

Systemic Barriers to the Care of Children and Adolescents with ADHD

INTRODUCTION

The American Academy of Pediatrics (AAP) strives to improve the quality of care provided by primary care clinicians (PCCs) through quality improvement initiatives including developing, promulgating, and regularly revising evidence-based clinical practice guidelines. The AAP has published a revision to its 2011 guideline on evaluating, diagnosing, and treating attention-deficit/hyperactivity disorder (ADHD) on the basis of the latest scientific evidence (see main article). This latest revision of the clinical practice guideline is accompanied by a process of care algorithm (PoCA [also found in the supplemental information]), which outlines the applicable diagnostic and treatment processes needed to implement the guidelines. This document, which is a companion to the guideline and PoCA, outlines common barriers that impede ADHD care and provides suggested strategies for clinicians, seeking to improve care for children and adolescents with ADHD, to work with other concerned public and private organizations, health care payers, government entities, state insurance regulators, and other stakeholders.

ADHD is the most common childhood neurobehavioral disorder in the United States and the second most commonly diagnosed childhood condition after asthma.¹ The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* criteria define 4 dimensions of ADHD:

1. ADHD primarily of the *Inattentive* presentation (ADHD/I) (314.00 [F90.0]);
2. ADHD primarily of the *Hyperactive-Impulsive* presentation (ADHD/HI) (314.01 [F90.1]); and
3. ADHD *Combined* presentation (ADHD/C) (314.01 [F90.2]).
4. ADHD *Other Specified*, and *Unspecified* ADHD (314.01 [F90.8])

National survey data from 2016 show that 9.4% of 2- to 17-year-old US children received an ADHD diagnosis during childhood, and 8.4% currently have ADHD.² Prevalence estimates from community-based samples are somewhat higher, ranging from 8.7% to 15.5%.^{3,4} Most children with ADHD (67%) had at least 1 other comorbidity, and 18% had 3 or more comorbidities, such as mental health disorders and/or learning disorders. These comorbidities increase the complexity of the diagnostic and treatment processes.⁵

The majority of care for children and adolescents with ADHD is provided by the child's primary care clinician (PCC), particularly when the ADHD is uncomplicated in nature. In addition, families typically have a high degree of confidence and trust in pediatricians' ability to provide this professional care. Because of the high prevalence of ADHD in children and adolescents, it is essential that PCCs, particularly pediatricians, be able to diagnose, treat, and coordinate this care or identify an appropriate clinician who can provide this needed care. Yet, despite having a higher prevalence than other conditions that PCCs see and manage—such as urinary tract infections and sports injuries—ADHD is often viewed as different from other pediatric conditions and beyond primary care's purview. In addition, several barriers to care hamper effective and timely diagnosis and treatment for these children and adolescents and must be addressed and corrected to achieve optimum outcomes for these children.⁶ These barriers are:

1. Limited access to care because of inadequate developmental-behavioral and mental health care training during residencies and other clinical training and shortages of consultant specialists and referral resources;
2. Inadequate payment for needed services and payer coverage limitations for needed

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47 medications;

48 3. Challenges in practice organization and staffing; and

49 4. Fragmentation of care and resulting communication barriers.

50

51 Addressing these barriers from a clinical and policy standpoint will enhance clinicians'

52 ability to provide high-quality care for children and adolescents who are being evaluated and/or

53 treated for ADHD. Strategies for improvement in the delivery of care to patients with ADHD and

54 their families are offered for consideration for practice and for advocacy.

BARRIERS TO HIGH-QUALITY CARE FOR CHILDREN AND ADOLESCENTS WITH ADHD

59 Multiple barriers exist in the primary medical care of children and adolescents that are

60 impediments to excellent ADHD care.

Limited Access to Care Because of Inadequate Developmental-Behavioral and Mental Health Care Training During Pediatric Residency and Other Clinical Training Programs and Shortages of Consultant Specialists and Referral Resources

64 There is an overall lack of adequate pediatric residency and other training programs for

65 pediatric clinicians on developmental-behavioral and mental health conditions, including ADHD.

66 The current curriculum and the nature of pediatric training still focus on the diagnosis and

67 treatment of inpatient and intensive care conditions—despite the fact that many primary care

68 pediatricians spend less and less time providing these services, which are increasingly managed

69 by pediatric hospitalists and intensive care specialists. Pediatric and family medicine residents do

70 not receive sufficient training in the diagnosis and treatment of developmental-behavioral and

71 mental health conditions, including ADHD, despite the high frequency in which they will

72 encounter these conditions in their practices.^{7,8}

74 In addition, many experienced pediatric clinicians believe that general pediatric and

75 family medicine residencies do not fully ensure that clinicians who enter primary care practice

76 have the organizational tools to develop, join, or function in medical home settings and address

77 chronic developmental and behavioral conditions like ADHD.⁷ The current funding of residency

78 and other training programs for pediatric clinicians, and the needs of hospitals, tend to limit those

79 aspects of training. The training challenges are subsequently not sufficiently addressed by

80 practicing pediatric and family medicine practitioners, in part because of the limited number and

81 varying quality of continuing medical education (CME) opportunities and quality improvement

82 projects focused on medical home models and/or the chronic care of developmental and

83 behavioral pediatric and mental health conditions.

85 The lack of training is compounded by the national shortage of child and adolescent

86 psychiatrists and developmental-behavioral pediatricians: the United States has only 8300 child

87 psychiatrists⁹ and 662 developmental-behavioral pediatricians.¹⁰ The additional training required

88 for child psychiatry and developmental-behavioral pediatrics certification increases education

89 time and costs, yet results in little or no return on this investment in terms of increased

90 compensation for these specialists.⁹ Given the high cost of medical school and the increasing

91 educational debt incurred by graduating medical students, physicians lack a financial incentive to

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92 add the extra years of training required for these specialties.¹¹ As a result, there are insufficient
93 numbers of mental health professionals, including child psychiatrists and developmental-
94 behavioral pediatricians, to serve as subspecialty referral options and/or provide PCCs with
95 consultative support to comanage their patients effectively.

96
97 The specialist shortage is exacerbated by the geographically skewed distribution of extant
98 child psychiatrists and developmental-behavioral pediatricians, who are concentrated in
99 academic medical centers and urban environments. Almost three quarters (74%) of US counties
100 have no child and adolescent psychiatrists; almost half (44%) do not even have any
101 pediatricians.¹² As a result, many PCCs lack an adequate pool of pediatric behavioral and mental
102 health specialists who can accept referrals to treat complicated pediatric ADHD patients and an
103 adequate pool of behavioral therapists to provide evidence-based behavioral interventions. The
104 result is that patients must often travel untenable distances and endure long waits to obtain these
105 specialty services.

Suggested Strategies for Change to Address Limited Access to Care

Policy-Oriented Strategies for Change

- 110 Promote changes in pediatric and family medicine residency curricula to devote more time to
111 developmental, behavioral, learning, and mental health issues with focus on prevention, early
112 detection, assessment, diagnosis, and treatment. Changes in the national and individual
113 training program requirements and in funding of training should foster practitioners'
114 understanding of the family perspective; promote communication skills, including
115 motivational interviewing; and bolster understanding and readiness in the use of behavioral
116 interventions and medication as treatment options for ADHD.
- 117 Emphasize teaching and practice activities within general pediatric residencies and other
118 clinical training, so pediatricians and other PCCs gain the skills and ability they need to
119 function within a medical home setting.
- 120 Support pediatric primary care mental health specialist (PMHS) certification for advanced
121 practice registered nurses, through the Pediatric Nursing Certification Board to provide
122 advanced practice care to help meet evidence-based needs of children or adolescents with
123 ADHD.
- 124 Encourage the development and maintenance of affordable programs to provide CME and
125 other alternative post-training learning opportunities on behavioral and developmental health,
126 including ADHD. These opportunities will help stakeholders—including PCCs, mental
127 health clinicians, and educators—become more comfortable in providing such services
128 within the medical home and/or educational settings.
- 129 Develop, implement, and support collaborative care models that facilitate PCCs' rapid access
130 to behavioral and mental health expertise and consultation. Examples include integration
131 (such as collaborative care or colocation); on-call consultation; and support teams such as the
132 Massachusetts Child Psychiatry Access Program,¹³ the New York State Department of
133 Mental Health's "Project Teach Initiative,"¹⁴ and Project ECHO (Extension for Community
134 Healthcare Outcomes), a collaborative model of medical education and care management that
135 can be targeted to pediatric mental health.¹⁵ In addition, federal funding had provided grants
136 to 18 states to develop Child Psychiatry Access Programs through HRSA's Pediatric Mental
137 Health Care Access Program.^{16,17} Promote incentives such as loan forgiveness to encourage

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138 medical students to enter the fields of child and adolescent psychiatry and developmental and
139 behavioral pediatrics, particularly for those who are willing to practice in underserved
140 communities.

141 • Expand post-training opportunities to include postpediatric portal programs, which provide
142 alternative ways to increase number of child and adolescent psychiatrists.

143

144 **Inadequate Payment for Needed Services and Payer Coverage Limitations for Needed 145 Medications**

146 Although proper diagnostic and procedure codes currently exist for ADHD care in
147 pediatrics, effective and adequate third-party payment is not guaranteed for any covered
148 services.¹⁸ Further, many payment mechanisms impede the delivery of comprehensive ADHD
149 care. These impediments include restrictions to medication treatment choices such as step
150 therapy, prior approval, narrow formularies, and frequent formulary changes. Some payers
151 define ADHD as a “mental health problem” and implement a “carve out” health insurance
152 benefit that bars PCCs from participation.¹⁹ This designation results in denial of coverage for
153 primary care ADHD services. Some payers have restrictive service and/or medication approval
154 practices that prevent patients from receiving or continuing needed care and treatment. Examples
155 include approval of only a limited number of specialist visits, limited ADHD medication options,
156 mandatory step therapy, frequent formulary changes resulting in clinical destabilization, and
157 disproportionately high out-of-pocket copays for mental health care or psychotropic medications.

158
159 Payments for mental health and cognitive services are frequently lower than equivalents
160 (by relative value unit [RVU] measurement) paid for physical health care services, particularly
161 those entailing specific procedures.¹⁸ Longer and more frequent visits are often necessary to
162 successfully address ADHD, yet time-based billing yields lower payment compared with
163 multiple shorter visits. These difficulties financially limit a practice’s ability to provide these
164 needed services. Payments for evaluation and management (E/M) codes for chronic care are
165 often insufficient to cover the staff and clinician time needed to provide adequate care.
166 Furthermore, many payers deny payment for the use of rating scales, which are the currently
167 recommended method for monitoring ADHD patients. The use of rating scales takes both the
168 PCC’s time and the practice’s organizational resources. Arbitrary denial of payment is a
169 disincentive to the provisions of this essential and appropriate service.

170
171 Finally, payers commonly decline to pay or provide inadequate payment for care
172 coordination services. Yet, office staff and clinicians are asked to spend large amounts of
173 uncompensated time on these activities, including communicating with parents, teachers, and
174 other stakeholders. Proposed new practice structures such as accountable care organizations
175 (ACOs) are predicated on value-based services and may provide new financial mechanisms to
176 support expanded care coordination services. Originally implemented for Medicare, all-payer
177 ACO models are under development in many states. To date, however, the specifics of these
178 ACO models have not been delineated and their effectiveness has not yet been documented.²⁰

179 The seemingly arbitrary and ever-changing standards for approval of services; the time-
180 consuming nature of prior approval procedures; and restrictive, opaque pharmacy rules combine
181 to create substantial barriers that result in many PCCs declining to care for children and
182 adolescents with ADHD.¹² According to a recent AAP Periodic Survey of Fellows, 41% of

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183 pediatricians reported that “inadequate reimbursement is a major barrier to providing mental
184 health counseling.”¹⁸ Of note, 46% reported that they would be very interested in hiring mental
185 health clinicians in their practice “if payment and financial resources were not an issue.”¹⁸

186 Payers’ practices regarding medication approval also create challenges for treating
187 pediatric ADHD. In conflict with best practice or evidence-based guidelines, payers commonly
188 favor 1 ADHD medication and refuse to approve others, even when the latter may be more
189 appropriate for a specific patient. Decisions seem to be made on cost which at times can be quite
190 variable. Certain drugs may be allowed only after review processes; others are refused for poorly
191 delineated reasons. Reviewers of insurance denial appeals often lack pediatric experience and are
192 unfamiliar with the effect of the patient’s coexisting condition(s) or developmental stage on the
193 medication choice. Step therapy protocols that require specific medications at treatment initiation
194 may require patients to undergo time-consuming treatment failures before an effective therapy
195 can be started. Changes to formularies may force medication changes on patients whose ADHD
196 had been well-controlled, leading to morbidity or delays in finding alternative covered
197 medications that might be equally effective in restoring clinical control.

198 Similarly, payers may inappropriately insist that a newer replacement drug be used in a
199 patient whose ADHD has been well-controlled by another drug of the same or similar class. The
200 assumption that generic psychoactive preparations are equal to brand-name compounds in
201 efficacy and duration of action is not always accurate.²¹ Although generic substitution is
202 generally appropriate, a change in a patient’s response may necessitate return to the nongeneric
203 formulation. In addition, because of the variation in covered medications across insurance
204 companies, when a family changes health plans, clinicians have to spend more time to clarify
205 treatments and reduce family stress and their economic burden.

206 Suggested Strategies for Change to Address Inadequate Payment and Payer Coverage 207 Limitations

208 Policy-Oriented Strategies

- 209 • Revise payment systems to reflect the time and cognitive effort required by primary care,
210 developmental-behavioral, and mental health clinicians to diagnose, treat, and manage
211 pediatric ADHD—and compensate these services at levels that incentivize and support their
212 use.
- 213 • Support innovative partnerships between payers and clinicians to facilitate high-quality
214 ADHD care. As new payment models are proposed, include input from practicing clinicians
215 to inform insurance plans’ understanding of the resources needed to provide comprehensive
216 ADHD care.
- 217 • Require that payers’ medical directors who review pediatric ADHD protocols and medication
218 formularies either have pediatric expertise or seek such expertise before making decisions
219 that affect the management of pediatric patients with ADHD.
- 220 • Advocate that health care payers’ rules for approval of developmental-behavioral and mental
221 health care services and medications is consistent with best practice recommendations based
222 on scientific evidence such as the AAP ADHD guideline. Payers should not use arbitrary
223 step-based medication approval practices or force changes to a patient’s stable and effective
224 medication plans because of cost-based formulary changes.

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- Advocate for better monitoring by the US Food and Drug Administration (FDA) of ADHD medication generic formulations in order to verify their equivalency to brand-name preparations in terms of potency and delivery.
- Partner with CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) and other parent support groups to help advocate for positive changes in payers' rules; these organizations provide a strong voice from families who face the challenges on a day-to-day basis.

Challenges in Practice Organization

ADHD is a chronic condition. Comprehensive ADHD care requires additional clinician time for complex visits, consultation and communication with care team members, and extended staff time to coordinate delivery of chronic care. Children and adolescents with ADHD have a special health care condition and should be cared for in a manner similar to that of other children and youth with special health care needs.²² Such care is ideally delivered by practices that are established as patient- and family-centered medical homes. Yet, the number of patient- and family-centered medical homes is insufficient to meet the needs of many children with ADHD and their families. Pediatricians and other PCCs who have not adopted a patient- and family-centered medical home model may benefit from the use of similar systems to facilitate ADHD management. For more information, see the recommendations and descriptions from the AAP and the American Academy of Family Medicine (AAFP) regarding medical homes.²²

Caring for children and adolescents with ADHD requires practices to modify office systems to address their patients' mental health care needs. Specifically, practices need to be familiar with local area mental health referral options, where available, and communicate these options to families. Once a referral has been made, the office flow needs to support communication with other ADHD care team members.²³ Other team members, especially those in mental health, need to formally communicate with the referring clinician, in a bidirectional process.

Making a referral does not always mean that the patient is able to access care, however. Practices need to consider that many families face difficulties in following through with referrals for ADHD diagnosis and treatment. These difficulties may arise for a variety of reasons, including lack of insurance coverage, lengthy waitlists for mental health providers, transportation difficulties, reluctance to engage with an unfamiliar care system, cultural factors, and/or the perceived stigma of receiving mental health-specific services.²⁴⁻²⁷

Many of these barriers can be addressed by the integration of mental health services within primary care practices and other innovative collaborative care models. These models can help increase the opportunities for families to receive care in a familiar and accessible location, and provide a "warm handoff" of the patient into the mental health arena. The implementation of these models can be hindered by cost; collaboration with mental health agencies may be fruitful.

Another challenge is the difficulty in determining which mental health subspecialists use evidence-based treatments for ADHD. Pediatricians and other PCCs can increase the likelihood that families receive evidence-based services by establishing a referral network of clinicians who are known to use evidence-based practices and educating parents about effective psychosocial

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270 treatments for children and adolescents to help them be wise consumers. It is also important to be
271 cognizant of the fact that, for some families, accessing these services may present challenges,
272 such as the need to take time off from work or cover any program costs.

273 Finding professionals who use evidence-based treatments is of the utmost importance,
274 because exposure to non-evidence-based treatments has the potential to harm patients in several
275 ways. First, the treatment is less likely to be effective and may be harmful (eg, adverse events
276 can and do occur in psychosocial treatments.²⁸ Second, the effort and money spent on ineffective
277 treatment interferes with the ability to meaningfully engage in evidence-based treatments.
278 Finally, when a treatment does not yield benefits, families are likely to become disillusioned with
279 psychosocial treatments generally, even those that are evidence-based, decreasing the likelihood
280 of future engagement. Each of these harms may place the child at greater risk of problematic
281 outcomes over time.

282

283 *Suggested Strategies to Address Challenges in Practice Organization*

284 *Clinician-Focused Implementation Strategies*

- 285 • Develop ADHD-specific office workflows, as detailed in the “preparing the practice” section
286 of the PoCA (see supplemental information).
- 287 • Ensure that the practice is welcoming and inclusive to patients and families of all
288 backgrounds and cultures.
- 289 • Enable office systems to support communication with parents, education professionals, and
290 mental health specialists, possibly through electronic communication systems (discussed
291 below).
- 292 • Consider office certification as a patient- and family-centered medical home.
- 293 • If certification as a patient- and family-centered medical home is not feasible, implement
294 medical home policies and procedures including care conferences and management. Explore
295 care management opportunities, including adequate resourcing and payment, with third-party
296 payers.
- 297 • Identify and establish relationships with mental health consultation and referral sources in the
298 community and within region, if available, and investigate integration of services as well as
299 the resources to support them.
- 300 • Promote communication between ADHD care team members by integrating health and
301 mental health services and using collaborative care model treatments when possible.
- 302 • Be aware of the community mental health crisis providers’ referral processes, and be
303 prepared to educate families about evidence-based psychosocial treatments for ADHD across
304 the lifespan.

305

306 *Policy-Oriented Suggested Strategies*

- 307 • Encourage efforts to support the development and maintenance of patient- and family-
308 centered medical homes or related systems to enable patients with chronic complex disorders
309 to receive comprehensive care.
- 310 • Support streamlined, coordinated ADHD care across systems by providing incentives for the

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311 integration of health and mental health services and collaborative care models.

312 **Fragmentation of Care and Resulting Communication Barriers**

313

314 Multiple team members provide care for children and adolescents with ADHD, including
315 those in the fields of physical health, mental health, and education. Each of these systems has its
316 own professional standards and terminologies, environments, and hierarchical systems.
317 Moreover, they protect communication via different privacy rules: the Health Insurance
318 Portability and Accountability Act (HIPAA)²⁹ for the physical and mental health systems and the
319 Family Educational Rights and Privacy Act (FERPA)³⁰ for the education system. These factors
320 complicate communication not only within but also across these fields. The lack of
321 communication interferes with clinicians' abilities to make accurate diagnoses of ADHD and co-
322 occurring conditions, monitor progress in symptom reduction when providing treatment, identify
323 patient resources, and coordinate the most effective services for children and adolescents with
324 ADHD.

325 Electronic systems can help address these communication barriers by facilitating
326 asynchronous communication among stakeholders. This is particularly useful for disparate
327 stakeholders—such as parents, teachers, and clinicians—who often cannot all be available
328 simultaneously for a telephone or in-person conference. Electronic systems can also facilitate the
329 timely completion and submission of standardized ADHD rating scales, which are the best tools
330 to assess and treat the condition.³¹ Because implementation of electronic systems lies partially
331 within the PCC's control, additional information is provided below on the strengths and
332 weaknesses of a variety of such systems, including telemedicine.

333 *Stand-alone Software Platforms and Electronic Health Records*

334 Stand-alone software platforms and electronic health records (EHRs) have the potential
335 to improve communication and care coordination among ADHD care team members.
336 Commercially available stand-alone software platforms typically use electronic survey interfaces
337 (either web or mobile) to collect rating data from parents and teachers, use algorithms to score
338 the data, and display the results cross-sectionally or longitudinally for the clinician's review.
339 Advantages of stand-alone platforms include the fact that they are designed specifically for
340 ADHD care and can be accessed via the Internet through computers and mobile devices. Once
341 implemented, these user-friendly systems allow parents, teachers, and practitioners from multiple
342 disciplines or practices to conveniently complete rating scales remotely. Stand-alone platforms
343 also offer the ability to customize rating scales and their frequency of use for individual patients.
344 Submitted data are stored automatically in a database, mitigating the transcription errors that are
345 often associated with manual data entry. Data are available for clinical care, quality
346 improvement, or research, including quality metrics.

347 A substantial downside to stand-alone ADHD care systems is the lack of data integration
348 into EHRs. Practitioners must log into disparate systems for different facets of patient care: the
349 stand-alone system to track ADHD symptoms, and the EHR to track medications records, visit
350 notes, and patient or family phone calls. To achieve data accuracy in the 2 different systems, the
351 practitioner must copy medication information from the EHR into the stand-alone system and
352 ADHD symptom and adverse effect ratings from the stand-alone system into the EHR. In
353 addition, stand-alone systems require clinicians to log in before each visit to review the relevant

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354 ADHD care data. Patients may use a variety of ADHD stand-alone tracking systems, requiring
355 the PCC to remember several accounts and passwords in addition to their own office and hospital
356 EHR systems, creating an added burden that may reduce enthusiasm for such platforms. Finally,
357 stand-alone systems typically charge fees to support the maintenance of servers, cybersecurity,
358 and technical and customer support functionalities.

359 An issue over which the PCC has little control is the fact that other stakeholders may use
360 stand-alone systems inconsistently. Parents (who may themselves have ADHD) must log in to
361 the platform and complete the requisite ADHD rating scales. Teachers may be required to log in
362 and complete the evaluation process, often for several students, on top of their other obligations.
363 The fact that different pediatricians may use different systems, each with their own login and
364 interface, adds to the activity's complexity, particularly for teachers who need to report on
365 multiple students to a variety of PCCs.

366 *EHRs for ADHD Management*

367 EHRs can be adapted to improve the timely collection of parent and teacher ratings of
368 ADHD symptoms, impairment, and medication adverse effects. Some EHRs use an electronic
369 survey functionality or patient portal - similar to that provided by ADHD care stand-alone
370 systems—to allow parents' access to online rating scales. A clear advantage of these EHR
371 systems is that they increase the ability to access documentation about an individual patient's
372 past treatment modalities and medications in the same place as information about his or her
373 ADHD symptoms. These EHRs' functionality may facilitate other care-related activities,
374 including evidence-based decision support, quality improvement efforts, and outcomes
375 reporting.³²

376

377 Despite these benefits, there are numerous limitations to managing ADHD care with
378 EHRs. First, health care systems' confidentiality barriers often prevent teachers from entering
379 ratings directly into the child's medical record. The large number and heterogeneity of EHR
380 systems and their lack of interoperability are additional barriers to their use for ADHD care.³³
381 Even when institutions use the same vendor's EHR, exchanging respective ADHD
382 documentation among a variety of clinicians and therapists is frequently impossible.³⁴ The
383 inability to share information and the lack of interoperability often results in incomplete
384 information in the EHR about a given patient's interventions, symptoms, impairments, and
385 adverse effects over time. Systems for tracking and comparing these aspects of a patient's care
386 are not standard for most EHR packages. The ability to construct templates that are congruent
387 with a clinician's workflow may be limited by the EHR itself. ADHD functionality must often be
388 custom-built for each organization—a cumbersome, expensive, and lengthy process—resulting
389 in lost productivity, clinical effectiveness, and revenue.

390

391 *General Issues with ADHD Electronic Tracking Systems*

392

393 EHRs have been linked to increased clinician stress. For this reason, it is important to
394 consider the potential for added burden when either stand-alone or EHR-embedded systems are
395 used to facilitate ADHD care.³⁵ Although the use of electronic ADHD systems to monitor
396 patients remotely may be advantageous, clinicians and practices may not be equipped or staffed

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397 to manage the burden of additional clinical information arriving between visits (ie, intervisit
398 data).

399

400 Clinicians must also consider the liability associated with potentially actionable
401 information that families may report electronically without realizing the information might not
402 be reviewed in real time. Examples of such liabilities include a severe medication adverse effect,
403 free-text report of suicidal ideation, and sudden deterioration in ADHD symptoms and/or
404 functioning. In addition, parents and teachers may receive numerous requests to complete rating
405 scales, leading them to experience “survey fatigue” and ignore the requests to complete these
406 scales. Conversely, they may forget how to use the system if they engage with it on an infrequent
407 basis. Some parents or teachers may be uncomfortable using electronic systems and within the
408 medical home might prefer paper rating scales, and others may not have ready access to
409 electronic systems or the Internet.

410

411 *Telemedicine for ADHD Management*

412

413 Telemedicine is a new and rapidly growing technology that has the potential—when
414 properly implemented within the medical home—to expand access to care and to improve
415 clinicians’ ability to communicate with schools, consultants, care management team members,
416 and especially patients and parents.³⁶⁻³⁸ Well-run telemedicine programs offer some promise as a
417 way to deliver evidence-based psychosocial treatments, although few evidence-based programs
418 have been tested via telemental health trials.^{39,40} Telemedicine is one of the foundations of the
419 new advanced medical home and offers advantages including:

- 420 • Offering communication opportunities (either face-to-face and synchronous as a
421 conversation, or asynchronous as messaging), which can be prescheduled to minimize
422 interruption of office flow.
- 423 • Enabling communication on a one-on-one basis or one-to-many basis (for conference
424 situations).
- 425 • Replacing repeated office visits for patient follow-up and monitoring, which reduces time
426 and the need for patients to travel to the PCC’s office.
- 427 • Facilitating digital storage of the telemedicine episode and its incorporation into multiple
428 EHR systems as part of the patient record.
- 429 • Enhancing cooperation among all parties in the evaluation and treatment processes.

430

431 Telemedicine has great potential but needs to be properly implemented and integrated
432 into the practice workflow to achieve maximum effectiveness and flexibility. Although some
433 new state insurance regulations mandate payment for telemedicine services, such mandates have
434 not yet been implemented in all states, limiting telemedicine’s utility. Finally, payment for
435 services needs to include the added cost of equipment and staff to provide them.

436

437 *Suggested Strategies to Address Fragmentation of Care and Resulting Communication 438 Barriers*

439

440 *Clinician-Focused Implementation Strategies*

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- Ensure the practice is aware of, and in compliance with, HIPAA and FERPA policies, as well as confidentiality laws and cybersecurity safeguards that impact EHRs' communication with school personnel and parents.⁴¹
- Maintain open lines of communication with all team members involved in the patient's ADHD care within the practical limits of existing systems, time, and economic constraints. As noted, team members include teachers, other school personnel, clinicians, and mental health practitioners. This activity involves a team-based approach and agreeing on a communication method and process to track ADHD interventions, symptoms, impairments, and adverse effects over time. Communication can be accomplished through a variety of means, including electronic systems, face-to-face meetings, conference calls, emails, and/or faxes.
- Consider using electronic communication via stand-alone ADHD management systems and electronic portals, after evaluating EHR interoperability and other administrative considerations.
- Integrate electronic ADHD systems into the practice's clinical workflow: decide who will review the data and when, how actionable information will be flagged and triaged, how information and related decision-making will be documented in the medical record, etc.
- Set and clarify caregivers' expectations about the practice's review of information provided electronically versus actionable information that should be communicated directly by phone.
- Promote the implementation of telemedicine for ADHD management in states where payment for such services is established; ensure the telemedicine system chosen is patient centered, HIPAA and FERPA compliant, and practice enhancing.

Policy-Oriented Suggested Strategies

- Promote the development of mechanisms for online communication to enhance ADHD care collaboration, including electronic portals and stand-alone ADHD software systems, to serve as communication platforms for families, health professionals, mental health professionals, and educators. Ideally, these portals would be integrated with the most commonly used EHR systems.
- Advocate for regulations that mandate a common standard of interoperability for certified EHR systems. Interoperability facilitates the use of EHRs as a common repository of ADHD care information and communication platform for ADHD care team members.⁴¹
- Advocate for exceptions to HIPAA and FERPA regulations to allow more communication between education and health and mental health practitioners while maintaining privacy protections.
- Ensure that billing, coding, and payment systems provide adequate resources and time for clinicians to communicate with teachers and mental health clinicians, as discussed previously.
- Provide incentives for integration of health and mental health services, collaborative care models, and telemedicine to facilitate communication among ADHD care team members, including telemedicine services that cross state lines.
- Fund research in telehealth to learn more about who responds well to these approaches and whether telehealth is feasible for underserved populations.

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486 CONCLUSION

487 Appropriate and comprehensive ADHD care requires a well-trained and adequately
488 resourced multidisciplinary workforce, with office workflows that are organized to provide
489 collaborative services that are consistent with a chronic care model and to promote
490 communication among treatment team members.⁴²⁻⁴⁵ Many barriers in the current health care
491 system must be addressed to support this care.

492 First and foremost, the shortage of clinicians, such as child and adolescent psychiatrists
493 and developmental-behavioral pediatricians, who provide consultation and referral ADHD care,
494 must also be addressed. The shortages are driven by the lack of residency and other training
495 programs for pediatric clinicians in the management of ADHD and other behavioral health
496 issues; the lack of return on investment in the additional training and debt required to specialize
497 in this area; and inadequate resourcing at all levels of ADHD care. The shortage is exacerbated
498 by geographic maldistribution of practitioners and lack of adequate mental health training as a
499 whole during residency and in CME projects. These challenges must be addressed on a system-
500 wide level.

501 A significant review and change in the ADHD care payment for cognitive services is
502 required to needed to ensure that practitioners are backed by appropriate resources that support
503 the provision of high-quality ADHD care. The lack of adequate compensation for ADHD care is
504 a major challenge to reaching children and adolescents with the care they need. Improved
505 payment is a major need to encourage primary care clinicians to train in ADHD subspecialty care
506 and incentivize child and adolescent psychiatry and developmental-behavioral pediatrics
507 practitioners to provide ADHD care in the primary care setting, so the provision of such care
508 does not result in financial hardship for the families or the practice. Improvement should also
509 include changes to payer policies to improve compensation for care coordination services and
510 mental health care.

511 As the pediatrician is often the first contact for a parent seeking help for a child with
512 symptoms that may be caused by ADHD, barriers to payment need to be addressed before
513 providing these time-consuming services. Some insurance plans direct all claims with a
514 diagnosis reported by *International Classification of Diseases, Tenth Revision, Clinical
515 Modification (ICD-10-CM)* codes F01-F99 to their mental and behavioral health benefits system.
516 Because pediatricians are generally not included in networks for mental and behavioral health
517 plans, this can create delays or denials of payment. This is not always the case, though, and with
518 a little preventive footwork, practices can identify policy guidelines for plans that are commonly
519 seen in the practice patient population.

521 The first step in identifying coverage for services to diagnose or treat ADHD is to
522 determine what payment guidelines have been published by plans that contract with your
523 practice. Many health plans post their payment guidelines on their Web sites, but even when
524 publicly available, the documents do not always clearly address whether payment for primary
525 care diagnosis and management of ADHD is covered. It may be necessary to send a written
526 inquiry to provider relations and the medical director of a plan seeking clarification of what
527 diagnoses and procedure codes should pass through the health benefit plan's adjudication system
528 without denial or crossover to a mental health benefit plan. It is important to recognize that even
529

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530 with documentation that the plan covers primary care services related to ADHD, claims
531 adjudication is an automated process that may erroneously cause denials. Billing and payment
532 reconciliation staff should always refer such denials for appeal.

533 Once plans that do and do not provide medical benefits for the diagnosis and treatment of
534 ADHD have been identified, advocacy to the medical directors of those plans that do not
535 recognize the role of the medical home in mental health care can be initiated. The AAP template
536 letter, Increasing Access to Mental Health Care, is a resource for this purpose. Practices should
537 also be prepared to offer advance notice to parents when their plan is likely to deny or pay out of
538 network for services. A list of referral sources for mental and behavioral health is also helpful for
539 parents whose financial limitations may require alternative choices and for patients who may
540 require referral for additional evaluation.

541 For services rendered, identify the codes that represent covered diagnoses and services,
542 and be sure that these codes are appropriately linked and reported on claims.

543 When ADHD is suspected but not yet diagnosed, symptoms such as attention and
544 concentration deficit (R41.840) should be reported. Screening for ADHD in the absence of signs
545 or symptoms may be reported with code Z13.4, encounter for screening for certain
546 developmental disorders in childhood. *Current Procedural Terminology* (CPT) codes 96110 and
547 96112-96113 should be reported for developmental screening and testing services.

548 Services related to diagnosis and management of ADHD are more likely to be paid under
549 the patient's medical benefits when codes reported are not those for psychiatric or behavioral
550 health services. Reporting of evaluation and management (E/M) service codes based on face-to-
551 face time of the visit when more than 50% of that time was spent in counseling or coordination
552 of care will likely be more effective than use of codes such as 90791, psychiatric diagnostic
553 evaluation. CPT E/M service guidelines define counseling as a discussion with a patient or
554 family concerning one or more of the following areas:

- 555 • Diagnostic results, impressions, or recommended diagnostic studies
- 556 • Prognosis
- 557 • Risks and benefits of management (treatment) options
- 558 • Instructions for management (treatment) or follow-up
- 559 • Importance of compliance with chosen management (treatment) options
- 560 • Risk factor reduction
- 561 • Patient and family education

563 Finally, staff should track claim payment trends for services related to ADHD, including
564 the number of claims requiring appeal and status of appeal determinations to inform future
565 advocacy efforts and practice policy.

566

567 Many AAP chapters have developed pediatric councils that meet with payers on pediatric
568 coding issues. Sharing your experiences with your chapter pediatric council will assist in its
569 advocacy efforts. AAP members can also report carrier issues on the [AAP Hassle Factor Form](#).

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570 These system-wide barriers are challenging, if not impossible, for individual practitioners
571 to address on their own. Practice organization and communication changes can be made,
572 however, that have the potential to improve access to ADHD care. Clinicians and other
573 practitioners can implement the office work-flow recommendations made in the “preparing the
574 practice” section of the updated PoCA (see supplemental information). Implementing a patient-
575 and family-centered medical home model, co-locating health and mental health services, and
576 adopting collaborative care models can also help overcome communication barriers and
577 minimize fragmentation of care. It is noted that these models must be adequately resourced to be
578 effective.

579 Finally, practitioners can implement innovative communication and record-keeping
580 solutions to overcome barriers to ADHD care. Potential solutions could include the use of EHRs,
581 other electronic systems, and high-quality telemedicine to support enhanced communication and
582 record-keeping on the part of myriad ADHD care team members. These solutions can also aid
583 with monitoring treatment responses on the part of the child or adolescent with ADHD.
584 Telemedicine also has the distinct benefit of compensating for the maldistribution of specialists
585 and other clinicians who can treat pediatric ADHD.

586 Many stakeholders have a role in addressing the barriers that prevent children and
587 adolescents from receiving needed evidenced-based treatment for ADHD. Pediatric councils, the
588 national AAP, and state and local AAP chapters must be advocates for broad changes in training,
589 continuing medical education, and payment policies to overcome the systemic challenges that
590 hamper access to care. On an individual level, practitioners can effect change in their own
591 practice systems and professional approaches and implement systems that address fragmentation
592 of care and communication. Practitioners are important agents for change in ADHD care. The
593 day-to-day interactions that practitioners have with patients, families, educators, payers, state
594 insurance regulators, and others can foster comprehensive, contemporary, and effective care that
595 becomes a pillar of advocacy and change.

596

Systemic Barriers to the Care of Children and Adolescents with ADHD

597 **ABBREVIATIONS**

- 598 • AAP, American Academy of Pediatrics
- 599 • ACO, accountable care organization
- 600 • ADHD, attention-deficit/hyperactivity disorder
- 601 • CDC, Centers for Disease Control and Prevention
- 602 • CME, continuing medical education
- 603 • EHR, Electronic health records
- 604 • FERPA, Family Educational Rights and Privacy Act
- 605 • FDA, US Food and Drug Administration
- 606 • HIPAA, Health Insurance Portability and Accountability Act
- 607 • PCC, primary care clinicians
- 608 • PoCA, process of care algorithm

610 **SUBCOMMITTEE ON CHILDREN AND ADOLESCENTS WITH ATTENTION- 611 DEFICIT/HYPERACTIVITY DISORDER**

612 The Council on Quality Improvement and Patient Safety oversees the Subcommittee

613
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636 **DISCLOSURES:**

Systemic Barriers to the Care of Children and Adolescents with ADHD

639 All authors have filed conflict of interest statements with the American Academy of Pediatrics
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647

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