VIEWPOINT

Abridged autism assessment speeds access to therapy

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Families traveling along a path toward an autism diagnosis experience delay upon delay. Parents may question their first suspicions, primary care physicians generally don't diagnose the condition, wait times at specialty clinics are extensive, and the evaluation process itself is comprehensive and lengthy.

Together, these factors create a lag time between a parent's initial concern and an ultimate diagnosis — several years is not unusual. Not surprisingly, families report high levels of dissatisfaction and worry during this time, and long delays are a large source of stress[1].

Adding to families' stress is the knowledge that early intervention is crucial. Evidence-based treatments such as **applied behavioral analysis (ABA)** have the most impact when children are young. Yet accessing ABA hinges on the diagnosis itself.

Those of us clinicians who specialize in autism want to provide the best care possible, of course. With families who have been waiting so long for their child to be evaluated, we want to take the time to do a thorough evaluation, to understand the child on multiple levels. But we also need to examine our own diagnostic process and practice with a broader awareness of the families who are waiting to come in the door.

Our team is working to shorten the diagnostic process so that providers can see more individuals in a given time. We aim to shrink the waiting list so that families do not have to wait so long for answers.

Fast service:

Parents tend to notice something different about their child's development between 18 and 24 months of age, but may feel uncertain and hesitate to bring up concerns to their pediatrician.

Primary care providers don't receive specialized training to confidently diagnose the condition[2]. So more time passes as physicians refer children to specialty clinics for diagnostic evaluations.

Wait times at hospital-based specialty centers in the United States average 14 months from first phone call to the receipt of diagnostic feedback[3]. Long wait times for appointments stem from two factors: a shortage of providers with the necessary expertise and the time it takes to do the evaluation — generally, between three and six hours.

The diagnostic odyssey takes even longer for families who are underserved by the U.S. healthcare system, such as those with lower incomes and members of **racial or ethnic minority groups**[4].

The field is chipping away at known contributors to this 'diagnostic bottleneck.' Large-scale campaigns such as **First Signs** are increasing awareness of autism's early signs among parents and providers. Screening for autism is increasingly common in primary care practices, leading to clearer paths for referral to specialty autism centers. Some autism centers have tweaked their processes to improve flow through the health system, resulting in shorter wait times for autism-related clinic appointments[3,5].

However, causes for delays during the course of diagnostic evaluation have largely gone unexamined. Various guidelines for best practices in diagnostic evaluations exist, and yet how exactly clinics follow these guidelines is unknown.

Ordinarily, a child or adult in need of an autism evaluation first sees the primary care provider, who then refers to outside specialists, such as a **developmental-behavioral pediatrician** or a psychologist. The evaluation process generally spans several weeks, includes at least two clinic appointments, and often involves testing for autism-related behaviors, language and cognitive skills. It also typically covers neurodevelopmental and psychiatric diagnoses besides autism.

At the Seattle Children's Autism Center, our group has developed a team evaluation model in which multiple providers see the family in a single day. Our process involves two clinicians with expertise in autism from different disciplines. Together, they make a diagnosis using criteria from the "**Diagnostic and Statistical Manual of Mental Disorders**." Our process is also specific to autism. We defer questions about alternative diagnoses or comorbidities for follow-up appointments with us or other specialists.

Less is more:

Last month, our group reported results from a comparison of our team model and standard approaches, in which psychologists or physicians lead the evaluation process. The standard approaches were in use at our center at the time we were rolling out the team model[6].

We reviewed medical records from 366 individuals seen in one of the three diagnostic tracks: 165

from psychology, 110 from physicians and 91 from team evaluations. Rates of autism diagnosis were similar across the tracks, ranging from 61 to 72 percent. But 90 percent of evaluations for children seen in teams were finished in a single day, compared with a series of appointments over several weeks for children in the other two tracks.

In addition, providers in our interdisciplinary teams billed nearly two hours less in total than those in the psychologist-led model (4.52 versus 6.31 hours), in which the psychologist collected relevant information about autism traits, completed testing and provided feedback over three to four separate appointments, generally a week or two apart. Psychologists are the most common type of provider completing autism evaluations in the U.S., making this comparison particularly relevant.

Individuals seen by our interdisciplinary teams also were the most likely to engage in recommended follow-up care, even when they had to travel long distances to do so. And providers using our system were more satisfied working in teams than independently — which may help combat the burnout that often accompanies clinical work.

Our data support the idea that a team-based, focused approach to autism evaluation is feasible, effective and efficient. It should lead to shorter wait times for families and also succeeds in engaging families in recommended follow-up.

Still, it can be difficult for providers to do less. Autism specialists have been trained to assess the whole child and have expertise in an array of neurodevelopmental disorders. Yet in our program, clinicians must focus only on the question of autism. To overcome this, we simply must remember the importance of meeting a need in our communities that far exceeds the number of providers with expertise in autism.

As providers, we must examine our own contribution to the diagnostic bottleneck. Our streamlined services model is one way to provide quality clinical service, not only for those in our care but also for those awaiting their turn.

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