

A Response to the "Challenging Cases" Article, "Questioning a Previous Autism Spectrum Disorder Diagnosis: Can You 'Lose' the Diagnosis?"

To the Editor:

We were interested to read the recent "Challenging Cases" article entitled "Questioning a Previous Autism Spectrum Disorder Diagnosis: Can You 'Lose' the Diagnosis?" We agree with all the points made by the commentators, including the description of age-appropriate social skills, the importance of assessing cognitive and emotional aspects of functioning to determine the type of assistance needed, regardless of the diagnosis, and the view that there are many "optimal outcomes," depending on the child's capability.

Our group published the original work describing individuals who lose the autism spectrum disorder (ASD) diagnosis¹ and followed this 2013 publication with a series of articles describing their executive functioning, academic skills, social and language abilities, psychiatric comorbidities, and a history of treatments (articles can be found at <https://altos.uconn.edu/publications/>).

The current "Challenging Case" poses 2 important questions: *Is it really possible to lose the ASD diagnosis? If so, are there concerns for the future?* We would like to address both issues.

Regarding the loss of diagnosis, we believe the data convincingly demonstrate that some individuals with a documented, expertly diagnosed history of ASD overcome their symptoms in all domains. Contrary to their history of social and communication impairments and repetitive behaviors, these individuals show typical responses on the typical responses on the Autism Diagnostic

Observation Schedule (ADOS), and are autism fully integrated with little or no assistance in their academic and social worlds.

Dr. Augustyn cited the study by Fountain et al.,² which found 7.5% of their sample (nearly 7000 children) to be "bloomers." Anderson et al.³ described a group of 85 children with ASD initially seen at the age of 2; a very similar rate (9%) had a "very positive outcome" at the age of 19 (no current symptoms and average or higher intelligence quotient).

Regarding future outcomes for these children, our data suggest that they are at risk for the same psychiatric conditions as individuals who still clearly meet the ASD criteria, particularly attention-deficit/hyperactivity disorder, anxiety, and depression, although at lower rates.⁴ Currently, we are following individuals from our 2013 study, evaluating how they handle the transition into young adulthood and meet the challenges of employment and education and social relationships. We also ask what role autism plays in their self-identity and whether they actively engage in "camouflaging" their symptoms.

In our many years of communicating with parents about the ASD diagnosis, we find that they generally comprise 3 groups: With a *new diagnosis*, parents almost always want to know about the long-term prognosis. We tell them that the prognosis is unclear until we can observe the child's response to several years of intensive evidence-based behavioral treatment, there is a large range of outcomes, and focusing on day-to-day progress is most effective. We try to support parents in tolerating uncertainty for the present and inform them that, surprisingly, the severity of early symptoms is not the best or most important predictor of long-term outcomes. Parents of *older children* (i.e., approximately age 8 and older) who still show very significant language, social, and/or behavioral difficulties may ask about

losing the diagnosis; with these parents, we are honest about the prognosis if asked but include in our discussion the child's strengths, for example, rote learning of self-help skills, temperament, and attachment to family. A *third group* is that described in the Challenging Case, in which the parent seeks confirmation that a child no longer meets the criteria for ASD. If this is not the case, we may explain that there is no clear threshold between ASD and specific personality traits and point out improvements in social/emotional or cognitive functioning. If indeed the child no longer meets the ASD criteria, we confirm this, evaluate potential comorbid diagnoses, and focus on the larger picture of general adjustment, health, and happiness.

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