Study finds wide variation in best-estimate clinical diagnosis of autism spectrum disorders

November 7 2011

In a study conducted at 12 university-based research sites, there was wide variation in how best-estimate clinical diagnoses within the autism spectrum were assigned to individual children, according to a study being published Online First by the *Archives of General Psychiatry*.

In the field of autism spectrum disorders (ASDs), diagnostic instruments have been helpful in defining populations, merging samples, and comparing results across studies, according to background information in the article. Nevertheless, best-estimate clinical (BEC) diagnoses of specific autism spectrum disorders have long been the gold standard. These specific ASDs include autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome.

Catherine Lord, Ph.D., of Weill Cornell Medical College, White Plains, New York, and colleagues conducted an observational study to determine whether the relationships between behavioral appearance and clinical diagnoses of different ASDs vary across 12 university-based sites. The study included 2,102 participants (1,814 male) between 4 and 18 years of age who met autism spectrum criteria on two diagnostic assessments and who had a clinical diagnosis of an ASD. The study authors collected demographic, diagnostic, and developmental data for genetic research.

The authors report that clinical distinctions among categorical diagnostic

ASD subtypes were not reliable, even across sites with well-documented fidelity using standardized diagnostic instruments.

"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," the authors write.

"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," they continue.

The authors suggest that differences in diagnoses could reflect regional variations. "For example, in some regions, children with diagnoses of autistic disorder receive different services than do children with other ASD diagnoses; elsewhere, autistic disorder diagnoses may be avoided as more stigmatizing than diagnoses of PDD-NOS or Asperger syndrome," they write.

The authors point out that their study results have implications for revisions of current diagnostic frameworks. "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," they conclude.

  More information: Arch Gen Psychiatry. Published online November 7, 2011. doi:10.1001/archgenpsychiatry.2011.148

Provided by JAMA and Archives Journals

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