Crossing the Divide: Cultural and Linguistic Perspectives in Evaluation and Treatment of Autism Spectrum Disorder and Other Developmental Disabilities

CANDO Meeting
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Agenda

• Demographic Trends Nationwide and in Colorado
• Ethnic and Racial Identity Terms
• Misdiagnosis and Delayed Autism Diagnosis among CLD Populations – A Review of the Research
• Overview of Findings from Recent Research Project
• Barriers and Solutions to This Phenomenon
• Questions

US Population Trends

• According to the 2010 US Census, over a quarter of children live in households where English is not the primary language spoken (US Census, 2010)
• Minority populations make up about 37% of the overall population, with the share projected to increase to 57% by 2060, according to the Census Bureau
• Looking ahead, nearly half of babies born in the U.S. today are a racial or ethnic minority, though they are not yet a majority
• In 2012, one in four births in the United States was Hispanic (Pro Research Center, 2014)

Colorado Population Trends

• Nearly 1 in 10 Coloradans is an immigrant (foreign-born), and 1 in 5 is Latino
• Colorado’s foreign-born population rose from 4.3% in 1990, to 8.6% in 2000, to 9.7% in 2011
• In 2011, Colorado was home to 494,760 immigrants, which is more than the total population of Sacramento, California (Immigration Policy Center, 2014)

English Language Learners in Colorado

• Colorado’s total PK-12 enrollment growth rate over the last ten years (2002-2012) = 14.9%
• Colorado’s PK-12 ELL total enrollment growth rate over the last ten years (2002-2012) = 44.8%
• ELL populations are increasing dramatically across the state, in all demographic and socio-economic classes (CDE State of the State, 2014)

How many school-aged English learners (ELs) are there in Colorado?

<table>
<thead>
<tr>
<th>Year</th>
<th>NEP/LEP (Non-English Proficient/Limited English Proficient)</th>
<th>FEP M1 (Fluent English Proficient Monitor Year 1)</th>
<th>FEP M2 (Fluent English Proficient Monitor Year 2)</th>
<th>Total ELs*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008-2009</td>
<td>84,746</td>
<td>10,128</td>
<td>6,708</td>
<td>101,572</td>
</tr>
<tr>
<td>2009-2010</td>
<td>90,994</td>
<td>8,784</td>
<td>8,685</td>
<td>106,663</td>
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<tr>
<td>2010-2011</td>
<td>92,392</td>
<td>8,652</td>
<td>5,839</td>
<td>106,883</td>
</tr>
<tr>
<td>2011-2012</td>
<td>98,757</td>
<td>9,349</td>
<td>7,649</td>
<td>115,773</td>
</tr>
<tr>
<td>2012-2013</td>
<td>100,782</td>
<td>9,375</td>
<td>8,563</td>
<td>118,720</td>
</tr>
</tbody>
</table>

* Total EL numbers do not include parent email. If included, the total number for 2012-2013 would be 118,679.
**Discussion**

- What type of population trends are you seeing in your clinics/agencies/professional context?
- How are you collecting and reviewing data on these population trends in your setting? If you are not collecting and reviewing this data regularly, how could you begin this process?
- What have you changed/implemented etc. based on demographic trends?

**State of the State: Autism Screening within CLD Populations**

- Professionals are less likely to screen for ASDs in CLD children (Begeer, El Bouk, Bousaid, Terwogt, & Koot, 2009)
- Pediatricians with a population of more than 30% Medicaid-insured patients were less likely to screen for ASDs, and less than half of pediatricians with a population of more than 50% CLD patients regularly screened for ASDs (Arunyanart et al., 2012).

**Misdiagnosis and Delayed Identification**

- Mandell and colleagues (2002) found that African-American children with ASDs are diagnosed an average of 1.4 years later than White children and spent an average of 8 months in mental health treatment prior to being diagnosed.
- Likewise, preschool-aged Hispanic children are consistently underrepresented in the autism educational eligibility category (Morton & Hess, 2012).
- The median age of Hispanic children who were identified with an ASD is 11% higher than the median age of White children (Shattuck et al., 2009).
- Hispanic children are less likely than White children to receive an appropriate ASD diagnosis at all (Overton, Felding, & Garcia de Alba, 2007).
- Although the prevalence of ASD in Hispanic children has increased, it remains significantly lower than that of White children (Pedersen et al., 2012).

**Barriers to Culturally and Linguistically Responsive Autism Assessment**

- There is limited information about best practices for early identification of CLD children with ASD, particularly among African American and Latino populations.
- The ASD identification process is lengthy and complicated and includes a complex symptomatology of social and communication behaviors, which are all impacted by cultural interpretations (Bernier, Mao, & Yen, 2010).
- Language barriers, families’ levels of acculturation, socioeconomic status (SES), and the range of culturally appropriate social and communication behaviors are likely to impact the identification of ASDs in CLD children.
Barriers to Culturally and Linguistically Responsive Autism Assessment (cont.)

- Lack of consideration of the following:
  - Language
  - Culture
  - SES
  - Family access and awareness of services
- Limited assessment tools
- Inappropriate use of assessment tools (i.e. interpretation of tool)
- Limited training
  - Extreme shortage of practitioners who are bilingual and trained in culturally responsive practices (Soltero, 2011).

Issues with Autism Assessment in CLD Populations

- ASDs are primarily diagnosed through social and communication behaviors, which develop within the context of one’s culture and family.
- Current autism diagnostic tools may not be sensitive to cultural variations or family expectations around social and communicative behaviors.
- A recent study of a community sample of Hispanic children with ASD found that most autism evaluators did not document assessment of the child in their native language or address the impact of language in their assessments (Williams, Atkins, & Soles, 2009).
- Studies have pointed to cultural variations in the initial concerns by parents regarding young children with ASD.
  - White Americans are more likely to identify delays or concerns with expressive language skills and are unlikely to provide information about social delays unless probed by the diagnostician (Coonrod & Stone, 2004).
  - Indian families are more likely to first identify delays in social behaviors and social difficulties (Daly, 2004).

Issues with Autism Assessment in CLD Populations (cont.)

- Two important observation components on the Autism Diagnostic Observation Schedule (ADOS) are observing eye contact and pointing behaviors; the absence of these behaviors might be an indicator of ASD.
- Zhang et al. (2006) noted that eye contact with adults and pointing with the index finger is considered inappropriate behavior within the Chinese culture.
- Norbury and Sparks (2013) note potential cultural differences surrounding pretend play, public displays of emotion, and the extent to which children (especially boys) play with toy dolls.
- These studies highlight cultural differences in behavioral expectations for young children, which can significantly impact the interpretation of scoring criteria for which practitioners have few guidelines.

What is Contributing to this Phenomenon?

- Professionals are missing behavioral indicators of ASD in CLD children or are hesitant to provide the ASD diagnosis for some reason; thus, these children are unlikely to receive the appropriate interventions to address ASD symptomatology.
- In partners or small groups, discuss the autism services provided in your own setting. Are these findings consistent with your setting? If so or if not, come up with three theories as to why this could be occurring.

View of Disability

- Practitioners might believe that all families hold a similar view of disability as themselves. In fact, the social values attributed to disabilities vary by culture; families might experience blame or have different expectations regarding certain skills or developmental milestones (Harry & Kalyanpur, 1994).
- How might your personal and professional view of ASD as a disability impact the families you work with?
- How can you be more responsive to families who may have different behavioral or developmental expectations for their children?

Review of Recent Study

  - While clear guidelines and best practices exist for the assessment of autism spectrum disorders (ASD), little information is available about assessing for ASD in CLD populations.
  - Four autism diagnostic tools and six autism screeners were selected and evaluated for their cultural and linguistic responsiveness.
Checklist (Based on DEC, APA, AERA, & NASP Recommendations)

Checklist Scores

Recommendations for Improving ASD Assessment Practices

Solution Goal Setting

Interpreting the Data

Questions?

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