Letter to the Editor

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The validity and usefulness of public health surveillance of autism spectrum disorder

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In their recent editorial, the editors of *Autism*, David Mandell and Luc Lecavalier (2014), question the validity of the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network's estimates of the prevalence of autism spectrum disorder (ASD) in US communities. They argue that "true" prevalence studies must be based on direct, clinical examinations of individuals, rather than comprehensive reviews of clinical and educational records from multiple sources. They also argue that the continued increases in ASD prevalence over time as well as variations in prevalence among sites within the ADDM Network are evidence that the prevalence estimates must not be valid. Both of these arguments reveal a lack of understanding of the methods and purposes of public health surveillance, and a surprising lack of familiarity with previous studies of the epidemiology of developmental disabilities.

The CDC and other public health agencies conduct surveillance for many different types of health outcomes and exposures to monitor their frequency in the population over time, identify trends and potential public health threats, stimulate actions to improve and protect the health of the public, and evaluate the impacts of health interventions and policies (Thacker et al., 2012). Rarely do these surveillance activities involve direct clinical examinations of individuals in the population. Rather, the use of reliable and valid protocols based on the review of administrative records is the preferred approach to public health surveillance for conditions that typically result in treatments, tests, or interventions that are documented in administrative records (e.g. health or school records). Cost and efficiency are just some of the advantages of reliance on the existing records for public health surveillance when such records are available. Other major advantages of this approach, relative to recruitment and clinical examinations of hundreds of thousands of individuals in the population to generate comparable data, are timeliness and the ability to generate prevalence estimates for entire populations, rather than just for select samples of volunteers agreeing and available to be tested.

In the United States, children with ASD and other disabilities are typically referred for developmental assessments and receive therapeutic and/or special educational interventions at some point during childhood. Often, these referrals, diagnostic assessments, and interventions occur at later-than-optimal ages and, for ASD, age at diagnosis has been monitored by the ADDM Network since 2002 (CDC, 2007, 2014; Maenner et al., 2013; Shattuck et al., 2009). The ADDM Network focuses primarily on the surveillance of ASD at the single age of 8 years on the assumption that by this age, but not necessarily earlier, children with ASD will have received developmental evaluations providing documentation of behavioral and social impairments consistent with an ASD diagnosis. Thus, surveillance at the age of 8 years is an efficient approach to public health monitoring of trends in the prevalence of ASD. Moreover, there is considerable evidence of both the reliability and validity of the ADDM methodology for determining the number of ASD cases in defined populations (Avchen et al., 2011; Bakian et al., 2014; Van Naarden Braun et al., 2007).

Even at the age of 8 years, however, as noted in the editorial, only about 80% of children meeting diagnostic criteria for ASD as determined by the surveillance system will have documentation in their records of an ASD diagnosis made by a health practitioner. A major strength of the ADDM Network methodology is that it does not rely on existing diagnoses, but rather applies consistent criteria over time and among sites in the determination of whether documented behaviors are consistent with an ASD diagnosis. The application of rigorous and uniform criteria for case determination is a standard practice in public health surveillance and is what makes it possible to compare frequencies over time and among populations. Thus, the use of standard protocols and criteria for ASD case determination instead of counting only cases with a previous diagnosis is not a weakness; it is an important strength of the ADDM Network ASD prevalence estimates and what sets them apart from estimates based simply on the number of children receiving special educational services for autism (Gernsbacher et al., 2005) or the number of children with

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ASD who are able to access an evaluation in specialized autism diagnostic centers (Wing, 1980).

A review of previous efforts to estimate the prevalence of ASD through direct screening and assessment of children in defined populations does not support the conclusion that this approach would provide a solution to the vexing problems of rising prevalence over time and disparities in ASD prevalence among populations. In the 1990s, Bertrand et al. (2001) conducted detailed clinical assessments of all children, ages 3–10 years, identified as possibly having autism in Brick Township, New Jersey, and found a prevalence of 6.7/1000. This estimate was more than 16 times higher than that found in the first epidemiologic study of autism in children, conducted in the 1960s in Middlesex County, England, which also involved thorough screening of the population and comprehensive clinical assessments to identify cases of autism (Lotter, 1967). In 2011, Kim et al. (2011) published the results of their epidemiologic study of autism among 7- to 12-year-old children in Goyang City, South Korea. This study, which also involved comprehensive screening and diagnostic assessments, has produced the highest estimate of the prevalence of ASD to date, of 26.4/1000 children.

We share the editors' dismay with the rising numbers of children found to meet criteria for ASD. No one is happy to see these numbers. Nor is this trend unique to the United States—studies throughout the world employing various methods of estimating prevalence have shown similar trends (Elsabbagh et al., 2012). Like the editors, we are troubled by the site-to-site variations among communities and sub-groups of the US population. But such variations are the grist of public health surveillance and analysis. Rather than wondering whether the use of more costly surveillance methods would eliminate the trends and site-to-site variations in ASD prevalence described in ADDM Network publications, we wonder what these trends and variations convey about the relative contributions of the following: changes in awareness and diagnostic practices, disparities in access to care and in outcomes, trends in parental age and other ASD risk factors, and impacts of genetic factors and environmental exposures on ASD risk. These are all active areas of research, in part stimulated or enabled by findings from ADDM Network surveillance and other population-based studies. It is unfortunate that the editors would rather see the ADDM Network cease to conduct population-based surveillance than confront the important trends and disparities in ASD prevalence that the surveillance data reveal.

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