Published in final edited form as:

Pediatrics. 2005 December ; 116(6): 1480–1486. doi:10.1542/peds.2005-0185.

Factors Associated With Age of Diagnosis Among Children With Autism Spectrum Disorders

David S. Mandell, ScD, Maytali M. Novak, MA, and Cynthia D. Zubritsky, PhD

Center for Mental Health Policy and Services Research, Department of Psychiatry, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania

Abstract

Objective—Early diagnosis of children with autism spectrum disorders (ASD) is critical but often delayed until school age. Few studies have identified factors that may delay diagnosis. This study attempted to identify these factors among a community sample of children with ASD.

Methods—Survey data were collected in Pennsylvania from 969 caregivers of children who had ASD and were younger than 21 years regarding their service experiences. Linear regression was used to identify clinical and demographic characteristics associated with age of diagnosis.

Results—The average age of diagnosis was 3.1 years for children with autistic disorder, 3.9 years for pervasive developmental disorder not otherwise specified, and 7.2 years for Asperger's disorder. The average age of diagnosis increased 0.2 years for each year of age. Rural children received a diagnosis 0.4 years later than urban children. Near-poor children received a diagnosis 0.9 years later than those with incomes >100% above the poverty level. Children with severe language deficits received a diagnosis an average of 1.2 years earlier than other children. Hand flapping, toe walking, and sustained odd play were associated with a decrease in the age of diagnosis, whereas oversensitivity to pain and hearing impairment were associated with an increase. Children who had 4 or more primary care physicians before diagnosis received a diagnosis 0.5 years later than other children, whereas those whose pediatricians referred them to a specialist received a diagnosis 0.3 years sooner.

Conclusion—These findings suggest improvements over time in decreasing the age at which children with ASD, especially higher functioning children, receive a diagnosis. They also suggest a lack of resources in rural areas and for near-poor families and the importance of continuous pediatric care and specialty referrals. That only certain ASD-related behaviors, some of which are not required to satisfy diagnostic criteria, decreased the age of diagnosis suggests the importance of continued physician education.

Early diagnosis of autism spectrum disorders (ASD) is critical for a number of reasons,^{1,2} perhaps most important because interventions to improve the functioning of children with ASD may be more effective with younger children.^{3–6} Evidence suggests that early treatment optimizes long-term prognosis,⁷ and treatment yields diminishing returns as children get older.⁸ Several studies have estimated that the gains in functioning associated with early treatment will result in considerable cost savings to both families of children with ASD and the systems in which they are served.^{9–11}

By definition, the onset of ASD is before 3 years of age.¹² There is increasing evidence that clinicians can reliably identify children on the autism spectrum as young as 2 years of age,¹³ and symptoms of ASD and related disorders may be identifiable in even younger children.¹⁴ In their comprehensive review of the early diagnosis of ASD, Charman and Baird¹³ pointed out that many children with ASD exhibit recognizable problems in social interactions in their first year of life. Although screening instruments for ASD in very young children still require refinement before they can be used at the population level,^{15,16} knowledge of early developmental difficulties among children with ASD has increased to the point where very early identification may be possible for a substantial proportion.

Despite our increasing ability to identify the early signs of ASD and general growing awareness of this set of disorders, studies have found that children with ASD do not receive a diagnosis, on average, until they are of school age.^{1,17–19} A number of factors have been implicated in exacerbating this delay, including the fact that many physicians have limited knowledge of the presentation, prognosis, and treatment of ASD²⁰ or other developmental disorders with polymorphous phenotypes.²¹ They therefore often delay for extended periods of time before referring families of children with ASD to specialists for assessment.^{22–24}

Few studies have examined factors that may delay or expedite the diagnosis of ASD. Related ecologic studies have found that education and health system resources are associated with disparities in the proportion of children who receive a diagnosis of ASD. Palmer et al²⁵ found that school districts' education-related spending in Texas was positively associated with the identification of children with ASD. Mandell and Palmer²⁶ replicated this finding at the national level and also found that the per capita availability of pediatricians and school-based health clinics were positively associated with the proportion of children who received a diagnosis of ASD.

A number of family-level factors also have been associated with delays in diagnosis. For example, in a study of Medicaid-eligible children, black children with ASD received a diagnosis an average of 1.5 years later than white children.¹ Although the authors did not test hypotheses regarding this finding, they draw on related research to suggest that differences by ethnicity may be associated with poverty,¹ differences in clinical presentation, differences in parental behaviors,^{27,28} and differential treatment by clinicians.^{29,30}

Although these studies provide important information regarding factors that are associated with the age of diagnosis of ASD, the generalizability of their findings is hampered by small sample size, the use of clinical samples, and the use of administrative or aggregate data. Perhaps more important, none has accounted for how the presentation or severity of ASD may affect diagnosis. This study attempted to address some of these limitations by examining clinical and demographic factors that are associated with the age of diagnosis in a large community sample of children with ASD.

METHODS

Data Collection

Data were collected as part of a state-sponsored effort to improve the quality of care for individuals with ASD in Pennsylvania. Survey data were collected from June 21 through September 30, 2004. Participants were recruited through a mailing to 273 caregivers of individuals with autism who had participated in previous quality improvement efforts and had indicated their willingness to participate in this research; they were asked to share information about the survey with other caregivers. Another 137 providers of autism-related

services were identified through state directories and requested to distribute a letter to families of individuals with ASD asking them to participate in the survey.

The survey invitation letter described the purpose of this project and provided a web address for completing the survey over the Internet and a toll-free number to call to receive a paper copy, which was mailed accompanied by a postage-paid return envelope. Both the Internet and paper versions of the survey again described the purpose of the survey and explained that all responses would be confidential. Participants were asked to complete the survey for their oldest child with ASD. Participants were given the opportunity to enter a drawing in which 40 people won cash prizes of \$50 each.

Survey Description

The survey included 92 questions that were designed to measure the quality and quantity of services and supports received by individuals with ASD from the time when concerns about development first were noted up to the present and took an average of 45 minutes to complete, depending on the age of the child. Questions about clinical and sociodemographic characteristics were also included. The survey was developed on the basis of information gathered from a series of 7 focus groups with parents of children with ASD about their service and support experiences; it was pilot-tested with 10 parents of children who had ASD and were aged 9 to 38 years and subsequently altered for comprehensibility and content.

Sample

A total of 1027 surveys were returned, 713 of which were obtained through the Internet; 9 Internet surveys contained few data and were deleted from the sample. Mothers of individuals with ASD composed 86% and fathers 7% of survey respondents. The remainder included other relatives and legal guardians. Respondents ranged from 23 to 70 years of age (mean: 42; SD: 8); the individuals with ASD about whom they responded ranged from 2 to 53 years (mean: 10; SD: 6). Consistent with epidemiologic findings, 83.4% of the individuals with ASD were male. The majority was white (83.5%); the remainder were black (9.8%), Latino (3.0%), Native American (2.4%), or Asian American (1.9%). Twelve percent of the sample had household incomes below the federal poverty level, 17% had incomes from the poverty level to 100% above the poverty level, and 71% had incomes >200% above the poverty level.

To determine the representativeness of the survey sample, we compared demographic characteristics with those of the 5200 children who were aged 3 to 21 in Pennsylvania and received autism-related special education services in 2003.³¹ The 2 groups deviated by no more than 1% in any ethnic category. Because children with ASD in Pennsylvania are eligible for Medicaid-reimbursed services regardless of family income, analyses were conducted to compare the service use of the sample to Medicaid-reimbursed claims for ASD in Pennsylvania (data not shown). Ten percent of the survey sample experienced a psychiatric inpatient episode compared with 8% indicated in the Medicaid claims; 46% had used a psychotropic medication compared with 42% indicated in the claims. These results suggest the similarity of the survey sample and children with ASD in Pennsylvania in general. For the purposes of this study, the sample was limited to the 969 surveys of individuals who had autism and were younger than <21 years and had a primary diagnosis of autistic, Asperger's, or pervasive developmental disorder not otherwise specified (PDD-NOS).

Analyses

Frequencies and means with SDs as appropriate were calculated for all variables of interest, stratified by diagnosis. The mean age of diagnosis associated with each variable and diagnostic category was also calculated. The distribution of the dependent variable (age of diagnosis) was examined using Kolmogorov-Smirnov and Shapiro-Wilks tests; deviations from normality were found but were of relatively small magnitude.

Linear regression therefore was used to predict the age of diagnosis among children with ASD, adjusting for clinical and demographic characteristics and families' report of interactions with the primary care system. To test for possible nonlinear relationships, we categorized continuous variables. Those with nonlinear relationships with the dependent variable (income and number of pediatricians) were entered into the regression model as categorical variables. We also tested a number of interactions that we decided a priori might be important or whose potential importance was indicated by the bivariate relationships presented in Table 1. They included the following interactions: (1) Asperger's diagnosis with age, urbanicity, and the presence of mental retardation; (2) urbanicity with diagnostic category and making a referral; (3) conducting developmental tests and making a referral; and (4) income and number of pediatricians. Only the coefficient associated with the interaction of Asperger's disorder and patient age was statistically significant; the coefficient associated with the interaction of conducting developmental tests and referring was not statistically significant but appreciably changed the coefficients associated with the main effects and therefore was kept in the final model. The institutional review board of the University of Pennsylvania approved the use of these data for this study.

RESULTS

Table 1 provides descriptive information on the sample. Of the 969 children in the sample, 39% received a diagnosis of autistic disorder, 23% of Asperger's disorder, and 38% with PDD-NOS. Children with autistic disorder received the diagnosis at an average age of 3.1 years, followed by children with PDD-NOS (3.9 years) and children with Asperger's disorder (7.2 years). The majority in each group lived in suburban settings and had household incomes >100% above the poverty level. Relative to national statistics, a large percentage of children were adopted in each group. All of the symptoms about which the survey asked were relatively common, with few occurring in <25% of any diagnostic group. Mental retardation occurred in 30% of children with autistic disorder and in 20% of children with PDD-NOS; seizure disorders occurred in 10% and 11%, respectively, of children with autistic disorder and PDD-NOS. The majority of children in each diagnostic group had 1 or 2 pediatricians before diagnosis. In response to concerns, pediatricians were more likely to refer children to specialists than to conduct developmental tests themselves.

Figure 1 provides information on the age of diagnosis by diagnostic and age categories. Modified box plots are used to present the data.³² The results suggest that younger children generally received the diagnosis at an earlier age than older children. There was also considerably more variability in the age of diagnosis among adolescents and young adults than in younger children. The discrepancy in age of diagnosis by patient age was especially apparent among children with Asperger's disorder.

Table 2 provides the results of the linear regression predicting age of diagnosis. Adjusting for other variables, children with Asperger's syndrome received the diagnosis an average of 1.8 years later than children with autistic disorder, and this difference increased by an additional 0.4 years for each additional year of patients' age. Diagnosis occurred 0.2 years later for each year of patients' age. Adopted children received the diagnosis an average of 0.8 years later than children who were not adopted. Children who lived in rural areas

received the diagnosis 0.4 years later than children who lived in urban areas, and children from near-poor households received the diagnosis 0.9 years later than children who lived in households with incomes >100% above the poverty level.

The presence of certain symptoms was also predictive of diagnosis. Children with severe language deficits received a diagnosis an average of 1.2 years earlier than other children. Oversensitivity to pain was associated with a 0.6-year increase in the age of diagnosis. Hand flapping, toe walking, and sustained odd play were associated with decreases in the age of diagnosis. The presence of a hearing impairment was associated with 0.8-year increase in the age of diagnosis.

Families' interactions with the primary care system and physician behavior were also associated with age of diagnosis. Children who had 4 or more primary care physicians before diagnosis received a diagnosis an average of 0.5 years later than children who had 1 primary care physician. Children who were referred by their pediatricians to a specialist in response to parental concerns received a diagnosis an average of 0.3 years earlier than other children.

DISCUSSION

This study found that children with autistic disorder, although not children with Asperger's disorder or PDD-NOS, received a diagnosis at a younger age than was found in previous studies and that diagnosis occurred at an earlier age among younger children compared with older children. It is important to note, however, that previous studies did not differentiate among ASD subtypes^{1,18} and reflect diagnostic practices from earlier time periods.³³ This issue is especially important because this study suggests that the decrease in age of diagnosis over time is happening more quickly for higher functioning children with ASD. The results also suggest that income, place of residence, clinical presentation, the number of pediatricians that children had before diagnosis, and physician behavior are associated with the age at which children with ASD receive the diagnosis.

Contrary to the previous study in this area,¹ ethnic minority children did not receive a diagnosis at an older age than white children. This result may be considered an encouraging finding regarding the elimination of health disparities; it may also be, however, that ethnicity is collinear with other variables, such as income, which had a stronger association with age of diagnosis. Bivariate analyses and tests of statistical interactions did not provide evidence for this hypothesis, however. It also may be that care-givers with greater resources, especially among ethnic minority families, were more likely to respond to the survey, thus biasing the relationship between ethnicity and age of diagnosis.

The relationship between income and age of diagnosis was not linear. Although there was no statistically significant difference between poor families and families whose incomes were >100% above the poverty level, near-poor children received a diagnosis an average of almost 11 months later than children from wealthier families. Income may be related to insurance status, with near-poor families least likely to be insured or to have insurance that fully covers needed services.^{34–37} Even among the insured, however, access to care may be worse for near-poor families than for those who have public insurance.³⁸

That children in rural settings received a diagnosis later than did children in urban areas echoes findings from a previous study regarding the relationship between urbanicity and the frequency of ASD diagnosis²⁵ and the growing recognition of the importance of place in predicting health and health care in general.^{39–42} A number of studies have found that children in rural areas have less access to regular and specialty care.^{43,44} It may also be that

a critical mass of children with ASD, which is more likely found in densely populated areas, may increase physicians' and families' familiarity with the disorder.

Some symptoms seemed to trigger earlier diagnosis than others. Children with severe language deficits, hand flapping, toe walking, and sustained odd play received a diagnosis earlier. Although language deficits are an important component of diagnosis for autistic disorder and PDD-NOS, the other 3 symptoms are not required for diagnosis. Physicians may be more familiar with these symptoms from portrayals of ASD in the popular media, or they may be more disturbing to parents and physicians alike, prompting additional evaluation. The association of oversensitivity to pain with later diagnosis may be because this symptom prompts clinicians to search for other organic causes and not consider developmental issues. Similarly, ASD symptoms in adopted children, who received a diagnosis almost 10 months later than other children, may be attributed to factors associated with early childhood experiences that result in temporary delay rather than a condition associated with chronic delay such as ASD.

Children with hearing impairments received a diagnosis almost 10 months later than other children. Hearing loss may make it more difficult to determine the presence of ASD; however, the frequent co-occurrence of ASD and hearing impairment (as well as mental retardation and seizures)⁴⁵ should alert clinicians to the possibility of ASD in this group.

Families' interactions with the health system were also associated with differences in the age of diagnosis. Children who had 4 or more primary care physicians before diagnosis received a diagnosis 6 months later than other children, whereas children whose pediatricians referred them to specialists in response to developmental concerns received a diagnosis earlier than did other children. Having many primary care physicians before diagnosis may be related to issues such as residential instability and poor access to health care that result in discontinuity of care, or parents could not recognize the importance of continuous pediatric care. Alternatively, switching physicians may be the result of families' frustration that their concerns are not being acknowledged or addressed.

It was disappointing to note that conducting developmental tests was not associated with a decrease in the age of diagnosis, especially in light of current federally funded efforts and American Academy of Pediatrics guidelines focused on increasing standardized, regular developmental screening. It may be that caregivers' report of whether physicians conducted testing is an invalid measure, whereas physician referrals are easier to ascertain accurately. In addition, the measures that physicians used may not be sensitive to the presence of ASD. A number of studies suggest that more physicians rely on clinical judgment or a few questions more than on standardized measures.^{46–50} Unless validated measures are implemented in a reliable manner, it may be more effective for physicians to rely on parental concern as a measure of need.^{51,52}

Limitations

A number of study limitations should be considered. Perhaps primary among them is the validity of ASD diagnoses and reporting of related symptoms, which were not standardized or validated. All respondents indicated that the diagnosis was made by a physician or a psychologist, however, and studies have found good to excellent reliability associated with both the diagnosis of ASD by health care professionals and the differentiation of subtypes.^{53–56} A related limitation is that we collected data only on some symptoms associated with ASD. Given the length of the survey, our goal was to focus only on those symptoms that we thought might differentiate subtypes of children with ASD. In the process, we may have missed important symptoms that are associated with changes in the age of diagnosis. For example, we do not have information on IQ other than the presence of mental retardation

and have limited information on issues related to social interactions. A third limitation is the potential bias in survey respondents, especially given the sampling method. Despite the similarities between the experiences and ethnicity of survey respondents and children with ASD in Pennsylvania described in Methods, families who were motivated to complete this survey may have characteristics and experiences different from those of nonresponders. An indication of bias toward higher functioning children in this sample is the large number of responding families relative to the known community prevalence of children with Asperger's disorder and without mental retardation.⁵⁷ A fourth limitation is that caregivers were asked to recall events that may have happened much earlier. Differential recall about, for example, pediatrician behavior or age of diagnosis may have biased the results.

Implications

Despite these limitations, there are a number of study implications. The results provide some evidence regarding the positive effects of having continuity in pediatric care. The American Academy of Pediatrics emphasizes the importance of coordinated, continuous health care for children with ASD,² and research shows the importance of this type of care in improving outcomes for children with special health care needs^{58,59}; however, fewer than half of children with special health care needs have care that meets these criteria.^{60,61} The reason for the discontinuity among children with ASD, whether it relates to access or frustration, for example, has important implications for the interventions to reduce it.

This study also suggests the importance of specialist referrals. The symptoms of ASD are sometimes difficult to differentiate from other health conditions,⁶² and generalists may not associate some of them with ASD. Specialist referrals for ASD are often accompanied by long wait times,¹⁸ however, and especially in rural settings and for uninsured or underinsured families, referrals may not be readily available. For example, the American Board of Pediatrics workforce report shows the paucity of board-certified developmental pediatricians and pediatric neurologists in many states.⁶³ Other studies have found that children with ASD have more difficulty obtaining specialty care than children with other special health care needs.⁶⁴ These data suggest the importance of parallel efforts to increase both the availability of specialist care for diagnosis and physician knowledge of the multiple ways in which ASD can manifest.⁶⁵

ABBREVIATIONS

ASD	autism spectrum disorders
PDD-NOS	pervasive developmental disorder not otherwise specified

References

1. 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]
2. American Academy of Pediatrics. The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics* 2001;107:1221–1226. [PubMed: 11331713]
3. Committee on Children with Disabilities. Technical report: the pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*. 2001. Available at: www.pediatrics.org/cgi/content/full/107/5/e85
4. Campbell M, Schopler E, Cueva J, Hallin A. Treatment of autistic disorder. *J Am Acad Child Adolesc Psychiatry* 1996;35:134–143. [PubMed: 8720622]
5. Rapin I. Current concepts: autism. *New Engl J Med* 1997;337:97–104. [PubMed: 9211680]

6. Volkmar F, Cook E, Pomeroy J, Realmuto G, Tanguay P. Practice parameters for the assessment and treatment of children, adolescents and adults with autism and other pervasive developmental disorders. *J Am Acad Child Adolesc Psychiatry* 1999;38(suppl):32S–54S. [PubMed: 10624084]
7. Lord C. Follow-up of two-year-olds referred for possible autism. *J Child Psychol Psychiatry* 1995;36:1365–1382. [PubMed: 8988272]
8. Mars AE, Mauk JE, Dowrick PW. Symptoms of pervasive developmental disorders as observed in prediagnostic home videos of infants and toddlers. *J Pediatr* 1998;132:500–504. [PubMed: 9544908]
9. Jacobson J, Mulick J, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behav Interventions* 1998;13:201–226.
10. Jacobson J, Mulick J. System and cost research issues in treatments for people with autistic disorders. *J Autism Dev Disord* 2000;30:585–593. [PubMed: 11261469]
11. Jarbrink K, Knapp M. The economic impact of autism in Britain. *Autism* 2001;5:7–22. [PubMed: 11708392]
12. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 4. Washington, DC: American Psychiatric Association; 2000. Text Revision
13. Charman T, Baird G. Practitioner review: diagnosis of autism spectrum disorder in 2- and 3-year-old children. *J Child Psychol Psychiatry* 2002;43:289–305. [PubMed: 11944873]
14. Charman T, Baron-Cohen S, Swettenham J, Baird G, Cox A, Drew A. Testing joint attention, imitation and play as infancy precursors to language and theory of mind. *Cogn Dev* 2000;15:481–498.
15. Baird G, Charman T, Cox A, et al. Screening and surveillance for autism and pervasive developmental disorders. *Arch Dis Child* 2001;84:468–475. [PubMed: 11369559]
16. Baron-Cohen S, Wheelwright S, Cox A, et al. Early identification of autism by the Checklist for Autism in Toddlers (CHAT). *J R Soc Med* 2000;93:521–525. [PubMed: 11064690]
17. Howlin P. Prognosis in autism: do specialist treatments affect long-term outcome? *Eur Child Adolesc Psychiatry* 1997;6:55–72. [PubMed: 9257087]
18. Levy SE, Mandell DS, Merhar S, Ittenbach RF, Pinto-Martin JA. Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *J Dev Behav Pediatr* 2003;24:418–423. [PubMed: 14671475]
19. 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]
20. Shah K. What do medical students know about autism. *Autism* 2001;5:127–133. [PubMed: 11706861]
21. Palfrey J, Singer J, Walker D, Butler J. Early identification of children's special needs: a study in five metropolitan communities. *J Pediatr* 1987;111:651–659. [PubMed: 2444688]
22. Knafl K, Ayres L, Gallo A, Zoeller L, Breitmayer B. Learning from stories: parents' accounts of the pathway to diagnosis. *Pediatr Nurs* 1995;21:411–415. [PubMed: 8684841]
23. Shevell M, Majnemer A, Rosenbaum P, Abrahamowicz M. Profile of referrals for early childhood developmental delay to ambulatory sub-specialty clinics. *J Child Neurol* 2001;16:645–650. [PubMed: 11575603]
24. Smith B, Chung MC, Vostanis P. The path to care in autism: is it better now? *J Autism Dev Disord* 1994;24:551–563. [PubMed: 7814305]
25. Palmer R, Blanchard S, Jaen C, Mandell D. The association between school district resources and identification of children with autistic disorder. *Am J Public Health* 2005;95:125–130. [PubMed: 15623872]
26. Mandell D, Palmer R. Differences among states in the identification of autistic spectrum disorders. *Arch Pediatr Adolesc Med* 2005;159:266–269. [PubMed: 15753271]
27. Coonrod E, Stone W. Early concerns of parents of children with autistic and nonautistic disorders. *Infants Young Child* 2004;17:258–269.
28. Daley T. From symptom recognition to diagnosis: children with autism in urban India. *Soc Sci Med* 2004;58:1323–1335. [PubMed: 14759679]

29. Cooper-Patrick L, Gallo J, Powe N, Steinwachs D, Eaton W, Ford D. Mental health service utilization by African Americans and whites: the Baltimore Epidemiologic Catchment Area Follow-Up. *Med Care* 1999;37:1034–1045. [PubMed: 10524370]
30. Cooper-Patrick L, Gallo J, Gonzales J, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA* 1999;282:583–589. [PubMed: 10450723]
31. United States Department of Education. Twenty-Fifth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act; Jessup, MD: Bureau of Special Education; 2003.
32. Tukey, J. *Explanatory Data Analysis*. Reading, MA: Addison-Wesley; 1977.
33. Howlin P, Moore A. Diagnosis of autism. A survey of over 1200 patients in the UK. *Autism* 1997;1:135–162.
34. Aday LA, Lee ES, Spears B, Chung CW, Youssef A, Bloom B. Health insurance and utilization of medical care for children with special health care needs. *Med Care* 1993;31:1013–1026. [PubMed: 8231334]
35. Dubay L, Kenney G. Health care access and use among low-income children: who fairs best. *Health Aff* 2001;20:112–121.
36. Moffitt R, Slade E. Health care coverage for children who are on and off welfare. *Future Child* 1997;7:87–98. [PubMed: 9170735]
37. Starfield B, Shi L. The medical home, access to care, and insurance: a review of evidence. *Pediatrics* 2004;113:1493–1498. [PubMed: 15121917]
38. Rosenbach M, Irvin C, Coulam R. Access for low-income children: is health insurance enough? *Pediatrics* 1999;103:1167–1174. [PubMed: 10353924]
39. Fisher E, Wennberg J. Health care quality, geographic variations, and the challenge of supply-sensitive care. *Perspect Biol Med* 2003;46:69–79. [PubMed: 12582271]
40. Kawachi, I.; Berkman, L. *Neighborhoods and Health*. New York, NY: Oxford University Press; 2003.
41. Sturm, R.; Ringel, J.; Andreyeva, T. Geographic disparities in children's mental health care. *Pediatrics*. 2003. Available at: www.pediatrics.org/cgi/content/full/112/4/e308
42. Wennberg J, Fisher E, Skinner J. Geography and the debate over Medicare reform. *Health Aff* 2002;(Suppl Web Exclusives):W96–W114.
43. Cohen P, Hesselbart C. Demographic factors in the use of children's mental health services. *Am J Public Health* 1993;83:49–52. [PubMed: 8417606]
44. Slade E. The relationship between school characteristics and the availability of mental health and related health services in middle and high schools in the United States. *J Behav Health Serv Res* 2003;30:382–392. [PubMed: 14593662]
45. Gillberg C, Billstedt E. Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatr Scand* 2000;102:321–333. [PubMed: 11098802]
46. Dearlove J, Kearney D. How good is general practice developmental screening. *Br Med J* 1990;300:1177–1180. [PubMed: 1693300]
47. Dobos A, Dworkin P, Bernstein B. Pediatricians' approaches to developmental problems: has the gap been narrowed? *J Dev Behav Pediatr* 1994;15:34–39. [PubMed: 7515076]
48. King T, Glascoe F. Developmental surveillance of infants and young children in pediatric primary care. *Curr Opin Pediatr* 2003;15:624–629. [PubMed: 14631210]
49. Li P, Logan S. The current state of screening in general practice. *J Public Health Med* 1996;18:350–356. [PubMed: 8887848]
50. Sices L, Feudtner C, McLaughlin J, Drotar D, Williams M. How do primary care physicians identify young children with developmental delays? A national survey. *J Dev Behav Pediatr* 2003;24:409–417. [PubMed: 14671474]
51. Glascoe F. Evidence-based approach to developmental and behavioural surveillance using parents' concerns. *Child Care Health Dev* 2000;26:137–149. [PubMed: 10759753]
52. Glascoe F. Are overreferrals on developmental screening tests really a problem? *Arch Pediatr Adolesc Med* 2001;155:54–59. [PubMed: 11177063]

53. Eisenmajer R, Prior M, Leekam S, et al. Comparison of clinical symptoms in autism and Asperger's disorder. *J Am Acad Child Adolesc Psychiatry* 1996;35:1523–1531. [PubMed: 8936920]
54. Fombonne E, Heavey L, Smeeth L, et al. Validation of the diagnosis of autism in general practitioner records. *BMC Public Health* 2004;4:5. [PubMed: 15113435]
55. Hill A, Bolte S, Petrova G, Beltcheva D, Tacheva S, Poustka F. Stability and interpersonal agreement of the interview-based diagnosis of autism. *Psychopathology* 2001;34:187–191. [PubMed: 11549928]
56. Mahoney W, Szatmari P, MacLean J, et al. Reliability and accuracy of differentiating pervasive developmental disorder subtypes. *J Am Acad Child Adolesc Psychiatry* 1998;37:278–285. [PubMed: 9519632]
57. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord* 2003;33:365–382. [PubMed: 12959416]
58. Cooley W, McAllister J. Building medical homes: improvement strategies in primary care for children with special health care needs. *Pediatrics* 2004;133:1499–1506. [PubMed: 15121918]
59. Palfrey J, Sofis L, Davidson E, Liu J, Freeman L, Ganz M. The pediatric alliance for coordinated care: evaluation of a medical home model. *Pediatrics* 2004;113:1507–1516. [PubMed: 15121919]
60. Bethell C, Read D, Brockwood K. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. *Pediatrics* 2004;113:1529–1538. [PubMed: 15121922]
61. Strickland B, McPherson M, Weissman G, van Dyck P, Huang Z, Newa-check P. Access to the medical home: results from the national survey of children with special health care needs. *Pediatrics* 2004;113:1485–1492. [PubMed: 15121916]
62. Ohta M, Nagai Y, Hara H, Sasaki M. Parental perception of behavioral symptoms in Japanese autistic children. *J Autism Dev Disord* 1987;17:549–563. [PubMed: 3680155]
63. Guerin, R. The American Board of Pediatrics 2003–04 Workforce Data. Chapel Hill, NC: American Board of Pediatrics; 2004.
64. Krauss M, Gulley S, Sciegaj M, Wells N. Access to specialty medical care for children with mental retardation, autism and other special health care needs. *Ment Retard* 2003;41:329–339. [PubMed: 12962535]
65. Volkmar F, Lord C, Bailey A, Schultz R, Klin A. Autism and pervasive developmental disorders. *J Child Psychol Psychiatry* 2004;45:135–155. [PubMed: 14959806]

Fig 1.
Median age of diagnosis by diagnostic and age categories ($n = 969$).

TABLE 1

Sample Characteristics

	Autistic Disorder (<i>n</i> = 382)		PDD-NOS (<i>n</i> = 366)		Asperger's Disorder (<i>n</i> = 221)	
	%	Age Diagnosed Mean (SD)	%	Age Diagnosed Mean (SD)	%	Age Diagnosed Mean (SD)
Total	—	3.1 (1.7)	—	3.9 (2.4)	—	7.2 (3.4)
Demographics						
Male	86	3.0 (1.6)	81	3.8 (2.3)	89	7.1 (3.4)
Female	14	3.4 (1.9)	19	4.0 (2.9)	11	7.3 (3.7)
2–5 y of age	40	2.7 (0.8)	34	2.7 (0.8)	8	3.9 (1.0)
6–9 y of age	26	2.9 (1.1)	29	3.6 (1.4)	31	5.4 (1.6)
10–13 y of age	22	3.4 (1.5)	23	4.6 (2.6)	39	7.5 (2.6)
14–17 y of age	9	3.9 (3.0)	9	6.3 (4.3)	19	9.8 (3.7)
18–21 y of age	3	6.9 (5.4)	5	5.9 (3.6)	3	14.6 (6.0)
White	82	3.1 (1.6)	82	3.9 (2.4)	90	7.1 (3.4)
Black	10	3.0 (2.4)	13	3.9 (5.6)	5	7.7 (5.0)
Asian/Pacific Islander	3	2.8 (0.7)	1	4.5 (3.7)	2	8.4 (3.8)
Native American	2	4.7 (4.8)	2	3.9 (2.4)	3	7.2 (3.4)
Latino	3	3.3 (1.1)	2	2.4 (0.5)	0	—
Adopted	3	3.5 (1.3)	7	5.2 (2.7)	7	9.0 (4.1)
Rural	22	3.5 (2.2)	18	4.2 (3.1)	24	8.1 (3.4)
Suburban	54	2.9 (1.1)	62	3.9 (2.3)	58	7.2 (3.4)
Urban	24	3.2 (2.2)	20	3.8 (2.0)	18	5.8 (3.2)
Income						
Below poverty level	15	3.6 (2.8)	11	3.9 (3.2)	8	6.1 (3.3)
From poverty level to 100% above	18	3.2 (1.9)	14	5.2 (2.9)	22	8.2 (3.8)
>100% above	67	3.0 (1.3)	75	3.6 (2.2)	70	7.0 (3.3)
Symptoms						
Does not respond when called	85	3.0 (1.6)	77	3.6 (2.0)	74	7.6 (3.5)
Self-injurious	47	3.0 (1.4)	36	4.0 (2.3)	38	6.8 (3.0)
Severe language deficits	90	3.0 (1.7)	75	3.4 (1.8)	22	5.8 (2.9)
Oversensitive to pain	16	3.3 (2.0)	19	4.9 (3.1)	32	7.6 (2.9)
Aggressive to others	49	3.0 (1.4)	45	4.2 (2.6)	55	6.8 (2.8)

	Autistic Disorder (<i>n</i> = 382)		PDD-NOS (<i>n</i> = 366)		Asperger's Disorder (<i>n</i> = 221)	
	%	Age Diagnosed Mean (SD)	%	Age Diagnosed Mean (SD)	%	Age Diagnosed Mean (SD)
Insists on sameness	72	3.1 (1.6)	68	3.8 (2.1)	80	7.2 (3.5)
Lack of eye contact	87	3.1 (1.7)	84	3.8 (2.2)	88	7.2 (3.3)
Sustained odd play	72	3.0 (1.4)	62	3.6 (1.9)	59	6.9 (3.4)
Echolalia	58	3.4 (1.9)	65	3.7 (2.1)	58	6.3 (2.8)
Hand flapping	68	2.9 (1.4)	49	3.6 (2.1)	38	6.6 (3.0)
Toe walking	52	3.0 (1.8)	34	3.4 (1.7)	24	6.0 (2.9)
Spins self	41	3.0 (1.3)	31	3.5 (1.9)	25	5.7 (2.6)
Other clinical features						
Mental retardation	30	3.3 (2.1)	20	4.5 (2.7)	2	3.0 (0.9)
Hearing impairment	3	4.1 (3.2)	2	4.7 (2.1)	1	6.8 (2.5)
Seizures	10	3.2 (1.6)	11	4.4 (2.9)	4	8.6 (4.1)
Health system interactions						
1 primary care physician before diagnosis	34	2.9 (1.0)	39	3.7 (2.1)	42	6.8 (3.2)
2 primary care physicians before diagnosis	39	3.2 (2.0)	36	3.6 (2.0)	31	7.2 (3.8)
3 primary care physicians before diagnosis	16	3.3 (2.1)	13	3.9 (2.5)	16	7.3 (3.4)
≥4 primary care physicians before diagnosis	11	3.2 (1.2)	12	4.7 (3.4)	11	8.1 (3.1)
In response to concerns about development, the primary care physician						
Conducted developmental tests	12	3.1 (1.3)	15	4.6 (3.2)	8	6.9 (3.2)
Referred to a specialist	34	3.0 (1.6)	32	3.8 (2.5)	23	6.4 (3.8)

TABLE 2

Linear Regression Predicting Age of Diagnosis in Years

	Coefficient	95% Confidence Interval
Diagnosis		
Asperger's disorder	1.8	0.8 to 2.9
PDD	0.2	−0.1 to 0.6
Interaction of Asperger's diagnosis and age	0.4	0.3 to 0.5
Demographics		
Male	0.2	−0.2 to 0.6
Age, y	0.2	0.1 to 0.2
Black	0.1	−0.7 to 0.4
Asian/Pacific Islander	−0.5	−1.5 to 0.4
Native American	0.0	−0.9 to 0.9
Latino	−0.8	−1.6 to 0.1
Child was adopted	0.8	0.2 to 1.5
Rural	0.4	0.1 to 0.7
Suburban	0.2	−0.2 to 0.6
Income below poverty level	0.2	−0.2 to 0.7
Income from poverty level to 100% above	0.9	0.5 to 1.2
Symptoms		
Does not respond when called	0.0	−0.4 to 0.4
Self-injurious	−0.2	−0.5 to 0.1
Severe language deficits	−1.2	−1.5 to −0.8
Oversensitive to pain	0.6	0.2 to 0.9
Aggressive to others	−0.1	−0.4 to 0.2
Insists on sameness	−0.1	−0.4 to 0.3
Sustained odd play	−0.3	−0.6 to −0.1
Echolalia	−0.2	−0.5 to 0.0
Hand flapping	−0.4	−0.7 to −0.1
Toe walking	−0.2	−0.5 to −0.1
Spins self	−0.1	−0.4 to 0.2
Other clinical features		
Mental retardation	−0.2	−0.6 to 0.2
Hearing impairment	0.8	0.1 to 1.6
Seizures	0.0	−0.5 to 0.5
Health system characteristics		
2 primary care physicians before diagnosis	0.0	−0.3 to 0.3
3 primary care physicians before diagnosis	0.0	−0.4 to 0.4
≥4 primary care physicians before diagnosis	0.5	0.1 to 1.0
In response to concerns about development		
Physician conducted developmental tests	−0.2	−1.0 to 0.6
Physician referred to a specialist	−0.3	−0.7 to 0.0

	Coefficient	95% Confidence Interval
Interaction of developmental testing and referral	0.3	−0.6 to 1.3

Adjusted $R^2 = 0.54$. Statistically significant findings at $P \leq .05$ are in bold. Reference group consists of female white children who received a diagnosis of autistic disorder, and live in urban settings with household incomes >100% above the federal poverty level.