

The misnomer of ‘high functioning autism’: Intelligence is an imprecise predictor of functional abilities at diagnosis

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The term ‘high functioning autism’ is consistently used in research, clinical practice, and in everyday language when describing someone with a diagnosis of autism without intellectual disability (ID). However, the term is not a diagnostic label and was originally coined to distinguish individuals with IQs above 70. Over time, use of the term often comes with expectations of better functional abilities and outcomes, despite autistic individuals, advocates, clinicians, and family members advocating against this claim. We sought to investigate whether individuals diagnosed with autism without ID (who could be labelled as ‘high functioning’) indeed have better functional outcomes than those with ID. We used a very large population-wide database of individuals diagnosed with autism in Western Australia. We compared 1041 people with ID and 1184 people without ID on functional abilities, as measured by an assessment called the Vineland Adaptive Behavior Scales (VABS). We found that those without ID had higher functional scores than those with ID. However, when compared to IQ scores, those ‘high functioning’ individuals exhibited a significant decrease in their functional scores relative to what their IQs would predict. This difference was large and consistent across age at diagnosis. These data indicate, in a large and representative sample, that IQ is not a good indicator of functioning when diagnosing autism, particularly for those without ID. We strongly recommend that ‘high functioning autism’ is an inaccurate clinical term when based solely on IQ and continued use of this term clinically or in research is disadvantageous to individuals, denying or limiting access to essential clinical services or supports, and restricting participation in research.