The Autism Paradox

Through the process of researching this issue, I became fascinated with recent research on neurodiversity as it applies to autism. To oversimplify vastly, neurodiversity is the idea that neurological differences (including autism) are the result of normal variation. In other words, we may be creating pathology where there is none. Should we consider autism a disease? Or is it a variation of normal? This question has been the source of heated debate, with many autism advocates arguing that autism should not be considered a disease or disorder.

As a pediatrician, this is a question I struggle with. I support autism advocacy and the rights of people with autism. I believe we need to adjust our mental framework and see people with autism as more than their diagnoses.

At the same time, I have witnessed—in my professional and my personal life—the devastating effects that profound autism can have on a child and his or her family. Some children are unable to reciprocate love or affection towards their parents or siblings. Others engage in self-harm behaviors, sometimes requiring medication in order to minimize harm to themselves. To me, it is evident that autism is frequently a very difficult experience for families. Dismissing this pain and suffering would be flippant and discourteous to the families who have experienced it.

Yet the argument for neurodiversity is compelling. I will leave the details and the task of persuasion to the excellent authors who have contributed to this issue, but I will say this: in my opinion, there are two truths here. First, autism can be devastating; and second, autism is not a disease. These truths exist in uncomfortable tension and may seem contradictory. It can be a complex and awkward stance for a pediatrician when the DSM-5 specifically categorizes autism as a disorder.

But complexity is not a drawback. Complexity encourages us to consider the ethical dilemmas autism unveils: questions of autonomy, decision making, and intrinsic worth. It forces us to question the assumption that people with autism can’t speak for themselves and to carefully balance the need for treatment with the respect for the person. Complexity asks us to weigh the risks of diagnosis with the benefits that may come from the empowerment that knowledge can bring.
To be clear, acknowledging this complexity does not discourage the treatment of autism when medically appropriate. As a medical community, we know that there are treatments for autism that can be effective for many. Recognizing the principle of neurodiversity does not negate the validity or necessity of treatment. Nor does it imply that these treatments should not be fully funded and supported. Rather, it means being mindful about the goals of our interventions and continuing to respect the personhood of people with autism when we consider which treatments to pursue.

It is now estimated that 1 in 68 children has an autism spectrum disorder (ASD) [1]. The diagnosis of autism increased 57 percent between 2002 and 2006 [2] and continues to trend upward. It is clear that these questions are not going away. Now is the time to evaluate our understanding of autism critically, and I thank all of our contributors for their efforts toward this goal.

I would also like to thank several special contributors for this issue. During the process of researching for the journal, I came across a book entitled Drawing Autism. This fantastically creative book highlights works of art by individuals with autism, several of whom were generous enough to share new works with this journal. We are proud to exhibit the work of these talented artists and hope that this will further our goal of promoting discussion during Autism Awareness Month.

References

Kathleen K. Miller, MD
PGY-1
Department of Pediatrics
University of Wisconsin
Madison, Wisconsin

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

Copyright 2015 American Medical Association. All rights reserved.
ISSN 2376-6980