HHS Public Access

Author manuscript

J Dev Behav Pediatr. Author manuscript; available in PMC 2015 June 30.

Published in final edited form as:

J Dev Behav Pediatr. 2012 June ; 33(5): 387–395. doi:10.1097/DBP.0b013e3182560b2f.

Retention of Autism Spectrum Diagnoses by Community Professionals: Findings From the Autism and Developmental Disabilities Monitoring Network, 2000 and 2006

Lisa D. Wiggins, PhD[*], **Jon Baio, EdS**[*], **Laura Schieve, PhD**[*], **Li-Ching Lee, PhD**[†], **Joyce Nicholas, PhD**[‡], and **Catherine E. Rice, PhD**[*]

[*]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

[†]Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

[‡]Department of Medicine, Medical University of South Carolina, Charleston, SC

Abstract

Objective—Past research is inconsistent in the stability of autism spectrum disorder (ASD) diagnoses. The authors therefore sought to examine the proportion of children identified from a population-based surveillance system that had a change in classification from ASD to non-ASD and factors associated with such changes.

Methods—Children with a documented age of first ASD diagnosis noted in surveillance records by a community professional (n = 1392) were identified from the Autism and Developmental Disabilities Monitoring Network. Children were considered to have a change in classification if an ASD was excluded after the age of first recorded ASD diagnosis. Child and surveillance factors were entered into a multivariable regression model to determine factors associated with diagnostic change.

Results—Only 4% of our sample had a change in classification from ASD to non-ASD noted in evaluation records. Factors associated with change in classification from ASD to non-ASD were timing of first ASD diagnosis at 30 months or younger, onset other than developmental regression, presence of specific developmental delays, and participation in a special needs classroom other than autism at 8 years of age.

Conclusions—Our results found that children with ASDs are likely to retain an ASD diagnosis, which underscores the need for continued services. Children diagnosed at 30 months or younger are more likely to experience a change in classification from ASD to non-ASD than children diagnosed at 31 months or older, suggesting earlier identification of ASD symptoms may be associated with response to intervention efforts or increased likelihood for overdiagnosis.

Address for reprints: Lisa D. Wiggins, PhD, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, NCB-DDD/CDC, 1600 Clifton Road, Mail Stop E-86, Atlanta, GA 30033; lwiggins@cdc.gov.

Disclosure: C.E.R. receives payments for a limited number of trainings on autism assessment. The other authors declare no conflict of interest.

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.

Index terms

autism; diagnostic stability; screening

Autism spectrum disorders (ASDs) are developmental disabilities that affect social, communication, and behavioral development and include the diagnoses of autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), and Asperger's disorder.[1] According to the Centers for Disease Control and Prevention (CDC), an average of 1 in 88 children in the United States currently have an ASD, which is higher than estimates previously reported but still a conservative estimate.[2,3] ASD symptoms typically emerge in the first 3 years of life, and earlier identification and intervention are often associated with improved developmental outcomes.[4–7] Yet the pattern of improvement in ASD symptoms is highly variable and can differ across domains of development.[8] Despite the possibility of symptom improvement, most studies find that children once diagnosed with an ASD still meet diagnostic criteria for an ASD when evaluated several years later. This suggests a high degree of diagnostic stability for the overall spectrum of ASDs.[9–12]

As the number of children identified as having ASDs is growing over time, it is important to explore factors associated with change in classification from ASD to non-ASD to inform early identification and intervention efforts. For all ASDs, the stability of an ASD diagnosis between 2 and 4 years of age has been reported to be as high as 91% to 100%,[9,12] and the stability of an ASD diagnosis between 2 and 9 years of age has been reported to be 88% to 90%.[10,11] However, the stability of subtype diagnoses within the autism spectrum is more variable. For instance, Chawarska et al[9] found that the stability of autism and PDD-NOS was 74% and 83%, respectively, compared with 100% for the entire category of ASDs; van Daalen et al[12] found that the stability of autism and PDD-NOS was 63% and 54%, respectively, compared with 91% for the entire category of ASDs. Direction of diagnostic changes within the ASD spectrum differs across studies, with some samples showing more movement from PDD-NOS to autism[10] and others showing more movement from autism to PDD-NOS.[12]

A handful of clinic-based studies conflict with the aforementioned research and report a fairly high percentage of toddlers who once met diagnostic criteria for an ASD did not meet diagnostic criteria when evaluated several years later.[13–15] This line of research leads to renewed questions regarding the stability of ASD diagnoses and specific factors associated with a change in ASD classification. For instance, Sutera et al[14] found that 18% of children diagnosed with an ASD around 2 years of age did not meet criteria for any ASD when evaluated around 4 years of age. These results were corroborated by other studies that showed 19% to 32% of children diagnosed with an ASD around 2 years of age no longer met criteria when evaluated between 4 and 6 years of age.[13,15] Factors associated with a change in diagnosis from ASD to non-ASD included earlier age of ASD diagnosis, diagnosis of PDD-NOS instead of autism, less developmental deficit at 2 years, fewer repetitive behaviors at 2 years, absence of developmental regression (or loss of previously acquired skills), and total hours of therapy between 2 and 3 years of age.[10,11,16] Children

diagnosed with an ASD at 30 months or younger are especially likely to have a change in diagnosis from ASD to non-ASD.[15]

Although past studies have enhanced our understanding of the course of ASDs in clinical settings, conflicting reports reveal the need to better assess population-level changes in ASD diagnoses and whether shifts in diagnoses of ASD to non-ASD are changing over time. Population-based analyses are especially important given the influence of confounding factors such as limited access to care for traditionally underserved populations, which may not be reflected in clinic-based samples. Moreover, population-based analyses may provide insights into variations in clinical practice and/or the "natural course" of ASDs across the population. Thus, the purpose of this study was to use a population-based surveillance dataset to examine the proportion of children that had a change in classification from ASD to non-ASD by community professionals and factors associated with change in ASD classification. We were particularly interested in child factors associated with change in ASD classification, to inform early identification and intervention efforts, although surveillance factors were also considered.

METHODS

Participants

Participants were children who had education and health records reviewed for autism spectrum disorder (ASD) surveillance by the Autism and Developmental Disabilities Monitoring (ADDM) Network in surveillance years (SYs) 2000 and 2006 (children born in 1992 and 1998), which were the earliest and the latest years with the complete data available from multiple sites throughout the United States at the time of this report. The ADDM Network conducts population-based education and health record-review surveillance of ASDs to estimate the prevalence of ASDs.

Procedures Used in the ADDM Network

Children are eligible for ADDM surveillance if they were 8 years old and had a parent or legal guardian who resided in the surveillance area during a designated SY. ADDM focuses on 8-year-old surveillance because previous analyses found peak ASD prevalence at this age (i.e., most children with ASD are identified by 8 years of age). Each ADDM site receives data from multiple sources, including public special education departments and health care facilities that evaluate children with disabilities. The ADDM methodology uses a 3-stage process for case identification and confirmation. First, children are selected for initial records screening based on discharge diagnoses, billing codes, reasons for referral, and education exceptionalities noted in service records. Some children with ASD symptoms may not have an ASD diagnosis noted in service records. To capture the broad array of children with ASDs, as well as those with and without a noted ASD diagnosis, service records of children with a range of conditions (e.g., ASD, intellectual disability [ID], and speech and language disorder) are reviewed for ADDM surveillance.

Second, trained abstractors screen selected records for ASD behaviors that relate to the social criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders—*

Fourth Edition—Text Revision (DSM-IV-TR),[1] such as limited interest in other children. All records that contain an ASD behavioral trigger are abstracted to collect verbatim (exactly as written) notes of developmental histories, descriptions of ASD symptoms, developmental test data, and information on co-occurring conditions noted by the community professional who evaluated the child. If multiple records are abstracted for the same child, all abstracted information is combined into a composite record.

In the third step, experienced clinicians apply a standardized coding scheme to the abstracted data based on the DSM-IV-TR to determine whether the child meets the ASD surveillance definition. To meet the ASD surveillance definition, a child must have sufficient behavioral descriptors noted in evaluation records that correspond to DSM-IV-TR ASD diagnoses. A documented ASD diagnosis is considered when determining surveillance case status but is not necessary to meet ASD surveillance criteria. Clinician reviewers are professionals with advanced degrees and specialized training and experience in ASD assessment and diagnosis (e.g., developmental psychologists and developmental pediatricians). All ADDM clinician reviewers achieve initial reliability for coding ASD surveillance records and maintain reliability through monthly review of a similar record. Results of the standardized coding scheme determine final ASD surveillance case status.

A previous validation study at the Georgia site suggested that the positive predictive value of the surveillance system is 79%, meaning that most children who meet ASD surveillance criteria also meet clinical criteria when examined in person with standardized diagnostic instruments by a qualified professional. Negative predictive value and specificity were also acceptable at 91% and 96%, respectively. However, the sensitivity of the system was 60%, which is lower than expected but comparable to screening instruments used to detect the broad array of ASDs.[3] Further details of the surveillance methods are described elsewhere.[3,17,18]

Procedures Used in This Study

There were 4 ADDM sites that contributed data in both SYs 2000 and 2006 and thus were included in this analysis (Arizona, Georgia, Maryland, and South Carolina). A total of 4958 children had records reviewed for ASD surveillance in these 4 sites during the SYs examined; a total of 2324 of these 4958 children met the ASD surveillance definition. Only children who had a documented age of first ASD diagnosis noted by a community professional who evaluated the child were included in the sample (n = 1392). This restriction of the sample was necessary to gauge how many children had an ASD excluded *after* diagnosed. Of the 1392 children in our final sample, 65 (5%) did not meet the ASD surveillance definition. Therefore, our sample included children with a documented ASD diagnosis and a documented age of first ASD diagnosis who may or may not have met the surveillance definition for a child with an ASD.

For children in our sample, documented ASD diagnoses were noted if the community professional who saw the child and authored the report noted (1) a 299.0 billing code for autism; (2) a 299.8 billing code for another ASD; or (3) specifically stated the child met criteria for autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), an ASD, or Asperger's disorder. The 299.9 billing codes were not included

because this code captures conditions other than ASD, such as child psychosis not otherwise specified. Surveillance clinicians also recorded co-occurring or alternative diagnoses, such as language delay or attention-deficit hyperactivity disorder (ADHD) that were recorded in education or health records by the community professional who evaluated the child. Children who had ASD characteristics or suspicion of an ASD noted in surveillance records without a confirmatory diagnosis were excluded from the sample.

Definition of Change in ASD Classification

We considered a child as having a change in ASD classification from ASD to non-ASD if a community professional excluded an ASD after the date of first documented ASD diagnosis. Thus, both the initial diagnosis of ASD and the change in classification to non-ASD represented the overall impression of the community professional(s) who evaluated the child (which could have been the same or different professionals but still represents clinical practices and community perceptions of children with ASDs). In order for a surveillance clinician who reviewed the records to note an ASD had been ruled out, the community professional had to specifically state that the child did not meet diagnostic criteria for any ASD (e.g., “testing assessment results indicate this child no longer meets criteria for any ASD” or “it is my opinion symptoms are better accounted for by ID rather than an ASD”). Again, ADDM Network conducts ASD surveillance on children who are 8 years old during a given SY. Thus, children in this study had an ASD diagnosis noted before 8 years of age and some had a change in that ASD diagnosis by the time they reached 8 years.

Statistical Analyses

All analyses were conducted with SPSS version 15.0. Descriptive analyses were performed to determine distributions of the sample based on sex, race, ID, final surveillance definition, age of first documented ASD diagnosis, subtype of first documented ASD diagnosis, examiner degree and specialty who recorded first documented ASD diagnosis, number of children who had a change in classification from ASD to non-ASD, and the most common diagnoses given when an ASD was excluded. ID was defined as a total standard score of ≤70 points on the most recent intelligence test identified. Based on previous analyses that suggest children diagnosed with an ASD before 30 months were especially prone to changes in ASD classification,[11] we dichotomized first age of ASD diagnosis into 30 months or younger and 31 months or older.

Chi-square analyses showed the influence of child and surveillance factors on change in ASD classification. Child factors included in analyses were race, sex, other diagnosed developmental conditions (e.g., ADHD, ID, and language delay), developmental regression, participation in a special needs classroom at 8 years of age, subtype of first documented ASD diagnosis (i.e., autism, other ASD, or subtype not stated), and timing of first documented ASD diagnosis (i.e., 30 months or younger or 31 months or older). Surveillance factors included in analyses were final surveillance definition (i.e., meets ASD definition or does not meet ASD definition), number of records available for review (i.e., 1 or multiple), type of professional who recorded first documented ASD diagnosis, source of records available for review (i.e., education, health, or both education and health), surveillance site, and SY. All variables were then entered into a multivariable logistic regression model to

determine factors most strongly associated with change in classification from ASD to non-ASD.

RESULTS

There were 1392 children in the sample who had a documented autism spectrum disorder (ASD) diagnosis and documented age of first ASD diagnosis noted in surveillance records and included in analyses. A majority of the sample was male (84%), and the racial and ethnic distribution of the sample was 59% non-Hispanic white, 24% non-Hispanic black, 8% Hispanic, 3% non-Hispanic Asian or Pacific Islander, and 6% other or missing race. A total of 1090 children had cognitive test data available to assess whether the child had co-occurring intellectual disability (ID) and 45% had ID. Most of the 1392 children with a documented age of first ASD diagnosis met the surveillance definition for ASD (95%).

Of the 1392 children in the sample, 59% were first diagnosed with autism, 40% were first diagnosed with another ASD, and 1% did not have a first ASD subtype noted. The mean age at first reported ASD diagnosis was 57 months (range, 12–106 mo). Children with a first known diagnosis of autism were, on average, diagnosed earlier than children with a first diagnosis of another ASD (52 vs 64 mo, respectively, $p < .01$). The types of community professionals who recorded the first known ASD diagnosis were PhD psychologists (23%), MD developmental pediatricians (22%), professional not stated (19%), other health professional (11%, such as master's level psychologists and speech/language pathologists), MD neurologists (9%), EDD or EDS educators (7%), MD other (6%), and PhD other (3%, most of the professionals in this category did not have a specialty stated). The types of community professionals who ruled out an ASD diagnosis after one had been recorded in education or health records were MD developmental pediatricians (31%), PhD psychologists (28%), EDD or EDS educators (10%), PhD other (10%), other health professional (6%), MD other (7%), professional not stated (5%), and MD neurologists (3%).

There were 61 children who had a change in ASD classification from ASD to non-ASD (4% of the sample). The mean age at first reported ASD diagnosis for children who later had an ASD excluded was 49 months (range, 18–95 mo) and the mean age when this ASD diagnosis was excluded was 69 months (range, 25–97 mo). The mean time between an ASD diagnosis and an ASD exclusion was 19 months (range, 1–69 mo); 14 children had a change in classification less than 6 months from first ASD diagnosis and 47 children had a change in classification 6 months or more from first ASD diagnosis. The percent of children with a change in classification from ASD to non-ASD would decrease from 4% to 3% if the 14 children with a change in classification less than 6 months from first ASD diagnosis were excluded. The most common diagnoses given at the time an ASD was excluded were language delay or disorder (39%), other specific developmental delay (adaptive, cognitive, motor, or social; 20%), and attention-deficit hyperactivity disorder (ADHD; 20%); 59 of the 61 (97%) children who had a change in ASD classification from ASD to non-ASD had at least 1 alternative diagnosis recorded when an ASD was excluded. Fifty children who had an ASD excluded after diagnosed were being served in a public school special education classroom at 8 years of age. The special education eligibility categories for these 50 children were autism (30%), learning disability (16%), speech/language impairment (16%), ID

(12%), other health impairment (10%), emotional disturbance (8%), orthopedic impairment (4%), and developmental delay (4%).

There were several child factors that influenced whether a child had a change in classification from ASD to non-ASD (Table 1). We present data on only those developmental conditions that were commonly diagnosed when an ASD was excluded (noted above); the presence of these conditions indicates that a diagnosis was reported in education and/or health records (Table 1). There were no significant differences in proportions of children who had a change in ASD classification and those who did not have a change in ASD classification on child race, child sex, or ASD subtype noted at first documented ASD diagnosis. Children were more likely to have a change in classification from ASD to non-ASD if they were first identified as having an ASD at 30 months or younger; did not experience a developmental regression (or loss of previously acquired skills); or had ADHD, language delay or disorder; or other specific developmental delay diagnosed in evaluation records. Only 11% of children in the sample were first diagnosed with ASD at 30 months or younger. Children were also more likely to have a change in ASD classification from ASD to non-ASD if they were being served in a public school special education classroom other than autism at 8 years of age.

There were also several surveillance factors that influenced whether a child had a change in classification from ASD to non-ASD (Table 2). Record source (i.e., education only, health only, or both education and health) and type of professional who noted the first documented ASD diagnosis did not influence whether a child had a change in ASD classification from ASD to non-ASD. However, all other surveillance variables significantly influenced changes in ASD classification (i.e., final surveillance definition [i.e., whether the child met ASD surveillance criteria], number of records reviewed, surveillance site, and surveillance year [SY]).

Child and surveillance factors were then entered into a multivariable logistic regression model to determine factors most strongly associated with change in ASD classification from ASD to non-ASD when all factors were considered simultaneously. The presence of language delay or disorder and other specific developmental delays were combined into 1 variable (i.e., presence of language or other specific delays) due to the significant correlation between these variables (r = .12–.42, p < .01). Results indicated that identification of a language or other specific delay, presence of developmental regression, professional who noted first documented ASD diagnosis, timing of first documented ASD diagnosis, and type of special education classroom at 8 years of age were associated with whether a child had a change in ASD classification from ASD to non-ASD. Specifically, children who had a language or other specific delay or ASD onset not characterized by developmental regression were more likely to have an ASD excluded after diagnosed than children who did not have a language or other specific delay or ASD onset characterized by development regression. Children first diagnosed by a professional with a PhD, but no specialty stated or no degree or specialty stated, were also more likely to have a change in classification from ASD to non-ASD than children first diagnosed by other professionals. Children served (at the time of record review) in a special education classroom with an eligibility designation other than autism (such as ID or learning disability) were also more likely to have a change

in classification from ASD to non-ASD. Finally, having a first ASD diagnosis at 30 months or younger was strongly associated with subsequent change in ASD classification from ASD to non-ASD (Table 3). These results were similar when children who had a change in classification less than 6 months from the first ASD diagnosis (n = 14) were excluded from regression analyses.

DISCUSSION

To our knowledge, this is the first population-based study of factors associated with change in classification from autism spectrum disorder (ASD) to non-ASD. We found that most children diagnosed before 8 years retain an ASD diagnosis at 8 years based on documented education and health records. ASD classification changed from ASD to non-ASD for only 4% of children in our sample (or 3% when children who had a change in ASD classification less than 6 months from initial ASD diagnosis were excluded). Our sample was unique because children were ascertained for ASD surveillance using population-based record-review surveillance instead of direct screening or clinical referral and changes in diagnosis from ASD to non-ASD were clearly documented in education or health records. Thus, our findings reflect documented community practices and indicate that young children diagnosed with an ASD in educational or health settings are likely to still meet criteria for an ASD when evaluated several years later,[9,10,12] which underscores the need for continued services. Although we could not assess symptom improvement in our study, some longitudinal analyses show that ASD symptoms may improve with age and intervention despite diagnostic retention.[8,19]

Our findings differ from reports suggesting that up to 20% to 30% of children will have a change in classification from ASD to non-ASD.[13–15] However, key differences between ours and these other studies are methodology and timing of first ASD diagnosis. Children in our study were identified from population-based surveillance methods and diagnosed on average at 57 months, whereas children in some other studies were identified from direct screening and/or clinical referral in the toddler years.[13,14] Therefore, the earlier an ASD diagnosis is noted, the more likely a child may experience change in classification from ASD to non-ASD. In fact, we found that children diagnosed with an ASD at 30 months or younger were more likely to have a change in ASD classification from ASD to non-ASD than children diagnosed with an ASD at 31 months or older. These results might indicate that children identified earlier are more apt to respond to interventions during a key period of development. Likewise, children identified later may present with more diagnostic clarity; thus, overdiagnosis at younger ages cannot be ruled out. Overdiagnosis may be especially relevant for those children who received a change in classification from ASD to non-ASD less than 6 months from their first ASD diagnosis (n = 14, for children in our sample); however, exclusion of these children did not change results of multivariate analyses that show earlier diagnosis is associated with greater probability of change from ASD to non-ASD.

Other factors associated with change in ASD classification in our study were onset other than developmental regression, presence of language or other specific delays, and participation in a special needs classroom other than autism at 8 years of age. It has been

reported that children who have an ASD and experience loss of skills have more cognitive and general impairment than children who have an ASD and do not experience loss of skills.[20,21] Thus, children who were not reported to have developmental regression (who may have less impairment than children who were reported to have developmental regression) may be more responsive to early intervention efforts or present with less diagnostic clarity in early childhood. Interestingly, children who had a language or other specific developmental delay were *more* likely to move from ASD to non-ASD than children who did not have another specific delay noted in evaluation records. This particular finding could imply difficulty with differential diagnosis between ASDs and language or other specific developmental delays in young children and need for more professional training on signs and symptoms that distinguish children with an ASD from children with other developmental concerns.

Children who had a first ASD diagnosis recorded by a professional with a PhD but no specialty stated or a professional who did not have a degree or specialty stated were more likely to change classification from ASD to non-ASD. However, the confidence intervals surrounding these estimates were wide, reflecting a great deal of uncertainty in the estimates. We did not have additional information in our dataset to further explore characteristics of these professionals, although professionals with no degree or specialty stated likely constitute a diverse group of professionals (e.g., nurses, occupational therapists, and physical therapists). Moreover, although child race only approached statistical significance in our final multivariable model, non-Hispanic black or African-American children were less likely to move from ASD to non-ASD than non-Hispanic white children. Other studies have found that non-Hispanic black children with ASD are, on average, identified later than non-Hispanic white children with ASD.[22] If timing of first ASD diagnosis is one of the most important predictors of changes in ASD classification, as we report, and if that change is based at least partly on a lessoning of symptomatology in response to early intervention, then these data underscore the need to reduce racial disparities in ASD identification.

We did not find that subtype of first recorded ASD diagnosis predicted change in ASD classification. This finding contradicts other studies that suggest ASD diagnoses are less stable over time if the child was first diagnosed with pervasive developmental disorder—not otherwise specified (PDD-NOS) rather than autistic disorder.[12,16] Our subtype data could only be categorized into autism, other ASD, and ASD subtype not stated because some children had a 299.8 billing code, which applies to both PDD-NOS and Asperger's disorder. Nonetheless, this particular finding suggests that autism spectrum diagnoses are more stable than subtype diagnoses, possibly because the subtype of PDD-NOS includes a broad range of symptoms and functional impairments. Consequently, ASD subtype may be a poor predictor of diagnostic trajectory and treatment response. Although children with ASD without an intellectual disability (ID) have shown greater symptom improvement than those with an ID,[19] we did not find that the presence or absence of ID predicted a change in ASD classification from ASD to non-ASD in our sample. These results indicate that variables such as timing of first documented ASD diagnosis may be associated more with change in ASD classification than the presence of ID when considered simultaneously.

There are a few limitations to our analysis that warrant discussion. First, change in ASD classification from ASD to non-ASD was defined by information contained in education and health records rather than direct assessment of the child (although previous analyses suggest that most children who meet our ASD surveillance definition also meet clinical criteria for the disorders[3]). Change in ASD classification less than 6 months from first ASD diagnosis could represent overdiagnosis rather than improvement in ASD symptoms. However, factors that influence change in ASD classification did not change when children who had an ASD excluded within 6 months of diagnosis were removed from the multivariate analysis. Furthermore, change in classification from ASD to non-ASD was defined by the earliest documented ASD diagnosis found in surveillance records, although a child could have been diagnosed with an ASD before this first recorded date. Nonetheless, information contained in surveillance records reflects community perceptions of ASDs according to the professional who conducted an evaluation of the child, which is useful for assessment of variations in clinical practice.

There could be many reasons why a child has a change in classification from ASD to non-ASD, including possible overdiagnosis and improvement due to participation in early intervention programs. Consequently, one other consideration in interpreting these data is whether participation in early intervention programs in the surveillance sites examined differs from national averages, which could affect whether these results can be generalized to other states. However, early intervention participation in our 4 sites in 2006 was generally comparable to the national average (i.e., 2.33% of the total population in our 4 states compared with the 2.41% national average). We therefore conclude that early intervention participation rates in the surveillance sites examined were comparable to national averages and not indicated as a confounding factor in our analyses.

Another consideration is that 1 previous study found that the surveillance system had moderate sensitivity, indicating some children with ASDs were not identified by Autism and Developmental Disabilities Monitoring (ADDM) record-review methods.[3] However, 11 of the 12 children with ASD who were not detected by ADDM methods in this study did not have an ASD diagnosis recorded in surveillance records.[3] Thus, the less than ideal sensitivity reported in this study could represent difficulty detecting children without a clear presentation of symptoms that warrant an ASD diagnosis, and all children in our study had an ASD diagnosis noted in service records. Furthermore, ADDM surveillance identifies service records available from birth to 8 years of age and symptoms of high-functioning autism or Asperger's disorder which may not be recognized in some children until later in childhood, or even later in life. Therefore, the proportion of children who experience a change in classification form ASD to non-ASD may be higher in samples that include children older than 8 years.

Although we could not assess the type or amount of intervention the child received since this information is not collected for ASD surveillance, we found the mean time between first diagnosis and exclusion of an ASD was 20 months. It is important to note the mean time between first ASD diagnosis and exclusion of an ASD also relied on age of first documented ASD diagnosis (and may be longer if the child received an ASD diagnosis before this time). Future analyses should consider type of treatment, length of treatment (from first ASD

diagnosis and beyond 8 years of age), and number of treatment hours and how these variables interact with timing of first ASD diagnosis to influence change in ASD classification from ASD to non-ASD.

Despite these limitations, our results support past research that suggests children with ASDs are likely to retain their ASD diagnosis up to 8 years of age, which indicates the need for continued support and treatment for children with ASDs and their families. Up to 4% of children with ASDs may experience a change in diagnostic classification from ASD to non-ASD as they move through the course of childhood. Although we cannot determine the underlying reason for the change in diagnosis from ASD to non-ASD, our findings might indicate some children may be overdiagnosed whereas other children may experience a positive change in symptomatology, particularly those children who have an onset other than developmental regression, language or other specific developmental delays and are identified at 30 months or younger. Nonetheless, only 11% of children in our sample were first diagnosed with an ASD at 30 months or younger (Table 1). Furthermore, children were diagnosed with a wide array of co-occurring developmental delays and conditions other than ASDs. Given the small percent of children with ASDs identified early and the developmental concerns noted by other diagnoses, these data support the American Association of Pediatrics' recommendations for early identification of symptoms of ASDs and developmental delays to help ensure children reach their maximum potential.[23,24]

Acknowledgments

This work was supported by the Autism and Developmental Disabilities Monitoring Network.

References

1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4. Washington, DC: American Psychiatric Association; 1994.
2. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators; Centers for Disease Control and Prevention (CDC). . Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. MMWR Surveill Summ. 2012; 61:1–19.
3. Avchen RN, Wiggins LD, Devine O, et al. Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. J Autism Dev Disord. 2011; 41:227–236. [PubMed: 20568003]
4. Corsello CM. Early intervention in autism. Inf Young Child. 2005; 18:74–85.
5. Landa R. Early communication development and intervention for children with autism. Ment Retard Dev Disabil Res Rev. 2007; 13:16–25. [PubMed: 17326115]
6. Rogers SJ, Vismara LA. Evidence-based comprehensive treatments for early autism. J Clin Child Adolesc Psychol. 2008; 37:8–38. [PubMed: 18444052]
7. Warren Z, McPheeters ML, Sathe N, Foss-Feig JH, Glasser A, Veenstra-Vanderweele J. A systematic review of early intensive intervention for autism spectrum disorders. Pediatrics. 2011; 127:e1301–e1311.
8. Charman T, Taylor E, Drew A, Cockerill H, Brown JA, Baird G. Outcome at 7 years of children diagnosed with autism at age 2: predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. J Child Psychol Psychiatry. 2005; 46:500–513. [PubMed: 15845130]

9. Chawarska K, Klin A, Paul R, Macari S, Volkmar F. A prospective study of toddlers with ASD: short-term diagnostic and cognitive outcomes. J Child Psychol Psychiatry. 2009; 50:1235–1245. [PubMed: 19594835]
10. Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, Pickles A. Autism from 2 to 9 years of age. Arch Gen Psychiatry. 2006; 63:694–701. [PubMed: 16754843]
11. Turner LM, Stone WL, Pozdol SL, Coonrod EE. Follow-up of children with autism spectrum disorders from age 2 to age 9. Autism. 2006; 10:243–265. [PubMed: 16682397]
12. van Daalen E, Kemner C, Dietz C, Swinkels SH, Buitelaar JK, van Engeland H. Inter-rater reliability and stability of diagnoses of autism spectrum disorder in children identified through screening at a very young age. Eur Child Adolesc Psychiatry. 2009; 18:663–674. [PubMed: 19421728]
13. Kleinman JM, Ventola PE, Pandey J, et al. Diagnostic stability in very young children with an autism spectrum disorder. J Autism Dev Disord. 2008; 38:606–615. [PubMed: 17924183]
14. Sutera S, Pandey J, Esser EL, et al. Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders. J Autism Dev Disord. 2007; 37:98–107. [PubMed: 17206522]
15. Turner LM, Stone WL. Variability in outcome for children with an ASD diagnosis at age 2. J Child Psychol Psychiatry. 2007; 48:793–802. [PubMed: 17683451]
16. Daniels AM, Rosenberg RE, Law JK, Lord C, Kaufmann WE, Law PA. Stability of initial autism spectrum disorder diagnoses in community settings. J Autism Dev Disord. 2011; 41:110–121. [PubMed: 20473589]
17. Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. JAMA. 2003; 289:49–55. [PubMed: 12503976]
18. Van Naarden Braun K, Pettygrove S, Daniels J, et al. Centers for Disease Control and Prevention. Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. MMWR Surveill Summ. 2007; 56:29–40. [PubMed: 17287716]
19. McGovern CW, Sigman M. Continuity and change from early childhood to adolescence in autism. J Child Psychol Psychiatry. 2005; 46:401–408. [PubMed: 15819649]
20. Rogers SJ. Developmental regression in autism spectrum disorders. Ment Retard Dev Disabil Res Rev. 2004; 10:139–143. [PubMed: 15362172]
21. Wiggins LD, Rice CE, Baio J. Developmental regression in children with an autism spectrum disorder identified by a population-based surveillance system. Autism. 2009; 13:357–374. [PubMed: 19535466]
22. Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among medicaid-eligible children with autism. J Am Acad Child Adolesc Psychiatry. 2002; 41:1447–1453. [PubMed: 12447031]
23. Johnson CP, Myers SM. American Academy of Pediatrics Council on Children With Disabilities Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics. 2007; 120:1183–1215. [PubMed: 17967920]
24. Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee; Medical Home Initiatives for Children With Special Needs Project Advisory Committee. . Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. Pediatrics. 2006; 118:405–420. [PubMed: 16818591]

Table 1

Child Factors That Influenced a Change in Classification From ASD to Non-ASD Noted in Surveillance Records

	No Change in ASD Classification, N = 1331 N (%)	Change in ASD Classification, N = 61 N (%)	χ^2	*p*
Child race				
Non-Hispanic white	779 (59)	40 (66)	3.85	.28
Non-Hispanic black or African-American	320 (24)	10 (16)		
Hispanic, Asian, American Indian, or Alaskan Native	152 (11)	5 (8)		
Other or missing race	80 (6)	6 (10)		
Child sex				
Male sex	1118 (84)	50 (82)	0.18	.72
Female sex	213 (16)	11 (18)		
Presence of co-occurring ADHD				
Co-occurring ADHD	184 (14)	17 (28)	9.31	.01
No co-occurring ADHD	1147 (86)	44 (72)		
Presence of co-occurring language delay or disorder				
Co-occurring language problem	665 (50)	47 (77)	17.1	.00
No co-occurring language problem	666 (50)	14 (23)		
Presence of co-occurring specific developmental delay				
Co-occurring specific delay	472 (35)	37 (61)	12.6	.01
No co-occurring specific delay	859 (65)	24 (39)		
Presence of developmental regression				
Developmental regression	315 (24)	6 (10)	6.29	.01
No developmental regression	1016 (76)	55 (90)		
Presence of ID				
ID	469 (35)	18 (30)	9.11	.01
No ID	566 (43)	37 (60)		
Missing ID data	296 (22)	6 (10)		
Public school classroom at 8 y				
In autism class at 8 y	819 (62)	15 (25)	33.1	.00
Not in autism class at 8 y	512 (38)	46 (75)		
Subtype of earliest ASD diagnosis				
Autism	791 (59)	34 (56)	0.077	.68
Other ASD	532 (40)	27 (44)		
Subtype not stated	8 (1)	0 (0)		
Timing of earliest ASD diagnosis				
Earliest ASD diagnosis 30 mo or less	139 (10)	11 (18)	3.49	.05
Earliest ASD diagnosis 31 mo or more	1192 (90)	50 (82)		

ASD, autism spectrum disorder; ADHD, attention-deficit hyperactivity disorder; ID, intellectual disability.

Table 2

Surveillance Factors That Influenced a Change in Classification From ASD to Non-ASD Noted in Surveillance Records

	No Change in ASD Classification, N = 1331 N (%)	Change in ASD Classification, N = 61 N (%)	χ^2	*p*
Final ADDM surveillance definition				
Meets ASD surveillance criteria	1273 (96)	54 (89)	6.64	.02
Does not meet ASD surveillance criteria	58 (4)	7 (11)		
Number of surveillance records				
One surveillance record	147 (11)	1 (2)	5.43	.02
Multiple surveillance records	1184 (89)	60 (98)		
Professional who recorded first ASD diagnosis				
EDD or EDS educator	97 (7)	3 (5)	12.0	.10
MD developmental paediatrician	284 (21)	15 (25)		
MD neurologist	118 (9)	4 (7)		
MD other	81 (6)	4 (7)		
PhD psychologist	313 (24)	10 (16)		
PhD other	42 (3)	5 (8)		
Other professional	154 (12)	3 (5)		
Professional not stated	242 (18)	17 (28)		
Source of surveillance records				
Education-only records	603 (45)	21 (35)	2.85	.24
Health-only records	194 (15)	10 (16)		
Both education and health records	534 (40)	30 (49)		
Surveillance site				
Arizona	400 (30)	19 (31)	15.5	.01
Georgia	417 (31)	29 (48)		
Maryland	342 (26)	3 (5)		
South Carolina	172 (13)	10 (16)		
Surveillance year				
2000	450 (34)	11 (18)	6.55	.01
2006	881 (66)	50 (82)		

ASD, autism spectrum disorder; ADDM, autism and developmental disabilities monitoring.

Table 3

Child and Surveillance Factors That Predicted a Change in Classification From ASD to Non-ASD Noted in Surveillance Records

	OR (95% CI)	*p*
Child race		
Non-Hispanic white (Ref)	1.00	
Non-Hispanic black or African-American	0.45 (0.20, 1.00)	.06
Hispanic, Asian, American Indian, or Alaskan Native	0.57 (0.20, 1.60)	.29
Other or missing race	1.32 (0.46, 3.75)	.61
Child sex		
Male (Ref)	1.00	
Female	0.91 (0.43, 1.90)	.79
Final surveillance definition		
Meets definition (Ref)	1.00	
Does not meet definition	2.39 (0.84, 6.76)	.10
Number of surveillance records		
One (Ref)	1.00	
Multiple	0.27 (0.03, 2.16)	.22
Presence of co-occurring ADHD		
Co-occurring ADHD (Ref)	1.00	
No co-occurring ADHD	0.80 (0.41, 1.56)	.51
Presence of co-occurring language or other specific delays		
Co-occurring specific delays (Ref)	1.00	
No co-occurring specific delays	0.32 (0.15, 0.71)	.01
Presence of developmental regression		
Developmental regression (Ref)	1.00	
No developmental regression	3.47 (1.37, 8.79)	.01
Presence of ID		
ID (Ref)	1.00	
No ID	1.47 (0.75, 2.90)	.26
Missing ID data	0.76 (0.23, 2.48)	.65
Professional who recorded first ASD diagnosis		
PhD psychologist (Ref)	1.00	
EDD or EDS educator	1.22 (0.30, 4.95)	.78
MD developmental paediatrician	1.47 (0.57, 3.49)	.46
MD neurologist	0.93 (0.26, 3.37)	.91
MD other	1.12 (0.31, 4.00)	.86
PhD other	5.58 (1.56, 19.9)	.01
Other professional	1.11 (0.28, 4.47)	.88
Professional not stated	2.53 (1.05, 6.13)	.04
Public school classroom at 8 y		
Autism special needs classroom (Ref)	1.00	

	OR (95% CI)	*p*
Other special needs classroom	6.26 (3.13, 12.5)	.00
Source of surveillance records		
Both education and health records (Ref)	1.00	
Education only records	0.60 (0.24, 1.49)	.27
Health only records	0.66 (0.32, 1.35)	.26
Subtype of earliest ASD diagnosis		
Autism (Ref)	1.00	
Other ASD	0.71 (0.37, 1.35)	.29
Subtype not stated	0.00 (0.00, 0.00)	.99
Surveillance site		
Arizona (Ref)	1.00	
Georgia	1.66 (0.78, 3.54)	.19
Maryland	0.44 (0.10, 1.89)	.27
South Carolina	1.31 (0.48, 3.60)	.60
Surveillance year		
2000 (Ref)	1.00	
2006	1.54 (0.74, 3.21)	.25
Timing of earliest ASD diagnosis		
31 mo or more (Ref)	1.00	
30 mo or less	3.66 (1.61, 8.32)	.00

OR, odds ratio; CI, confidence interval; ASD, autism spectrum disorder; ADHD, attention-deficit hyperactivity disorder; ID, intellectual disability.