ADHD Service Use Patterns in Youth

Laurel K. Leslie,1 MD and Mark L. Wolraich,2 MD
1Child & Adolescent Services Research Center (CASRC), Pediatrics Department at the University of California, San Diego, and Graduate School of Public Health at San Diego State University, San Diego, Calif USA and 2Department of Pediatrics, Oklahoma University Child Study Center, University of Oklahoma Health Sciences Center USA.

Objective To review what is currently known about service use by youth with attention-deficit/hyperactivity disorder (ADHD) and discuss research and policy implications. Methods Literature review. Results The primary care, mental health, and educational service system sectors all play an essential role in caring for youth with ADHD. Recent studies also suggest increasing use of stimulants and other psychoactive medication for youth with ADHD, decreasing mental health visits for ADHD unassociated with medication use, increased use of other psychotropic medications, and a number of barriers to care coordination across primary care, mental health, and schools. Conclusions Four important services, research, and policy areas that need to be addressed over the next decade include: 1) delving deeper into current service use, 2) paying attention to the context in which service use occurs, 3) operationalizing evidence-based care for real-world settings, and 4) learning what changes clinician and educator behavior.

Key words ADHD; attention-deficit/hyperactivity disorder; education; primary care; service utilization; specialty mental health; stimulants.

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurobiological disorders of childhood and adolescence with a prevalence rate of ADHD among US youth ranging from 3% to 16%, depending on the sampling design and restrictiveness of the definition of ADHD used.1 Its core symptoms include hyperactivity, impulsivity, and/or inattention. Coexisting mental health disorders and learning disorders are common,1,2 and the presence of comorbid mental health disorders predicts persistence of ADHD into adulthood as well as poorer outcomes.3–6 The impact of ADHD can include academic failure, strained peer and family relations, poor self-image, delinquency, and low occupational performance.7,8 Similarly, ADHD can affect the diagnosed child’s family, with associated direct and indirect costs.9–11 Fortunately, 2 evidence-based treatments for ADHD, psychotropic medications (predominantly the stimulant medications) and psychosocial interventions implemented in the home and school settings, have been extensively studied, and both treatment strategies, either alone or in combination, are effective in reducing ADHD symptoms.12–14 In addition, diagnostic and treatment guidelines have been published by the American Academy of Child and Adolescent Psychiatry (AACAP) and the American Academy of Pediatrics (AAP).15–18 The high prevalence rate of ADHD and its chronic nature suggest that youth with this disorder may have high rates of health-related service use and health care costs. In fact, compared with youth without ADHD, youth with ADHD are more likely to use psychotropic medications and to access primary care, emergency, mental health, social, and special education services.19–24 Youth with ADHD also incur health-related costs at least 2 times those of youth without ADHD.25–27 Identifying factors related to service use is critical for a number of reasons. First, understanding service use allows for resource planning and allocation, important during times of economic constraints on health care. Second, services research allows for the identification of areas of unmet need and factors that may cause
discrepancies in service use. Last, understanding current
service use patterns allows for better tailoring of guide-
lines published by professional organizations and for
targeted advocacy regarding the unique health care needs
of youth with this disorder.

This article provides a review of service use for youth
with ADHD (Appendix). We first detail the role of the
primary care, mental health, and educational sectors in
the care for youth with ADHD. We next review the types
of services youth with ADHD may receive including
diagnostic evaluations, psychotropic medications (pre-
scribed by either a primary care clinician or mental health
professional), specialty mental health visits, and school
services. When possible, we discuss trends in use over
time as well as child, family, and community factors that
have been found to be associated with service use. We
close with a discussion of the implications of these
findings for future research and policy decision-making
regarding service use among youth with ADHD.

Sectors Serving Youth with ADHD

Three major sectors provide health-related services to
youth with ADHD: the general medical sector, the
specialty mental health sector, and the educational
sector. Primary care clinicians conduct the majority of
visits for ADHD and prescribe the most stimulant
medications.28–32 The preponderance of care for youth
with ADHD in primary care is hypothesized to relate to a
number of factors including the high prevalence rate
which exceeds the capacity of mental health services, an
increasing focus on the neurobiological underpinnings
of ADHD, the role of the primary care clinician as
gatekeeper, the development of ongoing relationships
between families and primary care clinicians, limitations
in access to mental health services under managed
behavioral health care, and negative societal attitudes
toward mental illness.33

Specialty mental health services also play an
important role in the care of the child with ADHD, providing access to medication as well as behavioral
management strategies. These strategies have shown
significant empirical support in the literature,34 appear
to affect domains of impairment beyond core ADHD
symptoms,13 and appear to have positive effects particularly when comorbidities are present.35–37 In addition,
some have postulated that there exists an important
differential between youth with ADHD served in primary
care as opposed to specialty mental health sectors, with
psychiatrists and other mental health professionals
treating youth who are more severely impaired than
those cared for in primary care settings.38–42 However,
one recent case-control study10 comparing correlates of
ADHD among youth seen in pediatric and psychiatric
clinics in the New England area suggested similar levels
of comorbidity and dysfunction between the 2 groups.
Although studies of the differences in the rate of
comorbidities between primary care and mental
health patients have resulted in conflicting findings, it is
clear that there is a high rate of comorbidity in both
sectors.

School-based services are also critical to examine for
a number of reasons. First, the behaviors observed in
ADHD are contextually driven and may manifest
themselves more in concentration-demanding situations
like school, making communication with school person-
nel essential for the diagnosis of ADHD.15,17 Second,
findings from the Multimodal Treatment Study of
Children With ADHD (MTA study) suggest that tightly
titrated medication use, requiring close communication
between the prescribing clinician and the child’s teacher,
yields improved outcomes over standard community
care.12 Teachers’ input is thus essential for determining
an effective dosing regimen and monitoring side effects.
Third, there is a solid evidence-base for the effectiveness
of highly structured behavioral management strategies
implemented by school staff in addressing many of the
common areas of dysfunction present in children with
ADHD,37 particularly for more intensive programs in
special class settings. In addition, through both the
Individuals with Disabilities Education Act43 and Section
504 of the Rehabilitation Act,43 school systems are
mandated to provide accommodations in the mainstream
classroom and special education classes. In 1991, the US
Department of Education also stated that individuals
with ADHD could be considered disabled under the
“Other Health Impaired” categorization,44 potentially
increasing access to school-based services for youth
with ADHD.

Unfortunately, communication across sectors occurs
infrequently39,42,43,46 due to differences in cultures,
languages, and schedules across sectors; little to no
reimbursement for the time required for effective com-
munication; confidentiality requirements in both the
health (Health Insurance Portability and Accountability
Act) and school (Family Educational Rights and Privacy
Act) systems; and limited community and school
resources. Attempts at enhancing communication have
had limited effects.46 The recent growth in school-based
health clinics47 may provide an opportunity for collab-
orative care for youth with ADHD.
Service Use Among Youth with ADHD

Service use for ADHD includes a variety of service types. These include diagnostic/evaluative services as well as treatment services including medication, office visits, and school-based services. Recent data on these types of services are reviewed below and summarized in the Appendix.

Diagnostic/Evaluative Services

Because of the inherent difficulties in distinguishing between evaluation and treatment services using parental report or administrative records, few studies report on diagnostic services. Hoagwood and colleagues’ analysis of the National Ambulatory Medical Survey (NAMCS) found that diagnostic services increased overall from 22.3% in 1989 to 62.1% in 1996, with the largest increase from 1989 to 1991. Large differences between provider types were found with diagnostic/evaluative services noted on 80.6% of visits to psychiatrists, 64% to pediatricians, and 32.6% to family practitioners. Whether this variation reflects actual differences in the delivery of diagnostic services or only a difference in conceptualization and coding of visits is unclear.

Several studies have been undertaken to describe practice patterns with respect to the content of diagnostic services in primary care settings and have found limited use of diagnostic instruments. Research has also suggested it is difficult for primary care providers to collect information from a second source, such as the school setting. Two studies have also looked at child and family-level factors that may influence receipt of diagnostic/evaluative services. Stevens and colleagues, using 1995–2000 data from the NAMCS and National Hospital Ambulatory Medical Care Survey, found that latency age was more likely to be associated with receipt of a diagnosis than preschool or adolescent age. Medicaid insurance coverage was also positively associated with receipt of a diagnosis, compared with both private and no insurance. Complex interactions were noted between geographic regions, race/ethnicity, and whether or not an ADHD diagnosis was likely to be recorded at a visit. A recent Centers for Disease Control analysis of 2003–2004 data from the National Survey of Children’s Health found that male gender, higher family education level, geographic location, insurance coverage, and non-Hispanic, English-speaking racial/linguistic backgrounds were more often associated with receipt of a diagnosis.

Psychotropic Medication Use

Psychotropic medications, particularly the stimulant medications, play a critical role in the management of the child with ADHD. In fact, stimulants represent the treatment of choice for ADHD by most physicians. The efficacy of the stimulant medications in decreasing ADHD core symptoms has been adequately demonstrated in a number of studies. Although public controversy regarding the use of medications for ADHD continues in the public press, a national consensus statement from the National Institutes of Health, published professional guidelines regarding evidence-based use of the stimulant medications, and outreach to the lay public by groups such as Children and Adults With ADHD have increased public awareness and acceptance.

Paralleling this increased awareness of medication as a viable treatment option for ADHD has been a substantial increase in the use of psychotropic medications over the last decade, especially in the US. Hoagwood and colleagues’ analysis of the NAMCS data for the time interval from 1989 to 1996 found no significant difference in the proportion of treated children who received stimulants but did note an increase in the use of other psychotropic medications, particularly clonidine. These contrasting findings may reflect the fact that medication use was measured using different data sources. Alternatively, Olfson and colleagues’ comparison between the 1987 parent-reported National Medical Expenditure Survey and its subsequent version, the 1997 Medical Expenditure Panel Survey, found no significant difference in the proportion of treated children who received stimulants but youth are being treated more consistently, with higher overall doses, and over a longer period of time.

Research has documented considerable variation in medication use, raising concerns of both inappropriate and under utilization of these medications. For example, higher rates of stimulant use have been associated with child characteristics including male gender, latency age, and presence of impairment. Insurance status has been linked to stimulant medication use. Participation in special education, particularly programs for youth with emotional handicaps, has also been linked to receipt of medication. Similarly, receipt of mental health counseling has been associated with medication use.
Research has also documented considerable geographic variation, with respect to stimulants. Jensen and colleagues,\textsuperscript{73} study of 4 communities in the Methods for Epidemiology of Child and Adolescent Mental Disorders Study found that 5.1% of youths met criteria for ADHD but only 12.5% of these youths reported past-year stimulant use. Contrastingly, Angold and colleagues\textsuperscript{75} Great Smoky Mountains study indicated that almost three-quarters of children with a diagnosis of ADHD received stimulants. Research by Rowland and colleagues,\textsuperscript{69} Zito and colleagues,\textsuperscript{77} Rappley and colleagues,\textsuperscript{28} Shatin and Drinkard,\textsuperscript{78} and Hoagwood and colleagues\textsuperscript{48} has also demonstrated geographic variation. Community factors have been implicated; claims data from a commercially insured sample of youths demonstrated that higher income communities and greater proportions of white children are associated positively with use.\textsuperscript{67}

In addition, differences in prescription rates have been found by race/ethnicity in a number of studies.\textsuperscript{30,51,65,71,73} For example, Hoagwood and colleagues\textsuperscript{73} found discrepancies in medication use in the 1995–2000 NAMCS data, with whites nearly 9 times as likely to receive a prescription for stimulant medication compared with others, even when age, gender, length of visit, and insurance coverage were controlled. Stevens and colleagues also examined the effect of race/ethnicity on stimulant medication use with 1997–2000 Medical Expenditure Panel Survey data\textsuperscript{71} and found that African-Americans were less likely to be diagnosed with ADHD and to initiate stimulant medication treatment compared with whites. Stevens and colleagues\textsuperscript{50} reanalysis of the 1995–2000 data from NAMCS found that both diagnosis and prescriptions for psychotropic medications were less likely for Hispanics compared with whites. Importantly, their work suggested that no differences by ethnicity in medication use were noted once an ADHD diagnosis was made, suggesting that discrepancies in medication use by race/ethnicity may partially relate to the identification process. These differences in prescription use by race/ethnicity may reflect access to care issues such as insurance, transportation, and other barriers to care.

Discrepancies by race/ethnicity may also relate to important differences in cultural constructs regarding deviant behavior, help-seeking, and appropriate treatments, as parental belief that a child needs mental health treatment is the most important factor associated with service use in all populations.\textsuperscript{79} There is some evidence that the threshold for what is considered dysfunctional varies across cultures.\textsuperscript{80,81} Research to date exploring differences in cultural attitudes regarding stimulant medication is in its infancy but does suggest important differences.\textsuperscript{82,83}

Differences in medication use could also relate to provider propensity to prescribe these medications. Hoagwood and colleagues\textsuperscript{48} analyses of the NAMCS data from 1989 to 1996 found significant differences by provider types with three-fourths of psychiatrists and pediatricians prescribing stimulants to children diagnosed with ADHD compared with 94.9% of family practitioners. There are no studies published to date examining possible cultural determinants of physician prescribing behavior, although this is theoretically possible.

More recent studies have examined the longitudinal use of stimulant medications. These studies, regardless of the characteristics of their sample, suggest limited adherence to stimulant medication treatment regimens for ADHD.\textsuperscript{64,66,84} For example, Habel and colleagues\textsuperscript{32} examination of administrative data from a large California health plan found that, of the 11 698 children receiving at least one stimulant in 2000, 24% received a single prescription. Factors associated with limited adherence have not been extensively studied.

In summary, although the use of stimulant medication has been increasing, its use remains highly variable. Factors such as geographical location, race/ethnicity, and economic status appear to be determinants of its use and physician practices are far from uniform. Several studies have suggested that some differences in stimulant medication use may be decreasing for girls relative to boys,\textsuperscript{59,61} in adolescents relative to latency age children,\textsuperscript{59,61} and for African-Americans compared with whites.\textsuperscript{59} Limited studies available suggest poor compliance among youth taking stimulant medications, although factors affecting adherence have not been extensively investigated. In addition, there is an increasing trend to use other psychotropic medications, either alone or in combination with the stimulant medications.

**Office Visits**

The data on office visits for ADHD comes primarily from large administrative data sets or from national surveys of families or providers. The most comprehensive national study to date is Hoagwood and colleagues\textsuperscript{48} analyses of the NAMCS data which allow for examination of differences in care by provider type. Although data from 1989 to 1996 demonstrated an increase in the total percentage of visits to physicians where ADHD was identified, several disturbing trends were noted. First, there was a 45% decrease in the total percentage of visits...
where no drugs were prescribed, from 23.4% of visits in 1989 to 12.8% of visits in 1996. Second, there was an overall decrease in the percentage of visits where children received psychotherapy, from 40.1% of total visits in 1989 to 25.2% in 1996. Similarly, the total percentage of visits where follow-up services were recommended decreased from 91% in 1989 to 75.1% in 1996. Follow-up services differed by provider type with psychiatrists and pediatricians more likely to recommend follow-up visits compared with family practitioners.

Hoagwood and colleagues’48 review of data from the Child Behavior Study (CBS) is one of the few studies to look at the service mix for children cared for in primary care. The CBS includes a representative sample from a national pediatric practice network (Pediatric Research in Office Settings) and a national family practice network (Ambulatory Sentinel Practice Network). These primary care clinicians reported that 27.5% of children seen received no counseling, medications or referrals, 27% received counseling and medications, 17% receiving medications only and 11.5% received counseling only. Common barriers to care cited by participating physicians included lack of pediatric specialists, difficulty or delay in getting appointments, physician panel restrictions, complex appeals processes, and insufficient supply of Medicaid providers.

Stein and Orlando85 examined service mix in the mental health sector by studying claims data from 104 employer groups whose behavioral health care benefits were managed by United Behavioral Health, the third largest behavioral health care organization in the US. For their analyses, they excluded those children only cared for in the primary care sector or whose visits were limited to 1–2 sessions with a therapist. Their analyses demonstrated that the average number of visits for patients whose treatment was split between a therapist and a psychiatrist was almost twice that of a patient receiving treatment from either a therapist or psychiatrist, leading them to posit that “splitting treatment” between 2 providers may be less cost-effective.

As there is a strong evidence-base for the use of behavior modification for ADHD and other disruptive disorders,34 efforts to improve quality care should address the use of these methodologies in office visits. However, only a limited investigation regarding the content of visits has been carried out. A number of other interventions have been widely used including play therapy, individual insight therapy, cognitive behavioral therapies, biofeedback, and dietary interventions, but there is little support for their effectiveness in the literature.57 One recent study did inspect adherence to quality indicators for the outpatient care of ADHD, conduct disorder and major depression, including the use of behavior modification, for 813 children seen in 62 mental health clinics in California from August 1, 1998, through May 31, 1999. High adherence was documented for clinical assessment (78%–95%) for all 3 disorders. With respect to treatment of ADHD, a majority of charts indicated a referral for a medication evaluation (84%, SE = 2.32), but the use of evidence-based behavioral therapy (i.e., contracts, incentive systems, contingency management, parent training) was rated at 8.4% (SE = 2.53).86 The actual content of mental health visits for ADHD in these real-world settings and what proportion of care provided builds on an existing database deserves further exploration.

Results from the studies above documenting relatively fewer overall visits per child suggest a trend toward increased use of medication and decreased intensity of psychotherapeutic visits. The content and quality of available visits is still not known.

School-based Services

Relatively little data are available regarding the use of school-based services by children with ADHD. Only a limited number of studies62,64,66,75 have examined school service use, all have relied on parental report, and most have found service rates in the 25% range. Bussing and colleagues66 study of ADHD service use in a district sample suggested that African-American youth were more likely to receive school services than white children. Although these studies suggest a possible estimate of the prevalence rates of school-based services for children with ADHD, they do not allow for the examination of trends in service use over time or for extensive investigation of possible variation in service use related to child, family, or community characteristics as has been noted for both stimulant medication and for office visits.

In addition, limited research has been undertaken to examine the content, quality, and effectiveness of interventions currently available in existing school settings. The Department of Education is under considerable scrutiny by Congress to assure that educational services provided are a good investment of public monies. More evaluation of school-based services for ADHD should be forthcoming.87

Summary

It is clear that the current service use for youth with ADHD is highly variable and that, whereas good evidence-based information is available about diagnosing and
treating children with ADHD, much still needs to be done in order to translate the science into practice and improve the care of children with this condition. In addition, data regarding trends over time and factors affecting service use are much more detailed for medication use than for mental health visits. Finally, there is a serious paucity of available literature regarding service use in the educational sector.

Implications for Future Research and Policy

The previous sections have reviewed what is currently known about service use by youth with ADHD. Some clear limitations of the above-mentioned studies stand out. First, several of the studies reviewed that used administrative data sets have called for linkages with clinical data in order to validate diagnoses and allow for more precise descriptions of services for youth with ADHD, controlling for associated comorbidities. Second, few of the studies reviewed above have examined trends in service use following publication of the MTA study findings (1999 to date), the AACAP ADHD guidelines (1997), the AAP ADHD guidelines (2000, 2001), or efforts by the National Initiative for Children’s Healthcare Quality, the Texas Medication Algorithm Project, and other groups to apply quality improvement processes to ADHD care in primary care and specialty mental health. Clearly, more up-to-date information is needed. Last, the lack of research on service use in the educational sector for youth with ADHD is striking, particularly in comparison to the literature available on stimulant medication use.

In this next section, we begin to identify some of the additional research and policy areas that need to be prioritized over the next decade as we continue to try to understand and then make informed policy decisions aimed at improving service delivery for youth with ADHD in usual care settings. We have grouped these into 4 overall domains: 1) delving deeper into current service use, 2) operationalizing evidence-based ADHD care in real-world settings, 3) learning what changes clinician and educator behavior, and 4) paying attention to contextual factors that may affect service use.

Delving Deeper Into Current Service Use

Several of the findings described above—the variation in stimulant medication use, the role of outpatient mental health settings and schools as primary sources of mental health care for youths with ADHD, the suggested underutilization of evidence-based practice in public mental health—raise important questions regarding characteristics of currently available services. Studies are needed that examine the content and quality of services currently provided in the primary care, mental health, and educational sectors. Better delineation of content of care would also allow for more in-depth examination of the effectiveness of services currently utilized in these real-world settings. This type of data would also provide for a rich description of usual care procedures from which to work to develop community-based interventions to improve outcomes of ADHD care in these settings.

These types of studies require the use of novel research methodologies and approaches. Recently, pediatric mental health services researchers have called for hybrid practice research that uses techniques developed by intervention researchers to characterize treatment processes and examine how variations in treatment strategies relate to treatment outcomes within the context of usual community-based care settings. These researchers have pushed for the development of rigorous measurement methods for characterizing the approaches that clinicians take to working with youth and families, including the self-report of aspects of services provided, parental reports, or the use of independent observers who view videotapes and code visits. Qualitative and case-based methodologies drawn from the fields of anthropology and business may also provide novel models for this type of research.

Operationalizing Evidence-Based ADHD Care in Real-World Settings

As important as the descriptive studies of available care called for above are studies that begin to examine the core content and dosage of evidence-based ADHD care in efficacy studies and the operationalization of these components for usual care settings. Efficacy studies like the MTA provide important information for organizations seeking to develop guidelines for care of conditions like ADHD. However, the translation of care given during a research study to the clinical setting is often complicated by difficulties in operationalizing a research protocol to real-world settings.

As attempts are made to operationalize evidence-based care in usual care settings, it will be important to consider how to translate an interventional process from an efficacy trial across the 3 usual care settings of primary care, mental health, and schools. For example, the availability of informal consultative services by subspecialists as well as ready access to clinicians trained in behavioral modification in the home and school settings...
will be essential. This will require creative, efficient, and effective mechanisms developed for organizing behavioral health care services that span primary care, specialty, and educational services.

**Learning What Changes Clinician and Educator Behavior**

To assist providers in implementing and tailoring diagnosis and treatment guidelines, it will be important to understand what factors lead to changes in practice patterns across these 3 settings. The literature on the effectiveness of continuing medical education and on technology transfer make clear that although education is important, providing information to practitioners is seldom enough to encourage appropriate changes in practice, even when information has been successfully disseminated to an appropriate target audience.95–97

The challenge of changing physician behavior was kept in mind when the AAP planned its effort to develop training initiatives with regard to ADHD. Through partnerships between the AAP, the North Carolina Center for Children’s Healthcare Improvement, the Agency for Healthcare Research and Quality, and the National Initiative on Child Healthcare Quality, the AAP has developed the ADHD guidelines, an ADHD toolkit, and an interactive on-line training module on ADHD care in the primary care office setting, and has shepherded pediatric offices across the country through the process of implementing the ADHD guidelines.

The AAP approach utilized adult learning principles, systems change approach, a chronic illness model, and a feedback system (registry). Feedback from the offices participating in the process has been positive; interestingly, those practices who report the most success were able to find partners in the school and mental health systems and in the administration of their service system to address issues of implementation and sustainability. Although the approach appears conceptually and anecdotally promising, a rigorous assessment of its effectiveness at changing clinical behavior patterns and, more distally, outcomes for youth with ADHD, has yet to be completed.

**Paying Attention to Contextual Factors**

Lastly, studies are needed that characterize and incorporate the context in which these services are being delivered in their research design. Three recent publications, The National Institute of Mental Health’s Blueprint for Change: Research on Child and Adolescent Mental Health,99 the Surgeon General’s National Action Agenda for Children’s Mental Health,90 and a review by Hoagwood and colleagues entitled “Evidence-Based Practice in Child and Adolescent Mental Health Services”100 have pushed the health services research field conceptually with regard to deploying evidence-based practice into real world settings. All 3 publications state that implementation of evidence-based practice into these settings may fail unless contextual factors are built into the long-term design of new services. These critical factors need further elucidation in designing interventions to implement ADHD care in real-world settings, including the characteristics of the youth served and families served in a particular venue. Especially important to this discussion are possible cultural differences in threshold for deviant behavior, care-seeking from the general medical sector, and attitudes regarding appropriate treatment.

System characteristics also need to be examined. The reported high prevalence rate of ADHD indicates that the sheer number of youth with the disorder is too great for these youth to be feasibly treated by the mental health community alone and will require partnership with primary care. In addition, because many of the behaviors that youth with ADHD exhibit are manifested and managed while they are in school, the educational system also plays a vital role. Care then requires participation and collaboration among the primary care, mental health and educational communities.

There are several challenges to service delivery within the 3 service systems discussed in this paper. In the primary care sector, these barriers include limited training during residency in the diagnosis and management of developmental and behavioral problems, limited time to provide diagnostic or intensive treatment services in the current reimbursement system, and limited access to mental health services for consultation and referral (further exacerbated by the carving out of managed care, and limited contact with schools).101 In mental health, the data reviewed above suggest limited support for ongoing psychosocial interventions with an increased focus on medication management. In both primary care and mental health, increasing administrative and financial incentives and barriers imparted by third-party payers may affect clinician treatment plans, constrain referrals, and provide inadvertent disincentives to see youth with significant impairment. These programmatic changes in the health care system threaten the ability to develop multifaceted, longitudinal approaches to improving care for children with mental health problems, such as the incorporation of allied professionals within the primary care setting or the provision of case management with other sectors of care, including schools, social services,
and other groups. The educational sector faces its own challenges, including demands for increasing academic accountability under the No Child Left Behind Act, budget decreases in the majority of states, and limited training regarding evidence-based behavior modification or other educational interventions during teacher certification programs.

Providing high quality ADHD care will necessitate a number of changes in our current delivery systems. Research examining these and other factors related to the youth, families, and service systems will be critical to conduct in order to understand the impact of these factors on service use and stimulate creative policy and implementation strategies for improving care in real-world settings. In addition, demonstration projects that allow for creative, flexible funding for collaborative service provision theoretically could provide important cost-benefit data regarding coordinated, cross-sector care. In addition, any research conducted must include policy outcomes that are meaningful to large systems. Models include the recent examination of an administrative data set from a national Fortune 100 manufacturer examining the cost of lost work time caring for a child with ADHD and a survey of employers’ knowledge and attitudes about ADHD.

Evaluation of the effectiveness of these system design changes will require the collection of sophisticated utilization data and charges using clinical information systems. Innovative research methodologies that can account for clustering and address multilevel analytic techniques and small sample sizes at the level of the organization will need to be used.

Conclusions

Despite a large research base regarding its diagnosis and treatment, the care of youth with ADHD faces a number of challenges, including the interplay of service delivery among primary care, mental health, and educational service systems. Mental health services research plays a critical role in identifying current practice patterns and barriers to the delivery of evidence-based care. More in-depth research regarding the content and quality of effectiveness of care in usual settings is needed. Clearer delineation of youth, family, and service systems characteristics and their impact on usual care also needs to be determined, as does operationalization of efficacy research protocols for real-world settings. Implementation research regarding evidence-based practice that includes system perspectives and incorporates all 3 sectors will be essential. Addressing these policy-relevant research questions will catalyze the development of innovative, creative solutions that take into account the chronic, cross-sector characteristics of ADHD care.

Acknowledgments

Supported in part by National Institute of Mental Health grant K08-MH64816. We thank Brenda Bantados, Sasha Beram, and Amy Monn for their research and editorial assistance.

Received December 5, 2005; accepted May 14, 2006

References


54. Goldman, L. S., Genel, M., Bezman, R. J., & Slanetz, P. J. (1998). Diagnosis and treatment of


APPENDIX. Literature Review of Service Use by Youth With Attention-Deficit/Hyperactivity Disorder (ADHD)

<table>
<thead>
<tr>
<th>Study</th>
<th>Data Set/Sample</th>
<th>Major Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Part I. Diagnostic/Evaluative Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Centers for Disease Control and Prevention (CDC) (2005)</td>
<td>102,353 children &lt;8 years participating in the 2003–2004 National Survey of Children’s Health</td>
<td>National population estimates: 4.4 million children aged 4–17 years have a history of ADHD (boys more likely than girls; higher among non-Hispanic, English-speaking, insured children and in families where adult had high school degree/equivalent; variation by state).</td>
</tr>
<tr>
<td>Chan, Hopkins, Perrin, Herreras, Homer (2005)</td>
<td>861 primary care pediatricians from a national sample</td>
<td>58% of physicians used formal diagnostic criteria, but only 28% used criteria based on the DSM-IV. 70% used ADHD-specific rating-scales and 60% used global behavior scales. 83% obtained diagnostic information from teachers or schools. 25% obtained laboratory tests. Most routinely assessed coexisting conditions (74% for tic disorders, 91% for depression and conduct disorder). Diagnostic services for ADHD increased from 22.3% to 62.1%. Percentage of visits that included diagnostic services: psychiatric 80.6%, pediatric 64.0%, family practice 32.6%.</td>
</tr>
<tr>
<td>Stevens, Harman, Kelleher (2004)</td>
<td>All children &lt;18 years in the National Ambulatory Medical Care Survey (NAMCS) 1989–1996 at 5 time points</td>
<td>Latency age was more likely to be associated with receipt of a diagnosis than preschool or adolescent age. Complex interactions were noted between geographic region and race/ethnicity regarding whether an ADHD diagnosis was likely to be recorded during visits. An ADHD diagnosis was more likely to be recorded during visits by children with Medicaid than with other types of insurance.</td>
</tr>
<tr>
<td>Hoagwood, Kelleher, Feil, Corner (2000)</td>
<td>26,441 primary care visits recorded in the NAMCS, 1995–2000, and the National Hospital Ambulatory Medical Care Survey (NHAMCS), 1995–2000</td>
<td>38.3% reported using DSM-IV criteria to diagnose ADHD; 36.9% reported using standardized tools such as behavior-rating scales.</td>
</tr>
<tr>
<td>Wasserman, Kelleher, Bocian, et al. (1999)</td>
<td>401 primary care pediatricians and family practitioners in the Pediatric Research in Office Settings (PROS) and the Ambulatory Sentinel Practice Network (ASPN)</td>
<td></td>
</tr>
<tr>
<td><strong>Part II. Psychotropic Medication Use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Angold, Erkanli, Egger, Costello (2000)</td>
<td>4,500 youth aged 9, 11, and 13 at enumeration in the Great Smoky Mountains Study</td>
<td>Almost 3/4 of children diagnosed with ADHD received stimulants. 2x as many children were taking stimulants as had received a diagnosis. Male gender, younger age, impairment, and meeting criteria for oppositional defiant disorder were associated with stimulant use. 7% of youth with ADHD received stimulant medication during the past year; only 3.6% were continuing use at the time of the study. Male:female ratio of stimulant use was 10:1. ADHD, ADHD-NOS, impairment, and male gender predicted use.</td>
</tr>
<tr>
<td>Bauermeister, Canino, Bravo, et al. (2003)</td>
<td>1,890 Puerto Rican children aged 4–17 from a probability household sample</td>
<td>Children with ADHD and psychiatric comorbidity were less likely to use stimulants but more likely to use other psychiatric medications and polypharmacy.</td>
</tr>
<tr>
<td>Boles, Lynch, DeBar (2001)</td>
<td>1,941 children aged 5–12, with diagnosis of ADHD cared for at Northwest Kaiser Permanente from January 1997–July 1998</td>
<td>20% of sample were receiving medication. Rates of medication use were higher for boys, youth in special education secondary to emotional handicaps, whites, youth with insurance, youth from a higher socioeconomic status, and youth with more severe problems on parent reports. 35% of children received medication during a 2-year period and approximately 36% were no longer on medications at the end of the study. Boys were more likely to receive medications than girls.</td>
</tr>
<tr>
<td>Bussing, Zima, Perwien, Belin, Widawski (1998)</td>
<td>499 children in 2–4 grade receiving special education services in a Northern Florida school district</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Data Set/Sample</td>
<td>Major Findings</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Centers for Disease Control and Prevention (CDC) (2005)</td>
<td>102,353 children &lt;18 years participating in the 2003–2004 National Survey of Children’s Health</td>
<td>National population estimates: 56% with ADHD diagnosis took medication at some point (curvilinear with respect to age, males greater than females, higher among non-Hispanic, primary English-speaking, and insured variability, South greater than West). Male-female differences for current medication use disappear with diagnosis.</td>
</tr>
<tr>
<td>Cox, Mortheral, Henderson, Mager (2003)</td>
<td>Prescription claims from 178,800</td>
<td>Stimulant use was positively associated with age, male gender, fewer child dependents, living in higher income communities, living in communities with higher percentage of whites, living in the Midwest and South compared with the West, and in urban areas. Limited compliance with use; 54.0% received 1 prescription, 19.3% received 2, 15.8% received 3–4, and 10.9% received 5 or more during a 1-year period.</td>
</tr>
<tr>
<td>Habel, Schaefer, Levine, Bhat, Elliot (2005)</td>
<td>Computerized pharmacy, outpatient visits, and membership files among 500,000 enrollees in a California health plan</td>
<td>Annual percentage of stimulant use increased from 1.86% in 1996 to 1.93% in 2000. Stimulant use was lower and use of other psychotropics was higher for youth with coexisting psychiatric disorders. Of the 11,698 children receiving at least one stimulant in 2000, 24% received a single prescription; 55% were prescribed by pediatricians and 45% by psychiatrists.</td>
</tr>
<tr>
<td>Hoagwood, Kelleher, Feil, Comer (2000)</td>
<td>All children aged younger than 18 years in the 1989–1996 NAMCS at 5 time points</td>
<td>Prescriptions of stimulants increased from 54.8% in 1989 to 75.4% in 1996.</td>
</tr>
<tr>
<td>Hoagwood, Jensen, Feil, Vitiello, Bhatara (2000)</td>
<td>36,875 patient records on children &lt;18 years in the 1995 NAMCS</td>
<td>Factors associated with stimulant use included geographic region (living in the South), receiving mental health counseling, not receiving psychotherapy, and having health insurance. Whites 9x as likely to receive prescription for stimulant medications compared with other race/ethnicities. 5.1% of youths met criteria for ADHD, but only 12.5% of these youth reported past-year stimulant use.</td>
</tr>
<tr>
<td>Jensen, Kettle, Roper, et al. (1999)</td>
<td>1,285 children from 4 communities participating in the Methods for Epidemiology of Child and Adolescent Mental Disorders (MECA) Study</td>
<td>Factors associated with stimulant use included ADHD, ADHD-NOS, male gender, and younger age.</td>
</tr>
<tr>
<td>Marcus, Wan, Kemner, Olsson (2005)</td>
<td>11,537 claims in the Statewide California Medicaid data set (2000–2003) for youth aged 6–17 years</td>
<td>No significant difference in proportion of treated children receiving stimulants, but increase in number of prescriptions received. Increase in use of other psychotropic medications such as Clonidine.</td>
</tr>
<tr>
<td>Olsson, Gameroff, Marcus, Jensen (2003)</td>
<td>8,367 children from the 1987 National Medical Expenditure Survey (NMES) and 8,771 children from the 1997 Medical Expenditure Panel Survey (MEPS)</td>
<td>Dose titration occurred in 67% of children. 84% of children were compliant for &lt;2 months over the period they were refilling prescriptions. 3% had a diagnosis of ADHD. Factors influencing stimulant medication use included geographic region, comorbid conduct disorder, and use of a mental health provider. In addition, there was an interaction of region with race/ethnicity and mental health provider use.</td>
</tr>
<tr>
<td>Perwien, Hall, Swensen, Swindle (2004)</td>
<td>Claims data in an administrative claims data base for 604,538 children aged 18 or younger from 6 health plans from 4/1/97 to 9/30/99</td>
<td>A tenfold variation was noted in the percentage of children receiving medication when data were analyzed by county.</td>
</tr>
<tr>
<td>Radigan, Lannon, Roohan, Gesten (2005)</td>
<td>250,000 children in 35 managed-care organizations participating in the NY State Medicaid Managed Care Program</td>
<td></td>
</tr>
<tr>
<td>Rappley, Gardner, Jetton, Houang (1993)</td>
<td>52,590 prescriptions filed on 32,608 individuals through the Michigan TriPLICATE Prescription Program from 2/92 to 3/92</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Data Set/Sample</td>
<td>Major Findings</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Rowland, Umbach, Stallone, Naftel, Bohlig, Sandler (2002)</td>
<td>7,333 children grades 1–5 in a North Carolina County</td>
<td>Of diagnosed children, 71% were receiving medication. Medication treatments varied by sex (male&gt;female) and race/ethnicity (white&gt;other).</td>
</tr>
<tr>
<td>Safer, Krager (1988)</td>
<td>Time trends from the Baltimore County Health Department surveys of school nurses, 1971–1987.</td>
<td>Increase in use of stimulants since 1971, with 5.96% of all public elementary school students receiving medication treatment. 25% of children using stimulants were in special education classes or schools. 2.5-fold increase in prevalence of methylphenidate treatment of youths with ADHD between 1990–1995. Increases noted in girls, adolescents, and inattentive youth as well as an increase in duration of treatment.</td>
</tr>
<tr>
<td>Safer, Zito, Fine (1996)</td>
<td>Time trends from the Baltimore County Health Department surveys of school nurses, the Maryland Medicaid database, 3 pharmaceutical databases, and one physician audit, 1990–1995.</td>
<td>Factors associated with stimulant use included male gender, white race/ethnicity, special education status. Stimulant medication use increased from 23.8 to 30.0 per 1000 over the 5-year period. Geographic variation highest in one IPA of Midwest as well as in an IPA in the Northeast and in the Southeast. ADHD diagnosis and prescriptions for psychotropic medications less likely for Hispanics than whites. Medications more likely in the South and West than Northeast. No ethnic differences in medication use after diagnosis. Stimulant medication use greatest among latency age youth and youth with private or public insurance compared with uninsured. Factors associated with stimulant medication included geographic region of the state and white race/ethnicity. Twofold increase in methylphenidate use comparing Medicaid to HMO enrollees.</td>
</tr>
<tr>
<td>Safer, Malever (2000)</td>
<td>816,465 students in Maryland public schools</td>
<td></td>
</tr>
<tr>
<td>Zito, Safer, dosReis, Magder, Riddle (1997)</td>
<td>1991 Maryland Medicaid prescription drug reimbursement claims data for children aged 5–14 years</td>
<td></td>
</tr>
<tr>
<td>Zito, Safer, dosReis, et al. (2003)</td>
<td>Nearly 900,000 youths enrolled in 2 US health care systems from 3 sites (Medicaid: Midwest, Medicaid: Mid-Atlantic, HMO: Northwest) during 1987–1996</td>
<td>Overall, 10-year prevalence increase ranged from 2.5 fold to 3.7 fold for Medicaid youths and 7.2-fold for HMO youths. Increase in girls using stimulants relative to boys (particularly in HMO population). 48.6% decrease in white–African American disparity for Medicaid patients from the Mid-Atlantic site but not the Midwestern site, and in preadolescents/adolescents relative to latency age children. 45% decrease in total % of visits where no drugs were prescribed. Overall decrease in % of visits where children received psychotherapy. Decrease in the # of visits where follow-up services were recommended. Psychiatrists and pediatricians more likely to recommend follow-up visits than family practitioners. 27.5% children seen by primary care physicians received no counseling, meds, or referrals. 27% received counseling and meds, 17% received meds only, 11.5% received counseling only.</td>
</tr>
<tr>
<td>Part III. Office Visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoagwood, Jensen, Feil, Vitiello, Bhatara (2000)</td>
<td>36,875 patient records on children aged younger than 18 years in the 1995 NAMCS</td>
<td>45% decrease in total % of visits where no drugs were prescribed. Overall decrease in % of visits where children received psychotherapy. Decrease in the # of visits where follow-up services were recommended. Psychiatrists and pediatricians more likely to recommend follow-up visits than family practitioners. 27.5% children seen by primary care physicians received no counseling, meds, or referrals. 27% received counseling and meds, 17% received meds only, 11.5% received counseling only.</td>
</tr>
<tr>
<td>Hoagwood, Kelleher, Feil, Comer (2000)</td>
<td>Data from 401 clinicians participating in the Childhood Behavior Study of 2 national practice-based primary care research networks (PROS and ASPN networks)</td>
<td></td>
</tr>
</tbody>
</table>
### Study Data Set/Sample

<table>
<thead>
<tr>
<th>Study</th>
<th>Data Set/Sample</th>
<th>Major Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olfson, Gameroff, Marcus, Jensen (2003)</td>
<td>8,367 children aged 3–18 years in the 1987 NMES data set and 8,771 children aged 3–18 years in the 1997 MEPS</td>
<td>Rates of overall outpatient treatment (combined visit or receipt of medication) for ADHD increased from 0.9% to 3.4%. Adolescents experienced a larger proportionate increase in the rate of ADHD treatment than younger latency age children. There was also a proportionate increase in the lower-income families such that, by 1997, rates of ADHD treatment differed little by family income. Rates of treatment for uninsured remained less than half the rate of those with public/private insurance. Children who received psychotherapy for ADHD had an estimated 3.9 fewer visits in 1997 than in 1987.</td>
</tr>
<tr>
<td>Stein, Orlando (2001)</td>
<td>Claims data on 2,137 patients &lt;15 years of age at time of first clinical review and were covered by 104 employer groups using United Behavioral Health from 1/96 to 3/98. Children managed entirely by a non-mental health physician were excluded.</td>
<td>Youth with comorbid mood/anxiety disorder more likely to see a psychiatrist than a primary care provider or a therapist and are more likely to be comanaged by a psychiatrist and a therapist than by just one mental health professional. Splitting treatment between 2 providers may be less cost effective.</td>
</tr>
<tr>
<td>Stevens, Harman, Kelleher (2005)</td>
<td>27,802 observations on children aged 3–18 years in the MEPS 1997–2000</td>
<td>Latency age more likely to have physician visits compared with 3–6- and 13–18-year-olds. Medicaid/public insurance more likely to have physician visits compared with private (same for private versus no insurance). Same insurance finding held for psychotherapy/counseling sessions for ADHD and for other conditions. White Americans more likely to receive psychotherapy or counseling for conditions other than ADHD compared with African Americans or Hispanic-Americans.</td>
</tr>
</tbody>
</table>

### Part IV. School-Based Services

<table>
<thead>
<tr>
<th>Study</th>
<th>Data Set/Sample</th>
<th>Major Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bauermeister, Canino, Bravo, et al. (2003)</td>
<td>1,897 Puerto Rican children aged 4–17 from a probability household sample</td>
<td>26.5% of youth with ADHD were receiving school-based services.</td>
</tr>
<tr>
<td>Bussing, Zima, Mason, Hou, Garvan, Forness (2005)</td>
<td>Sample of 220 elementary school children in a Florida school district</td>
<td>28% of children accessed school services and continued to over a 2-year period. African American youths were more likely to receive school services than white children.</td>
</tr>
<tr>
<td>Jensen, Kettle, Roper, et al. (1999)</td>
<td>1,285 children from 4 communities participating in the MECA Study</td>
<td>24% of children diagnosed with ADHD received school-based services.</td>
</tr>
<tr>
<td>Olfson, Gameroff, Marcus, Jensen (2003)</td>
<td>8771 children aged 3–18 years in the 1997 MEPS</td>
<td>29.2% children aged 5–17 years treated for ADHD received special education or related services.</td>
</tr>
</tbody>
</table>