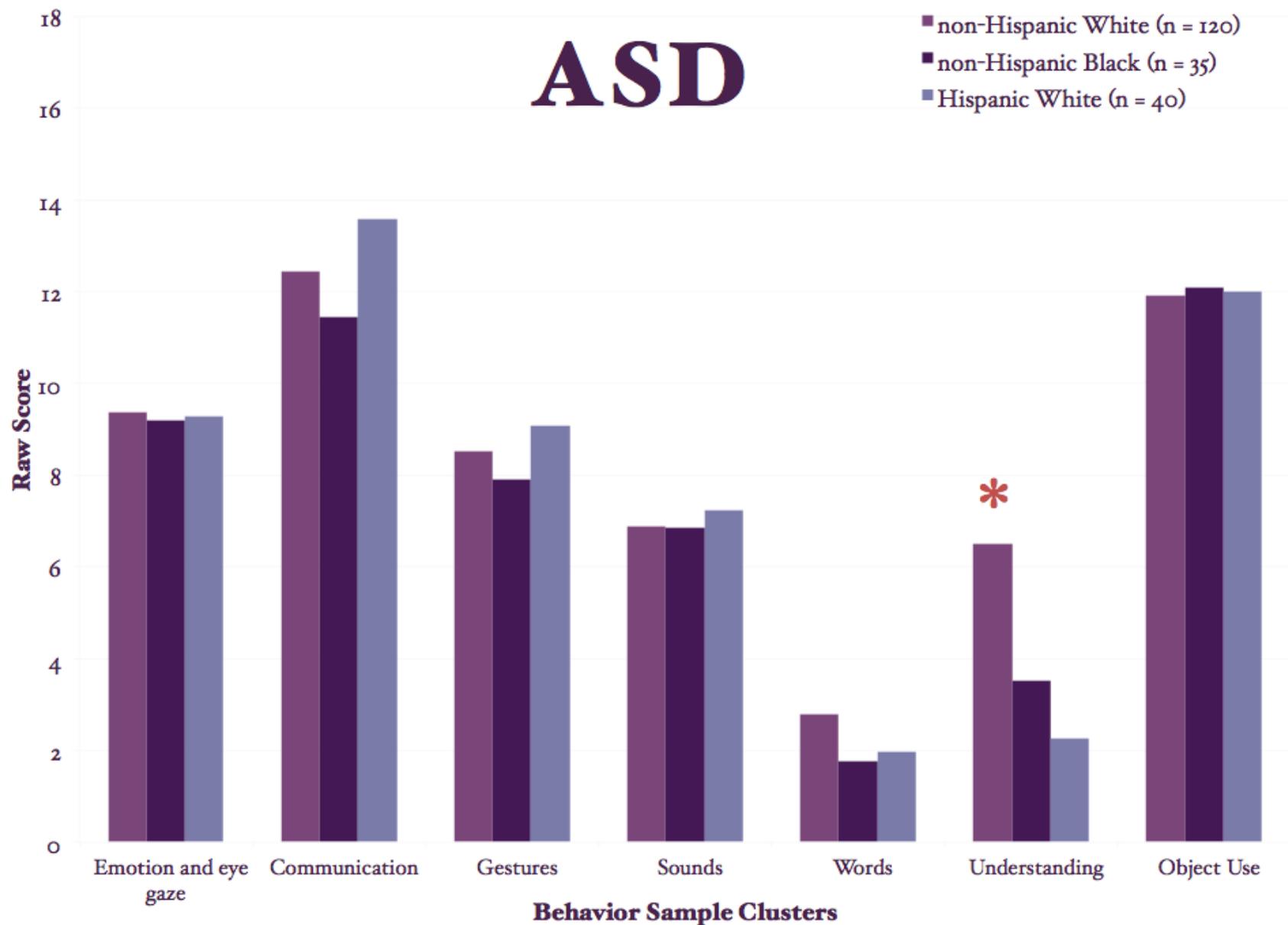
Group Differences on CSBS

- Significant main effect for **diagnostic classification**
- Significant main effect for **race/ethnicity**
- Non-significant interaction between diagnostic classification and race/ethnicity

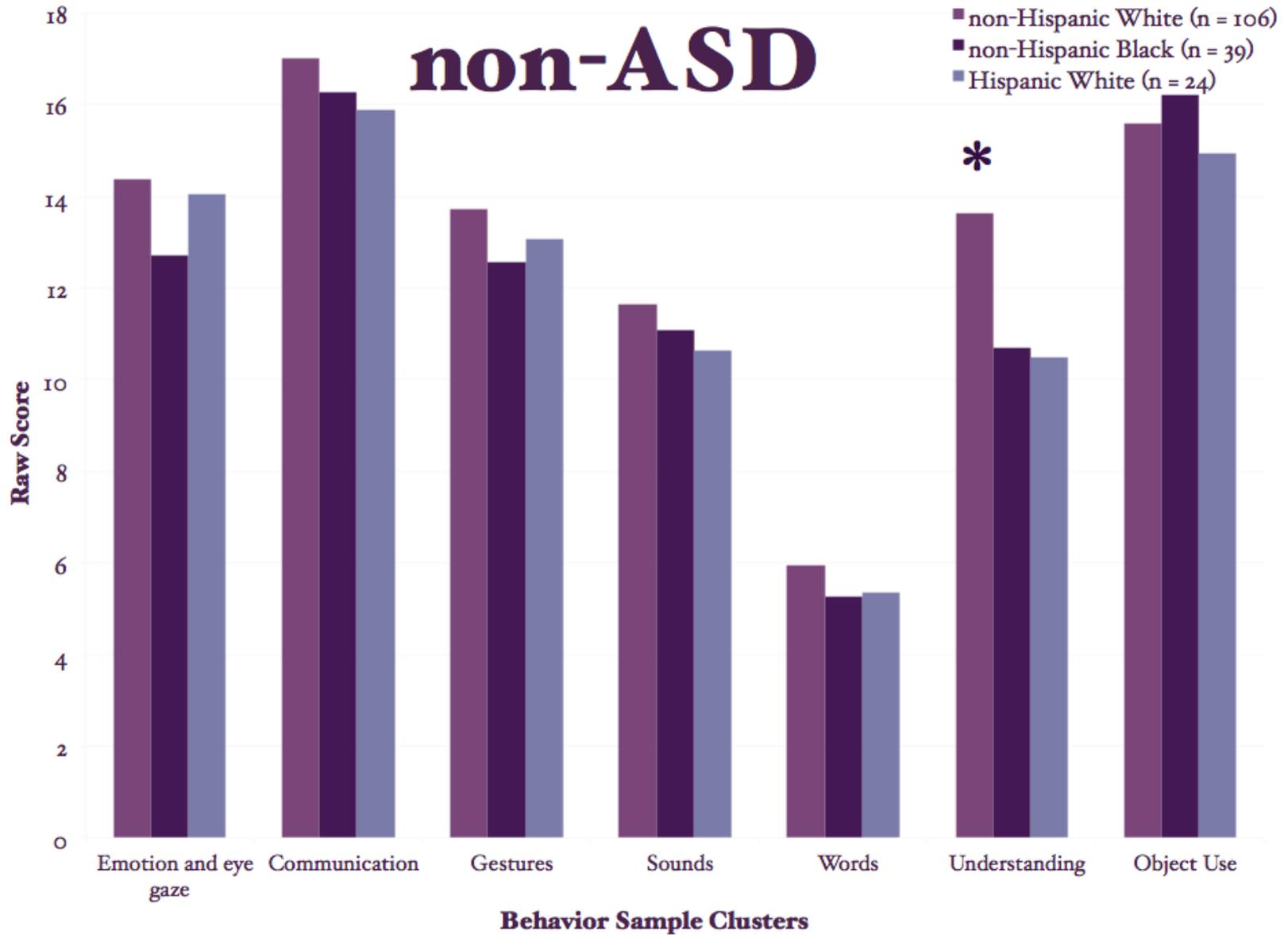


ASD

- non-Hispanic White (n = 120)
- non-Hispanic Black (n = 35)
- Hispanic White (n = 40)



non-ASD



Group Differences on ESAC

ASD (n = 176)

| | | | | Hedge's g | | |
|----------------|-------------------------------|------------------------------|--------------------------|-----------|-------|-------|
| | non-Hispanic White n = 109 | non-Hispanic Black n = 28 | Hispanic White n = 39 | nW-nB | nW-HW | nB-HW |
| ESAC M (SD) | 28.37 (12.05) | 29.58 (10.65) | 31.07 (11.41) | -.102 | -.225 | -.132 |

Non-ASD (n = 151)

| | | | | Hedge's g | | |
|----------------|-------------------------------|------------------------------|--------------------------|-----------|-------|-------|
| | non-Hispanic White n = 101 | non-Hispanic Black n = 29 | Hispanic White n = 21 | nW-nB | nW-HW | nB-HW |
| ESAC M (SD) | 14.11 (9.95) | 20.57 (8.27) | 15.21 (13.73) | -.668 | -.102 | .485 |



Relationships among Variables

| Score | Age in months | Maternal Education |
|----------------------|---------------|--------------------|
| Emotion and Eye Gaze | -.012 | -.040 |
| Communication | .006 | .056 |
| Gestures | -.044 | .103* |
| Sounds | .137** | .143** |
| Words | .196** | .133* |
| Understanding | -.031 | .174** |
| Object Use | .000 | .064 |
| ESAC Score | .085 | -.244** |



Relationships among Variables

Pearson partial correlations controlling for age and maternal education:

- Large, negative significant correlation was observed between **ESAC scores and total CSBS scores**
- Medium to large negative significant correlations were also observed for ESAC scores and Behavior Sample
 - social
 - expressive speech and language
 - symbolic



Summary of Findings

- ASD and non-ASD group differences on both measures
- No interaction effects for diagnostic classification and race/ethnicity
- Racial/ethnic differences only seen in understanding cluster of the CSBS
- Children with lower social communication scores also had higher parent report of autism red flags
- Higher maternal education for non-Hispanic White participants may reflect national educational disparity



Strengths

Analysis of group differences based on diagnostic classification, race/ethnicity, and maternal education

Observational and parent report measures used with translation into Spanish

Young age of identification in a diverse sample



Limitations

CSBS only normed to 24 months, raw scores used

Race/ethnicity used rather than culture

Autism red flags only measured through parent report



Clinical implications

National priority to reduce racial/
ethnic health disparities



Clinicians need to differentiate
difference from disorder



Improved detection of early delays
leads to earlier intervention



Future directions

Examine relationship between culture, environment, and early social communication

Describe characteristics of early social communication development and red flags of ASD across cultures

Develop culturally adaptive strategies for early intervention



Seen at University of Minnesota

- N=17; 14 with Autistic Disorder, 1 PDDNOS, 2 Nonspectrum
- 11 boys, 6 girls
- Age range 27 months to 14 years (mean=5 years)
- All heard Somali in their homes; some families used a combination of Somali and English
- Of children with ASD, **7 (47%) were nonverbal** (<5 words)
- All children with ASD were not speaking at age level in either language
- Of those with ASD, **10 children (59%) had nonverbal IQ <70**; 3 children (18%) had nonverbal IQ in the severe-profound range
- Of those with ASD, **3 children (18%) had nonverbal IQ in the average range**
- Severity scores on the ADOS were consistent with those from other research samples of children with ASD (e.g., Gotham et al., 2009; Hus et al., 2012)



Study of phenotypic differences in African Americans

- 46 African Americans from a multi-site study of ASD in southeastern US, compared with 298 Caucasians
- No differences in social, communication, or repetitive behaviors and restricted interests
- Large difference in language acquisition

| | African American | Caucasian |
|----------------------|------------------|-------------|
| Age of first words | 38.6 months | 26.7 months |
| Age of first phrases | 59.4 months | 41.3 months |



Culture and Behaviors Important to Diagnosing ASD





ASD is a social disorder, defined by social behaviors, which are culturally-bound



- Both positive (abnormal) behaviors, and negative (the absence of normal) behaviors are required to make a diagnosis of ASD.
- This means that contextual effects (in what kind of circumstances does the child or adult function?) can both have significant effects on diagnostic judgments.



Linguistic Competence

- The capacity of an organization and its personnel to effectively communicate with persons of
 - limited English proficiency,
 - those with low literacy skills or who are not literate, and
 - individuals with disabilities.
- The organization must have policy, structures, practices and procedures and dedicated resources to support this capacity.

Social communication across cultures

- Different cultures have different guidelines for
 - Personal space
 - Eye contact
 - Smiling
 - Touch
 - Silence
 - Discourse



Personal space

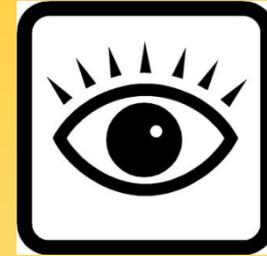
- European-Americans usually maintain an arm's length of space
- In other cultures people stand closer together to speak
- Violation of personal space is a common deficit in ASD
- Vineland Adaptive Behavior Scales question about personal space



"Personal Space" by Donna Williams



Eye contact



- Sign of respect in Western culture
- Sign of lack of respect or deference in some Asian cultures
- Extremely disrespectful when prolonged in Native American cultures
- Variations in eye contact in the African American culture: intense eye contact used within families, eye contact with authority figure considered disrespectful
- In some cultures, prolonged staring can be considered the “evil eye” which can bring harm to the person stared at



Smiling



- Russians smile only when happy, not to be friendly
- In the Vietnamese culture, smiling can indicate a variety of meanings, including smiling when being reprimanded to indicate acceptance of reprimand



Touch



- Can be a means of establishing or reflecting status
- In the Vietnamese culture, touching an individual on the head robs them of their soul
- Sign of friendliness and warmth in some cultures
 - In Italy, men often link arms when walking down the street together



Silence



- European-Americans fill in silence
- The Japanese allow for silence before responding to what someone else said in order to indicate that he or she is thinking about what was said
- Native Americans remain silent when asked about themselves so they are not perceived to be bragging



Sociolinguistics

Conventions or rules of conversation

- Wait time
 - Extended for Native Americans, reduced for Native Hawaiians
- Discourse structure/rhythm
 - Call-and-response interactions among African Americans versus traditional “switchboard” structure of Western classrooms
- Speech volume
 - Soft volume common for Native Americans
- Eye Gaze
 - Making eye contact with adults perceived as rude/noncompliant by some cultures



Diagnostic Evaluation

Necessary Ingredients:

- Developmental History Interview
- Structured observation including direct interaction with child
- Establish developmental levels—needed for differential diagnosis
 - Cognitive testing (separate nonverbal and verbal IQ scores)
 - Communication testing (separate expressive and receptive scores)
 - Adaptive skills: children with ASD usually score much lower on Adaptive skills than is expected based on cognitive scores



Culturally-competent Parent Interview

A good interview is examiner-led, resulting in detailed descriptions. The examiner judges whether the parents' descriptions support ASD or not.

- What is the common vocabulary used?
- Many social behaviors are universal...

...but the contexts can differ



Culturally-competent Parent Interview, con't

Knowledge on culture needed to:

- Ask about the relevant contexts where social communication occurs
- Give illustrative examples to elicit further description
- Make judgments about whether behaviors are consistent with ASD or not
- Be familiar with common interpretations of child behavior



When the gold standard isn't possible....

- Establishing cognitive level
 - Choose the test best for ASD, or best for international children?
- Assessing communication skills
- Training of interpreters
- Observations of toy/object use, social behaviors



Cultural Perspectives: Talking about the diagnosis

- Individualism v. collectivism
- Beliefs about causes

“People who see our children say, “Why is a normal child acting so strangely? Aren’t the parents sending him to school?” Children with autism often misbehave, so the first thing you think of when you see a kid with bad discipline is that there is a problem with their school or ability to learn or that they have a bad mother. I really think the parents of children who are not severely physically-disabled, like the parents the children with autism I know, suffer more than the parents of physically-handicapped children.”

--Mother from Seoul, quoted in R. Richard Grinker, *Unstrange Minds: Remapping the World of Autism*.



Beyond Translators

- Translation of written materials:
 - Literacy
 - Access and dissemination
 - Knowledge of language and dialect
- Interpreters
 - Adequate knowledge of content, scientific terms
 - Communicating the message, not just the words
 - Clinical sensitivity
 - Sensitivity to confidentiality



Training of Interpreters

- Adapted from the National Council for Interpreting in Health Care (NCIHC)
- “Credentialing”: Formal certification and training in interpretation
- **Basic language**: Speaks and understands the native language of the participant.
- Is aware of **ethical standards and decision-making**.
- **Recognizes confusion** that may arise from differing cultural views.
- **Knowledge of basic health care terms**
 - Knows terms commonly used in health or research settings (specific project glossary created).
- **Integrated interpreting skills**
 - Demonstrates interpreting skills (verified by certificate of ability or other document).
- Is able to give **oral translations**.



Take-home tips

For assessment:

- Still use standardized measures
 - But scoring may not apply
- Evaluate fluency in English as well as native language
- Nonverbal testing—adapted for ASD
- Rely on parent descriptions of their experiences, their child's skills
 - Clinician's job is to evaluate whether the behaviors described fit the pattern

For the project:

- Meaningful, defined stakeholder roles
- Trained, experienced interpreters
- Plan for ongoing communication



Thank you!

- Amy Hewitt, Joe Reichle, and Michael Reiff
- Colleagues at ASD Clinic:
 - Dr. Robin Rumsey
 - Desirae Rambeck
 - Pam Johnson



Contact Us

Amy Esler, ASD Clinic

esle0007@umn.edu

<http://med.umn.edu/peds/clinical-behavioral-neuroscience/autism/index.htm>

Sheri Stronach, Speech-Language-Hearing Sciences

sstronac@umn.edu

