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Diagnostic Experiences of Children With Attention-Deficit/Hyperactivity Disorder

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Abstract

Objectives—This report describes the diagnostic experiences of a sample of children in the United States diagnosed with attention-deficit/hyperactivity disorder (ADHD) as of 2011–2012.

Data sources—Data were drawn from the 2014 National Survey of the Diagnosis and Treatment of Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome, a follow-up to the 2011–2012 National Survey of Children’s Health.

Results—The median age at which children with ADHD were first diagnosed with the disorder was 7 years; one-third were diagnosed before age 6. Children with ADHD were diagnosed by a wide variety of health care providers, including primary care physicians and specialists. Regardless of age at diagnosis, the majority of children (53.1%) were first diagnosed by primary care physicians. Notable differences were found by age at diagnosis for two types of specialists. Children diagnosed before age 6 were more likely to have been diagnosed by a psychiatrist, and those diagnosed at ages 6 and over were more likely to have been diagnosed by a psychologist. Among children diagnosed with ADHD, the initial concern about a child’s behavior was most commonly expressed by a family member (64.7%), but someone from school or daycare first expressed concern for about one-third of children later diagnosed with ADHD (30.1%). For approximately one out of five children (18.1%), only family members provided information to the child’s doctor during the ADHD assessment.

Keywords: ADHD • NS–DATA • national survey

Introduction

Parental reports indicate that more than 1 in 10 school-aged children (11%; 6.4 million children) in the United States have received a diagnosis of attention-deficit/hyperactivity disorder (ADHD) from a health care provider (1). The percentage of children diagnosed with ADHD increased steadily from 1997 to 2006 (2), and increased 42% from 2003–2004 to 2011–2012 (1). Reports

of these increases in the diagnosed prevalence of ADHD have resulted in discussions about the validity of ADHD diagnoses in the United States more generally (3). Describing the diagnostic experiences of a representative sample of U.S. children with ADHD is an important step toward understanding how children are diagnosed with ADHD in the United States and helps to inform efforts that seek to ensure that best practices are used

in the evaluation and diagnosis of the disorder.

Recommendations for the evaluation and diagnosis of ADHD are similar across the American Academy of Pediatrics’ (AAP) immediate past and current clinical guidelines for ADHD (4,5). These best practices guidelines recommend performing a diagnostic evaluation for ADHD using criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (6,7) and assessing the extent of the child’s impairment and the pervasiveness of the impairment across multiple settings, while collecting information from multiple informants (e.g., parents, teachers, and other adults involved in the child’s care). The most recent guidelines also include the recommendation to involve the child as an informant in the evaluation process, as appropriate (5).

This report presents a national description of the ADHD diagnostic experience as reported by U.S. parents, with a focus on assessing the alignment between parent-reported characteristics of the diagnostic experience and AAP’s recommendations for the evaluation and diagnosis of ADHD. Comparisons are made between the experiences of children diagnosed before and after the age most children enter school, given the special considerations for diagnosing a child under age 6 (5).



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Methods

The data source for this report is the 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NS–DATA), a follow-up to the 2011–2012 National Survey of Children’s Health (NSCH). NSCH was a nationally representative, random-digit-dial telephone (both landline and cell phone) survey of households with children aged 0–17 in the United States, which examined the physical and emotional health of children. NS–DATA was a follow-up telephone survey conducted 2–3 years later and designed to collect information on the early experiences associated with the emergence and ultimate diagnosis and treatment of ADHD and Tourette syndrome (TS). NSCH and NS–DATA were conducted by the Centers for Disease Control and Prevention’s (CDC) National Center for Health Statistics (NCHS) as modules of the State and Local Area Integrated Telephone Survey (SLAITS). NS–DATA was sponsored by CDC’s National Center on Birth Defects and Developmental Disabilities and by NCHS.

Households eligible to be recontacted for NS–DATA had children aged 2–15 at the time of NSCH whose parents or guardians (hereafter referred to as parents) completed NSCH and reported that they had once been told by a doctor or other health care provider that their child had ADHD or TS. Respondents for NS–DATA had to be currently living in the same household as the sampled child and be knowledgeable about the child’s health, but they did not need to be the NSCH respondent. NS–DATA consists of two interview modules: one administered to parents of children ever having ADHD, and the other administered to parents of children ever having TS. Parents whose children had both conditions were administered both interview modules. A total of 2,976 ADHD and 115 TS interviews were completed from January to June 2014. The present report explores data from the ADHD module.

The ADHD module included questions about the diagnostic experience of when the sample child was first diagnosed with the disorder, presence of co-occurring disorders, medication

and behavioral treatment for ADHD, medication management and adherence, and presence of ADHD symptoms and impairment. Specific questions examined in the present report include age at diagnosis, type of diagnosing provider, first individual concerned about the sample child’s behavior, and individuals involved in the child’s diagnostic experience.

The sampled child’s ADHD diagnosis was confirmed during the NS–DATA screener (initial screening portion of the interview), when parents were asked, “Has a doctor or other health care provider ever told you that your child had ADHD or ADD?” If a parent could not confirm the ADHD diagnosis, the child was not eligible for NS–DATA. This screener question mirrored the phrasing of the 2011–2012 NSCH question when parents were asked, “Please tell me if a doctor or other health care provider ever told you that your child had Attention Deficit Disorder or Attention-Deficit/Hyperactivity Disorder, that is ADD or ADHD, even if he or she does not have the condition now.”

Estimates in this statistical analysis are weighted by the NS–DATA sampling weight, which is based on the NSCH sampling weight with adjustments for known survey response biases and further adjustments to ensure that weighted estimates match demographic control totals of the noninstitutionalized population of children ever diagnosed with ADHD between ages 2 and 15 from the 2011–2012 NSCH. As such, all weighted estimates shown in this report are intended to produce national estimates of the noninstitutionalized population of U.S. children with ADHD as of the 2011–2012 NSCH. Sampling weights were adjusted to account for differential probabilities of selection, nonresponse, and noncoverage. All differences between children diagnosed with ADHD before age 6 and those diagnosed at ages 6 and over were tested using bivariate logistic regression. All differences with a *p* value less than 0.05 were considered statistically significant. Statistical analyses were conducted using Stata 13.1 (8).

The NS–DATA response rate was 47.2%. Accounting for the 23.0% overall NSCH response rate, the overall

NS–DATA response rate was 10.9%.

When only noncooperation among successfully recontacted eligible households was examined, more than four out of five eligible households (80.8%) completed the survey.

Estimates based on telephone surveys with low response rates may be unreliable due to selection biases resulting from sampling, nonresponse, lack of coverage of households without telephones, and respondent classification and reporting errors. However, sample weights were calculated in accordance with best practices for sample surveys, which included adjustments for known demographic correlates of nonresponse that have been shown to minimize the potential for nonresponse bias. Furthermore, the demographic composition of the population of children ever diagnosed with ADHD based on NS–DATA was compared with that of children ever diagnosed with the disorder based on the 2011–2012 NSCH and the 2011 and 2012 National Health Interview Survey, with no differences found (estimates not shown).

In addition, a nonresponse bias analysis was performed, which suggested that, although the potential for bias cannot be ruled out, nonresponse bias in weighted estimates is likely smaller than sampling error (for details, see Technical Notes at the end of this report).

For more information on NSCH and NS–DATA, including sample design, data collection procedures, and questionnaire content, please visit: <http://www.cdc.gov/nchs/slaits.htm>.

Results

Parents were asked how old their child was “when you were first told by a doctor or other health care provider that he/she had ADHD?” The median age at ADHD diagnosis was 7 years, and about one in three children (30.7%) was diagnosed before age 6 (Figure 1). Approximately three out of four children (76.1%) were diagnosed with ADHD before age 9.

Parents were instructed to “think about a time before their child’s ADHD diagnosis” in order to provide information on the “first person who was concerned with their child’s behavior,

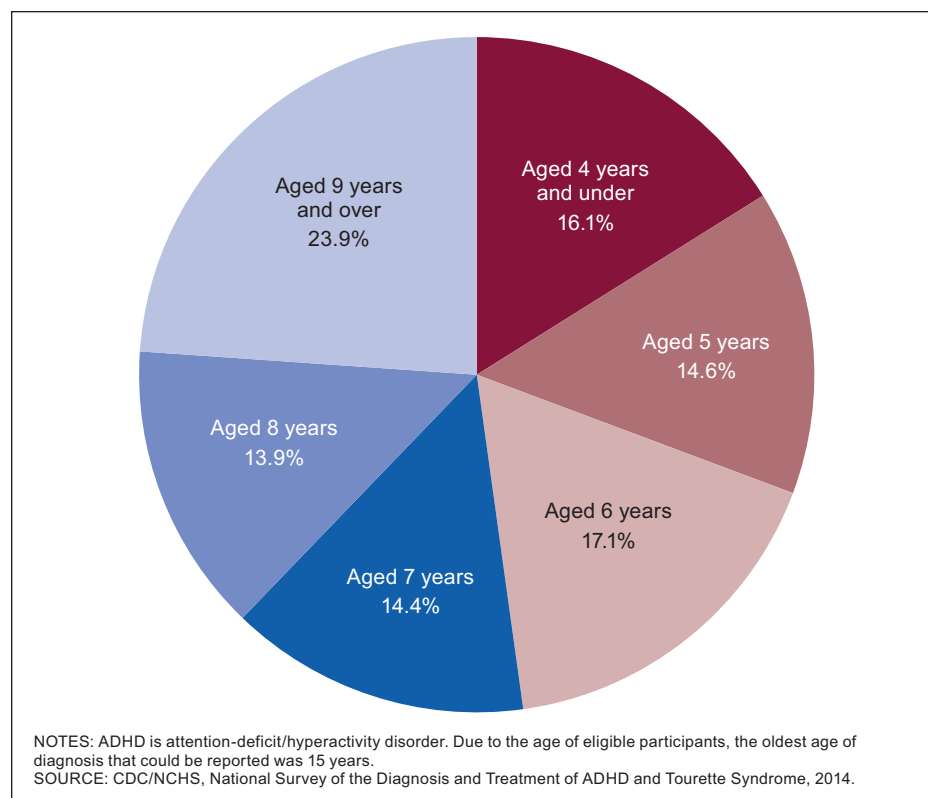


Figure 1. Child's age when parent was first told that child had ADHD, among children who were aged 2–15 years in 2011–2012 and had a diagnosis of ADHD: United States, 2014

attention or performance.” For about two out of three children diagnosed with ADHD overall (64.7%), and for three out of four diagnosed before age 6 (74.5%), the first individual concerned about the child's behavior, attention, or performance was a family member, which could include a parent (Figure 2). Relative to children diagnosed at younger ages, those diagnosed at older ages were more likely to have had concern first expressed by someone at school or daycare (35.3%; $p < 0.001$), but less likely to have had concern expressed first by a family member (60.5%; $p < 0.001$) or other individual (4.2%; $p < 0.05$).

The type of health care provider who first told parents that their child had ADHD was also examined (Figure 3). Approximately one-half of children with ADHD were first diagnosed by a primary care provider, including a pediatrician (39.0%) or general health physician (14.1%). Approximately one in four children diagnosed with ADHD before age 6 (23.7%) was first diagnosed by a psychiatrist; when diagnosed at an older age, children were less likely to be diagnosed by a psychiatrist

(15.6%; $p < 0.01$). Approximately one in six children diagnosed at ages 6 and over (15.7%) was first diagnosed by a psychologist; when diagnosed at a younger age, children were less likely to be diagnosed by a psychologist (10.8%; $p < 0.05$). Children were equally likely to be diagnosed by a pediatrician, general health physician, or neurologist, regardless of age at ADHD diagnosis.

Parents were asked a series of questions about the methods used by the diagnosing provider to assess their child for ADHD. They were also asked to recall whether a series of tools or methods were used by the diagnosing provider to “ask about symptoms of ADHD and their impact on the child” (Figure 4).

Behavior rating scales or checklists were used for about 9 out of 10 children assessed for ADHD (89.9%), and this did not differ by age at diagnosis. For nearly all children, the diagnostic process included a conversation with a parent about their child's behavior (96.3%). These conversations were used less frequently among children diagnosed at ages 6 and over ($p < 0.01$), although the difference was small.

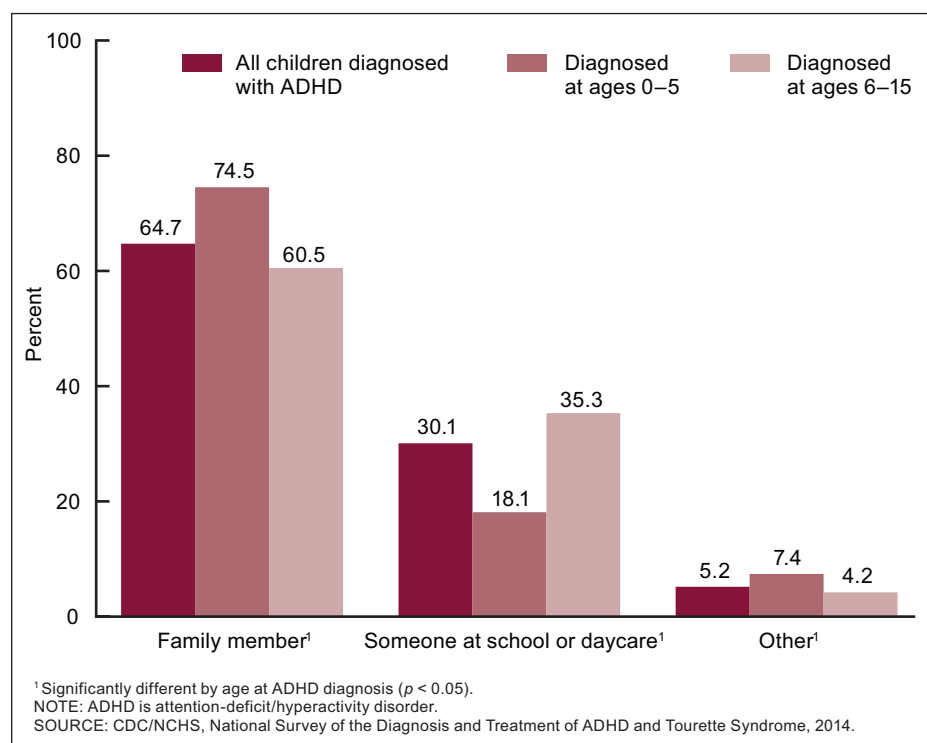
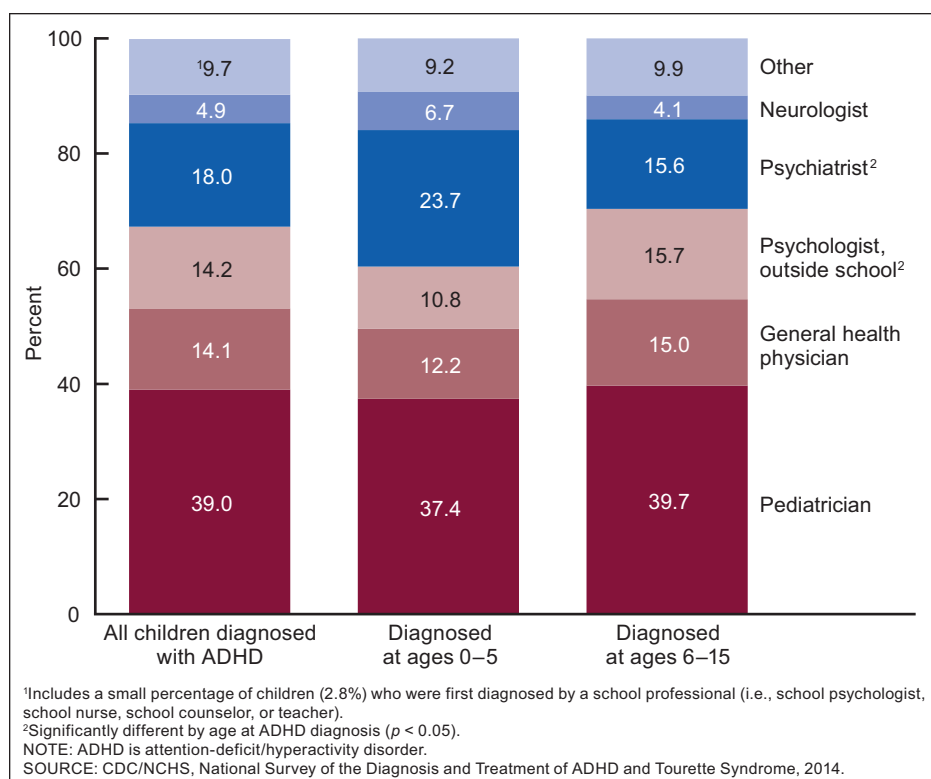


Figure 2. Individual first concerned about child's behavior, attention, or performance, among children who were aged 2–15 years in 2011–2012 and had a diagnosis of ADHD, by child's age at diagnosis: United States, 2014



The majority of children diagnosed with ADHD (68.0%) had undergone neuropsychological testing. More than three-quarters of children diagnosed before age 6 (76.4%), and nearly two-thirds diagnosed at ages 6 and over (64.3%), had received these psychological tests. Neuropsychological testing and medical tests were used significantly less frequently among children diagnosed at ages 6 and over, compared with those diagnosed at younger ages. Approximately one in three children (30.0%) received neurological imaging or laboratory tests as part of the diagnostic assessment, and this was more common among children diagnosed before age 6 (41.8%, compared with 25.0% for those aged 6 and over; $p < 0.001$).

Parents were also asked a series of questions about which individuals the diagnosing provider collected information from in order to assess the child for ADHD (Figure 5). This could include individuals from the family, as well as those who were part of the child's community. Children were

Figure 3. Type of health care provider who first told parent that child had ADHD, among children who were aged 2–15 years in 2011–2012 and had a diagnosis of ADHD, by child's age at diagnosis: United States, 2014

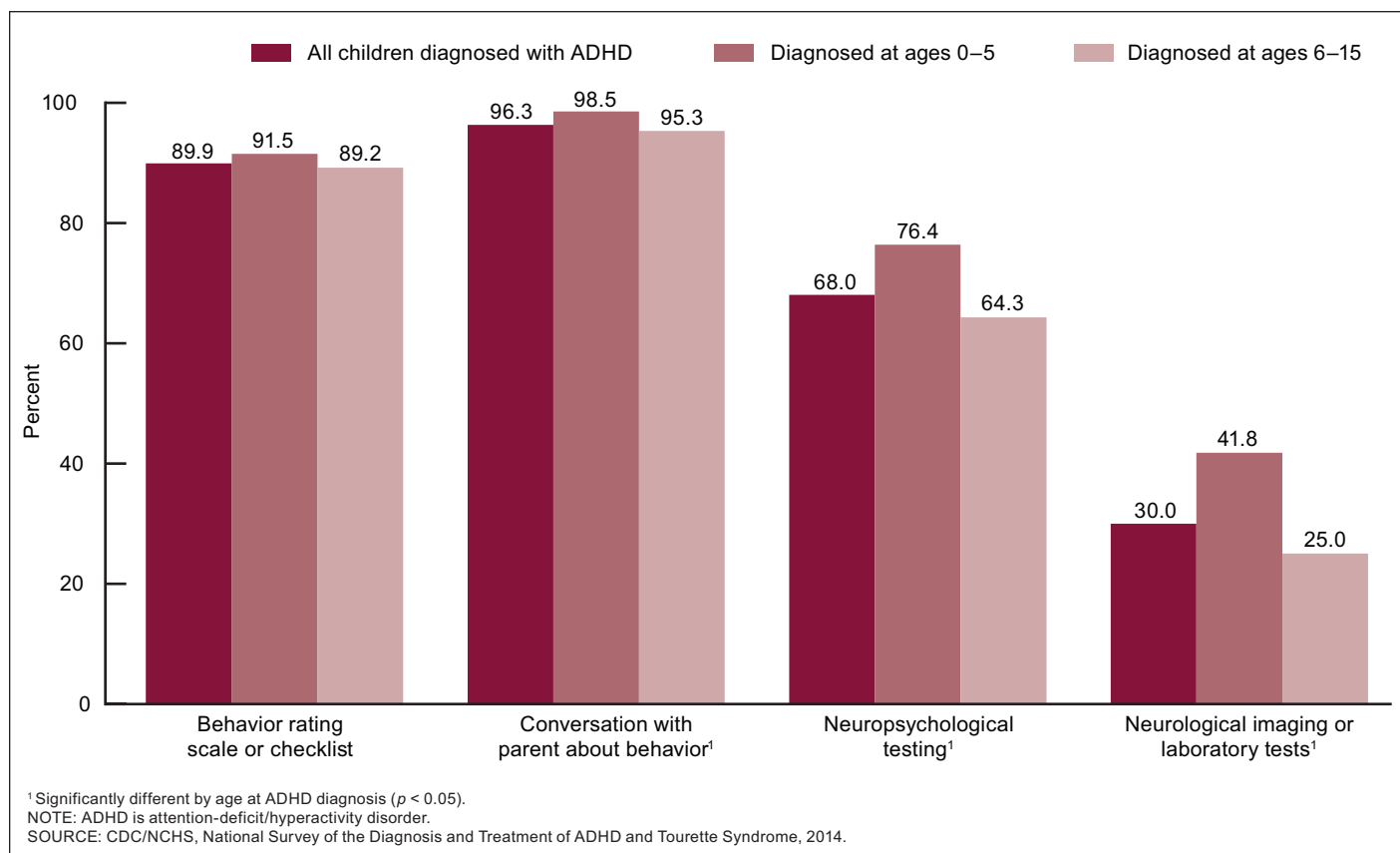


Figure 4. Methods used to assess for ADHD, among children who were aged 2–15 years in 2011–2012 and had a diagnosis of ADHD, by child's age at diagnosis: United States, 2014

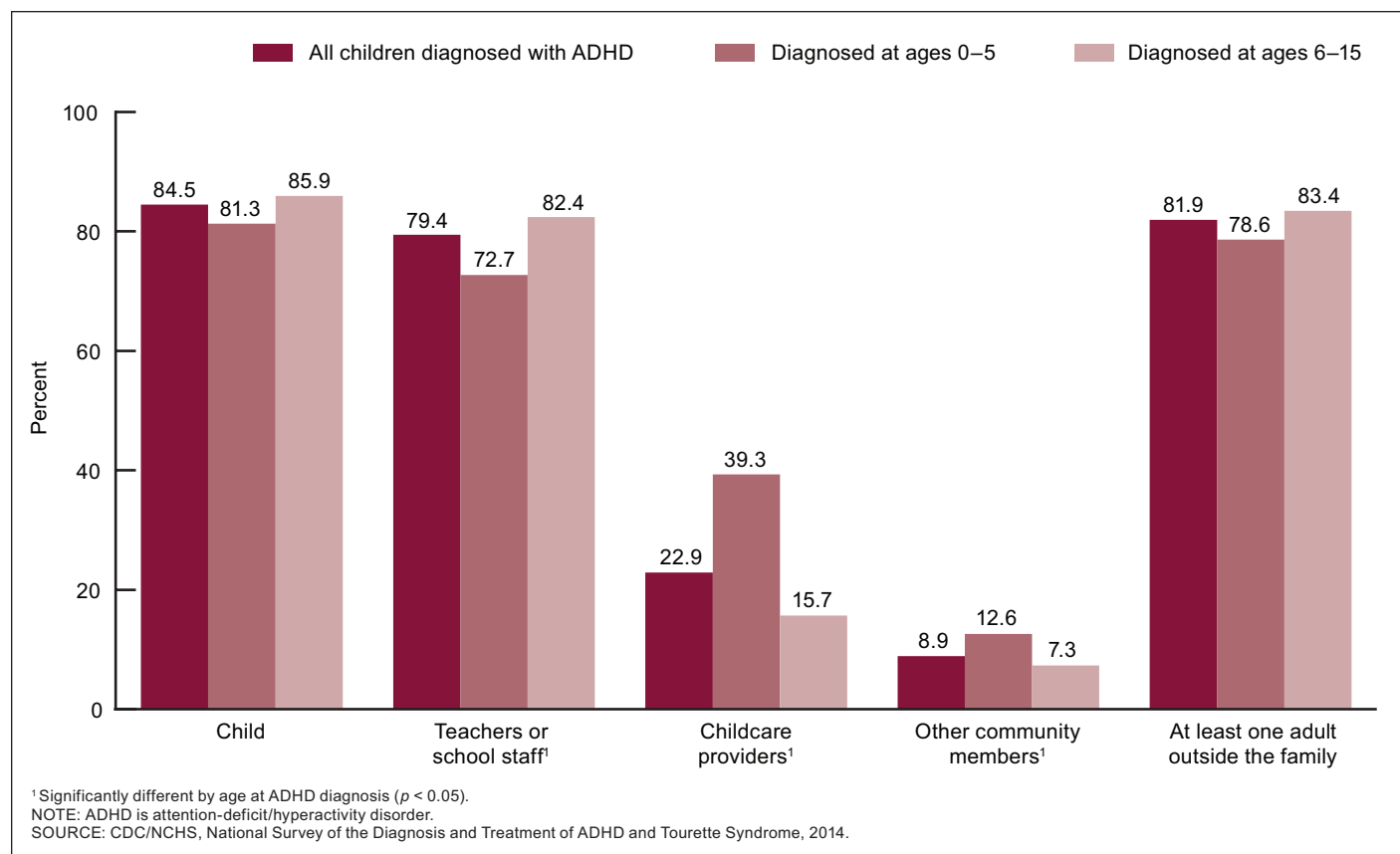


Figure 5. Individuals from whom information was collected to assess child for ADHD, among children who were aged 2–15 years in 2011–2012 and had a diagnosis of ADHD, by child's age at diagnosis: United States, 2014

typically included in this diagnostic process, including both children diagnosed before age 6 (81.3%) and those diagnosed at ages 6 and over (85.9%). Children first diagnosed before age 6 were more likely than those diagnosed at ages 6 and over to have childcare providers (39.3%; $p < 0.001$) or other community members (12.6%; $p < 0.05$) involved in the diagnostic process, whereas children first diagnosed at ages 6 and over were more likely to have teachers or school staff involved in the diagnostic process (82.4%; $p < 0.01$). For approximately four out of five children overall diagnosed with ADHD, and for children diagnosed before age 6 (78.6%) and at ages 6 and over (83.4%), adults outside the family provided input to the diagnostic process; this difference by age at diagnosis was not statistically significant. Children were equally likely to be involved in the diagnostic process, regardless of age at ADHD diagnosis.

Summary and Discussion

This report has presented a set of indicators related to the diagnosis of ADHD in a representative sample of U.S. children diagnosed with the disorder as of 2011–2012. According to data from NS-DATA, the median age at ADHD diagnosis was 7 years. About one in three children was diagnosed before age 6—an age at which there are few valid diagnostic tools to support diagnosis (5,9).

Parents indicated that the first individual concerned about the child's behavior, attention, or performance was most often a family member, with someone at school or daycare being the first person concerned for approximately one-third of children with ADHD in this study.

A variety of health care providers were involved in the ADHD diagnostic process, including pediatricians and general health physicians, psychiatrists, neurologists, and psychologists. About one-half of children with ADHD were

first diagnosed by either a pediatrician or a general health physician, with the single largest group being those diagnosed by a pediatrician.

The age at diagnosis was related to the type of diagnosing provider. Children diagnosed at ages 6 and over were less likely than those diagnosed before age 6 to be diagnosed by a psychiatrist; these children were more likely to be diagnosed by a psychologist than younger children with ADHD.

Consistent with best practices (5), behavior rating scales were used for the vast majority of children (about 9 out of 10) assessed for ADHD. Additionally, more than three-quarters diagnosed before age 6 and nearly two-thirds diagnosed at ages 6 and over had undergone neuropsychological testing. For the majority of children (81.9%), at least one adult outside the family was involved in the diagnostic process. This suggests that one out of five children had a diagnosing provider who relied only on information collected from family members, which is inconsistent with the AAP guideline to collect information

from individuals across multiple settings, including outside the home.

This report characterizes select components of the ADHD diagnostic process among a national sample of children diagnosed with the disorder, including methods of assessment and assessment across multiple informants. These findings may be used to inform assessments of the alignment between clinical practice and the 2011 AAP clinical practice guidelines for ADHD (5). Study findings do suggest that among children diagnosed with ADHD as of 2011–2012, diagnosing providers regularly used behavior rating scales and checklists.

Strengths and limitations

This study used data from the largest national survey to date dedicated to the diagnostic and treatment experiences of children diagnosed with ADHD. Because of its size and breadth, the survey data allowed for the presentation of a set of diagnostic indicators as a function of age at diagnosis.

Despite these strengths, the data and results presented in this report are subject to several limitations. One set of limitations is related to the time that elapsed between the identification of sample children who have ever received an ADHD diagnosis in the 2011–2012 NSCH and the time of the follow-up interview in 2014 (median was 29 months). As a result, only children who had received an ADHD diagnosis as of 2011–2012 were included in the eligible population; children who had received a diagnosis more recently are not represented in this followback survey population. Additionally, parents were reporting on a diagnostic experience that took place a minimum of 2 years earlier and thus may be subject to some degree of recall bias.

Other limitations are that the parent-reported information has not been validated against medical records or clinical notes, and the results are limited to the noninstitutionalized population of children with ADHD, excluding any children living in psychiatric hospitals, juvenile justice centers, and other institutions. A final limitation is the survey's low response rate; for more

information, please refer to the Technical Notes.

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Technical Notes

Response rate and analysis of nonresponse

The overall response rate for the 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NS–DATA) is the product of the response rate for NS–DATA and the response rate for the 2011–2012 National Survey of Children’s Health (NSCH). Individually, the response rate for NS–DATA was 47.2%, while the response rate for NSCH was 23.0%, for a combined response rate for the two surveys of 10.9%. The low response rate is partly due to the inclusion of cell phone samples in both surveys, to provide better coverage of the population of children. When only noncooperation among successfully recontacted eligible households was examined, more than four out of five eligible households (80.8%) completed the survey.

To reduce the potential for nonresponse bias, the sampling weights were adjusted for nonresponse and further adjusted to match external demographic control totals for the population of children with ADHD who were aged 2–15 in the 2011–2012 NSCH. Because data from NSCH were available for both NS–DATA respondents and nonrespondents, it was possible to adjust the weights precisely by those characteristics that differentiated NS–DATA respondents and nonrespondents. Nonresponse bias analysis was conducted to examine estimates before and after the nonresponse weighting adjustment. Results indicated that bias was found to greatly decrease after the weighting adjustment, and estimated biases using the final weights tended to be smaller than sampling error.

These results indicate that differences between survey respondents and survey nonrespondents should not have had a major impact on the conclusions in this report; however, the potential for such impact cannot be ruled out completely.

Definitions of terms

Attention-deficit/hyperactivity disorder (ADHD) diagnosis—Children included in the current report as ever having ADHD had parents or guardians who answered in the affirmative to two survey questions. The first, which appeared in the 2011–2012 NSCH, asked respondents to “Please tell me if a doctor or other health care provider ever told you that your child had Attention Deficit Disorder or Attention-Deficit/Hyperactivity Disorder, that is ADD or ADHD, even if he or she does not have the condition now.” The second question was part of the 2014 NS–DATA screener and asked the respondent (who did not need to be the NSCH respondent), “Has a doctor or other health care provider ever told you that your child had ADHD or ADD?” Children whose parents or guardians refused to answer either question, or who said they did not know the answer to either question, were not identified as ever having had ADHD.

Diagnosing health care professional—Respondents were asked, “What type of doctor or other health care provider first told you that [your child] had ADHD?” Responses were coded into 18 provider categories. For this report, providers were categorized in the following groups: (a) pediatricians, which include developmental or behavioral pediatricians; (b) general health physicians, which include family practice doctors; (c) psychologists outside of school; (d) psychiatrists (medical doctors); (e) neurologists; and (f) other providers, which include nurse practitioners, occupational therapists, physical therapists, speech therapists, team of professionals or multidisciplinary team, doctors of unknown specialty, school psychologists, school counselors, school nurses and teachers, and other health care professionals.

Concerned individuals—Respondents were instructed to “Think about the time before [your child]’s ADHD diagnosis” and then were asked, “Who was the first person who was concerned with [your child]’s behavior, attention, or performance?” Concerned individuals were categorized as follows: (a) “you or another family member,” (b) “someone at your child’s school or

daycare,” (c) “a doctor or healthcare professional not at your child’s school,” and (d) “someone else.” In this report, responses c and d were grouped into one category.

Diagnostic testing methods—NS–DATA contained a series of questions asking respondents whether specific methods had been used to assess for ADHD. These included (a) “a rating scale or checklist about the child’s behavior”; (b) “a conversation with you about the child’s behavior”; (c) “a series of tests to better understand how the child learns, reads, understands and processes information, also known as psychological tests”; and (d) “medical tests, such as an EEG, CT scan, MRI, or blood tests to test for lead exposure.” If necessary, respondents were provided a definition for medical tests. Medical tests are typically used to rule out other conditions.

Individuals involved in assessment—NS–DATA also contained a series of questions asking respondents whether “the doctor, health care provider, or school professional who diagnosed [your child] with ADHD collect[ed] information” from a series of individuals. Individuals were categorized as follows: (a) “[the child] himself/herself”; (b) “school teachers or other school staff”; (c) “childcare providers, such as a daycare teacher, nanny, or babysitter”; and (d) “other community members, such as a coach, music or dance teacher, religious leader, scout leader, or other group leader.” In this report, an additional group was formed based on responses b–d and was labeled “at least one adult outside the family.”

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