"It don't mean a thing?"

A popular business program airing daily on public radio plays different intro music for the segment on the stock market, depending on how the markets have fared that day. On a good day we hear "We're in the money" while a down market brings "Stormy weather." However, if the markets are mixed (e.g., Dow up, NASDAQ down), the news is heralded by the Duke Ellington standard, "It don't mean a thing if it ain't got that swing." Untroubled by this prelude, the commentators generally appear to believe that the shifts in the market do "mean a thing" (otherwise they wouldn't be commentators) and they give us their view of that meaning, whether we want it or not.

In short, conflicting data while often confusing are not meaningless. Indeed, such data may help us to better understand a complex subject. . . such as the diagnosis of Autism Spectrum Disorder, for example. As use of the Autism Diagnostic Observation Schedule (ADOS-2) and the Autism Diagnostic Interview-Revised (ADI-R) has become more widespread, a common question among clinicians is: "What do we do if the instruments don't agree?" While conflicting results may not have "that swing" that increases confidence in our diagnostic conclusion, they do mean something.

A new paper (Wiggins et al., 2014) published online in October in the Journal of Autism and Developmental Disorders addresses the issue of conflicting data from one perspective, i.e., when an individual meets ASD criteria on the ADOS but misses on the ADI-R. Of the possible disagreement scenarios, this is likely to be the more common one, given that the ADOS has very high sensitivity. If one uses the ASD cutoffs on the ADOS, there are very few false negatives (cf. Gray et al., 2008; Sappok et al., 2013) particularly using the current (revised) algorithms (Kamp-Becker et al., 2013).

[While not common, false negatives on the ADOS have been found to be more likely among individuals with DSM-IV diagnoses of Asperger’s Disorder or Pervasive Developmental Disorder Not Otherwise Specified, than among individuals with Autistic Disorder (cf. Risi et al., 2006). More about this in a minute.]

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When the ADOS is positive for ASD but the ADI-R is not, Wiggins and colleagues find that using alternative cutoff rules for the ADI-R yields a result that is more consistent with clinical diagnosis. Employing these alternative cutoff rules, the ADI-R is considered positive for ASD if:

- The individual meets the ADI-R Social cutoff and is within two points of the Communication cutoff;
- The individual meets the ADI-R Communication cutoff and is within two points of the Social cutoff;
- The individual meets the ADI-R Social cutoff and has at least two points noted on the behavioral domain.

The message from the data appears to be, when the ADOS is positive for ASD but the ADI-R is not (using the standard cutoffs), the ADOS more often reflects the “true” diagnosis and use of the alternative ADI-R cutoffs is supported.

The Wiggins et al. (2014) paper does not speak to the question of what to do with another form of disagreement, i.e., when the ADOS-2 result is “non-spectrum” but the ADI-R exceeds the “autism” cutoff. One might ask why we should even consider an ASD diagnosis if current presentation is not supportive of that diagnosis (i.e., the ADOS yields a non-spectrum result). There are at least two possible reasons: first, there may be idiosyncratic presentations of ASD that are not captured in the current ADOS algorithm. It is possible that some of those idiosyncratic presentations are better reflected in the ADI-R, leading to an ADI-R “diagnosis” of Autism. However, this scenario seems relatively unlikely; if the ADOS systematically misses some presentations of ASD that are captured by the ADI-R, there are no clear descriptions in the literature of what those presentations might be.

More likely is the case in which the individual in question presented with diagnosable features of ASD in the past (which are captured by the ADI-R) but, through excellent supports or great personal effort or some other set of circumstances, (s)he has succeeded in overcoming or suppressing those features to the extent that they no longer exceed the threshold for diagnosis.

If such an individual currently suffers no impairment (i.e., no limitation of functioning in any domain), there is no need for a diagnosis. Such cases may be celebrated as “cure” or “recovery” or “remission” or whatever we wish to call it but they do not meet criteria for a diagnosis of Autism Spectrum Disorder.

If, however, there are subtle weaknesses that are vestiges of the earlier presentation and that cause the individual some distress or limit the individual’s functioning in some way, then impairment persists (though it may be less severe than in the past). In that case, the value of retaining an ASD diagnosis may be to help the individual, and those professionals who are supporting the individual, to view the difficulties within the framework of ASD rather than from the perspective of some other mental condition that could lead to counterproductive interventions.

In such instances, a diagnosis of Autism Spectrum Disorder may be most appropriate, despite the fact that the ADOS fails to detect the social / behavioral differences at a level typically associated with that diagnosis. The onus is then on the clinician to clearly characterize what are the current cognitive / social / emotional challenges that are consistent with an ASD diagnosis and that underlie the impairment, and to pursue interventions that address those differences.
This discussion would be incomplete if we did not return to that clinician question ("What do we do if the instruments don’t agree?") and acknowledge that the real answer to the question is: “Do what we should always be doing anyway . . . use the data from these instruments as pieces of information that get incorporated into a comprehensive picture of the individual and then base the diagnosis on that comprehensive picture.” Diagnostic instruments are tools to be used in addressing a clinical / educational question but in isolation they do not give us the answer; only a thoughtful clinician (or better still, a thoughtful interdisciplinary team) can do that.

Conflicting data on ASD diagnostic instruments can offer an intellectual and a clinical challenge, but integrating those conflicting data in a comprehensive conceptualization can give us a richer picture of the individual’s strengths and challenges and can help us to serve our clients better. Such conflicts may also force us to re-examine our assumptions about the nature of autism and keep us humble with respect to the diagnostic enterprise; there is much that we do not know about autism and we do well to acknowledge the limits of that knowledge.

References


