

Linking the Medical and Educational Home to Support Children With Autism Spectrum Disorder: Practice Recommendations

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Abstract

Children with autism spectrum disorder (ASD) present with complex medical problems that are often exacerbated by a range of other intellectual and psychiatric comorbidities. These children receive care for their physical and mental health from a range of providers within numerous child-serving systems, including their primary care clinic, school, and the home and community. Given the longitudinal nature in which care is provided for this chronic disorder, it is particularly necessary for services and providers to coordinate their care to ensure optimal efficiency and effectiveness. There are 2 primary venues that serve as a “home” for coordination of service provision for children with ASD and their families—the “medical home” and the “educational home.” Unfortunately, these venues often function independently from the other. Furthermore, there are limited guidelines demonstrating methods through which pediatricians and other primary care providers (PCPs) can coordinate care with schools and school-based providers. The purpose of this article is 2-fold: (1) we highlight the provision of evidence-based care within the medical home and educational home and (2) we offer practice recommendations for PCPs in integrating these systems to optimally address the complex medical, intellectual, and psychiatric symptomatology affected by autism.

Keywords

autism spectrum disorder, primary care, medical home, pediatrics, interprofessional collaboration

Introduction

Integrated Care Movement

The integrated care movement is centered on making health care more accessible and effective. Although the notion of integrated care is not new, the concept of a model that coordinates physical and behavioral health services and providers within a unified delivery system was more recently reemphasized via the Patient-Centered Medical Home (PCMH) model in the Patient Protection and Affordable Care Act.¹ Unfortunately, there is an inadequate standard of care for a number of chronic health conditions, including developmental and behavioral disorders. More specifically, physical and behavioral health systems are largely silos of care, characterized by separate and distinct settings, providers, and care management approaches. These fragmented systems lead to diminished quality of care as a result of inefficiencies, lack of communication, duplication and gaps in services, and patients feeling overwhelmed and marginalized in their care.²

Integrated care is particularly important for children with special health care needs. The Maternal and Child Health Bureau describes children with special health care needs as being at “increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”^{3(p138)} These children typically require longitudinal care within a chronic care model (CCM) that recognizes that these conditions are lifelong disorders involving profound impairments that permeate a multitude of settings and

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systems. Relevant child-serving systems for children with special health care needs include the home, community, primary care clinic, and school.

Although the emphasis on integrated care has focused on coordinating physical and behavioral health services and providers within the medical home, the child's school system (ie, "educational home") often functions separately from this system of care. The educational home is where children spend roughly 40 hours a week in a performance-based environment where social, behavioral, cognitive, and academic challenges are most likely to present. Furthermore, this is a setting that positions a multidisciplinary team of school-based providers to support children with special health care needs on a daily basis over the span of years. Despite the scope of services offered in the school setting, research shows that this care is not coordinated with the medical home and that pediatricians have little interface with, and knowledge of, school support services such as special education programming.⁴ The current fragmented functioning of the medical and educational homes will continue to foster ineffective care as a result of the numerous identified systems inefficiencies.²

Autism Spectrum Disorder

Children with special health care needs, such as autism spectrum disorder (ASD) are in need of integrated health care services. In the *Diagnostic and Statistical Manual of Disorders, Fifth Edition (DSM-5)*, ASD is described as a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction across multiple contexts as well as restricted, repetitive patterns of behavior, interests, or activities. These symptoms must be present in the early developmental period but may not fully manifest until social demands exceed capacities. The complex symptoms related to ASD cause significant impairments in daily living, including social, occupational, and other important areas of current functioning.⁵ The diagnostic criteria for ASD elucidate the need for a variety of services across the medical and educational home to address the multitude of needs in this pervasive and chronic disorder. Given that ASD falls on a spectrum, children with this complex disorder present with a wide range of symptoms.⁶ Often, these children also are diagnosed with comorbid conditions related to their physical (eg, immunology, gastroenterology, and neurology), mental (eg, attention-deficit/hyperactivity disorder [ADHD], anxiety, and depression), and cognitive (eg, intellectual disability) functioning.^{7,8} The multifaceted nature of ASD speaks to the need for involvement from providers from multiple disciplines to be involved in a child's care.

Practice Guidelines

According to the American Academy of Child and Adolescent Psychiatry (AACAP), the multiple developmental and behavioral challenges associated with ASD necessitate comprehensive services. The AACAP practice parameters suggest the use of an interdisciplinary assessment and treatment approach and the coordination of care within and across those services.^{6,9} The coordination of services is particularly imperative as individuals reach milestone transitions, such as the transition from early childhood to school age or the transition from adolescence to adulthood. Transitions are often associated with a transfer of services from one system of care to another and, therefore, particularly prone to miscommunication.¹⁰ Although the AACAP guidelines for ASD allude to an integrated approach, by using words such as "comprehensive," "collaborative," and "interdisciplinary," there is no mention of a specific integrated care model or approach to care coordination (note: the term *integrated care* in this article is used to broadly refer to coordination of care across settings and providers to permit integration of services that is centered on comprehensive needs of the patient/family).

Primary care providers (PCPs) are ideally suited to facilitate integrated care for children with ASD. Given that the American Academy of Pediatrics (AAP) recommends ASD screening at the 18- and 24- month well-child visit, PCPs are often the first point of contact when parents have concerns about their child's development or behavior.^{11,12} With a valid screening and subsequent diagnosis, parents are often faced with a multitude of treatment options, given the 27 intervention practices that meet criteria for an "evidence-based practice" in ASD.¹³ Therefore, it is not surprising that families experience significant challenges to timely identification, diagnosis, and management of their children's needs.¹⁴ Children with ASD typically do not receive coordinated services. For example, Farmer et al¹⁵ asked 371 parents of children with ASD to complete the Access to Care Questionnaire. Less than one-third (29.9%) of the children received coordinated care. More than half of the children (63%) had unmet needs, with the highest unmet need for behavioral therapy. Furthermore, the challenges associated with integrated care are exacerbated for underserved communities, such as those living in rural areas and/or those from racial and ethnic minority groups.¹⁴

Systems of Care

Medical Home

The PCMH model was developed from the CCM framework with the goal of improving care for chronic health

conditions in primary care settings.¹⁶ The medical home model emphasizes regulations put into place by the ACA, which endorse preventive (ie, screening and early intervention) and continuous services through coordination with school and specialized care service sectors.^{17,18} The Agency for Healthcare Research and Quality defines PCMHs as encompassing 5 attributes:

1. *Comprehensive*: Care that meets both physical and behavioral health needs, including prevention, wellness, acute care, and chronic care from a team of care with multidisciplinary providers
2. *Patient-centered*: Care that is relationship based and values partnerships, sensitivity to needs, culture, values, and preferences and values patient engagement, autonomy, and choice in decision making
3. *Coordinated*: Care that is coordinated across all elements of the broader health care system, including primary care, specialty care, home health care, and community services and supports, such as schools
4. *Accessible*: Care that is responsive to patients' preferences regarding access and use of alternative methods of communication such as email and telephone contacts between service providers to facilitate more immediate access with shorter wait times
5. *Quality and safety*: Care that is guided by evidence-based practice parameters and clinical decision-support tools to assist shared decision making with patients and families and emphasis on patient experiences and satisfaction in care

Compared with other special health care needs, parents of children with ASD receiving services in the primary care setting are significantly less likely to report receiving care consistent with these stated attributes of the PCMH.¹⁹⁻²¹ For example, less than 1 in 5 children with ASD have a medical home and less than half receive family-centered care.¹⁵ Fueyo et al¹⁶ acknowledge that this finding stems from the complex mix of social, emotional, and behavioral needs that present with ASD and the difficulties in coordinating specialty care services within the medical home. PCPs report a lack of time, training, and reimbursement as barriers to effective service provision for children with ASD.^{22,23}

Given that children with ASD often require more medical, rehabilitative, behavioral health, and educational services than do children with other special health care needs,^{24,25} PCPs commonly rely on referring to specialists. Specialty care services which children with ASD often attempt to access include gastroenterology,

neurology, physical and occupational therapy, speech and language pathology, psychiatry, psychology, and other behavioral intervention services, among others. Unfortunately, families face many barriers in access to these specialty services given the lack of qualified providers to make referrals, long wait times until initial appointment, and insurance coverage issues.^{15,26}

Educational Home

The Individuals with Disabilities Education Improvement Act (IDEIA)²⁷ entitles children with disabilities to receive a "free and appropriate public education" in the "least restrictive environment" from infancy to young adulthood.²⁸ Children with ASD often experience their educational home earlier than typically developing children. If diagnosed as early as 18 months, these children are eligible for early intervention services that are covered by many private health insurance policies.²⁹ Early intervention may consist of therapies, such as applied behavioral analysis (ABA) techniques, structured teaching, the developmental individual-difference relationship-based model, speech-language, occupational, and physical therapies, and social skills instruction.¹³ Part C of IDEIA specifies birth-to-three treatment services that children with ASD qualify for, which are then legally documented in an Individual Family Service Plan. On entering the school system, the services that children with ASD receive are outlined in an individualized education program (IEP).³⁰ It is possible for a child with ASD to be deemed ineligible for special education services following a comprehensive evaluation by the educational team; IDEIA includes a clause requiring "adverse educational impact" to be present for special education eligibility. School-based services may be provided directly through in-house providers (eg, speech and language pathologists). Alternatively, schools can contract with community behavioral health agencies for services to be provided at school (eg, board certified behavior analysts). Unfortunately, school-based providers have limited interface with PCPs other than what is communicated through the parents. As a result, these providers may have little knowledge of the physical conditions, medications, and somatic complaints that may impede a student's success in the classroom.

Family System

Families, and the dynamic relationships that exist within them, play a critical role in the development and outcomes of its members. Unfortunately, parents of children with ASD experience a plethora of stressors within and outside their family. These parents are faced daily

with the physical, behavioral, and mental health challenges associated with ASD,^{31,32} complex sibling relationships that sometimes involve more than one child with a developmental concern,^{33,34} limited time for employment and subsequent increased financial burden,³⁵ marital strain,³⁶ and stigma and marginalization from the community.³⁷

There is substantial evidence that having a child with ASD is associated with negative mental health outcomes for parents,³⁸ including more parenting stress³⁹ and higher levels of depressive symptoms.⁴⁰ Several studies point to parent characteristics that mediate and/or moderate the relationship between ASD severity and mental health outcomes, such as social support, self-efficacy, and coping strategies.⁴¹⁻⁴³

The increased stress that parents of children with ASD experience may be exacerbated when faced with the overwhelming task of managing and coordinating services. Parents with ASD might be managing interventions that their children receive at home, yet also have to communicate and coordinate services provided by PCPs, specialty care clinics in the community, and school-based providers. Unfortunately, parents receive little support in this daunting task. For example, Russell and McCloskey⁴⁴ examined parents' perceptions of care and interactions with their PCPs. Most parents used their PCPs for general health maintenance but reported that their PCPs were ill-equipped to manage the challenges specifically associated with ASD. Additionally, parents did not have the expectation for support with behavioral management at home or school, nor help with the identification of community resources. Research to date suggests that parents of children with ASD often are dissatisfied with the quantity and quality of services.⁴⁵

Practice Recommendations

1. In each well-child visit, PCPs should monitor all areas of development with particular attention to language and social skills development (see AAP's Bright Futures Recommendations for Preventative Pediatric Health Care).⁴⁶ Screening is a method in which PCPs can accomplish this. There are a number of validated screening tools (eg, Infant-Toddler Checklist, Modified Checklist for Autism in Toddlers-Revised [M-CHAT-R], Childhood Autism Screening Test) specific to ASD that can be used in primary care. Even minimally trained PCPs can administer these screening tools reliably and efficiently during well-child visits.⁴⁷
2. For positive or elevated screening scores, PCPs should refer patients and families to specialists who can perform a comprehensive evaluation.¹¹ There are several tools that are necessary for a comprehensive ASD diagnostic evaluation that meets best-practice standards (eg, Autism Diagnostic Interview-Revised, Diagnostic Interview for Social and Communication Disorders, Autism Diagnostic Observation Schedule-Second Edition, Childhood Autism Rating Scale-Second Edition [CARS-2]), which require coordination with providers outside the medical home given the necessity for multiple source inputs (eg, caregiver interview, narrative reports or standardized rating scales completed by teacher, therapist, or paraprofessional aide). ASD evaluations also often include measures of behavior (eg, Child Behavior Checklist [CBCL]), adaptive skills (eg, Vineland Adaptive Behavior Scales-Third Edition) as well as cognitive and executive function (eg, Wide Range Assessment of Memory and Learning). Comprehensive evaluations may be conducted through community-based outpatient specialty clinics or schools. Given the various measures that can be used during an ASD evaluation across different settings, PCPs should be familiar with commonly used medical, clinical, and school-based ASD tools for proper care and management of their patients. For example, PCPs commonly use a screener such as the M-CHAT-R, whereas school-based providers often administer a rating scale such as the Gilliam Autism Rating Scale or CARS-2. The CBCL is often used in clinical settings, whereas the Behavior Assessment System for Children is sometimes preferred in school settings.
3. PCPs should direct any child with a suspected delay or symptoms of ASD to appropriate early intervention programming as soon as possible, even before a definitive diagnosis is available.¹¹ Unfortunately, many parents perceive that their PCPs do not act early enough when they first express concerns about their child's development.²² State-specific funding often is available for children who experience global delays but have not yet received a formal diagnosis. Once a diagnosis is received, PCPs should encourage parents to seek intensive early treatment in Naturalistic Developmental Behavioral Interventions.⁴⁸ Appropriate parental education should be provided in conjunction with a referral to more intensive evaluation services or early intervention/early childhood education services.⁴⁹

4. Given that children with ASD also are diagnosed with comorbid conditions related to their physical (eg, gastroenterology, neurology), mental (eg, ADHD, anxiety, depression), and cognitive (eg, intellectual disability) functioning, PCPs must collaborate with a range of relevant multidisciplinary providers. These may include colleagues from neurology, gastroenterology, psychiatry, speech and language pathology, audiology, and occupational therapy among others for referral and coordinated care. The function of these care providers is to assist with chronic care management within a medical home. PCPs should obtain parental consent to directly communicate with specialty care clinics or schools to reduce the burden on parents to continuously communicate (and sometimes miscommunicate) information between providers.
5. PCPs should ensure that their practice or unit has the built-in capacity for facilitating social support for its patients and families. Supporting patients includes having knowledge of and connections with local autism centers and organizations, developmental disabilities programs, and other professional organizations that have local referral resources to support services (therapists, alternative and augmentative communication technology, advocacy resources).⁴⁴ Supporting families includes making appropriate referrals to marriage and family counseling, parent-child therapy, and/or individual supports to manage the multitude of stressors related to having children with ASD.⁵⁰ Additionally, PCPs should also offer their (and the medical staff's) internal knowledge about insurance, network providers, and coverage to help parents navigate through their multiple treatment options. Having health insurance is strongly related with access to care for children.⁵¹ Unfortunately, many families of children with ASD report inadequate insurance coverage compared with families of children with developmental disabilities, mental health conditions, or both.⁵² Moreover, many parents are unaware that school-based mental health services may be reimbursed through Medicaid programs.⁵³
6. PCPs should be equipped to provide culturally competent care. Research shows that health care providers experience many barriers when working with diverse families of children with disabilities, including (1) lack of training in cultural sensitivity, (2) language and communication issues, (3) discrepancies in conceptualizations of disability between providers and parents, (4) building rapport, and (5) empowering parents to advocate for their children and themselves.⁵⁴ Many of these barriers contribute to children from economically disadvantaged or minority groups being, on average, identified later^{12,55} and, consequentially, not receiving the immense benefits of early intervention. According to the study by Magaña et al⁵⁶ of the National Survey of Children with Special Health Care Needs, Latino and Black children with ASD face greater challenges in receiving high-quality health care. It is imperative for PCPs to understand how culture may affect diagnosis (eg, differential reporting of symptoms across cultures) and treatment (eg, preference for homeopathic remedies rather than evidence-based practices). Providing screening in the family's native language, disseminating culturally appropriate materials, and partnering with community leaders and advocacy groups may be strategies to reduce racial and ethnic differences in integrated care.⁵⁷
7. PCPs should develop a relationship with local schools and districts. PCPs can connect with local schools, including Head Start and Early Head Start preschool programs, to learn about the services provided within the district (eg, ABA therapy) and capacity for involvement in surveillance/screening, evaluation, and treatment around ASD and developmental delays. PCPs can serve on school health advisory committees and be involved in student support service planning (IEP meetings, etc).⁵³ Because of restrictions on time and meeting availability, technology may facilitate the coordination of virtual meetings or teleconferencing. PCPs can directly communicate with the health (eg, school nurses) and mental health (eg, school psychologists, school counselors) care providers in schools regarding specific patients.⁵³ Having these established relationships may bidirectionally facilitate identification of ASD through surveillance, screening, and diagnostic evaluation (see the description by Janvier et al⁵⁸ of a Head Start preschool's screening program for ASD) and/or management practices, which include medical, behavioral, and educational interventions. For example, including medication frequency and dosage in the IEP may be informative for school staff monitoring the benefits and adverse effects of these medications on children with ASD in schools. Likewise, it is valuable for PCPs to receive cross-setting information in

- order to make informed choices about maintaining or changing medication. The comorbid conditions that are often medicated (eg, ADHD) in children with ASD require symptoms to be present in multiple settings.⁵³
8. PCPs should closely monitor and evaluate outcomes associated with these coordinated evaluations, interventions, and support services through follow-up appointments or other communication and information-sharing approaches. Many parents of children with ASD report that the care they receive through their PCP is not comprehensive, coordinated, and family-centered enough.²² Likewise, PCPs report that they lack the time and resources to improve their services. Therefore, it would be mutually beneficial to encourage medical systems that support extended visits, care coordination, and interdisciplinary collaboration. Within the PCMH model, the child receives ongoing longitudinal care in a physician-directed process in which close monitoring and surveillance of ASD symptoms occurs as well as for other conditions often associated with ASD (eg, seizures, gastrointestinal, sleep, behavior, cognitive/learning impairments). The school setting may again be well positioned to address these co-occurring conditions collaboratively with the PCP. For example, PCPs who manage patients with mental health concerns should coordinate care with school-based mental health professionals.⁵³
 9. PCPs should work collaboratively with educators and mental health providers to develop school-based mental health services. Encouraging families to utilize school-based mental health services eliminates the need for transportation and facilitates parent involvement, given that many children attend their local neighborhood schools. This may be particularly important for low-income or minority families given the financial (eg, lack of insurance) and/or cultural (eg, stigma) barriers associated with obtaining mental health services in unfamiliar settings.⁵³

Case Example

The following case is described to highlight the complexity of assessment and treatment needs for children with ASD. We use this case to exemplify use of the practice recommendations. The case example is based on a true child; however, all identifying information has been removed.

Johnny is a 5-year, 11-month-old boy of a mixed racial background. His family recently moved to the United States from a non-English-speaking country. No medical records are available from his native country. His parents think he has a medical diagnosis of encephalopathy. Disruptive and aggressive behaviors have been longstanding concerns for him. Johnny is physically aggressive to himself and others. He will frequently cry, scream, hit, and bite when he does not get what he wants, is presented with a demand, and/or while transitioning away from preferred activities. Johnny is sensitive to loud noises. He has a history of attacking others who he interprets to be speaking too loudly. Johnny is hyperactive and inattentive. He struggles to sit for longer than a few seconds. A highly preferred activity for him is to run around the house. If left unattended, Johnny will elope into the streets. He only speaks in single words. He also displays echolalia, often repeating the last word that he hears. Johnny needs help bathing, brushing his teeth, and toileting. His mother is happy to take care of these daily needs for him, given that in her culture it is appropriate for her to do so. Johnny has limited social engagement. He displays minimal interest in others and has fleeting eye contact. His challenges are frequent, severe, and consistent across home and school. Johnny has an IEP with a primary educational classification of autism. He is in a special education classroom with a 1:1 aide. He also receives pull-out services, including speech and music therapy.

Johnny has several medical needs. Genetic testing was recently completed. The results of whole exome sequencing indicated an extra piece of genetic material on his chromosome 2, but it is uncertain if this extra material could cause developmental issues or just be a benign variant. He has been diagnosed with focal seizures and is currently taking Lamictal for it. He was recently hospitalized because of uncontrollable screaming and crying as well as concerns about eating. He was evaluated by a Pediatric Feeding Disorders Clinic because of his refusal to eat and inability to gain adequate weight. He had an upper endoscopy conducted, and there were no significant findings. His diet has been supplemented with PediaSure. A referral was made for weekly feeding therapy, but Johnny's mother is having difficulty with transportation and, therefore, is unable to consistently take him to appointments. Johnny was taking Vyvanse medication for his ADHD symptoms, and there were improvements in his ability to sit. However, he is no longer on this medication because of his refusal to take the pills. His mother recently discontinued clonidine because he was having severe nightmares. Given his history of sleep disturbances, including breathing issues and snoring, he is on the waiting list to be evaluated by a Sleep Disorders Clinic for possible obstructive sleep

apnea. Johnny's mother asked her PCP about treatment options; however, she is unsure whether her insurance will pay for this service. Given that English is not her first language, she has difficulty understanding the nuances of insurance coverage.

Johnny's situation is not uncommon for children with ASD. With proper integrated care, Johnny's PCP, specialty care providers, school staff, and parents can work collaboratively to ensure optimal outcomes for him. Johnny's PCP is in an ideal position to start the diagnostic and treatment process for Johnny. During his regular well-child visit, Johnny's PCP may ask his mother about ASD symptoms, paying particular attention to how culture may affect reporting. His mother also can complete an autism screener for school-age children such as the Social Communication Questionnaire. Johnny can be referred to a multidisciplinary diagnostic team at a community-based autism clinic. The receptionist at the PCP's office can ensure that this specialty care is covered by the family's insurance plan. They can also help Johnny's mother get connected to a state-funded program for children with developmental delays. The comprehensive evaluation conducted at the specialty clinic should be directly communicated to the PCP and Johnny's school (with parental consent). With a formal diagnosis, Johnny may be eligible for in-home treatment services, targeting behavioral challenges, including medication refusal. He may also qualify for an insurance-covered behavioral specialist consultant to provide routine observations, intervention services, and recommendations for the classroom. If his parents sign a release for confidential information, his treatment plans can be shared across all providers. For example, the PCP might facilitate coordination between recommendations made at the feeding clinic and what occurs during lunchtime at school. Information related to medication should be included in Johnny's IEP. Once the in-home services help Johnny's mother get him to take his medication, all providers (medical, specialty, and school) should monitor Johnny's behaviors as well as any side effects on his seizures. His PCP should directly communicate with the Pediatric Feeding and Sleep Disorders Clinic about Johnny's past and upcoming services as well as the school nurse and psychologist. This can assist the PCP in making informed decisions about his medication management. His PCP should schedule a follow-up appointment with Johnny and his mother to monitor the outcomes of the integrated care services.

Future Directions

Training

Despite the high prevalence of ASD, community-based PCPs report feeling ill-prepared to provide care for ASD and co-occurring behavioral health issues (eg, sleep

problems, anxiety, depression, aggression). They also report a desire for increased education and training.^{23,59,60} Several ASD learning enhancement and support approaches for PCPs have been developed by the AAP, which include a Resource Toolkit for Clinicians⁶¹ for identification and ongoing management of children in the medical home as well as clinical guidelines for screening, diagnosis, and management.^{49,62} Other support strategies include intensive workshops⁶³ and telehealth mentoring and consultation.^{14,64} However, there is widespread recognition that behavioral health competencies should be more specifically addressed within the common touchpoint in which all PCPs matriculate—residency training.^{65,66}

To enhance developmental-behavioral pediatrics (DBP) training mandates of the Accreditation Council for Graduate Medical Education, the Centers for Disease Control, in partnership with the Maternal Child Health Bureau, developed a case-based autism training curriculum.⁶⁷ The curriculum focuses on screening, diagnosis, and management of children with ASD; curriculum competencies align with the DBP competencies of the Academic Pediatric Association's educational guidelines for pediatric residency training. Additionally, future PCPs should learn how to deliver evidence-based care not only within the context of specialty developmental clinics (which often occurs on DBP rotations), but also in community-based primary care clinics where services are most accessible.^{68,69} Training for screening, diagnosis, and management of ASD in the medical home is necessary, although future PCPs should also develop skills for interprofessional communication and collaboration with a team of multidisciplinary providers and parents as well as develop skills for care coordination across the medical, educational, and family/community systems.⁷⁰ Residency training experiences that provide exposure to behavioral health and subspecialty medical providers within ambulatory clinic training sites may enhance the knowledge base and clinical care of future PCPs in collaborative partnerships.⁷¹

Research

Research has identified numerous deficiencies in current training and practice in meeting the needs of children and families with ASD.² Areas for future improvement in ASD care pertain to addressing the lack of care coordination across medical, educational, and other subspecialty service systems,^{4,22} which lead to duplication and gaps in services^{15,26} and, ultimately, families feeling overwhelmed and marginalized in their care.^{32,45,72} More research is needed in the development and implementation of integrated care models using the CCM framework in the context of the PCMH model. Specifically, PCMH models that facilitate adherence to

evidence-based practice parameters by coordinating interdisciplinary care can remediate barriers that families face when seeking out care in specialty autism centers (eg, insurance coverage, long wait times, lack of follow-up from PCP office and school setting). Evaluation of these integrated care models should address the degree to which interdisciplinary collaboration improves access to, continuity of, and family engagement in care as well as overall clinical outcomes and value. Possible outcome measures for the evaluation of integrated care models include family satisfaction with care, child outcomes in multiple settings, short- and long-term costs, and communication across providers.

Conclusion

The often complex mix of medical, psychiatric, and intellectual problems with which many children with ASD present dictates that their clinical care be coordinated among the PCP and a range of subspecialists. This care coordination must extend across prominent child-serving systems, including the medical and educational home, where providers can coordinate services to ensure optimal efficiency and effectiveness. Integrated care models that strive to link the medical and educational home are well positioned to decrease fragmentation in care and increase multidisciplinary communication and collaboration in care, which may ease the burden and marginalization that families often feel when accessing necessary services for ASD. It is highly recommended that PCPs engage in this type of integrated care by linking prominent child-serving systems to improve the standard of care for youth with ASD.

Author Contributions

All of the authors are responsible for this commentary and have participated in the conceptual, writing, and editing process for this manuscript.


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