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Variance in Autism Prevalence: Links With State-Level Autism Resources

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Abstract

The prevalence of autism spectrum disorder (ASD) has varied over time and across the United States. This variability is likely related to external factors, such as regional differences in ASD-related resources. The study reported on here examined the links between ASD prevalence as measured by Individuals with Disabilities Education Act (IDEA) Part B child count data and four aspects of state infrastructure (health care and insurance policies, clinical resources, research infrastructure, and awareness-raising individuals/organizations). This study also investigated whether these constructs varied by geographical region. The data for this study were abstracted from publicly available databases. Information on state infrastructure was gathered from high-quality reports, resource guides, certificant registries, and databases. More comprehensive ASD-relevant insurance and health care policies, more clinical resources, and greater research infrastructure were associated with higher ASD state prevalence rates as measured by the IDEA Part B child count data. Prevalence of ASD was higher in eastern U.S. states compared with southern U.S. states, but state-level ASD resources did not statistically significantly differ across geographic regions. Implications for research, practice, and policy are discussed.

Keywords

autism, prevalence, IDEA Part B child count data, state-level resources

While originally considered a rare disorder, the prevalence of autism spectrum disorder (ASD) has been on the rise in the past decade (Matson & Kozlowski, 2011; Rice et al., 2012; Wing & Potter, 2002; Xu et al., 2018). In fact, the most recent prevalence estimates from the Autism and Developmental Disabilities Monitoring Network (ADDM), a group of programs funded by the Centers for Disease Control and Prevention (CDC), estimates that 1 in 54 children aged 8 years old in the United States meet diagnostic criteria for ASD (Maenner et al., 2020). This estimate is approximately 10% higher than the estimate for the 2014 data (1 in 59) and 175% higher than the estimate based on data collected in 2002 (1 in 150; Maenner et al., 2020).

Although many are speculating on the cause of the increase in ASD prevalence (Mazumdar et al., 2013; Williams et al., 2005), research has suggested that the rise in prevalence is a result of factors external to the condition itself, including changes in diagnostic criteria, new assessment instruments, inaccurate diagnoses, and greater awareness about ASD (Matson & Kozlowski, 2011; Wing & Potter, 2002). However, little research has investigated the role of potential external factors on ASD prevalence. Understanding the links between state-level contextual factors and ASD prevalence is important. Several studies have shown that a marked variability in the prevalence of ASD exists across U.S. states (Christensen et al., 2014; Xu et al., 2019). As one example, the current CDC and ADDM prevalence estimates support these findings with state prevalence estimates ranging from 1 in 76 children identified in Colorado to 1 in 32 children identified in New Jersey (Maenner et al., 2020). Just as policy, resources, and awareness differ among geographical regions in the United States, so do disparities in health outcomes (Centers for Disease Control and Prevention [CDC], 2013). If these state-level ASD-related resources are systemic drivers of observed differences in prevalence, then understanding geographical variability has the potential to suggest avenues of investigation related to the underlying drivers of ASD prevalence rates and help reveal inequity in access to resources related to ASD.

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ASD Prevalence Data

There are a limited number of high-quality resources that estimate the prevalence of ASD (Johnson et al., 2014). Two sources of ASD prevalence data that have representative sampling and are of high quality are the ADDM Network and Individuals with Disabilities Education Act (IDEA) databases. The ADDM Network, the largest ongoing ASD tracking system in the United States, utilizes a record-based surveillance and community screening approach to data collection that is based on the CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (Johnson et al., 2014). Though the ADDM utilizes a comprehensive, systematic, and reliable method for data collection, the data are limited to the 16 ADDM Network sites (CDC, 2020). Such a small sample of states limits the utility of investigating state-level ASD-related resources among the ADDM-participating states.

In contrast, the IDEA Part B child count data offer another means of obtaining ASD prevalence rates. The Individuals with Disabilities Education Act mandates that all schools submit documentation of all children receiving services under each of the 14 IDEA disability categories (e.g., autism, developmental delay) to their state department of education (Duncan et al., 2014). Thus, the IDEA Part B child count data are derived from individual school counts of children between the ages of 3 and 21 years who receive special education services in each state (IDEA Data Center, 2013). Compared with the ADDM data, the child count data are also typically disseminated more quickly. Thus, the IDEA Part B child count data provide an alternative prevalence estimate that addresses key weaknesses associated with the ADDM prevalence data. However, the IDEA Part B child count data are not representative of the entire population due to its focus on the educational system and exclusion of the medical system (Johnson et al., 2014). Additionally, the child count data rely on administrative data, which can be affected by state-specific reporting requirements and do not require validation of the ASD diagnosis (Mandell & Lecavalier, 2014).

State-Level Contextual Correlates of Variability in ASD Prevalence

Four key state-level ASD-related resources may relate to variability in ASD prevalence rates among states. These include health care and insurance policy, clinical resources, research infrastructure, and advocacy-raising activities.

Health care and insurance policies play an important role in what diagnostic, treatment, and supportive resources are available to individuals with ASD. As a result of high costs, insurance companies have historically been reluctant to pay for services for individuals with ASD (Johnson et al., 2014). For example, Ganz (2007) found that the cost of medical and nonmedical treatments for ASD varied throughout the lifespan with medical treatments peaking in the first 5 years of life and nonmedical treatments peaking in the mid-20s. Other studies estimated that the cost of intensive behavioral interventions for ASD to be between US$10,000 and US$100,000 a year depending on the intensity of services needed. (Bouder et al., 2009; Geggel, 2014; Zane et al., 2008). Studies have also highlighted additional costs for special education services, living accommodations later in life, and medical treatments such as occupational and speech therapies (Buescher et al., 2014; Christensen et al., 2014; Ganz, 2007).

Over the last decade, private insurance companies have increasingly been required to cover ASD treatments and services—including but not limited to educational, medical, and behavioral services—via mandates passed by state legislature, administrative action, or litigation (Johnson et al., 2014; Mandell et al., 2016). However, these mandates differ drastically in regard to their generosity, with significant variability in their age limits, price caps, and services covered (Callaghan & Sylvester, 2019). Furthermore, state insurance mandates do not apply to all insurance plans. Individuals who receive benefits from companies with self-funded health benefit plans are not guaranteed ASD coverage as these plans are regulated by the Employee Retirement Income Security Act. Autism Speaks (2018) reported that less than half of large companies with self-funded health benefit plans cover ABA services. Families whose insurance plans do not cover ASD services or who live in states without mandated coverage must rely on government-funded programs such as Medicaid to pay for these programs.

The National Institutes of Health (NIH) reviewed the 30 states that passed insurance mandates between 2001 and 2012 and found that states with a higher prevalence of ASD and a higher density of pediatricians were more likely to mandate insurance coverage (Johnson et al., 2014). Similarly, Callaghan and Sylvester (2019) found that states with more individuals covered under private insurance were more likely to enact generous ASD insurance mandates. One way to interpret this is that states with a weak infrastructure for diagnosing and treating ASD often also historically lacked the insurance mandates that help pay for treatments, creating a cycle of debt and a lack of high-quality assessment and treatment options for families (Geggel, 2014; Johnson et al., 2014).

Although insurance has not historically covered assessment and treatment for children with ASD, changes associated with the Affordable Care Act have mandated that Medicaid programs and most private insurance plans must cover "medically necessary diagnostic and treatment services" for individuals with ASD (Mann, 2014). However, in practice, not all states include ASD or offer comprehensive coverage for ASD services under their state's Essential Health Benefits (EHB) package. In their 2014 report, Easterseals (2014) found that only 30 states included autism

services under their EHB package on the marketplace exchange. As of 2019, all 50 states have enacted an ASD insurance mandate and more than half of states include ASD in their EHB packages, but these mandates and policies continue to differ in both quality and comprehensiveness (Choi et al., 2020).

In addition to policy, clinical resources for ASD, such as parent-selected treatment type, have been shown to vary across geographic regions of the United States (Hoffman et al., 2017; Mire et al., 2018). Specifically, Mire et al. (2018) found that children from the Northeast were more likely to be diagnosed with ASD and receive some form of treatment than children from other parts of the country. Mazumdar and colleagues (2013) found that children who moved into a neighborhood with more diagnostic resources than their previous neighborhood were more likely to receive a diagnosis of ASD in comparison to the children whose local resources did not change. Together, these findings suggest that the availability of clinical resources may play a role in the prevalence of ASD. It is also probable that geographical areas with insurance policies that cover ASD assessment and treatment will be associated with more providers who utilize the diagnosis, and thus, a higher prevalence rate (Johnson et al., 2014). As such, the regional differences in the availability of providers who can diagnose and treat ASD could also be a driver of the variability of ASD prevalence across states.

Finally, the quantity of ASD-specific research and awareness-raising activities by state or region may also play important roles in understanding variability in ASD prevalence. With regard to research, there are two indications that research infrastructure may relate to ASD prevalence increases over time and also to regional differences in ASD prevalence. First, NIH RePORTER, an online database of federally funded research projects, shows an increase in NIH-funded grants related to ASD over the last 25 years, from 54 in 1991 to 1,661 in 2016 (National Institutes of Health [NIH], 2020). Given that major federal funding often goes to high-quality research programs, it can be surmised that the allocation of these research dollars may vary regionally, which may contribute to regional variations in ASD prevalence. With regard to awareness, many researchers hypothesize that an increase in awareness could have an effect on the prevalence of ASD (Fombonne, 2009; Matson & Kozlowski, 2011; Wing & Potter, 2002). For example, as the general public's awareness of ASD increases, in part due to awareness-raising individuals and organizations, parents may be more likely to request that their children be evaluated for ASD (Matson & Kozlowski, 2011).

Current Study

The current study has two primary aims. For Aim 1, we sought to better understand the links between state-level contextual factors and ASD prevalence as estimated by IDEA Part B child count data. The four ASD-related resources we considered were health care and insurance policy, clinical resources, research infrastructure, and awareness-raising individuals and organizations. We hypothesized that states would have higher ASD prevalence rates:

Hypothesis 1 (H1): More generous ASD health care and insurance policies.
Hypothesis 2 (H2): More clinical services for individuals with ASD.
Hypothesis 3 (H3): More NIH-funded projects, funding, and research institutions relevant to ASD.
Hypothesis 4 (H4): More ASD awareness-raising activity.
Aim 2 was to investigate whether there was geographical variability in ASD prevalence and these four contextual factors—health care and insurance policy, clinical resources, research infrastructure, and awareness-raising individuals and organizations—with the goal of elucidating potential inequities by region.

Method

Procedure

The data for this study were gathered from publicly available information accessed through databases including PsycINFO and Google Scholar as well as a review of the resource packets on the national Autism Speaks and Autism Society websites. Publicly available data were abstracted from the IDEA Part B child count data, Easterseals State Autism Profiles, NIH RePORTER, BACB Certificant Registry, as well as Autism Speaks and Autism Society databases. The first author, the primary researcher, who has a bachelor's degree and some graduate training, and the sixth author, a research assistant with a bachelor's degree, collected the data. The research assistant was trained by the primary researcher until she demonstrated mastery of the data collection procedure. The team utilized a coding manual that provided operational definitions, detailed instructions, and examples for all data collection procedures. The coding manual is available upon request. The primary researcher completed the cleaning of data, including the removal of duplicates. Interrater reliability (IRR) was calculated for data that required coding, which were the policy and research infrastructure variables. Twelve states were randomly selected; IRR was 75% for the policy and 100% for the research infrastructure variables before discussion and 100% after discussion. Interrater reliability was not calculated for the clinical resources and awareness variables as these were raw counts that did not require coding. Data were abstracted over several weeks and were updated as of October 20, 2020. All data were entered into Google Sheets. Detailed state-level information about the ASD-related resources is in Appendix SA in the Online Supplemental Materials. This study, which did not include human participants, was exempt from institutional review board approval.

Measures

State prevalence of ASD served as the outcome variable. It indicates the number of students ages 6 to 21 years in each state during the 2016–2017 school year who were served under IDEA Part B, adjusted for state population (U.S. Department of Education, 2017). The 2016–2017 IDEA data were collected in the fall of 2016 and released on November 1, 2017, by the U.S. Department of Education. Wisconsin does not publish its IDEA Part B Child Count data.

Data on state health care and insurance policies were collected via the 2016 State Autism Profiles published by the Easterseals Office of Public Affairs (Easterseals, 2016), with additional data extracted from the L&M Policy Research report LLC 2014 (L&M Policy Research, LLC, 2014). Easterseals publishes a yearly report on the status of autism services and policies in all 50 states and the District of Columbia. Easterseals State Autism Profiles include data on IDEA Part B, state insurance coverage, autism coverage in the EHB under the state's health care exchange, Medicaid services, educational programs, special education criteria and other state Autism resources (Easterseals, 2016). The L&M Policy Research report is an in-depth analysis of state policies as well as services and supports for individuals with ASD within each of the 50 states. The L&M Policy Brief identifies three main policies that help cover the costs of diagnosis and treatment: the insurance mandate requiring coverage for those diagnosed with ASD, Home and Community-Based Services (HCBS) waivers from Medicaid, and ASD-specific HCBS waivers. Initial review of each state's policy was completed using the Easterseals State Autism Profiles with additional information regarding HCBS and ASD-specific waivers extracted from the L&M Policy Research report. In order to best compare the policies of different states, each state was assigned a score based on the following scheme: one point each for the three policy coverage options mandated by the state (having an insurance mandate, having an ASD-specific HCBS waiver, and having additional HCBS waivers that can be utilized to cover potential costs), one point each if the state-mandated policies had no age limit and no financial limit with regard to coverage, and one point if the state included autism in the EHB package on the state's health care exchange. Thus, the state policy total variable could range from 0 (no aspects of coverage) to 6 (all aspects of coverage without age and financial limits). The scoring procedure and an example can be found in Appendix SB in the Supplemental Materials.

Data on clinical resource availability were collected via a review of Autism Speaks online resource guides (Autism Speaks Inc., 2020), the Autism Society Autism Source database (Autism Society, 2020), and the certificant registry on the Behavior Analyst Certification Board (BACB) website (BACB Certificant Registry, 2020). The total number of providers who were listed as able to provide clinical services for ASD was recorded for each state. The clinical resource variable includes diagnosticians and interventionists, although it was not a requirement that clinicians be both. The search within the Autism Speaks database included all providers under the *Evaluation and Diagnosis* and *Treatment and Therapies* categories. Within the Autism Society Autism Source database, the search included providers listed under the diagnostic, early intervention, mental health professional, and therapists (other) categories. Autism Society data were downloaded and provided to the first author by staff at Autism Society. Duplicate diagnostic and intervention resources extracted from Autism Speaks and Autism Society databases were removed via visual inspection and the duplicate removal function within the Google Sheets software program. An additional search within the BACB registrant database was conducted to include those providers categorized as BCBA, BCaBA, RBT, and BCBA-D. Due to the nature of how the BCBA data were collected, however, potential duplicates listed on both the BCBA registry and on either or both of the Autism Speaks or Autism Society websites could not be removed. Although this introduces the potential duplication of providers in the resource count, we determined that excluding one of the primary treatment providers for individuals with ASD was unacceptable. A total clinical resources variable was created by calculating the sum of the diagnostic and intervention resources and the BCBA registrants.

Information on the total number of institutions receiving federal funding for ASD research, total funding, and total number of federally funded ASD research projects for each state in the 2016 fiscal year was collected via a search on NIH RePORTER (NIH, 2020). Searches were conducted with the keyword of *autism* and were limited to projects funded in the 2016 fiscal year. Three research infrastructure variables were abstracted for each state from NIH RePORTER: total institutions, representing the total number of institutions that received federal funding for ASD research; total funding, representing the total amount of funding provided to each state for federally funded projects and subprojects; and total research projects, representing the total number of active ASD specific projects and subprojects. Because the three research variables include both counts and dollar amounts, we standardized (i.e., transformed into z-scores) and averaged them to create one indicator of research infrastructure.

Data on the number of individuals and organizations aiming to raise awareness about ASD were obtained via the Autism Speaks resource guides (Autism Speaks Inc., 2020) and the Autism Society Autism Source database (Autism Society, 2020). Within the Autism Speaks database, the search included *advocacy, legal & financial, advocates, attorneys, financial planners, legal & financial, assistive technology, protection & advocacy*, and *special education office* within the categories of advocacy and state service

Table 1. Descriptive Statistics of State-Level Contextual Correlates.

Variable	*M/n* states out of 50	*SD*	Range
Policy	3.04	1.21	[1, 6]
Insurance mandate	44	—	—
No age limit on insurance mandate	7	—	—
No financial limit on insurance mandate	11	—	—
HCBS waiver	47	—	—
ASD waiver	15	—	—
ASD on health care marketplace	28	—	—
Clinical resources	2,370.20	4,094.51	[83, 20,777]
Diagnostic and intervention	166.06	183.56	[12, 932]
BACB registrants	2,204.14	3,937.94	[71, 20,196]
Research infrastructure (Z-score)	0	.98	[−.60, 4.49]
Institutions	5.10	6.92	[0, 30]
Projects	31.72	58.28	[0, 335]
Funding	US$13,295,092	US$26,238,800	[US$0, US$136,052,818]
Awareness	71.74	77.72	[15, 510]

Note. HCBS = home and community-based services; ASD = autism spectrum disorder; BACB = behavior analyst certification board.

and entitlements. The search within the Autism Society database included the *government agency, legal/advocacy*, and *Autism Society affiliate* categories. Autism Society data were downloaded and provided to the first author by staff at the Autism Society. Duplicates were removed via visual inspection and the duplicate removal function within Google Sheets software. A total awareness variable was created by calculating the sum of all awareness-raising individuals and organizations.

Finally, geographic region was coded using the NIH RePORTER geographic region categories (e.g., central, eastern, southern, and western; NIH, 2020).

Analysis

First, all variables except the policy variable were calculated to represent prevalence taking into account the state population using the CDC's formula (e.g., number of individuals/resources divided by the state population as derived from the 2016 census multiplied by 100; Christensen et al., 2014). The policy variable is not a count of individuals/resources and therefore was not transformed into a prevalence rate.

Descriptive statistics on the prevalence rate of ASD, comprehensiveness of health care and insurance policy, clinical resources, research infrastructure, and awareness-raising individuals and organizations were calculated. Aim 1 was evaluated using Spearman's rho non-parametric correlation coefficients between ASD prevalence rate as estimated by the IDEA Part B child count data and state health care and insurance policy, the availability of clinical resources, ASD-focused research, and awareness-raising individuals and organizations. Effect sizes for rho range from 0 to 1 and are associated with the following interpretation: .00–.19 = very weak, .20–.39 = weak, .40–.59 = moderate, .60–.79 = strong, and .80–1.0 = very strong. Aim 2 was evaluated using Kruskal–Wallis tests with post-hoc Dunn-Bonferroni tests to examine patterns in the IDEA Part B child count data, insurance policy, clinical resources, research infrastructure, and awareness by geographic region; effect sizes were calculated for Mann-Whitney *U* post-hoc pairwise comparisons and are interpreted as follows: .1 = small, .3 = medium, .5 = large. A significance threshold of $p < .05$ was used in all analyses.

Results

Descriptive Statistics

Descriptive statistics of the independent variables (insurance policy, clinical resources, research infrastructure, and awareness) are presented in Table 1. Results showed that the majority of states ($n = 44$) have an insurance mandate that requires diagnostic and intervention coverage for ASD. Of these 44 states, only 7 do not have an age limit and only 11 do not have a financial limit to the policy. Most states have HCBS waivers ($n = 47$) that can be applied to cover services for families. However, only 15 states have a specific ASD HCBS waiver. Additionally, only 28 states included coverage for ASD on the healthcare marketplace. The total policy scores ranged from 1 to 6, with states having, on average, about 3 ($SD = 1.2$) of the 6 elements of a comprehensive policy.

Considerable variability was present in the other three state-level ASD-related resources. Specifically, clinical resources ($M = 2{,}370.20$, $SD = 4{,}094.51$), research institutions performing ASD research ($M = 5.10$, $SD = 6.92$),

Table 2. Descriptive Statistics of IDEA Part B Child Count and Independent Variables by U.S. Geographic Region.

Variable	Central states (n = 13)	Eastern states (n = 10)	Southern states (n = 14)	Western states (n = 13)
IDEA Part B child count	9,860.00 (8,193.00)	11,663.10 (12,324.95)	13,727.29 (13,710.59)	11,193.46 (22,578.06)
IDEA Part B derived prevalence rate	.16 (.07)	.20 (.03)	.15 (.03)	.16 (.04)
Policy	3.08 (1.04)	3.40 (1.35)	2.64 (1.01)	3.15 (1.46)
Insurance mandate	11	10	12	11
No age limit	2	2	0	3
No financial limit	3	2	2	4
HCBS waiver	13	9	14	11
ASD waiver	5	4	2	4
ASD on health care marketplace	6	7	7	8
Clinical resources	1,502.00 (1,630.14)	1,846.50 (1,607.51)	3,302.79 (5,416.25)	2,636.92 (5,472.14)
Diagnostic and intervention	140.92 (136.28)	152.40 (137.09)	208.07 (195.84)	156.46 (245.71)
BACB registrants	1,361.08 (1,516.61)	1,694.10 (1,492.19)	3,094.71 (5,260.25)	2,480.46 (5,232.66)
Research infrastructure (Z-score)	−.27 (.31)	.53 (1.37)	−.09 (.47)	−.05 (1.38)
Institutions	3.31 (3.45)	9.40 (10.54)	4.71 (3.87)	4.00 (7.99)
Projects	16.31 (15.30)	56.50 (69.63)	26.93 (28.31)	33.23 (91.28)
Funding	US$6,112,175 (US$5,889,545)	US$27,188,351 (US$37,164,974)	US$10,162,495 (US$11,101,084)	US$13,164,454 (US$37,134,101)
Awareness	56.92 (36.63)	74.60 (56.85)	79.14 (52.34)	76.38 (132.66)

Note. Data represented as means (standard deviations) and number of states out of subtotal within geographical region. Wisconsin does not publish its IDEA Part B Child Count data. IDEA = individuals with disabilities education act; HCBS = home and community based services; ASD = autism spectrum disorder; BACB = behavior analyst certification board.

NIH-funded ASD research projects (M = 31.72, SD = 58.28), NIH funding (M = US$13M, SD = US$26M), and individuals and organizations that aim to raise awareness (M = 71.74, SD = 77.72) all possessed standard deviations that were greater than the average.

Aim 1: Associations Between Child Count Prevalence Rates and State-Level ASD-Related Resources

Consistent with hypotheses, more comprehensive insurance policies, $r_s(49) = .39$, $p < .01$, more clinical resources, $r_s(49) = .36$, $p = .01$, and more comprehensive research infrastructure, $r_s(49) = .44$, $p < .01$, were associated with a higher prevalence of ASD, as measured by IDEA Part B child count data. Contrary to the hypothesis, the number of awareness-raising organizations was not significantly associated with the IDEA Part B child count derived prevalence of ASD, $r_s(49) = -.02$, $p = .92$.

Aim 2: Variation in ASD Prevalence by Geographic Region

Descriptive statistics of the independent variables analyzed by geographic region are presented in Table 2. The average prevalence of ASD, estimated via the IDEA Part B child count data, significantly differed among geographical regions, $\chi^2(3) = 10.07$, $p = .02$, with eastern states having significantly higher prevalence rates (M = .20), on average than southern states (M = .15, $p = .01$). Geographical regions did not differ significantly in terms of their ASD-related resources. Specifically, there were no geographical differences among regions in health care and insurance policies, $\chi^2(3) = 2.83$, $p = .42$, clinical resources, $\chi^2(3) = 6.95$, $p = .07$, awareness resources, $\chi^2(3) = 6.86$, $p = .08$, or research infrastructure, $\chi^2(3) = 4.33$, $p = .23$.

Discussion

Prevalence rates vary nationally (ADDM, 2014; Baio, 2012, 2014) and within states (Hoffman et al., 2012, 2014; Van Meter et al., 2010). Recent research on ASD prevalence suggests that the increase in the prevalence of ASD over the past decade is likely not a result of more people developing ASD but rather a result of changes in diagnostic criteria, new assessment instruments, inaccurate diagnoses, and greater awareness about ASD (Matson & Kozlowski, 2011; Wing & Potter, 2002). Mandell and Lecavalier (2014) further suggest that local policies, resources, and awareness may be drivers of the observed differences in prevalence. This study aimed to better understand the links between ASD prevalence and state-level ASD-related resources, and also whether these constructs varied geographically. The findings from this study can suggest avenues of investigation related to the underlying drivers of ASD and reveal inequity in access to resources related to ASD.

Our findings indicate that health care and insurance policies, diagnostic and treatment resources, research infrastructure, and awareness-raising advocates and organizations

varied among states. We also found that states with more ASD-relevant policies, clinical resources, and research infrastructure had higher prevalence rates of ASD, per the IDEA Part B child count data. These findings support prior literature linking higher prevalence rates to better insurance coverage for ASD (Johnson et al., 2014) and more clinical resources (Johnson et al., 2014; Mazumdar et al., 2012). In contrast to the previous literature, however, we did not find a statistically significant relationship between the number of awareness-raising organizations and autism prevalence (Fombonne, 2009; Matson & Kozlowski, 2011; Wing & Potter, 2002).

Our analyses of the distribution of important state-level contextual factors relevant to ASD found considerable variation geographically with regard to prevalence. To test this variability, we evaluated differences among regions in the United States. We found that eastern states had significantly higher prevalence rates than southern states, as measured by IDEA Part B child count data. In contrast, health care and insurance policies, number of clinical resources, number of awareness resources, and state research infrastructure did not significantly differ across geographic regions. On one hand, this equity across regions is reassuring considering that inequity in access to resources relevant to ASD would be problematic. On the other hand, it is important to note that differences among states were still present despite the observed equity across regions. We were not able to make between-state comparisons in this study, and comparing geographical regions instead likely blurred distinctions between individual states. This finding is also in contrast to previous research, which found variability in the quality of coverage of ASD services across states (Callaghan & Sylvester, 2019; Easterseals, 2016). Studies have also documented disparities in access to ASD services based on race, socioeconomic status, gender, and geographic location (Bishop-Fitzpatrick & Kind, 2017), including between rural and urban settings (Antezana et al., 2017).

To best serve individuals with ASD, it is important that every state facilitate best-practice assessments and treatments for ASD through the hiring and retention of well-trained and certified providers, regardless of location within the state (Geggel, 2014; Johnson et al., 2014). Land-grant institutions, which are usually located in rural areas, provide occupational and career training and are responsible for public engagement and meeting society's needs. Such institutions can play a key role in addressing this workforce issue (Jamieson, 2020). Furthermore, in our study, we found that states, on average, had three of six components of a comprehensive policy in 2016. A 2020 study similarly found inequities in state mandates across the country (Choi et al., 2020). Although the researchers noted that mandated coverage had improved, their analyses, similar to ours, also highlighted that many states still limit services by age and cost limit.

Limitations and Future Directions

Despite this study's strengths, it is not without limitations. Some scholars have questioned the accuracy of IDEA Part B child count prevalence estimates (Mandell & Lecavalier, 2014). Although the IDEA Part B child count data provide comprehensive coverage of the U.S. population, they look only at the number of students receiving special education services for ASD, which may be an underestimate of the true prevalence of ASD. Specifically, this database is less likely to include children who are not enrolled in public school. Researchers have also pointed to important issues with the use of the IDEA Part B child count data, suggesting that these administrative data are vulnerable to idiosyncratic state reporting requirements, unvalidated diagnoses, and missed cases (Mandell & Lecavalier, 2014). Ideally, future work will focus on developing a methodologically stronger approach to gathering these important data from all states (Mandell & Lecavalier, 2014).

Second, these data were cross-sectional and correlational. For example, we could not detect if prevalence rates of ASD were higher in certain areas because families moved to parts of the country where an individual with ASD can receive the best treatment and the most support. In addition, the four state-level ASD-related resources investigated in this study are likely interrelated. For example, over time, it is possible that facilitative federal and state policies related to ASD could affect clinical, research, and awareness resources. Finally, it is unknown whether a greater prevalence of ASD might result in the creation of more clinical resources and an increased interest in ASD by researchers or if a greater number of resources in the area might lead to a greater prevalence. Future research should investigate the directionality of this relationship.

Third, data on the number of clinical resources and awareness-raising individuals and organizations came from the Autism Speaks and Autism Society online resource guides and the BACB certificant registry. Although these resources are well-known and come from national organizations, the data they include likely do not represent all resources available, since organizations and individuals must sign up to be included in the resource guides. In addition, due to how the BCBA data were collected, it was impossible to remove all potential duplicates listed on both the BCBA registry and on either or both of the Autism Speaks or Autism Society websites. These are predictable challenges with using publicly available databases, and the benefits likely outweigh the costs. Nonetheless, future studies may benefit from a more comprehensive search for clinical and advocacy resources.

Conclusion

In sum, this study evaluated the relationships among ASD prevalence, policy, clinical resources, research infrastructure,

and awareness-raising organizations using large, publicly available databases. Findings from this study suggest that states with more ASD-relevant policies, clinical resources, and research infrastructure have higher prevalence rates of ASD. This study also found that there was considerable variability among states on both autism prevalence and state-level ASD-related resources, though specific patterns were largely undetectable when comparing between geographical regions. Together, these findings provide a summary of the comprehensiveness, or lack thereof, of state infrastructure as it relates to ASD, shining a light on the needs of families and individuals with ASD. It also suggests that there may continue to be meaningful differences in ASD prevalence across the country, potentially driven by the inequities in ASD-related resources among states. As such, these findings can be used to inform research, practice, and policy related to ASD, in order to address the ultimate goal of providing all individuals with ASD care that is high-quality, comprehensive, and equitable.

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