Care of Children with Autism Spectrum Disorder

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KEYWORDS

- Autism spectrum disorder • Physician's role • Medical home
- Co-occurring conditions

KEY POINTS

- Physicians play an important role in the identification of children with possible autism spectrum disorder (ASD).
- Children with ASD often have co-occurring medical, mental health, and educational needs.
- Physicians need to refer children and families for appropriate diagnosis and treatment.
- Physicians should provide a medical home for the child with ASD.

INTRODUCTION

Autism Is Common and Complex

Recent data from the Centers for Disease Control and Prevention (CDC) and the Autism and Developmental Disabilities Monitoring (ADDM) network estimate that by age 8 years, 1 in every 68 children has a diagnosis of autism spectrum disorder (ASD). The average age of diagnosis for children has remained stable at 4.5 years of age.[1] Children having adequate language and cognitive skills are often not diagnosed until they enter school. As a result, many primary care physicians (PCPs) will be faced with the question "Doctor, does my child have autism?"

Diagnostic Criteria for Autism Spectrum Disorder

In addition to being common, ASD is also complex. In May 2013, new diagnostic criteria for ASD were published in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5).[2] The DSM-5 is a manual that presents a classification of mental disorders and diagnostic criteria used to identify and diagnose mental disorders. Perhaps the most notable change in the DSM-5 ASD criteria is the elimination of ASD subtypes (Asperger Syndrome, Autistic Disorder, Pervasive Developmental

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Disorder, Not Otherwise Specified,(PDD_NOS), Childhood Disintegrative Disorder). The new DSM-5 criteria allow for a single categorical diagnosis of ASD. The diagnostic criteria are now combined into 2 core symptom areas: deficits in social relatedness and social communication, and repetitive and restricted patterns of behavior. However, the behaviors and symptoms that were previously used to diagnose ASD are largely the same. Autism is still autism. The DSM-5 recommends that the diagnostician identify "specifiers" about the individual with ASD, so that providers will have a better understanding of areas of strength and needs. The DSM-5 diagnostic criteria for ASD can be found in the DSM-5[2] or at http://www.cdc.gov/ncbddd/autism/hcp-dsm.html.

A diagnosis of ASD is given when individuals meet *all 3 criteria* in the area of deficits in social communication/social interaction, and *at least 2 criteria* in the area of repetitive and restricted behaviors/interests. Symptoms must be present in early childhood, cause significant impairment in functioning, and are not better accounted for by intellectual disability or global developmental delay. Recent changes to ASD criteria in the DSM-5 should not affect individuals previously diagnosed with an ASD using the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, Text Revision, (DSM-IV-TR).[3] According to the DSM-5, if an individual was diagnosed using the DSM-IV-TR, he or she is considered to meet ASD criteria using DSM-5; therefore, diagnoses given using DSM-IV are not being removed based on the new criteria (**Box 1**).[2]

Roles for the Primary Care Physician

The primary care physician (PCP) plays a vital role for children with ASD. This article focuses on the roles of PCPs in the Medical Home, which include:

1. Performing developmental surveillance, screening, and referral
2. Assisting in the diagnostic process
3. Identifying and managing co-occurring conditions
4. Supporting children and families across systems

MEDICAL HOMES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

Pediatricians and PCPs are likely to be familiar with the definition and principles of the family-centered (or patient-centered) medical home.[4–6] The pediatric medical home is "a model of delivering primary medical care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."[5]

Box 1
Major changes to the DSM-5, Autism Diagnostic Criteria

Major Changes to the DSM-5 Include:

Category name changed from Pervasive Developmental Disorders to Autism Spectrum Disorders

- Elimination of specific ASD subtypes (Asperger Syndrome, PDD-NOS, Autistic Disorder, Childhood Disintegration Disorder) and a move to one diagnosis, Autism Spectrum Disorder
- Reduction/combination of core symptoms categories from 3 to 2 (socialization and communication are now one combined category, repetitive and restricted behaviors/interests). Inclusion of sensory differences in criteria
- Recommendation to identify "specifiers" to better understand the individual needs of each child with ASD (cognitive and language ability, level of supports needed, co-occurring medical and mental health conditions)
- Inclusion of co-occurring mental health disorders (eg, attention-deficit/hyperactivity disorder)

However, PCPs may be less familiar with building a medical home for children with ASD. Children with ASD are less likely to be served in a medical home.[7] A medical home for children with ASD requires substantial collaboration and coordination across systems, and may be more complicated than medical homes for children with other chronic conditions.[8] A physician survey found that physicians feel less competent in caring for children with ASD (and other neurodevelopmental conditions) than with children with other chronic medical conditions.[9] In a series of focus groups, Carbone and colleagues[10] explored the perspectives of parents and pediatricians with regard to caring for children with ASD within the medical home. Carbone found parents to be unfamiliar with the concept of medical home. After defining it, he found that parents of children with ASD did not expect to receive help with comprehensive and coordinated care from their physicians, and believed that their physicians were unlikely to be able to provide the services described. Physicians understood what the families of children with ASD faced, but considered themselves ill-prepared to meet the array of needs (**Box 2**).

PERFORMING DEVELOPMENTAL SURVEILLANCE, SCREENING, AND REFERRAL

Although this article focuses on ASD in the school-age child, many families note symptoms years earlier. The diagnostic journey for families of children with possible ASD is often difficult, time-consuming, and expensive.[11,12] Families are often frustrated by their physicians' lack of attention to red-flag symptoms for ASD, and report that referral for diagnosis and treatment is often delayed months or years following initial reported concerns.[5,7,13–15] Although ASD symptoms can be recognized at or before the age of 2 years in most children, the average age at which a child receives an ASD diagnosis is 4.5 years (**Box 3**).[1]

With the growing evidence that early intervention improves developmental outcomes for even very young children,[16] much of the focus by the American Academy of Pediatrics (AAP) has been on autism surveillance and screening in toddlers. A significant percentage of children, however, either are not screened as toddlers or do not have symptoms that can be clearly recognized until school-age, when universal screening is no longer recommended (**Box 4**).

Identification of the child with developmental delays and/or autism symptoms is recognized to be part of the physician's responsibility in providing well child care.[17] Physicians often hold the keys to access evidence-based interventions that yield the best outcomes for the futures of children with ASD.[18] In 2007, the AAP published 2 clinical reports on ASD. The first, *Identification and Evaluation of Children with Autism Spectrum Disorder* (http://pediatrics.aappublications.org/content/120/5/1183.full) provides background information and an algorithm to help PCPs develop

Box 2
AAP guidelines for surveillance and screening

"Surveillance entails asking parents at every well-child visit about developmental or behavioral concerns, observing for early signs of autism, and documenting a family history of ASDs."

"Screening involves administering an autism-specific test to all children at their 18- and 24- [or 30-] month office visits, not just to children who demonstrate autistic behaviors."

From Carbone PS, Farley M, Davis T. Primary care for children with autism. Am Fam Physician 2010;8:453–60.

Box 3
Possible red flags for ASD

A child with ASD might:

- Not respond to their name by 12 months of age
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

From Centers for Disease Control and Prevention. Autism spectrum disorder. Signs and symptoms. Available at: http://www.cdc.gov/ncbddd/autism/signs.html. Accessed September 19, 2014.

Box 4
ASD symptoms in the school-age child

Doctor, Does My Child Have Autism?

Symptoms in the School-Age Child

My child…

- Has no friends
- Likes to play alone
- Has poor eye contact
- Repeats lines from TV
- Cannot carry on a conversation
- Has intense interests that occupy all of his/her time
- Lines up his/her toys
- Does strange things with his/her hands
- Has to have things a certain way
- Only talks about his/her interests
- Has difficulty with changes in routines
- Gets teased
- Has problems with transitioning from activity to activity
- Is a picky eater and will only eat certain types and textures of foods
- Has extreme tantrums
- Does not understand social cues

a strategy for early identification of children with ASD.[19] Pediatricians are to incorporate developmental surveillance at every well child visit, and conduct routine screening of all infants for ASD at the 18-month and 24- or 30-month visits, as well as at any visit that a parent raises concern. Children who fail autism screens are to be referred both to the early intervention system and to developmental specialists for definitive diagnosis of ASD. At present, the AAP does not recommend universal screening for school-age children. However, there are some evidence-based screening tools that can help determine whether further evaluation is needed. For a review of characteristics of some of the school-age screening tools, see Norris and Lecavalier[20] (**Table 1**).

The Primary Care Physician's Role in the Diagnosis of Autism Spectrum Disorder

Beyond screening, who can diagnose ASDs? There is substantial variability of symptoms, which makes diagnostic decision-making challenging. Definitive diagnosis of ASD may be beyond the scope of primary care practice. The AAP recommends that children identified as being at risk for a diagnosis of ASD be referred for a comprehensive developmental and diagnostic assessment. ASD diagnosis is often given by pediatric subspecialists such as developmental-behavioral pediatricians, neurologists, child psychiatrists, or licensed psychologists. Expertise in the area of ASD has been found to be more important to accurate diagnosis than particular credentials.[19,21,22] The insurance systems in many states, however, require that a medical diagnosis of ASD be given only by a physician or psychologist.[18]

Medical Diagnosis of Autism Spectrum Disorder

A medical diagnosis of ASD is something of a misnomer. Autism is not "a disease," but rather a behaviorally defined disorder resulting from atypical development of the immature brain.[23] Use of the term medical diagnosis conflates categorical DSM-5 diagnosis and etiologic diagnosis. Both are important, but each requires PCPs to collaborate with different groups of specialists.

Although children with ASD by definition have deficits in social communication, social interaction and restricted, repetitive patterns of behavior, there is a wide spectrum of symptom presentation and severity. Unfortunately, there is no biological marker that predicts the DSM-5 diagnosis of ASD. Best practices in ASD diagnostic evaluation require the assessment of multiple areas of functioning. A comprehensive evaluation must include a parent interview and an observation of the child's current functioning by a clinician experienced with ASD.[24]

Table 1
ASD screening tools for the school-age child

Screening Tool	Age Range (y)	How to Access?
Social Communication Questionnaire (SCQ)	4 to adult	www.wpspublish.com
Social Responsiveness Scale (SRS)	4–18	www.wpspublish.com
Autism Spectrum Screening Questionnaire (ASSQ)	7–16	http://scatn.med.sc.edu/screening/ehlers-assq-1999[1].pdf
Childhood Autism Spectrum Test (CAST)	4–11	http://www.autismresearchcentre.com/arc_tests

As per AAP recommendations, physicians who are providing care for a child with symptoms of autism are to refer to developmental specialists or interdisciplinary autism diagnostic teams, which are often located within urban, university-based settings. Follow through with these referrals may be problematic given that subspecialty services are limited in number and may not be accessible to rural and underserved populations. Furthermore, wait times for diagnostic evaluations at specialized diagnostic centers are long and may exceed 9 to 12 months, thus delaying children's diagnosis of ASD.[18] However, this should neither delay the assessment of the child in the educational system nor the treatment of co-occurring conditions in the medical home. Both families and physicians need to be aware that children may be eligible for an educational identification of Autism and for special education services through the public school district without having a clinical DSM-5 diagnosis of ASD. The school district can complete an educational evaluation to determine the child's need for special education services and support through the development of an Individualized Education Plan (IEP). Families may be told that a "private" or "medical" diagnosis of ASD is required for the child to be eligible for educational support. However, this is not true, and violates the requirements of the Individuals with Disabilities Education Act (IDEA).[17]

The PCP is not well positioned to determine whether the child meets DSM-5 criteria for ASD. However, the PCP has a significant role in the child's medical management. Every child with cognitive impairment and/or suspected ASD should see a physician with the aim of finding the underlying cause of the developmental problems. Diagnosing the underlying cause for ASD may require the PCP to coordinate genetic testing and referral to a genetic subspecialist.

IDENTIFYING AND MANAGING CO-OCCURRING CONDITIONS

Children with ASD have the same basic health needs as typically developing children, but are significantly more likely than other children to have a variety of medical and psychiatric symptoms and diagnoses, more frequent physician visits, and to be prescribed psychotropic medication.[25–28] The second Clinical Report published by the AAP in 2007 was *Management of Children with Autism Spectrum Disorder* (http://pediatrics.aappublications.org/content/120/5/1162.full). This report provides guidance to PCPs on management of the child with ASD in the medical home.

Physicians in the medical home should provide medical care and, when necessary, refer to subspecialty medical care. PCPs are also in the position to direct families to appropriate behavioral specialists for disruptive or maladaptive behavior (**Box 5**).[8,27]

Box 5
Physician's roles: identifying and managing co-occurring conditions

- Review commonly presenting medical issues that co-occur in ASD, including seizure, gastrointestinal symptoms and dietary restrictions, and sleep disorders. Consult with necessary medical subspecialists.
- Review commonly presenting behavioral/psychiatric issues that co-occur in ASD, including attention-deficit/hyperactivity disorder, anxiety, obsessive-compulsive disorder, mood disorder, and disruptive behavior. Consult with necessary behavioral subspecialists.
- Collaborate with both medical and behavioral specialists with regard to medication management of co-occurring symptoms.

Physician Roles in Managing Medical Co-Occurring Conditions

Seizures, gastrointestinal problems, and sleep disturbance are commonly reported by parents of children with ASD, and can cause both children and families considerable distress.[19,29]

- Seizures occur in approximately 25% to 30% of individuals with ASD. Children who have developmental delay or intellectual disability associated with their ASD are at particularly high risk for seizures. Just as for typically developing children who have seizures, PCPs may need to consult child neurologists regarding medication management.[19,29]
- There has been debate about the frequency and nature of gastrointestinal disorders in children with ASD.[29] Children with ASD with gastrointestinal symptoms deserve the same thorough diagnostic evaluation as a child who does not have ASD.[30] Problem behaviors can occur because of underlying gastrointestinal symptoms. Children with ASD can have very restricted eating, and may have more constipation than children with a more normal diet. Treatment of constipation can improve toilet training and decrease disruptive behaviors.[10,25,29–31]
- Sleep disorders are more common in children with ASD than in typically developing children.[8,10,32] Melatonin is often effective for sleep-onset disorders in children with ASD[33] and seems to be safe. PCPs should become comfortable with prescribing melatonin. Children who have severe sleep problems and fail to respond to behavioral interventions or melatonin may benefit from being evaluated in a sleep disorders clinic.

Physician Roles in Managing Behavioral Co-Occurring Conditions

Children with ASD often have co-occurring disruptive behavior and may meet criteria for co-occurring psychiatric diagnoses.[27,34,35] Tantrums and aggression are particularly difficult for families of children with ASD.[36] Children with ASD who have behavioral deterioration need to have a physical examination with consideration that pain or discomfort may be the cause. Physicians should work with behavioral specialists to identify the functions of disruptive behavior. Functional analysis of behavior can inform both appropriate behavioral intervention and medication management. Unfortunately, PCPs often have difficulty in finding appropriately trained mental health providers who can help determine the causes and treatments for disruptive behaviors and who will communicate regularly with the medical home.[36] Understanding which factors exacerbate or maintain the behavior is critically important to designing behavioral interventions, and may be important in determining appropriate use of psychotropic medications.[8] A handout from the AAP's 2012 Autism Toolkit on Behavioral Principles is available at http://www.medicalhomeinfo.org/downloads/pdfs/Behavioral%20Principles.F0620.pdf.

The PCP can expect to receive specific details about the child that support the diagnosis from the diagnostician.[24] The report should also include treatment recommendations that are specific to the child's autism symptoms and co-occurring conditions. The PCP will need to have some familiarity with commonly recommended evidence-based treatments.

One of the most requested evidenced-based treatments for ASD is applied behavior analysis (ABA).[37,38] ABA is based on the science of learning and behavior, and is one of the only scientifically based treatments for children with ASD.[39] ABA uses the "laws" of behavior to promote skill acquisition (eg, language, adaptive

skills, and academic skills) and decrease unwanted behaviors (eg, aggression, self-injury, and repetitive behaviors). ABA interventions are structured and systematic. These interventions involve data collection on target skills and behaviors with the use of positive strategies for behavior change. ABA-based interventions may include discrete trial teaching, verbal behavior approaches, and pivotal response training. ABA providers can be found at http://bacb.com/. In addition, Autism Speaks has developed a parent toolkit describing ABA services. The toolkit can be downloaded at http://www.autismspeaks.org/family-services/toolkits/.

Physician Roles in Managing Psychotropic Medications

There is still little evidence that medication effectively treats the social and communication impairments of ASD.[40,41] Although risperidone (Risperdal) and aripiprazole (Abilify) are approved by the Food and Drug Administration for ASD and have been shown to decrease irritability and disruptive behavior, a substantial percentage of children on atypical neuroleptics experience excessive weight gain, limiting the use of these medications.[42,43] PCPs may or may not be comfortable with medicating the symptoms of attention-deficit/hyperactivity disorder (ADHD) and anxiety that frequently co-occur with ASD. Many physicians may consult psychiatrists or developmental-behavioral pediatricians who are more familiar with medications. Given the limited access families often have to developmental-behavioral pediatricians and psychiatrists, PCPs may need to collaborate with these subspecialists to prescribe and manage psychotropic medications (**Box 6**).[8,10]

BARRIERS TO THE PRIMARY CARE PHYSICIAN'S ROLE

Barriers to Adoption of Best Practices in the Diagnosis of Children with Autism Spectrum Disorder

As already noted, there is a lack of clarity with regard to what is meant by screening, educational identification, and clinical diagnosis of ASD among both the educational and the broader health care systems, creating a disconnect between the systems.[22] The disconnect between the health care, educational, and family systems frequently results in delayed diagnosis of ASD because symptoms are initially overlooked or misdiagnosed. Children in rural or underserved populations are often diagnosed later because of limited access to diagnostic services and the lack of knowledge and experience with ASD across these systems.[44]

Barriers to Adoption of Best Practices in Early Identification of Children with Autism Spectrum Disorder

Physicians face significant challenges in adopting best practices. It has only been over the last 15 to 20 years that ASD has been recognized to be a common, rather than an uncommon disorder.[45] Many physicians still receive little training about ASD. Families, physicians, and educators may have confusion over the roles that PCPs should play in

Box 6
CDC resources

The Centers for Disease Control and Prevention (CDC) has published a free resource to help PCPs with identification and management of children with ASD. *Autism Case Training: Specific Anticipatory Guidance* is available at: http://www.cdc.gov/ncbddd/actearly/autism/case-modules/anticipatory-guidance/page3b.html.

the diagnostic process. If the PCP is unable to make a clinical diagnosis of ASD based on DSM-5 criteria, it is appropriate to refer the child for a more comprehensive diagnosis. Unfortunately, autism diagnostic teams often have long wait lists, leading to lengthy delays between a failed screen and definitive diagnosis, thus increasing parent and physician level of frustration and anxiety.[18] Families of children who fail autism screening tools often wait months between screening and appointments for definitive diagnosis. During this time, these families will need ongoing support from the medical home.

Barriers to Adoption of Best Practices in Management of Co-Occurring Conditions

There are barriers to providing optimal care to children with ASD.

- Communication impairment often limits the child's ability to communicate discomfort, and difficult behaviors may make adequate physical examination difficult.
- The complexity of ASD warrants collaboration across systems (ie, medical, mental health, educational, family, and community), which can be complicated.
- Parents may also have beliefs about the cause of the child's autism that physicians do not share, which may adversely affect the family's relationship with the medical home. Parent refusal or delay of vaccines is common and particularly challenging for many physicians.[9,46,47] Many, if not most families of children with ASD also use complementary and alternative medicine (CAM). Physicians feel inadequately prepared to discuss CAM, and report the CAM use is a barrier to providing primary care.[9,48] Families and physicians may disagree about the use of CAM, and many popular treatments have not been well studied and have limited evidence for efficacy.[49] However, it is important to understand parental beliefs. The AAP recommends family-centered care, which includes open communication and sensitivity when managing differences around immunizations, treatments, and philosophy.[9] The CDC and AAP have developed resources to support physicians and educate families as they negotiate differences in beliefs.[50,51]

OPPORTUNITIES TO SUPPORT CHILDREN AND FAMILIES ACROSS SYSTEMS

This article highlights the vital role of the PCP in identifying, managing, and supporting school-age children with ASD within the medical home. Gaining familiarity with symptom presentation, course, and the most recent DSM-5 diagnostic criteria for ASD will help PCPs recognize this disorder in the school-age population they serve. Once the concern for ASD is raised, the PCP should then refer for diagnostic evaluation by an autism specialist and evaluation by the child's educational team.[24] These 2 referrals are the most important the PCP can make to ensure the child receives an accurate diagnosis and appropriate educational and behavioral services. The diagnostic process may be a long and stressful, and families will require support from their PCP. One way to reduce stress is to refer the child for intervention to treat specific symptoms while the child is waiting for the diagnostic evaluation. For example, the child may benefit from a referral to community behavioral and mental health agencies to address symptoms that commonly occur with ASD (eg, anxiety, depression, behavior problems, activity level). As mentioned earlier, the educational team should not wait on clinical diagnoses before beginning the evaluation process to determine if the child is eligible for special education services. Making these referrals will help support families while they wait for a definitive diagnosis of ASD.

The PCP should expect to receive a report from the autism diagnosticians that fully describes the individual with ASD in terms of symptom severity, cognition and

language abilities, and co-occurring medical and behavioral conditions. This information should guide the PCP in providing optimum care for the school-age child with ASD in the medical home. In summary, PCPs plays an integral role in the identification, management, and care for their patients with ASD. The following case illustrates the key points of this article.

Case in Point

Caitlyn is an 8-year-old girl who is in the second grade and has experienced some difficulty with learning to read. She does not have an IEP through the public school system. Caitlyn's 2-year-old brother has severe developmental delays, and you had referred him for evaluation, including genetic testing. He was just diagnosed with Fragile X syndrome. Caitlyn's parents are overwhelmed with the needs of both children. Caitlyn is noncompliant, has frequent tantrums, and has difficulties with completing her homework. Although she has fewer disruptive behaviors at school, at the recent Parent-Teacher meeting her parents were told that Caitlyn has attention problems, is anxious with any change to daily routine, and is very rude to her classmates. Caitlyn seems to want friends, but she is rarely included in any play at recess. Caitlyn's parents tell you that she is never invited to activities outside of school. Caitlyn's parents need some help, and ask what they should do next.

You think that Caitlyn's problems may be related to her learning problems or possibly ADHD, but you are concerned about the school's report of social problems. You ask Caitlyn's parents to complete the Childhood Autism Screening Test (CAST). The score on the CAST suggests referral for a comprehensive autism evaluation. You refer Caitlyn to the nearest autism diagnostic center, which is 3 hours away.

Question 1

Given the concerns, does Caitlyn need to "fail" a screen to be referred?

Answer 1

No. Although the CAST may help you discuss your concerns with Caitlyn's parents who are just adjusting to their son's diagnosis and who have no knowledge of autism, the school's concerns about Caitlyn's social difficulties and problems with transition is sufficient reason for referral.

After you complete the referral, Caitlyn's parents complete the required paperwork, and are told that the wait list for the diagnostic center is approximately 6 months. As a result of her brother's Fragile X diagnosis, Caitlyn is also tested and also is found to have Fragile X syndrome. Caitlyn was suspended from school for 3 days because she attacked a teacher.

Question 2

Which of the following would be the most appropriate next step for Caitlyn and her family?

A. Tell the family that it is likely that Fragile X syndrome explains Caitlyn's behaviors, and refer the family to the local Fragile X support group. Cancel the autism diagnostic evaluation appointment.
B. Ask the school to do complete psychoeducational testing to look at Caitlyn's learning strengths and weaknesses, and to determine whether Caitlyn needs an IEP.
C. Wait for the recommendations from the autism diagnostic clinic appointment before doing any more referrals, because you know that Fragile X syndrome can be associated with ASD.

D. Refer the family to a behavioral therapist who has expertise in treating children with ADHD and oppositional behaviors.
E. B and D

Answer 2

E. Although the underlying etiology for Caitlyn's learning and behavioral problems is likely to be Fragile X syndrome, she needs an evaluation to determine whether she meets DSM-5 criteria for ASD, ADHD, anxiety, and/or possible learning disabilities. The school has a responsibility to determine whether Caitlyn needs educational supports. As there is a concern about ASD, it might be helpful to advocate for an autism educational specialist to be involved. Caitlyn also has very challenging behaviors at home and at school, and her family would benefit from working with a therapist who could help them manage her challenging behaviors. You could also help by assisting in an evaluation to see whether Caitlyn may have ADHD symptoms that could potentially respond to medication management.

Caitlyn is seen by the autism diagnostic team. As per best practice recommendations, the autism diagnostic team includes information from your office, from Caitlyn's school, and from her family. The team administers gold-standard autism diagnostic tools, which include a parent interview [Autism Diagnostic Interview-Revised (ADI-R)] and a play-based assessment (Autism Diagnostic Observation Schedule, Second Edition, ADOS-2). Their impressions are as follows:

1. Meets DSM-5 Criteria for ASD
   Severity of social communication: Level 1 (requires support)
   Severity of restricted, repetitive behaviors: Level 2 (requires substantial support)
2. Specifier: Without accompanying intellectual impairment (IQ 90) but with significant variability between verbal and performance IQ, at risk for learning disability
3. Specifier: With fluid speech, but with pragmatic (social) language difficulty
4. Specifier: Associated with Fragile X syndrome. Complicating medical problem: sleep-onset disorder
5. Specifier: Associated with ADHD and anxiety as per evaluation from PCP, school educational specialists, and information provided by behavioral therapist

The recommended recording procedure for autism diagnosis offers an opportunity to clearly understand a child's strengths, weaknesses, and needs, and can help with guiding medical care in the PCP's office, support to families, and appropriate referrals. Based on the information gathered from the autism diagnostic team, the PCP office, the school, and the behavioral therapist, Caitlyn was identified in the school as having "Autism," which is one category under IDEA. An IEP was developed to meet Caitlyn's educational needs. Because of her difficulty with reading, Caitlyn received reading support in addition to social skills supports and visual supports to help with transitions. In the medical home, the PCP worked with the family to gather information regarding ADHD, and referred the family for behavioral therapy while waiting for the evaluation for possible autism. Although girls with Fragile X syndrome often have learning disability rather than intellectual disability, they often have the problems that Caitlyn presented with. The PCP referred the family to a Fragile X support group. Finally, this family benefited from ongoing support in the medical home. The PCP started melatonin for sleep-onset disorder. He also managed referrals and comanaged medication management for ADHD and anxiety with a psychiatrist the family saw twice a year. The family felt that their PCP was a true advocate for their child with ASD (**Box 7**).

Box 7
National Center for Medical Home Implementation

The National Center for Medical Home Implementation (NCMHI) is a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP). The NCMHI is housed in the AAP Division of Children with Special Needs. Information specific to ASD is also available at http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Recent-Information.aspx. At this Web site, AAP resources for professionals and families include:

- Sound Advice on Autism, which is a collection of interviews with pediatricians, researchers, and parents of children with ASD
- *Information on Autism: Caring for Children with Autism Spectrum Disorders: A Resources Toolkit for Clinicians*, second edition
- Information on the book: *Autism Spectrum Disorders: What Every Parent Needs to Know*
- Prevalence data from the CDC
- AAP policy documents related to ASD

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