Diagnosis of Autism Spectrum Disorder by Developmental-Behavioral Pediatricians in Academic Centers: A DBPNet Study

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OBJECTIVES: To describe the clinical practices of physicians in the Developmental-Behavioral Pediatrics Network (DBPNet) to (1) diagnose autism spectrum disorders (ASDs), identify comorbidities, and evaluate etiology and (2) compare actual practice to established guidelines.

METHODS: A total of 56 developmental-behavioral pediatricians completed encounter forms, including demographic/clinical information, for up to 10 consecutive new-patient visits given a diagnosis of ASD. Data were summarized by using descriptive statistics. Analysis of the statistical significance of differences between sites (n = 10) used general estimating equations and mixed-effects logistic regression to adjust for clustering by clinician within site.

RESULTS: A total of 284 ASD forms were submitted. Most assessments (56%) were completed in 1 visit (27.5% in 2 visits, 8.6% in 3 visits). Use of the Childhood Autism Rating Scale, Autism Diagnostic Observation Schedule, or Screening Tool for Autism in Toddlers and Young Children varied across sites from 28.6% to 100% of encounters (P < .001). A developmental assessment was reviewed/completed at 87.7% of encounters (range: 77.8%–100%; P = .061), parent behavior rating scales were reviewed/completed at 65.9% (range: 35.7%–91.4%; P = .19), and teacher behavior rating scales were reviewed/completed at 38.4% (range: 15%–69.2%; P = .19). Only 17.3% (95% confidence interval: 12.8%–21.7%) of evaluations were completed by an interdisciplinary team. A majority (71%) of patients had at least 1 comorbid diagnosis (31% had at least 2 and 12% at least 3). Etiologic evaluations were primarily genetic (karyotype: 49%; microarray: 69.7%; fragile X: 71.5%).

CONCLUSIONS: Despite site variability, the majority of diagnostic evaluations for ASD within DBPNet were completed by developmental-behavioral pediatricians without an interdisciplinary team and included a developmental assessment, ASD-specific assessment tools, and parent behavior rating scales. These findings document the multiple components of assessment used by DBPNet physicians and where they align with existing guidelines.

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Autism spectrum disorders (ASD) are complex neurodevelopmental disorders with behavioral impairments characterized by deficits in social communication skills and restrictive, repetitive behaviors and interests. On the basis of surveillance data from the Autism and Developmental Disabilities Monitoring Network, the reported prevalence of ASD continues to increase, with most recent estimates being 1 in 68 children in the United States. Although the clinical diagnosis of ASD is based on behavioral criteria, there is accumulating evidence for diverse etiologies and associated comorbid disorders that have important implications for diagnosis, treatment, and prognosis.

The importance of early identification and treatment of optimal outcomes is also becoming increasingly clear, yet difficulties with access to specialty care, long clinic waiting lists, and other barriers to early diagnosis and treatment exist in most parts of the United States. Varying recommendations for diagnostic assessment of ASD in clinical practice have been proposed that include the use of interdisciplinary assessments as well as standardized assessments using research-validated instruments such as the Autism Diagnostic Observation Scheduleless (ADOS) and the Autism Diagnostic Interview–Revised (ADI-R). In addition, recommendations for etiologic assessments in ASD continue to change with advances in clinical research and accessibility to genetic technology.

Several guidelines have been published by the American Academy of Pediatrics (AAP), the American Academy of Child and Adolescent Psychiatry (AACAP), the American Academy of Neurology (AAN), and the American College of Medical Genetics and Genomics (ACMG); however, the extent to which these recommendations and guidelines are currently incorporated into general or subspecialist clinical practice is not known. Common components of the guidelines published by the AAP, AACAP, and AAN include the following: obtaining historical and current information on medical, family, developmental, and behavioral characteristics, ideally from multiple sources; physical examination; behavioral observation; developmental/cognitive testing; and laboratory evaluation. These guidelines include the recommendation that ideally the definitive diagnosis of ASD should be made by a team of child specialists with expertise in ASD, and emphasize that a multidisciplinary evaluation should address 3 major diagnostic challenges: functional impairments, making the categorical diagnosis of an ASD, and determining the extent of the search for an associated etiology.

Developmental-behavioral pediatrics (DBP) is a subspecialty of pediatrics focused on the evaluation of children with a variety of special health care needs, including developmental disabilities, and management of these conditions within the context of the child's family and community. Thus, the field has overlap in training, research, and/or clinical populations served with child and adolescent psychiatry, neurology, and genetics and is closely connected to the broad range of developmental and behavioral pediatric issues seen in general pediatrics. Although ASD is a core competency for the subspecialty of DBP, no studies have described the clinical practice patterns of DBP in the diagnosis or management of ASD or the degree to which they align with published guidelines from the AAP, AACAP, AAN, and ACMG. This information would be helpful in determining if there is a need to develop guidelines for DBP subspecialty practice and training, as well as to facilitate referrals, collaborative assessments, and treatment models of care between general pediatrics, DBP, other subspecialties, and community resources. It would also provide important information for parents, insurance programs, and policy makers by substantiating the complex components of subspecialty diagnostic assessments.

The objectives of this study were to describe the clinical practices of physicians in the Developmental-Behavioral Pediatrics Network (DBPNet), a research consortium of 12 developmental behavioral pediatric training sites, to (1) diagnose ASD, identify comorbidities, and evaluate etiology and (2) compare DBPNet practice with established guidelines.

**METHODS**

**Subjects**

This study was part of a broader study of the assessment practices of developmental-behavioral pediatricians performing a new-patient evaluation for either attention-deficit/hyperactivity disorder (ADHD) or ASDs, which has been previously described. Briefly, the study was conducted by DBPNet, a national research network composed of 12 of the 36 academic health centers in which developmental-behavioral pediatrician fellowship training occurred in 2010. The DBPNet sites range in size from 3 to >10 faculty per site, and all 12 DBPNet sites agreed to participate in the study; all 78 board-certified or board-eligible developmental-behavioral or neurodevelopmental disabilities pediatricians who provided clinical care within the sites were invited to participate. Data collection began December 2011 and ended June 2012.

The institutional review board (IRB) approval process varied across sites. The study was approved by
the IRBs at the following sites: The Children’s Hospital of Philadelphia, Boston Children’s Hospital, Stanford University, Albert Einstein College of Medicine, Rhode Island Hospital, University of Arkansas, University Hospitals Case Medical Center, and the University of Oklahoma. Other participating sites either declared the study exempt or designated The Children’s Hospital of Philadelphia’s IRB as the IRB of record. Eligible physicians received a letter describing the study, indicating that participation was voluntary. Completion of ≥1 Diagnostic Encounter Survey forms was interpreted as consent.

**Design**

The study design was a descriptive study. Physicians completed a Diagnostic-Encounter Survey (DES) at the conclusion of consecutive diagnostic visits in which the child received a definite or provisional primary diagnosis of either ADHD or ASD. For sites that regularly use multivisit diagnostic assessments, physicians were instructed to complete the form at the final visit and to consider all information gathered at earlier visits. Clinicians could code a diagnosis as provisional if they thought it was the most likely diagnosis but still wanted to gather additional information to confirm the diagnosis. Once they began to participate, the physicians continued until they completed 10 surveys or had participated for 2 months, whichever was shorter.

**Measures**

A Clinician Survey asked participating developmental-behavioral pediatricians to self-report demographic factors, including age, gender, years since completing subspecialty certification, and information about their clinical practices, including the number of clinical sessions worked and percentage of patients with ASD. We considered these clinician demographic features as potential sources of practice variation.

The DES form was closely modeled after forms of the National Ambulatory Medical Care Survey (NAMCS),22,23 which have been found to generate data with high concordance to direct observation of physician behavior. Furthermore, the survey was reviewed by the DBPNet site principal investigator at each participating site for relevance, clarity, and face validity. The DES form included demographic data about the patient, primary diagnosis, and coexisting diagnoses. The form asked which types of developmental or laboratory tests the physician “reviewed” (the assessment was completed before the physician visit), completed as part of the diagnostic encounter(s) “done” and “ordered” (the assessment was recommended to occur after the visit). The form asked about other clinicians involved in the evaluation and whether those clinicians were working with the developmental-behavioral pediatrician as part of an interdisciplinary team, as well as about medications the child was taking or had been prescribed at the visit, and the number of times the physician saw the child for the diagnostic assessment.

**Analysis**

Analysis was performed by using Stata 13.0 (StataCorp, College Station, TX). Demographic variables and case descriptions were summarized by standard descriptive statistics (eg, means and SDs for continuous variables, such as age, and percentages for categorical variables, such as gender). The majority of primary end points were dichotomous variables. The percentage of patients in which the outcome of interest occurred (eg, microarray reviewed or recommended) was calculated with ranges and/or a 95% confidence interval (CI). A sample size of at least 200 encounter forms was based on the number required to precisely estimate the percentage of patients in which the outcome of interest occurred. With a sample size of 200, the 95% CI will extend ±6.9% from the observed percentage if the expected percentage of occurrence is 50% (eg, in 50% of encounters a particular test was done). If the expected percentage of encounters is <50%, then the 95% CI will be tighter. For example, if the expected occurrence is 5%, the CI will extend ±3% from the observed percentage.

The study tested the hypotheses that characteristics of the ASD evaluation differed across sites by using 2-tailed tests with a P value <.05 as the criterion for statistical significance. The 2 sites reporting <13 encounters were excluded from this analysis. The study data had 2 levels of clustering: visits by individual physicians and physicians by study locations. Testing to compare proportions was initially conducted by using the χ² test for independent data.

Additional analyses were also conducted that accounted for the clustering of observations. To compare proportions between sites, generalized estimating equations (GEEs) were used to fit a logistic regression model of the outcome variable on indicator variables for each site (with 1 site serving as the reference site). The GEE approach accounted for correlation within physicians by fitting exchangeable correlation structures that assumed equal correlation between any 2 measurements within a clinician. Similar GEE models, but with site level–exchangeable correlation structures, were used to relate the probability of dichotomous outcomes with clinician characteristics. Sandwich covariance matrices were used to estimate the covariance of the estimated regression parameters for the GEE models. Wald tests were performed to test the hypothesis.
that the regression coefficients for site were simultaneously equal to zero. In addition, a sensitivity analysis was conducted to confirm that the results were unchanged when fitting a multilevel mixed-effects logistic regression model by using the melogit command in Stata. The mixed-effects approach used likelihood ratio tests of the hypothesis that the regression coefficients for the site variables were zero. If there was disagreement between the approaches, we reported the largest P value; our goal was to take a conservative approach to assessing differences between sites while accounting for the multilevel structure of the data.

RESULTS

Participating Clinicians and Practice Patterns

Overall, 78 physicians were invited to participate, and 65 (83%) returned at least 1 survey for a child diagnosed with either ASD or ADHD. As shown in Table 1, respondents represented all DBPNet sites. In total, 508 surveys were returned, but 13 that were missing a primary diagnosis were excluded. The mean number of encounter forms returned per participating physician was 7.6 ± 2.6, with 71% of the physicians returning ≥7 encounter forms with a primary diagnosis. Of the 493 encounter forms with a primary diagnosis, 284 indicated that the child had a primary diagnosis of ASD. Those that indicated a primary diagnosis of ADHD were excluded from this report (Fig 1).

Fifty-six developmental-behavioral pediatricians (86% of respondents) returned surveys indicating that they had at least 1 diagnostic encounter with a patient with a primary diagnosis of ASD. Fifty-two physicians completed the Clinician Survey. Demographic data on the participating physicians are shown in Table 2. The clinicians were predominantly female, experienced, and working full time. For 66% of diagnostic encounters, the physicians reported that they saw patients on their own, 15% with fellows, and 6% with residents or nurse practitioners; the variable was unspecified for 13% of encounters.

Demographic Characteristics of the Patients

Demographic characteristics of the patients seen at the 284 encounters with a primary diagnosis of ASD are summarized in Table 3. The sample was predominantly male and European American, although there was some diversity in terms of race (15.5% African American),

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TABLE 1 Participation and Characteristics of Evaluation by Site

<table>
<thead>
<tr>
<th>Site</th>
<th>Developmental-Behavioral Pediatricians, n</th>
<th>Percentage of Evaluations Completed in, %</th>
<th>Percentage of Interdisciplinary Team Evaluations and Disciplines Included, %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Eligible</td>
<td>Participating</td>
<td>Number of ASD Encounters</td>
</tr>
<tr>
<td>1</td>
<td>11</td>
<td>8</td>
<td>35</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
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<tr>
<td>11‡</td>
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<td>4</td>
</tr>
<tr>
<td>12‡</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

‡ Site-specific encounter characteristics not reported due to low number of encounters.

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TABLE 2 Participating Clinician Demographic Data

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD, y</td>
<td>48.1 ± 8.7</td>
</tr>
<tr>
<td>Female gender, %</td>
<td>84</td>
</tr>
<tr>
<td>Full-time, %</td>
<td>64</td>
</tr>
<tr>
<td>Full-time equivalent effort for part-time physicians (n = 19), mean ± SD (range)</td>
<td>71.8 ± 17.6 (30–80)</td>
</tr>
<tr>
<td>Board-certified or eligible in DBP, %</td>
<td>98.1</td>
</tr>
<tr>
<td>Board-certified or eligible in NDD, %</td>
<td>15.4</td>
</tr>
<tr>
<td>Years since completing fellowship (n = 47), mean ± SD (range)</td>
<td>13.9 ± 11.2 (0–50)</td>
</tr>
<tr>
<td>Number of clinical sessions per week seeing patients on own, mean ± SD (range)</td>
<td>3.5 ± 2.4 (0–8)</td>
</tr>
<tr>
<td>Number of clinical sessions per week seeing patients in supervisory capacity, mean ± SD (range)</td>
<td>1.3 ± 1.4 (0–7)</td>
</tr>
</tbody>
</table>

N = 52. Data were missing for 4 of the 56 physicians who returned encounter forms. NDD, neurodevelopmental disabilities.

TABLE 3 Demographic Information on Children Receiving Diagnosis of ASD

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD, y</td>
<td>4.5 ± 3.1</td>
</tr>
<tr>
<td>Male gender, %</td>
<td>84.9</td>
</tr>
<tr>
<td>Race/ethnicity, %</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>70.2</td>
</tr>
<tr>
<td>African American</td>
<td>15.5</td>
</tr>
<tr>
<td>Other races</td>
<td>14.3</td>
</tr>
<tr>
<td>Hispanic (n = 268) reported</td>
<td>19.8</td>
</tr>
<tr>
<td>Source of payment, %</td>
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</tr>
<tr>
<td>Private insurance</td>
<td>50.0</td>
</tr>
<tr>
<td>Medicaid</td>
<td>40.9</td>
</tr>
<tr>
<td>Other or Unknown</td>
<td>9.1</td>
</tr>
</tbody>
</table>

N = 284.

Assessment Characteristics

Most assessments (159 of 284; 56%; 95% CI: 50.0%–61.8%) were completed in 1 visit to the developmental-behavioral pediatrician, 27.5% were completed in 2 visits, and 8.6% were completed in ≥ 3 visits. There was large site variation in the number of visits to complete the evaluation (Table 1). Only 17.3% (95% CI: 12.8%–21.7%) of evaluations were completed by an interdisciplinary team. These interdisciplinary teams most often included psychologists and/or speech and language pathologists, and infrequently included occupational therapists (Table 3). In an additional 25.7% of cases, the physician had evaluations from another discipline available to them before making the ASD diagnosis, but these professionals were not part of an interdisciplinary team (data not shown by site).

We evaluated whether any standardized evaluation that involved direct observation of ASD symptoms was reviewed or completed as part of the assessment. We coded semistructured interactive assessments such as the ADOS24 or the Screening Tool for Autism in Toddlers and Young Children25 separately from unstructured clinician observation such as the Childhood Autism Rating Scale (CARS).26 Semistructured interactive assessments were reviewed or completed for 66.2% (95% CI: 60.1%–71.6%) of diagnostic encounters and the CARS was reviewed for 21.5% (95% CI: 17.3%–27.2%). As shown in Fig 2, the availability of semistructured interactive assessments at the time of diagnosis varied from 12.9% to 100% (P < .001) at the 10 sites reporting at least 13 encounters; CARS use varied from 0% to 83.9% (P < .001). The use of the CARS, ADOS, or Screening Tool for Autism in Toddlers and Young Children varied from 28.6% to 100% of encounters at sites (P < .001; site-specific data not shown). We investigated whether clinician factors predicted use of these assessments. Younger clinicians (those whose age was below the median for clinician age in the study) were more likely to have reviewed or completed the semistructured interactive assessment than older clinicians (77% vs 48%; P < .001). Those who more frequently diagnosed ASD were also more likely to have reviewed or completed a semistructured interactive assessment (70% vs 57%; P = .041), but both of these differences in clinician factors were no longer significant when adjusting for clustering by site. Structured parent interviews using the ADI-R27 or the Diagnostic Interview for Social and Communication Disorders28 were completed in only 3.9% of visits.

Standardized developmental testing was reviewed or completed at 87.7% of encounters (range: 77.8%–100% across sites; P = .061; see Fig 2). A parent behavior rating scale was reviewed or completed at 65.9% of diagnostic encounters (range: 35.7%–91.4% across sites; P = .19; site-specific data not shown), and a teacher behavior rating scale was reviewed or completed at 38.4% of diagnostic encounters (range: 15%–69.2% across sites; P = .19; site-specific data not shown).

We investigated whether the number of visits in which the evaluation was completed affected the types of assessments done as part of the evaluation and/or the amount of physician time involved in the evaluation (Table 4). The semistructured interactive assessments and standardized developmental testing were more likely to be done as part of the assessment when assessments occurred over >1 visit. However, the number of visits did not seem to affect whether physicians considered the ASD diagnosis as definite or provisional, because the diagnosis was considered provisional 20% of the time when the evaluation occurred in 1 visit, 19% when it occurred in
2 visits, and 10% when it occurred in ≥3 visits (P = .36). Physician time face-to-face with the family increased when evaluations were performed in >1 visit, but there was no difference in time spent reviewing or writing reports. Overall, physicians spent >2 hours either face-to-face, writing, and reviewing reports when the evaluation occurred in 1 visit and close to 3 hours if the evaluation occurred in ≥2 visits (Table 4).

### Comorbidities

The majority of children with a primary diagnosis of ASD had ≥1 additional comorbid diagnoses: 71% had at least 1 comorbid diagnosis, 31% had at least 2 comorbid diagnoses, and 12% had at least 3 comorbid diagnoses. The most common comorbidities included speech/language disorders (31.4%; 95% CI: 25.9%–36.9%), intellectual disability/developmental delay (ID/DD; 26%; 95% CI: 21.4%–31.9%), ADHD (12.4%; 95% CI: 8.4%–16.3%), sleep disturbance (13.5%; 95% CI: 9.4%–17.6%), motor/movement disorder (11.7%; 95% CI: 7.8%–15.5%), feeding disorder (5.8%; 95% CI: 3.0%–8.6%), and anxiety disorder (4.7%; 95% CI: 2.2%–7.3%). There was a trend toward developmental-behavioral pediatricians being more likely to diagnose at least 1 comorbidity when evaluations occurred over a greater number of visits (1 visit = 66%, 2 visits = 76%, ≥3 visits = 83%), but this difference did not reach significance (P = .071).

### Laboratory and Medical Tests

Etiologic evaluations reviewed, completed, or recommended included genetic testing (karyotype in 49.6% [95% CI: 43.7%–55.6%] of encounters, microarrays in 70.0% [95% CI: 64.6%–75.5%], and fragile X testing in 72.3% [95% CI: 66.9%–77.6%]). Additional medical tests reviewed, completed, or recommended included EEG in 11.7% (95% CI: 7.8%–15.5%) of encounters, MRI of the head in 7.3% (95% CI: 4.2%–10.4%), and metabolic testing in 2.9% (95% CI: 1.0%–4.9%). Genetic testing was more likely in children with comorbid ID/DD (microarray: 65.7% without ID/DD versus 79.7% with ID/DD; P = .025), but none of the differences in genetic testing by ID/DD comorbidity were significant after adjusting for clustering by clinician. Children <5 years of age were more likely to have both microarrays (75.0% vs 60.2%; P = .013) and fragile X testing (79.4% vs 58.2%; P < .001) after adjusting for clustering by clinician.

### DISCUSSION

The majority of diagnostic evaluations for ASD within DBPNet included a standardized developmental assessment, ASD-specific assessment tools, and parent rating scales, with significant variability in the ASD assessment tools used across sites. These findings document the multiple components of assessment used by DBPNet physicians and the amount of physician time involved in clinical ASD diagnostic evaluations, as well as the variability across academic training sites. Our findings related to

| TABLE 4 Relationship Between Number of Visits, Types of Assessment, and Physician Time |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                                 | Developmental Testing | Semistructured Observation | CARS | Face-to-Face | Reviewing Reports | Writing Report |
| 1 Visit                         | 29               | 43               | 16 | 87 | 19 | 31 |
| 2 Visits                        | 46               | 63               | 20 | 113 | 22 | 40 |
| ≥3 Visits                       | 58               | 80               | 5  | 113 | 21 | 35 |

a Physician time was reported for encounters in which physician was not supervising a resident or fellow.

b P ≤ .001 for difference between number of visits.
ASD-specific assessments have both some similarities and significant differences from the practices recently reported by the European Autism Intervention (EAI) clinical network, which surveyed 66 sites in 31 countries in Europe.

The EAI network found that 82% of sites used the ADOS, but 74% of sites used the Autism Diagnostic Interview, which was rarely used at DBPNet sites. The EAI study did not ask about use at specific encounters, so we do not know how frequently these assessments were used at each site. We did not ask clinicians why they did not use structured diagnostic interviews such as the ADI-R or Diagnostic Interview for Social and Communication Disorders, but note that the 2 to 3 hours needed to administer them is longer than the mean face-to-face time developmental-behavioral pediatricians spent with families, even when evaluations were conducted over 2 or 3 visits. The common components of published guidelines by the AAP, AACAP, and AAN for diagnostic assessment of ASD were summarized earlier. These guidelines include the recommendation that “ideally the definitive diagnosis of ASD should be made by a team of child specialists with expertise in ASD,” with the assumption that the clinician will need the collaboration of other subspecialists, such as psychologists and/or speech-language pathologists with specialized training in ASD, to complete the recommended components of a diagnostic evaluation. The AAP guidelines recognize the reality that “teams are not available in every locale and when they are, long waiting lists may exist.” The guidelines emphasize that a multidisciplinary evaluation should address 3 major diagnostic challenges: functional impairments, making the categorical diagnosis of an ASD, and determining the extent of the search for an associated etiology. Our findings suggest that many developmental-behavioral pediatricians in our network complete the suggested components as a single discipline evaluation and many within a single face-to-face visit.

To meet the diagnostic components above, developmental-behavioral pediatricians invest a significant amount of time collecting historical data by interview, using validated parent/teacher behavioral ratings, and completing standardized developmental tests as well as autism-specific direct-assessment measures as part of the diagnostic assessment, all adding to the complexity and time required to complete the assessment. Both complexity and time are likely to be factors that contribute to the difficulty in accessing diagnostic assessments for many children and families.

In addition, developmental-behavioral pediatricians commonly diagnose a variety of comorbid conditions in children evaluated for ASD, which is likely facilitated by the multiple-component evaluations. These comorbidities are important in that they often influence treatment recommendations as well as family counseling regarding prognosis. We identified ID/DD in 26% of the children diagnosed with ASD, which is below the 54% found in the most recently reported Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring Network study at 8 years of age. However, our sample average age of 4.5 years is younger than the Centers for Disease Control and Prevention sample. Both intellectual disability and speech/language impairments may not have been specifically listed as comorbidities in some children who were being recommended for further evaluations by other specialties, such as psychology and/or speech-language pathologists. Varying rates of additional medical and psychiatric comorbidities have been reported, although most have been with relatively small numbers and/or focused on a single comorbidity. Using electronic medical record abstraction to identify the comorbidity burden of children (<18 years) with ASD, Kohane et al found that 19.4% had a diagnosis of seizure disorder, 12.4% central nervous system abnormality, 11.7% bowel symptoms, 2.4% schizophrenia, 1.1% sleep disorders, and 0.7% autoimmune disorders. Sleep, motor, and feeding disorders were identified in our study more frequently than reported by Kohane et al, although, somewhat surprisingly, neither seizure nor gastrointestinal disorders were among the comorbidities commonly identified by developmental-behavioral pediatricians in this study. Kohane et al reported cumulative comorbidities up to age 18, but their data are difficult to compare with our findings due to the age of our sample and the fact that this study used data from initial diagnostic evaluations in DBPNet only to determine comorbidities.

Developmental-behavioral pediatricians in DBPNet commonly include genetic tests as part of their etiologic evaluation, particularly in younger children, consistent with recommendations by the ACMG and AAP. Other laboratory or medical tests were infrequent, also consistent with the ACMG and AAP recommendations, and some, such as EEGs, are likely related to concerns about comorbidities other than ASD specifically.

The methods we used in this study were modeled after the NAMCS, a survey that influences policy and clinical decisions. Unlike surveys
that ask physicians to summarize their clinical practices or to estimate the proportion of time they use to complete various procedures or recommend various treatments, the method used in NAMCS and this study required physicians to complete a detailed questionnaire on unselected consecutive cases in whom the diagnosis of ASD was made. This method has been found to generate data with high concordance to direct observation of physician behavior. The number of respondents, although modest, represents ~10% of all board-certified developmental-behavioral pediatricians who are active in clinical practice. All of the respondents were affiliated with academic medical centers, in divisions of DBP. Approximately 50% of all developmental-behavioral pediatricians work in similar settings. All of the participating centers train fellows, and approximately half of all fellows in training were at 1 of these sites at the time this study was completed. Given these factors, the approaches of developmental-behavioral pediatricians in this study reflect subspecialty practices in academic health centers and the approach to practice being taught to subspecialty fellows in the field.

Site variability was seen in the use of specific ASD diagnostic tools, frequency of evaluations by interdisciplinary teams, and the number of visits to physicians to complete the assessment, but not in the use of developmental testing and parent or teacher questionnaires. Site variations and deviations from practice guidelines written for other groups are not surprising but raise important questions about the reasons for the differences and the most efficient and effective practices. This study did not find clinician factors that explained the differences and was not designed to look at other factors, such as differences across sites in expectations for clinical productivity and reimbursement, regional differences in assessment requirements for eligibility to intervention programs, and differing patterns across sites that align clinical assessments to support research eligibility as part of clinical practice.

One finding in particular need of further study is the finding that interdisciplinary team evaluations occurred at <20% of encounters, and assessments by other disciplines were available in less than half of the encounters in which a diagnosis of an ASD was made. The reasons that assessments are not interdisciplinary and the impact of this variation cannot be determined from this study. Perhaps interdisciplinary diagnostic assessments are less necessary when physicians can conduct both the medical components of the evaluation and the diagnostic testing, but the impact of this variation in practice has not been studied. Site variability in the use of interdisciplinary teams raises questions about factors that allow some sites to conduct interdisciplinary assessments more than other sites and about factors used to determine when an interdisciplinary assessment is necessary at sites, because no site used interdisciplinary teams in >50% of diagnostic evaluations. Finally, although our findings suggest that many developmental-behavioral pediatricians in our network are able to complete the suggested diagnostic components as a single discipline, we did not address the use of additional assessment components after diagnosis for comprehensive treatment development and monitoring that involve other specialists, such as psychologists and speech-language, occupational, and physical therapists.

The generalizability of this study is limited by the fact that all of the participating developmental-behavioral pediatricians were in 12 academic medical centers in DBPNet. DBPNet represents a diverse set of academic medical centers from 9 states across the United States, which vary greatly in size (3 to >10DBP or Neurodevelopmental Disabilities faculty) and represent 10% of all practicing developmental-behavioral pediatricians. Nonetheless, the practice patterns in these academic settings may differ from practice patterns in other settings, especially in private practice. The patients may also differ from those evaluated in other settings. Therefore, we cannot generalize the findings of this study to other patient populations or other practice settings. All of the data were based on self-report without verification from chart review, parent interviews, or impartial observers, and requirements to complete an encounter form may have altered the practice patterns of the responding physicians.

However, we used methods modeled on NAMCS that have been found to generate data with high concordance to direct observation of physician behavior. We did not collect information on the specific rating scales or standardized developmental tests administered or on whether individuals administering the ADOS were research reliable. In addition, our data do not allow us to determine the methods the developmental-behavioral pediatrician used to identify comorbidities.

Further study is warranted to investigate how the variability described may be related to site-specific factors, such as referral numbers, wait lists, reimbursement constraints, age of patients, and eligibility requirements for intervention programs. In the face of the increasing incidence and prevalence of ASD and the significant variability in assessment practices across sites, it will be important for future research to
identify the assessment practices that are efficient as well as reliable and valid. Describing the diagnostic assessment practices of developmental-behavioral pediatricians may facilitate referrals and collaborative assessment and treatment models of care between developmental-behavioral pediatricians and primary care pediatricians, other subspecialty clinicians, and community resources. This type of research can inform the development of subspecialty guidelines that we hope will facilitate the early diagnosis and treatment of ASD and comorbid conditions, which are important for improving long-term outcomes for children with ASD and their families.

ACKNOWLEDGMENTS

The DBPNet Steering Committee not specifically named as authors includes the following individuals: Marilyn Augustyn, MD, Boston Medical Center; William Barbaresi, MD, Children’s Hospital Boston; Jill Fussell, MD, University of Arkansas for Medical Sciences; Robin Hansen, MD, University of California–Davis MIND Institute; Pamela High, MD, Hasbro Children’s Hospital; Nancy Roizen, MD, Rainbow Babies and Children’s Hospital; Terry Stancin, PhD, MetroHealth Medical Center; Ruth E.K. Stein, MD, Children’s Hospital at Montefiore; Carol Weitzman, MD, Yale–New Haven Children’s Hospital; Susan Wiley, MD, Cincinnati Children’s Hospital Medical Center; and Mark Wolraich, MD, University of Oklahoma Health Sciences Center. The DBPNet Steering Committee would like to thank the following individuals who also contributed to the development of the study: Daniel Coury, MD, Christopher Forrest, MD, PhD, Connie Kasari, PhD, and Amy Kratchman, BS. In addition, we thank David Schonfeld, MD, who helped initiate this study at Cincinnati Children's Hospital Medical Center, and all of the physicians at DBPNet sites who voluntarily completed the encounter forms for this study.

Study data were collected and managed with the use of Research Electronic Data Capture (REDCap) electronic data-capture tools hosted at Children’s Hospital of Philadelphia. REDCap is a secure, Web-based application designed to support data capture for research studies, providing (1) an intuitive interface for validated data entry, (2) audit trails for tracking data manipulation and export procedures, (3) automated export procedures for seamless data downloads to common statistical packages, and (4) procedures for importing data from external sources.

Dr Hansen was primarily responsible for the conception and design of this study and was involved in acquisition, analysis, and interpretation of data and drafting and revising of the article. Dr Blum made a substantial contribution to the conception and design; acquisition, analysis, and interpretation of data; and drafting and revising of the article. Ms Gahman made a substantial contribution to the acquisition and analysis of data and drafting of the article; Dr Shults made a substantial contribution to the acquisition, analysis, and interpretation of the data and drafting and revising the article; and all authors approved the final version as submitted and agree to be accountable for all aspects of the work and to ensure that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

DOI: 10.1542/peds.2015-2851F

Accepted for publication Nov 9, 2015

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FINANCIAL DISCLOSURE: Dr Blum has received grant funding for research from the Pfizer Foundation; and Dr Hansen, Ms Gahman, and Dr Shults have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: The Developmental-Behavioral Pediatrics Network (DBPNet) is supported by cooperative agreement U5MC20218 from the Maternal and Child Health Bureau (Combating Autism Act of 2006), Health Resources and Services Administration, Department of Health and Human Services (Project Director: Dr Blum).
REFERENCES


25. Stone WL, Conrod EE, Turner LM, Pozdol SL. Psychometric properties of


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