

Epidemiology

Examination of the Time Between First Evaluation and First Autism Spectrum Diagnosis in a Population-based Sample

LISA D. WIGGINS, M.S., M.A.

Battelle Memorial Institute, Centers for Public Health Research and Evaluation

JON BAIO, M.A., Ed.S
CATHERINE RICE, Ph.D.

Developmental Disabilities Branch, Centers for Disease Control and Prevention, Atlanta, GA

ABSTRACT. Early identification of young children with an autism spectrum disorder (ASD) can lead to earlier entry into intervention programs that support improved developmental outcomes. The purpose of the present study was to examine identification and diagnostic patterns of children with ASD who live in a large metropolitan area. One hundred fifteen 8-year-old children diagnosed with ASD were identified from a population-based surveillance system at the Centers for Disease Control and Prevention. Primary variables of interest included earliest age of evaluation and earliest age of diagnosis identified from surveillance records, type of initial ASD diagnosis, evaluation sources that documented first ASD diagnosis, characteristics of professionals assigning first ASD diagnosis, and diagnostic tools used to aid the diagnostic process. We found that children with ASD identified by the surveillance system were initially evaluated at a mean of 48 months but were not diagnosed with ASD until a mean age of 61 months. There were no differences in timing of diagnosis based on sex or racial/ethnic classification, although degree of impairment associated with ASD predicted mean age at first evaluation and mean age at first ASD diagnosis. Most children were identified at nonschool sources, such as hospitals and clinics; 24% of the sample did not receive a documented ASD diagnosis until entering school. Most practitioners (70%) did not use a diagnostic instrument when assigning the first ASD diagnosis. Implications for early identification of ASD are discussed. *J Dev Behav Pediatr* 27:79-87, 2006. Index terms: *early identification, diagnosis, autism spectrum disorder, Centers for Disease Control and Prevention.*

Autism spectrum disorders (ASD) are a set of complex neurodevelopmental disorders that affect social, communication, and behavioral development as well as other associated areas such as sensory processing. ASD are usually detected in early childhood and are considered lifelong developmental abilities. The Centers for Disease Control and Prevention (CDC) estimated that the prevalence of ASD in 1996 was 3.4 per 1000 children aged 3 to 10 years.¹ Together with estimates from special education and other service provision agencies, these data raise concern about a potential increase in the prevalence of ASD when

compared with rates reported from previous years,²⁻⁵ although it is uncertain whether this is a true increase or an increase due to expanded diagnostic criteria and enhanced public and professional awareness. Indeed, there has been recent concern that the prevalence of ASD is reaching unprecedented proportions.⁶⁻¹⁰

The concern over increased prevalence coupled with greater public and professional awareness has led to an emphasis on early identification of children with ASD. Identification of children at the onset of symptom presentation can lead to earlier entry into interventions associated with improved developmental outcomes.¹¹ Many of these studies associate gains in verbal and nonverbal communication, intelligence test scores, and peer interaction with early intervention efforts.¹²⁻¹⁷ Accordingly, there is consensus in the professional community that early intervention is a fundamental treatment approach and that children with ASD should participate in therapeutic programs as early as possible.¹⁸

Received September 2005; accepted February 2006.

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

Address for reprints: Lisa D. Wiggins, M.S., M.A. Developmental Disabilities Branch Centers for Disease Control and Prevention MS E-86 1600 Clifton Rd., Atlanta, GA 30333; e-mail: lwiggins@cdc.gov.

Although the concept of early identification is encouraged by health care professionals, a significant time lag between age at first parental concern and age at first ASD diagnosis is consistently reported in the literature. Frith and Soares¹⁹ found that a majority of parents of children diagnosed with autism first became concerned about their child's development between 12 and 23 months of age. Yet these children were not professionally diagnosed until 36 to 70 months of age. Howlin and Asgharian²⁰ replicated these findings and found that parents of children diagnosed with autism noted concerns by a mean of 18 months of age, although an actual diagnosis was not confirmed until a mean of 66 months of age. In a more recent population-based study, Sivberg²¹ found a delay of 20 to 60 months between parental suspicion and diagnosis by a medical professional depending on severity of the disorder and autism classification.

The implications for delayed diagnosis extend far beyond developmental gains associated with early intervention. Most parents of children with ASD experience considerable amounts of stress related to parenting a child with atypical development.^{22,23} The uncertainty of diagnosis accentuates parental anxiety and delays the introduction of behavioral management training that can reduce secondary symptoms in the child.^{23,24} If the child is school-aged, a formal diagnosis may be required to receive necessary educational services and classroom supports. In addition, a diagnosis of ASD increases the likelihood that children will be identified by ASD surveillance systems, which can provide valuable information on population trends in ASD prevalence. Accurate prevalence counts subsequently assist in educational and treatment planning, guiding policy decisions, and generating hypotheses on etiological risk factors.

Yet, investigations of diagnostic delay alone may be inadequate to promote early identification efforts. Identifying facilities and professionals who first evaluate children later diagnosed with ASD will provide data to inform clinician education and training efforts. Understanding the diagnostic tools most commonly used in evaluating children with possible ASD could also aid in formulating clinician educational and training programs.

To date, there are no population-based studies that explore the combined variables of diagnostic delay, type of initial diagnosis, facilities where children with ASD are identified, professionals assigning an initial ASD diagnosis, and diagnostic tools used to assist in diagnosing children with ASD in the same geographic population. The only population-based study that reported findings on diagnostic delay was conducted in Sweden, which has a considerably different health care system than the United States.²¹ Limitations of smaller select sample investigations include a failure to confirm ASD diagnosis with educational or medical reports, using data from a single source, participant response bias, and little consideration of varying diagnostic patterns based on sociodemographic influences such as sex and race/ethnicity, co-occurring conditions such as mental retardation (MR), and degree of impairment associated with ASD.

The purpose of the current investigation is to examine the identification and diagnostic patterns of children

diagnosed with ASD in a large metropolitan region of the United States. Primary variables of interest include the following: (1) earliest age of first evaluation ascertained by a large population-based surveillance program, (2) earliest age of first ASD diagnosis identified from surveillance records, (3) type of initial ASD diagnosis, (4) surveillance sources where children diagnosed with ASD were identified, (5) characteristics of professionals assigning an initial ASD diagnosis, and (6) diagnostic tools used to aid in first ASD diagnosis. Additional analyses were conducted to determine if sex, race/ethnicity, the presence of MR, and the degree of impairment associated with ASD influence primary variables of interest.

METHODS

Study participants were identified through the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) of the Centers for Disease Control and Prevention (CDC). MADDSP is an on-going population-based surveillance system established in 1991 to monitor the rates of mental retardation (MR), cerebral palsy, hearing loss, and vision impairment. Autism spectrum disorders (ASDs) were added to the list of surveillance conditions in 1996. To be identified by MADDSP, children must be 8 years old during a specified study year, have a parent or legal guardian who resides in a five-county metropolitan Atlanta area at any point during the study year, and meet specific surveillance definitions for at least one of the conditions monitored by the surveillance program.

To qualify as a MADDSP ASD surveillance case, a child must meet criteria for ASD as defined by the Diagnostic and Statistical Manual of Mental Disorders—fourth edition, text revision (DSM-IV, TR) and operationalized for MADDSP ASD surveillance (a full description of the identification of children for ASD surveillance is outlined in "Identification of Children for Autism Spectrum Disorder Surveillance"). A preexisting ASD diagnosis is considered when determining surveillance case status but is not necessary to meet ASD surveillance criteria. Of all children identified as an ASD surveillance case, 115 had a documented ASD diagnosis in surveillance records and were considered for the present analysis. Children without a documented diagnosis either met autism eligibility at an educational institution or had sufficient behavioral descriptors in surveillance records to warrant inclusion as a case for MADDSP ASD surveillance. This latter group of children, however, did not have the diagnostic data needed to assess primary variables of interest. The subset of 115 children that were considered for this study had a documented diagnosis of autistic disorder, Asperger disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), or general ASD made by a qualified professional. Children classified with specific subtypes (i.e., autistic disorder, PDD-NOS, Asperger disorder) were subtyped by the qualified professional who authored the evaluation ascertained for surveillance. All other indications of an autism spectrum diagnosis were included under the general category of ASD.

Identification of Children for Autism Spectrum Disorder Surveillance

MADDSP autism surveillance identifies children with an ASD through review of existing evaluation records. For the purposes of MADDSP, children are identified as potential ASD cases through public schools or nonschool sources. Public schools are considered a major source of case identification, primarily because of the Individuals with Disabilities Education Act,²⁵ which states that all individuals with disabilities are entitled to a free, appropriate, and public education. MADDSP school data sources are the nine public special education departments serving five counties in metropolitan Atlanta. Nonschool data sources are also considered major sources of case identification and include the Georgia Department of Human Resources, Atlanta-area hospitals and clinics, diagnostic and evaluation centers that serve children with developmental disabilities, and private practitioners who assess and provide interventions for children with developmental disabilities. As a public health authority, CDC works with healthcare providers to track rates of autism and has also partnered with local, state, and federal Departments of Education to track autism through information in existing evaluation records.

School sources were asked to identify all children evaluated for special education services who met age and residency requirements as specified by MADDSP. Nonschool sources were asked to identify children with a discharge diagnosis, billing code, or reason for referral for a range of developmental and psychiatric conditions (i.e., ASD, MR, and obsessive-compulsive disorder). Abstractors screened records for specific ASD behavioral triggers, such as limited or no interest in other children, as specified by MADDSP abstraction guidelines. All records that contained a behavioral trigger for ASD were further evaluated for reports written by a qualified professional. A qualified professional is defined as a medical, clinical, or educational professional with specialized training in the observation of developmental disabilities; these include but are not limited to, developmental pediatricians, pediatric neurologists, child psychiatrists, clinical and child psychologists, speech and language pathologists, and special education teachers. All reports written by a qualified professional were then abstracted for degree and specialty of the qualified professional, institutional affiliation, date of evaluation, demographic information of the child, provider service data, verbatim descriptions of behaviors associated with autism, psychometric test results (e.g., intelligence, developmental adaptive, autism-specific information), developmental histories, diagnostic summaries, hearing and vision test results, and select medical conditions.

Information abstracted from potential ASD case records are reviewed by trained clinician reviewers who applied a standardized coding scheme to assign surveillance case status. An ASD clinician reviewer is defined as a qualified diagnostician with specialized training and experience in ASD assessment and diagnosis. All MADDSP clinician reviewers meet this definition and have achieved acceptable reliability standards for coding ASD reports. Based on

preliminary results from the 2000 study year, CDC clinician reviewers demonstrated 92% agreement ($\kappa = .80$) on final ASD case status in a random sample of 64 records reviewed by two clinicians (Catherine Rice et al, unpublished data). Additional details on CDC surveillance methodology can be found in Yeargin-Allsopp et al.¹

Identification of Children with an Autism Spectrum Disorder Diagnosis

Children with an ASD diagnosis were identified from diagnostic summaries contained in existing evaluation records. It is important to note that MADDSP clinician reviewers score both ASD evaluation diagnoses and non-ASD evaluation diagnoses. An ASD evaluation diagnosis is recorded only if the professional who authored the report specifically states that the child meets diagnostic criteria for autistic disorder, Asperger disorder, PDD-NOS, or general ASD. Behavioral descriptions or indicators that the child may potentially have one of these diagnoses are coded as “characteristics” or “suspected” and are not considered an ASD diagnosis. Any ASD diagnosis documented in an evaluation is scored as a previous ASD diagnosis and is considered when determining surveillance case status but is not sufficient for inclusion as a surveillance case. Non-ASD evaluation diagnoses are classified into distinct categories and include general developmental delay, language delay, motor delay, adaptive delay, social delay, cognitive delay, play delay, MR, language disorder, attention-deficit hyperactivity disorder (AD/HD), epilepsy/seizure disorder, other, and not stated.

Clinician reviewers provide a rating on degree of impairment associated with ASD determined from all information contained in the source record. The rating of degree of impairment is coded on a three-point Likert scale and is used to summarize the child’s social, communication, behavioral, and adaptive functioning. Clinician reviewers are instructed to determine degree of impairment independent of cognitive function. Degree of impairment is rated as mild (the child shows few symptoms of autism that does not prevent participation from taking part in most activities of daily living or inclusive education), moderate (the child shows a number of symptoms of autism and has persistent difficulty in daily living that affects his or her ability to participate without modifications or support), or severe (the child shows many symptoms of autism that are persistent and significant and require modifications or assistance to participate in most activities of daily living). Interrater reliability on 44 records showed that two clinician reviewers never disagreed on degree of impairment by more than 1 point, yielding a gamma coefficient of .86.

Primary Variables of Interest

The primary variables of interest included earliest age of evaluation and earliest age of first ASD diagnosis identified from surveillance records, type of initial ASD diagnosis, surveillance source where the child was first diagnosed with ASD, professionals assigning an initial

ASD diagnosis, and tools used to aid in first diagnosis. Earliest age of first evaluation was abstracted directly from the nonschool or school record and was defined as the first report containing a trigger for ASD as recorded by a qualified professional. Earliest age of first ASD diagnosis was determined by the first report written by a qualified professional where a definitive ASD diagnosis was recorded. Both earliest age of evaluation and earliest age of diagnosis were coded as age in months.

Type of ASD diagnosis was recorded as autistic disorder, Asperger disorder, PDD-NOS, or general ASD (no subtype stated) and was obtained from the aforementioned ASD evaluation diagnosis. Surveillance source where the child was first diagnosed with ASD was coded as a categorical variable, including school sources and nonschool sources, and was linked to the earliest age of documented diagnosis. Professionals assigning the first ASD diagnosis were categorized by professional degree and area of specialty. Available categories for professionals were medical doctor (pediatrician, neurologist, psychiatrist, other), psychologist (education specialist, doctor of education, masters level, doctor of philosophy, doctor of psychology), other (education specialist, masters level, not otherwise specified), and unknown.

Tools used to aid in diagnosis were linked to earliest age of diagnosis and contained assessments routinely recorded by MADDSP abstractors. Available values for autism-specific tests included the Asperger Syndrome Diagnostic Scale (ASDS), Autism Behavior Checklist (ABC), Autism Diagnostic Interview-Revised (ADI-R), Autism Diagnostic Observation Scale (ADOS), Childhood Autism Rating Scale (CARS), Gilliam Autism Rating Scale (GARS), and other ASD test.

Statistical Analyses

All data analyses were performed using SPSS version 12.0.²⁷ Differences in categorical variables (i.e., type of initial diagnosis) based on sex, race/ethnicity, and presence of MR were assessed with χ^2 analyses for categorical data. Differences in all other numeric variables (i.e., age at first evaluation and age at first ASD diagnosis identified in surveillance records) were assessed with ANOVA analyses that test mean differences between study groups (F). Tukey's b post hoc analyses were applied if there was a significant mean difference in a dependent variable with more than two levels. Linear regression was performed to determine variables that predicted age at first evaluation and age at first diagnosis, and to control for simultaneous effects of related independent variables on numeric dependent variables. Standardized regression coefficients were reported (β) for linear regression analyses. All other statistical analyses were descriptive in nature, including the mean and total number of subjects in the analysis (N).

RESULTS

The study sample contained 104 boys and 11 girls, which yielded a male-female ratio of 9.5:1. Ethnic/racial categories were categorized as white, black, not stated, and other. Those of Hispanic origin were included in the other

category because of the small numbers in this population. The other category also included racial groups such as Asian-Pacific Islander and American Indian. The racial composition of the sample was 53.0% white, 33.0% black, 9.7% other, and 4.3% not stated.

Mental retardation (MR) was determined by the most recent intelligence test data available in surveillance source records (for more information on MR surveillance, see the work of Boyle et al²⁷). Of the 115 children with an ASD diagnosis, 107 had available intelligence test data to assess MR. Fifty-seven (53.3%) had intelligence test scores above 70 and 50 (46.7%) had intelligence test scores at or below 70. There were no significant differences in the presence of MR based on race/ethnicity in our sample of children with a documented ASD diagnosis. When black and white children were compared, the clinician coding of degree of impairment associated with ASD yielded a significant racial/ethnic difference in that white children with an ASD diagnosis were rated as significantly less impaired than black children with an ASD diagnosis ($F_{1,97} = 10.71, p = .001$). Children with MR were also rated as significantly more impaired than children without MR ($F_{1,105} = 54.06, p < .001$).

The most common type of initial diagnosis was autistic disorder, followed by general ASD, pervasive developmental disorder—not otherwise specified (PDD-NOS), and Asperger disorder (Table 1). There were no statistically significant differences in type of diagnosis based on sex, although descriptive statistics showed that none of the girls in the sample were diagnosed with Asperger disorder. There were few differences in type of initial diagnosis based on race/ethnicity when black and white children were compared ($\chi^2 [3, N = 99] = 7.17, p = .07$), indicating that white children were more likely to be diagnosed with Asperger disorder and general ASD than black children and black children were more likely to be diagnosed with autistic disorder than white children. Children with MR were also more likely to be diagnosed with autistic disorder ($\chi^2 [3, N = 107] = 13.77, p = .003$), as were children rated with the most severe level of impairment (Yate $\chi^2 [6, N = 115] = 32.64, p < .001$).

Time Between First Evaluation and First Autism Spectrum Disorder Diagnosis

The mean age of first documented evaluation recorded by a qualified professional was 48 months (range, 160–103 mo) (Table 2). The mean age at first documented ASD diagnosis was 61 months (range, 17–105 mo) (Table 2). The average delay between mean age at first documented evaluation and mean age at first ASD diagnosis was 13 months.

Analysis of variance (ANOVA) indicated a slight tendency for girls ($N = 11$) to be evaluated earlier than boys ($N = 104$) ($F(1,113) = 3.29, p = .07$). There were no significant differences in age at first evaluation based on racial/ethnic classification. Children diagnosed with Autistic Disorder and general ASD were evaluated significantly earlier than children diagnosed with Asperger's Disorder ($F(3,102) = 3.12, p = .03$, mean, 43, 48, and 60 mo, respectively).

Table 1. Number and Frequency of Earliest Identified Autism Spectrum Disorder Diagnosis Among 8-year-old Children Living in Metropolitan Atlanta

	Diagnostic Classification (%)			
	Autistic Disorder	Asperger Disorder	PDD-NOS	General ASD
Total sample (n = 115)	38.3	11.3	18.2	32.2
Sex				
Male (n = 104)	38.5	12.5	19.2	29.8
Female (n = 11)	36.4	0	9.1	54.5
Race				
White (n = 61)	29.5	16.4	14.8	39.3
Black (n = 38)	52.6	7.9	18.4	21.1
Other (n = 11)	45.4	0	36.4	18.2
Not stated (n = 5)	60.0	0	20.0	20.0
MR				
IQ > 70 (n = 57)	28.1	19.3	22.8	29.8
IQ ≤ 70 (n = 50)	50.0	0	16.0	34.0
Degree of impairment				
Mild (n = 25)	24.0	36.0	16.0	24.0
Moderate (n = 55)	27.3	7.3	23.6	41.8
Severe (n = 35)	65.7	0	11.4	22.9

Items in boldface indicate statistical significance of $p < .01$ within diagnostic classification groups. PDD-NOS, pervasive developmental disorder-not otherwise specified; ASD, autism spectrum disorder; MR, mental retardation.

The effects of MR and level of impairment associated with ASD were simultaneously controlled in regression analyses given these variable were significantly correlated ($r = 5.8, p < .01$). Results found that level of impairment independently predicted age at first evaluation ($\beta = -.35, p < .01$); children with severe impairment were evaluated earlier than those with mild impairment (mean, 41 and 62 mo, respectively). MR, sex, and race/ethnicity did not independently predict age at first evaluation after level of

impairment was considered. MR did not independently influence age at first evaluation after level of impairment was considered. Children diagnosed with autistic disorder and general ASD were evaluated significantly earlier than children diagnosed with Asperger disorder ($F(3,102) = 3.12, p = .03$, mean, 43, 43, and 60 mo, respectively).

Non-ASD evaluation diagnoses from the first evaluation identified were classified into distinct diagnostic categories including none stated, general developmental delay, language delay, motor delay, adaptive delay, social delay, cognitive delay, play delay, MR, language disorder, attention-deficit hyperactivity disorder (AD/HD), epilepsy/seizure disorder, and other. The initial evaluation diagnoses in our sample of children were other, 27.2%; not stated, 16.5%; general developmental delay, 13.9%; language delay, 8.4%; motor delay, 7.7%; adaptive delay, 7.3%; social delay, 5.0%; cognitive delay, 5.0%; MR, 3.1%; language disorder, 2.7%; AD/HD, 2.3%; epilepsy/seizure disorder, 1.1%; and play delay, 0.8%.

There were no significant differences in mean age of first documented ASD diagnosis based on racial/ethnic classification. The mean age of first ASD diagnosis was 8 months younger for girls (mean, 54 mo) as compared to boys (mean, 62 mo), although the small number of girls in the sample ($N = 11$) made it difficult to analyze and interpret statistical differences based on sex. Mean age of first documented ASD diagnosis was also significantly influenced by type of initial ASD diagnosis ($F(3,111) = 6.40, p = < .001$). Tukey's *b* post hoc analyses revealed that children with autistic disorder, PDD-NOS, and general ASD were diagnosed earlier than children with Asperger disorder (mean, 59, 65, 53, and 82 mo, respectively).

When level of impairment associated with ASD and MR were simultaneously controlled, level of impairment independently predicted age at first documented ASD diagnosis ($\beta = -.27, p = .02$), whereas MR did not

Table 2. Mean Age at First Documented Evaluation and at First Documented Autism Spectrum Disorder Diagnosis for 8-year-old Children Living in Metropolitan Atlanta

	Age at First Evaluation (mo)		Age at First ASD Diagnosis (mo)		Diagnostic Delay (mo)
	Mean	Range	Mean	Range	
Total sample	48	16-103	61	17-105	13
Sex					
Male	49	22-103	62	27-105	13
Female	38	16-72	54	17-100	16
Race					
White	48	16-95	62	27-105	14
Black	50	22-97	60	33-97	10
Not stated	38	19-62	51	19-99	13
Other	45	17-103	63	17-103	18
MR					
IQ > 70	53	26-103	63	27-103	10
IQ ≤ 70	41	16-96	58	17-105	17
Degree of impairment					
Mild	62	33-95	72	35-100	10
Moderate	46	17-103	59	17-103	13
Severe	41	16-97	55	19-105	14

ASD, autism spectrum disorder; MR, mental retardation.

independently influence age at first documented ASD diagnosis. Descriptive statistics showed that children with severe impairment were diagnosed 17 months before those with mild impairment. Sex and race/ethnicity did not uniquely predict age at first ASD diagnosis.

Characteristics of Identification Source and Professional Assigning First Autism Spectrum Disorder Diagnosis

One hundred fourteen children in the sample had an identifiable evaluation source linked to the first evaluation where a definitive ASD diagnosis was recorded. Seventy-six percent of the entire sample received an initial ASD diagnosis at a nonschool source (i.e., hospital, specialty clinic, private practitioner) and 24% received an initial diagnosis at school. It is important to note that although only 24% of this sample received the first documented ASD diagnosis at a school source, the majority of ASD surveillance cases (52.6%) were ascertained at an educational institution (reflecting the tendency of school sources to assign autism eligibility codes rather than a clinical diagnosis). ANOVA revealed a significant difference in mean age of first ASD diagnosis based on identification source ($F(1,112) = 15.0, p < .001$), with children diagnosed at nonschool sources being diagnosed earlier (mean, 56 mo) than children diagnosed at school sources (mean, 74 mo). There was also a significant difference in identification source based on type of initial ASD diagnosis ($\chi^2 [3, n = 114] = 7.80, p = .05$). Descriptive statistics showed that 68.2% of children diagnosed with autistic disorder, 84.6% of children diagnosed with Asperger disorder, 61.9% of children diagnosed with PDD-NOS, and 89.2% of children diagnosed with general ASD were diagnosed at nonschool sources.

The majority of initial ASD diagnoses were assigned by psychologists with a degree of doctor of philosophy (32.2%), followed by medical doctor neurologists (17.4%) and medical doctor developmental pediatricians (14.8%). Other types of professional assigning a first ASD diagnosis were medical doctor psychiatrists (12.2%), psychologists who are education specialists or doctors of education (10.4%), other/unknown (12.1%), and psychologists with a degree of doctor of psychology (0.9%). Differences in professionals assigning initial ASD diagnoses based on sex and racial/ethnic classification were assessed by collapsing examiner specialty into three categories: (1) medical doctor, (2) psychologist, and (3) other/unknown. Chi-square analyses revealed no significant differences in professionals assigning initial ASD diagnosis based on sex or racial/ethnic classification. The distribution of type of initial diagnosis by type of professional assigning the initial diagnosis is presented in Figure 1.

Diagnostic Tools Used to Aid in Initial Autism Spectrum Disorder Diagnosis

Autism-specific diagnostic tools were administered in 30% of evaluations linked to an initial ASD diagnosis (Fig. 1). The Childhood Autism Rating Scale (CARS) was

administered by the large majority of practitioners (68%), followed by the Autism Behavior Checklist (ABC) (14%). The Asperger Syndrome Diagnostic Scale (ASDS), Autism Diagnostic Interview-Revised (ADI-R), Autism Diagnostic Observation Scale (ADOS), and Gilliam Autism Rating Scale (GARS) were rarely or never used to aid in initial ASD diagnosis (0%, 0%, 7%, and 11%, respectively). There were no statistically significant differences in the use of diagnostic tests based on the child's sex, racial/ethnic classification, MR, level of impairment, or type of initial ASD diagnosis. There were also no statistical differences in mean age of first ASD diagnosis based on the use of a standardized instrument.

DISCUSSION

This study examined identification and diagnostic patterns of children living in metropolitan Atlanta with a documented ASD diagnosis in evaluation records. We found that the mean age of first evaluation was 48 months and the mean age of first ASD diagnosis was 61 months, reflecting an average 13-month delay in between initial evaluation and initial diagnosis. Demographic characteristics such as sex and race/ethnicity rarely influenced primary variables of interest, although the degree of impairment associated with ASD was a significant predictor of age at first evaluation and age at first ASD diagnosis. This finding is not particularly surprising

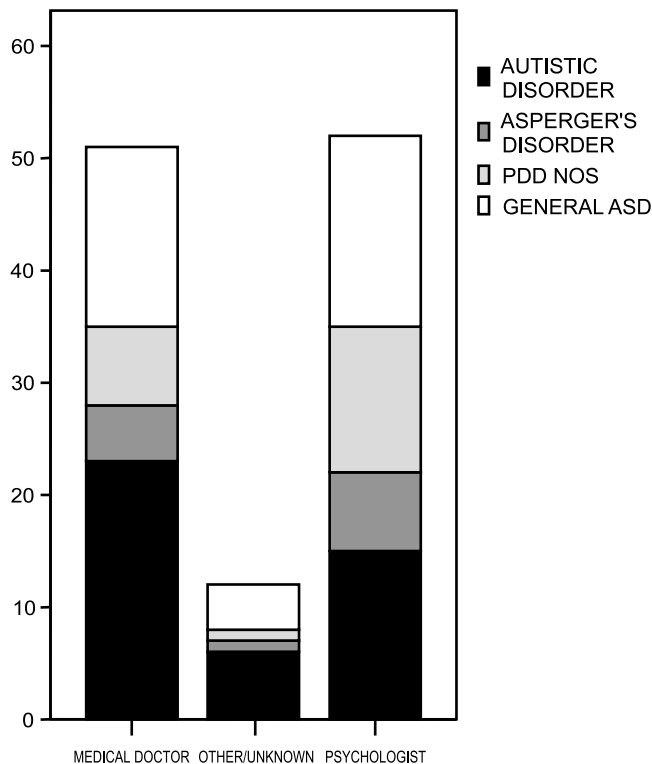


FIGURE 1. Distribution of type of initial autism spectrum disorder diagnosis by type of specialty of examiner assigning initial diagnosis for 8-year-old children living in metropolitan Atlanta.

because level of impairment considers deficits principally associated with autistic disorder, such as lack of social and emotional reciprocity and unusual use of language.

Few studies have examined degree of impairment associated with ASD and how this variable influences ASD identification and diagnostic patterns. Our results indicate that degree of impairment is a significant factor independent of cognitive functioning that should be considered when evaluating the mean age when children with ASD are first assessed by a qualified professional and the mean age when children with ASD are first diagnosed. It is interesting to note that when the effects of level of impairment associated with ASD and mental retardation (MR) were simultaneously controlled, only level of impairment uniquely predicted age at first evaluation and age at first documented ASD diagnosis. This finding is not particularly surprising given that level of impairment considers deficits principally associated with autistic disorder, such as lack of social and emotional reciprocity and difficulties with pragmatic communication.

Our results also build on previous research that demonstrates a significant delay between age at first parental concern and age at first ASD diagnosis: formal diagnosis is also delayed an average of 13 months beyond the point when a child is first evaluated by a qualified professional. As mentioned previously, there are considerable implications for delayed ASD diagnosis in early childhood. In addition, recent research has shown significant gains in expressive and receptive language and pivotal social skills are associated with targeted early intervention approaches.^{28,29} Thus, because of the importance of early identification, it is imperative that all children receive routine developmental screening. Children with identified delays should be referred for further ASD screening and evaluation.^{31,32}

Although parents of children with ASD typically become concerned about their child's development between 12 and 23 months of age,¹⁹ the current report shows that children are not evaluated by a qualified professional until an average of 48 months of age. Consequently, efforts exist to increase professional and parent training focusing on specific characteristics associated with an ASD diagnosis. Educated parents can then collaborate with health care providers to expedite referrals to diagnostic specialists so that appropriate interventions can be implemented. Community awareness campaigns designed to educate parents and health care providers about early detection of developmental disabilities are ideal for addressing this particular need.³⁰

Another indication of diagnostic delay is that 24% of the current sample was identified at a school source, compared with 76% of the sample who were identified at a nonschool source and that children who were identified at nonschool sources were identified significantly earlier than those identified at school sources. The majority of children diagnosed with autistic disorder, Asperger disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), and general ASD were diagnosed at a nonschool source, and this tendency was especially pronounced for children diagnosed with general ASD. It

is important to note that the school sources included in this analysis typically evaluate children to determine eligibility for educational services and not to provide a formal clinical diagnosis. The significance of our data is that results show many children are not being diagnosed at clinical sources before becoming school-aged. Again, delaying diagnosis until a child enters school may delay delivery of specialized services that may enhance academic performance and improve social interaction skills. Another consideration is the disproportionate impact that delay of service delivery may have on children who rely on free educational evaluation and intervention.

Professionals assigning an initial ASD diagnosis used a standardized diagnostic tool in 30% of evaluations; 70% of evaluations were not accompanied by a standardized assessment instrument. Although we found that mean age of first ASD diagnosis was not influenced by use of a standardized diagnostic test, 38.3% of our sample were diagnosed with autistic disorder, which can be less complicated to diagnose than other spectrum classifications. Moreover, practice parameters clearly indicate the importance of using standardized instruments when both screening and diagnosing an ASD.^{31,32} When a diagnostic tool was administered, the CARS was most commonly used, followed by the ABC. Both the CARS and ABC are brief diagnostic instruments that can be used relatively easily within a busy hospital or clinic. These results stress the importance of the development and refinement of assessment instruments that are relatively easy to administer and score and can be applied to the range of ASD phenotypes. More comprehensive diagnostic tools (that require additional time and resources) can then be considered for subsequent assessment of symptom profile and empirical investigations.

Although the focus of these analyses was on children with a documented ASD diagnosis in evaluation records, our surveillance system identified another group of children who met ASD case definition but did not have a documented ASD diagnosis. This latter group of children is particularly interesting, considering they did not have an ASD diagnosis documented in their evaluation records but either met autism eligibility at an educational institution or had sufficient behavioral descriptors to warrant inclusion as an ASD surveillance case. In turn, this group of children without a documented diagnosis may show different diagnostic patterns than those analyzed in this report. For instance, although race/ethnicity did not influence mean age of first evaluation among children with a documented diagnosis, the mean age of first evaluation was influenced by an interaction between race/ethnicity and presence of MR in the larger sample of all ASD surveillance cases (the presence of MR resulted in a statistically earlier age of diagnosis for children classified in the "other" category and a clinically earlier age of diagnosis for all racial categories other than black). In addition, for the subset of children with a documented ASD diagnosis considered in this report, boys were overrepresented (9.5:1 male-female ratio) when compared with the entire group of ASD surveillance cases (5.5:1 male-female ratio). The unusually high sex ratio in our sample could be a result of diagnostic classification: the

majority of children included in our analyses were diagnosed with autistic disorder and the majority of girls ($N = 11$) were diagnosed with a general ASD. Since the larger surveillance sample includes children with ASD characteristics or an autism classification for special education services but not an ASD diagnosis, it could be that this larger group includes more girls diagnosed with a general ASD (as opposed to autistic disorder) or girls who display characteristics of ASD but who are not formally diagnosed with a spectrum disorder. Future analyses should further examine the distinct characteristics of the group of children who met ASD surveillance case status but did not have a documented ASD diagnosis and how they differ from children in our sample.

When interpreting study results, it is important to consider the study population, geographic location, and general study design, all which may affect how results are interpreted and whether they can be generalized to other communities with distinct demographic characteristics. Our study population was obtained from surveillance records reviewed in metropolitan Atlanta, which has a large middle-class black population. Results from previous studies that found racial/ethnic differences in first age of

evaluation, first age of ASD diagnosis, or diagnostic delay may be a product of socioeconomic influence rather than pure racial/ethnic differences.³³ In addition, CDC does not review public early intervention records; which may have biased the age of first evaluation found in our analyses.

In summary, this report builds on previous research on delayed diagnosis of ASD by demonstrating that children with ASD are not diagnosed, on average, until 13 months after initial evaluation by a qualified professional. Sex and racial/ethnic classification did not significantly impact diagnostic delay, although degree of impairment associated with ASD was a significant predictor of mean age at first evaluation and mean age at first ASD diagnosis. Most children were identified at nonschool sources, such as hospitals and clinics; 24% did not receive a formal diagnosis until entering school. Although diagnostic tools can aid in making an ASD diagnosis, many practitioners do not use standardized diagnostic instruments and instruments that are used tend to be brief and relatively easy to administer. The implications of these findings are significant in demonstrating a societal need to train both parents and professionals on the early detection of ASD and the importance of early intervention.

REFERENCES

1. Yeargin-Allsopp M, Rice C, Karapurkar T, et al. Prevalence of autism in a US metropolitan area. *J Am Med Assoc.* 2003;289:49–55.
2. Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children: confirmation of high prevalence. *Am J Psychiatry.* 2005;162:1133–1141.
3. Croen L, Grether J, Hoogstrate J, et al. The changing prevalence of autism in California. *J Autism Dev Disord.* 2002;32:207–215.
4. Fombonne E. The epidemiology of autism: a review. *Psychol Med.* 1999;29:769–786.
5. Newshaffer C, Falb M, Gurney J. National autism prevalence trends from United States special education data. *Pediatrics.* 2005;115:277–282.
6. Blaxill T. The prevalence of autism spectrum disorders. *Public Health Rep.* 2004;119:536–551.
7. Charman T. The prevalence of autism spectrum disorders. *Eur Child Adolesc Psychiatry.* 2002;11:219–256.
8. Fombonne E. Is there an epidemic of autism? *Pediatrics.* 2001;107:411–412.
9. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord.* 2003;33:365–382.
10. Gilberg C, Wing L. Autism: not an extremely rare disorder. *Acta Psychiatr Scand.* 1999;99:399–406.
11. Rogers S. Empirically supported comprehensive treatments for young children with autism. *J Clin Child Psychol.* 1998;27:168–179.
12. Dawson G, Osterling J. Early intervention in autism. In: Guralnick M ed. *The Effectiveness of Early Intervention.* Baltimore, MD: Brookes Publishing; 1997:307–326.
13. Lovaas O. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol.* 1987;55:3–9.
14. McEachin J, Smith T, Lovaas O. Long-term outcome for children with autism who received early intensive behavioral treatment. *Am J Mental Retard.* 1993;97:359–372.
15. Ozonoff S, Cathcart K. Effectiveness of a home based program intervention for young children with autism. *J Autism Dev Disord.* 1998;25–32.
16. Rogers S, Lewis H. An effective day treatment model for young children with pervasive developmental disorders. *J Am Acad Child Adolescent Psychiatry.* 1989;28:207–214.
17. Sheinkopf S, Siegel B. Home-based behavioral treatment of young children with autism. *J Autism Dev Disord.* 1998;28:15–23.
18. Charman T, Baird G. Practitioner review: diagnosis of autism spectrum disorders in 2 and 3 year-old children. *J Child Psychol Psychiatry.* 2002;43:289–305.
19. Frith U, Soares I. Research into earliest detectable signs of autism: what parents say. *Communication.* 1993;27:17–18.
20. Howlin P, Asgharian A. The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. *Dev Med Child Neurol.* 1999;41:834–839.
21. Sivberg B. Parents' detection of early signs in their children having an autism spectrum disorder. *J Pediatr Nurs.* 2003;18:433–439.
22. Gray D. Ten years on: a longitudinal study of families of children with autism. *J Intell Dev Disabil.* 2002;27:215–222.
23. Pisula E. Parents of children with autism: review of current research. *Arch Psychiatry Psychother.* 2003;5:51–63.
24. Howlin P. *Children with Autism and Asperger's Syndrome: A Guide for Practitioners and Parents.* Chichester, UK: Wiley, 1998.
25. The Education for All Handicapped Children Act of 1975. Pub L No. 94-145, 20 USC 1401 et seq, 42 *Federal Register* 163 (August 23, 1977):42474–42518.
26. *SPSS Inc* [computer program], Version 12. Chicago, IL: SPSS Inc; 2003.

27. Boyle C, Yeargin-Allsopp M, Doernberg N, Holmgreen P, Murphy C, Schendel D. Prevalence of selected developmental disabilities in children 3–10 years of age: the Metropolitan Atlanta Developmental Disabilities Surveillance Program. *MMWR CDC Surveill Summ.* 1996;45:1–14.
28. Kasari C, Freeman S, Paparella T. Early intervention in autism: attention and symbolic play. *Int Rev Res Mental Retard.* 2001; 23:207–237.
29. Landa R, Holman K, Sullivan M, et al. Language and social change in toddlers with ASD: early intervention. Paper presented at: International Meeting for Autism Research; May, 2005; Boston, MA.
30. Centers for Disease Control and Prevention. Learn the Signs, Act Early. February 2005. Available at: <http://www.cdc.gov/actearly>. Accessed June 15, 2005.
31. Filipek P, Accardo P, Ashwal S, et al. Practice parameter: screening and diagnosis of autism. *Neurology.* 2000;55:468–477.
32. Filipek P, Accardo P, Baranek G, et al. The screening and diagnosis of autistic spectrum disorders. *J Autism Dev Disord.* 1999; 29:439–484.
33. Mandell D, Listerud J, Levy S, Pinto-Martin J. Race differences in the age at diagnosis among Medicaid-eligible children with autism. *J Am Acad Child Adolescent Psychiatry.* 2002;41:1447–1453.