Whittling Down the Wait Time:

Exploring Models to Minimize the Delay from Initial Concern to Diagnosis and Treatment of Autism Spectrum Disorder

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Over the last several decades, autism spectrum disorder (ASD) has become an increasingly recognized developmental disability, affecting thousands of children, adults, and their families. According to the most recent statistics,[1] 1 in 68 school-aged children in the United States has been identified with ASD. This prevalence has increased over the last decade, from 1 in 150 in 2002, to 1 in 110 in 2006, to 1 in 68 in 2010[2] and 2012.[1,3–5]

Children with ASD can be diagnosed as early as 2 years of age,[6,7] but on average, the age of diagnosis is after 4 years.[2] There is even evidence that parents may detect developmental concerns in children with ASD before 12 months of age.[8,9] There are multiple factors that account for the more than the 2-year difference between earliest signs to diagnosis that may delay entry into early intervention (EI) programs. These barriers, which include time-consuming evaluations,[10] cost of care,[11] lack of providers,[12] lack of comfort in diagnosing by primary care providers,[12] and other challenges, each require different approaches in order to begin to close this gap.

There is also increasing emphasis on earlier identification of ASD and initiation of specialized interventions, due to evidence that starting these therapies as early as 18 months leads to better long-term outcomes.[13–15] The American Academy of Pediatrics (AAP) and other professional organizations have therefore emphasized that children with suspected or

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confirmed ASD should receive services that address a combination of approaches, and that therapy should begin as soon as possible.[16]

As such, ASD as an increasing public health concern has not gone unnoticed. Multiple legislative efforts have been made to support ASD awareness and services. ASD is included as a diagnosis of eligibility under the Individuals with Disabilities Education Act, established in 1990 to provide EI therapeutic services to children under age 3 years with disabilities. The US Congress later passed the Combating Autism Act of 2006, followed by the Autism Care Act in 2014, funding ASD research, surveillance, and education. The Centers for Disease Control and Prevention has also held collaborative summits in an effort to support states' abilities to implement early identification programs and EI services for children with ASD.[17] Often these EI services are supplemented with additional therapies. Insurance coverage is variable across therapy type and can be quite different in different states. Having an ASD diagnosis can change the type and amount of coverage that a child may have through insurance and public EI and education programs.

These collaborative efforts have yielded research and screening tools to detect ASD signs and symptoms in children less than 24 months of age.[18] Despite this, mean age of diagnosis in the United States remains stable at 3.5 to 5 years.[1,2] Multiple factors influence the process described by parents as the "diagnostic odyssey," from first concerns to age of diagnosis. Most notably, throughout the country, there is a backlog of patients waiting to be seen[11] and a lack of qualified providers.[19]

Thus, there exists a need for a public health approach that intersects with clinical care in order to facilitate diagnosis and acquisition of services for children with ASD. In this article, the authors describe the traditional models for this process as well as new and innovative approaches to address this issue.

THE AUTISM "DIAGNOSTIC ODYSSEY": THE TRADITIONAL MODEL

For most families, initial concerns for ASD are brought up by a parent at a routine well-child visit or identified by routine screening at the 18- and 24-month well-child visit.[20] Ideally, according to AAP guidelines, a child is then referred by the provider for audiologic evaluation, EI education services, and a comprehensive ASD evaluation.

Therefore, what is a comprehensive ASD evaluation? There is wide variability in the clinical structure of these subspecialty service providers[21]; however, in many clinical settings, a comprehensive ASD evaluation consists of a visit or multiple visits for evaluations by a multidisciplinary team, including a physician, psychologist, speech language pathologist, and sometimes other providers, such as a social worker, occupational therapist, and/or genetic counselor. Each specialist brings different expertise to aid in diagnosis and recommendations for the patient. These comprehensive assessments include clinical evaluation as well as use of standardized instruments. The ADOS,[22] or Autism Diagnostic Observation Schedule, has become the goldstandard diagnostic tool and is often helpful, but not required, for a diagnosis of ASD. The ADOS is a 40- to 60-minute, play-based, standardized assessment for children 12 months and up that is typically performed by a

developmental pediatrician, speech language pathologist, or psychologist. This evaluation, as well as other neuropsychological testing and medical evaluation by a developmental pediatrician, child neurologist, or child psychiatrist, is taken to provide a comprehensive diagnosis and recommendations for therapeutic services.

This multidisciplinary team approach can provide excellent comprehensive evaluation, diagnosis, and detailed recommendations. However, these evaluations are time-consuming for both the patient and the care team. Some clinics require a screening process before scheduling appointments with forms of up to 200 questions.[11] Clinical testing can take 2 to 3 hours in addition to face-to-face time spent with the physician, and some clinics require more than 3 separate visits.[21] Consequently, clinics are limited in the number of patients that can be seen.

In addition, there exist national shortages of subspecialist providers, adding to the wait time for diagnosis. A 2012 survey by the Children's Hospital Association reported national shortages in all of the pediatric subspecialties that diagnose and treat ASD: Developmental Pediatrics, Pediatric Neurology, and Child and Adolescent Psychia-try.[23] According to this study and others, the average wait time to schedule an appointment with these specialists was 3.5 months[11]; however, in some areas of the country, wait times are significantly longer, and it may take up to a year to have a comprehensive evaluation.[24] Families are highly dependent on resources in their local community, which may be variable. In rural settings, access to subspecialists for ASD evaluation is even more difficult, as most multidisciplinary teams practice in major urban academic centers. Only 7% of developmental pediatricians practice in rural areas. Some states do not have a developmental pediatrician.[25]

Ideally, toddlers suspected of having ASD are referred to Part C EI services at the same time that concerns arise, and they are enrolled in services as they await a subspecialty evaluation. A diagnosis of ASD is not required to qualify for these EI services. However, in many cases, children are not referred to EI services until *after* a confirmed diagnosis that results from a comprehensive ASD evaluation, which may be many months later. Once a child has a diagnosis of ASD as opposed to nonspecific developmental delay, the type of services he or she receives may change. An ASD diagnosis may allow the child to be eligible for different and increased services, specific to ASD. These services often include ABA or applied behavioral analysis therapy, an evidence-based technique that has proven efficacy in ASD.[26–28]

NOVEL AND INNOVATIVE MODELS FOR AUTISM SPECTRUM DISORDER DIAGNOSIS

The problem of prolonged wait times for ASD diagnosis and services has not gone unrecognized by families or by ASD service providers. Public outcry has spurred multiple autism centers around the country to devise creative and novel clinical models to reduce the waiting time that families endure between initial concerns and diagnosis, delaying initiation of therapy.

Autism Diagnosis Education Project

In Ohio, the substantial wait times experienced at specialty autism centers and the lag time from initial concern to diagnosis of ASD sparked the development of the Autism Diagnosis Education Project (ADEP).[22] ADEP was developed in collaboration with ASD providers and leaders in state public health and early childhood education. ADEP facilitates unique partnerships between community-based primary care practices and professionals providing EI and early childhood services, to increase access to local and timely standardized, comprehensive diagnostic evaluations for children suspected of having an ASD. Launched in 2008, the ADEP was originally piloted through funds from the Ohio Department of Health and administered by the Ohio Chapter of the AAP. The piloting of the project concluded in June 2011. The ADEP resumed and was expanded in October 2012 with funding from the Governor's Office of Health Transformation, awarded to the Ohio Department of Developmental Disabilities. The Department partnered with Akron Children's Hospital, Family Child Learning Center, and the Ohio Center for Autism and Low Incidence to coordinate and implement the ADEP expansion. The project's work aligns with the Ohio Autism Recommendations,[29] which emphasizes the importance of early identification and diagnosis of autism.

The goals of the expanded ADEP included (1) reduction of the time from initial family concern to diagnosis from 18 months to less than 9 months; (2) reduction of the time from initial contact with Ohio's Help Me Grow[30] assessment system to diagnosis to within 90 days; and (3) lowering the age of diagnosis from age 36 months to 30 months. Through persistent efforts and a willingness to overcome barriers, the teams involved with ADEP have lowered the average age of diagnosis in Ohio to 28.9 months of age.[29] This age is still above the age of 24 months, which has been found to be an age at which autism diagnosis remains stable. The ADEP teams continue to change the ways in which families can receive an early diagnosis of ASD in the state of Ohio.

Vanderbilt Treatment and Research Institute for Autism Spectrum Disorders

Vanderbilt Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) developed a program[31–33] specifically to address the underserved areas in the state of Tennessee, where wait times for diagnostic or interventional services for children with ASD can be as long as 6 to 12 months. They advocate training primary care practitioners to use a validated interactive screening tool for ASD called STAT (Screening Tool for Autism in Toddlers and Young Children).[31,32] The STAT is an approximately 20-minute assessment that evaluates toddlers ages 24 to 35 months using 12 interactive items based on social-communication behaviors evidenced to differentiate 2 year olds with and without ASD. This measure has been validated to correctly identify 75% to 90% of children with ASD.

In their model, the Vanderbilt team suggests that children with a positive ASD screen at routine 18- and 24-month pediatric visits could then undergo the STAT as a prompt diagnostic assessment within primary care providers' clinical practices. The Vanderbilt team has initiated training programs in order to develop a network of pediatricians throughout the state who are capable of identifying and immediately referring children at high risk for ASD for appropriate EI services, avoiding long waits for diagnosis or treatment.[34,35] On follow-

up, this network of primary care pediatricians reported an 85% increase in diagnosis of children with ASD within their own practices. Extrapolating to address the statewide need for ASD evaluation services in Tennessee, it was estimated that 20 pediatricians performing one assessment per week could serve more than 1000 patients a year.[36]

Community-based Autism Liaison and Treatment Program

Several other states have developed similar programs that train local pediatricians to diagnose ASD. Arkansas has created the Community-based Autism Liaison and Treatment, or CoBALT Program, an educational training program for "mini-teams" of one community-based pediatrician coupled with a one speech language pathologist. The goal of this training is to establish community-based teams capable of providing diagnostic developmental assessments. The CoBALT program also emphasizes directly connecting these trainees to representatives in the local EI, Early Childhood Special Education, and Department of Developmental Services programs, and other services in order to facilitate network building and communication within the professional community that serves these children.[37] Since its start in 2011, the CoBALT program has trained 12 teams that provide services throughout the state of Arkansas, including rural counties.

Other centers around the country are starting to develop their own creative models to tackle this same problem. Connecticut Children's Medical Center has an Autism Spectrum Assessment Program that reports to have reduced wait times by half.[38] Their model focuses on obtaining comprehensive information before the appointment, simultaneously referring to EI and capitalizing on the increased ratio of speech language pathologists to developmental pediatricians by using the physicians on an as needed basis.[39]

A second program in Ohio focuses on reducing wait times within their own ASD intervention centers at Cincinnati Children's Hospital Medical Center and Nationwide Children's Hospital by systemic analysis of supply, demand, and activity to identify and target sources of delay.[24] Their analysis found that by collapsing multiple visit types and reducing the complexity within the clinical system, as well as reviewing wait lists and modifying wait list policies in favor of scheduling more appointments, these centers successfully reduced the wait time and nearly eliminated wait lists.

ADDITIONAL OPPORTUNITIES IN TECHNOLOGY AND PUBLIC POLICY

Other opportunities may exist for creative models that improve access to care for children requiring evaluation for ASD. Some of these next steps capitalize on modern technology or may call for changes in public policy. Here, a few examples of models that have the potential to further expand upon the strategies above are discussed.

Telemedicine programs are expanding throughout medicine, including those that focus on developmental disabilities, and have improved access to care, particularly for patients in rural settings.[40] There is emerging research on applying this practice for children with ASD in a variety of ways. Some centers have published studies reporting that ASD evaluations performed through video conferences directly between a family and an interdisciplinary team may be an accurate and accessible means for evaluation.[41–44] Other centers have used

telemedicine to provide peer-to-peer sub-specialty consultations[45,46] for developmental disabilities, in their local communities and internationally.[47] One study has even designed a diagnostic tool using home videos recorded by parents.[48] Specifically, a program in Kansas uses professional teams in the patient's local community to perform standardized assessments, which are then presented to the family and a university-based medical center team that makes the final diagnostic assessment and provides recommendations via telemedicine.[42] As academic hospital centers rapidly expand their technological resources, telemedicine provides a modern venue for increasing accessibility to specialized services for children with developmental concerns.

Additional efforts that have been considered directly address the shortage of pediatric subspecialty providers, including those that provide services for children with ASD: developmental pediatricians, child neurologists, and child and adolescent psychiatrists. The AAP has issued a policy statement[19] delineating objectives to increase the numbers of appropriately trained pediatric subspecialists. They have also advocated for legislation that provides incentives for new physicians to pursue pediatric subspecialties through graduate medical education funding, loan repayment programs, training grants, and appropriate payment for services.[49] Specifically, legislation being considered by Congress includes the Ensuring Children's Access to Specialty Care Act of 2015 (H.R. 1859) that would amend the Public Health Service Act to include pediatric subspecialists in the National Health Service Corps loan repayment program. In addition, the House and Senate Labor-Health and Human Services-Education appropriations bills authorized funding for the Children's Hospital Graduate Medical Education program, which provides funding to support pediatric residency and fellowship positions.[50]

Finally, it has been suggested that the development of open source and open access tools to diagnose for autism may eliminate some of barriers in the diagnostic process.[51] Currently, the high costs to use these proprietary tools and to train professionals to use them consequently limit the number of proficient providers, particularly in resources-limited settings, and may add to the bottleneck for families at ASD centers. In contrast to many of the "gold-standard" assessments such as the ADOS[22] and Autism Diagnostic Interview–Revised,[52] open source tools are free to access without cost. Introducing more open access diagnostic tools may have the potential to facilitate the ASD diagnostic process, particularly in low-resource settings.

NEXT STEPS

All of the novel models discussed have shown positive impact on the local communities that they serve. However, efforts to redesign clinical services for the diagnosis of ASD are not pervasive in the medical community. This lack of generalized reform of clinical models is evidenced by the fact that despite substantial efforts by these and other programs, the average age of ASD diagnosis in the United States has still not declined. There is still more work to do to implement innovative programs on a national scale.

In general, many of these approaches focus on simultaneously referring children for services while the diagnostic process is underway. This multifaceted strategy of simultaneous referral

and diagnostic workup underscores a need for a change in the clinical approach to ASD from a primary focus of diagnostic labeling to a focus on function. A functional approach[53] may better serve the child and the family by prioritizing implementation of services and therapies as soon as concerns are identified in order to improve the outcome for that child. Limiting these services based on a diagnostic label may only detrimentally delay this process.

The diagnostic odyssey for parents of children with ASD remains a challenging process that demands remodeling from the clinician level to the public health level in order to better serve families. Some promising ideas are emerging to address these needs. The systems of care built to identify ASD need to continue to evolve in order to serve the growing number of individuals with ASD that await their services.

Acknowledgments

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KEY POINTS

- The "diagnostic odyssey" in autism, from initial concerns to diagnosis, is often a long and complicated process for families, prolonged by wait-lists due to a backlog of patients awaiting evaluation by subspecialists.

- Multiple clinical autism centers throughout the United States have implemented innovative programs to directly address this diagnostic bottleneck, resulting in decreased wait times in their local communities.

- A change in clinical approach from a focus on diagnosis to a focus on referral to therapeutic services may better serve families as they undergo diagnostic evaluation.

- A public health approach that intersects with clinical care is needed to facilitate diagnosis and acquisition of services for children with autism.