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Parents' developmental concerns and age variance at diagnosis of children with autism spectrum disorder

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ABSTRACT

Although early recognition of autism spectrum disorder (ASD) is important, the age of children at diagnosis is variable. Forty-five participants diagnosed with ASD were divided into groups based on age at diagnosis and compared on age when parents first became concerned about various aspects of their development. Results demonstrated no differences between the two groups with regard to most factors except Early Intervention referral. While concerns about atypical behavior and attainment of milestones were similar between the groups, parents in the early diagnosis group noted social development concerns at an earlier age (mean 18.0 vs. 25.3 months), suggesting close surveillance of this particular developmental domain may facilitate earlier ASD referral and diagnosis.

Early recognition of autism spectrum disorder (ASD) can significantly affect a child's well being and functioning in society, as the child can be enrolled in an Early Intervention program to address speech/language, cognitive, social, and self-help skills (Dawson & Osterling, 1997; Rogers, 1996). Structured behavioral intervention can help decrease the development of secondary behavior problems (Lovaas, 1993) and allows for more effective learning in the classroom. Children enrolled in Early Intervention programs are better able to achieve their educational goals and improve overall outcomes (Butter, Wynn, & Mulick, 2003; Committee on Children with Disabilities, 2001; Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999). However, even though the onset of autism occurs by 36 months of age

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(American Psychiatric Association, 2000), there is often wide variation in the age at which children present for diagnosis to a specialized developmental center.

One cause for these delays may be due to the lack of access to care, whether for diagnosis or to obtain necessary therapy, in certain socioeconomic groups (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Another possible cause includes the varying ages at which parental concern for atypical behavior develops. Several studies have shown parents become concerned about autistic behavior at 12–30 months (Gray & Tonge, 2001) and in one study, sought professional advice at a mean age of 24 months, usually for speech and language concerns (De Giacomo & Fombonne, 1998). Severity of ASD may also impact parental concern and age at diagnosis (Howlin & Asgharian, 1999). Demographic factors, such as the presence of a sibling also affected by ASD or mental disabilities or typically developing older siblings may also alert parents to problems at an earlier age (Howlin & Asgharian, 1999). Previous studies have shown that gender, socioeconomic status, and place of residence did not impact identification of the problem by parents (Howlin & Asgharian, 1999). Additionally, parents perceive different aspects of their child's behavior patterns compared to clinicians, which may also contribute to delays in diagnosis (Stone, Hoffman, Lewis, & Ousely, 1994).

Identifying the characteristics of patients with ASD that may be associated with earlier vs. later diagnosis could assist primary physicians and parents in screening for these characteristics. In this study, we examined a sample of patients evaluated and diagnosed at a referral center for developmental disorders. We tested the hypothesis that age at diagnosis of ASD varies by sociodemographic factors, referral factors, or age when parents became concerned about particular aspects of their child's development.

1. Methods

We conducted a cross-sectional retrospective medical record review of patients evaluated at a tertiary referral center for developmental disorders in the Midwestern US. Participants were divided into two groups based on age at the time of diagnosis (12–36 vs. >36 months). The study was approved by the Institutional Review Board.

1.1. Study population

The study population included children previously evaluated and diagnosed at the developmental center between January 1, 2000 and February 28, 2005, ages 1–18 inclusive, who had been identified as having a diagnosis of Autism, Pervasive Developmental Delay, or Asperger syndrome, using the *International Classification of Diseases, Ninth Revision, Clinical Modification* codes 299.0, 299.8, and 299.9 (1998). To ensure accuracy of coding, participants' records were reviewed to ensure they met DSM-IV criteria for autism spectrum disorder.

Children were excluded from the study if they were previously diagnosed at another facility, had comorbid genetic syndromes or other identified neurologic disorders, if their parents could not recall the age of the child when the parents first became concerned about their child's atypical development, or if pertinent information could not be ascertained or verified by review of the existing medical record.

1.2. Evaluation

All participants included in the study were diagnosed with ASD by a comprehensive neurodevelopmental assessment by a Developmental-Behavioral Pediatrician. Prior to their visit to the developmental center, parents were mailed a questionnaire which asked families to provide information pertaining to previous evaluations, current services, current level of functioning, pertinent birth/medical history, educational history (if applicable), family and social history. Additionally, parents were asked to recall the age at which their child achieved particular milestones, as well as the age of the child when parents first became concerned about social skills, attainment of milestones, and atypical behavior.