

Virtual Mentor

American Medical Association Journal of Ethics
December 2011, Volume 13, Number 12: 856-860.

CLINICAL CASE

When Diagnosis is a Double-Edged Sword

Commentary by Mary Lynn Dell, MD, DMin

Dr. Mitchell, a psychiatrist, specializes in childhood development disorders. One day, a mother and her 5-year-old son came to Dr. Mitchell's private practice for a first visit.

"Ravi's been having problems ever since he started school," his mother explained. "He doesn't have many friends and is very shy. I've been doing research online about Asperger disorder, and I'm worried that Ravi could have it. All the articles mentioned not making eye contact, and I've noticed now that Ravi never really looks at me."

After asking Ravi some questions while she was examining him and observing him while she talked with his mother, Dr. Mitchell agreed that aspects of his behavior correlated with symptoms of Asperger disorder. She believed, in fact, that his was a borderline case. Since Ravi's problems had not been observed for long, Dr. Mitchell was reluctant to diagnose him with the condition. She worried that the diagnosis would affect how Ravi's teachers and other adults treated him and that their behavior could affect Ravi's self-perception. She was also concerned about the label's accuracy.

Ravi's mother explained that if her son were diagnosed with Asperger disorder, he would be eligible to receive special services from the school that would help him develop socially. "The sooner he receives these services, the better," she said. "He is falling farther and farther behind his classmates."

Dr. Mitchell explained her concerns about a premature diagnosis, but Ravi's mother insisted that special services would help her son enormously. Dr. Mitchell also believed that Ravi would benefit from such services.

Commentary

Asperger's disorder [1] is classified in the *Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition (Text Revision) (DSM-IV-TR)* as one of five pervasive developmental disorders. It is characterized by impairments in social interactions and repetitive and stereotyped behaviors, activities, and interests. Difficulties in social interactions can include impaired use and interpretations of nonverbal behaviors, developmentally inappropriate peer relationships, and lack of spontaneity and social and emotional reciprocity in interpersonal interactions. These qualities and behaviors are the root of clinically significant social, interpersonal,

academic, occupational, and functional impairment. Unlike more severe forms of pervasive developmental or autism spectrum disorders, there are no significant delays in language, cognitive development, age-appropriate self-help skills, nonsocial adaptive behaviors, and general curiosity about the world [2].

Dr. Mitchell's hesitancy to diagnose Ravi with an autism spectrum disorder (ASD), in this case Asperger's disorder, highlights several important diagnostic and ethical issues that have become more relevant in the last few years as the incidence of ASDs have increased. First, while the diagnosis of Asperger's is based on patient history and may be reasonably evident at an initial appointment, it is wise to obtain collateral information from other parties with experience and knowledge of the child in multiple settings, including school personnel, primary care physicians, and other caregivers. Reports from current physical examinations, hearing screens, and, when possible, psychological testing and developmental assessments by adequately trained psychologists should be obtained. Though the diagnosis may seem readily apparent during the initial appointments with some children, premature declaration of an ASD may lead to overlooking important medical, psychiatric, family, and other information vital to treatment planning.

Secondly, debate exists in both professional and lay circles regarding the degree or extent to which Asperger's is a "disorder" rather than a way of being, perceiving the world, and interacting with others that, while particular or even peculiar to some, should not be considered pathological at all. This issue has come to the forefront recently as preparations are under way for the next *Diagnostic and Statistical Manual of Mental Disorders*, the *DSM-5* [3]. Many experts in the field believe that Asperger's is not a unique syndrome, but a point at the high-functioning end of the more inclusive autistic disorders spectrum.

On the other hand, many advocates, especially in lay circles, wish to retain the Asperger's concept and even the name, but redefine the category as one of a variety of "normal" human developmental patterns. This view holds that the conceptualization of Asperger's as psychopathology in need of treatment or remediation is not only inaccurate and unjust, but it may be prejudicial and minimizes the strengths and talents and limits the potential of those considered to have Asperger's. It is possible that Dr. Mitchell's sensitivity to this issue is influencing her reluctance to declare a diagnosis swiftly, especially if she cares for older adolescents and adults with Asperger's or has been in practice long enough to have followed former child patients into adulthood.

Indeed, societal stigma is a factor in coping and living with mental illness, and those with ASDs are not spared the public scrutiny and possibility of biases and misunderstandings. Historically, those with physical, intellectual, and developmental disabilities have been ignored, discriminated against, abused, and denied adequate medical care, education, vocational training, and employment opportunities. Many people without disabilities feel uncomfortable in the presence of developmentally disabled individuals. The atypical behaviors, quirks, and oddities in interpersonal

interactions of those with Asperger's syndrome and other ASDs often challenge the comfort level of people who are not well informed, have not known or spent much time with anyone with an ASD, or whose attitudes toward anyone different are rigid or who are slower to become more tolerant and accepting.

On the other hand, significant strides have been made in education of the general public about ASDs and the diagnosis, treatment, educational needs, strengths, and resiliencies of affected individuals. Recent state and federal legislation and position statements and practice parameters issued by medical specialties that work with people with ASDs have been instrumental in disseminating information to medical professionals and school officials, thereby facilitating earlier diagnosis and treatment and helping to decrease stigma. ASD research is a top priority at the National Institute of Mental Health, and organizations such as the Autism Society of America and Autism Speaks have been tireless in their efforts to support research, education, and assistance of all kinds for affected individuals and their families. Yes, stigma still exists, but noticeable progress is being made to diminish bias so that fear of discrimination does not override the benefits to be reaped with accurate diagnosis and access to services.

And so, what about Ravi, his mother, and Dr. Mitchell?

What nearly all clinicians and educators who work with individuals with Asperger's and ASDs agree upon is that early recognition of signs and symptom expressions is imperative, quickly followed by appropriate interventions tailored to a child's specific needs. Upon obtaining the initial history and examining Ravi in her office, Dr. Mitchell does note that some "aspects of his behavior correlated with symptoms of Asperger disorder." In considering what is in Ravi's best interest, clarity of diagnosis, assessment for comorbid medical and psychiatric findings, and cooperation with the school system to achieve a daily environment that promotes optimal academic and social growth are paramount. Defining specific deficits and strategizing about how to address them (a target symptom approach) may be most helpful initially.

In most situations, the psychiatrist has the advantage of collaborating with other professionals who can formally assess and quantify hearing, speech, and language problems, accompanying medical concerns, intellectual and developmental functioning, and social development. These are all categories that merit assessment and intervention on their own, even if the target symptoms fall short of a formal Asperger's or ASD diagnosis in terms of number of symptoms or symptom severity.

If after a multidisciplinary assessment, or subsequent visits to Dr. Mitchell, the Asperger's diagnosis is indeed determined to be accurate, Ravi's mother is right that services available because of the diagnosis will be helpful. This is especially true for individuals with Asperger's, who are at greater risk than typical youth for interpersonal, academic, and occupational impairment later in adolescence and adulthood due to poor social skills.

With the increasing diagnosis of ASDs in school-age children—1 of 110 8-year-olds demonstrate a diagnosable ASD according to a 2006 study by the Autism and Developmental Disabilities Monitoring Network [4]—the educational profession offers individual education plans (IEPs) and regular monitoring of educational needs and goals for children who need evaluation and extra services. In other words, the next step for Ravi is potentially the same or similar whether or not he meets complete criteria for Asperger’s—a multidisciplinary assessment, followed by an IEP or equivalent plan in the school setting, with regular reassessment of his goals and progress toward those goals. In many educational settings, services to address the concerns shared by Ravi’s mother and Dr. Mitchell are available without a diagnosis of Asperger if criteria are not met. However, it behooves all clinicians to be familiar with the resources and procedures of school systems and services in the geographical area in which they practice, for access to specific services can indeed be diagnosis-driven and specific.

Finally, though it appears that Ravi’s mother, teachers, and others important in his life have his best interests at heart, thorough assessment must include at least a brief consideration of other factors that could affect clinical and ethical decision making in this instance. Given Ravi’s young age, his mother (or father or other guardian) is the medical decision maker. Are there concerns about her decision-making capacity, and does she have additional preferences about his care? Are there quality-of-life considerations, in addition to the social interactions she mentioned, that are relevant to diagnosis and treatment planning? Are there other family, economic, financial, religious, or cultural factors that need to be considered? How will providing optimally for Ravi’s needs affect other family members? Is Dr. Mitchell aware of any issues she may have professionally or personally that will influence her medical judgment and care of Ravi? Do parents, psychiatrists, or school officials have any potential conflicts of interest that could affect Ravi’s care and educational interventions [5]?

Assessing and treating patients with Asperger’s syndrome and ASDs are challenging endeavors requiring up-to-date medical knowledge, compassion and respect for patients and families, and sound ethical principles and practice. Clinicians who work in this area will find collegial and collaborative partners in parents, educators, social workers, occupations, speech and language therapists, physical therapists, psychologists, and others who share common goals for the many children, adolescents, and adults whose lives are affected by autism spectrum disorders.

References

1. The *DSM-IV-TR* uses the term “Asperger’s disorder.”
2. American Psychiatric Association. *Diagnostic and Statistical Manual, Fourth Edition (Text Revision)*. Washington, DC: American Psychiatric Association; 2000.
3. The American Psychiatric Association has changed its abbreviation system for the fifth edition of the manual.

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