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Brief communication

Statewide county-level autism spectrum disorder prevalence estimates—seven U.S. states, 2018

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ABSTRACT

Purpose: Autism spectrum disorder (ASD) prevalence information is necessary for identifying community needs such as addressing disparities in identification and services.
Methods: Seven Autism and Developmental Disabilities Monitoring (ADDM) Network sites participated in a pilot project to link statewide health and education data to generate statewide and county-level prevalence estimates for a broader age range for their states for the first time.
Results: Statewide prevalence of ASD for ages 3–21 years in 2018 ranged from 1.5% in Tennessee and Wisconsin to 2.3% in Arizona. The median county-level prevalence of ASD was 1.4% of residents ages 3–

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Amanda V. Bakian reports a relationship with Price, Parkinson, & Kerr that includes: consulting or advisory. Deborah Bilder reports a relationship with Taysha Gene Therapies, Inc. that includes: board membership and consulting or advisory. Deborah Bilder reports a relationship with BioMarin Pharmaceutical Inc that includes: consulting or advisory, speaking and lecture fees, and travel reimbursement. Deborah Bilder reports a relationship with Encoded Therapeutics that includes: consulting or advisory. Deborah Bilder reports a relationship with Synlogic that includes: consulting or advisory. Maureen Durkin reports a relationship with University of Maryland Baltimore that includes: speaking and lecture fees. Maureen Durkin reports a relationship with Autism Speaks that includes: travel reimbursement. Maureen Durkin reports a relationship with SUNY Downstate Health Sciences University College of Medicine that includes: speaking and lecture fees. Jennifer Hall-Lande reports a relationship with Clearbrook that includes: speaking and lecture fees. Zachary Warren reports a relationship with JADD (journal) that includes: board membership. Zachary Warren reports a relationship with Autism (journal) that includes: board membership. Angelica Salinas reports a relationship with Autism Speaks that includes: travel reimbursement.

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21 years. More boys than girls had ASD at all sites, and prevalence was lower among non-Hispanic Black, Hispanic, Asian/Pacific Islander, and American Indian/Alaska Native residents compared to non-Hispanic White residents at most sites. ASD prevalence estimates for children aged 8 years were similar to 2018 ADDM Network estimates that used record review to provide more in-depth information, but showed greater variation for children aged 4 years.

Conclusions: Linkage of statewide data sets provides less detailed but actionable local information when more resource-intensive methods are not possible.

Introduction

Autism spectrum disorder (ASD) is a developmental disability characterized by deficits in social communication and interaction and the presence of restricted interests and repetitive behaviors. The Autism and Developmental Disabilities Monitoring (ADDM) Network has tracked ASD prevalence among children aged 8 years since 2000 and early ASD identification among children aged 4 years since 2010 [1,2]. For these activities, competitively-funded recipients ("sites") conduct active surveillance within a defined geographic area, reviewing and abstracting information from health and education records. This approach allows in-depth collection of important characteristics including co-occurring intellectual disability and age at diagnosis but requires significant resources for manual record review. This study piloted the use of adapted ADDM Network methods to assess using a less resource-intensive approach to produce actionable local ASD estimates.

Methods

Supplemental funding was available for existing 2018 ADDM Network sites to link statewide health and education data. Seven sites (Arizona, Arkansas, Minnesota, New Jersey, Tennessee, Utah, and Wisconsin) applied and received funds to participate (Table 1)[*].

To identify state residents with ASD, special education records with eligibility codes were requested from educational sources, and billing and administrative records with specific International Classification of Diseases, Ninth Revision (ICD-9) or Tenth Revision (ICD-10) codes were requested from health sources (medical and service providers that evaluate or serve children with developmental disabilities). All sites were able to receive statewide education data, and six sites had access to statewide health data.[†] The statewide project used the same data management tools and record linkage process as ADDM with minor modifications to maintain data in SAS files (since the project did not require additional data abstraction). The statewide project did not include a full record review for written diagnoses, but used the other two components of the ADDM surveillance case definition for ASD: a special education classification of ASD, or an ASD ICD-9 code 299.00–299.99 or an ICD-10 code in the F84 range.[‡]

ASD prevalence was calculated as the percent who met the ASD surveillance case definition among people aged 3–21 years.[§] Prevalence was calculated statewide overall, by sex, and by race and ethnicity for non-Hispanic White (White), non-Hispanic Black (Black), Hispanic, Asian/Pacific Islander (A/PI), and American Indian/Alaska Native (AI/AN) residents. Prevalence was also calculated at the county level. Sex information was missing for 0.2%; race information was missing for 3.1% (an additional 8.3% had race recorded as "other" or "multiracial"); and county residence information was missing for 2.6%. Those with missing (including "other" or "multiracial" for race) information were included in overall analyses but excluded from analyses stratified by the missing variable. Prevalence estimates were compared in the counties where ADDM Network methods were applied for children aged 4 and 8 years in 2018 [1,2]. Prevalence estimates with a relative standard error ≥30% were considered unstable and suppressed. Prevalence ratios were calculated to compare prevalence by sex, race, and ethnicity. The Wilson score method was used to calculate 95% confidence intervals (CIs) for prevalence and prevalence ratios (significance for ratios determined by 95% CIs that did not include 1). R software (version 4.1.2; R Foundation) was used for all data analyses and visualizations.

Results

The statewide prevalence of ASD for ages 3–21 years ranged from 1.5% in Tennessee and Wisconsin to 2.3% in Arizona (Table 1). More boys than girls had ASD at all sites, with male-to-female ratios ranging from 3.5 (Utah) to 4.7 (Minnesota) (data not shown). Compared to White residents, prevalence among Black residents was lower at 5 sites and overall, prevalence among Hispanic residents was lower at six of seven sites and overall, prevalence among A/PI residents was lower at six of seven sites and overall, and prevalence among AI/AN residents was lower at four of seven sites and overall.

ASD prevalence ranged from 0.5% to 2.9% in the 385 counties that met the threshold for reporting (Fig. 1; data for counties available at https://data.cdc.gov/dataset/county-level-ASD-prevalence-estimates/7vg3-e5u2). The median county-level prevalence of ASD was 1.4% of residents ages 3–21 years.

Patterns of ASD prevalence by year of age among sites varied (Fig. 2), but generally were highest during late elementary school ages (except in Utah, where prevalence was highest among teenagers).

Within the 2018 ADDM surveillance areas, ASD prevalence estimates for children aged 8 years were similar between the ADDM estimate and the linkage project estimate for sites (Fig. 3), from 12.3% lower (Minnesota) to 16.6% higher (Tennessee). For children aged 4 years, prevalence estimates showed greater differences, with linkage project estimates from 41.8% lower (Minnesota) to 129% higher (Arizona) than the ADDM estimates. Overall, linkage project estimates were 6.2% and 17.6% higher for children aged 8 years and 4 years, respectively.

Discussion

Generating statewide prevalence estimates for ASD involved novel data sources but were still similar to ADDM estimates among children aged 8 years, suggesting linking statewide education and

[*] All sites functioned as public health authorities under the Health Insurance Portability and Accountability Act of 1996 Privacy Rule and met applicable local institutional review board, privacy, and confidentiality requirements under 45 CFR 46.

[†] Minnesota health data were limited to its ADDM Network surveillance area.

[‡] Arizona ICD codes were limited to 299.00 and F84.0

[§] 2019 bridged-race population estimates for 2018 from https://www.cdc.gov/nchs

Table 1
Statewide autism spectrum disorder prevalence estimates among residents aged 3–21 years by site—7 U.S. states, 2018

			Prevalence (%) age 3–21 years					
State	N with ASD	Population	Overall	Non-Hispanic White	Non-Hispanic Black	Hispanic	Asian/Pacific Islander	American Indian/Alaska Native
Arizona*	41,616	1,771,955	2.3 (2.3-2.4)	2.7 (2.7-2.8)	1.9 (1.9-2.0)†	1.2 (1.1-1.2)†	1.4 (1.3-1.5)†	1.0 (0.9-1.1)†
Arkansas	12,626	749,252	1.7 (1.7-1.7)	1.8 (1.7-1.8)	1.2 (1.2-1.3)†	1.2 (1.1-1.3)†	1.4 (1.2-1.5)†	0.3 (0.2-0.5)†
Minnesota*	22,063	1,375,708	1.6 (1.6-1.6)	1.6 (1.5-1.6)	1.8 (1.8-1.9)‡	1.3 (1.3-1.4)†	1.7 (1.6-1.8)	2.7 (2.5-2.9)‡
New Jersey	38,321	2,070,221	1.9 (1.8-1.9)	1.7 (1.7-1.8)	1.8 (1.8-1.9)	1.6 (1.5-1.6)†	1.5 (1.5-1.6)†	0.8 (0.6-1.2)†
Tennessee	24,221	1,603,558	1.5 (1.5-1.5)	1.4 (1.4-1.4)	1.2 (1.1-1.2)†	1.1 (1.1-1.2)†	1.3 (1.2-1.4)†	1.2 (0.9-1.6)
Utah	20,223	972,725	2.1 (2.1-2.1)	2.0 (2.0-2.1)	1.4 (1.2-1.6)†	1.3 (1.2-1.3)†	0.7 (0.6-0.8)†	1.0 (0.9-1.3)†
Wisconsin	20,629	1,391,837	1.5 (1.5-1.5)	1.3 (1.3-1.4)	1.2 (1.1-1.2)†	1.5 (1.4-1.5)	1.1 (1.0-1.2)†	1.6 (1.4-1.8)
Total	179,699	9,935,256	1.8 (1.8-1.8)	1.7 (1.7-1.8)	1.5 (1.5-1.5)†	1.3 (1.3-1.3)†	1.4 (1.4-1.4)†	1.3 (1.2-1.3)†

Abbreviation: ASD = autism spectrum disorder.
* Arizona International Classification of Diseases, Ninth Revision or Tenth Revision billing codes were limited to 299.0 and F84.0; Minnesota health linkage was limited to the parts of three counties included in ADDM surveillance
† Prevalence significantly lower than White.
‡ Prevalence significantly higher than White.

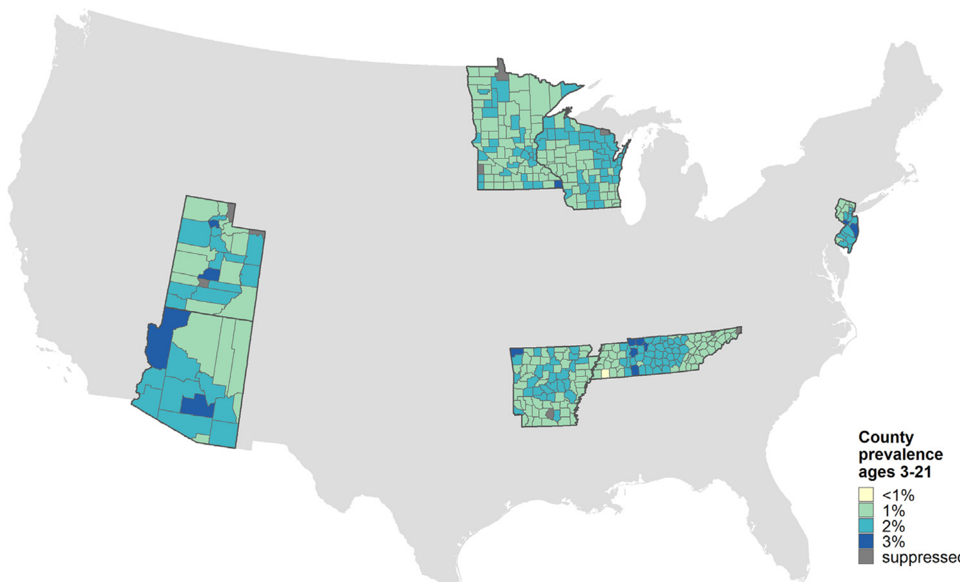

Fig. 1. County-level prevalence of autism spectrum disorder among residents ages 3–21 years*—7 U.S. states, 2018. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)
*County estimates suppressed when standard error for prevalence was ≥30% of estimate (n = 9 counties below threshold); 2.6% of state residents were missing county information.

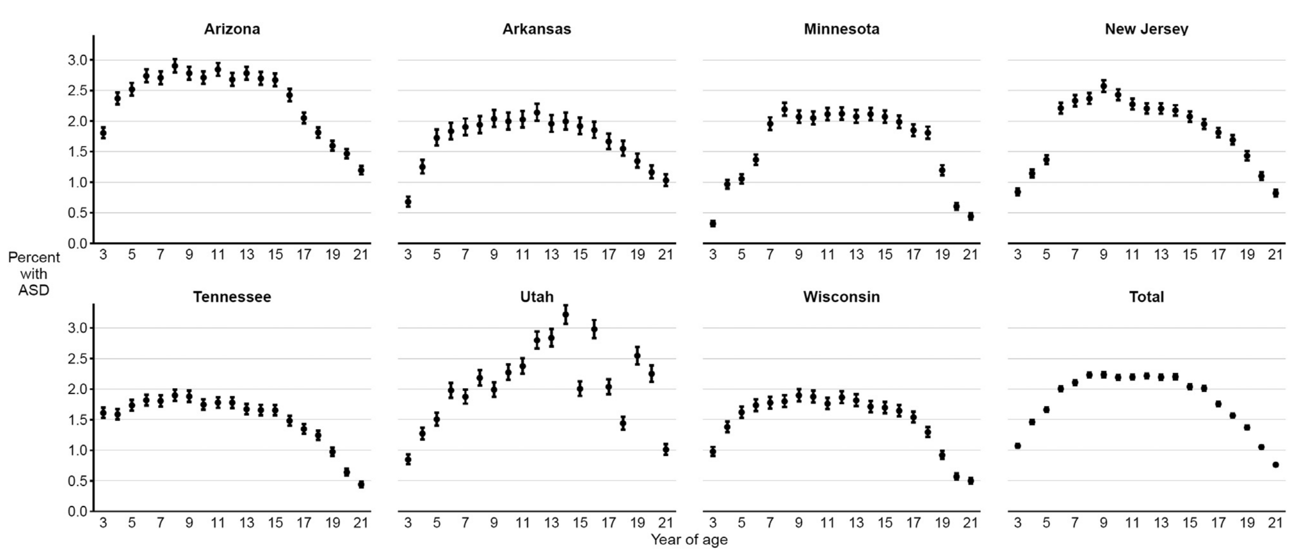

Fig. 2. Statewide prevalence of autism spectrum disorder by year of age by site—7 U.S. states, 2018. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

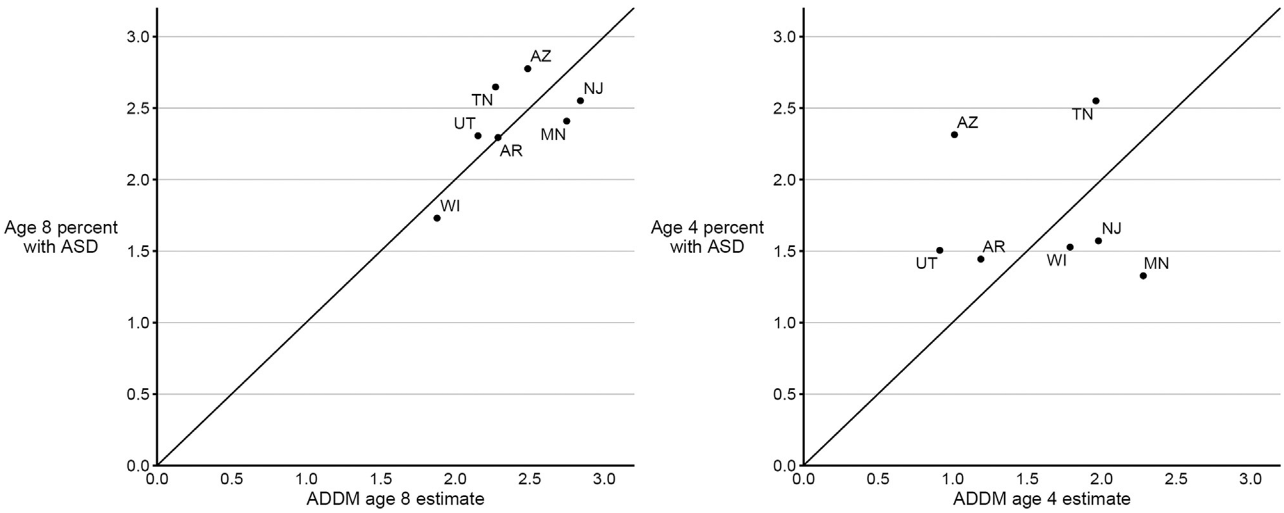

Fig. 3. Comparison of ADDM Network and statewide data linkage ASD estimates among children aged 8 and 4 years within ADDM surveillance areas*—7 U.S. states, 2018. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)
*Limited to entire counties included in MMWRs – 1 county in Arizona; 21 counties in Arkansas; 3 counties in Minnesota; 2 counties in New Jersey; 11 counties in Tennessee; 3 counties in Utah; 8 counties in Wisconsin.

health data can generate reasonable autism prevalence information for this age group in the absence of more resource-intensive record review methods. These estimates reflect community practices identifying ASD among children. Children without an ASD ICD code or eligibility would not be included in estimates, and some children might receive a code or eligibility and later have ASD ruled out [1]. Tracking other conditions could be feasible but would require the development and assessment of a case definition based on ICD codes and special education categories (https://sites.ed.gov/idea/regs/b/a/300.8).

Prevalence estimates among children aged 4 years were more variable by site, likely reflecting data sources included in the project. The site with the greatest difference, Arizona, included Medicaid data among other data sources for their surveillance for the first time, which could have particularly influenced the younger age group. Minnesota's estimate was much lower than from ADDM; however, they did not receive statewide health data and were limited to clinical data for their study area, which did not include entire counties. The availability of early intervention data sources could limit estimates at earlier ages, and statewide education data would likely be most comprehensive for children 6–17 years of age. ASD identified after age 17 may also not be captured in education data. Utah's pattern of higher and more variable prevalence in teenage years could reflect the pattern of historical data requests made for specific birth cohorts; some data systems included records that could not be queried retroactively to fill in gaps. In the 6–17 years age range at most other sites, prevalence among younger children matched or exceeded the prevalence of older children.

The ADDM Network has previously reported disparities in ASD prevalence by race and ethnicity among children aged 8 years, but site estimates could not necessarily be generalized to the entire state. The statewide project provided state-level estimates of these disparities for the first time, showing lower ASD prevalence among Black, Hispanic, A/PI, and AI/AN residents compared to White residents aged 3–21 years. In recent years, the gaps in ASD prevalence among children aged 8 years in the ADDM Network narrowed, with no overall difference between Black and White children aged 8 years in 2016 (children born in 2008) [3] and no overall differences between Black and White or Hispanic and White children in 2018 (children born in 2010) [1]. The broader age group included in the statewide project (born 1997–2015) mirrored ADDM Network findings prior to 2016 [4], likely reflecting persistent disparities in ASD prevalence among older cohorts.

Accessing data for public health surveillance requires an investment of time in community engagement and respect for community concerns and perspectives related to privacy and local control of data. Even when partners were enthusiastic about participation and in agreement about requirements, most sites faced challenges with the amount of time required to execute formal data-sharing agreements. Though some data agreements and requests were instant (when data sources were institutional partners), most data agreements required 1–3 months to develop, and receiving data could take an additional month or more (in a few cases close to a year). In one case, a data-sharing agreement could not be reached in the 2-year time frame of the project. Existing data systems that link data from multiple state agencies/programs (e.g., early childhood integrated data systems or health information exchanges) hold promise for facilitating work with linkages if these systems also streamline the data agreement process.

Once agreements were made, data access was highly variable by site and data source. Identifiable data were not available at some sources, and sometimes getting other desired data elements was an iterative process involving multiple requests. Though acquiring most data did not incur a cost, two sites reported less than $10,000 cost for statewide education data and four sites reported less than $5000 cost for coding support at a source (usually linkage to vital records). Data completeness varied; linking multiple data sources helped mitigate missing data. Sex and race information was available for most cases (99.8% and 96.9%, respectively). Most (97.4%) residents could be assigned to a county using information from their health or education records in the surveillance year. Approaches to estimating ASD with ICD codes vary [5], but a documented diagnostic statement or special education classification of ASD was found in records for 91.9% of children aged 8 years and 90.6% of children aged 4 years with an ASD ICD code in ADDM in 2018 [1].

Unique circumstances such as privacy and information technology requirements also caused complications (e.g., sites required to work with data inside virtual machines that could not run the provided data analysis tools). Once implemented, processes such as privacy-preserving record linkage could offer solutions to some privacy concerns [6], but logistical and practical obstacles to developing this capacity remain.

The infrastructure and present-day capacity for rapidly conducting statewide ASD surveillance varied by state. Although less detailed than data produced by more in-depth ADDM Network surveillance, the statewide linkage project provided similar prevalence findings and also provided local ASD estimates from linked health and education sources for many of these communities at the county-level for the first time. This less resource-intensive method could be feasible for states with or without an ADDM site. Statewide county-level estimates can help communities, health care and education providers, and policymakers identify needs and plan services and support for individuals with ASD and their families.

CRediT authorship contribution statement

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