

Prevalence of Autism in a US Metropolitan Area

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INDIVIDUALS WITH AUTISM HAVE UNUSUAL social, communicative, and behavioral development and may have abnormalities in cognitive functioning, learning, attention, and sensory processing. Given the complex nature of autism and the spectrum of related disorders, current prevalence rates and whether rates have increased are highly debated topics.¹⁻⁵ Much of the descriptive epidemiology of autism comes from studies outside the United States (a summary of autism prevalence rates from epidemiologic studies is available from the authors). Autism prevalence rates from studies published before 1985 are 4 to 5 per 10000 children for the broader autism spectrum and approximately 2 per 10000 for the more narrowly defined condition termed *classic autism*.⁶⁻¹² Since 1985, non-US studies have reported higher rates of autism, ranging from a prevalence of 7 to 10 per 10000 children for autistic disorder and an estimated prevalence for autism spectrum disorders 1.5 to 2.5 times higher.^{7,13} A recent study conducted in the United Kingdom reported a prevalence rate of 16.8 per 10000 children for autistic disorder and 62.6 per 10000 for the entire autism spectrum.¹⁴

These reports raise concerns about possible increases in autism prevalence.

For editorial comment see p 87.

Context Concern has been raised about possible increases in the prevalence of autism. However, few population-based studies have been conducted in the United States.

Objectives To determine the prevalence of autism among children in a major US metropolitan area and to describe characteristics of the study population.

Design, Setting, and Population Study of the prevalence of autism among children aged 3 to 10 years in the 5 counties of metropolitan Atlanta, Ga, in 1996. Cases were identified through screening and abstracting records at multiple medical and educational sources, with case status determined by expert review.

Main Outcome Measures Autism prevalence by demographic factors, levels of cognitive functioning, previous autism diagnoses, special education eligibility categories, and sources of identification.

Results A total of 987 children displayed behaviors consistent with *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* criteria for autistic disorder, pervasive developmental disorder—not otherwise specified, or Asperger disorder. The prevalence for autism was 3.4 per 1000 (95% confidence interval [CI], 3.2-3.6) (male-female ratio, 4:1). Overall, the prevalence was comparable for black and white children (black, 3.4 per 1000 [95% CI, 3.0-3.7] and white, 3.4 per 1000 [95% CI, 3.2-3.7]). Sixty-eight percent of children with IQ or developmental test results (N=880) had cognitive impairment. As severity of cognitive impairment increased from mild to profound, the male-female ratio decreased from 4.4 to 1.3. Forty percent of children with autism were identified only at educational sources. Schools were the most important source for information on black children, children of younger mothers, and children of mothers with less than 12 years of education.

Conclusion The rate of autism found in this study was higher than the rates from studies conducted in the United States during the 1980s and early 1990s, but it was consistent with those of more recent studies.

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However, little is known about the prevalence rate of autism in US populations because only 4 US population-based studies of autism have been conducted.¹⁵⁻¹⁸ Three of these studies, conducted in the 1980s or early 1990s, found very low prevalence rates, ie, approximately 4 per 10000 children.¹⁵⁻¹⁷ The fourth, a recent study of autism prevalence in 1998 in Brick Township, New Jersey, reported a higher rate than any previous US study¹⁸: 40 per 10000 3- to 10-year-old children had autistic disorder and 67 per 10000 children were within the entire autism spectrum. The ability to generalize these results to the broader US population is uncertain because

the study comprised a small population of children in a community where increased autism prevalence was suspected. However, these rates are supported by findings from several recent non-US studies.^{14,19-21} In addition, data from US service providers (hereafter, *service provider* is defined as an agency or program or an individual providing

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health, educational, or social services to children with developmental disabilities) indicate large increases in the number of individuals receiving services for autism in the last decade, but these numbers do not represent population-based rates.^{22,23}

This article describes the prevalence of autism in metropolitan Atlanta in 1996 as determined by a multiple-source, population-based developmental disabilities (DDs) surveillance program. Autism prevalence is reported by child demographic factors, including race and sex. Other measures include level of cognitive functioning, previous autism spectrum diagnosis, special education eligibility category, and identification source (ie, school or nonschool). Throughout this article, the terms *autism* and *autism spectrum disorders* (ASDs) refer to autistic disorder, Asperger disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS).

METHODS

Children with autism were identified in 2 phases. In phase 1, all children suspected of having autism who met the age, study year, and parental residence requirements were identified through screening and abstraction of source files at multiple medical, clinical, and educational sources. In phase 2, abstracted data from phase 1 were systematically scored by expert reviewers to determine whether the identified children met the autism surveillance case definition. Expert reviewers included 3 clinical or developmental psychologists and 1 diagnostician, each with specialized training and experience in autism assessment and diagnosis.

An *autism case* was defined as a child who was 3 to 10 years old during the 1996 study year, whose parent(s) or legal guardian(s) resided in the 5-county (ie, Clayton, Cobb, DeKalb, Fulton, and Gwinnett) metropolitan Atlanta area at any time during the 1996 study year, and who displayed behaviors (as described by a qualified professional) consistent with the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV)*²⁴ criteria for autistic disorder, PDD-

NOS (including atypical autism), or Asperger disorder on evaluations conducted through 1996. A *qualified professional* was defined as a clinical or educational professional with specialized training in the observation of children with DDs (eg, developmental pediatrician, child psychiatrist, pediatric neurologist, clinical or developmental psychologist, special education teacher). Children with childhood disintegrative disorder and Rett disorder were not included because of the rarity of childhood disintegrative disorder and the debate regarding whether Rett disorder is an ASD.

Phase 1: Case Ascertainment

Children with autism were identified as part of the Centers for Disease Control and Prevention's (CDC) Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), an ongoing, active population-based surveillance program to monitor the occurrence of 5 DDs (autism, cerebral palsy, hearing loss, mental retardation [MR], and vision impairment) among 3- to 10-year-old children in the 5-county metropolitan Atlanta area.^{25,26} The total number of 3- to 10-year-old children residing in metropolitan Atlanta in 1996 was 289 456 (51% male; 58% white, 38% black, and 4% other racial group).²⁷

Public schools were a primary source for case identification. As a consequence of the Individuals with Disabilities Education Act (Public Law 94-142 as amended),²⁸ many children identified by MADDSP were enrolled in a public school special education program or other Department of Education program for children with DDs (eg, state schools for children with hearing loss or vision impairment, regional psychoeducational centers). Potential non-school sources were identified through input from public school administrators, a local Parent-to-Parent organization, the state health department, programs that serve children with special needs, diagnostic clinics, and area clinicians. Non-school case identification sources included State Department of Human Resources facilities for children with DDs, pediatric hospitals

and associated clinics, comprehensive diagnostic and evaluation centers for individuals with DDs, and private physicians and clinicians who provide diagnostic services for children with DDs, particularly autism. This study was approved by the CDC institutional review board. Because this activity was considered public health surveillance, parental consent was not required. Instead, permission to access records was obtained from each data source.

At the school sources, we screened the most recent psychoeducational assessments of all children evaluated for placement in a special education program. We also screened the special education program files of all children receiving special education services with select eligibility categories (eg, autism, intellectual disabilities). At the non-school sources, we screened the source files of all children with an ASD as the discharge diagnosis, billing code, or reason for referral. No clinical examinations of children were performed. Children were identified as possible cases if their source files included a confirmed ASD diagnosis, an indication that the child might have ASD, or descriptions of behaviors associated with autism diagnostic criteria.

From the source files of each child identified as a possible case, we abstracted demographic variables, school service data, verbatim descriptions of behaviors associated with autism, psychometric test results (eg, intelligence, developmental, adaptive, autism-specific assessments), developmental history, evaluation diagnostic summaries, hearing and vision test results, associated medical conditions, family history, laboratory and genetic test results, and, for children with cerebral palsy, physical and neurological findings. Follow-up abstraction was conducted at other MADDSP data sources where the child had been evaluated.

MADDSP records are linked to Georgia birth certificate files and to the Metropolitan Atlanta Congenital Defects Program, a CDC birth defects surveillance program covering the same geographic area as MADDSP.²⁹ These linkages provide additional demographic

information and verification of structural malformations.

Phase 2: Expert Review

A coding guide was developed to classify behavioral indicators of the *DSM-IV* criteria for autism based on behavioral descriptions from the *DSM-IV* guidelines for autistic disorder, Asperger disorder, and PDD-NOS, and from a sample of abstracted evaluations. All abstracted evaluations for each child were reviewed and scored by an expert in autism. Any statement of developmental delays in the areas of social skills, language, or symbolic play at age 3 was scored, as were any notes indicating behavioral regression or a plateau in skill development. We also scored descriptions of associated features (eg, abnormalities in cognitive development, odd responses to sensory stimuli, self-injurious behaviors). We did not code estimates of severity level of impairment for each behavior. A child was defined as having a previous autism diagnosis if the evaluation diagnostic summary for 1 or more evaluations contained a diagnosis or diagnostic impression of an ASD.

Based on systematic review of behaviors in the abstracted evaluations, each child was classified as a case, suspected case, or not a case. Autism cases (N=987) included children who clearly had at least 1 social and either 1 communication or 1 behavioral criterion for autism, ie, *DSM-IV* behavioral criteria for PDD-NOS. However, 91% of the children who qualified as a case had at least 6 total criteria with at least 2 in social, at least 1 in the communication, and at least 1 in the behavioral domains, ie, *DSM-IV* behavioral criteria for autistic disorder. Since the differential diagnosis between autism subtypes requires a qualitative assessment of behaviors difficult to obtain through record review, our results were not reported by subtype. Seventy-seven percent of children with autism had developmental delays and behavioral symptoms before age 3. Children were classified as suspected cases (n=52) if they had behaviors associated with autism, but sufficient behavioral information was not available to confirm case

status. If a child met the criteria for autism but the primary reviewer questioned the applicability of this diagnosis, a second and independent review of the case was initiated. If case status was still questionable, a third party review was undertaken.

A random sample of abstracted evaluations (20%) was independently scored by a second reviewer to determine reliability of the autism classification system. Reliability was evaluated using percentage of agreement and a simple κ coefficient. A κ of 0.47 and 96% agreement was achieved for a case meeting the MADDSP autism case definition. The paradox between a low κ and a high percentage agreement was due to the high prevalence of autism in the sample because abstracted source files were prescreened for autism symptoms. The higher random chance of a child meeting the case definition for autism led to a larger correction of chance than would be expected if there were more non-suspect cases or controls in the sample. This larger correction of chance will push the κ into the moderate (0.40-0.60) range, even when apparent agreement is high.³⁰

Psychometric data were available for 880 (89%) of the 987 children with autism. Of these, 676 (77%) had been administered a standardized intelligence test, and the others had received a developmental test (a list of psychometric tests is available from the authors). Children with a full-scale IQ of 70 or less or a score of 2 or more standard deviations below the mean on the cognitive domain of a developmental test were classified as having a cognitive impairment.

For children who were administered IQ tests, severity of cognitive impairment was defined according to the *International Classification of Diseases, Ninth Edition (ICD-9)*,³¹ MR categories: mild (50-70), moderate (35-49), severe (20-34), and profound (<20). Children whose IQ scores could not be assigned to a discrete category were designated as having MR—not otherwise specified (MR-NOS). Precise level of cognitive impairment could not

be established for children who were administered a developmental test.

Analytic Methods

Period prevalence estimates were calculated using, as the denominator, the number of 3- to 10-year-old children who resided in the 5-county metropolitan Atlanta area in 1996 according to the Bureau of Census post-censal estimates for that year (N=289456). We used the Poisson distribution to calculate 95% confidence intervals (CIs) for prevalence rates.³² Race-specific rates used the categories white, black, and other. Children of Hispanic origin were included in either the white or black category according to self-identification. The other race category included racial groups such as Asian Pacific Islander and American Indian. A *P* value of .05 was used to determine statistical significance.

RESULTS

Prevalence Estimates and Demographics

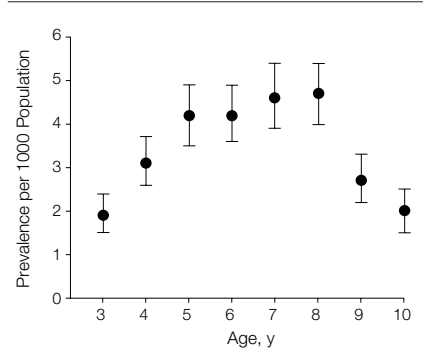
Nine-hundred eighty-seven of the 289456 children aged 3 to 10 years in metropolitan Atlanta in 1996 were determined to have autism, a rate of 3.4 per 1000 (95% CI=3.2-3.6). Prevalence ranged from 1.9 per 1000 in 3-year-old children to 4.7 per 1000 in 8-year-old children. Additional χ^2 tests showed significant differences in the prevalence rates between 3- and 4-year-olds (*P*=.001), between 4- and 5-year-olds (*P*<.02), and between 8- and 9-year-olds (*P*<.001). Autism prevalence rates for 5- to 8-year-olds were not significantly different from each other (*P*=.50) (FIGURE).

Autism prevalence rates were remarkably similar when examined by race (TABLE 1). Furthermore, in each racial category, a predominance of males was found, yielding a sex ratio of 3.8 among whites, 4.3 among blacks, and 3.5 among the other racial group.

Among the children with autism (N=987), 62% had at least 1 coexisting MADDSP-defined disability or epilepsy. Of the children with an IQ or developmental test result (N=880), 68% had cognitive impairment (64% based on

IQ data alone). Among children with psychometric test data (N=880), 20% had mild MR, 11% moderate MR, 7% se-

Figure. Prevalence of Autism Among 3- to 10-Year-Old Children Identified by MADDSP, Metropolitan Atlanta, 1996



MADDSP indicates Metropolitan Atlanta Developmental Disabilities Surveillance Program; circles, prevalence rates; and error bars, 95% confidence intervals.

vere MR, 3% profound MR, and 28% with an unspecified level of cognitive impairment that included 9% classified as MR-NOS using IQ data and 19% classified using developmental scores (TABLE 2). In addition, of the children with autism, 8% had epilepsy, 5% had cerebral palsy, 1% had vision impairment, and 1% had hearing loss. We found that as the severity of MR increased the sex ratio decreased (4.4 to 1.3), indicating a greater proportion of females in the severe and profound levels of impairment (Table 2).

Autism-specific test results were available for 479 children (49%) with autism. Of these, 414 (86%) had been administered the Childhood Autism Rating Scale.³³ Eighty-four percent of the 414 children for whom a Childhood Autism Rating Scale score or diagnostic category was reported had scores in the autistic range.

Agreement between previous ASD classifications and designation as a MADDSP autism case through expert review was high: 98% of children with a previous ASD diagnosis, 99% of children with a previous autism eligibility for special education services, and 100% of children with both a previous ASD diagnosis and an autism eligibility were classified as autism cases.

Data Sources and Previous Classifications

Fifty-seven percent of the children with autism were identified at both school and non-school sources. Importantly, 40% of the children with autism were identified at school sources only and 3% of the children were identified at non-school sources only, indicating a major contribution of unique cases from school sources.

Among children uniquely identified either at school or non-school sources, we found that most children, regardless of age, were identified at school sources only; however, 3- and 4-year-old children were more likely than older children to be identified at non-school sources only (27% vs 5%). Black children, children of younger mothers (<30 years), and children of mothers with less education (< 12 years) were primarily identified at school sources. As maternal education and maternal age increased, there was a greater likelihood that children were identified only at non-school sources. A Fisher exact test was performed to measure the significance of certain demographic factors across source type; age, race, maternal education, and maternal age were significantly associated (P<.001) with the type of identification source (TABLE 3).

Most (91%) of the children received special education services at some time during the 1996 study year. Autism was the primary eligibility category for 41% of these children, while 59% had other special education eligibility categories, such as significant developmental delay, intellectual disabilities, or speech and language impairment.

Of the children who met the surveillance case definition for autism, 62%

Table 1. Prevalence of Autism Among 3- to 10-Year-Old Children by Race and Sex,* Metropolitan Atlanta, 1996

Sex	Race					
	White		Black		Other	
	No.	Rate per 1000 (95% CI)	No.	Rate per 1000 (95% CI)	No.	Rate per 1000 (95% CI)
Male	457	5.3 (4.8-5.8)	305	5.4 (4.8-6.1)	25	4.3 (2.8-6.4)
Female	120	1.5 (1.2-1.8)	70	1.3 (1.0-1.6)	7	1.4 (0.5-2.8)
Total	577	3.4 (3.2-3.7)	375	3.4 (3.0-3.7)	32	2.9 (2.0-4.1)

Abbreviation: CI, confidence interval.

*The total number of children studied was N = 987, but 3 were excluded because of unknown racial origin. The denominator was obtained from the 1996 post-censal estimates.

Table 2. Level of Cognitive Functioning Among 3- to 10-Year-Old Children With Autism, Metropolitan Atlanta, 1996

Level of Cognitive Functioning	Male-Female Ratio	Total (N = 880) With Psychometric Test Data, No. (%)*
No cognitive impairment†	6.7	280 (32)
IQ test	7.3	243 (28)
Developmental test	4.3	37 (4)
Cognitive impairment†	3.3	600 (68)
IQ test score	3.3	432 (49)
Mild MR (IQ 50-70)	4.4	174 (20)
Moderate MR (IQ 35-49)	3.5	99 (11)
Severe MR (IQ 20-34)	2.1	59 (7)
Profound MR (IQ <20)	1.3	23 (3)
MR-NOS	4.5	77 (9)
Developmental test	3.2	168 (19)

Abbreviations: MR, mental retardation; MR-NOS, mental retardation—not otherwise specified.

*Percentages were rounded to the nearest whole number.

†Cognitive impairment is the full-scale IQ score ≤70 or an IQ score ≥2 SDs below the mean on the cognitive domain of a developmental test.

had been previously diagnosed with an ASD by a qualified professional; 19% had indications of suspected ASD; 16% had non-ASD diagnoses, such as attention deficit hyperactivity disorder, communicative disorder, psychiatric illness, or MR; and 2% did not have a previous diagnosis of any disability stated in their evaluation files. Children aged 6 to 10 were more likely to have had a previous ASD diagnosis than those children aged 3 to 5.

Mean age at first ASD diagnosis on an abstracted evaluation was 3.9 years. Boys had a significantly ($P = .03$) lower mean age of diagnosis than girls (3.6 years and 4.1 years, respectively). Although we found no differences by race or maternal age in the proportion of children who had had a previous diagnosis, children of mothers with higher education levels (≥ 16 years) were more likely to have had a previous ASD diagnosis.

COMMENT

The prevalence of autism in metropolitan Atlanta in 1996 for children aged 3 to 10 was 3.4 per 1000. This overall rate is 10 times higher than rates from 3 other US studies that used *DSM-III*²⁴ or *ICD-9*³¹ criteria to identify children with autism and pervasive developmental disorders in the 1980s and early 1990s.¹⁵⁻¹⁷ Our rate is closer to that found in a recent prevalence study in Brick Township, New Jersey,¹⁸ that used *DSM-IV*²⁴ criteria (4.0 per 1000 for autistic disorder and 6.7 per 1000 for the entire autism spectrum). Our findings also are similar to rates from several recent European studies^{14,19-21} that used *ICD-10*³⁵ or *DSM-IV* criteria (2-6 per 1000 for autism). Our study demonstrated that prevalence rates vary by age, ranging from 1.9 in 3-year-olds to 4.7 in 8-year-olds. Not surprisingly, younger children have lower prevalence rates than older children since many young children may not yet have come to the attention of professionals.³⁶ However, reasons for lower prevalence rates at ages 9 and 10 (ie, 2.7 and 2.0 per 1000, respectively) are not readily apparent. Lower rates in 9- and 10-year-olds may reflect the use of narrower diagnostic cri-

teria for autism before the publication of *DSM-IV* in 1994 and the increased availability of educational, health, and social services for children with autism in the early 1990s.¹

Debate continues about whether the overall prevalence of autism has increased or whether past rates underestimated true prevalence.^{1,3,4} This debate is difficult to resolve retrospectively. In the United States, the increase in the number of individuals receiving services for autism^{22,23} may be attributed to several factors. Changes in diagnostic criteria have expanded the concept of autism to a spectrum of disorders.^{1,37,38} Heightened public awareness of autism also has had an effect, due in large part to efforts of parent and advocacy groups, availability of more medical and educational resources, increased media coverage of affected children and families, and more training and information for physicians, psychologists, and other service providers.^{2,5,39,40} Also, in 1991, the US Department of Education added autism as a category for special education services, possibly leading to increases in the number of children classified with autism because of the availability of these services. The mandate for early intervention services for children with DDs, including autism, also has contributed to greater attention being placed on autism. At the same time, studies are suggesting that some children with autism respond well to early, intense educational intervention.⁴⁰ The combined influence of these factors has probably contributed to the identification of more individuals with autism. However, it remains unclear whether specific environmental,^{42,43} immunologic,⁴⁴ genetic,⁴⁵ or unidentified factors also have contributed to these higher reported prevalence rates.

Because the diagnosis of autism is based on the presence of unusual behavioral patterns, determining prevalence is challenging. There is no medical or genetic screening or diagnostic laboratory test for autism, and clinicians may apply clinical criteria differently to arrive at a diagnosis of autism and related subtypes.^{36,37,46} Our surveillance system was designed to address these challenges by

Table 3. Race, Age, and Maternal Characteristics of 3- to 10-Year-Old Children With Autism, by Identification Source,* Metropolitan Atlanta, 1996†

Characteristics	School Sources Only, No. (%)	Non-school Sources Only, No. (%)
Age of child, y		
3-4	41 (73)	15 (27)
5-10	350 (95)	17 (5)
Race‡		
White	168 (88)	24 (13)
Black	206 (98)	5 (2)
Other	16 (89)	2 (11)
Maternal education, y§		
<12	35 (92)	3 (8)
12	102 (97)	3 (3)
13-15	64 (97)	2 (3)
≥16	49 (73)	18 (27)
Maternal age, y§		
<20	20 (95)	1 (5)
20-29	145 (94)	9 (6)
30-34	58 (87)	9 (13)
≥35	27 (79)	7 (21)

*Information obtained from birth certificate files of children born in Georgia.

†Fisher exact test was used to measure statistical significance; $P < .001$ for within group comparisons. Percentages may not add up to 100% due to rounding.

‡One child in the school source and 1 child in the non-school source group had missing race information.

§Children identified at both school and non-school sources were excluded from the table.

collecting information from a wide range of sources on a large number of children with behaviors that might meet our surveillance criteria for autism. We did not rely solely on a child's previous diagnoses or eligibility category to classify a child as a case or suspected case of autism. Instead, case status was determined by a panel of clinicians with expertise in identification and assessment of autism who systematically reviewed the abstracted information based on the *DSM-IV* autism criteria.

Few studies have examined the prevalence of autism by race because of the racial homogeneity of many of the populations studied. Atlanta, however, has a large black community and provides an excellent source of racial heterogeneity. We found that the prevalence of autism did not vary by race, even within race and sex subgroups. Two recent US studies, both using developmental disabilities service data, however, found a higher prevalence in black children than in white children.^{41,47} Such findings may be due to the use of a single public provider of services for identification of chil-

dren with autism compared with our multiple source system that also includes private service providers. Our findings that more boys than girls had autism (4:1) and that the sex ratio declined as MR severity increased are consistent with previous studies that examined trends and prevalence estimates among children with autism and MR.^{13,48}

Of the 987 children identified with autism, 18% did not have a previous ASD diagnosis or indications of suspected ASD. This could be due to many reasons, such as developmental difficulties becoming more apparent as the child enters school or the tendency to classify preschoolers with general developmental delays rather than specific classifications. This information suggests that limiting identification of children with autism to those who already have a diagnosis will underestimate the true prevalence.

Our multiple-source-ascertainment method is likely to underestimate the number of children with PDD-NOS, high functioning autism, and Asperger disorder, since many children with these conditions may not receive special education services, may attend regular education classes or private schools, may be home-schooled, or may not have come to the attention of a professional early in childhood. Future plans to address underascertainment of children with milder subtypes include expanding the range of diagnostic codes reviewed at clinical sources to include conditions such as developmental delay, attention deficit hyperactivity disorder, speech and language delay, and emotional disturbance.

While we recognize that there are limitations in using a record review methodology, including possible over- or underestimation of the prevalence, other methods of case confirmation have limitations that also must be recognized. For example, a study that uses clinical examinations for case confirmation will have challenges of attrition because of the inability to find the current location of the child and from incomplete participation of families in the study. A methodology using multiple-source record review is less costly

and more time-efficient and may provide more complete coverage of a large population. We plan to conduct a clinical validation study of children with autism identified by MADDSP and to evaluate the completeness of MADDSP case ascertainment sources.

It is not surprising that 64% of the children with autism had MR (based on IQ test data) and 68% had cognitive impairment (based on IQ or developmental test scores). While older studies report that as many as 75% to 80% of children with autism have MR, more recent studies have found lower proportions (a review of the data can be obtained from the authors). For example, a study by Chakrabarti and Fombonne¹⁴ found that only 25.8% of the 97 children with ASD had MR. Data from the California Department of Developmental Services also indicate that a greater percentage of children referred for autism services in 1987 (76%) had MR than children referred in 1998 (48.5%).²² The percentage of children with autism and cognitive impairment or MR identified in our study might suggest that our sample largely reflects children with the profile of autistic disorder.

Many children (70%) we identified with autism had more than 1 diagnostic evaluation, and 61% (data not shown) were seen at more than 1 educational or medical program in the community, thus providing independent information on the behaviors used to determine case status. Use of this surveillance method showed excellent agreement with children who were previously diagnosed with an ASD, had autism eligibility for special education services, or both.

School records were a major source of information on children with autism in metropolitan Atlanta and were a unique source for 40% of the children with autism. Because the Individuals with Disabilities Education Act mandates educational services for children as young as 3, most children with autism receive evaluations or services through local public school systems at some time during their school years, usually during elementary school. In addition, since public school services are free, school sources

are more likely to reach children with a range of sociodemographic characteristics. In this study, more black children with autism and children with autism whose mothers had less education were identified from school records than from non-school records.

Although diagnostic criteria include the onset of symptoms before age 3, mean age at first ASD diagnosis in the abstracted source files was 3.9 years. While earlier identification is still needed, there appears to be a trend toward slightly earlier ASD diagnosis than previous estimates of 4.5 years.³⁶ Only screening of all children during routine well-child visits, as is done in the United Kingdom, would allow children with autism to be consistently identified earlier.^{19,49,50} Autism screening instruments have only recently become available and their usefulness in terms of sensitivity and specificity is still being debated.^{19,48,51-54} Reliable, valid diagnostic tools for clinicians also have only recently become available.⁵⁵⁻⁵⁷ Current use of these instruments is not widespread in the United States.

Population-based data are essential for the ongoing monitoring of this important and complex condition. However, challenges of monitoring autism in the United States cannot be overstated. Data must be obtained from multiple diagnosticians and service providers within the community. Challenges in gaining access to case ascertainment sources remain. Schools were the most complete source of this information in our population, but education records usually are not available to epidemiologists conducting research on health and developmental outcomes in children. Furthermore, the quality of information contained in service provider records varies greatly and such records may not contain needed information.

In summary, we have developed an ongoing surveillance system for determining the autism prevalence in metropolitan Atlanta. We hope that the recent formation of an autism surveillance network across several states will provide valuable information on autism prevalence in the future. Using a similar methodology in geographically and

demographically varied populations, these programs should provide a more complete picture of autism prevalence in the United States and serve as a basis for conducting epidemiologic studies.

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REFERENCES

- Fombonne E. Is there an epidemic of autism? *Pediatrics*. 2001;107:411-412.
- Cowley G. Understanding autism. *Newsweek*. July 31, 2000:46-54.
- Heussler H, Polnay L, Marder E, Standen P, Chin LU, Butler N. Prevalence of autism in early 1970s may have been underestimated [letter]. *BMJ*. 2001;323:633.
- Blaxill M. Any changes in prevalence of autism must be determined [letter]. *BMJ*. 2002;324:296.
- Children's Health Act of 2000. HR 274, Title I of Pub L No. 106-310, § 101-105, 114 Stat 1101.
- Wing L. The definition and prevalence of autism: a review. *Eur Child Adolesc Psychiatry*. 1993;2:61-74.
- Gillberg C, Wing L. Autism: not an extremely rare disorder. *Acta Psychiatr Scand*. 1999;99:399-406.
- Lotter V. Epidemiology of autistic conditions in young children. *Soc Psychiatry*. 1966;1:124-137.
- Brask BH. A prevalence investigation of childhood psychosis. In *Nordic Symposium on the Comprehensive Care of Psychotic Children*. Oslo, Norway: Barnepsykiatrisk; 1972:145-153.
- Wing L, Gould J. Severe impairments of social interaction and associated abnormalities in children. *J Autism Dev Disord*. 1979;9:11-29.
- Gillberg C. Infantile autism and other childhood psychoses in a Swedish urban region. *J Child Psychol Psychiatry*. 1984;25:35-43.
- Hoshino Y, Kumashiro H, Yashima Y, Tachibana R, Watanabe M. The epidemiological study of autism in Fukushima-ken. *Folia Psychiatr Neurol Jpn*. 1982;36:115-124.
- Fombonne E. The epidemiology of autism: a review. *Psychol Med*. 1999;29:769-786.
- Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children. *JAMA*. 2001;285:3093-3099.
- Burd L, Fisher W, Kerbeshian J. A prevalence study of pervasive developmental disorders in North Dakota. *J Am Acad Child Adolesc Psychiatry*. 1987;26:700-703.
- Ritvo ER, Freeman BJ, Pingree C, et al. The UCLA-University of Utah epidemiologic survey of autism: prevalence. *Am J Psychiatry*. 1989;146:194-199.
- Kirby RS, Brewster MA, Canino CU, Pavin M. Early childhood surveillance of developmental disorders by a birth defects surveillance system. *J Dev Behav Pediatr*. 1995;16:318-326.
- Bertrand J, Mars A, Boyle C, Bove F, Yeargin-Allsopp M, Decouffe P. Prevalence of autism in a United States population. *Pediatrics*. 2001;108:1155-1161.
- Baird G, Charman T, Baron-Cohen S, et al. A screening instrument for autism at 18 months of age: a 6-year follow-up study. *J Am Acad Child Adolesc Psychiatry*. 2000;39:694-702.
- Arvidsson T, Danielsson B, Forsberg P, Gillberg C, Johansson, Kjellgren G. Autism in 3-6-year-old children in a suburb of Göteborg, Sweden. *Autism*. 1997;1:163-173.
- Kadesjo B, Gillberg C, Hagberg B. Brief report: autism and Asperger syndrome in seven-year-old children. *J Autism Dev Disord*. 1999;29:327-331.
- California Department of Developmental Services. *Changes in the Population of Persons With Autism and Pervasive Developmental Disorders in California's Developmental Services System: 1987-1998. A Report to the Legislature*. Sacramento, Ca: California Department of Developmental Services; March 1999.
- US Dept of Education, Office of Special Education Programs, Data Analysis System (DANS). *Number of Children Served Under IDEA by Disability and Age Group, During the 1989-1990 Through 1998-1999 School Years*. Cited by: US Dept of Education. *Twenty-second Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*. Washington, DC: US Dept of Education; 2000; II-20.
- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Washington, DC: American Psychiatric Association; 1994.
- Centers for Disease Control and Prevention. Prevalence of selected developmental disabilities in children 3-10 years of age. *Morb Mort Wkly Rep*. 1996;45(S2):1-14.
- Yeargin-Allsopp M, Murphy CC, Oakley GP, Sikes RK. A multiple-source method for studying the prevalence of developmental disabilities in children. *Pediatrics*. 1992;89(4 pt 1):624-630.
- Population Estimates Program, Population Division, US Census Bureau. US Census Bureau Web site. Available at: <http://eire.census.gov/popest/archives/1990.php>. Accessibility verified November 20, 2002.
- The Education for All Handicapped Children Act of 1975. Pub L No. 94-145, 20 USC 1401 et seq. *Federal Register*. August 23, 1977; 42(163):42474-42518.
- Edmonds LD, Layde PM, James LM, Flynt JW, Erickson JD, Oakley JP Jr. Congenital malformations surveillance: two American systems. *Int J Epidemiol*. 1981;10:247-252.
- Feinstein A, Cicchetti D. High agreement but low kappa: I: the problems of two paradoxes. *J Clin Epidemiol*. 1990;43:543-549.
- International Classification of Diseases, Ninth Revision, Clinical Modification*. Washington, DC: Public Health Service, US Dept of Health and Human Services; 1988.
- Selvin S. Statistical power and sample-size calculations. *Statistical Analyses of Epidemiologic Data*. 2nd ed. New York, NY: Oxford University Press; 1996.
- Schopler E, Reichler R, Rochen Renner B. *The Childhood Autism Rating Scale (CARS)*. Los Angeles, Ca: Western Psychological Services; 1998.
- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Third Edition*. Washington, DC: American Psychiatric Association; 1980.
- World Health Organization. *International Classification of Diseases, 10th Revision (ICD-10)*. Geneva, Switzerland: World Health Organization; 1992.
- Siegel B, Pliner C, Eschler J, Elliot G. How children with autism are diagnosed. *J Dev Behav Pediatr*. 1988;9:199-204.
- Lord C, Risi S. Diagnosis of autism spectrum disorders in young children. In: Wetherby A, Prizant B, eds. *Autism spectrum disorders: a transactional developmental approach*. Baltimore, Md: Paul H. Brookes Publishing Co; 2000:11-30.
- Berney TP. Autism—an evolving concept. *Brit J Psychiatry*. 2000;176:20-25.
- American Academy of Pediatrics: The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*. 2001;107:1221-1226.
- National Research Council, Committee on Educational Interventions for Children With Autism, Division of Behavioral and Social Sciences and Education. *Educating Children With Autism*. Washington, DC: National Academy Press; 2001.
- Croen L, Grether J, Hoogstrate J, Selvin S. The changing prevalence of autism in California. *J Autism Dev Disord*. 2002;32:207-215.
- London E and Etzel R. The environment as an etiologic factor in autism: a new direction for research. *Environ Health Perspect*. 2000;108:401-404.
- National Institutes of Health Interagency Autism Coordinating Committee. *Potential cellular and molecular mechanisms in autism and related disorders*. Papers presented at: 2001 Scientific Conference; September 6-7, 2001; Bethesda, Md.
- Comi A, Zimmerman A, Frye V, Law P, Peeden J. Familial clustering of autoimmune disorders and evaluation of medical risk factors in autism. *J Child Neurol*. 1999;14:388-394.
- Bailey A, Phillips W, Rutter M. Autism. *J Child Psychol Psychiatry*. 1996;37:89-126.
- Howlin P, Moore A. Diagnosis of autism. *Autism*. 1997;1:135-162.
- Hillman RE, Kanafani N, Takahashi TN, Miles JH. Prevalence of autism in Missouri. *Mo Med*. 2000;97:159-163.
- Lord C, Schopler E. Differences in sex ratios in autism as a function of measured intelligence. *J Autism Dev Disord*. 1985;15:185-193.
- Baron-Cohen S, Allen J, Gillberg C. Can autism be detected at 18 months? the needle, the haystack, and the CHAT. *Br J Psychiatry*. 1992;161:839-843.
- Fombonne E, Simmons H, Ford T, Meltzer H, Goodman R. Prevalence of pervasive developmental disorders in the British nationwide survey of child mental health. *J Am Acad Child Adolesc Psychiatry*. 2001;40:820-827.
- Siegel B. Detection of autism in the 2nd and 3rd years: the Pervasive Developmental Disorders Screening Test (PDDST). Poster presented at the Biennial Meeting of the Society of Research in Child Development; 1999. Albuquerque, NM.
- Baird G, Charman T, Cox A, et al. Screening and surveillance for autism and pervasive developmental disorders. *Arch Dis Child*. 2001;84:468-475.
- Robins D, Fein D, Barton M, Green J. The Modified Checklist for Autism in Toddlers. *J Autism Dev Disord*. 2001;31:131-144.
- Berument S, Rutter M, Lord C, Pickles A, Bailey A. Autism screening questionnaire: diagnostic validity. *Br J Psychiatry*. 1999;175:444-451.
- Lord C, Rutter M, LeCouteur A. Autism Diagnostic Interview-Revised. *J Autism Dev Disord*. 1994;24:659-685.
- Lord C, Rutter M, DiLavore P, Risi S. *Autism Diagnostic Observation Schedule - WPS Edition*. Los Angeles, Ca: Western Psychological Corp; 1999.
- Wing L, Leekam S, Libby S, Gould J, Larcombe M. The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *J Child Psychol Psychiatry*. 2002;43:307-325.