

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

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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)

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

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)

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 (Pew Research Center, 2014)

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

	NEP/LEP (Non-English Proficient/Limited English Proficient)	FEP M1 (Fluent English Proficient Monitor Year 1)	FEP M2 (Fluent English Proficient Monitor Year 2)	Total ELs*
2008-2009	84,736	10,128	6,708	101,572
2009-2010	90,994	6,784	8,685	106,463
2010-2011	92,352	8,652	5,839	106,843
2011-2012	98,775	9,349	7,649	115,773
2012-2013	100,782	9,375	8,563	118,720

*Total EL numbers do not include parent refusal. If included, the total number for 2012-2013 would be 119,082.

Updated by Office of Data, Program Evaluation, and Reporting. Data Source: 2008-2009 through 2012-2013 Student October (excludes students with missing or duplicate SASSID)

Languages Spoken by Colorado English Language Learners Attending Public School

Spoken by Colorado ELs

Rank	Languages	Number of ELs	Percent	Rank	Languages	Number of ELs	Percent
1	Spanish	99,853	84.11%	11	French	529	0.45%
2	Vietnamese	2,248	1.89%	12	Chinese, Yue	428	0.36%
3	Arabic	1,564	1.32%	13	Karen, Pa'o	393	0.33%
4	Russian	1,233	1.04%	14	Burmese	392	0.33%
5	Chinese, Mandarin	1,086	0.91%	15	Tagalog	373	0.31%
6	Korean	868	0.73%	16	German, Standard	349	0.29%
7	Nepali	857	0.72%	17	Tigrigna	312	0.26%
8	Amharic	793	0.67%	18	Japanese	252	0.21%
9	Somali	788	0.66%	19	Swahili	230	0.19%
10	Hmong	552	0.46%	20	Khmer, Central	222	0.19%

* In 2012-2013, English learners (ELs) had 208 home or primary languages other than English.

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).

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?

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 (Morrier & 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, Fielding, & 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).

What's in a Name?

- Defines your identity and thus can be emotionally charged
- Ethnic identity vs. racial identity, Hispanic, Latino, ELL, Second Language Learner, Dual Language Learner CLD, Asian, American, Chicano...
- How do you determine what terms to use with the populations you work with?
- How can you improve the way you use ethnic and racial identity terms with your clients?

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).

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.

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).

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?

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 testing results for which practitioners have few guidelines.

Review of Recent Study

- Harris, B., Barton, E.E. & Albert, C. (2013). Evaluating autism diagnostic and screening tools for cultural and linguistic responsiveness. *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-013-1991-8
- 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 for Assessing the Cultural Relevance of ASD Assessments				
Quality Indicator	Yes	No	UC*	NOTES
1. Normative sample included sufficient percentages (based on US census) of CLD children with ASD.				
2. Normative sample included English-language learners with ASD.				
3. The technical report (or manual) includes utility information from consumers (e.g., people who use the assessments including practitioners and parents).				
4. The procedures support obtaining family input regarding the child's functional responses during daily routines in natural settings with familiar children and adults.				
5. The procedures support obtaining information from additional caregivers or service providers about the child's behavior (e.g., child care providers, speech language pathologists).				
6. The procedures include observations in natural settings.				
7. The procedures include specific adaptations for CLD children and families.				
8. The procedures include obtaining adequate information about the child and family's language proficiency and the child's language dominance.				
9. The procedures include obtaining adequate information regarding the child's functional communication skills in his / her native or dominant language (if other than English).				
10. The assessment requires information about the child's functional communication skills in authentic contexts (e.g., daily routines at home).				
11. Procedures include obtaining adequate information regarding the child's functional social skills in authentic contexts.				
12. Procedures include guidelines for using an interpreter.				
13. Procedures include guidelines for using translated test materials.				
14. The assessment includes gathering information about the child's non-verbal skills that are not related to language comprehension (e.g., this might include observing the child independently playing with blocks, or putting together a puzzle).				
15. The assessment promotes teamwork between the family and professionals (i.e., assessors and family members working together to score and interpret results).				
16. The assessment promotes gathering information on child and family's level of acculturation.				

Recommendations for Improving ASD Assessment Practices

- **People completing autism assessment or screening:**
 - The population you are assessing should be adequately represented in the standardization sample
 - Collect information from multiple sources, standardized data may be less beneficial than other sources of data
 - Observations in natural settings should be encouraged, especially when the child speaks a language other than English
 - If modifications are made when completing a standardized assessment, you may be breaking standardization – this is especially true for interpretation of an assessment
 - Obtain information about language abilities in all languages if the child is an ELL
 - Be aware of the acculturation process and the potential impact on behavior in particular
- **People providing autism services yet not involved in assessment or screening:**
 - Advocate for the above recommendations within the agencies you work with
 - Get feedback from families regularly about what could be improved in the assessment/intervention process
 - Regularly review state and national data
 - Serve on or create taskforces to address this issue
 - Improve the barriers to access that families may feel which may contribute to the delay in assessment

Checklist Scores

Table 3. Checklist Scores

Assessment	Total Checklist Score ^a	"No" Indicators	"Unclear" Indicators	Average Reliability
Diagnostic Tools	ADOS	1, 2, 3, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16	-	88%
	ADI-R	1, 2, 3, 5, 6, 7, 8, 9, 12, 13, 14, 16	-	88%
	ABRS	2, 3, 7, 8, 9, 12, 13, 14, 16	-	89%
Screening Tools	CARS-2	2, 3, 7, 8, 9, 12, 13, 16	-	82%
	ASQ:SE	1, 2, 5, 8, 9, 13, 16	-	76%
	ASSQ	1, 2, 3, 6, 7, 8, 9, 12, 13, 14, 16	1	85%
	GARS	2, 3, 7, 8, 9, 12, 13, 14, 16	1	82%
	MCHAT	1, 3, 5, 6, 7, 8, 9, 12, 13, 15, 16	-	73%
QCHAT	1, 2, 3, 5, 6, 7, 8, 12, 13, 15, 16	-	82%	
SCQ	1, 3, 5, 6, 7, 8, 9, 12, 13, 15, 16	-	79%	

^aIndicates the total number of quality indicators met.
^{ab} Average reliability across these graduate students.

Solution Goal Setting

- In the next month, what is one goal you can work on related to the material presented today?
- Write down three goals for the next six months and three goals the next year.
- Share these goals with your partner or small group.
- What might get in the way of realizing these goals? Problem solve with your colleagues.

Interpreting the Data

- Test publishers and best practice guidelines do not generally provide information about how to modify or improve your assessment processes with CLD children
 - Potential solution: This checklist may be beneficial when determining what assessment to use or concepts to think about during the assessment process
- How else might you utilize this information in your own setting?

Questions?

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