The Value of State Differences in Autism When Compared to a National Prevalence Estimate

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This issue's article, "The Prevalence of Parent-Reported Autism Spectrum Disorder Among US Children," revealed that the parent-reported prevalence of autism spectrum disorder (ASD) in the National Survey of Children's Health (NSCH) is now 1 in 40, representing 2.50% of US children ages 3 to 17 years.[1] This estimate represents the latest point data on an ever-increasing trend of ASD prevalence in recent years.

But what does this new estimate mean? As an average value representing the entire United States, perhaps not as much as one might think. Studies from the Autism and Developmental Disabilities Monitoring (ADDM) Network have consistently documented considerable heterogeneity in ASD prevalences across states. The most recent data from 2014 revealed prevalence estimates ranging from 13.1 per 1000 children in Arkansas to 29.3 per 1000 children in New Jersey, which is more than a twofold difference. Moreover, the range of state-level prevalence estimates was many times larger than the 95% confidence interval around the mean prevalence rate (16.4–17.3 per 1000 children), with only 1 state-level estimate falling within that 95% confidence interval.[2] Already large, differences in state-level estimates of ASD prevalence appear to be getting larger over time.[3] For example, from 2000 to 2012, Alabama's ASD prevalence grew at an average annual rate of 12% (relative rate = 1.12), whereas the prevalence in North Carolina grew at an average annual rate of 28% (relative rate = 1.28). A single prevalence rate for the entire United States fails to capture this variance.

Therefore, we recommend publishing metrics of heterogeneity alongside national estimates of ASD prevalence. Just as reporting of 95% confidence intervals is considered a best practice in research publications because it offers important information on a statistical estimate's reliability, metrics of statistical heterogeneity have long been a standard in meta-analyses that seek to summarize evidence across multiple, sometimes disparate sources. Adopting a similar standard for reports of national prevalence rates would raise awareness regarding the extreme variance in ASD prevalence across the United States and stimulate careful consideration of its causes.

Ideally, increased awareness of heterogeneity will facilitate conversation about the meaning of national estimates of prevalence, in particular how they conceal underlying heterogeneity that may reflect important differences in policies, educational and medical practices, and/or causal environmental exposures at the local level. For example, researchers who seek to understand causes of the rise in ASD diagnoses should carefully consider why prevalence is rising faster in some states than in others. This requires attention to local conditions and variations. For example, if the rate at which clinicians offer and parents

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accept ASD diagnoses is dependent on service availability, local policy, or community factors, then we should expect to find differences in ASD prevalence across states that differ in these ways.

Fortunately, a heightened appreciation of heterogeneity may reveal opportunities to investigate such factors. Unlike the ADDM Network, the NSCH collects data on service availability, use, and satisfaction. Although NSCH samples are too small to support state-level estimates of ASD prevalence in all 50 states, comparisons are feasible between groups of states, whether they are defined by region or common factors in policy context or service systems. The ADDM Network and others have speculated that trends in ASD prevalence over time may be attributable to the following: (1) changes in the true prevalence of ASD resulting from trends in exposure to risk factors, such as environmental toxins; and/or (2) changes in the ascertainment of ASD attributable to increased awareness of or sensitivity to ASD symptoms.[2,4–7] If such factors could be well characterized at the state level, then they could be used to define clusters of states that could be compared with regard to ASD prevalence and (if future versions of the NSCH maintain the same questions and methodology) trends in ASD prevalence.

To be clear, we commend the authors for highlighting a continued trend showing increasing national prevalence of ASD in the United States as a whole, which is an important finding to guide national policy and service planning, and we have no doubt that the findings are valid. As a national survey, the NSCH is representative of the United States, and the authors cite a number of studies that are used to support the validity of parent reports of ASD diagnoses. Moreover, the authors highlight the positive association between child age and ASD prevalence, a finding that suggests that the true likelihood that a child in the United States will be diagnosed with ASD may actually be even higher than the point prevalence reported in this study, an estimate that is based on a sample of children with a wide age range.

That said, given strong evidence of heterogeneity at the state level that may reflect important differences in policies, educational and medical practices, and/or causal environmental exposures, we question the meaning of any national estimate of ASD prevalence. More detailed reporting of heterogeneity in ASD prevalence offers an important first step.

ABBREVIATIONS

ADDM: Autism and Developmental Disabilities Monitoring
ASD: autism spectrum disorder
NSCH: National Survey of Children's Health

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