

Minority Status and Autism Diagnosis – A summary of some articles  
(from Fred Volkmar M.D. and Kari Sassu Ph.D).

## References

Bendell, R., et al. (1989). "Children's effects on parenting stress in a low income, minority population." Topics in Early Childhood Special Education 8(4): 58-71.

Investigated relationships between parenting stress as measured by the Parenting Stress Index (PSI) developed by R. R. Abidin (1983) and other maternal and child characteristics in 66 low income Black mothers (who delivered their 1st child during adolescence) and their children (aged 5-8 yrs). Other measures used included the Eyberg Child Behavior Inventory and the Peabody Picture Vocabulary Test--Revised (PPVT--R). Findings indicate concurrent and construct validity support for the PSI. Child characteristics (self-esteem, behavior conduct, and spelling achievement) and maternal characteristics (self-esteem, and crowding stress) related to parenting stress in this sample. (PsycINFO Database Record (c) 2002 APA, all rights reserved).

Brown, J. R. and S. J. Rogers (2003). Cultural Issues in Autism. Autism Spectrum Disorders. R. L. Hendren, S. Ozonoff and S. Rogers. Washington, D.C., American Psychiatric Press: 209-226.

Chung, K.-M., et al. (2012). "Cross cultural differences in challenging behaviors of children with autism spectrum disorders: An international examination between Israel, South Korea, the United Kingdom, and the United States of America." Research in Autism Spectrum Disorders 6(2): 881-889.

Challenging behaviors are deemed extremely common within the autism spectrum disorders (ASD) population. Numerous factors and their effects upon the presence and severity of challenging behaviors within this population have been investigated. However, there has been limited research to investigate the effects of cultural differences on challenging behaviors. The aim of the current study was to examine differences between cultures in the reported presence and severity of a multitude of challenging behaviors commonly displayed by children with ASD. The Autism Spectrum Disorders-Behavior Problems for Children was used to assess possible differences between the United States and three other countries (South Korea, Israel, and the United Kingdom). Relatively few differences were found between the United States and both South Korea and Israel, with the United States endorsing a higher presence and severity on items that differed. In contrast, the United States and the United Kingdom differed on nearly half of the behavior items assessed with the United Kingdom reporting greater endorsements. The potential implications of these results are discussed. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract).

Freeth, M., Milne, E., Sheppard, E., & Ramachandran, R. (2014). Autism across Cultures: Perspectives from Non-Western Cultures and Implications for Research. Handbook of Autism

and Pervasive Developmental Disorders. F. R. Volkmar, Paul, R., Rogers, S.J., & Pelphrey, K.A., Wiley. 2.

Grinker, R. R., et al. (2015). "Cultural adaptation and translation of outreach materials on Autism spectrum disorder." Journal of Autism and Developmental Disorders **45**(8): 2329-2336.

In order to connect with families and influence treatment trajectories, outreach materials should address cultural perceptions of the condition, its causes, and post-diagnostic care. This paper describes the cultural adaptation and translation of the Autism Speaks First 100 Days Kit into Korean for the purpose of improving autism spectrum disorder (ASD) diagnosis, assessment, and interventions. The goal of this study is to describe a methodology for future cross-cultural adaptations and translations of outreach materials on ASD, using the Autism Speaks First 100 Days Kit as an exemplar. The research involved two stages of qualitative interviews: unstructured individual and group interviews with 19 Korean child health and education professionals in Queens, NY, followed by structured cultural consensus modeling interviews with 23 Korean mothers, with and without children with ASD, in Queens, NY and the greater Washington, DC area. We conclude that a systematic approach to cultural translation of outreach materials is feasible. Cultural consensus modeling yielded information about numerous barriers to care, had a demonstrable effect on the translation of the kit, and was efficient when employed with coherent segments of a relatively homogeneous population and focused on a single condition. (PsycINFO Database Record (c) 2015 APA, all rights reserved) (journal abstract).

Lopez, K. (2014). "Sociocultural perspectives of Latino children with autism spectrum disorder." Best Practices in Mental Health: An International Journal **10**(2): 15-31.

Latino children with autism spectrum disorder (ASD) encounter disproportionate factors that limit intellectual knowledge about their experiences and result in reduced access to and utilization of intervention. Using the Socio-cultural Framework for Health Service Disparities (SCF-HSD), this article defines these disparities as a social injustice to Latino children and families. It explores the factors that produce cumulative disadvantage and hence preclude understanding of the Latino family experience and limit the development of culturally informed interventions for Latino children with ASD and their families. The SCF-HSD has been expanded to include child and parent factors, as well as relevant ASD-related outcomes such as family burden. A modified conceptual model that includes variables at the micro, meso, and macro levels will be introduced. This modified model offers several new hypotheses for researchers to explore in an effort to expand the understanding of Latino families raising children with ASD, to inform the development of culturally informed policies and care, and to reduce disparities in ASD diagnosis and treatment among Latinos. (PsycINFO Database Record (c) 2015 APA, all rights reserved) (journal abstract).

Lord, C., et al. (2012). "A multisite study of the clinical diagnosis of different autism spectrum disorders." Archives of General Psychiatry **69**(3): 306-313.

Context: Best-estimate clinical diagnoses of specific autism spectrum disorders (autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger syndrome) have been used as the diagnostic gold standard, even when information from standardized instruments is available. Objective: To determine whether the relationships between behavioral phenotypes and clinical diagnoses of different autism spectrum disorders vary across 12 university- based sites. Design: Multisite observational study collecting clinical phenotype data (diagnostic, developmental, and demographic) for genetic research. Classification trees were used to identify characteristics that predicted diagnosis across and within sites. Setting: Participants were recruited through 12 university- based autism service providers into a genetic study of autism. Participants: A total of 2102 probands (1814 male probands) between 4 and 18 years of age (mean [SD] age, 8.93 [3.5] years) who met autism spectrum criteria on the Autism Diagnostic Interview-Revised and the Autism Diagnostic Observation Schedule and who had a clinical diagnosis of an autism spectrum disorder. Main Outcome Measure: Best-estimate clinical diagnoses predicted by standardized scores from diagnostic, cognitive, and behavioral measures. Results: Although distributions of scores on standardized measures were similar across sites, significant site differences emerged in best-estimate clinical diagnoses of specific autism spectrum disorders. Relationships between clinical diagnoses and standardized scores, particularly verbal IQ, language level, and core diagnostic features, varied across sites in weighting of information and cutoffs. Conclusions: Clinical distinctions among categorical diagnostic subtypes of autism spectrum disorders were not reliable even across sites with well-documented fidelity using standardized diagnostic instruments. Results support the move from existing subgroupings of autism spectrum disorders to dimensional descriptions of core features of social affect and fixated, repetitive behaviors, together with characteristics such as language level and cognitive function. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract).

Lotter, V. (1980). "Cross cultural perspectives on childhood autism." J Trop Pediatr **26**(4): 131-133.

Mandell, D. S., et al. (2006). "Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder." Journal of Autism & Developmental Disorders.

Mandell, D. S., et al. (2002). "Race differences in the age at diagnosis among medicaid-eligible children with autism." Journal of the American Academy of Child & Adolescent Psychiatry. **41**(12): 1447-1453.

OBJECTIVE: To examine racial differences in the age at which Medicaid-eligible children first receive an autistic disorder (AD) diagnosis and to examine time in mental health treatment until an AD diagnosis was received. METHOD: Philadelphia Medicaid specialty mental health claims identified 406 children who received services in 1999 for AD. Claims from 1993-1999 were used to identify the date of first mental health visit, first receipt of AD diagnosis, and number of visits occurring between those dates. Linear regression was used to examine the relationship among race, age at first diagnosis of

AD, time in mental health treatment, and number of visits until the diagnosis was made. RESULTS: On average, white children received the AD diagnosis at 6.3 years of age, compared with 7.9 years for black children ( $p < .001$ ). White children entered the mental health system at an earlier age (6.0 versus 7.1 years,  $p = .005$ ); however, after adjusting for age, sex, and time eligible!

Mandell, D. S., et al. (2010). "Age of diagnosis among Medicaid-enrolled children with autism, 2001-2004." Psychiatric Services **61**(8): 822-829.

OBJECTIVE: This study examined child- and county-level factors associated with age of diagnosis of autism among Medicaid-enrolled children and the change in age of diagnosis over time. METHODS: National Medicaid claims from 2002 to 2004 were used to identify age of diagnosis and characteristics of children younger than ten years old with a diagnosis of autism (ICD-9 codes 299, 299.0x, or 299.8x). These data were linked to county-level education and health care variables. Linear regression with random effects for state and county was used to examine associations between these variables and age of diagnosis. RESULTS: A total of 28,722 Medicaid-enrolled children newly diagnosed with an autism spectrum disorder were identified. Their average age of diagnosis was 64.9 months. Adjusted average age of diagnosis dropped 5.0 months for autistic disorder and 1.8 months for other spectrum disorders during the study period. Asian children were diagnosed earlier than children in other racial or ethnic groups, although these differences were much more pronounced for other spectrum disorders than for autistic disorder. Children eligible for Medicaid through the poverty category were diagnosed earlier, on average, than children who were eligible through disability, foster care, or other reasons, although this difference decreased over time. Children in large urban or rural counties were diagnosed later than children in small urban or suburban counties. CONCLUSIONS: Findings showed that diagnosis of autism occurs much later than it should among Medicaid-enrolled children, although timeliness is improving over time. Analyses suggest that most of the observed variation is accounted for by child-level variables, rather than county-level resources or state policies.

Mandell, D. S., et al. (2005). "Factors associated with age of diagnosis among children with autism spectrum disorders." Pediatrics **116**(6): 1480-1486.

OBJECTIVE: Early diagnosis of children with autism spectrum disorders (ASD) is critical but often delayed until school age. Few studies have identified factors that may delay diagnosis. This study attempted to identify these factors among a community sample of children with ASD. METHODS: Survey data were collected in Pennsylvania from 969 caregivers of children who had ASD and were younger than 21 years regarding their service experiences. Linear regression was used to identify clinical and demographic characteristics associated with age of diagnosis. RESULTS: The average age of diagnosis was 3.1 years for children with autistic disorder, 3.9 years for pervasive developmental disorder not otherwise specified, and 7.2 years for Asperger's disorder. The average age of diagnosis increased 0.2 years for each year of age. Rural children received a diagnosis 0.4 years later than urban children. Near-poor children received a diagnosis 0.9 years later than those with incomes  $>100\%$  above the poverty level. Children with severe

language deficits received a diagnosis an average of 1.2 years earlier than other children. Hand flapping, toe walking, and sustained odd play were associated with a decrease in the age of diagnosis, whereas oversensitivity to pain and hearing impairment were associated with an increase. Children who had 4 or more primary care physicians before diagnosis received a diagnosis 0.5 years later than other children, whereas those whose pediatricians referred them to a specialist received a diagnosis 0.3 years sooner. CONCLUSION: These findings suggest improvements over time in decreasing the age at which children with ASD, especially higher functioning children, receive a diagnosis. They also suggest a lack of resources in rural areas and for near-poor families and the importance of continuous pediatric care and specialty referrals. That only certain ASD-related behaviors, some of which are not required to satisfy diagnostic criteria, decreased the age of diagnosis suggests the importance of continued physician education.

Mandell, D. S., et al. (2005). "Trends in Diagnosis Rates for Autism and ADHD at Hospital Discharge in the Context of Other Psychiatric Diagnoses." Psychiatric Services **56**(1): 56-62.

(from the journal abstract) Objective: Concerns have been raised over observed increases in the number of children who are given a diagnosis of a neurodevelopmental disorder. The goal of this study was to examine trends by age and calendar year in the diagnosis of two of these disorders, autism and attention- deficit hyperactivity disorder (ADHD), in the context of other psychiatric disorders in a sample of hospitalized children. Methods: Data from the Healthcare Cost and Utilization Project (HCUP) were used for descriptive analyses of secular trends of diagnosed psychiatric disorders between 1989 and 2000. Changes over time in rates of diagnosis of autism, ADHD, affective disorders, and substance-related disorders were examined and compared. Results: Substance-related disorders were the most common mental disorders recorded at hospital discharge and increased by 39 percent between 1989 and 2000. Affective disorder was the next most common diagnosis and increased by 138 percent. Although autism and ADHD were far less common, their diagnosis rates nearly quadrupled over the course of the study. Although rates of diagnosis of affective and substance-related disorders generally increased over the lifespan, diagnosis of autism and ADHD followed a very different pattern, with peaks in rates at ages seven and 12. Conclusions: Increases in rates of diagnosis of etiologically unrelated mental disorders suggest that there have been changes in diagnostic practices over time, increases in community prevalence of these disorders, and increased likelihood of hospitalizations for different mental disorders. (PsycINFO Database Record (c) 2005 APA, all rights reserved).

Mandy, W., et al. (2014). "Investigating the cross-cultural validity of DSM-5 autism spectrum disorder: Evidence from Finnish and UK samples." Autism **18**(1): 45-54.

Rutter, M. (2003). "Poverty and Child Mental Health: Natural Experiments and Social Causation." JAMA: Journal of the American Medical Association **290**(15): 2063-2064.

Comments on the article by E. J. Costello et al (see record 2003-08976-002) which tested the role of social selection vs social causation of childhood psychopathology using a

natural experiment. Costello et al put the social selection vs social causation dichotomy under rigorous test when a casino was established on an American Indian reservation during the course of their own longitudinal epidemiological study of child psychopathology. The natural experiment derives from the agreement that every adult and child tribe member would receive income from the proceeds of the casino and that this would happen without regard for what the families did. The findings from the study showed that the Indian children whose family income was no longer below the poverty line showed a significant reduction in behavioral symptoms of oppositional/defiant and conduct disorder, although there was no effect on anxiety and depression symptoms. The study allows a reasonably strong inference that the effect represented social causation. Societies need to recognize that economic levels do have important implications for both family functioning and child mental health but, equally, policy makers need to ensure that economic benefits actually have the intended psychological benefits. (PsycINFO Database Record (c) 2003 APA, all rights reserved).

Stein, M. T., et al. (2004). "Cultural and Linguistic Determinants in the Diagnosis and Management of Development Delay in a Four Year Old." Journal of Developmental & Behavioral Pediatrics **25**(5S): S43-S48.

This reprinted article originally appeared in the Journal of Developmental & Behavioral Pediatrics, 2002, Vol 23(5) Oct, 371-376. Also presented are comments from a web site discussion concerning the original article. (The following abstract of the original article appeared in record 2002-06142-010.) A case is presented of Jose, a 4-yr-old Puerto Rican boy diagnosed with high-functioning autism. Jose's mother is concerned because she believes he is in a regular, English-only mainstream classroom at school and worries that he is not receiving appropriate services in the school. Jose's mother brought copies of her son's medical records to the office visit. He had normal developmental milestones at all of his health supervision visits through 9 mos of age. During an acute care visit for gastroenteritis when Jose was 10 mos old, his mother noted that she thought Jose was suffering from 'empacho,' which she treated with a 'special powder.' At 12- and 18-month-old well-child visits, Jose's only words were 'Mama' and 'Papa.' Between 13 and 20 mos of age, he had seven episodes of bilateral otitis media, which were treated with antibiotics; the last three episodes occurred with antibiotic prophylaxis. He underwent bilateral myringotomy and tympanostomy tube placement at 20 mos old. The former pediatrician was not concerned about Jose's language delay because, as documented in his notes, 'it is expected that children who are trying to learn two languages at the same time will have more speech problems and language delay.' Several commentaries are provided about this case. (PsycINFO Database Record (c) 2005 APA, all rights reserved).

Tek, S. and R. J. Landa (2012). "Differences in autism symptoms between minority and non-minority toddlers." Journal of Autism and Developmental Disorders **42**(9): 1967-1973.

Little is known about whether early symptom presentation differs in toddlers with ASD from ethnic minority versus non-minority backgrounds. Within a treatment study for toddlers with ASD, we compared 19 minority to 65 Caucasian children and their parents on variables obtained from the Mullen Scales of Early Learning, Autism Diagnostic

Observation Schedule, and Communication and Symbolic Behavior Scales Caregiver Questionnaire. The majority of parents were from the upper classes irrespective of ethnic membership. Minority children had lower scores in language, communication, and gross motor than non-minority children. Findings indicate that subtle communication delays may be undetected or presumed unremarkable by parents of minority toddlers, and that more significant delays are needed to prompt the search for intervention services. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract).